



CANADA

Multiple Sclerosis Society of Canada
250 Bloor St. E., Suite 1000, Toronto, Ontario M4W 3P9

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MS caregiver program targets individual needs

“The caregiver project gave me a sense that my role of being a caregiver is not taken for granted...and [it] was recognized that I also need a break...”

That is how one participant in the MS Society of Canada’s Family Caregiver Pilot Project described how the three-year-program helped her.

Almost 400 caregivers of persons with MS in Saskatchewan, Manitoba and Atlantic Canada participated in the program, which was funded by The J.W. McConnell Family Foundation. A key part of the

program was providing up to \$300 to help caregivers with their own health promotion needs.

“Caregivers used the funding to access a range of activities from traditional types of respite care such as alternative caregiving services to more individualized needs such as joining a community exercise program. We wanted to go beyond the ‘one size fits all’ concept,” said Michelle Gibbens, project manager.

Targeting individual needs was met with enthusiasm. An evaluation of the program found that more than 95 percent agreed it was very important that the program allowed them to identify their own needs and use the funding where and when they felt it would do the most good.

In addition, almost 75 percent said they felt the support they received benefited the person with



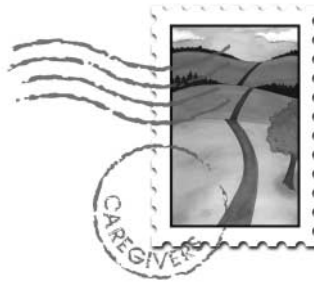
RBC Fights MS - Three members of the Royal Bank team in the Niagara MS Bike Tour enthusiastically salute fellow participants. From left are David Cox, Carole Carpentier and Christina Virag. They were among 9,350 cyclists who took part in the 20 MS Bike Tours from coast-to-coast. This record number of cyclists also raised the most funds ever for the MS Bike Tours -- \$4.83 million for MS research and services.

continued on next page

Self care for caregivers:

Tips from other caregivers of people with MS

- Recognize that self care is a necessity not a luxury.
- Self care doesn't just happen, you have to plan and schedule it in order to have time for yourself.
- You can't change some things about your situation but you can make choices about the attitude you have towards your situation and how you cope.
- Communicate openly with the people around you (especially the person with MS) and encourage them to do the same with you.
- Seek support from others who will validate and encourage your commitment to self care.
- Self care is different for each of us so explore your options.
- If you are making changes to your self care plan, take one step at a time so that self care doesn't just become one more thing on a never-ending "to do list".



Adapted from *Taking Care: A Travel Guide for Your MS Caregiver Journey*. It is available from the MS Society at www.mssociety.ca (select Caregivers from the menu on the How We Can Help page), or in print format from your local division or chapter, or e-mail caregivers@mssociety.ca to request your copy.

Other MS Society of Canada resources for caregivers:

- *Taking Care: A Guide for Well Partners*
- *Caring and Sharing: Spouses and Partners*

Flu vaccination and multiple sclerosis



Since winter – and flu season – is just around the corner, some have asked whether people with MS should choose to be vaccinated against influenza.

Since any vaccination can cause fever in some cases, people with MS and their doctors sometimes worry whether the vaccine or the fever might trigger an MS attack.

There is reassurance in the 1997 study by Dr. Aaron Miller, Maimonides Medical Center, Brooklyn. He found that people with relapsing-remitting MS, who had the flu vaccine, did not have more relapses than those who received a placebo injection.

“This study clearly supports the view that influenza vaccination is not associated with a statistically significant increase in MS attacks or worsening. People with MS should discuss the issue with their own physicians when making a decision about the flu vaccine,” said Dr. William J. McIlroy, national medical advisor.

MS caregiver program (continued from page 1)

MS and almost half said it benefited the entire family.

The MS Society is using the findings from the program in two ways. A new resource *Taking Care: A Travel Guide for Your MS Caregiver Journey* is now available. The new publication is based on the experiences and advice from more than 100 caregivers including how to access information and community resources.

In addition, the MS Society has received phase two funding from the J.W. McConnell Family Foundation to extend the project.

“This two-year extension of the program will help us consolidate what we learned about caregiver needs in the initial pilot program,” said Ms. Gibbens.

MS Canada

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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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Berlex Champions of Spirit call for nominations

The Multiple Sclerosis Society of Canada is pleased to join Berlex Canada in the search for 2004 Champions of Spirit nominees.

Berlex Champions of Spirit is a cross-Canada program to recognize ten Canadians who live with multiple sclerosis and who have enhanced their own lives and those around them by exemplifying courage and compassion.

