



CANADA

Multiple Sclerosis Society of Canada



Paddle Up!
Camp for kids
with MS is here

Believe.
MS Awareness Month is now
Special Report
Stem cell research & MS

Message from Yves



At every turn, I see clear evidence of this organization's strength. In the first few months as your new president, I have met skilled staff and volunteers whose diligent work is keeping our mission alive every day. I've met people with MS and talked with family members and caregivers who tell me how they benefit from our services and enjoy getting involved to help realize our goals. And I've met some of the many scientists and health professionals who form this country's strong research and clinic network - all of whom are changing the landscape and moving us closer to a future free of MS.

I am extremely proud to be among these dedicated people and honoured to work with them as we build on Alistair Fraser's 25 years of service as president and his impressive legacy.

In my years in the voluntary sector, I have honed a passion for the inclusion of people with disabilities and see rich opportunities to move forward in that regard. Our government relations and social action network across the

country is literally changing laws and affording greater support to people with MS than they have had in the past. This advocacy work is a constant and strategic effort that requires great persistence, and it's creating change where it's needed most.

As well, there is ongoing work and outstanding growth within our world-class research network. The current choice of treatments for MS has emerged only in the last decade, and we are consistently updating our body of knowledge of MS, which bodes very well for our future prospects. Canada remains a global leader in MS research and I am excited to help guide our path to greater heights as we move toward the day we end MS.

I have made a commitment to travel throughout Ontario and to all our divisions across Canada by the end of June to meet as many members of our community as I can. We have begun an in-depth strategic planning process to map our direction and allow for effective and innovative ways to achieve our mission. I am anxious to get the perspective of the men and women who are an integral part of our community, and whose voices are vital in shaping our future ■

Yves Savoie
President and Chief Executive
President, Ontario Division



MS Canada, Summer 2007

Published by the Multiple Sclerosis Society of Canada
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

Charitable Registration no. 10774 6174 RR0001

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.

President & Chief Executive: Yves Savoie

Editor: Marianne Chilco

Translator: Charlotte de Celles

ISSN 0315-1131 – Issued quarterly
Canadian Publications Mail Product
Sales Agreement No. 40063383



Cover photo: Camp Merrywood, Perth, Ont.

Note to our valued MS Society members

We are proud to introduce a new look for *MS Canada* to our members and supporters. For many years, we've kept the same design using cost-effective methods of producing the quarterly publication. That philosophy of accountability hasn't changed.

Even though we've introduced colour to the newsletter, our costs remain reasonable and responsible due to advancements in the printing industry. We hope this new design helps communicate the very best the MS Society has to offer its valued community ■

Adventures await kids with MS at summer camp



At this time of year, kids all over the country are getting anxious to kick off their shoes and jump right into summer. For children and teens with MS, there's a cozy cabin by a beautiful lake waiting for them to do just that.

The MS Society of Canada is piloting our first ever Canadian camp for children and teens with MS. The camp is generously funded by the RBC Foundation and an anonymous family foundation, and is the result of collaborative work with the Hospital for Sick Children's Pediatric MS Clinic staff.

The camp takes place August 12 - 16 at Camp Merrywood, an Easter Seals camp in Perth, Ontario (about one hour from Ottawa). Fully accessible with air-conditioned cabins, the camp offers a wide range of activities including sailing, swimming, kayaking, sports and games, crafts and more. All programs will be adapted to meet the needs of the campers, with an MS nurse on site and a neurologist on call.

Most children and teens with MS do not know kids their own age who also have MS. The camp provides an opportunity for them to meet others who are going through similar

issues because of the disease. While those attending the camp can feel free to initiate conversations about MS, there will be no formal discussions about MS, nor will the fact that they all have MS be emphasized. Instead, it will be a chance for kids and teens with MS to spend a few unforgettable days of new adventures and friendships, in a beautiful, accessible and supportive environment.

There is space for 30 campers, who must meet these criteria:

- Be a child or teen between the ages of 7-19 followed clinically as a person with Pediatric MS;
- Fill out and send (by fax or regular mail) the application form along with a signed letter from a neurologist confirming diagnosis of MS;
- Children and teens from the United States are welcome to apply, but space preference will be given to Canadians.

Applications are available at MS Society chapters, divisions, MS Clinics, and online at our website (www.mssociety.ca). We will accept applications beginning May 22, 2007, and acceptance will be on a first-come, first-served basis. Any Canadian applicants placed on a waiting list will have the first opportunity to attend the camp in 2008, should funding continue to be available.

