

# **Why National MS Societies Are Not Acting in the Best Interests of Persons with MS**

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## **Introduction**

With the advent of CCSVI as a major factor in multiple sclerosis, it has become painfully apparent that national MS societies do not have the best interests of persons with MS as their highest priority. This has taken many people by surprise because most people are under the assumption that the main concern of national MS societies is the well being of persons with MS. This assumption is not, and has never been, true. Perhaps one more benefit of the discovery of CCSVI as an important causal factor of MS, has been to expose the myth the national MS societies have people with MS as their #1 priority.

## **The Groups of the MS Societies**

To understand the priorities of national MS societies, it is essential to understand the various groups which compose their structure. These groups are the scientific advisors, the staff members, the board members, and the members of the society who are mainly persons affected by MS. Each of these groups plays a very specific role in how a given national MS society functions.

The most important and influential group is the scientific advisors who determine the type of information the society provides to the members and to the public at large. They also determine what research will be done and what overall policies will be followed when it comes to lobbying efforts to influence government decisions. The scientific advisors are clinical neurologists who specialize in multiple sclerosis. Many of them also carry out research activities in addition to their clinical work.

The next important group is the paid staff of the society and, in the case of a large society, they can number in the hundreds. Their salary and benefit packages are on par with workers in similar jobs in both the private and public sectors. Importantly, the staff, for the most part, puts into action the policies and plans of the scientific advisors, that is, the neurologists. There is a very strict adherence to this and no deviation or independent thinking is tolerated. The staff members are like soldiers who do what they are told and are not expected to contribute to the scientific or public policies of the society. They are simply the “go-betweens”, the neurologists and the all those seeking information from the society. Notably, most staff members are not affected by MS.

By far the greatest responsibility of the staff is to raise money by running various fund raising projects. Most of staff time is spent on this critical activity which is understandable given the majority of the money raised goes to pay staff salaries and benefits. Staff members also arrange some programs for people with MS in terms of education but this activity is rather minor in terms of actual time and effort expended. The staff also fields questions from persons with MS and, as noted previously, the provided information is only that sanctioned by the scientific advisors (neurologists).

The board of directors of a given national society is most often composed of people who usually have good connections for fund raising from corporations or who have strong political connections. Usually a few persons with MS are included on a board but, in most cases, the majority of board members are not affected by MS. One or more staff members also usually are part of the board.

Most board members have at best a rudimentary understanding of science in general and the science of MS in specific. They have very little influence on any major policies of the society and, in most cases, simply rubber stamp the scientific and political policies determined by the neurologists and implemented by the staff. Their main responsibility seems to be ensuring that the society is on

a firm financial footing and discussing the merits of proposed fund raising campaigns.

The final group in a national MS society consists of the members themselves and they, for the most part, are persons affected by MS. They are the consumers of the products of the society which consist mainly of information dictated by the neurologists and packaged by the staff. Such information is both hard copy and web-based. Some members act as volunteers and volunteer activities are related to both money raising activities and to helping other people with MS. The members essentially have no say in terms of the main policies of the society although on a local level they can help to get new member services initiated.

In summary, a national MS society spends most of its time raising money which is used to pay fund-raising costs, the salaries and benefits of the staff members, and substantial administrative expenses. Such expenses require about 80-85% of all money collected. The amount left over is mainly used to fund research projects approved by the scientific advisors (neurologists) and, not surprisingly, projects of former and current advisors usually are well funded. Proposals from "outsiders" don't fare so well.

### **Past Situation**

In the past, everything went along rather smoothly with the society advertising the need to raise money to cure MS, with such a cure being attainable through the research activities funded by the society. Given the severe disabilities sometimes associated with MS, the need for finding a cure for MS is not a hard sell, and the large MS societies raise tens of millions of dollars every year. In the 60 years this routine has been going on, the research funded by the societies has not brought us anywhere even remotely near the prospect of developing an effective treatment for MS. This impressive failure has only led to louder calls for more money for more research.

The scientific and medical information provided by a national MS society is entirely centred on drug therapies that have been approved for use. The staff members strongly advocate the use of such drug therapies and almost all other proposed therapies are ignored, discouraged and/or denigrated. The main government lobby efforts of the societies usually are to fight for the approved use of the drugs.

It is imperative to appreciate that most (often all) of the scientific advisors of the societies and the societies themselves have strong financial ties to the pharmaceutical companies which manufacture and market the approved drug therapies for MS. The most blatant of such ties is that of the NMSS of the United States. It partners with drug companies and gives substantial grants to them.

The existence of such financial ties readily accounts for the policy that only drug therapies are advocated and that the value of such therapies is never, ever remotely questioned. These financial ties also create a serious conflict of interest for the neurologists and MS societies when it comes to any proposed, non-drug therapy and that is one, big reason why non-drug therapies are ignored or downplayed by the societies.

There can be no doubt that the national MS societies are there mainly for the benefit of the neurologists (scientific advisors) in that they provides them much needed research funding. The societies also provide an excellent vehicle for promoting drug therapies which are financially very important for the neurologists. Of course the societies are also there for the benefit of the staff members who make a good living from keeping everything running smoothly and ensuring the information from the neurologists reaches the desired destinations.

Before the advent of CCSVI, the drug therapies were the only conventional medical therapies available. By advocating such therapies, the societies could easily claim to be acting in the best interests of persons with MS even though such advocacy was driven mainly by the best interests of the neurologists and

the societies themselves. Whether or not the use of the current drugs is really in the best interests of persons with MS is a completely separate issue and will be explored in a separate document.

