Chair’s Report

Happy New Year. I wish everyone all the best in 2011. Thanks to all who purchased Christmas cookies, we had a very successful fundraising event. And, while it seems like winter will never end, we are approaching our next major fundraiser, the MS Walk. It will be held on Sunday April 17th, starting at St. Brother Andre High School. As you know, 50% of the funds raised by Walkers stays in our Chapter and is our biggest source of money for supporting our Special Assistance and Equipment programs.

I am sorry to report that Jeff Scott has resigned as Client Services Director. Jeff worked tirelessly in this portfolio for two years, and will be missed by our clients and fellow Board members. He has also retired from the Board, but plans to be an active event volunteer.

CCSVI continues to be an active topic, the MS Society of Canada has published the first six month report on the Research Teams progress on projects focusing on CCSVI and MS. It can be found at www.mssociety.ca. There is also a video by a doctor with MS that is very informative. It is 2.5 hours long and can be located at http://www.ustream.tv/recorded/12720508.

Look forward to seeing you on Sunday April 17th. I encourage everyone to bring together your family and friends and put in a Team!

Jan van Velzen
On November 10, 2010 I had treatment for Chronic Cerebral Spinal Venous Insufficiency. I researched many clinics in the US and overseas and after being on many waiting lists chose to go to Clearwater, Florida because this clinic was operating using the protocol established by Dr. Zamboni in Italy and they were also accepting patients very quickly.

My husband and I flew to Florida the evening of the 8th, went to the clinic for testing and a meeting with the vascular surgeon on the 9th and had the surgery on the 10th. Except for a 4 hour delay in the procedure everything went well. I was awake but given a drug to make the ballooning more comfortable. The angiogram indicated that I had 3 blockages (left internal jugular vein, right internal jugular and the azygous veins). The right jugular was completely blocked and when it was ballooned I experienced a sharp pain in my ear and popping sounds, that was all I remember and it only seemed like it took about 5 minutes but it was in fact an hour. I didn't experience any immediate improvements but in the two weeks after that I experienced improved balanced (can stand without holding on to walker) reduced numbness, less spasticity, no more headaches, improved strength, pain along spine is gone, bladder urgency has improved, 6 weeks after the procedure my blurry vision got and remained better.

My mobility has not gotten much better but I am trying to exercise to repair my atrophied muscles. I have spent 25 years getting in this shape and don't expect drastic improvement, I am told the repairing of the veins can take as long as 6 months and the increased blood flow can result in improvements up to a year. I go to a clinic in Barrie on Feb. 24th for an ultra sound doppler to ensure the veins remained opened. Unfortunately restenosis or veins becoming blocked again seem to be occurring in some patients without explanation. I will not be able to have my veins reopened if they are blocked due to the considerable cost (9500.00 US) to have the testing, procedure and the travel expense. I was fortunate enough
to have had immense financial support from my family and friends for this procedure.

Although I still have a long way to go the most significant result is the positive feeling that my MS progression has stopped, my future is brighter, I am not worried about becoming a burden to my family.

I am trying to stay positive that the Canadian healthcare system will come on board and begin treating MS patients' blocked veins. It is a risk free procedure that will benefit MS patients significantly. Everyone that I know that has been tested have the blockages and everyone I know that has been treated has had improvement in varying degrees. Unfortunately the studies that are being conducted to see how many MS patients have blockages, abnormal veins or reflux of blood flow are not being done by the protocol set out by Dr. Zamboni and his team so it remains to be seen what will happen next. This is very disappointing and I am sad for those MS sufferers who cannot afford or are physically unable to leave the country for this life saving procedure. There are some dedicated people meeting with representatives in Ottawa to help them understand the science behind CCSVI and appeal for the rights of Canadians living with MS.

This adventure has been exciting and somewhat frustrating due to the lack of commitment by many to move ahead and help MS patients, but I have not forgotten just how lucky we are to have the vision of one dedicated man who set out to help his MS afflicted wife find help and then pass it on to the rest of the world. I know many MS patients who range in symptoms from very mild to severe and even if the results for some have been small the result is often miraculous. Imagine having the procedure and then begin speaking again, taking a step for the first time in years, being able to feed yourself, no longer being feed through a tube, get out of bed without help, the list goes on....

This is an uphill battle – we need testing, treatment and followup care!

