

MShope MSheroes

SPRING 2007

Across BC

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.



Photo by Craig Hodge, Tri-City News

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MS

Multiple
Sclerosis
Society of
Canada

Société
canadienne
de la sclérose
en plaques

SP

Multiple Sclerosis Society of Canada
BC Division | 1.800.268.7582
www.mssociety.ca/bc

MS Bequest
Week **May 28 -
June 1**

A FUTURE FREE FROM MS IS YOURS TO GIVE

1-866-679-4557 | msbequesthelpdesk.ca

*Bring hope to the 8,000
British Columbians living with
MS and purchase carnations for
Mother's Day.*



Dear Face the World.

I would like to thank you for your kind donation to the MS Society of Canada's Equipment Provision Program. Because of your support they were able to help me buy a new power wheelchair. It has changed my life.

My entire professional career I had been in industrial sales, travelling the world for my job. I had also been quite athletic - running, biking, skiing and playing baseball, soccer and racquetball. Life as I knew it changed in 1996 at age 43 when I was diagnosed with Progressive MS. I experienced a rapid loss of leg use, restricted use of my right hand and now spend most of my days in a wheelchair.

Not having my legs cooperate with the rest of my body has been a hard pill to swallow and excursions have been limited under my own steam in my manual wheelchair. Not anymore. My new power



wheelchair has given me back my independence. I can now go out on my own to get my hair cut or buy my groceries and explore my neighbourhood.

Thanks from a very appreciative person with MS.

*Hugh Glass, Member
Lower Mainland Chapter*

This is only one of many letters we have received from people living with MS whose quality of life has been enhanced through equipment provided by the Equipment Provision Program. The MS Society of Canada is grateful for the generous donation of \$20,000 to this program from Jaquie Cohen & Face the World Foundation.

UPCOMING EDUCATIONAL WORKSHOPS

Thanks to the generous support of biogen idec, through an unrestricted educational grant, the MS Society of Canada, BC Division will be hosting **Treatment Update Workshops** this year in the following communities:

Victoria, March 31

Fraser Valley, May 5

Kelowna, May 26

Lower Mainland, Sept 22

Prince George, TBA

Watch for details in your Chapter newsletter or contact your local Chapter.

CRASH TEST MOMMY Understands MS

Sherri Allen and her sister Trina have always been best friends. They do everything together, including watching Life Networks *Crash Test Mommy*. Often teasing each other about the concept ('mom' goes off for a spa getaway leaving 'sis' to take care of the kids) so Sherri was surprised to see an audition request in a school newsletter. A three hour phone call followed by a three hour live screening later, Sherri and her sister were booked on the spot - and the fun all began the weekend of Jan 13, 2007.

Now while raising two young boys can be challenging at the best of times - try adding some MS symptoms into the pot just to stir things up. *Crash Test Mommy* was particularly intrigued when Sherri



left to right:
Darian, Aunt Trina, Sherri & Tristin

told them she had multiple sclerosis - and they were keen to incorporate an educational component into the show.

The MS Society of Canada (BC) gratefully accommodated their request to bring 'Aunt Trina' and the kids Tristin, 6 and Darian, 5 in for an 'MS lesson'. Casting Gab Veto, long-time MS Society volunteer as 'teacher,' she led them through some activities so that they would better understand the symptoms that MS can sometimes cause. Spreading Vaseline on safety glasses showed them that sometimes MS causes blurry vision. To demonstrate partial paralysis each of them had to put a sock on using just one hand. A spoonful of peanut butter followed by a task to repeat a simple sentence illustrated how sometimes MS can affect speech.

While Trina was trying to cope with two very busy boys, Sherri was enjoying a weekend being 'wined, dined and pampered' from her penthouse suite of the Granville Island Hotel. She was particularly moved when the crew showed her



a 'lesson clip' of her sister trying to turn pages of a 'bedtime story' with oven mitts on her hands. "That is really what I experience sometimes when my fingers go numb - now Trina knows it is for real," Sherri points out.

Prior to 'the lesson' Trina had been in complete denial of her sisters MS-particularly as it is for the most part an invisible disease. This lesson was probably the biggest lesson of all for her that weekend. 'I have gained a whole new appreciation of Sherri and her ability to cope with the symptoms that MS throws her way - all the while raising two young kids,' she admits. "Before *Crash Test Mommy* we were as close as two sisters can be - but our relationship is even stronger now - and I owe it all to a TV show!"

This Crash Test Mommy episode will air in the Fall of 2007. Watch for it!

