



CANADA

Multiple Sclerosis Society of Canada
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Growing Up Strong Project aids children of MS parents

When Sylvie Desmarais was a child she thought her family was different from any other family in Winnipeg.

“Unlike my friends, my sister and I had to do our own laundry and there were times when we couldn’t go out with friends,” she recalled. “I don’t remember my mother being able to walk because of MS.”

Thinking back, Sylvie Desmarais, now 21, said she probably could have used more information about the disease, but, even more importantly,

she would have liked to have met other children who had a parent with MS just to know she and her sister weren’t that different.

That’s why she has agreed to become part of the Advisory Committee for a new MS Society of Canada project called Growing Up Strong: Supporting the Children of Parents with Multiple Sclerosis.

Growing Up Strong is a two-year project to develop, evaluate and deliver integrated services and programs across Canada for children aged six to 18 who have a parent with MS.

“Supporting children whose parents have MS has long been a concern to MS Society volunteers and staff. In response, a number of divisions and chapters have initiated programs that have been quite beneficial,” said Jon Temme, vice-president, Client Services.

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MS AWARENESS CAMPAIGN ON PARLIAMENT HILL - Paddy Torsney, MP for Burlington (right), and Ottawa Chapter volunteers and staff launched the annual MS Awareness Month by presenting carnation boutonnieres to all Members of Parliament in early May. From left are: Mary McGregor, Ottawa Chapter board volunteer, Heather McMartin, assistant to Ms. Torsney, Clare Gillespie, executive director, Ottawa Chapter, and Ms. Torsney. The MS Carnation Campaign raised \$1.3 million across the country.

Growing Up Strong (continued from page 1)

“Unfortunately, until now we haven’t been able to evaluate existing programs and take the best components of each to build a comprehensive, age-appropriate program for children. Thanks to funding from the Population Health Fund of Health Canada, we are able to do exactly that,” he explained.

One of the first steps is a national survey to gather infor-

You can join the project by filling in the Growing Up Strong Survey.

mation from children of parents with MS, parents themselves, their spouses and adult children of

parents with MS.

You can join in by filling out the survey which will be available November 15. You can participate in two ways: Go to the home page of MS Society of Canada web site (www.mssociety.ca) and click on “Survey, Growing Up Strong.”

Or you can call 1 888 242-8684 and ask for a copy of the survey. Please provide your name, address, postal code and preferred language (English or French). The first 1,000 callers will receive the survey.

When the project ends, the MS Society will have developed age-appropriate information resources, programs and services to



meet the needs of this important group. MS Society volunteers and staff will receive training in how to use the new materials and programs.

“This is a very exciting project which will fill a major gap in our programming. We are very grateful to Health Canada for its support,” Mr. Temme said.

Introducing: Client Services

Individual and Family Services is now known as Client Services.

There was widespread agreement that this new name would be more inclusive of all the clients the MS Society of Canada serves. Clients include people living with MS, family and friends, care providers, health professionals, employers, institutions, donors and all others affected by MS.

The National Board of Directors endorsed the name change at its May 2002 meeting.

MS: Its Effects Newly updated

The booklet *MS: Its Effects on You and Those You Love* is available in a newly updated and larger size edition.

MS: Its Effects has been called the MS Society’s single best resource about MS. Published in question and answer format, it provides a basic introduction to MS and symptoms, information about treatments and research and gives tips on living with MS.

MS: Its Effects is available on the MS Society web site (www.mssociety.ca then click on Information and then Publications). Or you can call your division office at 1 800 268-7538 for a copy.

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multiple sclerosis and enabling people
affected by MS to enhance
their quality of life.

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MS IN THE NEWS

When headlines mislead

People with MS were startled recently by news reports linking the disease with several eye-catching but unproven theories.

In one case, media outlets reported that pet bird ownership seemed to be occur more frequently in women with MS than in non-MS controls.

In the other, a researcher who had re-worked old data, suggested that MS might be a sexually transmitted disease. His interpretation was condemned by the MS scientific community.

“While the headlines were drawn from research studies, not all research is equal, and results are subject to misinterpretation,” said Dr. William J. McIlroy, national medical advisor.

