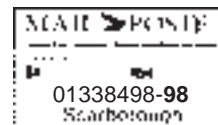


# MS

# CANADA

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



Volume 28

Number 2

May 2001

## Gold medallist Simon Whitfield is MS Ambassador

Twenty-five year old Canadian triathlete and Olympic gold medallist Simon Whitfield has agreed to be an MS Ambassador for the Multiple Sclerosis Society of Canada.

Mr. Whitfield, who won the gold medal at the Olympic Summer games in Sydney, readily accepted the Society's invitation. He sees 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 — as near to his heart.

MS has affected the life of his uncle Hugh Ames for more than 20 years. Mr. Ames lives in a Kingston continuing care hospital and uses an electric wheelchair which he controls with head movements.

"He is incredible," said Mr. Whitfield, who describes his uncle as one of the most inspiring people he has ever known. "Coping with his MS, he runs an Olympic triathlon everyday. Any hardship or obstacle I face, pales in comparison."



**Simon Whitfield, right, with his uncle, Hugh Ames.**

Although there is no known cause or cure for MS, advances in research and treatment are giving hope to people with MS — something Simon Whitfield hopes to do as well.

"Simon is an inspiration to many Canadians, and we welcome him as an MS Ambassador," said Alistair M. Fraser, MS Society president and chief executive. "We believe his example of commitment, perseverance and supporting his community will inspire others to do the same as they take part in our fund raising events and become MS Society volunteers."

Hugh Ames was diagnosed with MS in 1980. At that time he was living in Truro, N.S., where he owned a successful clothing store. Unfortunately, he has a progressive form of MS and decided to return to Kingston to be near his parents and sister's family.

Hugh Ames took a very active interest in Simon's athletic career and made a point of being at as many school track meets as possible to cheer him on.

"Hugh and Simon have a very close relationship," said Win Ames, Simon's grandmother and Hugh's mother. When Simon returns to Kingston, one of the first things he does is drop by his uncle's cozy, memorabilia filled room at St. Mary's of the Lake Hospital.

### MS Awareness Month

May is MS Awareness Month, the time to remind all Canadians that "MS lives here". Join in the many awareness activities by contacting your chapter or calling your division office at 1-800-268-7582.

The MS Carnation Campaign takes place on May 10, 11 and 12.



*(continued on page 2)*

**Simon Whitfield**  
(continued from page 1)

Souvenirs of the Sydney Olympics are on display along with Hugh's prized photographs of the beloved vintage cars he owned previously, movie posters and his own paintings. The paintings are the product of his newest hobby, which he does by mouth.

Obviously perseverance runs in this family.

As an MS Ambassador, Simon Whitfield appears along with his uncle in a short video, which will be distributed to all divisions and chapters very soon for their internal use.

## MS Canada

Volume 31, No 2, May 2001  
Published by the  
Multiple Sclerosis Society of Canada  
250 Bloor St. E., Suite 1000  
Toronto, Ont. M4W 3P9  
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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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ISSN 0315-1131  
Issued quarterly

Canadian Publications Mail Product  
Sales Agreement No. 0178497

Charitable Registration  
No. 10774 6174 RR0001

## Sylvia Lawry 1917 – 2001

The woman who inspired the founding of national MS Societies and the international MS movement passed away February 14.

Following her brother's diagnosis of MS, Sylvia Lawry placed a classified ad in *The New York Times* in 1945 asking for information about the disease.

She received hundreds of letters from people in the U.S. and Canada, which led her to found the National MS Society in the United States in 1946 and to encourage the founding of the Multiple Sclerosis Society of Canada in 1948 and many other national MS Societies in the coming years.

Ms. Lawry was instrumental in the establishment of the Multiple Sclerosis International Federation, as it is now known.

Thousands of people around the world will remember her tenacity in the fight against MS and her determination that the MS problem will be solved.

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

### GET ON THE MS INFORMATION PATHWAY

To keep informed about the latest developments on MS, do not miss the third yearly *INFORMATION PATHWAY SERIES*.

- For people with MS and their caregivers
- Over 30 information sessions across Canada
- From April 15 to June 15, 2001

Each event will be advertised in printed media in the communities where they will be held. Look out for the details on the MS INFORMATION PATHWAY event happening nearest you.

