



Connections

Information for People Living with MS

Volume 11, No. 2 June 2003

MEMBER PROFILE

Liz Tokar - Wolff

When you speak with Liz Tokar-Wolff, it is immediately evident that she is a unique individual. If you were at last year's family conference, you will remember her compelling presentation, *Patience and Passion - Living with Chronic Disease*. The response to this session was very positive and she will be returning for both the health care professionals' and the members conferences in November (see page 3 for details.)

What makes Liz exceptional is her personal experiences and her extraordinary dedication to the people she works with. She is a Marriage and Family Therapist who knows first hand what her clients are experiencing - because she's been there. She's been a patient, a caregiver, as well as a therapist.

She entered the field of marriage and family therapy after she herself underwent a




In 1996, Liz was diagnosed with cancer. *"It was an extremely difficult time in my life,"* she recalls. *"I was keenly aware of the effect my illness had on my family."* Her youngest daughter in particular

reacted strongly, becoming more attached, almost clingy. Liz sought professional assistance for her daughter during this time. Although her cancer is now in remission, Liz subsequently developed depression for which she still takes anti-depressant medication.

Just three years ago, Liz's husband was diagnosed with pre-clinical multiple myeloma, a form of cancer affecting bone marrow. The caregiver role has been reversed, giving her a greater understanding of the many challenges faced by caregivers.

individuals and families facing marital conflict, issues with sexual identity, depression and psychological illness. She holds a variety of workshops including *Women and Self Esteem* and *Divorce Adjustment*.

Above all, Liz stresses the importance of open communication between family members. When faced with adversity such as family illness, divorce or separation, it makes all the difference. Liz is available for counselling services in Winnipeg. If you would like a referral, please call Susan at the MS Society at 988-0901. 

CONTRIBUTORS

Thank you to the following contributors to this issue of *MS Connectons*: Tracy Brown, Dennis Dyck, John Hudson, Gwenda Nemerofsky, Sandy Popham, Robin Searle, Sharon Segal, Cristina Toporas, Norm Velnes and Jennifer Wilson.



We are aware that there are other organizations whose names sound like ours. Look for the broken MS symbol to ensure you are dealing with the MS Society of Canada.

Waiver: The Manitoba Division of the MS Society is proud to be a source of information about multiple sclerosis. The content in *MS Connections* does not represent therapeutic recommendation or prescription. For specific information and advice, consult your physician. Articles in this newsletter do not

News from the Chapters

The South Central Chapter is pleased to welcome several new staff members: Diane Nesbitt, Deb Petersen and Cheryl Fedorchuk. Diane coordinates the fundraising in the Portage area, assists with office administration and facilitates the Carman Caregiver Support Group held the second Wednesday of every month in the Carman Memorial Hospital. Deb and Cheryl jointly coordinate the fundraising events in the Morden area and assist with office administration. Cheryl facilitates the Self-Help/Education Group that meets the third Wednesday of every month in the Ron Wiebe Agencies Building.

The Parkland Chapter has been very busy over the past 10 months. With the donated office space in the Swan River & District, we have been able to provide client services and programming to more northern parts of the province. As of this printing, client services programs have ended for the months of June, July and August, but will be starting up again in September. The Swan River office will be closed during these months as well, but immediate Client Services are available by calling 1-204-734-6343.

Manitoba Division Client Services Staff

Client Services is made up of staff and volunteers, providing a wealth of knowledge, experience and commitment. Staff members provide services directly and assist volunteers in helping people with MS to help themselves. **All can be reached through the MS Society's toll-free line: 1-800-268-7582** or directly at the numbers below:

Norm Velnes..... Executive Director
(204) 988-0916

Tracy Brown..... Director of Services
(204) 988-0907

Dennis Dyck..... Resource Coordinator &
Program Planner
(204) 988-0902

Sharon Segal..... Social Action Coordinator
(204) 988-0904

Judy Hermiston..... Client Services Assistant
(204) 943-9595

Susan Hologroski... Manager, Winnipeg
Chapter **(204) 988-0901**

Jennifer Wilson..... Office Administrator,
South Central Chapter
Portage office
(204) 239-1308
Morden office
(204) 822-1397

Kara Happy..... Acting Manager, Brandon
& District **(204) 571-5672**

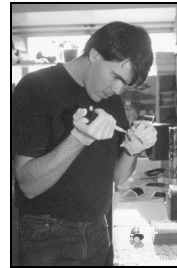
Robin Searle..... Manager, Parkland
Chapter **(204) 622-2940**

TBA..... South East Chapter

Conference News

Two are Better Than One!

