

**11 May 2010**

**Canada** gave the world insulin, mobile blood transfusion, and the "Montreal Procedure" — a *surgical* treatment for epilepsy. Back then, the barriers were at the *frontiers* of medicine. Today, they are *between* the specialities of medicine: we are up against myths and self-serving practices.

Fortunately, there is a solution. Venograms and Venoplasty are already insured services under the Canada Health Act. So, let MS patients have access to them now.

*My name is Rebecca Cooney, co-founder of MS Liberation, a group of 350 MS patients. Thank you for hearing our concerns and solutions.<sup>1</sup>*

All Canadians with vascular problems can be tested and treated in Canada... unless they have MS. Since I am diagnosed with CCSVI<sup>2</sup>—my family doctor has recommended I see a vascular specialist, but none will see me without a referral from my neurologist... who in turn just won't do it.

Why? Treatment of CCSVI is held to the myth of risk-free medicine. What's the reality? In 2007, the *British Medical Journal* analyzed 2,500 common medical treatments and found that only a third actually had proven benefits. The "Montreal Procedure" for epilepsy was implemented without double blinded trials. Without clinical trial, Angioplasty was accepted as the safe and economical way to treat coronary diseases. If I had heart disease I could get angioplasty without a neurology referral. Why is CCSVI held to a different standard?

There is also the myth that the **treatment of CCSVI is experimental**. In fact, venoplasty is used for thrombosis of the jugular vein and sigmoid sinus. Another myth is that **there are conventional drugs** for people with progressive MS<sup>3</sup> – there are none. Still another myth is *why fix something that is not proven to help MS?* The plain answer is that better blood circulation improves health, MS or no MS, and the goal is to treat the patient, not just MS.

I am not a medical doctor. But I have is an MBA and 15 years experience in Risk Assessment. In delaying or acting now on CCSVI, we need to assess three things: risks, costs and benefits.

**The risk** of venoplasty is minimal: it has been performed very safely for many years on thousands of people. *Conversely, the medical risks of existing drugs for MS are well known.*

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<sup>1</sup> [www.msliberation.ca](http://www.msliberation.ca)

<sup>2</sup> MRI and MRV results for Rebecca Cooney, Interpreted by radiologist Samir E. Noujaim

<sup>3</sup> Publically stated by the *Collège des Médecins du Québec*  
[http://news.sympatico.ctv.ca/Canada/ContentPosting?newsitemid=CTVNews%2F20100505%2Fms-ccsvi-rallies-100505&feedname=CTV-NATIONAL\\_V3&show=False&number=0&showbyline=True&subtitle=&detect=&abc=abc&date=True](http://news.sympatico.ctv.ca/Canada/ContentPosting?newsitemid=CTVNews%2F20100505%2Fms-ccsvi-rallies-100505&feedname=CTV-NATIONAL_V3&show=False&number=0&showbyline=True&subtitle=&detect=&abc=abc&date=True)

**The costs** to test and treat CCSVI are minimal, estimated to be \$1,500 per person, less than the cost of one-month of drugs for a patient with relapsing-remitting MS.

**The benefits** of venoplasty are the most encouraging yet for MS. Venoplasty actually improves the condition of some patients –*something that MS drugs rarely do*. It stops the progression of the disease in some patients –*something no MS drugs does*. And for people with progressive MS, it is the **ONLY** safe option. There are no drugs for progressive MS.

Resources must be deployed strategically<sup>4</sup>. The MS society has asked for 10 million dollars. Since their competition does not cover researching the treatment of CCSVI, I have serious concerns that I will leave unsaid.<sup>5</sup>

What I will stress, is that immediately, the Government of Canada can:

1. Declare CCSVI diagnosis and treatment “insured services” under the Canada Health Act;
2. Require that all CCSVI data be documented in a nation-wide, clinical trial;
3. Ensure that treatment of CCSVI and clinical studies be done in parallel, not in sequence.

Four years ago, MS halted my career. Here’s what’s next: wheelchair bound, incontinence, debilitating headaches, inability to swallow food, dementia. However, e-mails from across Canada remind me that I am not alone.

For every patient, there are scores of friends and relatives, deeply affected. One email from a mother stands out:

*‘The only thing worse than not having a treatment for your child’s MS, is knowing that there is a treatment out there, but you are denied access to it by your own government’* .

Ladies and gentlemen, you can change that. And for that, I thank you in advance.

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<sup>4</sup> Proposal written by R.Cooney and Dr.Mark Haacke given to both the Ontario Health Office and the Federal Health Ministry’s office in January 2010.

<sup>5</sup> Letter to Yves Savoie of the National MS Society, written by Christopher Alkenbrack Wolfville, Nova Scotia : <http://www.facebook.com/topic.php?topic=125&uid=110317832313822>