

THE UNIVERSITY OF BRITISH COLUMBIA MS CLINIC
A member of Vancouver Coastal Health



December 9, 2009

On November 21st the Globe and Mail and CTV W5 featured the story of an experimental diagnostic and surgical procedure for Multiple Sclerosis called **chronic cerebrospinal venous insufficiency (CCSVI)**. Multiple Sclerosis is the leading cause of disability in Canada. Over 60,000 Canadians are affected by this disease and many are now wondering about the validity of this research. Many of us in the MS clinical and research community watched this story with great interest, but also with some natural skepticism as we have seen similar claims of potential causes and cures in the past.

As MS clinicians and researchers at the University of British Columbia and Vancouver Coastal Health, our goal is to provide the best treatment that is safely available to our patients and to pursue research that could lead to improvements in their lives. With respect to the validity of CCSVI, the work recently published by Dr. Zamboni on the narrowing of the veins in the neck does suggest that this may be common in people with MS.

We had been aware of this story in the MS research community prior to the news report and had been developing plans in collaboration with radiology (including interventional vascular specialists) and physics experts at the University of British Columbia and Vancouver Coastal Health to try and confirm the findings independently using a variety of imaging techniques. We need to determine how common this abnormality is and how easily it can be detected with routine tests available throughout our region. With the support of the MS Society of Canada we will investigate this as rapidly as possible. However, all research activities must go through a careful process of review by the Clinical Research Ethics Board at UBC as well as Vancouver Coastal Health before anyone with MS can participate. This process can take several months.

The news report also discussed an experimental treatment for correcting the narrowing of the veins using a catheter (a tube that goes into a blood vessel with a balloon attached to it). The people who were interviewed expressed that they dramatically improved after they were treated, and it is their enthusiasm that has really caused much of the excitement about this treatment. We must urge caution when reading these results as we believe that this part of Dr. Zamboni's experiment is not well controlled. By this we mean that all patients in his study were treated with the procedure. There was no group of patients who acted as control or untreated subjects. The reason for designing a study with a control group is to avoid bias and the placebo effect. Therefore, we believe that it is important to test the validity of this experimental treatment within a well designed study that avoids the potential influence of bias. Dr. Zamboni also agrees with this approach. We hope to work with other MS centers within Canada and worldwide. This type of study takes many months to organize, fund, and get underway, but it is the safest and only way to move forward and determine independently the value of treating CCSVI.

Many questions remain unanswered. We hope the following list of questions and answers will help those of you with MS who want immediate information on this; however, some questions can only be answered with further testing, which we hope to get underway as soon as possible.

Frequently Asked Questions about CCSVI and MS

Q: Do these reports of a possible association between insufficient vein drainage and MS mean that MS is caused by venous insufficiency?

A: No. Based on results published about these findings to date, there is not enough evidence to say that obstruction of veins causes MS, or to determine when this obstruction may occur in the course of disease.

Q: If CCSVI turns out to be important in MS, can it be treated?

A: No one knows yet. Dr. Zamboni's work suggests that not all patients benefit from the surgery, and for those that do, the benefit may only be short term. Surgical procedures for CCSVI in MS are still experimental and should be undertaken only as part of formal clinical trials that include all of the standard safeguards that are followed in such trials.

Q: I have MS. Should I be tested for signs of CCSVI?

A: No, unless you are involved in a research study exploring this phenomenon. At this time there is no proven therapy to resolve any abnormalities that might be observed, and it is still not clear whether relieving venous obstructions would be beneficial. We are applying for funding from the MS Society of Canada to determine the most practical and reliable test for CCSVI. Patients interested in participating in these studies can leave their name and contact details with their neurologist or clinic.

Q: Should I get my veins tested at a private diagnostic facility?

A: No. The validity of this testing is not proven as yet. Furthermore, treatment of any abnormality is experimental and would not occur at a hospital in Canada unless it was part of a study approved by the hospital and ethics committees.

Q: Can my MRI be checked for CCSVI?

A: No. A routine MRI would not include the required detail of the veins to check for CCSVI.

Q: Does CCSVI make the standard treatments of MS meaningless?

A: No. There is ample evidence proving that the Health Canada approved therapies for MS provide benefit for people with most forms of MS.

Q: Are other Canadian centres performing routine testing or surgery for CCSVI?

A: No. The UBC MS Clinic is a member of the Canadian Network of MS Clinics. A consensus statement from this network recommends that further research is required to test Dr. Zamboni's findings. Discussions are underway through this network looking at the possibility of doing a Canada wide study.

Q: Will the MS Society of Canada fund research into CCSVI in MS?

A: The MS Society welcomes research proposals from any qualified investigators whose research questions are relevant to multiple sclerosis. All proposals received are thoroughly evaluated for their relevance and excellence by our volunteer scientific peer review panels.

Q: How can I support this work?

A: Funding to support this important research will be critical. Donations can be made through the MS Society of Canada (www.mssociety.ca), the VGH and UBC Hospital Foundation (www.worldclasshealthcare.ca), the UBC faculty of Medicine (www.med.ubc.ca) or the UBC Brain Research Centre (www.brain.ubc.ca).

Q: Where can I get updates?

www.mssociety.ca
www.mriresearch.ubc.ca/
www.nationalmssociety.org
www.cnmsc.org/

Sincerely

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