Pregnancy Hormone Offers Hope for Treatment of MS

It has long been believed that MS tends to go into remission while women are pregnant. However a ground breaking study out of the University of Calgary took this theory one step further.

The study conducted on mice found that the hormone prolactin encourages the spontaneous production of myelin that coats nerve cells - the very substance that MS attacks. It is the first study to determine that prolactin, which increases in the body during pregnancy, is directly responsible for the formation of new myelin in the brains and spinal cords of pregnant mice. Further, when non-pregnant mice with MS-like lesions were injected with prolactin, their myelin was also repaired.

"It is thought that during pregnancy, women's immune systems no longer destroyed the myelin," said Dr. Samuel 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." The findings represent the first example of a natural, biological mechanism that produces new myelin in the adult brain and spinal cord. While more tests on animal models are required,

the identification of prolactin as a potential therapeutic substance for future testing in people with MS shows great promise.

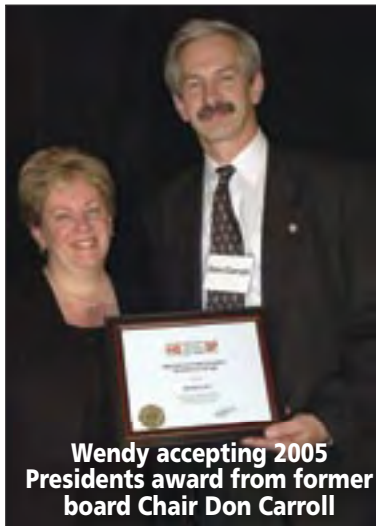
"This discovery has the potential to take MS therapy a step further than current treatments that stabilize the disease in its early stages. By promoting repair, which is the goal of prolactin therapy, we have hope of actually improving symptoms in people with MS," says Dr. Luanne Metz, director of the Calgary MS Clinic in the Department of Clinical Neurosciences, University of Calgary and Calgary Health Region.

"I was very enthused to learn of the results of this study," says Era Hancock of Surrey who was relieved that during her pregnancy five years ago she was free of MS symptoms. "The fact that we may be able to reverse the effects of this disease with a naturally produced hormone gives me great hope for my future and the future of my daughter."

The study was funded by the Canadian Institutes of Health Research and the Multiple Sclerosis Society of Canada, with the support of the Alberta Heritage Foundation for Medical Research and the Stem Cell Network.

Board Members **WALK for MS**

Volunteers are the heart and soul of the MS Society - particularly during WALK season when the MS Society hosts its largest fundraising event of the year. Many of BC Division's Board members got their start with the MS Society by volunteering for the Super Cities WALK for MS - and fortunately for us they continue to play a very active role in this event.



Wendy accepting 2005 Presidents award from former board Chair Don Carroll

In 2005, Wendy Galt was BC Division's President Award winner - with a list of achievements that would fill this entire page. In brief, she first came to the MS Society of Canada as a client, went on to become a Chapter Board member and today sits on the Division Board. In 1996 'as a way to help out with the fundraising side

of things,' she became a Tri-Cities WALK committee member. From committee member to Committee Chair she loves the job - but is quick to give credit where credit is due **"Thanks to my great committee members* and the many familiar walkers that come out and raise so much every year!"**

*2006 Tri-City WALK Committee featured on front cover

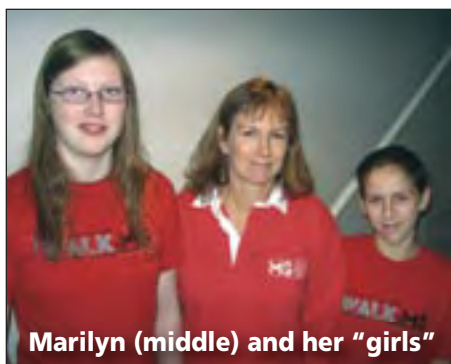
Although Dan Carlson watched his mother struggle with MS he didn't give it much thought. However, when he was diagnosed with MS in 2000 he was suddenly aware of the implications this diagnosis could have. Determined to



Dan (L) and Award of Merit winner Marilyn Smoch

keep moving forward, in 2001 he participated in Nelsons' SuperCities WALK for MS and was the 2nd top fundraiser in the West Kootenays! That just whet his appetite to do more. From Chapter Board Chair to Division Board Member - today the West Kootenay Chapter is BC's 'Little Chapter that Does' - their WALK raises the most provincially (per capita); they contribute the most (per capita) to research and in 2006 member Marilyn Smoch received BC's Member Award of Merit. His hope for the future? **"I hope that soon there will be no need for volunteer positions like mine. Let's end MS."**

This year Marilyn Lenzen has picked up the reins as Chair of the North Shore WALK committee - after four years as a committee member.