All costs associated with the camp (including travel) are covered ■

For more information about the camp for children and teens with MS, or Pediatric MS in general, please contact:

Nadia Pestrak

Coordinator, National Information Resource Centre

Toll-free: 1-866-922-6065 extension 3049

Direct line: (416) 967-3049

Email: nadia.pestrak@mssociety.ca

Multiple Sclerosis Society of Canada



First chapter closes on 2007-2008 Scholarship Program

The inaugural MS Society of Canada Scholarship Program, supported by Billy Talent and Friends, has accepted its final applications for the 2007-2008 school year. Launched in February, this first-ever MS Society initiative provides scholarships to teenagers and young adults directly affected by multiple sclerosis.

The program received an enthusiastic response from across the country, with messages of interest and support coming from as far away as the Netherlands. All applicants will be advised by mid-June whether their submission was a successful one. The MS Society thanks all applicants for their interest in the program, and wishes them the best with their educational endeavours. Watch for notice of next year's program in early 2008 ■

A future free from MS is your legacy to give

MS Bequest Week

May 28 - June 1, 2007



Leigh-Ana and her mother

In 1984, at 23 years-old, Leigh-Ana was working as a registered nurse when she began to experience MS symptoms. Leigh-Ana recognized these symptoms as her

mother had been diagnosed with MS in 1977.

Leigh-Ana knows that finding a cure is just around the corner—and she has made a commitment to a future free from MS by leaving a bequest in her will.

“Just like the kids of today don’t know what a record is—I want the kids of tomorrow to not know what MS is. I hope that I might live to see the day when a cure to end MS is found. I am pleased to be able to do what I can by investing towards a future free of MS for the generations that follow me.”

You too can create a legacy of hope for future generations—contact us to find out how easy it can be ■

1-866-MS WILLS (679-4557)

www.msbequesthelpdesk.ca

MS Awareness Month

Since the late 1970s, the Multiple Sclerosis Society of Canada has marked the month of May as MS Awareness Month. Why? To generate excitement and commitment among Canadians to share our goal to end MS.

Across the country, we aim to increase awareness about multiple sclerosis among the general public, promote the MS Society mission and inspire new and existing supporters to become engaged with our mission and activities.

This year’s theme is **Believe**, something we all have in common. Our staff and volunteers believe in our mission; our researchers believe they’ll soon uncover a cure; our clients believe in the quality of their chapters’ services; our supporters believe in our ability to transform donations into life-changing services and research; and we all believe we can end MS.

Our sub-theme this year is **Women and MS**, something that has emerged from recent research findings, including the facts that women now are three times more likely than men to be diagnosed with MS and that the pregnancy hormone, prolactin, may hold the secret to myelin regeneration. Also important is the fact that when someone is diagnosed with MS, often the entire family is affected.

Ads and posters (see right) feature Terri and Caitlin Kernaghan, who have been extremely supportive in helping spread the word both nationally and within the reach of their Hamilton & District chapter in Ontario. We welcome

the involvement of all of our communities, thank all participants and look forward to a wonderful month of awareness and activity ■

MS Imagine life without it.

believe

We will end MS. With your help.

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

At eight years old, Terri's daughter Caitlin was diagnosed with multiple sclerosis. Read her story at www.mssociety.ca and find out how you can help us end MS. 1-800-268-7582



The Cycle of Life

The RONA MS Bike Tour is a pledge-based fundraising event that provides Canadians with the opportunity to ride through scenic and often spectacular parts of the country. Over 10,000 cyclists are expected to participate in the 22 one- and two-day tours taking place across Canada between May and September.

Register and raise \$250 online to be entered into a draw for a \$500 RONA gift certificate, and receive a ballot for every additional \$250 raised online. For more information on this year's RONA MS Bike Tour please call 1-800-268-7582 or visit www.msbiketours.com.

This past year, Edmonton YMCAs joined forces to create something special for the MS community. Ninety-eight fun-loving and generous souls, affectionately known as “Y-Ride”, participated in the RONA MS Bike Tour-MS 150 from Leduc to Camrose, Alberta. In only their second year participating in the tour, the team raised a total of \$57,041 and was only a few people short of being the largest bike team in Canada!

The incredible results of Team Y-Ride were achieved thanks to the vision of Team Captain Brad Fehr. A few years ago Brad participated in the RONA MS Bike Tour-MS 150 with his training partner as part of their triathlon training. “When we arrived in Camrose,” says Brad, “I realized that there were a lot of people from the Castle Downs YMCA doing the ride. I suggested we put a team together the next year and we had about 60 participants.”

In 2006, Brad decided to take his team to another level by recruiting three captains from the four Edmonton YMCA centers. Together, new captains Melcon Pascual, Jenna Lewis and Travis Jackman formed a team of 98 participants. “I found that almost everyone had a connection to MS in some way. We have members here at all of our YMCA centers that are living with MS and are proud to see other YMCA members, staff and volunteers raising money and riding for this great cause,” says Brad.