Learning, Leading, Living
Saturday, November 8, 2003
Delta Hotel



The MS Society has great plans already in place for the 2003 annual conference. Two one-day conferences will be held simultaneously; one for members, and *for the first time in Manitoba*, a conference for health care professionals. The conference will provide health care professionals with increased knowledge and current information to assist them to better care for their patients with MS.

The overall theme for both conferences is **Learning, Leading, Living**. The members' conference is called "**YES, YOU CAN!**" The Health Care Professionals' Conference is called "**Keeping Up With MS**".

The information provided by a committee of people affected by MS, combined with information gathered from the past two years' conference evaluations, determined the majority of the content of the members' conference. There will be core sessions of



YES YOU CAN!

Topics will include:

1. Overview of the MS Society - A brief report on the future directions of the Society, including an overview of services from all chapter managers and information from the Social Action Coordinator about current social action initiatives.

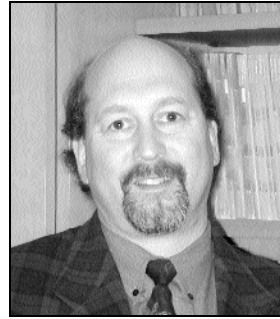
2. Epidemiology - a Manitoba Viewpoint: Have you ever wondered why Manitoba has such a high incidence of MS? This presentation by **Dr. Lawrence Elliott** will help explain this phenomenon. Dr. Elliott recently collaborated on a pilot study on the subject of MS in Manitoba.

3. Choice of one of two sessions:

a) **Getting Past No!**

A panel discussion of people with MS who have worked through self-imposed barriers that sometimes affect decisions. Marriage & family therapist **Liz Tokar-Wolff** (see article on front cover) returns by popular demand to moderate this session.

b) **Cognitive Effects: Tips for**



Dr. Mark Freedman

4. MS Society Funded Research - Dr. Mark Freedman, Director of the Multiple Sclerosis Research Unit, will give an overview of research projects funded by the MS Society, including his highly publicized work in bone marrow transplantation. (Joint session of both conferences)

5. Choice of:

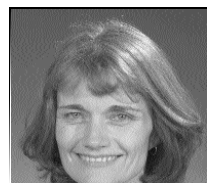
a) **Navigating the Home Care System in Manitoba**, facilitated by **Norm Freedman**, Case Coordinator, Special Programs at Home Care and two MS Society members will discuss their experiences - one with self-managed care, the other with standard home care.

b) **Benefits of Remaining Active** will be presented by **Jutta Hinrichs**, an occupational therapist coordinating the outpatient multiple sclerosis rehabilitation program, 'OPTIMUS' in Calgary.



Jutta Hinrichs

6. Choice of:



a) **Living with Progressive MS** presented by **Colleen Harris**, Nurse Coordinator of the University of Calgary

years experience in the areas of functional design for products and buildings in respect to issues of disabilities, aging and universal design,

- **Bill Brereton**, a Mechanical Engineer from the Electronics and Mechanical Assistive Technologies section of the Rehab Engineering Dept., Health Sciences Centre and
- **Carrie Houston**, Senior Occupational Therapist from Community Therapy Services.



The conference ends with a joint banquet featuring live entertainment by Manitoba singer/songwriter **Damien Lussier**.

Both conferences are being held at the Delta Winnipeg Hotel. A block of rooms has been secured including all wheelchair accessible rooms. Additional wheelchair accessible rooms have been booked at the neighbouring Sheraton Hotel. Current members will receive a conference mailout in September.

Health Care Professionals' Conference: **KEEPING UP WITH MS**

We have done an extensive mailing to health care professionals (including physicians, pharmacists, nurses, psychologists, counsellors, physiotherapists, occupational therapists and more) province-wide. Ask

Practitioner, MS Clinic, Winnipeg.

