

BC CCSVI Registry Info Sheet

December 8, 2011

Background

- The BC CCSVI Registry is a province wide program operated by the MS Clinic at UBC Hospital at Vancouver Coastal Health
- Funding for the program, \$700,000 over three years, has been provided through the BC Ministry of Health
- The BC CCSVI Registry is the second registry to be launched in Canada. Alberta has also begun a registry.
- The purpose of the BC CCSVI Registry is to better understand the impact of interventional venous treatment.
- Specifically, the Registry hopes the data collected on the patient perspective of outcome (both positive and negative), the physician perspective of outcome (both positive and negative), and any safety concerns will help in developing treatment guidelines for ongoing care for those patients who have received treatment abroad and returned to BC.
- The information will also help provide information with respect to potential risks to study participants who may be considering participating in future CCSVI clinical trials in Canada.
- General findings from aggregated and de-identified data will be made public.

Information for patients interested in participating:

*****This Registry is for patients who have *had* a CCSVI procedure and would like to share their experience. It is not to register to have the procedure done.**

- Please call the following toll-free number **1-800-668-2291** or send an email to address **bc_ccsvi.registry@ubc.ca** and leave your contact information.
- You can also give verbal consent to your physician (neurologists/family physicians) so that your contact information can be sent to the Registry for follow up.
- A Registry Interviewer will return your call or email, or follow up on your request via your physician, and provide you with details about the Registry.
- Registration is voluntary. If you wish to register, you will be sent two copies of the Informed Consent Form - one is to be signed and returned to the Registry; the other is to be kept for your records.

- Once your consent has been received, you will be interviewed by telephone using standardized questionnaires.
 - There will be up to four interviews in total (one “Initial” interview and three “Follow-up” at 6-months, 12-months and 24-months after the Initial Interview).
 - You will be asked specific questions about your CCSVI procedure, health, activities, and MS.
 - You may be asked for your signed consent so that the Registry can obtain your medical records from physicians and/or hospitals to complete your medical history on MS.
- Your information will be privacy protected. You will be assigned a study code so that your identity (i.e. your name or any other information that could identify you) will stay confidential
- Only aggregated and de-identified data from the Registry will be used in analyses, and at certain points within the three year period, findings will be made public.

Information for physicians interested in participating:

- Physicians can inform the Registry about their perspective of patients’ outcomes after their CCSVI treatment.
- Data forms will be available for download through the BCMA secured login link, or by calling **1-800-668-2291** or emailing at bc_ccsvi.registry@ubc.ca
- Patient data will be de-identified and privacy protected.

Further updates on the program will be available on this website www.vchri.ca under the MS – CCSVI button.