

MS

CANADA

Multiple Sclerosis Society of Canada
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**Celebrate
International Year of
Volunteers**

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Say MS with flowers

Haligonians are reminded of multiple sclerosis and the MS Society of Canada every time they use the MacKay Bridge which connects Halifax and Dartmouth. The MS logo was chosen to grace a flowerbed near the bridge this summer.

New program focuses on MS caregivers

“It seems sometimes we are just invisible.”

These words express the feelings of many MS caregivers – the all-too-often unsung heroes who help care for their loved ones who have multiple sclerosis.

Knowing the voiced needs of so many MS caregivers, the Multiple Sclerosis Society of Canada leapt at the chance to pilot a project to assist them when the J.W. McConnell Family Foundation offered funding under an innovative initiative called *Whatever it takes: Caring for the informal caregiver*.

“We saw this as an opportunity to further support the 'family' in our Individual and Family Services Program,” explained Jon Temme, vice-president, individual and family services.

The MS Society proposed an idea for an MS Family Caregivers Pilot Program. The McConnell Foundation liked the idea and is funding it for \$278,100 over three years. The program began allocating special assistance caregiver funding in February 2001 to people in Saskatchewan, Manitoba and Atlantic Divisions.

“Caregivers, who are most often family members or friends of the person with MS, provide a wide range of caregiving activities. These include emotional support, physical assistance with personal care and mobility, housekeeping, yard work, helping to access medical, social and recreational services,” said Michelle Gibbens, manager, Family Caregiver Pilot Program.

Studies, including some conducted by the MS Society, have found the burden on caregivers can be heavy. One caregiver in a 1992 Ontario-based study of services and quality of life for people with MS and caregivers stated:

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"I feel the role of the caregiver is sadly under-rated and misunderstood. The most difficult part is not the extra work load and physical demands, although they are both tiring and stressful, but in [the] loss of a friend, companion and mate."

The focus to date has been on developing and implementing the Caregiver Special Assistance Program. In the coming months, program staff and volunteers will develop measurement tools to evaluate the program's impact, produce caregiver educational materials through the use of focus groups that can be used across the country and establish a framework for the MS Society to provide ongoing caregiver educational programs nationwide.

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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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Sydell Stein: "Generous positive program"

Sydell Stein of Winnipeg learned about the MS Caregiver Pilot Program from a friend who is also an MS caregiver and found out more about it at a caregiver focus group meeting.

"I thought it was an incredible, generous, positive program that an organization would actually think of the caregiver."

Mrs. Stein has been the primary caregiver for her husband Moshe since he was diagnosed 20 years ago. He now uses a wheelchair in the home and while teaching at the University of Manitoba.

Although the family has many home supports, one aspect of caregiving that can be wearing over time is always being on call. "You forget to have time for yourself," is the way Mrs. Stein puts it.

She plans to use her respite care to have a solo visit with her daughter and young grandson in Montreal later this year.

Participating divisions report a positive response to the program.

Since the start of the program, family caregivers have applied for a wide range of services and activities. These include fitness and recreation activities, counselling services, massage therapy and other services that offer respite, housekeeping and yard work, take-

out meals and alternate caregiving services.

"We have found that the needs are as individual as the people involved. It can be more challenging to deliver a flexible program like this, but ultimately it is much more rewarding for all concerned," said Mr. Temme.

This issue of MS Canada is supported through an unrestricted educational grant from Teva Neuroscience Canada.

■ Teva Neuroscience offers Shared Solutions, an information and support service available to individuals with MS. You may contact Shared Solutions at 1-800-283-0034 from 8 a.m. to 8 p.m., Monday to Friday.

■ Teva Neuroscience is proud to sponsor the Living Well with MS educational series this fall.



MS RESEARCH IN THE NEWS

Head-to-head therapy trials

“Does any one of the MS medications work better?”

People with MS and their physicians have asked this question frequently ever since the disease-modifying therapies were approved.

The answer is still not known, but two recent clinical trials are providing more information.

EVIDENCE study

Dr. Patricia Coyle, State University of New York at Stony Brook, presented data from the six-month head-to-head clinical trial of the Serono product Rebif against the Biogen product Avonex at the World Congress of Neurology in June. Both products are interferon beta-1a, but are administered differently and in different dosages. Serono Inc. sponsored the study.