- c) Pain in MS and Current Treatment Strategies, *Dr. Catherine Archibald*, Clinical psychologist, OPTIMUS Program/MS Clinic, Calgary
- d) Effects of Rehabilitation on Impairment, Activity, Participation, and Quality of Life, *Jutta Hinrichs (see p.4)*
- e) Cognitive and Emotional Aspects of MS, *Dr. Catherine Archibald (see above)*
- f) Children and MS, *Dr. Brenda Banwell*, Pediatric neurologist, Toronto Sick Children's Hospital
- g) Helping Families Master the Challenge, *Liz Tokar-Wolff*
- h) Confronting Issues of Fatigue in MS, *Susan Forwell*, Occupational therapist, University of British Columbia
- i) Psycho-Social Issues - Tips for Health Care Professionals, *Dr. Jennifer Rodgers (see p.4)*
- j) Bladder and Bowel Dysfunction, *Diane Lowden*, Clinical Nurse Specialist, MS Program, Montreal Neurological Hospital, McGill University Health Centre



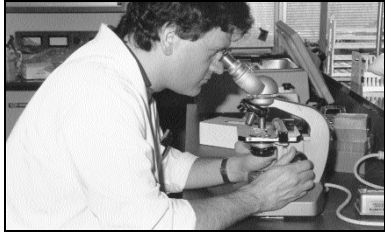
Dr. Catherine Archibald



Dr. Brenda Banwell



Susan Forwell



Research News

Misoprostol in the Treatment of Trigeminal Neuralgia Associated with Multiple Sclerosis

What is trigeminal neuralgia?

Neuralgia, the sudden pain that occurs along the distribution of the peripheral nerve, is often lightning-like in quality and extremely severe. Trigeminal neuralgia involves the part of the trigeminal nerve that innervates the face, cheek and jaw. It affects two percent of all people with MS and is 400 times more common in people with MS than in the general population.

Multiple sclerosis can be associated with trigeminal neuralgia and is often difficult to treat. An open prospective trial on the efficacy and safety of the prostaglandin-E1-analogue misoprostol (600 &mgr;g per day) in the reduction of attack frequency and pain intensity in patients with refractory trigeminal neuralgia associated with multiple sclerosis was conducted. Eighteen patients completed the study period and 14 of them showed a reduction of more than 50% in attack frequency and intensity beginning five days after treatment onset. There were only mild and transient drug related side effects.

Bone Marrow Transplant Study Update Participant Death Appears Related to Transplant Complications

Medical Update Memo

May 15, 2003

The Multiple Sclerosis Society of Canada has been informed that a death has occurred in the bone marrow transplant study, which appears to be related to one of the drugs used in the transplant procedure. The Multiple Sclerosis Society of Canada regrets this death. While the study participant and his family were aware of the potential risk of having this experimental treatment, this outcome is sadly felt by all involved.

The transplant group is very closely reviewing the details surrounding the death and will report to the safety committee for the study. The committee will carefully evaluate the procedures being used and determine if any changes should be made. No additional participants will be transplanted until after the safety committee has met, but potential candidates will continue to be screened. The possibility of a death occurring with this procedure is a known risk and all of the participants are made aware of that during the screening procedures.


Background:

The Multiple Sclerosis Scientific Research

severely disabled. Twenty-four of the participants are to receive bone marrow transplantation while eight other people with the same kind of MS but who do not wish to have the procedure will be the control group.

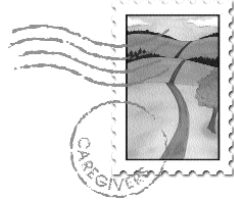
Seven participants have been treated to date with six coming through the procedure safely. Bone marrow transplantation is used frequently to treat leukemia. Because of the invasive nature of the treatment, there is a statistical possibility of a 5 to 8% mortality rate.

Six of the seven transplant recipients had no serious complications as a result of the treatment. In initial follow-up, the indications are that their disease has stabilized. They are being monitored closely with MRI scanning and immunological testing.

This report and more research information are available on the national website at www.mssociety.ca/en/research 

NEWS FLASH!

As of May 1, 2003, Betaseron® has been approved for treatment of secondary-progressive MS.