This partnership is mutually beneficial for YMCA and the MS Society on a few fronts. “Through the team, we increased contact between staff and members while providing them with a tangible fitness goal,” says Brad. Apart from the benefits to the YMCA, Brad says that “partnering with the MS Society allows us to help find the cause and cure for multiple sclerosis and improve the quality of life experienced by those living with MS.”

To commemorate the 100th Anniversary of the YMCA in 2007, Team Y-Ride has set a goal to recruit 100 team members and raise \$100,000 at this year's RONA MS Bike Tour-MS 150. “We feel incredibly fortunate to be able to work alongside the YMCA and celebrate their successes,” says Daniella Sabo, Manager of Development and Corporate Relations, Alberta Division. “We are also very excited to see what they will accomplish this year ■”



A chat with Dr. Owens, Part II



MS Canada recently sat down with Dr. Trevor Owens, chair of the MS Society's Biomedical Research Review Committee. In this role, he sees all research funding proposals submitted to the MS Society.

Last issue, Dr. Owens discussed his own work and the research application process. Part II covers his thoughts on progressive MS and Canada's standing in the MS research world.

Q: What can you say about the course of MS research in the last 10 years?

In the last 10 years, we've been reminded of something that was known for 100 years: that there is axonal damage from MS. There is therefore a neurodegenerative component to the disease. This was not news. However, as a community, we had lost sight of it.

Q: What implications does this have?

That we need to pay attention to repair and replacement as components of MS therapy, as well as preventing damage. The focus on repair and regeneration brings attention to the potential of stem cells and precursor cells as potential therapies.

Q: Can you speak to primary-progressive MS and if there is anything happening in that area?

There's clearly a difference between progressive and relapsing-remitting MS. One of the interesting ways that it differs is that it does not show the same bias towards females that relapsing-remitting MS does. It also seems to be a disease with a different primary cause than relapsing remitting. Having said that, I should remind you that we don't know the cause, but

it looks and feels like a different disease. It is, however, a part of the spectrum of MS.

Q: Is it fair to say that by answering some of the key questions in MS, we can impact both progressive and relapsing remitting MS?

Yes, but it's very likely that the ultimate therapies for the two will be different. We will probably be able to use overlapping therapies, but the therapies that are most effective for primary-progressive MS may not be the same as those that are most effective for relapsing-remitting.

Q: There is a lot of research taking place all over the world. From your position in speaking to volume and quantity of research in Canada, where do you think we stand?

Canada has excelled in the epidemiological study of MS, which is a huge contribution, and Canada's well developed network of MS clinics contributed to that. MS research in Canada stands well against other countries, especially on a per capita basis. The MS Society is, I think, a world leader in the level of funding that it maintains. This speaks to fundraising, but it also speaks to allocation of resources. The MS Society of Canada plays a major role as a funding agency of basic research in the country, dedicated to understanding MS but embracing basic research in bringing new interactions. I think that Canada can be very proud of the role it plays in this regard.

Q: When do you think we're going to find a cure?

As soon as possible, of course. But it's going to come gradually. We're going to see a gradual crumbling of the problem. I don't think that it will be an overnight cure that will cure all MS at once, but we'll more and more be able to tackle individual components ■

STEM CELL RESEARCH

Stem Cells and MS: What the investigators see

By Martha King, Illustrations by Jill K. Gregory

Adapted, translated and reprinted from *INSIDEMS*, February-March 2007 issue, with permission of the National MS Society, USA.

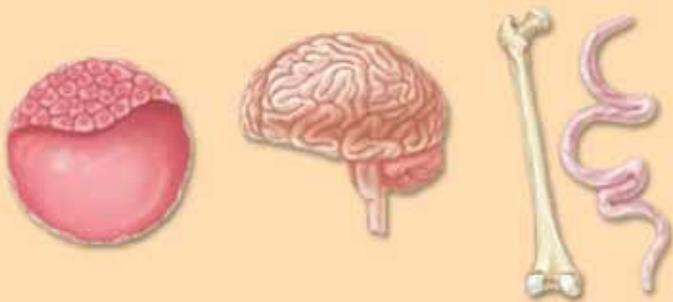
In January 2007, the National MS Society and MS International Federation (MSIF), with additional support from the MS Society of Canada, hosted an international meeting in San Francisco, which allowed 30 cutting-edge investigators to present new findings, share insights, and debate some issues emerging from this frontier in MS research. After lengthy discussions, they forged preliminary agreements about the best ways for the MS research community to move ahead.

