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Vancouver Coastal Health MS Clinic to establish provincial CCSVI registry and surveillance guidelines

(VANCOUVER – BC) The UBC Hospital MS Clinic is launching a new program to better understand the impact of interventional venous treatment. The Clinic will receive over \$700,000 in provincial funding to establish a CCSVI patient registry, care-related protocols, and a rapid access pathway to expert care for both patients and health care providers. British Columbians with multiple sclerosis (MS) have been seeking the treatment from overseas clinics for the last 12 – 18 months.

“We have increasing numbers of patients at UBC Hospital and other clinics across the province who have received interventional venous treatment,” says Dr. Tony Traboulosee, medical director of the UBC Hospital MS Clinic and assistant professor in the UBC Faculty of Medicine. “Often they are uncertain as to whether to tell their neurologist they have had the procedure, and in turn neurologists are uncertain as to appropriate after care. Our goal is to establish province wide standards of care and better understand the risks and benefits for MS patients.”

CCSVI (chronic cerebrospinal venous insufficiency) is a hypothesis suggesting narrowing of the veins that carry blood to and from the brain and spinal cord is a possible cause of MS. The theory proposes narrowed veins create congestion of blood that leads to iron deposits which trigger attacks of inflammation. Treatment to open these veins involves a relatively simple angioplasty procedure, by either balloon or coated metal stent.

Interventional venous treatment is generally marketed as being risk free, but because veins, unlike arteries, fluctuate in size and shape, a vein that has been opened with balloon angioplasty will likely rapidly narrow again. As a result, many treatment centres are opening veins with stents that are meant to stay permanently in place. It is this type of treatment where complications can ensue. Stents can dislodge and migrate to the heart requiring emergency surgery. They can also cause blockages and hemorrhaging. All patients who undergo a procedure for stents must take blood thinning medication, which can cause severe complications.

While wide-scale, peer reviewed research on the hypothesis and treatment of CCSVI is underway around the world, including a study led by the UBC Hospital MS Clinic, it is still considered only a theory. Treatment is not available in Canada, but MS patients have been seeking the procedure elsewhere and returning to BC without pre-planned follow-up or clear instructions for care.

“Ensuring patient safety and consistency of care is our first priority,” says Dr. Traboulosee. “Both patients and clinicians will benefit from having a province-wide protocol of care. We also hope the data collected through this program will enhance the current research being conducted on this proposed theory of MS.”

The provincial funding is spread over three years and allows the UBC Hospital MS Clinic to establish post-care treatment guidelines; a voluntary registry to determine the number of BC residents who have had testing and/or liberation treatment, and the perception of benefits and complications; and a rapid-access to expert care pathway. This key component of the program will enable health care providers across the province to reach one of the experts at the UBC Hospital MS Clinic in situations of need.

“We greatly support this program,” says Janet Palm, president, MS Society of Canada, BC & Yukon division “This funding is much needed to support BC’s leadership on MS research and

care, and will help ease the minds of British Columbians who have MS who have either explored overseas treatment or are considering it.”

The UBC Hospital MS Clinic is led by a world renowned MS clinical research team. The Clinic, which cares for 80 – 90 percent of MS patients in BC, is globally reputed for its emphasis on treatment, education, and translational research. The MS clinical research team comprises specialists in pharmaceutical and interventional therapies, imaging, and genetics. The clinic is a national clinical trial centre for new pharmaceutical therapies; is leading Canada’s only imaging study investigating the theory of CCSVI; and is home to the world’s largest MS database of over 7500 patients who have been followed for over 25 years. It is a world leader for innovative research using MRI to study and evaluate MS treatments. The UBC Hospital MS Clinic is a member of the Canadian Network of MS Clinics, a national network of academic and community based clinics established for the advancement of patient services, education, and research in Multiple Sclerosis.

About multiple sclerosis and the Multiple Sclerosis Society of Canada

Multiple sclerosis is a chronic, often disabling disease of the brain and spinal cord. It is the most common neurological disease of young adults in Canada. Most people with MS are diagnosed between the ages of 15 and 40, and the unpredictable effects of MS last for the rest of their lives. The MS Society provides services to people with MS and their families and funds research to find the cause and cure for this disease.

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