FAMILY CAREGIVER PILOT PROGRAM UPDATE

Through the Family Caregiver Pilot Program, we have been able to learn a lot about the needs of family caregivers of persons with MS as well as services and strategies for meeting those needs. The evaluation of the Caregiver Special Assistance Pilot Program and the development of the education resource are both in the final phases.

Taking Care: A Travel Guide for Your MS Caregiver Journey is a new resource for caregivers of persons with MS which will be available in the summer of this year. This “travel guide” has been developed based on the input of more than 100 caregivers of persons with MS who shared their knowledge, experiences, opinions and advice by participating in focus groups and advisory groups as part of the MS Society Family Caregiver Pilot Program funded by The J.W. McConnell Family Foundation.

This information guide for caregivers provides information and tips from other caregivers on the topics of caregiver self care and accessing information and commu-

Division office. To request travel guide materials, please contact **Dennis Dyck** at 988-0902 or 1-800-268-7582 or by e-mail at: dennis.dyck@mssociety.ca or **Michelle Gibbens**, 832-2492 or by e-mail at: caregivers@mssociety.ca

Caregiver Special Assistance Pilot Program Evaluation Wrapping Up

Almost 400 caregivers received funding from this pilot program. This enabled these caregivers to access a wide range of services, activities and items that they identified as contributing to their emotional, spiritual, physical and/or social rejuvenation and enabling them to have the reserves and resources they needed to care for their family member or friend with MS. The evaluation report and recommendations are currently being finalized. Watch the next issue of *MS Connections* for more information on next steps beyond the pilot program or please contact **Michelle Gibbens**, Family Caregiver Pilot Program Manager at (204) 832-2492 or e-mail: michelle.gibbens@mssociety.ca



Results of Growing Up Strong Survey: Supporting the Children of Parents With MS

In the drive to support day-to-day efforts of people with MS, and to find treatments and a



of Parents with MS, a two-year project funded through a grant from Health Canada. This project will develop, evaluate and deliver integrated programs and services nationwide for children aged 6-18 who have a parent or parents with MS.

You may recall the survey information included in the Fall 2002 issue of *MS Connections*. The survey, developed by the National Client Services Department and administered in late 2002 and early 2003 identified areas in which additional programs and support would be beneficial for children of parents with MS. We would like to offer you an overview of the survey results and thank everyone involved in this process for their valuable support for the development and completion of this important step.

The overall survey process included a set of questionnaires designed for three separate groups (children aged 12-18 of parents with MS, adult children of parents with MS, and parents) and a series of five focus groups for children aged 6-12 of parents with MS. Half of the 368 questionnaires received were completed by a parent, 1/4 by an adult, and 1/4 by a child aged 12-18. Thirty children aged 6-12 participated in the focus groups held in Barrie, Hamilton, Hull, Ottawa, and Montreal.

The survey had a strengths-based approach. We asked the respondents to

Self-Help Groups and One-on-One Peer Support

The MS Society is pleased to offer a variety of support programs to meet the varying needs of individuals living with MS. Some people enjoy being part of a group experience for the social interaction, information and for the diverse and experiential support it offers. Others are more comfortable relating one-on-one and so this new option, *One-on-One Peer Support* is now available throughout the province. For more information, or to start a group in your area, please call the contact person nearest you or call **Dennis Dyck at 1-800-268-7582.**

Brandon

MS Society office,
Unit 8 - 920 6th Street -
7:00 p.m., 2nd Tuesday of
the month and/or 2 p.m.
each 3rd Wednesday
Contact: Kara Happy
(204) 571-5671

Carberry

Contact: Donna Pingert
(204) 834-2557

Carman

Southern Manitoba
Caregiver Group. Meets
the 2nd Wednesday
of the month at Carman
Memorial Hospital's
Multipurpose Room.
Contact: Diane Nesbitt
(204) 239-1308

Dauphin

Contact: Robin Searle

Flin Flon

Contact: Debbie Bailey
(204) 687-3256

Gimli

Contact: Kathy Wiebe
(204) 642-5760

Lac Du Bonnet

(Beausejour, Pine Falls,
Pinawa) **Contact: Bob**
Dickey (204) 268-2178

Morden/Winkler

Contact: Dennis Dyck
1-800-268-7582

Pipestone

Meets 1st or 2nd Sunday
of each month alternating
between Pipestone
and Moosomin
Contact: Donna Low
(306) 646-2286 or
Lorraine Fidelak