Prospects for "endogenous" stem cells

In San Francisco, Dr. Anne Baron-van Evercooren led a discussion with colleagues from the U.K. and the University of Rochester in New York on the potential

and current limitations for "endogenous" stem cell therapies. These cells reside in the individual's central nervous system. In her laboratory in Paris, she and her colleagues have shown that tissues damaged by MS attacks send distress signals. These signals appear to trigger endogenous stem cells to begin differentiating into immature myelin-making cells, a first step in the body's natural repair process. These stem cells are therefore candidates of great interest in the quest to enhance myelin repair. Her studies also show that they migrate into areas of MS damage in very limited numbers. "We need to find ways to enhance migration and recruitment by the MS lesions," she said. Her group is deep in work with laboratory animals to learn more about how this might be done.

Where stem cells come from... and what stem cells may do



Stem cells derived from blastocysts (below left), neural tissue (center) and bone marrow or cord blood (right) have different properties. Some might be transplanted directly to differentiate into myelin-making cells or nerve cells or to prompt regrowth of these cells. Some can spark growth of a new immune system to replace one that continually attacks an individual's myelin. Still others might be genetically modified before being transplanted to make them stimulate development of cells that produce nerve-protecting molecules. And finally, drugs could be developed that recruit a person's own—or endogenous—stem cells to a specific area in the body. Once in an injured area, these cells can promote repair and limit additional injury.

Prospects for adult stem cells

Dr. Jeffrey Kocsis and his team at Yale have been analyzing the potential of stem cells from the human nose, called olfactory ensheathing cells (or OECs); of cells that produce myelin for the nerves outside the central nervous system (called Schwann cells); and of stem cells found in bone marrow.

The Yale team is finding that OECs have a remarkable ability to heal and protect. Surgically transplanted OECs supported regrowth of broken axons (or nerve fibres), protected damaged axons, and promoted remyelination of stripped axons in lab animals. Moreover, the remyelinated axons showed no sign of abnormalities that could spell poor nerve conduction or pain.

The team is also injecting gene-modified stem cells into lab animals with brain injuries and seeing reduc-

tions in lesions and improved function.

Dr. Kocsis and his group expect to learn a great deal more about the potential of bone marrow-derived stem cells to repair MS damage from studies of spinal cord injury repair now going on at Tulane University Medical Center. Cross-disciplinary collaboration like this is becoming a norm in this rapidly developing field.

Prospects for the youngest of the adult cells

The healing potential of stem cells derived from umbilical cord blood is of interest to researchers in spinal cord injury and a long list of neurologic diseases including MS. These cells have less potential for differentiation than embryonic cells but far more than do adult stem cells from fully developed individuals.



This special insert and this issue of *MS Canada* are supported through an unrestricted education grant from Bayer HealthCare.



Sponsored by

Bayer HealthCare
Pharmaceuticals



Moreover, blood in an infant's umbilical cord can be readily and harmlessly retrieved right after birth.

Researchers from around the world discussed cord blood studies and listened intently to an update from Dr. Joanne Kurtzberg of Duke University, a world-renowned expert in this area. She described successes in cord blood-derived transplants for children with neurologic diseases. These experiences may translate into workable strategies for people with MS.

Something completely different

There are a number of researchers who believe that one potential of embryonic stem cells lies in their ability to help scientists identify effective treatments. An enhanced ability to measure safety and effectiveness means, quite simply, speeding the movement of new findings out of the lab to something useful for people with MS. Picking up the turtle-pace of new drug development should also help reduce the expense.

Dr. Wendy Macklin of the Cleveland Clinic Foundation is working with mouse embryonic stem cells. Her group is using them to screen thousands of chemical compounds looking for any that can prompt immature precursors to develop into mature myelin-making cells. Compounds that do this in the animal cell cultures will be tested in human embryonic stem cell cultures. If they prove safe and effective there, trials of the compounds in people with MS can be planned. This new and very rapid I.D. method allows Dr. Macklin's

group to assess an array of substances that might never have been tested for possible MS therapy by conventional methods.

Go slow to go fast

"There is a real and achievable prospect that stem cells will enable us to repair damaged tissue in MS," said Dr. Robin Franklin, of the Cambridge (England) Centre for Brain Repair, which is taking part in the Society's multicenter Repair and Protection Initiative. "That said, we are still in the very early days," he said, cautioning people to keep their hopes in perspective. "The prospects are too precious to damage them by rushing ahead too fast."

"There is no doubt that stem cell technology holds great promise in healing the lesions of MS," said Dr. Wee Yong, Professor in the Clinical Neurosciences and Oncology Departments at the University of Calgary, and Chair of the Medical Advisory Committee, MS Society of Canada. "However, significant challenges lie ahead. For instance, we have to learn how to steer stem cells to become the right type of cell for repair, rather than wayward ones that might produce unintended side effects." Dr Yong continued, "Nonetheless, scientists are making progress. For example, the MS Society of Canada is funding a major study in Canada which is exploring the potential for a patient's own resource of neural stem cells to replace the cells that are lost in MS."