Do you know a Champion of Spirit?

A Champion of Spirit may be a person who has MS or is a caregiver.

- Champions conquer extraordinary personal challenges
- Champions make a difference in their communities

Nominations will be accepted starting November 24, 2003.

To nominate someone for the 2004 Berlex Champions of Spirit search, look for nomination forms at your local MS Clinic or call the MS Society at 1 800 268-7582. You can also nominate online by clicking on the Champions of Spirit link at www.mssociety.ca, or visit www.mspathways.ca

The 2002 Champions of Spirit program generated a flood of entries. Ten finalists – all having MS – were selected by an independent panel consisting of MS neurologists and nurses and an MS Society representative.

In tribute to Canada's Champions of Spirit, award-sponsor Berlex Canada donated \$20,000



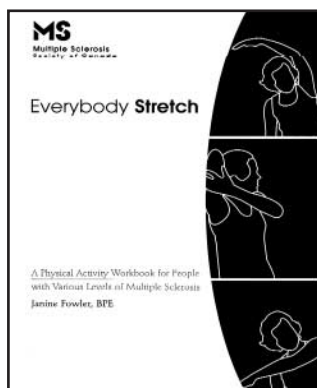
—\$2,000 to the MS-related charity of each winner's choice so that others living with MS can benefit from their strength and compassion.

To find out more about how you can nominate someone and to read about the 2002 award recipients, go to www.mssociety.ca and click on Champions of Spirit.

Everybody Stretch book brings exercise to all

"I picked up a large can of tomatoes!"

It was a triumphant moment for the Friday Fun and Fitness group in Calgary. Through the exercise program *Everybody Stretch*, one participant had worked her way up from lifting a small can of pineapple to the heaviest can on the grocery store shelf.



It was only one of many benefits. Previously the group had dubbed themselves "Fun & Fatness" with a focus on socializing and donuts.

Janine Fowler, the new outreach coordinator for the Calgary Chapter in 1997, knew that since many of the participants had serious limitations because of MS and some used wheelchairs, they would need a variety of exercise levels.

She began developing a series of stretching and flexibility exercises with different versions of each exercise, depending on the person's abilities. Before long, the group began to see results.

"Any time you're doing any type of physical activity it's going

to lead to health benefits. Anything that reduces stress, or increases your flexibility or mobility, is a help," explained Janine Fowler, now director, Client Services in the Atlantic Division.

This 41-page, coil-bound illustrated workbook contains 34 exercises covering every part of the body, from eyes and hands to legs and abdominals. The exercises come with adaptations, so that users can develop a flexible, individualized program that can be adapted to changing physical abilities.

Everybody Stretch can be viewed on the MS Society web site (www.mssociety.ca – follow the links from the home page) or call your division office at 1 800 268-7582.

RESEARCH IN BRIEF

Avonex approved for those 'at risk' for MS

In September, Health Canada extended the labelling of Avonex (interferon-1a) to include people who are "at risk" of developing MS – people who have had one attack and supporting MRI-detected brain lesions consistent with multiple sclerosis.

The approval was based on the "CHAMPS" study, published in 2000, which involved 383 participants in Canada and the United States. The study showed that Avonex can delay the onset of a second attack by 44 percent compared to placebo. A person having a second attack would be considered to have clinically definite MS.

It is expected that provincial governments and third-party insurers will use the expanded labelling decision in considering whether to reimburse the cost of Avonex for people with one attack and supporting MRI data. The MS Society will work with provincial governments on this issue.

Currently, Quebec is the only province to reimburse for monosymptomatic MS. It reimburses for both Avonex and Rebif, another type of interferon beta-1a.

The Rebif study involved 308 people with one neurological event and MRI brain lesions suggestive of MS. They received active treatment (the lower 22mcg dose of Rebif every other day injected under the skin) or placebo for two years. The treated group had a slower progression to clinically definite MS, with the conversion reduced by 24%. Participants had fewer new and enlarging brain lesions.

"The Health Canada decision on expanded labelling for Avonex is supportive of a growing body of evidence that early treatment has a positive impact in delaying a second MS attack. In addition, many MS specialists believe early treatment may reduce the development of more permanent clinical disabilities," said Dr. William J. McIlroy, national medical advisor.

Study looks at sunlight and MS risk

Australian research suggests that higher exposure to ultraviolet light delivered through sunshine may reduce the risk of developing MS. The benefit appears to be linked to increased sun exposure in children and young adolescents.



