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Simcoe County Chapter
MS Society
Newsletter — October 2010

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Physical Address: 1102-44 Cedar Point Dr. Barrie, ON
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Fax: (705) 719-3098 E-Mail: scmsc@bellnet.ca
www.mssociety.ca/chapters/simcoe

MS Society Simcoe County Chapter’s
Annual Christmas Dinner December 1st, 2010

Location: Holiday Inn 20 Fairview Rd. Barrie Churchill Room

Start Time: Doors open at 6:00pm

Cost: $22.00 per person

Tickets may be purchased at the MS Society Simcoe County Chapter Office, Everyone is welcome to attend this fun filled event! All in attendance have a wonderful time.

There will be a Live and Silent Auction with a large variety of items to choose from. For more information please contact the MS Office at 733-0488 or 1-800-634-5618

If anyone has any items to donate for the Auction it would be greatly appreciated if you call us in advance.

Mission Statement
To be a leader in finding a cure for Multiple Sclerosis and enabling people affected by MS to enhance their quality of life.
Synopsis on Dr. Brown’s Presentation on CCSVI

Dr. Bill Brown, Neurologist with St. Joseph’s Care Group MS clinic gave a follow-up lecture on CCSVI research progress on June 21st at the 55 Plus Centre. There were approximately 120 people in attendance. This is the biggest turn out we have had for any of our lectures. The session was taped and DVD’s are available at the MS Office. Dr. Brown highlighted the research that needs to be done to identify a true venous occlusion versus positional or temporary occlusion.

Dr. Brown gave a good demonstration of the difference between a vein and an artery by holding up two types of latex tubing. Veins were represented by the thin flat tubing used by lab technicians to tie around your upper arm before taking blood samples. Arteries were represented by thicker, stouter rubber tubing much like that used for strengthening during exercise classes. Arteries, due to their thickness, are less likely to kink or twist enough to cause occlusion. Veins, due to their thinness, on the other hand, are very susceptible to kinking, twisting and occluding depending on the position of the head and neck during MRI and Doppler ultrasound testing. This may be some of the cause for the significant variation between Dr. Zamboni’s research results and that of the 2010 Buffalo study.

This contrasts markedly with the over 95% to 100% correlation found in the smaller unblinded studies previously reported on by the Dr. Paolo Zamboni”

Dr. Brown suggested that head position standards need to be set for Doppler technicians involved in future CCSVI studies. He stated that initially, research will need to clarify whether venous occlusions exist in all persons with MS. If this proves to be so then the next question that needs to be answered is “what is the best method to reduce the occlusion?” Can the methods now used to reduce a blocked artery-balloon angioplasty and stents be applied to thinner walled veins? Dr. Brown is confident that by the end of 2010 the first question will be answered.

The researchers and sights in Canada that were chosen by MS Society Canada to do CCSVI research are explained in Summer 2010 edition of MS Canada.

(This article was taken with consent from the MS Thunder Bay Chapter Newsletter August 2010)
Research

Emerging Therapies in Relapsing-Remitting Multiple Sclerosis

Disease modifying therapy (DMT) first became available for relapsing-remitting multiple sclerosis (RRMS) fifteen years ago with the development of the moderately effective injectable agents interferon (IFN)-~ and glatiramer acetate (GA). The subsequent licensure of mitoxantrone (MX) and natalizumab (NZ) has allowed for better control of refractory disease at the expense of potentially life-threatening side effects in a minority of patients. This dichotomy between DMT potency and safety also characterizes the next generation of DMTs.

Five oral medications (fingolimod, cladribine, teriflunomide, laquinimod and fumarate) are at various stages of phase III clinical trials and it is anticipated that at least some of these will be on the market within the next year. The development of oral agents would be a tremendous advance with respect to convenience and it is anticipated that this would dramatically increase the number of patients on therapy. In parallel with oral therapies, powerful immunosuppressive monoclonal antibodies alemtuzumab, rituximab / ocrelizumab, daclizumab (delta-9-tetrahydrocannabinol 27 mg/mL (from Tetrabinex® - cannabis sativa L. extract - Bayer Inc.) as adjunctive treatment for symptomatic relief of

A ChIP-seq-defined genome-wide map of vitamin D receptor binding: Associations with disease and evolution

The extent to which vitamin D deficiency may increase susceptibility to a wide range of diseases is dramatically highlighted in research just published. Scientists have mapped the points at which vitamin D interacts with DNA – and identified over two hundred genes that it directly influences.