Stem Cells and MS: Some basic definitions

The world of stem cell research swirls with unfamiliar terms as well as voices of profound objection by some and unrealistically optimistic expectation by others. Here's a review of the basics, as a service to all those who hope to clarify these issues for themselves.

"Differentiation"

When an ordinary cell divides, whether skin cell, red blood cell, or a cell lining internal organs, the product is two cells that are copies of the original. But a stem cell can divide into two cells that become something differ-

ent. This differentiation is a basic life process, and, thanks to the tools of molecular biology, differentiation offers enormous possibilities for human health.

Stem cells of various types may be a source of replacements for sick or injured tissues anywhere in the body. In recent years, adult human stem cell transplants, derived from bone marrow, have slowed or stopped MS progression in a limited number of people with very rapidly worsening disease that didn't respond to anything else.

In a groundbreaking animal study, immature neural stem cells, found in adult mice, were injected into mice with an MS-like disease. The cells were able to travel to the area of damage, stimulate tissue repair, and suppress damaging immune attacks. These findings suggest that neural stem cells residing in the adult brain may not only foster tissue repair, but may, in some circumstances, protect the brain from inflammatory attacks.

In other studies, new glial cells (the glial family includes the cells that make myelin) have been grown from animal stem cells in culture.

And finally, living nerve tissue has been grown from stem cells, although robust normal nerve function has not yet been achieved. The diagram on page 7 helps explain what scientists mean when they use the term "stem cell."

The earliest stage

Embryonic stem cells, or ESCs, taken from a human blastocyst are capable of the greatest range of differentiation and are the object of the most intense ethical concern. These stem cells are obtained from a blastocyst, a human egg that has been fertilized— typically from a fertility clinic storage facility. (Clinics store fertilized eggs that are left over after in vitro fertilization procedures; the couple may opt to donate them.)

Alternatively, ESCs are obtained from an unfertilized human egg, from which all of the mother's DNA was extracted. The egg is then induced to grow using artificial hormones and DNA from a body cell given by the person for whom this therapy is being tailored. This method,

called SCNT or "somatic cell nuclear transfer," offers a promise of producing cells and tissues that will not be rejected as foreign by the recipient's body.

Should an egg like this ever be implanted and survive to term, the infant would be a clone of the DNA donor, an exact genetic copy of just one person. Both law and science agree that this must not happen. Instead, stem cells are removed from the center of the blastocyst between day 4 and 6, to be cultured in laboratory dishes.

While SCNT-based therapy promises to avoid immune-system rejection, the great Catch-22 of transplantation, SCNT therapy would work only for the donor whose cell provided the DNA. In short, this therapy would be engineered one by one, for just one person— a painstaking process, by no means guaranteed of success every time.

The later stages

Since stem cell research began in earnest, scientists have learned that adult humans have many later-stage stem cells in various parts of their bodies with various potentials for differentiation. Research laboratories have isolated stem cells from bone marrow, skin, and nasal linings, as well as somewhat less accessible parts of the body, such as the retina. They have also identified later-stage cells, called progenitor or precursor cells, that differentiate into mature cells of a specific type if they are exposed to biological prompts.

As scientists learn more about cell development and differentiation pathways, they are more and more encouraged about eventually being able to tap their potential for healing MS damage or stopping MS injury.

For more information on stem cell research, including podcasts and transcripts from the Stem Cell Summit held in January 2007, as well as information on stem cell research occurring in Canada, go to:

<http://www.mssociety.ca/en/research/stemcell.htm> or call your local MS Society chapter or division ■

Life lessons



Rubiana Malla was 21 when she sat in a neurologist's office and was told she had multiple sclerosis. "Devastating," she says as she recalls hearing the diagnosis. "I was in the prime of my life. The last thing that occurred to me was that I had a

health issue, let alone an incurable disease."

At first, Rubiana didn't even tell her best friend. "I felt ashamed," she says.

As time went by, she found the strength to share her feelings. "When you're first diagnosed, you're not ready for the whole world to know. You need to go through the process yourself. But then you need to let off steam, and find some-

one you trust."

Sixteen years after her diagnosis, Rubiana is that someone for many facing an MS diagnosis. As peer support volunteer at our B.C. Division, Rubiana talks with other people with MS. "I get to know the person. Be supportive. The bottom line is that we're different once we've been diagnosed. It puts you in a different category. You can't change that. You just have to figure out the best way to deal with it."

This positive outlook has characterized Rubiana's journey. As she experienced reduced mobility, she tried her best to avoid a wheelchair. "I now realize I should have started using it five years earlier than I did. It actually gave me my life back."

