New Data on CCSVI and Vitamin D Underscore the Need for Taking Action

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CCSVI

Any suggestion that CCSVI testing and treatment should not be available until definitive trials have been done (5 -10 years), is irresponsible, reckless and completely out of touch with the needs of persons with MS. Time is Brain and everyone wants to preserve as much brain as possible.

Key findings from two recent studies show that CCSVI is a major problem in MS and each person with MS should be tested and, if need be, treated for CCSVI as soon as possible.

Having CCSVI makes MS worse - it is a significant driver of the MS disease process and any person with MS and CCSVI has a much higher chance of major disease progression.

Of course the major problem facing persons with MS right now is that those in power, the neurologists and the big MS charities, are dead set against such testing and treatment. There is no easy solution to this problem and it is basically a test of wills.

I suspect the only hope persons with MS have is to get the media to see the obvious logic of why CCSVI testing and treatment is necessary and to expose the self serving and harmful agenda of the neurologists and MS charities. It took a big media production (CTV documentary) to force the neurologists and charities to finally acknowledge the existence of CCSVI. And it will take similar media exposure to embarrass them sufficiently so that they will have to do what is best for people with MS.

Definite Link Between CCSVI and MS

Two recent American trials have shown a definite link between CCSVI and MS. One is ongoing at the University and Buffalo where researchers are testing 1600 people for the presence of CCSVI in three phases. The 1600 includes 950 with MS, 100 who experienced an initial demyelinating event, 300 with other CNS diseases, and 350 healthy controls.
The results of Phase 1, which involved 500 patients (280 MS, 161 healthy controls, 59 others), included:

- 56% of persons with MS had CCSVI
- 22% of healthy controls had CCSVI
- 38% of those with an initial demyelinating event had CCSVI
- 80% of those with more advanced MS had CCSVI

The second study at Georgetown University looked at the nature and origin of the venous malformations responsible for CCSVI. The vascular researchers found that the venous malformations are of congenital origin and are not the product of post-birth, environmental insults or the MS disease process itself.

This in utero formation of the venous malformations means CCSVI occurs BEFORE the MS disease process begins, an important constraint for understanding the cause/effect relationship between MS and CCSVI.

**CCSVI Makes MS Worse**

The combination of the Buffalo results with those from Georgetown allow us to draw three main conclusions:

* Given 25% of healthy controls and only 56% of those with MS have CCSVI, it would appear that CCSVI is not the primary cause of MS.

* CCSVI is definitely associated with MS and, given that CCSVI precedes MS onset, this means CCSVI must contribute to the MS disease process.

* Having CCSVI makes MS worse. The increasing presence of CCVSI with increasing disability level means CCSVI is a significant driver of the MS disease process. Thus if CCSVI is part of a person’s MS, they have a much higher chance of major disease progression.

To me, the simplest model for MS, which fits all the data, is that MS is an autoimmune disease which is greatly exacerbated by the chance (and common) presence of CCSVI. Thus, almost all those with high levels of disability are likely to have CCSVI whereas most of those with benign MS are likely not to.

The bottom line of these key findings is that CCSVI is a major problem in MS and each person with MS should be tested and, if need be, treated for CCSVI as soon as possible. This must be shouted from the roof tops.
To help everyone understand why it is imperative that CCSVI treatment and testing be done as soon as possible I have prepared a “Pascal’s Wager” Diagram.

<table>
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<th>CCSVI Is a Key Factor in MS</th>
<th>CCSVI Is Not a Key Factor in MS</th>
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<tbody>
<tr>
<td>Relieve CCSVI</td>
<td>Major Gain</td>
<td>Minor loss, rare significant side effects</td>
</tr>
<tr>
<td>Do Not Relieve CCSVI</td>
<td>Major Loss</td>
<td>No loss/gain</td>
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The question at hand is whether or not persons with MS should get tested or treated for CCSVI. The answer to this is on the diagram.