Marilyn (middle) and her "girls"

She originally became involved with the WALK to fill the void she faced when she had to leave her career in sales and marketing. After lamenting to a WALK committee member that she missed coordinating events she suddenly found herself on the North Shore WALK Committee - and appointed Team Captain of BC's top fundraising team - The Success MS Self help Group (\$36,000 raised in 2006!) What's her Success Secret?

"To get something to grow and succeed you need fantastic group synergy - The SUCCESS MS self-help group team is a great example of this."

Gerry Bramhill, 'Mr Electrical' hasn't missed a Vancouver WALK or bike event in 10 years. He's in charge of all things power related - namely hot coffee on those cold WALK mornings!! Gerry, first became involved with the MS Society more



Gerry and BC Division President Janet Palm

than 13 years ago when IBEW* colleague Jim Wolfgang asked him to join their Board. Today, Gerry is Division Board Chair - and we couldn't ask for a more 'powerful' chief. **"I don't want recognition. I do what I do because I want to, and believe it is for a good cause".....**

*The IBEW adopted the MS Society of Canada as their charity of choice Canada-wide almost 25 years ago and to date has donated more than \$2 million dollars

HELP WANTED



The success of the Super Cities WALK for MS is dependent on the support of thousands of volunteers at 20 different WALK sites throughout the province. From behind the scenes committee work to day of event set-up we'll be sure to find a job just right for you! If you aren't participating in our event - we could use your help.

Contact your nearest Chapter office (see back page) or 1-800-268-7582.

Super Cities WALK for MS from Coast to Coast

Bernadette Burgess might have MS, but MS doesn't have Bernadette.

Bernadette Burgess, Bernie, lives on the "other side of the country" in Dartmouth, Nova Scotia. She was diagnosed with MS at age 29 when she was pregnant with her third child, daughter Katie. Her gals (four of them) essentially "grew up" with the disease but they never knew it, for despite the obstacles Bernie faced, she was "unstoppable". Twenty-five years later, Bernie still maintains that positive attitude despite the fact that she needs a walker to get around. Essentially nothing stands in the way of this determined lady.

So when an opportunity presented itself to go to Vancouver and visit her two youngest daughters (Katie, who had just moved to Vancouver and Janice who would travel from Calgary) Bernie was more than up for the challenge to make this cross country trip. Katie, a customer service manager at TD Canada Trust, was particularly excited about showing her mom around Vancouver and had lots of activities planned just for the occasion. "We did it all, Granville Island, horse & carriage ride around Stanley Park, the Aquarium, Grouse Mountain," recalls Katie. However, her mom had no idea what Katie had planned as a "grande finale."

Early in the morning on Sunday, April 9, Katie got her mom to rise and shine extra early. Unfortunately, the weather wasn't exactly the "shining kind" and Vancouver's damp drizzle met them as they made their way to Stanley Park with Bernie in a wheelchair that Katie had thoughtfully rented especially for the occasion. But they weren't the only ones braving the weather. Bernie was moved to tears when



they were met by a whole contingent of old family friends and Katie's college pals who had come out to "WALK for Katie's Mom" in the Super Cities WALK for MS.

After Bernie regained her composure she eloquently put into words what she was feeling. "You know, I'd never been out to the Super Cities WALK for MS in Nova Scotia - and never experienced the magic and spirit of the event. This is so remarkable that "Team Bernie" has come out here just for me - and that the rest of the folks are all here for the same reason - to end MS. It has given me new hope that a cure for MS will be found - and until that day I am going to cherish the magic of today."

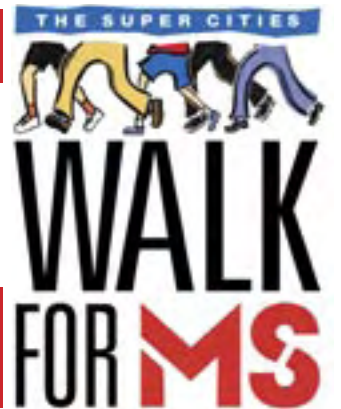
Katie has already begun to recruit her 2007 team which will be bigger than last years team of 11 members. She is hoping that her mom might be able to return to BC for a repeat performance - with hugs, tears and all - and hopefully a dash of sunshine for good measure.