**BERLEX CANADA INC.**



*Searching for better solutions*

*A service working for people with MS*

# Speeding up MS research

How can MS research be speeded up is a question that everyone who has MS has asked.

One answer may lie with the work just beginning at the new Sylvia Lawry Centre for MS Research in Munich, Germany. Led by the MS International Federation, a number of national MS Societies, including the MS Society of Canada, and other supporters are funding this unique data centre.

Data about MS from a variety of sources will flow to the Sylvia Lawry MS Research Centre where it will be scrutinized using the most sophisticated methods of statistical analysis.

“Some researchers are saying it is no longer ethical or logistically feasible to continue to carry out large, double-blind, controlled studies since we now have treatments that are beneficial for some types of MS. By combining both clinical and MRI data from population-based studies and clinical studies carried out by pharmaceutical companies, the centre should be able to create ‘virtual’ placebo groups. This information would be available to researchers carrying out clinical studies in the future,” explained Dr. William J. McIlroy, national medical advisor.

The Sylvia Lawry MS Research Centre just opened its doors this spring following the awarding of the contract to the Institute for Medical Statistics and Epidemiology at the Technical University of Munich.

“Work in establishing and staffing the centre has proceeded at lightning speed under the direction of Professor Albrecht Neiss,” said Reid Nicholson, who is part of the MS International Federation group that is overseeing the project. He visited the centre in Munich earlier this year and was impressed by the knowledge and dedication of the staff. Mr. Nicholson is a member of the MS Society of Canada National Executive Committee and National Board of Directors.

“The centre is a very appropriate memorial to that great lady Sylvia Lawry who founded the MS movement more than 50 years ago,” he added. (See page 2 for a tribute to the late Sylvia Lawry.)

## Federal research agency funds major MS study

The study of some very small substances has turned into a very large MS research project for Dr. Voon Wee Yong and his colleagues at the Universities of Calgary, Alberta, Manitoba, McGill and Montreal.

Dr. Yong has been studying MMPs (matrix metalloproteinases) for several years at the University of Calgary with the help of funding from the MS Society of Canada.

MMPs are enzymes that have an important role in the body’s development, but in MS they seem to turn into “bad guys”, allowing immune system cells into the central nervous system to start the attack on myelin.

In February, the federal Canadian Institutes of Health Research announced that Dr. Yong’s col-

laborative project on MMPs was one of just 10 funded across Canada.

The \$5 million study will allow the investigators to pool their resources to probe the role of



**Dr. V. Wee Yong**

MMPs even more closely and to begin to test whether the common acne medication minocycline can suppress MMP activity. Preliminary work on animal models and on human cells in the test tube has been **p o s i t i v e .**

The researchers also plan to test in animal studies whether the effectiveness of the current therapies beta interferon or glatiramer acetate can be improved by combining them with minocycline.

(For more information, go to the MS Society web site at: [www.msociety.ca](http://www.msociety.ca) and click on the MS Research section under Research and Medical Library.)



**A Year To Celebrate**  
International Year  
of Volunteers

## MS RESEARCH IN THE NEWS

### Edmonton researchers test treatment for MS

A news release from an Edmonton company announcing that it had agreed to acquire all of the issued securities of another company caused some excitement outside the investment world.

The stir occurred because the acquisition involved EPS Capital Corp. acquiring shares in Rycor, a company which has a license for a possible treatment that may be of benefit for people who have progressive forms of multiple sclerosis.

The potential treatment has been in development by Drs. Kenneth Warren and Ingrid Catz of the University of Alberta for more than 20 years. Dr. Warren is director of the MS Research Clinic in Edmonton, and Dr. Catz is a senior scientist at the University of Alberta.

The Edmonton researchers have developed a synthetic segment of myelin basic protein. Called MBP8298, the substance, according to a company news release, puts people with progressive MS in remission, as measured by antibody levels in cerebrospinal fluid during Phase I clinical trials.

Myelin basic protein (MBP) is one of the major proteins that make up myelin, the protective insulating sheath that surrounds nerve fibres. Myelin is composed of both proteins and fats.

The investigators have given MBP8298 to approximately 100 people in either Phase I or Phase II trials over the past 10 years. Currently, it is given by intravenous infusions (into the vein) at intervals

of several months, according to information from the company.