The study involved 136 people with MS and 272 non-MS controls living in Tasmania, the most southern part of Australia and the farthest away from the equator.

MS has a well-known and varied distribution throughout the world. It is more common in countries that are farther away from the equator. It also has a striking north-south gradient, i.e., MS is more common in the northern United States than in the south, and conversely, is more common in southern Australia than in the north.

A number of environmental and genetic factors have been investigated to try to understand

this variation including migration patterns and exposure to common viruses. More recently, researchers have turned their attention to the possible role of sunlight in reducing the risk of developing MS.

The Australian researchers found that people who had spent more time in the sun when they were between the ages of six and 15 were less likely to develop MS than those who had less exposure to sunlight. Having higher sun exposure during the winter months seemed particularly important.

Sunlight delivers ultraviolet radiation, which upon coming in contact with the skin, stimulates the body to produce Vitamin D. Several studies have shown that ultraviolet radiation and Vitamin D suppress the activity of immune T cells. Several other studies involving an animal model of MS found the animal disease could be prevented or delayed by giving ultraviolet radiation or the active form of Vitamin D.

"While the study of sunlight exposure and MS risk in Tasmania is promising, larger studies must be conducted to determine if higher levels of sunlight or Vitamin D supplements can actually prevent the development of MS," cautioned Dr. William J. McIlroy, national medical advisor.

In addition, unprotected exposure to sunlight is linked to the development of skin cancer and premature skin aging. Not enough is known about Vitamin D supplementation in people to determine if it or heightened exposure to sunlight during childhood and early adolescence can prevent multiple sclerosis.

RESEARCH IN BRIEF

Zenapax and Campath studied as potential MS therapies

Two types of powerful laboratory-created monoclonal antibodies are being studied as potential MS therapies with initial positive results.

Two research teams reported at the recent meeting of the American Academy of Neurology the results of small studies testing daclizumab (Zenapax), which blocks the activity of a key immune activator in MS. In the study headed by Dr. John Rose, University of Utah, 11 people with relapsing-remitting or secondary-progressive MS found that participants MS disability stabilized or improved. The participants received either Zenapax alone by monthly intravenous infusions or in combination with interferon beta.

The second study involved 10 people with either relapsing-remitting or secondary-progressive MS receiving monthly intravenous infusions of Zenapax and interferon beta. Dr. Bibiana Bielekova, National Institutes of Health, reported MRI-detected disease activity was reduced in all 10 participants.

A larger placebo-controlled clinical trial of Zenapax is underway in the United States. Zenapax is used to treat organ rejection following transplants.

Alemtuzumab (Campath-1H), another type of monoclonal antibody, is also being tested. Dr. Alastair Compston, Cambridge University, reported that the use of Campath to treat aggressive relapsing-remitting MS has been more successful than previous studies using it to treat secondary-progres-

sive MS. Side effects have been a concern in using Campath which is utilized in treating forms of cancer. A large, placebo-controlled multi-centred study of Campath is just beginning.

“This interest in both Zenapax and Campath, as well as another monoclonal antibody called Antegren, illustrates the increasing amount of research currently underway to find more treatments for MS. These treatments appear to be promising based on limited pilot studies. We will all be anxiously waiting for the results of the larger studies now getting underway,” said Dr. William McIlroy, national medical advisor.

Aricept tested in MS to improve memory

A drug used in Alzheimer’s disease may be useful as a treatment to improve memory in MS.



The oral drug donepezil hydrochloride (Aricept) was tested on 35 people with MS for 24 weeks. Their ability to perform a memory test was compared to 34 people who were not treated. People receiving Aricept modestly improved their performance reported Dr. Lauren Krupp, State University of New York, Stony Brook, at the American Academy of Neurology meeting in April.

Aricept is thought to enhance memory by temporarily increasing the concentration of messenger

chemicals in the brain that are involved in memory. Problems with memory can occur in MS.

Larger studies of Aricept are needed to confirm safety and the initial findings.

Possible MS link to Epstein-Barr virus

The possibility that MS might be triggered by a number of common viruses received some more support with the announcement that people with MS had higher antibodies to the Epstein-Barr virus (EBV) than did controls.

Researchers at Harvard School of Public Health and the Walter Reed Army Institute of Health looked at blood samples from 83 cases of MS among US military personnel. Antibodies to EBV were consistently higher in those who had MS than in the controls.