It's one of many liberating lessons Rubiana learned since her diagnosis. "It's a matter of helping each other as much as we can," she says. "We all have limitations and we all just do what we can. And, in the end, we get there" ■

ASK THE EXPERT



100 questions expertly answered

Ask the Expert is a popular feature on our website that invites people to send in questions about all aspects of MS. Supported by an unrestricted education grant by Biogen Idec, Ask the Expert enlists top health professionals and researchers in the MS field to answer questions on topics such as daily living with MS, family issues, research, treatment, diagnosis and mobility. We recently answered our 100th question and, as of early April, these questions had been viewed 67,819

times since the site's launch in April, 2006. A new feature on the site allows you to subscribe to receive email notification when new questions have been posted. We welcome any and all questions so that information about living with MS can be shared with people across the country and around the world. Drop by Ask The Expert at www.msanswers.ca anytime and let the learning begin!

RESEARCH IN BRIEF



Dr. Sam Weiss

Pregnancy hormone key to repairing nerve cell damage

The mystery of why multiple sclerosis tends to go into remission while women are pregnant may be the secret to repairing damage caused by the disease. According to University of Calgary researchers, prolactin, a pregnancy-related hormone, is responsible for rebuilding the protective coating around nerve cells. The study was partially funded by the MS Society of Canada.

In a paper published in a recent edition of *The Journal of Neuroscience*, a team of researchers from the U of C's Faculty of Medicine reported that a study conducted on mice found that prolactin encourages the spontaneous production of myelin, the fatty substance that coats nerve cells and plays a critical role in transmitting messages in the central nervous system.

"It is thought that during pregnancy, women's immune systems no longer destroyed the myelin," said Dr. Sam Weiss, director of the Hotchkiss Brain Institute and senior author of the study. "However, no previous study has tested whether pregnancy actually results in the production of new myelin, which may lead to improvement of symptoms."

"It represents a new insight of how we might be able to reverse some of the effects of the disease and improve the quality of life for those who live under its influence," adds Dr. William McIlroy, MS Society national medical advisor.

For more details, go to www.mssociety.ca and enter key search word "prolactin."

Clinical trial results for oral therapy fingolimod

Results of a Phase II controlled clinical trial of oral fingolimod (also known as FTY720) have been published in *The New England Journal of Medicine*. Fingolimod is a class of compound proposed for the treatment of relapsing-remitting MS.

The study found fingolimod significantly reduced MS attack rates and signs of inflammation on MRI scans. Fingolimod binds to a docking site on immune cells, including T cells and B cells that have been implicated in causing nervous system damage in MS.

The once-a-day pill induces them to remain in lymph nodes, preventing these cells from migrating into the brain and spinal cord.

Novartis Pharmaceuticals Corp is sponsoring two clinical trials of fingolimod: a larger Phase III study at 125 centres worldwide, including 10 in Canada and another study at 130 sites worldwide including four in Canada.

For more details, go to www.mssociety.ca and enter key search word "fingolimod."

New insights in benign MS

A study by three researchers from the University of British Columbia, Dr. Ana-Luiza Sayao, Dr. Virginia Devonshire and Dr. Helen Tremlett, suggests some new ideas about how MS progresses.

Published in the February 13, 2007 issue of *Neurology*, the study of 169 people from BC revealed that 20 years from disease onset, the disease had progressed in nearly half of those whose MS was considered benign at 10 years.

This study offers new insights into the course of this disease, and provides physicians with new data to support that

even those with mild symptoms and stable disease need to be monitored over the long term.

It also supports the need for people with MS to stay connected with specialists and MS clinics so that their symptoms, even if mild and occurring some time after diagnosis, can be understood. This data tells doctors that the progression of the disease is individual and predicting outcomes is more complex than has been previously understood.

The study was supported in part by the MS Society's Don Paty Career Development Award.

For more details, go to www.mssociety.ca and enter key search words "benign MS" ■

A question of research



The 2007 MS Research Teleconference was held March 1 with guest speaker Dr. Mark Freedman, director of the Multiple Sclerosis Research Unit at the Ottawa Hospital, leader of the

Canadian Bone Marrow Transplant Study in multiple sclerosis and principal investigator on clinical trials with new therapeutic agents for MS. Listeners from across the country tuned in for two hours of fascinating information exchange. From the questions and answers on the call, we publish one question often posed by those interested in funding specific or general research projects:

Moderator: "Second to cancer, there are more clinical trials relative to MS than anything. Given the relatively rare incident rate, why would that be?"