The results indicate after six months Rebif showed a statistically significant benefit over Avonex for all primary and secondary endpoints including the proportion of people remaining relapse-free and the accumulation of MRI-detected lesions in the brain. The study took place at 56 research sites and involved 677 people with relapsing-remitting MS.

EVIDENCE stands for Evidence for Interferon Dose Effect: European-North American Comparative Efficacy. Each product was given at its standard dose strength and method of delivery. Avonex is injected into the muscle once a week

at a total dose of 30 mcg. Rebif is injected under the skin three times a week at a total weekly dose of 132 mcg (high dose version).

The primary endpoint was the proportion of participants relapse free at the end of six months which was announced as 74.9% for those on Rebif and 63.3% for those on Avonex. Looked at another way, of those treated with Rebif, 25.1% had MS relapses during the six months, compared with 36.7% of those treated with Avonex.

Steroid use to treat MS relapses was lower in the Rebif group, as reported by Dr. Coyle.

Participants also had monthly MRI scans during the six month period. Those on Avonex showed 50% more “combined unique lesions” than those on Rebif.

EVIDENCE study conclusions have been challenged by Biogen. The company received an injunction from a Swiss court which ordered Serono to stop saying that those in the Rebif arm of the study had a 90% greater chance of remaining relapse-free in the 24-week treatment period and that those treated with Avonex had more MRI-detected brain lesions than those on Rebif.

A spokesperson for Biogen said the company also has concerns about the design of the study and the conclusions that have been drawn from it.

Despite the court injunction, the presentation at the World Congress of Neurology in London went ahead.

INCOMIN study

Dr. Luca Durelli, director, University MS Centre, Torino, Italy, presented the results of a 12-month comparison study of Betaseron (interferon beta-1b) and Avonex (interferon beta-1a) at the American Academy of Neurology meeting in May. The study was sponsored by the MS Foundation of Italy and the Italian Ministry of Health. INCOMIN stands for Independent Comparison of Interferon.

At the six-month mark, participants on Avonex had a lower rate of MS attacks and fewer people had relapses compared to Betaseron. However, at the end of the second six-month period this had reversed in favour of Betaseron: those on Betaseron had an exacerbation rate of 0.13 and 11% of people had relapses while those on Avonex had an exacerbation rate of 0.24 and 20% had relapses.

Using the one-year treatment period as a whole, 7% of people on Betaseron had a sustained progression of disease as measured by the Expanded Disability Status Scale compared to 25% on Avonex.

Using MRI scans of the brain at the one-year mark, participants on Betaseron had fewer new lesions (15% vs. 30% for Avonex); had fewer enhancing lesions (9% vs. 22% for Avonex) and had less MRI activity (18% vs 35% for Avonex).

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Therapy trials

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In a letter to physicians following the study results release, Biogen Canada pointed out the study was not properly blinded and was of short term duration. In addition, among other criticisms, the company said it appeared the clinical and MRI data were not adjusted to take into account that the Avonex-treated group had higher numbers of MRI lesions at the beginning of the study.

The study took place at 15 MS centres in Europe and involved 188 people with relapsing-remitting MS. Each product was given at its standard dose and method of delivery. Betaseron is injected under the skin every other day at a total weekly dose of 24-32 MIU. Avonex is injected into the muscle once a week at a total dose of 30 mcg.

Unknowns

“While these studies provide additional information, there are still a number of unknowns,” pointed out Dr. William McIlroy, national medical advisor.

“The studies provide short-term data only while MS is a life-time disease. We still don’t know if one therapy is superior over the long run,” he added.

Another unanswered question is whether the interferon betas lose effectiveness over time because of the development of so-called neutralizing antibodies in reaction to the injected medications. There is some evidence that neutralizing antibodies develop more rapidly in the higher dosage therapies, however, there is still controversy as to

whether these antibodies actually have an impact on effectiveness.

In addition, neither the EVI-DENCE nor the INCOMIN study results have been published as yet in a peer-reviewed medical journal which would permit physicians greater access to the study data.

“These two head-to-head

studies are another step forward, however, it may be too early to draw definitive conclusions,” Dr. McIlroy advised.

(For more information, go to the MS Society web site at: www.mssociety.ca and click on the MS Research section and then click Research and Medical Library.)

