

# **Why Direct-MS Advocates that Persons with MS Should Get Tested and Treated for CCSVI As Soon As Possible**

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## **Introduction**

**Currently, the biggest controversy in the world of multiple sclerosis is whether or not persons with MS should get tested and treated for CCSVI as soon as possible. Two distinct camps have developed in regards to this controversy.**

## **No Treatment for a Long Time Position**

**The neurologists and the National MS Societies (e.g. MS Society of Canada, NMSS) have taken the stance that persons with MS should not get tested and treated for MS until proper research which clearly demonstrates the effectiveness of such treatment is done and published. The rationale for this position is that we do not know if such treatment will be helpful and that it is possibly harmful.**

**These groups neglect to mention that the research they want to have will take at least 8-10 years to complete and this is a very optimistic estimate given the well established length of time to test MS drugs (15 years and counting for Campath). Furthermore, Dr Mark Freedman, a neurologist who in January publicly declared CCSVI is a hoax, has recently stated that such research would cost in the vicinity of 50 million dollars. No one has ever mentioned where such huge amounts of money would come from. We do know that drug companies that fund almost all MS clinical trials will not be contributing to such research.**

The bottom line is that the neurologists and MS Societies are telling persons with MS to wait until the research is done (likely at least 10 years and possibly never) before getting tested and treated for CCSVI.

The decision-making chart below helps to understand why they are advocating for delayed treatment.

<b>Neurologists and MS Societies Perspective on CCSVI Treatment</b>		
	<b>CCSVI Relief Is of Significant Value for MS</b>	<b>CCSVI Relief Is Not of Significant Value for MS</b>
<b>CCSVI Treatment Available Soon</b>	<b>Major Loss</b>	<b>No loss/gain</b>
<b>CCSVI Treatment Notably Delayed and/or Denied</b>	<b>No loss/gain</b>	<b>No loss/gain</b>

As can be seen on this chart, if CCSVI treatment becomes available soon and it is very effective, the neurologists and MS societies will suffer a major loss. For the MS societies it will be a large loss in donations (MS is no longer a mysterious disease) and for the neurologists it will be a large loss in clientele (MS patients will be treated mainly by vascular doctors). If the treatment is of little to no value, neurologists and MS societies will be unaffected and it will be business as usual. On the other hand, if treatment is significantly delayed or denied, the neurologists and MS societies will be unaffected regardless of treatment effectiveness.

**Given the above straightforward analysis, it is readily understandable why the neurologists and MS societies have chosen to advocate for a major delay of treatment availability. Anyone with common sense would not choose a path which would potentially significantly harm them when they can just as easily choose a path with no potential harm.**

**As will be demonstrated below, any claim by the neurologists and MS societies that delayed introduction of treatment is in the best interests of the MS patients is not supportable and is fundamentally not true.**

### **Treatment As Soon As Possible Position**

**The other position in this controversy is that persons with MS should get tested, and if need be, treated for CCSVI as soon as possible and this is advocated by many patient groups around the world and by small, patient-centred charities such as Direct-MS. Notably, Dr Lorne Brandes, an oncologist and medical researcher who has written extensively about CCSVI and MS, has recently strongly supported this position.**

**The rationale for having testing and treatment available sooner rather than later is:**

- The available science shows that it is very likely CCSVI is an important part of the MS disease process.**
- Relief of an established factor in the MS disease process is very likely to be of significant benefit.**
- The vascular procedure to relieve CCSVI is very safe by medical standards and compares to a similar, very safe procedure for**

arterial disease. At least 750 procedures have been done so far with only two anecdotal, serious adverse effects, both of which occurred in the same centre soon after treatments started.

- Many reliable and impressive, anecdotal reports of significant improvement of MS-related symptoms following CCSVI relief have been reported in the news and online.
- Perhaps most importantly, in the next 10+ years when the research is (hopefully) being conducted, many people with MS will suffer major, irreversible, increased disability.

The bottom line is that CCSVI treatment is as safe as a medical procedure gets and appears to be quite effective for improving many MS symptoms.

The chart below presents the decision-making perspective of a person with MS in regards to the timing of CCSVI treatment.

<b>MS Patient's Perspective on CCSVI Treatment</b>		
	<b>CCSVI Relief Is of Significant Value for MS</b>	<b>CCSVI Relief Is Not of Significant Value for MS</b>
<b>CCSVI Treatment Available Soon</b>	<b>Major Gain</b>	<b>Minor loss</b>
<b>CCSVI Treatment Notably Delayed and/or Denied</b>	<b>Major Loss</b>	<b>No loss/gain</b>

**As can be seen on this decision-making chart, persons with MS have different outcomes than the neurologists and MS societies did. If CCSVI treatment becomes available soon and it is very effective, the MS patients will enjoy a major gain with a significant lessening of disabilities or, in some cases, a complete resolution of the disease process. If the treatment proves to be of little value, they will suffer only a small loss of time and minor side effects.**

**In contrast to this, if treatment is substantially delayed and the treatment eventually is shown to be very effective, then persons with MS will have suffered a huge loss represented by all the preventable, additional disabilities accumulated during the delay in treatment introduction. If the treatment has little to no benefit, then persons with MS will not be affected by the delay.**

**It is easy to understand why persons with MS are strongly advocating for widespread availability of the treatment as soon as possible. It is only common sense to choose a path of with outcomes of either major gain or minor loss versus a path which holds either major loss or no loss/gain. Note the neurologists/MS societies are claiming that MS patients would be better off if they chose the major loss or no loss/gain path, a claim which is clearly not correct.**

### **Summary**

**We are currently at an impasse in regards to the timing of the introduction of CCSVI testing and treatment. The neurologists and MS societies have little choice but to advocate against treatment availability**

**so as to escape a potential major loss. On the other hand, it clearly is in the best interests of MS patients to introduce treatment as soon as possible given their potential major gain. Furthermore, the neurologists/MS societies' claim that their position is based on their concern for the welfare of their patients rather than on their own welfare is simply not tenable as this analysis clearly demonstrates.**

**Direct-MS takes the position that this issue must be decided in favour of what is best for the MS patients rather than what is best for the neurologists and the MS societies. Thus, we strongly advocate for the introduction of CCSVI testing and treatment as soon as possible and will continue to fight for this until it happens. It is a sad reality that MS patients will have to fight long and hard against the neurologists and MS societies to get a treatment they clearly need if they are to avoid spiraling into a life of disability.**