The 2007 Super Cities WALK for MS - 20 Sites Across BC

April 15
VANCOUVER ISLAND

April 22
LOWER MAINLAND
FRASER VALLEY
INTERIOR

June 10
PRINCE GEORGE



For registration information, site locations and start times please call your local MS Society Chapter or 1-800-268-7582 or go to supercitieswalk.com

Gear up for Fun, for a Challenge, for a Cure!

With yellow bandana's streaming from their helmets and plenty of ear to ear smiles, "Team Agwest", a team of 10 moms, return to pedal their way to a weekend of fun at the RONA MS Bike Tour's Fraser Valley Grape Escape. They also intend to keep their top fundraising team title by topping last year's tally of \$8,278.

The team draws inspiration from friend and Team Captain, Rachael Chaisson, who was diagnosed with multiple sclerosis in 2003. Rachael is equally inspired by their support, "Just the fact that this wonderful group of teammates, my friends, are willing to join me in this effort to end MS fills me with hope and motivates me."

The girls are looking forward to this 3rd annual "gals getaway weekend" complete with 'sleepover' at Trinity Western and plenty of laughs - and hope to keep up a faster cycling pace so they have more time to savour the tastes of the Fraser Valley's fine wines.

PS. If you can't make the Fraser Valley Grape Escape - plan on exploring the Cowichan Valley's wine region in August. But book early - last years tour was a sell out!



- Fraser Valley "Grape Escape" - June 9 & 10**
- Vancouver Scenic City Tour - August 12**
- Cowichan Valley "Grape Escape" - August 11 & 12**
- Kamloops Thompson River Ride - September 9**

www.ms biketours.com

Working with MS and Making it Work

Grace Pyo was a Program Director for the International Language Schools of Canada when she first experienced MS-like symptoms. Lucky for Grace, her employer has been accommodating. Instead of travelling to meetings throughout the Lower Mainland, they brought the meetings to her. When she temporarily required a wheelchair for mobility, she was met at the entrance by her work colleagues. She has the option to work from home - and is given projects that work for her. Over the past 2 1/2 years Grace has required various periods of disability, but she knows she is valued as an employee.

This is just one example of the hundreds of people working with MS who have employers that go the distance to accommodate and understand the needs of those living with chronic illness. Judy Smith's story is another example of what a great employer can be. Judy was working for the Greater Vancouver Regional District when she first started experiencing MS symptoms. A few years later she had her diagnosis. "I told my employer very soon after I got the news and they said we'll deal with it as it comes and that was very reassuring for me. My direct supervisor was superb. There have been two or three key people over the years that have made things much smoother for me."

As Judy's MS progressed so did her employer's response; a headset for her phone, a re-arrangement of office furniture, ensuring all the doors on her floor were accessible, even adding a couch to her office so she could rest as needed. As Judy's fatigue got worse she began working from home one day a week. Her employer even hired an Occupational Therapist to assess her office and her home. "They are always open to my suggestions and that has made a big difference." Today, Judy is on LTD but still working three part-time days a week. As the Superintendent of Water Quality and Microbiology Judy recognizes, "It's a win-win situation for both of us. I can continue working albeit on a reduced level and the GVRD is able to keep the experience I have about how the system works."

Many employers also recognize and support the role played by caregivers of people with MS. The Victoria based company Aspreva Pharmaceuticals is one such example, and they are very



Grace Pyo (r) and daughter Nicki (l)

supportive of Executive Assistant Marnie O'Neill. Her husband Cam Cavaco was diagnosed with chronic progressive MS in January 2000 and Marnie is grateful for their flexibility. There are days when she needs to take Cam to appointments and days when she can't leave him alone and she is able to work from home.

Last year, in a grand show of support for 'Marnie and Cam' forty-five Aspreva employees formed a Super Cities WALK for MS team - 'Cam's Posse' and raised \$21,000!! Richard Glickman, CEO of Aspreva Pharmaceuticals says, "I am extremely proud of the commitment and support Aspreva and its employees have given not only to Marnie and Cam, but also to the MS community. Our passion is to make a difference in the lives of people living with less common diseases, and there is nothing better than seeing this passion in action in our local community." The outpouring of support shown by the Aspreva team also led to the establishment of a generous 'Aspreva Legacy Fund,' to be used to improve the quality of life for those people living with MS on Vancouver Island for years to come.