RESEARCH IN BRIEF

Nerve growth vaccine may be useful in MS

Two long-time MS Society-supported researchers have developed a vaccine technique that may stimulate nerve growth after injury and which may have implications for multiple sclerosis.

A research team led by Dr. Samuel David, McGill University, developed the approach to overcome the molecules in the myelin sheath itself that actually prevent nerve regeneration. Dr. Peter Braun also at McGill University and Dr. Lisa McKerracher at the University of Montreal were part of the team.

They devised a way around this problem by using purified myelin which, when injected into disabled mice, stimulated their immune systems to produce antibodies to the nerve regeneration inhibiting molecules. They used a modified immunization procedure to prevent autoimmune disease against certain myelin proteins. As a result, the mice experienced regeneration of motor neurons and the recovery of some limb function.

According to Dr. David, the discovery should have application to MS since damage to the nerve fibres can occur in addition to myelin injury. He cautioned much work needs to be done to refine the vaccine before it can be transferred to testing on people.

Society research funding

The Multiple Sclerosis Society of Canada announced \$3.2 million in new research funding to launch MS Awareness Month in May.

Following rigorous scrutiny of research grant proposals by the Society’s grant review committees, the MS Society approved funding for 14 research projects and 46 research scholarships.

Half of the research projects focus on how myelin can be repaired or regrown. Myelin is the vital protective covering of the central nervous system damaged in MS.

The other major research focus is immune system studies. The immune system is involved in launching the attacks that lead to inflammation and myelin injury.

Managing MS fatigue

by Lynn McEwan, R.N.

Fatigue is a universal symptom. We have all experienced fatigue at some time or another usually due to lack of sleep, over work, stress or the flu.

However, fatigue experienced by many individuals with MS is often described as ever present. It rarely goes away completely, but fluctuates in intensity over the day, week or month. MS fatigue can interfere with function and activities of daily living.

The MS Council for Clinical Practice Guidelines defines MS fatigue as a subjective lack of physical and / or mental energy that is perceived by the individual to interfere with usual and desired activities.

MS fatigue is the most common of MS symptoms with a prevalence as high as 90%. For some, fatigue is their worst MS symptom and is often listed as one of the top three most disabling symptoms.

There are two types of MS fatigue, subjective and physical. **Subjective fatigue** is a feeling of being tired, lack of energy or sense of lassitude. It can be so severe that concentration and thinking are difficult. **Physical fatigue** or fatigability is focal muscle fatigue that occurs with persistent activity, such as a limp with walking. Resting will allow recovery from this type of fatigue.

Contributing factors

The exact cause of MS fatigue is poorly understood, however there are a number of factors that are known to contribute to the

problem: temperature, disease activity, level of disability, medications, lifestyle habits and secondary medical conditions.

Temperature

Fatigue tends to fluctuate with the body's natural temperature variations known as diurnal temperature. Our body tempera-

“My family gets frustrated with me. They can't understand how I could have slept all night, got up, got dressed and ate breakfast, but now I have to lie down because I'm tired.”

ture usually peaks mid to late afternoon and is at its lowest around 2 or 3 a.m.

This is certainly reflected in persons with MS who find their fatigue is worse in the afternoon, best in the morning and may improve in the evening. Fever and elevated environmental temperatures can also worsen fatigue. Demyelinated nerve fibres are more sensitive to temperature changes.

Disease activity

Increased disease activity, such as a relapse, is often associated with increased fatigue. Activation of the immune system, as part of an inflammatory process, results in the release of substances such as lymphokines and cytokines.

It is this immune response

that is responsible for the fatigue experienced with the flu or MS relapses. Suppression of the immune response with immunomodulating therapies and steroids may explain why some people experience an improvement of their fatigue on treatment.

Level of disability

The greater the level of disability the more effort or energy is used to compensate for the physical impairment. A person expends a lot of energy to walk with a weak leg or poor balance.

Studies have shown that disabled individuals use twice as much energy to perform the same function as an able-bodied person. As well, physical disability can result in deconditioning, adding further to the problems of both fatigue and weakness.

Medications

Unfortunately many of the medications used to treat MS symptoms have the potential to cause sedating side effects. In particular, drug therapies for pain, spasticity and tremor all have sedating properties that may intensify the problem of fatigue.