Dr. Freedman: "There are a number of reasons but, we've done our homework - MS has become the prototypic

disease. If you are a company developing a new therapy, and you want to test it, and you think it might be good for an auto-immune disease - you will want an answer quickly. What better way to test a therapy than to use an excellent system that is already established? This is what we have done. With all the Canadian MS clinical trials and clinical trial experience, we've got a system wherein someone can come with a new neurological product and say, "Tell me if this is going to work, or not". We can tell them in six months if there's a chance that it works for this disease. So if they can get into the auto-immune disease world maybe it will apply to other auto immune diseases like orthostatic, like juvenile diabetes, maybe even thyroid disease. Our MS patients are going to benefit from the fact that the work we've done in the last couple of decades has created a very flexible system for novel therapies to be tested, and if one of them works for MS, we are the winners!"

You can listen to the full research teleconference online at www.mssociety.ca. Or contact Claudette at 1-866-922-6065, ext. 2217 for a copy of the audio CD.

GOVERNMENT RELATIONS & SOCIAL ACTION

VIA Rail must be accessible: Supreme Court

In late March, the Supreme Court of Canada ruled that VIA Rail must make its rail cars wheelchair accessible. The ruling upheld a similar decision by the Canadian Transportation Agency in 2003 which VIA Rail appealed.

As a result of the Supreme Court decision, VIA Rail will have to alter 40 of approximately 100 of the Renaissance rail cars that it bought from France in 2000 at a greatly reduced cost. At the time, VIA Rail said it would make the necessary changes to make them wheelchair accessible, but then claimed it would cost too much.

The Canadian Transportation Agency ordered VIA Rail to make the changes but the company appealed the decision to the Federal Court of Appeal, which ruled it did not have to make the upgrades. At that point, the Council of Canadians with Disabilities (CDA) led the appeal to the Supreme Court of Canada. The MS Society and a number of other organizations supported CDA's initiative.

Federal budget offers several supports

The federal budget, tabled on March 19, included several initiatives which should have positive implications for people with disabilities. The first is a new Registered Disability Savings Plan to help parents and guardians establish long-term savings for family members with severe disabilities.

To address the so-called "welfare wall", the federal government said it will work with provinces to introduce a Working Income Tax Benefit (WITB) to assist lower income workers to stay in the workforce. The WITB will be provided as a refundable tax credit, effective for the 2007 tax year, with payments beginning in 2008.

An additional supplement will be provided for low-income working Canadians with disabilities who are eligible for the disability tax credit (DTC). Benefits from the WITB will start when the earnings of the DTC-eligible individual reach \$1,750.

The budget also included an Enabling Accessibility Fund of \$45 million over three years to contribute to the capital costs of construction and renovations related to physical accessibility for persons with disabilities. Program details are being developed.

In addition, the budget restored most of the program that provides funding to summer students working for non-prof-

it, public sector and small business. The program is now called Canada Summer Jobs and will be very similar to a program that was cut last September.

Newfoundland drug campaign update

"Premier, have a heart."

On Valentine's Day, MS Society representatives delivered this message written on a giant heart-shaped cookie to Danny Williams, premier of Newfoundland and Labrador. The MS Society's Atlantic Division has been conducting an intense campaign to convince the provincial government to include an MS drug cost reimbursement program in its 2007 budget.

As *MS Canada* went to press, it still wasn't known if the Newfoundland and Labrador government would institute an equitable and accessible drug program for people with MS. Updates to follow.

MS Society Day on the Hill



From left: Deanna Groetzinger, vice-president, Government Relations and Policy; Susan Murray, chair, National Government Relations Committee; Yves Savoie; president and chief executive and president, Ontario Division; Minister Solberg; and Neil Pierce, president, Alberta Division

On March 1, members of the National Government Relations Committee met with selected MPs in Ottawa to highlight priority issues including disability income, caregiver supports and health care. A key meeting was with Monte Solberg, minister of Human Resources and Social development. ■

Living Well with MS: Medical Research & Hope

There has never been a more hopeful time for people affected by multiple sclerosis. Research is taking place across the globe at an unprecedented pace. Do you want to learn more about the science behind current and future research? This education series focuses on neuroprotection and its potential application in current and future MS treatment. One of the leading Canadian MS researchers, Dr. Wee Yong, a Professor at the University of Calgary Departments of Oncology and Clinical Neurosciences, will present a brief introduction to the pathology of MS, as well as an overview of current MS research, describing the science behind the exciting field of study in neuroprotection. A clinical neurologist will then offer a brief introduction to MRI and discuss

how a neurologist uses MRI in patient care. The session will also feature a generous amount of time for your questions. Informative, practical, and hopeful – come learn more and join us for a very worthwhile two hours.