Bird contact

A study by University of Montreal epidemiologist Dr. Parviz Ghadirian reported that a group of almost 200 people with MS were more likely to relate contact with a wide range of factors compared to a group of people who did not have MS.

Among these factors were contact with pet birds (for women with MS only), smoking in the year prior to diagnosis, a family history of other diseases such as mumps, measles, rubella and cancer and a family history of MS (this is consistent with genetic susceptibility studies).

“This is interesting research, but must be interpreted cautiously,” said Dr. Christina Wolfson, professor, Department of Epidemiology and Biostatistics, McGill University. “The study did not include an

investigation of the possible differences in genetic backgrounds of the two groups, and recall bias may have influenced the findings.

“Recall bias is the result of the fact that after developing a disease, people may over interpret exposure to any number of factors because they need to explain why they developed the disease,” she explained.

Sexual transmission theory faulty

British neurologist Christopher Hawkes’ paper suggesting that MS may be sexually transmitted was immediately condemned as not being supported by existing evidence.

Dr. Hawkes reexamined a number of immigration studies and small “epidemics” of MS and suggested that MS may be the result of an unidentified virus that is

transmitted by sexual contact.

Reaction from MS experts was swift. Dr. Alastair Compston, professor of neurology, Cambridge University, said, “As no new facts have been reported, this paper has little if any scientific value. The hypothesis falls down quickly and repeatedly in the face of known facts.”

A study by the Canadian Collaborative Study Group of conjugal MS was cited as refuting the theory. That study found that spouses of people with MS were at low risk of developing the disease, and their chance of developing it was no greater than the general population.

Pregnancy hormone may benefit

In a small study of the hormone estriol, six women with relapsing-remitting MS improved over their pre-treatment state.

Estriol is a form of estrogen. It is elevated during the later stages of

(continued on page 4)

This issue of *MS Canada* is supported through an unrestricted educational grant from Biogen Canada Inc.

Biogen Canada supports the MS community with educational activities, patient support programs and various other helpful services. By calling the Biogen Canada support line, people with MS, their care partners and healthcare providers can receive valuable information on therapy and patient services such as:

- The quarterly *Compass* magazine, the *MS Alliance* newsletter and additional support materials
- MS patient counselling
- Reimbursement counselling
- Practical self-injection training
- Direct delivery of medication to home or workplace
- Medical information for healthcare providers

To contact a Biogen MS Alliance support specialist, call 1-877-674-6365, or visit www.msalliance.com. Customer support specialists are available 24 hours a day, seven days a week.

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CANADA

The Drive to Discover. The Discipline to Deliver.

MS IN THE NEWS

(continued from page 3)

pregnancy. Researchers have noted that pregnant women with MS have fewer MS symptoms and relapses during the second and third trimesters.

This pilot study was led by Dr. Rhonda Voskuhl, University of California at Los Angeles, and involved six women with relapsing-remitting MS and six with secondary-progressive MS. All 12 received 8 mg estriol in pill form, once a day for six months.

The women with relapsing-remitting MS had decreased numbers of MS lesions and reduced levels of immune proteins (having higher levels indicates inflammation is present).

The six women with secondary-progressive MS (steadily worsening disease after initially having relapses) did not improve while on therapy.

Estriol was well tolerated and appeared to be safe. The investigators concluded that estriol should be studied further in relapsing-remitting MS either as a single therapy or in combination with established MS treatments.

Marijuana supply still a puzzle

People with MS and others who hold permits to possess marijuana for medicinal purposes are apparently still without a legal way to obtain marijuana unless they grow it themselves.

There is confusion as to whether the marijuana being grown in a secure former mine in Manitoba will be distributed to medicinal marijuana permit holders. In August, statements from Minister of Health Anne McLellan suggested that the

marijuana will be used only for clinical studies.

One result was the launching of a court challenge in September to compel Health Canada to distribute the marijuana that has been grown in the mine.

In another development, the Senate Special Committee on Illegal Drugs released a summary report of its study of cannabis (marijuana) in Canada. Among its recommendations was that the current Marijuana Medical Access regulations be amended to provide new rules for eligibility, production and distribution of marijuana for medical purposes.