Lifestyle

Sleep - We all know how we feel after little or no sleep. We usually feel draggy, have poor concentration, are irritable and even unwell. Disrupted sleep is quite common in MS for many reasons such as frequent voiding, muscle spasms, pain, anxiety and inactivity.

Nutrition - When tired we do not feel like cooking a meal and tend to

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go for fast and snack-like foods. These are usually high in carbohydrates but low in nutrition. They may give us a quick energy boost but this is not sustained and often leads to greater fatigue. Missing a meal, especially breakfast, is a com-

Fluid is another important resource. Drinking enough fluids is essential for circulation, elimination of toxins and our complexions.

Deconditioning

It is not uncommon to reduce or limit one's activities to conserve energy but this in fact can add to the problem of fatigue and weakness. In addition, inactivity may increase the risk for other medical conditions such as high blood pressure, obesity or reduced bone density. Studies have shown that regular exercise improves fatigue as well as one's sense of well-being.

Secondary medical conditions

Fatigue is a common symptom for a number of medical conditions including: depression, diabetes, infection, thyroid and blood disorders. People experiencing an unexplained change in their level of fatigue should see a physician to rule out other causes. Most of these conditions can be effectively treated.

Management of MS fatigue

Fatigue for the most part is a subjective experience. It is invisible to others making it difficult for family, friends, co-workers and health practitioners to fully understand the impact this problem has on the individual. As well, individuals experience and cope with their fatigue differently and what may

work well for one person may not help another.

The first step in managing MS fatigue is to have an understanding of the nature of the problem, what factors may be contributing to it and what makes it better.

Drug therapies

There are medications that can reduce MS fatigue. Treatment response varies with notable improvement for some and modest or no fatigue reduction in others.

“It’s difficult to explain to others that putting my feet up and resting for a few minutes won’t make me feel better. Sometimes it’s several hours before my energy returns.”

Amantadine - (Symmetrel) is an antiviral agent used to reduce the risk of influenza infections. It also helps increase dopamine (neurotransmitter) activity in the brain. It is unclear how the medication works in MS fatigue, but it seems to act as a stimulant.

Ritalin - (Methylphenilate) is used in the management of attention deficit disorder (ADD) in children. It is a central nervous system stimulant and in adults helps reduce fatigue and improve mental alertness. It is part of a classification of drugs known as amphetamines and can aggravate problems of anxiety, depression or insomnia.

Alertec - (Modafinil) is another central nervous system stimulant but differs from amphetamine-like

drugs. The newest addition to the fatigue management medications, it is used in the treatment of excessive daytime sleepiness associated with narcolepsy. However, recent studies have shown benefit in MS fatigue.

Prozac/Zoloft - (Fluoxetine/sertraline) Both of these medications are selective serotonin re-uptake inhibitor (SSRI) antidepressants used in the treatment of depression and fatigue. These antidepressants influence serotonin levels in the brain, helping to improve mental alertness.

(Editor — Unfortunately, all of these medications have potential side effects, and drug coverage for some is limited at this time. Please consult your own physician for advice.)

Other fatigue management strategies:

Energy conservation

- Ask for and accept help.
- Work smart – prioritize activities.
- Minimize energy expenditure by using assistive devices and mobility aids.
- Organize your environment.
- Plan ahead.

Recharging

- Do pleasurable activities – hobbies, listen to music, read or chat with friends.
- Allow time for rest periods, even 15-20 quiet minutes can help.
- Establish a regular sleep schedule, treat symptoms that disrupt sleep.

Enhancing resistance to fatigue

- Regular exercise has been shown to improve fatigue and have a positive impact on quality of life.
- Good dietary habits of a well balanced meal at regular intervals prevents fatigue.
- Adequate fluid intake of 1600 to 2000 mls/day (6 to 8 cups/day).

Positive attitude

- Having a positive outlook can be emotionally uplifting and creates a sense of well-being. Feeling angry or worried all the time is emotionally and physically draining.

Keep cool

- If you are heat sensitive then plan activities in the cooler part of the day or in cool environments.
 - Keep iced water or drinks readily available.
- Wear layered clothing that can be removed if needed.
- Take a cool shower or bath before or after exercise.

As with many aspects of MS, the cause of MS fatigue remains poorly understood. However, the ability to recognize those factors that may contribute to or worsen this symptom helps to provide more effective management.

(This article is intended for general information only. People should contact their own physicians with specific questions or concerns.)