Fatigue, sleepiness, and physical activity in patients with multiple sclerosis

Fatigue is a frequent and disabling symptom in patients with multiple sclerosis (MS). The objective of the study was to compare fatigue and sleepiness in MS, and their relationship to physical activity.

Health Canada has approved Sativex® for the treatment of spasticity in MS.

Health Canada has approved Sativex® [delta-9-tetrahydrocannabinol 27 mg/mL (from Tetrabinex® - cannabis sativa L. extract - Bayer Inc.) as adjunctive treatment for symptomatic relief of
spasticity in adult patients with MS.

Relevance of cognitive deterioration in early relapsing-remitting MS: a 3-year follow-up study
The aim of this study was to assess longitudinally cognitive functioning in people with relapsing-remitting multiple sclerosis (RRMS) and its relationship with clinical and MRI variables.

The natural history of secondary progressive multiple sclerosis
A study of over 5,000 people with MS, researchers pinpointed motor symptoms at onset (such as muscle stiffness known as spasticity) and male gender as factors associated with a faster progression from relapsing-remitting MS to secondary-progressive Researchers were funded by the National MS Society, the MS Society of Canada and others.

Pathophysiology of multiple sclerosis and the place of teriflunomide
Significant progress in multiple sclerosis (MS) treatment has been made over the last two decades, including the emergence of disease-modifying therapy (DMT). However, substantial unmet medical need persists and has stimulated the search for new therapeutics.

Survey

PHYSICAL ACTIVITY PARTICIPATION AND ACCESS AMONG INDIVIDUALS LIVING WITH MULTIPLE SCLEROSIS (MS) IN ONTARIO
This research study is being conducted at Wilfrid Laurier University by Dr. Margaret Schneider PhD, Dr. Patricia Mandalfino MD, and Dr. Kimberley Dawson PhD. The purpose of this study is to determine the current state of physical activity participation among individuals living with MS in Ontario, and to highlight any barriers or facilitators they may face in their active pursuit of these opportunities.

The researchers are looking for men and women with the following characteristics:

⇒ 18 years of age or older
⇒ Formal diagnosis of MS (any type)
⇒ Resident of Ontario

There are two phases to this research study and while you may complete both, you are not required to do so. As a research participant in phase one, you will be asked to complete a brief survey. As a research participant in phase two, you will engage in a personal interview. The total time commitment will be approximately 2 hours over the course of data collection (should you complete both phases of the study).

For more information on these and other ongoing research projects, go to www.mssociety.ca or call 1-800-268-7582
If you meet the above criteria and are interested in participating in this study, please contact Dr. Margaret Schneider at mschneider@wlu.ca or (519) 884-0710, extension 4214.

You may also complete the survey on-line at:
(http://www.surveymonkey.com/s/mspa2010)

This study has been reviewed and approved by the WLU Research Ethics Board (REB#2476).

A&W Photo Contest Winner!
The MS Society Simcoe County Chapter was the WINNER of the PHOTO CONTEST for the A&W National Event. Photos were taken at almost every A&W location that was participating in Simcoe County and one of our Photos was chosen as the winner of the contest. Thanks to all A&W’s for giving us the opportunity to enter these photos in this contest and for their support in “Cruisin’ for a Cause”.

LIBRARY
We have an extensive lending library. There are a number of books, DVD’s and videos that can be taken out on a monthly basis. A complete listing can be obtained by stopping in at the MS Office or calling 733-0488.

END MS Car Magnets
If you wish to purchase END MS Car Magnets please either stop in to your local MS Office or call 733-0488 to make other arrangements.
The magnets cost $5.00 each and are a great way to bring awareness to your community while donating to a great cause!

Volunteers
Anyone wishing to Volunteer is always welcome. We have varying needs throughout the year. At present the WALK Committees are beginning to plan for next years WALKS. The MS Walks', take place APRIL 17, 2011. If you would like to help with any of the Walks, at the committee level, or on the day of, please call the MS Chapter office and we will forward your name to the appropriate person or we’ll give you a contact number. The WALKS in Simcoe County are again in, Alliston (New Tecumseh), Barrie, Collingwood, Midland and Orillia.

EDITOR’S NOTE
The opinions expressed in the articles contained within are those of the authors and do not necessarily reflect those of the Simcoe County Chapter and those of the MS Society of Canada. Articles on products or services are for information only and should not be seen as endorsements.
Dr. Dawn Langdon

Dr. Langdon from the University of London, England, presented on Cognition at our Education Event September 16, 2010. She is a world renowned Neuropsychologist where research centres on psychological aspects of MS. It was a very informative and interesting session. She has been instrumental in the formation of the website stayingsmart.org.uk which focuses on cognitive issues in MS.