Typically, a Phase I clinical trial involves a small number of people, all of whom receive the active treatment. No placebo is given. The primary outcome is to determine whether a therapy is safe.

A Phase II clinical trial involves more people, some of whom receive active treatment and some of whom receive a placebo therapy. The inclusion of a placebo group allows researchers to collect data on whether a therapy is effective as well as continuing to monitor safety.

“The MS Society welcomes this news and looks forward to the launch of a large, multi-centre, double-blind, placebo controlled Phase III study that should provide definitive information about the therapy,” said Dr. William J. McIlroy, national medical advisor.

A Phase III study may begin next year, according to the company. (For more details, go to the MS Society web site: [www.msociety.ca](http://www.msociety.ca) and click on the MS Research section.)

### MS and diabetes have some similarities

Can a disease that attacks the central nervous system and another that targets the pancreas have much in common?

Maybe, say researchers at the Hospital for Sick Children in Toronto. In addition, they suggest, milk products may be involved in both MS and type I (juvenile) diabetes, although the association is still tentative.

A study headed by Dr. Michael Dosch and reported in two separate papers in *The Journal of Immunology* found more evidence the immunological reaction in the two diseases have a number of features in common. In particular, they found there was a high degree of similarity in their immune cells and how they behaved in the test tube.

The April 1 published report focused on the possible link of high cow milk consumption to the risk of MS and type I diabetes developing in genetically susceptible people.

The researchers found signs of abnormal immunity to cow milk in the 38 people with MS in the study. A possible link between cow milk consumption and type I diabetes, MS and autoimmune diseases in general is controversial.

In the case of MS, various dietary triggers including consumption of dairy products have been suggested over the years, but the problem of designing and carrying out well-defined studies have left previous investigators without clear-cut conclusions.

Both Dr. Dosch and Dr. Paul O'Connor, director of the MS Clinic in Toronto and a member of the research group, cautioned that the results of the study were not substantiated enough to advise people to stop using milk or milk products.

Genetic as well as environmental factors are suspected to be involved in both diseases.

“The studies provide interesting observations and new leads in studying both MS and type I diabetes,” stated Dr. William J. McIlroy, national medical advisor.

(For more details, go to [www.msociety.ca](http://www.msociety.ca) and click on the MS Research section.)

## Hepatitis B vaccine not linked to MS

Two separate studies have found that vaccination for hepatitis B does not increase the risk of developing MS and that vaccinations in general and for hepatitis B, tetanus and influenzas in particular do not increase the risk of MS relapses.

There has been controversy in recent years, especially in France, whether vaccinations against hepatitis B might trigger MS.

“These two well-designed, large database studies provide reassurance to people with MS and their physicians that vaccinations against these diseases are not linked to the development of MS or MS relapses,” said Dr. William J. McIlroy, national medical advisor.

(For more details, go to [www.msociety.ca](http://www.msociety.ca) and click on the MS Research section.)

## Cholesterol-lowering drug tested for MS

Simvastatin, a common cholesterol-lowering drug, will be tested in a small Phase I (non-controlled) study for safety and to determine if the drug has any effect on MS brain lesions as measured by MRI scans.

The study, which will take place at three sites in the United States, follows observations at the Medical University of South Carolina that simvastatin (tradename Zocor) had a positive effect on rats with an MS-like disease.

## Recent clinical trial results:

### Antegren

A company news release suggests Antegren (natalizumab) re-

sulted in a reduction of the proportion of people experiencing relapses, compared to those on inactive placebo. The six-month study was conducted at 26 sites in Europe and North America and involved 213 people with relapsing-remitting MS or secondary-progressive MS.

The results were based only on MRI scans of the brain to detect active MS lesion (areas of inflammation). Other study results, including clinical effects, are expected to be released in the future.

Antegren is a monoclonal antibody which is injected in the hope of interfering with the movement of potentially damaging immune cells into the central nervous system.

Further study would be needed before Elan Corporation and Biogen, Inc. could apply for marketing approval of the drug.

### Avonex

In a study published in the December issue of *The Annals of*

*Neurology*, investigators have found that Avonex (interferon beta-1a) had a modest beneficial effect on a number of cognitive functions among people with relapsing-remitting MS.

