

UBC HOSPITAL MS CLINIC

March 4th, 2010

Update on CCSVI.

There remains considerable ongoing interest in the experimental diagnostic and surgical procedure for Multiple Sclerosis called **chronic cerebrospinal venous insufficiency (CCSVI)**.

Update on independent research reports in CCSVI: Preliminary results from Dr. Zivadinov at the Jacobs Center in Buffalo demonstrated that approximately 56% of MS patients had abnormalities on ultrasound suspicious for CCSVI but so did 22% of healthy volunteers. This is somewhat different from the 100% rate of abnormality Dr. Zamboni reported in MS patients and 0% in healthy volunteers. It could suggest that CCSVI is less common or less distinct than previously thought. Or, it could suggest that ultrasound is not accurate enough to detect CCSVI. It does clearly show the importance of independent research in any new medical claim.

Update on safety of surgical treatment of CCSVI: In February, it was reported that two patients had serious complications from stents (metal tubes) used in their veins. One patient suffered a fatal blood clot in the brain, while another had to undergo open heart surgery after a jugular vein stent dislodged into her right ventricle.

Update on the Hamilton, Ontario meeting: Physicians and researchers attended a meeting on CCSVI in Hamilton, Ontario in February 2010. Several members of the BC/SASK team attended as well. Speakers included Drs. Zamboni, Zivadinov, Dake, Haacke and others. This was mostly a repeat of previous research. It did include several physicians who shared their personal experience with diagnosing and treating CCSVI. While the discussions and interaction were lively, there was no new research on the validity of CCSVI or effectiveness of treating CCSVI presented at this meeting.

Update on UBC and Vancouver Coastal Health plans: In collaboration with the MS Centre at the **University of Saskatchewan (the BC/SASK Research Team)**, we have submitted a research proposal to the MS Society of Canada. If successful, this will allow us to use the best test possible, called catheter venography, to detect CCSVI. We will compare that to MRI and ultrasound as well (subjects will have all 3 tests performed). We believe that catheter venography is the most reliable way at this time to study CCSVI.

A second research proposal was submitted to the Canadian Institutes of Health Research (CIHR) on March 1st. If successful we will investigate the role of brain iron in CCSVI and MS and we will develop new MRI techniques for the neuroimaging of MS.

Our research can not start until we receive funding and ethics approval.

Frequently Asked Questions about CCSVI and MS – March 2010 update

Q: CCSVI was in the news in November. Why is it taking so long to start the research?

A: Research takes planning and funding. Our MS research teams at UBC, VCH, and University of Saskatchewan have invested an enormous amount of energy into planning a study that would definitively prove or disprove CCSVI and determine the best test for detecting it. We can't do the research without funding to pay for the tests and to support the staff required for this project. We've submitted several grant applications to support this work and will not know until the summer of 2010 if we will have the funds to get started. However, we are actively working on getting ready to start, ensuring we have everything in place including ethics and hospital approval.

Q: How will I find out when the BC/SASK study is starting?

A: The MS Society and local media will be informed once we are able to start.

Q: Can I get tested for CCSVI at a public hospital or private clinic?

A: No. The best test for detecting CCSVI is not yet known. We continue to speak with physicians around the world interested in CCSVI, and have come to the conclusion that there remains a lack of standardization on the best way to diagnose CCSVI.

Q: My ultrasound said I have CCSVI. What can I do?

A: While this may be accurate, it is also possible that the test is providing a “false positive” result due to lack of standardization and lack of experience. Furthermore, detecting CCSVI would not necessarily lead to immediate treatment until that treatment is proven to be safe and effective.

Q: I want my MRI checked for CCSVI.

A: Most MRI’s for the routine monitoring of MS do not include pictures of the veins and would not be suitable for checking for CCSVI. A specialized MRI examination, known as MR venography (MRV) is needed. However, work is needed to see if MRV is sensitive and accurate enough to detect CCSVI.

Q: I saw an advertisement that offered to test for CCSVI at a private facility.

A: The best test for CCSVI is not yet established. We do not recommend testing for CCSVI until it is clear how best to test for it.

Q: Where can CCSVI be treated?

A: Several private and mostly for profit groups are advertising surgical procedures for CCSVI. This treatment in MS is 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: How do I know if treatment of CCSVI is part of a research study?

A: You should be given an informed consent form that has been reviewed and approved by an ethics board. The ethics board should be clearly identified on the consent form. In general, there should be no cost or payment for participation in a research study.

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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