The Senate Committee also urged more research both on the use of marijuana medically and as a recreational substance.

Whether marijuana could be beneficial in relieving pain and spasticity in people with MS is not proven although a number of people are convinced it is helpful.

A small study at the University of Massachusetts Medical School using a synthetic derivative of the active ingredient in marijuana found it was effective in pain relief. It also appeared to have several advantages over marijuana: it isn't smoked which eliminates the concern about smoking. In addition, it does not appear to have marijuana's side effect of making the user "high". The synthetic version is not yet commercially available.

For more information about applying for a permit to possess marijuana, call the Health Canada Office of Cannabis Medical Access at 613 954-6540 or go the Health

Canada web site www.hc-sc.gc.ca/hecs-sesc/ocma/notice56.htm. To access a copy of the Senate report, go to the Senate web site www.cannabislink.ca/gov/senatesumm.htm

(Note: With information from John Feld, Toronto freelance writer.)

Drug warnings from Health Canada

Health Canada recently provided warnings related to two drug products.

Baclofen (Lioresal) must not be stopped abruptly

Those who use the drug Baclofen (Lioresal) delivered through an implanted pump should take care not to stop the medication abruptly. The implanted Baclofen pump is used to treat severe spasticity.

Abrupt discontinuance can lead to a number of severe side effects including high fever, mental confusion, rebound spasticity and muscle rigidity. In rare cases, it can lead to multiple-organ failure and death.

People using the implanted pump, their caregivers and health-care professionals should insure that the pump is refilled when scheduled.

The implanted pump can be helpful for people with MS who have severe, painful spasticity and who do not respond to oral medications.

Kava sales stopped

Health Canada has directed that all sales of products containing kava be stopped. This action follows reports of serious liver dysfunction in people who used kava-containing products in a number of countries.

Kava has been used by some people as a treatment for anxiety or insomnia.

International conference pulls together research information

by William J. McIlroy, M.D.

World renowned MS scientific experts gathered in Baltimore, Maryland in September to present and debate the latest information about multiple sclerosis research.

The second joint meeting of ACTRIMS andECTRIMS attracted 2,000 participants, the largest scientific meeting ever held devoted exclusively to MS.

(ACTRIMS stands for Americas Committee for Treatment and Research in Multiple Sclerosis andECTRIMS stands for European Committee for Treatment and Research in Multiple Sclerosis.)

Besides the official scientific sessions, a number of pharmaceutical company sponsored symposia took place where current and future therapies were discussed.

The consensus of most attendees of the meeting is that while no scientific “breakthroughs” were announced, it was extremely useful to discuss where we are now and where we hope to be going in MS research. It was also reassuring to observe the open sharing of information on a world-wide scale.

Dr. Samuel Ludwin, professor at Queen’s University and chair of the MS Society Medical Advisory Committee, gave the keynote address at the opening session. He reviewed the inter-relationships of inflammation, demyelination and axonal loss in the pathology of MS.

These studies, supported by MRI data, confirm the presence of axonal (nerve fibre) loss early in the



Dr. McIlroy

course of the disease and show that inflammation is the most important factor in MS relapses (attacks). Less inflammation and

more axonal loss are seen as the disease advances into the more progressive and degenerative stage of the disease.

These observations favour early treatment of MS with the need for a more concerted effort to find ways of protecting the axons from permanent damage as well as finding ways of repairing already damaged nerve fibres.

Another area of focus was the blood-brain barrier, the cellular barrier that keeps immune cells out of the central nervous system.

There is interest not only in the inflammatory cells that must cross this barrier to get into the central nervous system, but also in the chemical mediators (chemokines) that make this possible.

Drugs are already being developed to inhibit this activity and are being evaluated in clinical trials (e.g., the small study of minocycline at the University of Calgary and a larger Phase III study of natalizumab [Antegren]).

Presentations at the meeting made it clear that the three beta interferons (Avonex, Betaseron and Rebif) and glatiramer acetate

(Copaxone) all have a positive effect in reducing the frequency and severity of MS attacks and in delaying the rate of progression of the disease.

What is less certain, however, is the long term efficacy of these drugs, and the need for longer follow-up studies was emphasized by a number of speakers.