Russell

Contact: Rachel Chipelski
(204) 773-2199 11

Selkirk

Contact: Dan Payne
(204) 757-4773

Steinbach

Contact: Dennis Dyck
1-800-268-7582

The Pas

Contact: Robin Searle
(204) 622-2940

Thompson

Contact: Debbie Thorne
(204) 677-5265

Winnipeg

Male Caregivers Self-Help
Group, Optimists, Coping
with MS, CHuMs, Well-
Grads, Faces of MS (ages

of strong families. At the end of this section, it asked whether respondents agreed or disagreed with the statement *“Overall we are a strong family.”* Scoring methods show that the respondents’ assessment of the strength of their families is quite accurate. The survey data has been analyzed comparing the views of “strong” and “weaker” families. “Strong” families are defined as all respondents indicating that they “agree” or “strongly agree” with the statement, and “weaker” families are defined as all respondents indicating that they “disagree”, “strongly disagree” or “neither agree nor disagree” with the statement. Our approach tried not to focus solely on the negative aspects of the disease, to avoid undermining the situation of families with MS. The data was analyzed comparing the views of "strong" and "weaker" families.

The results indicate that 37% of children find their parent's MS upsetting. MS has the highest levels of impact on the children's emotional development, participation in recreational activities, behaviour, and social activities with friends. School performance/ physical activities are much less affected.

Thirty to 40% of respondents believe that children are affected by their parent's mood changes and emotional outbursts, worry about the parent's MS, the stresses it causes between their parents and not knowing what to expect. In all these areas,

the disease by knowing what to expect, particularly whether a person could die from it.

Children also want other people - including the general public - to be better educated about MS.

However, many of the families do not employ strategies that could be effective in reducing the impacts. Results show that 40% of children say they do not talk about emotions and fears that result from a parent's MS. Children learn how to deal with their feelings first and foremost from family members. Approximately 35% of adult children and 23% of children aged 12-18 indicate that

"I think that all concerned need to realize that children whose parents have any form of disease or disability are profoundly affected. [...] Camps, weekend excursions, etc. would be wonderful - to be able to be with people who understand and to GET AWAY from the stress and the situation. Schools and churches both need to recognize that there are many unseen stresses on children whose parents are disabled. I think that everyone was so focused on the fact that my mother was affected that no one stopped to think about the children. We put on a good show for the outside world. We looked well adjusted so no one asked if I was affected. I don't think that my mother realizes that I am still very bitter about many of the things that happened to me due to the whole situation."

respondents indicate that most of the information available is aimed at teenagers; there is much less material for younger children. Parents need parenting tips for families with MS; children need information on how to talk to their parents and friends.

The programs that respondents indicate would be most helpful are:

- Programs that strengthen the understanding in schools and communities about the challenges faced by children whose parents have a health problem or disability.
- Programs that focus on developing skills for creating “strong” families.
- Programs specifically geared to activities and support for children and families.

Respondents indicate that the best way to get such information is through videos, followed by the Internet, written materials and school programs, more than meetings.

The survey results will enable the project team, working together with Chapters and Divisions, to evaluate the existing programs, pilot new ones to fill the identified gaps and deliver programs and resources for children of parents with MS and their families.

The results of the survey will be posted on the Society's web site in mid-June. For additional information, please contact Cristina Toporas, Project Manager, at cristina.toporas@mssociety.ca or at (416) 922-6600 ext. 2200.



LIBRARY NEWS

Division Library Renewed, Revamped

Thanks to a great deal of dedicated volunteer work, the MS library has now been reorganized, with books and videos properly catalogued. Resource material has been reviewed and outdated material has been removed. We have also acquired an impressive selection of new books. *Stop by and have a look; take a book!*

Have Books, Will Travel: New Travelling Library

The Manitoba Division is pleased to report that we now have a travelling library to help meet the needs of our rural members. You will now have increased access to and receive the most up-to-date information. The travelling library will be in each chapter for three months at a time. It is now at the Parkland Chapter and will be there until the end of June; it will then be in Brandon from July to October, South Central Chapter from November to January 2004, then off to the South East Chapter from February to April.