NEW EMPLOYMENT RESOURCE GUIDE

A Guide to Employment and Income Support provides comprehensive, practical information and guidance on a wide range of income and employment issues relevant to living with MS including:

- Working with MS
- Leaving the workplace
- Returning to work
- Income support
- Financial assistance
- Tax relief

Also available is a booklet "MS in the Workplace" written for employers. For free copies contact your local chapter or view online at:

<http://www.mssociety.ca/en/information/pubs.htm>

MS Society brings disability "Loophole" to



In early January, Vancouver radio station CKNW prominently featured one of the MS Society's priority disability income issues on 'Nightline'. Cheryl Elliott from Ottawa who lives with MS described the dilemma, "I didn't qualify for Canada Pension Plan disability benefits once my 15 weeks of Employment Insurance (EI) was finished."

Deanna Groetzinger, VP, Government Relations and Policy of the MS Society explained that the issue of not "being disabled enough" affects many people with MS that have moderate or episodic disabilities. The MS Society is recommending EI and CPP disability benefits be more flexible so people can work part-time and receive benefits part-time.

This issue was front page news in The Globe and Mail in late December. Essentially it broke the news that the federal government may be looking at ways to close an income support gap faced by many people with moderate or episodic disabilities and illness.

A study by University of Victoria professor Michael Prince recommends extending EI benefits, introducing a CPP program to cover partial disabilities or creating a new program for people with episodic disabilities. The MS Society will continue work on moving this important issue forward.



Deanna Groetzinger, VP Government Relations & Policy

MS Then. MS Now. MS Tomorrow.

In 1977, Marjorie McGinity, a mother of six was diagnosed with multiple sclerosis. Despite the fact that MS was a widely documented disease, thirty years ago diagnosis did not come easily. It took more than two years to confirm - a process that was both arduous and emotionally draining. Her initial assessment considered a possible brain tumor, instilling a great deal of fear. Medical personnel also suspected alcohol abuse which was not the case and created embarrassment and further stress. However, under this pretense, Marjorie was given valium which, unfortunately, worsened her symptoms. While diagnosis was a challenge, there were also no treatments available to alleviate MS symptoms and, of course, no cure. Unfortunately, Marjorie's

disease worsened rapidly and in 1994 she passed away due to complications arising from the disease.

Just 5 years after Marjorie's diagnosis, her daughter Leigh-Ana, 23, began to experience MS symptoms. However, with new medical knowledge of suspected genetic susceptibility and Leigh-Ana's family history of MS, doctors made a relatively swift diagnosis compared to the years of misdiagnosis her mother had endured. Yet while diagnosis was quick - there were still no therapies available to treat the disease.

Looking back over the years, Leigh-Ana is amazed at how much



research has progressed since her diagnosis in 1983. In 2001, when she could no longer continue working as a registered nurse, MRI technology helped her apply for long-term disability. With a family history of MS, Leigh-Ana has been particularly interested in following the findings of the world's largest study on genetic susceptibility led by University of British Columbia researcher, Dr. A. Dessa Sadovnick. Since her diagnosis, Canada has approved five disease modifying therapies which have helped thousands of Canadians living with MS.

Leigh-Ana knows that finding a cure to end MS is just around the corner - and she has made a commitment to a future free from multiple sclerosis by leaving a bequest in her will. "The kids of today have no idea what a record player is. I hope that the kids of tomorrow will never need to know what MS is. I sincerely believe that a cure to end MS will be found, hopefully in my lifetime and I am pleased to be able to do what I can to support this belief by investing in a future free of MS for the generations that follow me."

The MS Society of Canada has invested more than \$13 million to date on genetic susceptibility studies and has funded research in MRI technology which is now a standard diagnostic tool used worldwide. If you are interested in leaving a gift in your will contact Lisa Fratpietro at 604-602-3216 or lisa.fratpietro@mssociety.ca

MS Research - Canadian Milestones

- 1949** MS Society funds first grant for MS research: \$10,000
- 1973** MS Scientific Research Foundation established; the only fund in the world strictly dedicated to MS research.
- 1981** First MRI pictures of a brain affected by MS - revolutionizing MS diagnosis and dramatically expediting the pace of MS research.
- 1986** First Canadian genetics project studies MS in twins and siblings.
- 1993** MS Scientific Research Foundation approves \$2.27 million to support collaborative, multi-centre study in genetic susceptibility to MS.
- 1995** Betaseron, The first disease modifying therapy for MS approved in Canada.
- 1996** Canadian researchers find a gene linkage to MS susceptibility.
- 1997**
 - Copaxone. The second MS therapy approved in Canada.
 - MS Scientific Research Foundation approves \$4.7 million for Phase II of the genetic susceptibility to MS study.
- 1998**
 - Avonex, The third disease modifying therapy for MS approved in Canada.
 - MS genetic susceptibility study reveals key findings related to the detection of MS in siblings.
 - Rebif, the fourth disease modifying therapy approved in Canada
- 2006** Tysabri. The fifth disease modifying therapy approved in Canada

