

May 19, 2010

Dear Ms Levy and Dr Lang,

I read your recent column on the treatment of CCSVI (Liberation or placebo effect? MS surgery, Montreal Gazette) and was very surprised at how much you left out about the science of CCSVI. You completely missed the implications of the key scientific findings of CCSVI and why these findings strongly indicate that it is important to be treated for CCSVI sooner than later.

First of all the current science has left no reasonable doubt that CCSVI is associated with MS, that is, it is far more common in persons with MS than the general population. This is based on Dr Zamboni's research as well as published information from other centres, including a major study at the University of Buffalo. No credible researcher is disputing this clear association. Of course, association alone does not mean cause. Your statement "CCSVI, if that condition actually exists" indicates that neither of you have not read the literature (e.g. the April issue of International Angiology which had 13 contributions on CCSVI). How you think you can write an intelligent column without such background reading boggles my mind.

Another critical scientific finding which you seemingly know nothing about is that the venous malformations that drive CCSVI are almost exclusively congenital, that is, they were there at birth. Again comprehensive papers have been published on this and it is very widely accepted. This is critical because it shows that CCSVI precedes the MS disease process and is not an effect of it.

Finally, it is also well accepted that biological mechanisms which are a consequence of CCSVI, such as reflux of venous blood back to the brain, the deposition of iron in the brain, hypoperfusion, and the upregulation of adhesion molecules on the endothelium of the venules, all can be reasonably related to the MS disease process.

I would also emphasize that no one credible is claiming MS is not an autoimmune disease. The huge MS data base shows it almost assuredly is. However, it also must be emphasized that the biological mechanisms associated with CCSVI all significantly enhance the autoimmune process.

This brings us to another of your ill-conceived statements. "CCSVI, and MS, breaks down on a number of other fronts, including the fact that patients who have impaired blood flow in their veins as a result of surgeries, for example, don't develop MS. Similarly, vessels tend to narrow as we age and yet MS is not a disease of older individuals. The blocked vein theory of MS is so out of keeping with our understanding of the disease that it might be compared to fixing a

burned out car radiator by changing the tires of a car.” I was embarrassed for both you when I read it. MS is an autoimmune disease which is substantially aggravated by the co-occurrence of CCSVI. Not everyone with MS has CCSVI and not everyone with venous problems has MS. This again is well established in the literature. I cringe when I read ridiculous statements which attempt to discredit the CCSVI/MS association. You two are better than the nonsense you wrote.

I might note that CCSVI helps to explain a major puzzle in MS. As you both well know, the brain is protected from the blood-borne, immune system by what is known as the blood-brain barrier (BBB); greatly strengthened, blood vessel walls which prevent the passage of immune cells into the CNS. It has always been a problem to explain why the autoimmune cells were able to cross the BBB so easily in the MS disease process, given that evolution had ensured this would not happen. Of course the trick is that the biological mechanisms associated with CCSVI degrade the integrity of the BBB and allow the autoaggressive immune cells to cross the BBB much more easily. Thus, with CCSVI as part of MS, we now have an improved, more theoretically reasonable, disease model which fits an evolutionary perspective.

Given all of the above, there can be little doubt that CCSVI is an important part of the MS disease process because 1) it is associated with MS, 2) precedes MS and 3) can reasonably contribute to the actual MS pathogenesis. As an analogy, just imagine if people with persistent back pain were found to have a pin sticking in their backs. If, in most cases, it was found the pins were there before the back pain and the pain was associated with the pin, then it would be reasonable to postulate the pins were part of the problem. Of course, if the pins were shown to be there after the pain, then one would assume the pin is not a big player in the problem and may be an effect of it (a failed treatment?).

The question now becomes now that once it is established that the pins precede the back pain and can help to explain it, do we wait for 7 years of research before pulling the pins, or do we pull the pins and at the same time do research to determine how they got there, how they cause the pain, what is the safest way to remove them etc. Clearly the latter is the common sense approach. Any advocacy of the first option immediately raises the spectre of a hidden, self-serving agenda.

Exactly the same logic applies to CCSVI and MS except it is more important that treatment be done as soon as possible. This is because, in the 7-10 years needed for all the research, many people with MS will suffer serious, irreversible damage to the CNS and will experience serious clinical symptoms because of such damage. Because CCSVI is almost assuredly an important part of the MS disease process as the current science has shown, then it is important that it be

resolved as soon as possible. There is no doubt that large amounts of research are needed on CCSVI but treatment of those with MS cannot wait until this research is completed.

In summary, what the media (including you) have missed is that the current science says CCSVI is very likely a key part of the MS disease process and consequently needs to be treated as soon as possible. This is not a treatment which addresses symptoms but one which addresses a main driver. I am not surprised that many people are experiencing major improvements in their MS symptoms once CCSVI is relieved. I expect those with the pin in their backs would also enjoy some relief upon pin removal. Any time you counter a key part of a medical problem, from a bacteria which causes an ulcer, to immune suppression in autoimmunity, relief is to be expected. Claims that all the impressive improvements are simply “placebo effect” are also nonsense. They are just as real as the few cases of adverse effects.

Persons with MS are simply asking for a serious pathology (impaired venous flow from the brain), which science says is very likely to be a part of their disease process, to be corrected. To an objective observer, and hopefully to the media, this should be seen as a most reasonable request.

I also hope you can understand why pharmaceutical companies and those who receive substantial financial benefits from such companies (neurological community, MS Society), all of whom have much to lose from the introduction of CCSVI as a standard treatment, are strongly opposed to making CCSVI treatment available. Who can blame them? However, given their blatant and rather large conflict of interest, their opinions on this matter have to be weighed very carefully and seen in the light of the strong subjectivity they carry. Given that you are mouthing the same hollow arguments of those opposed to CCSVI, I have to wonder “who got to you”. A drug company, your favourite neurologist or perhaps a representative from the MS Society?

I hope this helps you understand why there is so much turmoil concerning CCSVI treatment. From an objective, scientific point of view, CCSVI needs to be treated anytime it is found. From a financial point of view, various factions are strongly opposed to such treatment. I hope some day the media gets at the real stories –1) science supports CCSVI treatment as soon as possible and 2) There is a war going on with the stakes being the physical health of persons with MS versus the financial health of drug companies, neurologists and national MS societies. Which is more important to our society? I know what side you two are on and it is not something you should be proud of. Beating up on persons with MS for financial reasons is as about as ugly as it gets. You are out doing the bankers in terms of a complete disregard for the values of our society.

I hope I have given you a broader perspective on CCSVI and the importance of treating it sooner rather than later. This issue will not go away until “the right thing to do” is done.

Sincerely,

Dr Ashton Embry
President, Direct-MS