This still is not a perfect solution, and we will continue to try to develop initiatives to improve access to the library for *all* members. Your feedback is always welcome to assist us in making improvements to our

New Articles in ASK MS:

- Positive Sexual Effects of Chronic Illness
- The Therapeutic Potential of Stem Cells from Adults
- Breaking the Silence: Women Living with MS & Urinary Incontinence
- Vitamin B12 & Its Relationship to Age of Onset of MS
- Studies suggest a link exists between smoked meat consumption & MS
- Randomized, comparative study of interferon B-1a treatment regimens in MS
- A randomized, double blind, dose-comparison study of weekly interferon B-1a in relapsing MS
- Needed in MS - Evidence, not EVIDENCE
- Key issues in the diagnosis & treatment of MS: An Overview
- Juvenile multiple sclerosis: Clinical features and prognostic characteristics
- Seizures in patients with MS seen at Mayo Clinic, Rochester, Minn, 1990-98
- Gender-specific differences in the process of coping in families with a parent affected by a chronic somatic disease (e.g. MS)
- New look at force-frequency relationship of human skeletal muscle: Effects of Fatigue
- Multiple Sclerosis in Childhood; report of 16 Cases
- Is there a Role for Human Herpesvirus-6 in the Course of MS?

FUNDRAISING NEWS

Upcoming Event Schedule

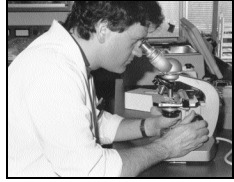
- May - October** Hit a Ball for MS at golf tournaments across Manitoba 
- August 23 & 24** Biking to the Viking MS Bike Tour (Stonewall to Gimli)
- September 13 & 14** Riding Mountain Challenge MS Bike Tour (Dauphin to Wasagaming)
- September 14** Elite Communications' Cruisin' Manitoba for MS Classic & specialty car cruise Winnipeg/Carman/Altona/Winnipeg)

We always need volunteers for our events. Please call us at **1-800-268-7582** or **988-0919** (in Winnipeg) if you would like to become part of the fundraising effort that supports services and MS research.

THANK YOU to everyone who came out to walk, volunteer or cheer on the day of the Super Cities Walk for MS, held in 10 Manitoba communities! We are pleased to report that we raised **over \$701,000** province-wide.

Planned Giving

Help the MS Society Fund Research



Over a century has passed since MS was first diagnosed. Since our founding in 1948 more than \$80 million has been invested in life-changing research. Although we still have not found the cause and cure we've come a long way since MS was first diagnosed in the 1860s.

In spite of the fact that we've made progress, we have to continue the search for effective treatments and the cause and cure for MS. This very specialized task takes the right people and sufficient funds to not only maintain current research but to launch new research programs. Very few of us can sit at a table in a lab conducting experiments but most of us can help fund current and future research. The MS Society of Canada funds approximately 60% of all the MS research in Canada. Some of that research is now happening in Winnipeg through the St. Boniface Research Centre and the MS Clinic at the Health Sciences Centre (see *Words of Inspiration* on next page.)

So dream about a future free of MS and then think about a planned gift that is designated for research. We do have the ability to shape the future - and a planned gift

Confidential Reply Form

Please contact me with information:

Name _____

Address _____

Postal Code _____

Phone _____

E-mail _____

Return to: Norm Velnes, Executive Director, MS Society of Canada, MB Division - 400 -141 Bannatyne Ave., Winnipeg, MB R3B 0R3
Fax: (204) 943-8444 **or**
E-mail: norman.velnes@mssociety.ca

Collaborative Program Supports Parents and Children with MS

While MS in children is rare, children who develop MS have unique needs and so do their parents and other family members.