These sessions are offered free of charge and are being sponsored by an unrestricted education grant from Shared Solutions® and Teva Neuroscience ■

These events will take place:

Ottawa ON – June 12, 2007

For more information please call 613.728.1583 ext. 124

St. John's NL – June 13, 2007

For more information please 1-800-268-7582

Serving both sides of our mission



The 2006 fiscal year was a real financial success. The Society's income exhibited the highest increase in its history, growing from 26.6 to 30.1 million dollars. If this had been the only highlight, we would already be quite satisfied. But there is more. After several years of ongoing group efforts, we now have reached a balance between services and research, providing each with 9 million dollars.

"So what?" you may ask...Well, a decade ago, for every \$100 available, less than \$40 went to research, and the rest went to services. Services are important and, they still are. Nonetheless, it became evident that the Society needed to intensify its research initiatives to accomplish that part of the mission: to find the cause and cure for multiple sclerosis.

Under Reid Nicholson's leadership, then president of the National Services Committee, a group of people asked themselves: "How can we share our expenses between research and member services?" Eighty per cent responded as follows: for each dollar donated to research, give one dollar to services.

Achieving balance between research and services then became a goal for the Society. Yet, it was out of the question to cut down on contributions provided to services in order to reach this goal. Balance had to be achieved by increasing the total revenues generated and use this growth wisely to benefit research. As secretary-treasurer, David Knight made this his ultimate goal by continuously motivating executives and volunteers throughout every division. In 2003, the board of directors decided that balance needed to be reached by year-end 2007.

Since this happened by year-end 2006, we are one year ahead of schedule. This performance was made possible thanks to the leadership of the boards of directors and division and chapter executives. We must also acknowledge the commitment of the 13,500 volunteers and employees at the Society, at every level of the organization and throughout the Canadian regions.

You all deserve a warm round of applause! But it would be a mistake to stop now. Finances are somewhat like walking on a high wire: it's not all to achieve balance; the key is to keep it! We know now we can do it!

Daniel Larouche

Secretary-treasurer, National Board of Directors

Call for artwork

The MS Society of Canada is looking for your artwork! If you are a person with MS who has produced artwork that could be used for the covers of our publications, we'd love to see it.

Multiple entries are welcome on an ongoing basis, provided they meet the criteria below:

Format: We request a high resolution, electronic image of the work, preferably in TIFF format (300dpi).

Medium: We accept images of work in any medium (water-colour, oil, charcoal, pastel, mixed media etc). Photography is also welcome.

Subject: The work can be on any subject or be abstract. The artwork need not relate to the topic of a given publication.

Submissions are kept on file for possible use in future publications. Artists whose work is selected receive a small honorarium. If the selected artists consent, their name, the title of their work, the fact that they have multiple sclerosis and a description of their work or themselves is included in the publication.

For more information, or to submit artwork on an ongoing basis, please contact Nadia Pestrak, National Coordinator, Client Services and Research:

Email: nadia.pestrak@mssociety.ca

Toll free: 1-866-922-6065 ext. 3049

Direct line: (416) 967-3049



Our warm thanks to artists Sylvia Jennesson from B.C. and Helen Carson from Saskatchewan whose work appears on these MS Society publications. Sylvia's piece, used on the Key Facts of MS cover (left), is called *Wednesday Morning*. Helen's is *Evening Gold*.

Congratulations to our Top TeamMS WALK Teams!

These dedicated teams raised more than \$20,000 each toward our mission. Our great thanks go to each team member for their efforts and to their donors for such generous support. And best wishes to these and all WALKers in our 2007 season!

Team Name	Site
Munnky Krunchers	Edmonton, AB
Curves	Winnipeg, MB
Biogen Idec Team Express	Toronto, ON
SUCCESS MS Self-Help Group	North Shore, BC
Country 105 Rhodes' Warriors	Calgary, AB
Hot Tamales	Calgary, AB
Curves for Women	Halifax, NS
Team Hytek	Steinbach, MB
Team René	Vernon, BC
Team WAMS	Toronto, ON
PricewaterhouseCoopers	Montréal, QC
Al's Pals	St. Catharines-Thorold, ON
ENERFLEX for MS	Calgary, AB
John Ernewein Limited	Kincardine, ON
Les Labo-rieuses	Laval, QC
Cam's Posse	Victoria, BC
Millennium Stars	
Self-Help Group	Victoria, BC
Moxies Marauders	Edmonton, AB
Buddies for Life - Team London Life	London, ON
Sisters Triumph	Toronto, ON
Baum Squad	Banlieue Ouest, QC

MS CANADA

To update your mailing address or subscription preferences, please contact your division office.

Division contact information can be found at:

www.mssociety.ca,

or you can call

1-800-268-7582

or email:

info@mssociety.ca



RETURN UNDELIVERABLE
CANADIAN ADDRESSES TO:
Multiple Sclerosis Society of Canada
700 - 175 Bloor St. E.
Toronto, ON M4W 3R8

Publications
Mail Agreement
40063383