

# The Sad, Sad State of CCSVI Research in Alberta

Ashton Embry, December 23<sup>rd</sup>, 2010

## Introduction

It is well established that Alberta and Saskatchewan have by far the highest rates of multiple sclerosis in the world with a prevalence of at least 360/100,000 and an incidence of 24/100,000. This is about double to triple the rates of any other area in the world where MS is considered common (e.g. Scandinavia). Other important facts are that there are no effective treatments for MS and there is no good scientific evidence that any of the currently prescribed drugs do anything in regards to slowing disease progression.

Given the above, one would think that both Alberta and Saskatchewan, which spend huge sums of money every year on treating persons with MS to no avail, would be most interested in determining whether or not CCSVI treatment was of significant value for MS and perhaps might even halt disease progression if applied soon enough. The humanitarian and financial benefits which would flow from an effective treatment for MS are enormous and CCSVI treatment currently represents our best hope for such a treatment.

The current scientific data indicate that CCSVI treatment may well live up to such expectations. The key science includes:

- 1) Impaired venous drainage (CCSVI) has been found to be highly associated with MS with over 90% of 10,000+ persons examined with venography (gold standard) having indisputable CCSVI. In this regard a few negative (and highly quoted) studies of MS/CCSVI association can be readily discounted given the use of equivocal, non-invasive techniques by inexperienced operators in very small populations.
- 2) Many of the venous blockages that cause CCSVI are clearly congenital in origin and thus precede the MS disease process (i.e. CCSVI is a primarily a contributor to MS not an effect).
- 3) Established biological mechanisms associated with CCSVI can readily account for aspects of the MS disease process and also help to explain previously inexplicable features of MS.
- 4) Thousands of reliable and well documented accounts of substantial symptom relief following CCSVI treatment have been made available. Notably, no other

therapy in the 170 year history of MS has ever produced such numerous benefits in so many people.

Given MS is a huge and very expensive problem within both jurisdictions, it is most instructive to contrast the response of the Alberta government to the immediate and important need for proper research on the value of CCSVI treatment with that of the neighbouring Saskatchewan government.

### **Alberta Response**

The Alberta response to the need for such research is not acceptable and does not meet the needs of persons with MS. The main strategy of the government is to fund a three year collection of data from Albertans who have had CCSVI treatment in a wide variety of clinics throughout the world. The only explanation for the creation of such a bizarre and worthless project is that it was concocted by the Alberta neurologists who are on record as claiming CCSVI is nonsense (equivalent to Santa Claus and the Easter Bunny according to Dr Brad Stewart, a University of Alberta neurologist). Furthermore, the head of the Calgary MS Clinic, Dr Louanne Metz, gave a public talk on CCSVI in which she denigrated the concept, implied Dr Michael Dake, a renown vascular doctor in the USA who has done CCSVI treatments, is a killer, and stated in no uncertain terms that Avis Favaro, the health reporter who broke the CCSVI story, is a liar. Tellingly, the MS Society of Canada, which had promised to put up a video of the Metz talk on their website, declined to do so. You know when MSSC refuses to put up an anti-CCSVI piece, it must be beyond bad.

The Alberta MS neurologists also produced an Alberta Health Services “Information Sheet on MS and CCSVI” and it was so awful that Dr Zamboni, the originator of the CCSVI concept, felt compelled to write a rebuttal to the Alberta government. I also wrote a detailed critique of the AHS “Information” Sheet which was filled with numerous factual errors, misleading statements, half truths and blatant, fear mongering (<http://www.direct-ms.org/magazines/An%20Open%20Letter%20to%20the%20Honourable%20Gene%20Zwozdesky.pdf>). The bottom line is that the actions, statements and publications of the Alberta MS neurologists demonstrate beyond question a very strong, anti-CCSVI bias which has no scientific basis.

The overt, anti-CCSVI prejudices of the Alberta neurological fraternity readily explain how and why such a pointless, observational study was created and sold to the provincial government. The key is in the length of the study. It is planned to start in mid-2011, will run for 3 years, and will be followed by up to a year of data analysis and publication. This takes us well into 2015 before Alberta can even think about doing any serious research on the value CCSVI treatment. It doesn't take a rock scientist to see

that the planned, worthless “study” is nothing more than a ruse by the neurologists to stall any meaningful research on CCSVI treatment for at least 5 years.

In case anyone is wondering why the MS neurological community is so anti-CCSVI and wants desperately to delay any worthwhile research for as long as possible, the answer lies in the fact that MS is rampant in Alberta. This has resulted in many people being readily available for clinical trials to test a myriad of drugs and, over the last 20 years, Alberta neurologists have gotten large sums of money from the MS drug companies through testing, prescribing and advocating for the use of proposed MS drugs. The thought that a non-drug treatment such as venous angioplasty might supplant the rich MS drug trade is an unthinkable nightmare to many neurologists.

The bottom line is that the neurologists have a major financial conflict of interest when it comes to any advice on CCSVI treatment research and the fact that Alberta Health Minister, Gene Zwozdesky, looks to them for such advice is indefensible and definitely not in the best interests of either persons with MS or all Albertans for that matter.

In summary, the Health Ministry of Alberta has adopted a very unfortunate and harmful policy when it comes to CCSVI by supporting a worthless, observational study which will only accomplish one thing –a very long delay (5 years minimum) of the required clinical study of the benefits of CCSVI treatment. The only question that remains is whether or not the Alberta government has been taken in by the self-serving neurologists or is part of the ugly charade to ensure no worthwhile clinical research on CCSVI for the foreseeable future. Regardless, the people of Alberta, especially those affected by MS, are being badly served by the provincial government on this issue.

### **Saskatchewan Response**

The absurdity of the Alberta response to the need for CCSVI treatment is made even more obvious by the response of the Saskatchewan government to the same requirement. Notably, the Saskatchewan government has ignored the advice of the self-serving neurologists in Saskatchewan and has put aside \$5,000,000 to fund a proper, clinical trial of the effectiveness of CCSVI treatment for MS. The trial will likely begin in 2011. Given it is imperative to establish as soon as possible if CCSVI treatment is a worthwhile or not, this is a responsible, intelligent and objective response to the available science and the obvious needs of those with MS.

### **Reason for Different Responses**

So why is the Saskatchewan government acting in such an intelligent and responsible manner whereas the Alberta government is doing exactly the opposite by concocting a flawed, thoughtless and eventually harmful response to the need for CCSVI treatment research. The answer lies in the abilities and sensibilities of the involved politicians. In

Saskatchewan, Premier Wall and his health minister, Don McMorris, have wisely gone out and seen for themselves the results of CCSVI treatment and, not surprisingly, have been suitably impressed. It is clear that Premier Stelmach and his health minister, Gene Zwozdesky, have not bothered to gather their own data but instead have sat in their plush offices and relied on the highly biased and self-serving information they have received from neurologists.

## **Summary**

The Alberta government has chosen a path of purposefully delaying any meaningful research on CCSVI and MS for at least 5 years by supporting a long term, worthless, observational study. The government's irresponsible action stems from highly subjective advice from neurologists and, predictably, such an action is not in the best health interests of persons with MS but rather is in the best financial interests of the neurologists.

In stark contrast to this, the Saskatchewan government has ignored the advice of neurologists and has acted responsibly and caringly by funding a research project to test the effectiveness of CCSVI treatment. The diametrically opposed reactions of the two governments, to the critical need of determining if CCSVI treatment is effective, clearly demonstrate the importance of strong and intelligent leadership in government, something which is sadly lacking in Alberta but which is flourishing in Saskatchewan.