

3 May 2010

**Subject:** Multiple Sclerosis (MS) and CCSVI: it's time to act impartially, rationally, and with compassion, the Canadian way.

Dear Member of Parliament:

We have one of the highest rates of MS cases in the world; between 55,000 and 75,000 Canadians suffer from this disease that typically strikes those between the ages of 20 and 40. MS affects the nervous system and causes chronic fatigue, vision loss, numbness, loss of coordination, incontinence, and so on. Drugs costing up to \$40,000 a year per patient promise, at best, to slow down its progress. This debilitating disease has had no known cause, potential cure nor treatment.

Groundbreaking research conducted by Dr Paolo Zamboni and a team of scientists at the University of Ferrara in Italy was published in November 2009. They found that people with MS also have a condition called **CCSVI** or *Chronic Cerebro-spinal Venous Insufficiency*, which very few in the control group had. This condition, caused by narrowed veins in the neck, prevents blood from draining properly, causing corrosive iron deposits in the brain. Using angioplasty, the problem veins were corrected. This known and safe procedure, used for many years in a variety of other treatments, stopped the progression of MS in 76% of patients —something that no existing MS drug does— and reversed the disability in some —something that no existing MS drug does. Since then, their research has been replicated in the United States, Poland, Jordan and Kuwait, all with positive results.

Over the last few months, doctors in Canada and from around the world, have carried out the procedure with such notable results that this unblocking of veins has been coined 'The Liberation Procedure'. Within minutes, patients—who are awake during the procedure— feel warmth and less numbness in their face and extremities. In the longer-term their improvements are far less fatigue, better mobility and balance. These results have led Australia and Kuwait to make the Liberation Treatment available to all citizens who have CCSVI.

Yet in Canada, where the costs associated with MS are \$1 billion/year and rising, doctors are being prevented for doing this procedure, even though using **balloon angioplasty, the recommended procedure for venous malformations and thus CCSVI, is an insured service under the Canada Health Act**. The reason given is that correcting blocked veins has not been proven to help MS specifically. Yet, it is recognized that CCSVI is detrimental to anyone's health, whether one has MS or not. Indeed, people with diabetes or hypertension who also have blocked veins or arteries are routinely treated with angioplasty and stenting. Under the universality clause of our Health Care Act, people with MS should also have access to angioplasty if they have severely blocked veins. Instead, Canadians with MS have had to go to Poland, India and elsewhere at great personal expense, and limited

follow up, to get that treatment. Canada—a world leader in universal and equitable health care—has the opportunity and the duty to take a leadership role in the diagnosis and treatment of CCSVI for MS patients, by doing the following:

- 1) Fund existing non-invasive tests for CCSVI, which use Doppler ultrasounds and MRIs, as insured services under the Canada Health Act.
- 2) Honour the patients' right to treatment under the Canada Health Act, by ending the unjustified restrictions on the treatment of CCSVI in MS patients in Canadian hospitals.
- 3) Have all of the procedures, testing and related data included in a national, clinical trial under the Canada Health Act, so that opportunities for improvements to safety and treatment are not lost.

Nay-sayers propose postponing treatment of CCSVI for several years, at great health and economic expense, by taking the unusual step of calling for double-blind studies to prove its specific linkage with MS and the benefits of its treatment specifically for MS sufferers. The perceived requirement for double-blind studies is unfounded, since many procedures are done without clinical trials if they are known to be safe and with patients' consent. Given the compelling evidence widely reported in the published literature and in the media, as well as testimonials from vascular doctors in North America and around the world, it is unethical, irrational and uneconomical to deny treatment for CCSVI to MS patients. Given the degenerative nature of their disease, simply halting its course for some patients, at a fraction of the cost of the drugs they now use, would be a great benefit to them and to society in general. I quote Ontario vascular surgeon, Dr. Sandy McDonald in a recent Maclean's article, *"It's okay to get bigger breasts or a facelift, yet patients with MS, a debilitating, degenerative disease, have to wait for double-blind studies. Welcome to Canada."*<sup>1</sup>

Well, this is ***not*** how it should be in Canada. On the 27<sup>th</sup> and 28<sup>th</sup> of April 2010 Senator Angus made a compassionate plea for action on the floor of the Senate in that regard. As a Member of Parliament, you have the power to do the right thing, right now. It's really up to you.

With sincere thanks,

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*P.S. Please note that there will be a rally on Parliament Hill, and in cities across Canada, on May 5, 2010*

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<sup>1</sup> Source: <http://www2.macleans.ca/2010/04/19/the-%E2%80%98miracle-cure%E2%80%99/>

<sup>2</sup> [www.msliberation.ca](http://www.msliberation.ca) is a grassroots movement with over 350 members