The investigators, reporting in the March 26, 2003 *Journal of the American Medical Association*, suggested that EBV may be associated with an increased risk of developing MS. Epstein-Barr virus is one of the most common viruses in the world. By age 40, 95% or more of all adults show signs of having been exposed to it. EBV causes infectious mononucleosis and other disorders.

“This study adds to the large body of work suggesting possible links between MS and infectious agents including many common virus infections. It does not mean the Epstein-Barr virus causes MS but does provides some clues about how the immune systems of people who may be genetically susceptible to MS respond to virus infections,” said Dr. William McIlroy, national medical advisor.

**Multiple Sclerosis Society of Canada
Notice of Annual Meeting of Members**

NOTICE IS HEREBY GIVEN that the Annual Meeting of the members of Multiple Sclerosis Society of Canada will be held at the Sutton Place Hotel, 955 Bay Street, Toronto, Ont. M5S 2A2, on Saturday, November 22, 2003 at 1:00 p.m. (Eastern Standard Time) for the following purposes:

- i) Receiving the report of the members of the National Board of Directors and the financial statements for the year September 1, 2002 to August 31, 2003; together with the report of the auditors thereon;
- ii) Electing members of the National Board of Directors;
- iii) Appointing auditors;
- iv) Considering changes to the by-laws as specified below;
- v) Such further and other business as may properly be brought before the meeting.

Members who are unable to attend the meeting in person are requested to date and sign the form of proxy below, detach and return it to the head office of the Society, 250 Bloor Street East, Suite 1000, Toronto, Ont. M4W 3P9 by November 14, 2003, Attention: Jacqueline A. Munroe.

DATED at Toronto, Ontario this 18th day of October 2003.

David L. Knight, Secretary-Treasurer

**Multiple Sclerosis Society of Canada
By-Law Number 13**

BE IT ENACTED, and it is hereby enacted that By-law No. One of the Multiple Sclerosis Society of Canada be amended by adding the following as paragraph no. 47a :

In lieu of the appointment of division/chapter auditors and the preparation and presentation of audited financial statements, the division/chapter Boards shall rely upon the audit of the consolidated National financial statements and the preparation and presentation of those audited financial statements. In this circumstance, unaudited financial statements of the division/chapter, prepared in accordance with generally accepted accounting principles, will be presented at the annual meeting of members of the division/chapter. Notwithstanding the foregoing, a division/chapter Board in any given year may by resolution after consultation with the National Audit Committee, appoint auditors to audit financial statements of the division/chapter.

**Multiple Sclerosis Society of Canada Proxy
for Annual Meeting of Members, November 22, 2003**

The undersigned hereby appoints Louis P. Desmarais, or failing him, Harry O. Bensler or David L. Knight or Susan A. Murray or Reid G. Nicholson or Bruce R. Richmond or David L. Torrey or _____ as proxy with power of substitution, to attend and vote for the undersigned at the Annual Meeting of members to be held November 22, 2003 and at any adjournment or adjournments thereof and to vote and otherwise act thereat for and on behalf and in the name of the undersigned in respect of all matters which may come before the meeting in the same manner the undersigned would do if personally present thereat.

DATED this _____ day of _____ 2003 _____

(Signature of member)

Please date, sign and return this proxy to the Secretary-Treasurer, Multiple Sclerosis Society of Canada, National Office, 250 Bloor Street East, Suite 1000, Toronto, Ont. M4W 3P9 by November 14, 2003, Attention: Jacqueline A. Munroe.

Élise Clément

Act of hope becomes legacy for the future



1995 was a difficult year for Élise Clément and one that she won't soon forget. That was the year she was diagnosed with multiple sclerosis. People experience a diagnosis in different ways. For Élise, her new reality included the reactions she saw when talking about her diagnosis: "What

a shock! It frightened me to see the concern in a co-worker's eyes."

"For me," explains Élise, "it was as simple as this: Diagnosis: Multiple sclerosis; Treatment: None; Prognosis: Not good."

Today Élise is more hopeful – in part due to her own actions and in part due to the work of the MS Society of Canada.

"In Quebec, in 1995, there were no drugs available for people with MS. What did the future hold for me? I was really scared! In 1996, people demonstrated to the Quebec government to have the first interferon drug added to the list of drugs covered by the Quebec health insurance board. Happily, we succeeded."

To continue her legacy of positive change, Élise has also named the MS Society of Canada in her will. Someday her gift will positively benefit people with MS just as she was able to help affect change in 1996: "I decided to turn my fear into an act of hope. I made a bequest to make an active contribution towards the future of people who have MS."