Dr. Jill Fischer of the Cleveland MS Clinic analyzed data from a subset of 166 people enrolled in the original Phase III clinical trial of interferon beta-1a. She reported that at the end of two years, those receiving treatment did better than those on placebo on cognitive functions such as information processing, learning and memory.

Cognitive problems occur in about half of people with MS with the most common problems being memory deficits and slowed information processing. Recognizing that cognitive problems can occur is important since ways to assist with memory difficulties and slowed processing of information can be instituted.

(For more details, go to [www.msociety.ca](http://www.msociety.ca) and click on the MS Research section.)



**MS 2000: Symposium on Conquering MS** – Stimulating research to find more effective treatments and ultimately the cure for MS was the goal of this first conference to bring together MS Society-funded researchers and students. Held in December, the multi-disciplinary approach featured sessions on myelin regrowth, possible causes, immunology and potential treatments. Shown here is studentship recipient Julie Richard, Dalhousie University, and researcher Dr. Jack Antel, McGill University.

# Being proactive

by Keith Daniels Whitcher

I greatly enjoy reading about others with MS. It is comforting to hear from others who share similar circumstances although this past fall was the first time I attended an MS Society function. It was the Saskatchewan Division's Family Conference in Saskatoon.

Eleven years have gone by since I was diagnosed. I had avoided any MS associated social events. I suppose I was, for the most part, in denial about having MS and believed if I was around others with the same disease I would become further depressed. The prospect of being shown how physically disabled I might be truly frightened me.

Fortunately and unfortunately my life over recent years has turned stranger than fiction. I could never have imaged the likelihood of what I have had to overcome: From meningitis to a brain tumour and a

seizure to a fractured vertebrae and loads of MS complications.

In between it all, one good thing that has come from all this is knowing how incredibly important loved ones, family and extended family, and rapport with caring doctors are to overcoming unexpected dilemmas. With supportive team members, a successful end can be achieved.

I have now learned that the only real disability with MS is one's frame of mind. My joyous discovery, found by attending this conference, was in knowing how extensive my extended family really is.

I am an artist and have been since the time I was diagnosed with



This piece is entitled "Musical Chair Person".

MS. The stereotypical mystique of "The Artist" coupled with MS led me toward a life of reclusion. It was for a while a beneficial period for reflection and self-discovery.

It is now impossible for me to remain a recluse. I had a taste of being proactively assertive at the MS Family Conference. One speaker Dr. Cate Archibald spoke of the importance of being proactive about one's MS and that hit home for me with respect to my own self exploration.

I would even take it so far as to say I strive for a rapport with my MS rather than distancing myself from it as if it were an enemy. The proactive aspects I had been developing myself suddenly got a cue to direct outward to my new extended family.

*(Keith Daniels Whitcher is a Saskatoon-based artist. To view more of his art, check out: [www3.sk.sympatico.ca/clue](http://www3.sk.sympatico.ca/clue))*



Keith Daniels Whitcher and friends.

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# Start surfing with 'tried and true'

By Carrie Bell

Today's query: where's John Feld and why am I writing his column? John has accepted a new challenge, and graciously suggested that I, Carrie Bell – freelance writer, mom, resident of Toronto, and regular patient at the MS Clinic at St. Michael's Hospital in Toronto – take up the task of continuing *Surfing with MS*.

Happy for the opportunity, I wish John all the best of success with his new endeavour, and hope that this column will continue to offer helpful tips and useful information about navigating the web and discovering ways that technology can enhance our days.

I am an avid Internet surfer. I surf for entertainment's sake, I surf when doing academic research, and I surf for the daily news. I do my banking on-line and am gradually coming to be quite reliant on cyberspace for communication (Yea e-mail!). I've recently been exploring new ways and methods of using a computer to establish a viable work base, one that will generate some income and allow me to remain an active, productive member of the community-at-large

This little project has led me on many a wild goose chase as the hours tick by and the laundry piles up. There's one heck of a lot of information out there, and as I continue on my odyssey, I find it increasingly necessary to focus on a few tried and true launching points that have proven themselves credible and user-friendly.

My favourite starting point is the *Adaptive Technologies Resource Centre* web site. The ATRC



is part of the *Information Commons* located at Robarts Library on the University of Toronto's St. George campus. Loaded with learning resources and highly skilled, friendly staff, their site provides a wide breadth of information.