This Event was made possible through an unrestricted grant from Bayer Inc.

Participant Perspective

Dr. Dawn Langdon, Clinical Neuropsychologist did an education event on September 16, 2010 at St. Joseph’s High School for all who were interested in learning more about how cognition is affected by those who have MS. She was very informative and spoke in terms for everyone to understand. She explained a lot about the psychological aspects and how it affects members of the family as well as the individual with MS. After Dr. Langdon’s talk, there was an open question and answer period at which she answered all of our questions.

Karen O'Donnell

Special Assistance Program and Equipment Program

To access the forms for these Programs please log on to: www.mssociety.ca/chapters/simcoe.ca Go to the menu on the left. You may print these forms at home and have them filled in by the appropriate person.

PRO EQUINE RIDING LESSONS

Familiar with limited mobility issues.

Located on Big Bay Pt. Rd.

For information please call: Tracey at 734-3649 or Sylvia at 431-1854

Brand New: Toilet Safety Frame - (items for sale cont’)

- Knock Down Design
- Fully adjustable
- Padded arms
- 250lbs weight capacity

For inquiries contact Chuck @ 705-722-9851

Shower Chair with back

Please call Sophie at 737-2734

Manual Wheelchair

16” seat $100.00

Ceiling Lifts

2 lifts with tracking and sling, 350 lb. weight capacity. $1,500.00 each

Free standing trapeze bar $75.00

Arco rail for $50.00.

Please call Irene at 424-9567 for any of these items.
How to make an Online Donation to the MS Society

Simcoe County Chapter

If you wish to make a donation to the MS Society Simcoe County Chapter, you may do this online as well as in person or by mail. For online donations type in www.mssociety.ca/chapters/simcoe, on your address bar, click on Simcoe County. Click on “Donate Now” and fill in the prompts. You may also make a donation by cheque, visa, or cash by either mail or by coming into the MS Office in Barrie. The physical and mailing address are on the front of the Newsletter.

This will ensure that your donation will give your support to the Simcoe County Chapter. Please read below to see how your donations help us.

HOW OUR DONATION AND FUNDRAISING MONEY IS USED

Our Donation money is used for various programs and assistance for people with MS throughout Simcoe County. Our Primary Focus is to ensure that our Clients receive Services and Equipment. Some of this equipment is quite costly and not affordable for all people. Therefore we ensure persons in need have the appropriate devices to live comfortably. We also help people who are unable to do household duties independently. We hold Education Events that are open to persons with MS, their families and persons connected to MS. We have had excellent turnouts at our Education Events, exceptional speakers who have given a tremendous insight into MS and it’s many faces.

We have a Library at the MS Office where we keep updated information for people to sign out books, to take pamphlets, or to look at filed information. In the Library we also have DVD’s and VHS available for use. There is a quiet space for anyone to come in and read the literature or if they wish they may talk with a client service person. We also have a Newsletter that we send out to approximately 360 people every 6 weeks. We are able to send the Newsletter out by e-mail also. The Office is primarily volunteer based so our administration costs are very low.

Our Self/Help and Exercise Groups are another service we provide to persons with MS. We have a group in 6 different areas in Simcoe County. (See last page for details)

The rest of our funds/donations go towards MS Research in our fight to End MS! We greatly appreciate the help of our volunteers from all aspects of the Chapter. Our Board of Directors is a Working Board, Each member takes on a task within the Chapter. These are all people who have chosen to donate their time to helping our Chapter with all it’s needs. Without them we would be unable to assist persons with MS on the level that we do. Thank you to all of you!
**Update on “MS Paddles for Cure”**

The MS Society Simcoe County Chapter Boat “ONE” won the “Copper Division, Consolation Plaque” for the excellent effort put into our excellent paddlers. Thanks again to all who participated and made this a day to remember.

For anyone interested in joining the MS Dragon Boat Committee for 2011, we are now looking for members to help us plan for the Event. Please give us a call 733-0488.

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**The Royal Order of the Pumpkin**

The MS Society Simcoe County Chapter is pleased to accept a donation of $180 from the Royal Order of the Pumpkin. Below you will see the members and two of our Board Members accepting the Donation. Thank you for your generosity.