Factors that will influence the choice of therapy for an individual patient will include dosage, route and frequency of injection and the presence or absence of neutralizing antibodies which appear to have an effect on long-term clinical outcomes.

To date there is no effective treatment for primary-progressive MS, and the effectiveness of the current therapies diminishes once the progressive stage of MS is reached.

The only therapy that has been approved for rapidly progressive MS is mitoxantrone (Novantrone), a potent chemotherapeutic agent used in cancer therapy. However, the risk of cardiac toxicity limits its use to a two-to-three year period. (See page 8 for more information about mitoxantrone.)

There was agreement that combined therapies and the use of different drugs at different stages of the disease will become more common, but the big challenge will be to develop treatments for the primary and secondary-progressive stages of MS.

These therapies will come from the basic laboratories where scientists are actively working on the biomedical, genetic, immunological and reparative aspects of the disease. Canadian scientists with funding from the MS Society of Canada are making significant contributions to this search.

Dr. McIlroy is national medical advisor to the Multiple Sclerosis Society of Canada.

Personal Financial Planning At All Income Levels

by Mike den Haan

Most donors I work with are looking for three things: they want enough money to live out their days in relative comfort; they want assurance that their loved ones will be financially okay; and they want to help the MS Society so that friends and family may not have to face the burden of MS.

Donors often ask for help with developing an estate or financial plan – and the MS Society has resources to assist. Whether donors consider themselves well-off or in need, financial and estate planning is important.

YES! I want to help continue the fight against MS!

- I would like information about wills, bequests, and annuities.
- I have named the MS Society of Canada in my will.
- I want to donate today. Please find my gift enclosed.

Name: _____

Address: _____

City: _____ Province: _____

Telephone: _____

Email: _____

Please complete and return to:
MS Society of Canada
Office of Planned Giving
1000 - 250 Bloor St. E.
Toronto, ON M4W 3P9

Or call us at:
1-800-361-2985
www.mssociety.ca

More and more, older donors say they are concerned about their financial health. For seniors who face particular financial need one government resource is the Guaranteed Income Security.

In addition to Old Age Security payments (OAS), lower income seniors also have access to Guaranteed Income Security payments (GIS) which they can claim as a matter of right. Eligibility is linked to income as reported on the prior year's tax return (and no "capital" test is involved).

It is important to note that you have to apply for the GIS, and you have to apply every year (unlike the one time application process for the OAS). The Canadian Association of Retired Persons (CARP) has found that about 100,000 seniors every year lose their benefits because they fail to renew the applications. If you are a senior in need, make sure the GIS part of your plan.

For more information available on the Internet you may want to consult the following web site: www.hrdc-drhc.gc.ca/isp/oas/ispb184.shtml#a or call 1-800-277-9914.

Whether you consider yourself wealthy, in need, or somewhere in the middle, resources exist that can help you with financial and estate planning. If you have any questions, please call the MS Bequest Help Desk at 1-866-679-4557.

Mike den Haan is assistant vice-president, Major Gifts/Planned Giving, for the Multiple Sclerosis Society of Canada, Ontario Division.

How having dinner can help fight MS

Did you know you can help fight MS just by having a dinner party?

Thanks to a new international initiative, you can do just that. On February 27, 2003, people around the world will be holding dinner parties in support of MS research worldwide. Instead of a hostess gift or bottle of wine, guests will be asked to bring a donation for the MS cause.

To find out how you can get involved, go to the MS Society web site (www.mssociety.ca) and click on MS Global Dinner Party. Or call your division office at 1 800 268-7582.

The MS Global Dinner Party is an initiative of the MS International Federation supported by member organizations including the MS Society of Canada.



Society web site recognized

Chatelaine magazine has recognized the MS Society of Canada web site as one of the top web sites in Canada in providing information about health issues. The MS Society is listed in the *Chatelaine's* annual web guide, published in September.

Ideas for articles

Many readers called, e-mailed and wrote letters praising the *MS Canada* article about MS attacks (August 2002).

Thanks for your input and please let us know what other topics you would like to read about.

Send your ideas by mail to: *MS Canada*, 250 Bloor St. E., Suite 1000, Toronto ON M4W 3P9; by e-mail to info@mssociety.ca or fax: 416 922-7538.



