

Dispelling the Myths



10 myths about MS, the MS Society, and CCSVI (the Liberation Treatment)

The Multiple Sclerosis Society of Canada is a charitable, nonprofit organization created and governed by people with MS to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life. The strength and success of the organization rests on the age-old practice of *“members helping members.”* In recent months the MS Society has been criticized for not advocating for the immediate approval of CCSVI treatments. Not surprisingly, breaking news about a possible new treatment fuels considerable speculation and sometimes misinformation. We have created this information brochure to address some of the myths that keep appearing in various forms of media so that we can set the record straight. The MS Society shares the hope of all Canadians and is working quickly to kick start the further research that is needed to better understand the promise this new treatment offers.

Myth #1

The MS Society is giving only \$200,000 toward CCSVI research.

Fact: The MS Society has not placed a limit on how much money will be given to study CCSVI. Each research project can receive up to \$200,000. There is no cap on the total number of CCSVI research projects we will fund. On June 14 we will announce how many CCSVI research projects will receive funding and how much each project will receive. Visit: [or see our Facebook page: “MS Society Alberta.”](#)

Myth #2

The MS Society is blocking CCSVI treatment because it may compromise the funding we receive from pharmaceutical companies.

Fact: The MS Society of Canada receives 2% of its total budget from pharmaceutical grants. In Alberta, the percentage is well under 1%. These grants are “unrestricted”, meaning the drug companies have absolutely no influence in how we use the money. These grants are used primarily to host education sessions to inform people about the latest research and treatments in MS.

Myth #3

The MS Society and the MS Clinics in Edmonton, Calgary and Red Deer are the same organization.

Fact: The MS Society and the MS Clinics are different organizations. The MS Society does not perform MRIs or any type of diagnostic service or medical treatment of any kind. The MS Society has never denied access to a diagnostic service or treatment. We are not a medical organization.

Myth #4

The MS Society is blocking CCSVI treatment because that will lead to a cure and we will be out of a job.

Fact: Employees of the MS Society have made a choice to work in the nonprofit sector. Every day we choose to work for the MS Society because we want to make a difference in the lives of people living with MS. When a cure is discovered, this half of our mission will be fulfilled.

Myth #5

The MS Society knew about Dr. Zamboni's research before it became public and bought the Internet domain "ccsvi.ca" in order to control what people read about CCSVI.

Fact: The MS Society became aware of Dr. Zamboni's research shortly before it was first shown on W5. Part of our mission involves providing people affected by MS with timely and accurate information in order for them to make informed decisions. We believe that by creating a website with the name "ccsvi.ca", this provided the best opportunity for people to find the information they were looking for quickly and easily.

Myth #6

CCSVI treatments are available in many other countries but not Canada.

Fact: Kuwait is the only country in the world which is providing the treatment using government health dollars. Every other location where this treatment is available is through a for-profit private clinic.

Myth #7

The MS Society is doing little to obtain government approval of the CCSVI Liberation Treatment.

Fact: The MS Society in Alberta has been meeting with Senior Alberta Cabinet Ministers since December 2009 to encourage government support of the CCSVI research that needs to be done before treatment approval can be considered by Health Canada and Alberta Health Services. More recently, the National MS Society of Canada has called upon the federal government to invest \$10 million into CCSVI research to accelerate the process. These actions have been in response to the voice of Canadians living with MS.

Myth #8

The MS Society can arrange for you to receive the Liberation Treatment or put you on a list to participate in a clinical trial.

Fact: The MS Society does not endorse or recommend any treatment options, or make arrangements for someone to have a treatment done. We provide information so people can make informed decisions with their doctor and family. We cannot put someone on a list to participate in a clinical trial. That is done by the researcher performing the trial.

Myth #9

The liberation treatment is a cure for MS.

Fact: We do not know what the real relationship is between CCSVI and MS. We do not know if CCSVI causes the disease or is the result of the disease. We do not know why some people with MS have CCSVI and others do not. We do not know why people without MS have blockages in their veins but do not experience any symptoms of the disease. The research and medical community simply does not have enough information to say a cure has been found.

Myth #10

Donors cannot directly support CCSVI research.

Fact: Fact: If donors choose, they can allocate their donation specifically for CCSVI research.