### **CCSVI Rocks the Boat**

The sudden emergence of CCSVI as an important factor in MS, and the great promise of CCSVI treatment for slowing and perhaps even halting MS disease progression for many, have caused a great problem for MS societies around the world. Given all that we now know about CCSVI and its treatment, the national MS societies would best serve the interests of persons with MS by immediately funding a major, comprehensive research program which definitively tests the effectiveness of CCSVI relief in the next few years. Furthermore, it would also be in the best interests of persons with MS if the MS societies lobbied to have CCSVI treatment available as soon as possible given the health problems associated with having impaired venous drainage from the brain and the many hundreds of credible, experiential accounts of very significant positive changes following CCSVI treatment.

The MS societies have studiously avoided funding any clinical trial studies for CCSVI treatment as was clearly demonstrated by the rejection of proposals from top CCSVI researchers by North American national MS societies. (e.g. University of Buffalo, Stanford University, McMaster University). Notably, those who got their proposals accepted seem to have either very strong ties to the pharmaceutical industry (e.g. Wolinsky at U of Texas) or do not know what they are doing. A fine example of this latter category is Dr Kathleen Knox at the University of Saskatchewan who recently was quoted as saying “The biggest difficulty her team faces, is that they don’t know how to test patients to see if they have the blocked veins”. This is a stunning admission of incompetence and shows the type of researchers favoured by the national MS societies when it comes to CCSVI “research.”

Some national MS societies are actively lobbying their respective government NOT to allow CCSVI treatment. A fine example of this is a recent letter the director of the Ontario division of the MS Society of Canada wrote to the Ontario Health Minister emphasizing that the province should not fund any CCSVI testing or treatment. The notice on the website of the Multiple Sclerosis Society of Canada says it all - "the MS Society does not recommend that people with MS be examined or treated for CCSVI outside of an established research protocol". All in all, any thought that MS societies are acting in the best interests of persons of MS must be abandoned. So who's best interests are they serving with their actions?

When it comes to CCSVI, the interests of the neurologists and the societies are best served by having CCSVI marginalized, by not funding any CCSVI treatment research, and by lobbying the government to not allow any treatment of impaired venous drainage in persons with MS despite the obvious health hazard such a condition represents. The reasons for such actions are straightforward.

If CCSVI treatment by venous angioplasty turns out to be far more effective than the current drug treatments, and there is every reason to expect it will be, then MS drug revenues will plummet precipitously. Such a huge loss of revenue will have a devastating effect on the financial well being of MS neurologists and the national MS societies themselves. Furthermore, persons with MS will be treated primarily by interventional radiologists, thus adding to the financial losses of the neurologists. There is no question that any activity which helps to bring the implementation of CCSVI treatment forward is not in the best interests of the neurologists and the national MS societies that they control and everyone is well aware of this indisputable but somewhat awkward fact.

Because of the advent of CCSVI, we now have an unprecedented situation of conflicting interests. What is in the best interests of persons with MS is clearly not in the best interests of both the neurologists who provide the scientific guidance

for the MS societies and the staff of the societies who put into effect the policies of the neurologists.

### **The Current Reality**

Not surprisingly, the best interests of the neurologists and the society staff members will always trump the best interests of the persons with MS. Thus the policies and actions of the national MS societies have been to avoid any funding of proposed CCSVI treatment studies and to lobby government bodies not to provide any CCSVI treatment. They also advise persons with MS not be tested or treated for CCSVI despite the obvious medical need for such treatment (blocked veins are hazardous to one's health).

The neurologists and the MS societies also have instituted a policy of casting doubt on the validity of the CCSVI concept and on the safety of CCSVI treatment. This has even gone as far as blatant fear-mongering when it comes to having venous angioplasty to relieve CCSVI. One good example of this recently appeared in a governmental health report written by MS neurologists. The writers claimed that the only venous blockages that exist in persons with MS are clots caused by angioplasty and the only results of venous angioplasty are injuries to the vein. This is of course sheer nonsense but, as they say, truth is the first casualty in any war.

The current actions of the national MS societies regarding CCSVI are entirely rational once the structure of the societies is understood. The societies are acting in the best interests of the neurologists and staff members as they always have and always will. Unfortunately, when it comes to CCSVI, such actions are not in the best interests of persons with MS. However, it is the false perception that the national MS societies are there primarily to serve the best interests of persons with MS that has created the shock and disappointment with the current actions of the societies in regards to CCSVI. When it comes to the policies and actions of the national MS societies, persons with MS must fully realize that they are

lower in priority than the neurologists and staff members. The CCSVI issue has clearly demonstrated this beyond any reasonable doubt.

### **Consequences of the Actions of the National MS societies**

We now have sufficient data to say that, each day a person with MS suffers the consequences of impaired venous drainage, they are doing harm to themselves and such a reality has to be clearly understood. It has been said, “MS Never Sleeps” and one of the main reasons for this is that **impaired venous drainage never sleeps** and this serious pathology is causing problems every day for persons with MS. Thus it logically follows that every dollar the national MS societies raise is potentially doing harm to persons with MS because that dollar is potentially contributing to actions that are designed to delay the availability of CCSVI treatment for all persons with MS.

Given the above, it is clear that the interests of persons with MS would be best served by halting any support of national MS societies and by supporting groups which are actively promoting the need for CCSVI treatment research and government support for the availability of CCSVI treatment as soon as possible.

### **Summary**

The advent of CCSVI has revealed the highest priorities of the national MS societies. These are actions and policies that are in the best interests of neurologists and society staff members. The interests of persons with MS are a distant third in this contest of competing interests. Continued support for national MS societies is potentially harmful for persons with MS because of the societies' deliberate lack of appropriate and much needed actions regarding CCSVI. All persons affected by MS should be supporting organizations which are funding clinical trials to test the effectiveness of CCSVI treatment and which are lobbying governments to make CCSVI treatment widely available in the near future.