Children with MS: North American Family Support Network is a collaborative program of the MS Society of Canada and the National MS Society (USA). Through the program, parents can access regular teleconferences featuring specialists in pediatric MS, parent support groups, short-term telephone counselling, information and referral, and for children and parents

Words of Inspiration

by John Hudson

The word "inspiration" is, by simple definition, anything that motivates somebody to do something. It is that which encourages someone into greater efforts, or greater enthusiasm and creativity. Inspiration has driven mankind to lofty enterprise; our species has left dusty footprints on the surface of the moon, a feat made possible only by those who dared to dream, and achieve.

Inspiration, by its very nature, creates innovation and hope. For the 50,000 Canadians living with multiple sclerosis, the promise of a better future can be realized if the appropriate resources are provided to navigate the infinite labyrinth of medical research. Indeed, we're beginning to see the benefits that such research can bring. Some of the most innovative research into better treatments for MS patients is happening *right here in Manitoba*, in the city of Winnipeg.



Dr. Maria Melanson

Dr. Michael Mayne, of the St. Boniface Hospital Research Centre, and **Dr. Maria Melanson**, director of the MS Specialty

It is generally agreed upon by the medical community that multiple sclerosis is primarily an autoimmune disorder. The body's immune system initiates an attack and



Dr. Michael Mayne

destroys a white fatty substance called myelin, which acts as an insulator for the electrical pathways of the central nervous system. Under normal circum-

stances, this type of damage is thwarted by the presence of the blood brain barrier, a tightly packed layer of cells, which encapsulates and protects the central nervous system from intruders. In people with MS however, immune system components such as T-cells are somehow able to adhere to, and penetrate the blood brain barrier. *"If we stopped these types of cells from entering the nervous system, we may be able to protect the patient,"* says Dr. Mayne. *"Right now, we are attempting to understand what drives the movement of these cells. We are extremely interested in the involvement of a specific T-cell subtype, known as CD4, because these cells tend to be present in high numbers in MS lesions."*

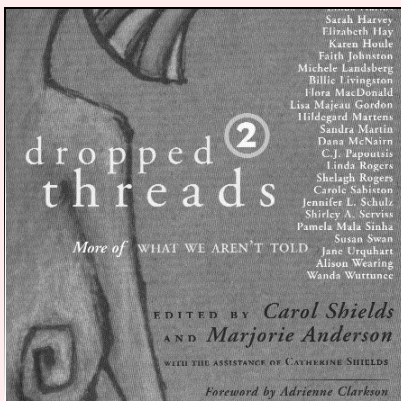
For the initial stage of this research, blood samples were drawn from patients with the

"Cells in the human body are generally not flat; they have a supporting structure that is known as the actin cytoskeleton. This cytoskeleton, which is highly flexible, not only gives T-cells and other cells their structure, but it also enables the cells to move and adhere to surfaces. We now know that the CYFIP protein governs the function of the cytoskeleton, so by regulating levels of this protein we might be able to prevent the movement of T-cells into the central nervous system, where they do the damage that presents clinically as multiple sclerosis."

To reinforce this theory, Dr. Mayne and colleagues performed in vitro testing, in which specific drug treatments were used to reduce the level of CYFIP protein in T-cells taken from MS patients. The result of this testing was encouraging: "In the lab, we essentially took these cells and stuck them down on test plates. We observed that, after treating the cells with specific substances, they lost their ability to adhere to the surface and lifted off the plate."

While the results of this research are very encouraging, Dr. Mayne still acknowledges that this approach does not constitute a cure for MS. "What we have done here is increased our chances of developing new drugs that are a vast improvement over current MS therapies. We haven't eliminated MS, but I think that we can find a way to prevent some of the damage, and protect the patient from further disability."

As the frontier of medical science advances, the gulf between the known and the unknown continues to narrow. Progress imparts a sense of purpose, and sows the seeds of hope. And that is what inspiration is all about.



DID YOU KNOW?

In the current bestselling book, ***Dropped Threads 2***, an anthology of stories by women about women's life experiences, there is a very moving piece by Ingeborg Boyens, a Manitoba journalist and person who lives with MS. Called *On the Water's Edge*, it offers a unique and accurate insight into everyday life with multiple sclerosis, including the often dismaying reactions of the well-meaning general public.



The MS Society would like to acknowledge
the contribution made toward this newsletter by
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educational grant.

BERLEX CANADA INC.



Multiple Sclerosis
Society of Canada
Manitoba Division

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