Calgary nurse receives award

Colleen Harris, coordinator of the MS Clinic at Foothills Hospital in Calgary, has won the 2002 June Halper Award for Excellence in Nursing. The award is given to an outstanding member of the International Organization of MS Nurses.

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 23, 2002 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, 2001 to August 31, 2002; together with the report of the auditors thereon;
- ii) Electing members of the National Board of Directors;
- iii) Appointing auditors;
- iv) 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 15, 2002, Attention: Jacqueline A. Munroe.

DATED at Toronto, Ontario this 18th day of October 2002.

David L. Knight, Secretary-Treasurer

Multiple Sclerosis Society of Canada Proxy for Annual Meeting of Members, November 23, 2002

The undersigned hereby appoints Louis P. Desmarais, or failing him, Norman Latowsky 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 23, 2002 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 _____ 2002 _____

(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 15, 2002, Attention: Jacqueline A. Munroe.

SOCIAL ACTION ROUND-UP

MS Society pushes DTC issue forward

The MS Society and other organizations are keeping the pressure on the federal government to make access to the disability tax credit (DTC) fairer to Canadians who are disabled.

In October, the DTC coalition sent a second letter to all members of Parliament asking them to support meaningful consultations on the DTC application form and to oppose amendments to the Income Tax Act that would result in further restricting access for people with feeding and dressing disabilities.

“We are disturbed that government is simply not engaged on this matter. Consultations meant to provide relief to the disabled community have resulted in additional restrictions. In response to court rulings that favour people with disabilities, the government has proposed changes to counteract those decisions,” said Susan Murray, chair, National Social Action Committee.

“In recent meetings with government officials, the MS Society has expressed its deep concern for what appears to be a systematic misinterpretation of the Tax Act and the needs of disabled Canadians. As chair of the National Social Action Committee, I think it is important we address the source of the problem, rather than the outcomes,” she added.

You can add your voice to this issue by writing to your MP. A sample letter and background information is available by calling your division office at 1 800 268-7582 or on the

MS Society web site at www.mssociety.ca/en/involved/socialact

Brief to Finance Committee

The MS Society of Canada focussed on the need for adequate income support for people with MS in its brief to the House of Commons Standing Committee on Finance.

The MS Society was asked to participate in pre-budget consultations and used the opportunity to highlight concerns relating to access to CPP disability benefits and the disability tax credit.

The brief also urged the federal government to continue to increase funding for medical research and to look at ways to simplify the administration of tax receipting that would be less costly for charities.

The brief is posted on www.mssociety.ca/en/involved/socialact under Position Papers.

Romanow Report due in November

The eagerly anticipated report by the Commission on the Future of Health Care in Canada (Romanow Commission) is due in November.

For your information, in recent months many informative research papers and reports on health care issues have been posted to the Commission web site, which is www.healthcarecommission.ca

Mitoxantrone therapy for aggressive MS

A growing number of Canadian neurologists are turning to a cancer therapy to treat rapidly advancing secondary-progressive MS and relapsing-remitting MS that does not respond to the approved disease modifying therapies.

Mitoxantrone (Novantrone®), while approved in the U.S. for MS, is available in Canada to treat some forms of cancer. However, it can be prescribed for MS and is then usually given by cancer specialists.

Mitoxantrone is administered intravenously (into the vein) in hospital, usually in an out-patient setting. The dosage and frequency of administration vary depending upon the person's weight and stage of the disease. The treatment may continue over a two-year period.

There is a lifetime maximum dosage for mitoxantrone because of the danger of damage to the heart. Other side effects may include loss of appetite, reduced white blood cells, sterility (often temporary) in men, temporary stop to menstruation and possible hair loss.

Mitoxantrone is not a cure. Clinical studies in Europe found that recipients have fewer relapses, fewer lesions as detected by MRI and slower disease progression compared to controls.

Contact your physician for information about whether mitoxantrone might be considered for you.

(With information from an article in MS Quebec by Josée Poirier, B.Sc., Nursing. Ms. Poirier is coordinator of the MS Clinic, Notre Dame Hospital, Montreal.)