As can be seen on the diagram, one has major gain by getting treatment and major loss by not getting treatment if CCSVI is indeed a key factor in MS as all the data are now telling us.

On the off chance CCSVI is not a key part of MS, there is overall minor loss by having the treatment and no gain by not having it. **Actions which entail major gain or minor loss always trump actions which entail major loss or no gain.**

I hope this diagram helps to make it clear that persons with MS should keep advocating very strongly for proper care which means testing and treatment for CCSVI right now.
New Discoveries on Vitamin D –
More Reasons To Take Adequate Amounts

Now, onto the new discoveries in the relationship between vitamin D and MS, a topic which I have been shouting about for over a decade.

Many researchers have now realised that vitamin D deficiency is a significant part of MS onset and progression. In the last few months the results of five - yes five - notable studies have become available, mainly as abstracts for the upcoming American Association of Neurologists Convention.

Vitamin D and the Risk of MS

In the last few years studies have shown that MS correlates to birth month with more people with MS being born in the spring and fewer in the fall. There are two ways to explain this. One is a lack of vitamin D in utero and the other is an infection during pregnancy. Both these risk factors are more common in winter thus resulting in more spring births.

Research at Harvard has shown that pregnant women who consumed more vitamin D through supplements and/or milk consumption had a lower chance of having a child with MS. Thus, it would appear that vitamin D intake during pregnancy is indeed an important factor and I would recommend all pregnant women take 5000 IU every day.

An Australian study has shown that there is a strong North-South gradient for persons experiencing a first demyelinating event (FDE) which, in most cases, is a precursor to MS. Interestingly, the gradient for males was notably larger than that for females and the reason for this is that males spend more time in the sun. They had much lower rate of FDE in the sunny, low latitude area (1/6 of the female rate!) leading to the higher gradient. Notably, males in these areas have a much higher rate of skin cancer than do females. Thus, there is little doubt that it is UVR exposure/vitamin D intake in childhood /adolescence which is responsible for the North South gradient of FDE, demonstrating once again that adequate vitamin D greatly lowers the risk of MS.

Vitamin D and MS Disease Activity

Two new vitamin D studies have shown that vitamin D status also influences disease activity. In one study, done at the University of California at San
Francisco, it was found that the lower blood level of vitamin D, the higher the relapse rate in pediatric-onset multiple sclerosis. For every 25 nmol/l increase in the blood level of vitamin D, there was a 34% decrease in the rate of subsequent relapses. Now that is significant!

In the other study it was found that people deficient in vitamin D were over two times more likely to have active CNS lesions that those with adequate vitamin D level. Notably, they defined adequate vitamin D level as 75 nmol/l, an amount which I would call insufficient. One can only imagine how few people with MS would have active lesions if everyone had with an optimal level of vitamin D (> 150 nmol/l).

The final vitamin D study looked at a new benefit that is likely derived from having an optimal level of circulating vitamin D. Scott Sloka, a young, very sharp neurologist who recently established an MS Clinic outside Toronto, looked at the potential for vitamin D to be neuroprotective. He found that “vitamin D reduces neuronal injury in EAE (the mouse version of MS) and has the potential to reduce neuronal and axonal loss”.

These three studies leave no doubt it is important for persons with MS to be taking 6000-8000 IU of vitamin D every day.

**How Do CCSVI and Vitamin D Relate To Each Other?**

With all these new data relating both CCSVI and vitamin D to MS, an obvious question becomes “How do CCSVI and vitamin D relate to each other in MS?” Unfortunately, I do not have a solid answer for this.

The data say vitamin D is very important for controlling autoimmune reactions and that is one obvious reason why it is so effective in MS. On the other hand, we know that vitamin D also affects venous health so the possibility exists that adequate vitamin D in utero and childhood may prevent, or greatly lessen the effect of, CCSVI. The relationship between vitamin D and CCSVI in MS is begging for some innovative research.