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Laquinimod: Potential oral medication for treating relapsing-remitted multiple sclerosis (RRMS) in Phase III clinical trials

February 17, 2010

Current drugs on the market for the treatment of MS are targeted towards reducing the inflammatory disease activity and all of the established drugs require intravenous or typically subcutaneous injection. Obviously most patients would prefer a simpler and safer therapy however the creation of an oral drug is typically more difficult to manufacture due to the differing environments as it is ingested and the resulting negative side effects. Fingolimod (Gilenya®) is the first oral treatment for RRMS and was recently approved by the FDA. Currently there are ongoing clinical trials for the next possible orally administered drug, laquinimod.

Laquinimod is a synthetic substance which has a broad mechanism of action that includes immunomodulatory and neuroprotective mechanisms. It is currently in Phase III clinical trials and the results from the trial are expected to be announced within this year.

One trial was a Phase IIb study which was a multi-center, placebo-controlled, double-blind, randomized clinical trial that lasted 36 weeks. They had three treatment groups, 0.3 or 0.6 mg/day laquinimod or placebo treatment. After looking at the Gd enhancing lesions they found a significant reduction in lesions for the 0.6 mg/day laquinimod group compared to placebo. They extended this treatment for an additional 36 weeks with the placebo group receiving laquinimod treatment or continuation of treatment of laquinimod. They found that subjects that were switched from placebo to 0.6 mg/day laquinimod treatment showed a reduction of lesions by 52%, however the effects on clinical scores such as Expanded Disability Status Scale (EDSS) were not significant.

In regards to the safety of laquinimod, there have been no significant differences in adverse events in the treatment groups versus the placebo groups. Common adverse events include increased liver enzymes, elevated fibrinogen levels, respira-
tory tract infections, headache, insomnia, nausea, diarrhea and cough to name a few.

The ongoing Phase III studies are the ALLEGRO study and the BRAVO study and they both are placebo-controlled, randomized, double-blind studies investigating the efficacy, tolerability and safety of laquinimod (0.6 mg/day) in RRMS patients. Hopefully the results of these trials will be able to confirm neuroimaging findings in the Phase II trials and reveal differences in clinical end points. Clinical end points are important to determine since they include number of relapses and the severity of the symptoms of the disease and if these clinical end points are not maintained or improved it may not be an appealing drug for MS patients.

Cassandra Belo

References:


Ask the Expert

Q.: I participated in a hot yoga class and found that I could not balance as well as I can normally. I have also found that I cannot stay in a hot bath for very long since I start to feel dizzy. I have RRMS. Why does heat have this effect on me? Am I making my MS worse?

A.: It is expected that people with MS may feel a worsening of symptoms when they are exposed to heat. Nerve conduction is already not optimal due to the deterioration of the myelin sheath around the axons. When heat is added, your body temperature rises and this negatively affects nerve conduction along the demyelinated axons. Everyone responds differently to varying degrees of heat since there are different tolerance levels. The symptoms experienced after heat exposure are considered pseudo-exacerbations since they are temporary and do not last long enough to be classified as an attack. An attack is defined as symptoms lasting over 24 hours without a sign of infection or fever.

Although there is a worsening of symptoms, exposure to heat does not appear to speed up the disease progression. However to avoid the negative repercussions try to avoid unnecessary heat exposure. Do regular yoga instead of hot yoga (Join yoga on Monday nights which is free for York East members!), take a bath with cooler water, use an air conditioner in the summer or do your exercising in a pool. You may need to make a few changes to avoid getting overheated but even if you are caught in the heat you know that there are not any lasting effects from the exposure.
Through my adventures with MS I have learned to take one day at a time.

This is very hard for me as I like to plan ahead. A few weeks ago when I said to my husband, "I feel great but I guess I should lay down and rest in my electric, reclining wheelchair." One hour later I had a severe case of vertigo from an inner ear infection. This led to a call to 911, a trip to the hospital by ambulance where I spent the next 8 days.

My one day at a time was reinforced. I am fine now.

**Jo Sargent**

I read this recently and would like to share it.

"We do not change as we get older, we just become more clearly ourselves."
The Latest from CCSVI.ca

January 31, 2011
Research Teams Report Progress from First Six Months of 2-Year Projects Focusing on CCSVI and MS

September 16, 2010
MS Society of Canada commits $1 million for CCSVI clinical trial

June 11, 2010
Over $2.4 Million Committed to Support Seven Operating Grants to Explore the Relationship of CCSVI to Multiple Sclerosis

May 5, 2010
MS Society lobbies government for $10 million for funding into CCSVI and MS research

The MS Society—York East chapter would like to thank The FSA Group for their continued support and for publishing The Spokesmaster at no cost to the chapter, the society or its members.

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