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**2nd Annual Charitable Dental Hygiene Clinic**

**Together We Can Beat MS!**

**Where:** Victoria Village Manor, Wellness Room

**When:** Saturday November 6th, 9-4

BY APPOINTMENT ONLY

**Cost:** By donation only! (estimated time per person is 45 minutes)

Email: info@toothpicksdental.com to request your dental cleaning appointment and support our local MS Society!

**Services provided by Michelle Castano, RDH**

**Sponsored by Toothpicks**

**Finalist in The City of Barrie 2010 Business Awards!**

On the left with the black robe is the Past Pumpkinmaster (Bob Coryell). The next gentleman is our "Pumpkin Sprout" (Bill Oxford). Next is our "Pumpkinmaster" (Ron Kunce). Fourth is our "Pumpkinmaster-Elect" (Harry Daffern). Last on the right, is our "Director of Frivolity" (John Capstick).

The Board Members are Cathy Groves who is in the centre and on the left side Marilyn Morasse.

If you wish to read more on this wonderful group please go to our Website where you will find how this fantastic group of men started and what they do with their fundraising money.
SELF-HELP/EXERCISE GROUP MEETINGS

BARRIE
Meets every Friday morning at 10am for Exercise followed by informal Support and refreshments. Located at Grove Park Home 234 Cook Street, Barrie. Contact the MS Society Simcoe County Office at 733-0488.

ORILLIA Self-Help Group
Meets the second and last Monday of each month from 1:00 pm – 2:00 pm at the Helping Hands Building 126B Memorial Ave. Contact: the MS Simcoe County Office 733-0488 or Irene Hooper 329-2613.

ORILLIA MS Exercise Group
Meets on the second and fourth Monday’s from 2:00 pm – 2:45 pm at the Helping Hands Building 126B Memorial Ave. Contact: Barrie MS Society Simcoe County Office for more information at 733-0488.

MIDLAND (Location Change)
Meets the third Tuesday of each month from 6:00 pm – 8:00 pm at the Midland Public Library 2nd floor Board Room 320 King St. (accessible). Contact: the MS Simcoe County Office at 733-0488 or Marilyn Morasse at 705-526-4567.

ALLISTON (New Tecumseth and Area)
Meets on the first, second, and the fourth Tuesday of the month at 4:30 pm at the Community Living Association for South Simcoe building 125 Dufferin Street. The 3rd Tuesday of the month is at the Royal Canadian Legion 111 Dufferin Street, Alliston. Contact: the MS Simcoe County Office at 733-0488 or Donna Ellis at 435-4199.

WASAGA BEACH
Meets the third Monday of each month at 7:00 pm at the Real Canadian Superstore In the Community Room upstairs (elevator to the right of stairs) 25 - 45th Street, Wasaga Beach. Contact: the MS Society Simcoe County Office at 733-0488 or Patty Barnes 422-1759.

COLLINGWOOD
Meets for Exercise and Support on the third Thursday of every month at 3:00pm at Breaking Down Barriers, 115 Hurontario ST. All are welcome. For further information please contact the MS Society Simcoe County Chapter at 705-733-0488 or 1-800-634-5618.
In Memory of Ann and Hugh Mayne

“It is with great regret that we announce the passing of a pillar of the MS Simcoe County Chapter, Mr. Hugh Mayne, who passed away on Wednesday, October 13, 2010, and this is only 5 months after his wife, Ann passed away.

Hugh had been a volunteer with the MS Simcoe County Chapter for more than 16 years. His wife, Ann Mayne, was one of MS Simcoe Chapter volunteers who gave much of her time to the Chapter, while struggling with MS herself.

Hugh made sure that he was forever Anne's caregiver and constantly remembered her in all that he was doing. Besides being a caregiver to Ann, he was also a caregiver to the Barrie Support Group of the MS Simcoe County Chapter.

After Ann's passing, Hugh continued to volunteer with the MS Simcoe County Chapter. Hugh always made sure we had our coffee on time, served it to us remembering who wanted what each week and assisted with tables, chairs and whatever else we needed. Hugh was always available to help out anyone who needed assistance.

Hugh and Ann participated in the MS Walks in Barrie since its inception - 16 years ago. They enjoyed friendly competition with their neighbor, Mr. John Henderson, to see who would raise more monies for MS at the walks each year.

Hugh was a constant bright light and joked with everyone, hence they looked forward to seeing Hugh.

All who know Hugh are devastated by his passing and many tears have been shed over the last few days.