Dear Ms. Martinuk,

Thank you for sending us your email address so I could correspond with you. I am the president and research director of the federally-registered charity, Direct-MS. We provide science-based information on MS to help those affected by MS make informed decisions regarding potential, non-drug therapies and we fund research on such therapies.

I have been a geological research scientist for some 42 years and have been involved in MS since my oldest child was diagnosed some 15 years ago. At that time I decided to learn everything I possible could about MS and have read many thousands of scientific papers on MS and related subjects. I have also published a few papers on MS in medical journals and was the senior author of one of the first papers (Embry et al, 2000) which related vitamin D intake to MS. I am pleased that now, 10 years later, most MS clinicians are finally advising their patients to take adequate vitamin D. I am attaching my recent editorial on CCSVI and autoimmunity, published as part of a special issue of International Angiology on CCSVI.

Our charity became interested in Dr Zamboni's research last summer and have been providing science-based information on it since last August. When it was apparent the research and the associated treatment option were being totally ignored by MS researchers and clinicians, not to mention the MS Society of Canada, we brought it to the attention of Avis Favaro of CTV. She saw the importance of it for MS and the resultant, excellent documentary has brought CCSVI the attention it deserves.

Your article implies that CCSVI may be mainly hype and that the media has misled people to see the treatment of CCSVI as an important therapy. Actually, the reality of the situation is almost the opposite. The media have missed the implications of the important scientific findings of CCSVI and these findings strongly indicate that it is important to be treated for CCSVI sooner than later.

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

The second, critical scientific finding is that the venous malformations that drive CCSVI are almost exclusively congenital, that is, they were there at birth. Again this 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 emphasize that I agree completely, as my recent editorial stresses, that MS is an autoimmune disease. However, it also must be emphasized that the biological mechanisms associated with CCSVI all significantly enhance the autoimmune process.

In fact, CCSVI helps to explain a major puzzle in MS. 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. Notably, 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.

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 (possible feedback role) and may be an effect of it (a failed treatment?).

The question now becomes, 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.

Exactly the same logic applies to CCSVI 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. Our charity has already provided $125,000 USD to CCSVI research at the University of Buffalo, the leading centre of CCSVI research in North America.

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 an bacteria which causes an ulcer, to immune suppression in autoimmunity, relief is to be expected.

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.

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) the major conflict of 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 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