Canada has one of the highest rates of MS in the world. Élise Clément and nearly 400 other volunteers and supporters of the MS Society of Canada are affecting change today and tomorrow through their planned gifts.

If you would like to name the MS Society of Canada in your will, or make another type of planned gift, please contact Mike den Haan at the MS Bequest Help Desk: 1 866 679-4557.

I would like information on:

- Estate Planning Bequests
 Life Insurance

- Yes** I have already made a provision for the MS Society.
 I am interested in making a provision for the MS Society.
 I am sending a donation today.

Yes please contact me

Name: _____

Address: _____

City/Town: _____

Prov.: _____ Postal Code: _____

Tel: () _____

E-mail: _____

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

Mail this form to:

MS Bequest Help Desk
1000 - 250 Bloor St. E., Toronto, ON M4W 3P9
OR fax it to: 416 922-7538

The MS Society collects personal information requested on this form for the purpose of communicating to you information about the MS Society and its fund raising activities. By completing this form, you hereby consent to the collection, use and disclosure by the MS Society of your personal information in accordance with the MS Society privacy policy. If you have any questions about your personal information, please contact National Vice-President, Communications, at 1 866 922-6065. Our privacy policy is available from any MS Society office or at www.mssociety.ca.

Estate Planning Information from a Trusted Source

MS Bequest
Help Desk

1-866-MSWILLS • www.msplannedgiving.ca

ANSWERS
TO YOUR
QUESTIONS
ARE JUST A
CALL AWAY

Maybe you'd like to create a future that will provide for your family and leave a legacy to assist people living with MS in your community.

Seems like a tall order. Unless you have information to help create your plan. Don't know where to start? MS Society of Canada supporters count on us for the resources they need to create a plan that cares for loved ones and benefits people living with MS.

The MS Society has the resources and knowledge to help you create your estate plan.

CALL TOLL-FREE 1-866-MSWILLS (1-866-679-4557)

SOCIAL ACTION ROUND-UP

MS Society stresses DTC and CPP issues

Once again the Multiple Sclerosis Society of Canada has been asked to let the Finance Committee know our priorities for the 2004 federal budget.

“We are using the opportunity to highlight our recommendations for improvements to the disability tax credit (DTC) and Canada Pension Plan disability benefits as well as the need for stable federal funding for Canada’s health research program,” said Susan Murray, chair, National Social Action Committee.

“We are also proposing a break on postage rates for registered charities to assist with mail costs,” she said.

MS Society representatives presented in person to the Standing Committee on Finance in early November. The brief is posted on the MS Society web site: www.mssociety.ca under *Advocacy/Social Action*.

The MS Society brief to the Technical Advisory Committee on Tax Measures for Persons with Disabilities is also posted on the web site. It highlights current problems with the DTC and offers solutions.

“Over the summer, the MS Society participated in an extensive consultation on how to improve the 2004 DTC application form. The result should be a more user friendly and fairer form,” Ms. Murray said.

MS Society logo

Something old, something new...

There is a new look for the Multiple Sclerosis Society logo that includes “something old” – the well-recognized broken MS and SP symbols.

“The new logo leverages the highly recognizable elements of the original MS/SP logo, yet provides a more modern look consistent with the future of the MS Society of Canada.

Having a dynamic-looking logo whose use can be standardized across Canada easily and effectively, will help promote awareness and recognition among our volunteers, members, donors, event participants, healthcare professionals and the general public,” said Tony Pigott, chair of the National Public Education Committee.

Why update?

While surveys showed the broken MS and SP had a high recognition factor, the logo was sometimes adapted, which led to inconsistencies. It also cost more to manage literally hundreds of different versions.

We needed to establish our brand image as national, united and consistent across all the communities we serve.

We needed to move to 21st century technology, providing the logo in easy-to-use formats to volunteers and staff.

A Branding Task Force worked with J. Walter Thompson, a global advertising agency, to create a new logo and graphic standards manual that combined the best of the old logo with a new and easy-to-use design.

The result is the dynamic new logo presentation you see here. The new logo is self-contained with a broken bar above and below that expands on the familiar broken MS/SP symbols. The breaks in the logo symbolize how the signals from the brain to the body are disrupted due to multiple sclerosis. The MS/SP is accompanied by a wordmark that is compact and easy to read.

All parts of the MS Society will begin using the new logo in 2004. It will be phased in to reduce cost.

(If you have any questions about the new logo, please contact your division communications director/ manager at 1 800 268-7582.)



New English logo



New bilingual logo for English users (a bilingual logo for French users with the French logo to the left is in development).