Since 2000, MS Scientific Research Foundation has funded:

- 2000** \$4 million to study bone marrow transplantation that hopes to halt progress of MS
- 2001** 3.5 million to support a study of remyelination in MS
- 2002** \$5.1 million for Phase III study of genetic susceptibility
- 2004** \$4.3 million to study the development/causes of MS in Canadian children
- 2005** \$2.25 million to support Phase II study of remyelination in MS.

BC ROUNDUP

NORTH VANCOUVER ISLAND

More than 70 participants came out to Mount Washington to Ski for MS on Jan 21 - and raised more than \$12,000. The Top Fundraising Team was Investors Group. They raised \$1,440. The Team Spirit Prize was captured by The Coastal Cruisers - they wore hula skirts and leis all day! Special thanks to presenting sponsor Investors Group and Mount Washington for hosting this fantastic event. See you on the slopes next year!



CAPITAL REGION CHAPTER

The Capital Region Chapter has given curb appeal a whole new meaning! In the course of planning last years Super Cities WALK for MS at Willows Beach in Oak Bay, it was noted that five intersections on the route did not have accessible curb cuts. This was a big problem for a route that requires accessibility as almost 35% of event participants use wheelchairs, scooters, walkers, or canes.

Despite hearing that "these types of expensive requests don't have a chance" the Chapter simply started asking to see if anyone knew someone who could help them. Luckily a planning committee member had a friend on Council, and City Council gave it the green light to go ahead. Currently construction is underway at all intersections - it will be completed by WALK weekend. Change is possible! Thanks CRC and Victoria Council for making a real difference in the lives of those affected with MS - and the many others who will enjoy this new accessible walkway in the community.



KAMLOOPS & AREA

To Feldenkrais or not to Feldenkrais? That was the question that TRU nursing students Sarah Law and Carolyn Mulroy considered as they evaluated Kamloops Feldenkrais program. Accommodating all levels of mobility, Feldenkrais uses purposeful movements to engage the mind. As a result unused electrical pathways are rediscovered - alternatives to those damaged by MS. Their study gave Feldenkrais two thumbs up - with participants indicating it helped reduce pain, stiffness and stress. Why not try it? Feldenkrais in Kamloops is here to stay.



WE'RE SORRY! In our haste to get the annual report out to our members – we accidentally excluded Dan Carlson from the list of 05/06 Division Board Members. Dan is a valued member of the Division Board – and we wanted to publicly acknowledge this. Thanks Dan for all you do for us Provincially – and for the West Kootenay Chapter. Read more re: Dan on page 3

British Columbia CHAPTERS

Capital Region

- Duncan 250.748.7010
- Victoria 250.388.6496

Central Island 250.754.6321

Fraser Valley 604.853.8623

Kamloops 250.314.0773

Lower Mainland 604.689.3144

North Vancouver Island
250.286.0999

Okanagan

- Kelowna 250.762.5850

Prince George 250.564.7074

South Okanagan/ Similkameen

250.493.6564

West Kootenay 250.229.4994

There are more than 40 independently run self-help groups in BC. To find a group near you call your Chapter or 1-800-268-7582.

ARE YOU A MEMBER?

As a member of the MS Society you: Have a say in the future of the MS Society | Allow us to speak with a more powerful voice on behalf of Canadians with MS | Receive Chapter, Division and National newsletters | Have access to MS Society programs and resource library

**Annual membership \$10
Become a member today!
1-800-268-7582**

MS HOPE MS HEROES

If you are receiving a copy of MS Hope MS Heroes for the first time – it is because you have been identified as one of our MS Heroes who has made a real difference in the fight to end MS. As a member, donor, sponsor, volunteer, event participant, or researcher – you are part of our world - a world that wants to end MS.

If you would prefer to receive this newsletter as an e-mail – or simply wish to be removed from our mailing list – please contact us at 1-800-268-7582 or info.bc@mssociety.ca.

Thanks for your support.

MShope MSheroes Spring 2007

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