A click on their Technical Glossary heading provides an introduction (with photographs) to what's on the market today, including Braille embossers, alternative keyboards and external speech synthesizers. Though they do not endorse any specific products, a look at this catalogue might present a sense of new possibilities for anyone struggling with disability – especially the uninitiated. The site also provides a great list of well-organized links for quick referrals to manufacturers' web sites.

For example: Dragon Dictate and Naturally Speaking, two very current and popular voice-recognition software programs. These programs require some set-up (they have to learn your personal voice patterns) and using them effectively takes a little patience and practice. However, when typing is a problem, they can be a godsend. Do check the hardware specifications from the company (these

can be checked on-line at [www.dragonsys.com](http://www.dragonsys.com)) or look for links to web sites for other voice systems on the ATRC's product reference site. Though voice-recognition programs require a lot of computer memory and are quite costly, once mastered, they are well worth the investment.

The ATRC web site also outlines educational opportunities, including potential on-line programs specifically geared toward students living with disabilities. During the school year ATRC holds a series of workshops on adaptive technology. These are free, and open to students, staff, faculty, and members of the community. The web site also includes easy to spot e-mail links to staff, should one wish to consult one of the experts.

The Adaptive Technologies Resource Centre address is [www.utoronto.ca/atrc](http://www.utoronto.ca/atrc)

Another interesting site hails from the Trace Research & Development Center, a part of the College of Engineering at the University of Wisconsin-Madison. The URL is [www.trace.wisc.edu](http://www.trace.wisc.edu)

Finally, look to the Microsoft Corp. and Apple Web sites for news about software developments and trends.

Happy surfing!

*(To contact Carrie Bell, e-mail her at [info@mssociety.ca](mailto:info@mssociety.ca) Indicate that your message is for Carrie Bell. Or you can write to her at MS Canada, MS Society of Canada, 250 Bloor St. E., Suite 1000, Toronto ON M4W 3P9; fax number: 416 922-7538.)*

# PEOPLE IN THE NEWS

People with MS are very creative and active individuals. Here are some recent examples.

## **Rebecca Naylor: Playwright**

**Rebecca Naylor** was just 17 in 1997 when she was diagnosed with MS. With the encouragement of her London, Ont. high school drama teacher, she turned that experience into a 20-minute scene which has become a play called *Equability* which toured Ontario in March.

The play, first produced at Ryerson Polytechnical University in 1999, where she is a student, uses five actors who portray the various emotions of dealing with disease and disability. The actors take turns portraying the individual who has been diagnosed and the other characters.

## **Ahmed Hassan: Composer**

**Ahmed Hassan**, percussionist and composer, initiated and directed *14 Remembered*, a collaborative requiem that took place in December 2000 in Toronto in honour of the 14 women killed at l'École polytechnique December 6, 1989.

Although he can no longer play himself because of MS, he combined and directed the contributions of 12 other musicians and dancers in what has been called a cry of protest against violence towards women.

Born in New York, Mr.

Hassan lived and studied for many years in Egypt and Halifax, before moving to Toronto.

## **Jim Stinson: Activist**

**Jim Stinson** of Sydenham, Ont., found himself on the front page of the *Kingston Whig-Standard*, just for being himself. When he was no longer able to work because of MS, he decided to pursue a degree in environmental studies at the University of Waterloo through long-distance education. He accomplished that goal last year, with his final project focusing on urban accessibility.

Accessibility is a subject he and his family have experienced first hand, especially when they try to attend community events or

travel. Now, he has turned his attention to urging governments to make accessibility a priority.

## **Book featuring MS nurses nominated for prize**

**André Picard's** book *Critical Care: Canadian Nurses Speak for Change* is a finalist for the top science book of the year. The book explores the changing role of nurses and looks at the shortage of nurses in the health-care system.

Two of the nurses featured are **Wendy Morrison**, nurse and research coordinator at the MS Clinic, University of British Columbia, and **Colleen Harris**, nurse and clinic coordinator at the MS Clinic, Foothills Hospital, Calgary.



**The Manitoba Division adapted the new MS Society "MS lives here" public awareness campaign for a month of free advertising courtesy of Winnipeg Transit. Hundreds of thousands of transit riders and drivers saw the MS Society message throughout January.**