Adapted with permission from the Spring 2001 newsletter for the MS Clinic, London Health Sciences Centre. Lynn McEwan, R.N., is the nurse practitioner/clinical nurse specialist at the MS Clinic.

Living Well with MS

Education series looks at the top ten things you need to know

Being diagnosed with multiple sclerosis generates many emotions and questions. Living a full life with multiple sclerosis post-diagnosis is also a challenge.

An innovative, four-city educational series being offered this autumn will help meet these challenges.

“The series is called *Living Well with MS: the top 10 things you need to know*. Speakers will look at MS from their own perspectives and offer the best information they feel people need based on their areas of expertise” said Jon Temme, vice-president, individual and family services.

A person with MS will speak at each of the sessions. Health care professionals, including a neurologist, will talk about the psycho-social aspects of MS, as well as medical and general health issues. The series is sponsored by an unrestricted educational grant from Teva Neuroscience Canada.

“Today, while there is a range of options for treatment and for cop-

ing with the disease, it can be difficult to decide what is credible, what sources to trust, and where to turn for answers,” he noted.

At each session, ample time will be available for the audience to ask questions and to learn new and helpful information about coping with MS.

“We hope that these sessions are just the beginning of a new series that can be expanded in the coming months,” Mr. Temme said.

Stéphane Leduc, marketing manager, Teva Neuroscience Canada, added, “We know that the MS Society of Canada is a trusted source of information for people dealing with this illness, and we are pleased to be able to work with them to offer this innovative series.”

For more details, contact your division office at 1-800-268-7582 or go to the MS Society of Canada web site: www.mssociety.ca and look for the *Living Well with MS* quick link on the main page.

Living Well with MS

- ◆ Halifax, September 23
- ◆ Montreal, September 29 (French and English sessions)
- ◆ Burnaby/Vancouver, October 4
- ◆ Hamilton, October 23

Become more involved!
Please see the insert
for details

We are pleased to provide information about planned giving, fund raising events and volunteering with a new *MS Canada* insert in this issue.

Increasingly, volunteers and supporters are considering a planned gift to the MS Society of Canada through a gift in their will. Gifts by will are a growing part of the long-term funding of our important services and research programs.

MS Society Planned Giving staff are available across the country to assist you with information about gifts by will as well as other types of planned gifts (stocks, life insurance, gift annuities, etc.).

Just mail back the insert or call the Office of Planned Giving at the national office at 1-800-361-2985 (416-922-6065) or your division office at 1-800-268-7582.

PEOPLE IN THE NEWS

Award to Society **IFS staff member**

Sandra Simpson, regional manager, individual and family services, Ontario Division, received the Berlex Award at the recent MS Consortium of MS Centers conference in Texas for her poster presentation on how she effectively used video conferencing to provide up-to-date information about MS to healthcare professionals in northern Ontario.

Based in Sudbury, she has been the IFS manager serving northern Ontario for 14 years.

YWCA honours **Calgary clinic director**

Dr. Luanne Metz, director of the MS Clinic in Calgary, was honoured with one of the YWCA Women of Distinction Awards for 2001 in the health, wellness and active living category.



Jon Temme, vice-president, individual and family services, congratulates Sandra Simpson on receiving the Berlex Award for her poster presentation.

She was praised for continuing to develop the clinic into one of the most respected MS medical centres in the world. Dr. Metz is also active in clinical care and teaching at the University of Calgary.

MS Canada: Are you on the list?

The MS Society of Canada throughout the country is switching to a new, more efficient computer system to better serve member, volunteer and donor needs and to keep costs down.

Part of the change involves moving the *MS Canada* mailing list from several different systems to a single system that will allow us to enter members' names directly at chapter, division and national levels.

However, as we merge the lists starting with this issue of *MS Canada* there may be some growing pains. To ensure no one is left out, we are sending this August issue to all names on all lists. We are

trying to remove any duplicate names, but it is possible some people may receive an additional copy. Or you may receive the publication in the wrong language choice.

The next issue will be sent in November after the lists have been stripped of names that appear to be out of date. At that time, possibly someone who was on an old list may not receive *MS Canada* at all.

If you or someone else you know has a problem receiving *MS Canada* please let us know as soon as possible. You can call your division office at 1-800-268-7582 or call the national office at 1-800-361-2985 and ask for Jean Mercier in donor and member services.