

Comments on MSSOC's Funding of CCSVI Research

Ashton Embry

The recently announced program of CCSVI research by the Multiple Sclerosis Society of Canada (MSSOC) is totally inadequate from both scientific and financial support perspectives. First of all, the amount of money allotted to CCSVI research is \$350K a year or about 0.5% of the annual haul of MSSOC. This is a major insult and slap in the face to all persons who have supported MSSOC with their time and money. Notably MSSOC is trying to hide this paltry amount by trumpeting the total amount for two year grants from both NMSS and MSSOC. They never mention the \$350K number for obvious reasons.

Secondly, and of even more concern, the research that is being funded is reinventing the wheel, given it only addresses the question of the association of CCSVI and MS. Perhaps MSSOC does not yet realize or does not want to acknowledge that the association of MS and CCSVI is already well established by the University of Buffalo research and by the 1000+ CCSVI treatments already done throughout the world. These data solidly and unquestionably confirm Dr Zamboni's original findings. In this regard, I might also mention Sandy MacDonald's work which demonstrated that 90% of almost 300 MS patients at his Barrie clinic have CCSVI. The MSSOC claim that their planned research program is needed to establish the association of MS and CCSVI is erroneous and completely unsupportable.

The bottom line is that there is no doubt that CCSVI and MS are associated. Thus the planned MSSOC research program is almost worthless. The only positives I can see are that it will contribute to determining how many non-MS individuals have CCSVI and the work on children and twins will add new information. Unfortunately numbers being tested are small and hence the results will be ignored by the anti-CCSVI crowd if need be.

One major concern is the ability of the researchers to detect CCSVI with the Doppler technology. It is well established that extensive training is needed and one can only wonder if the technicians doing the Doppler at the various study sites will be adequately trained. This is never discussed in the summaries but the training of the technicians is a very critical part of any research project to detect

CCSVI. One worries that detection will be a major problem due to lack of operator competency.

Another significant problem is the inclusion of researchers who have strong ties to the drug industry. You don't want compromised individuals who have a major conflict of interest anywhere near research which has the potential to adversely affect the drug industry in a very big way. Such conflicts of interest need to be scrupulously avoided. The presence of Mark "It's a Hoax" Freedman as part of the Ottawa research team is an affront to science and all persons with MS. We need objective people doing CCSVI research, not those strongly linked to pharmaceutical companies and who want to vindicate their claims that CCSVI is a hoax. Given the combination of potential Doppler problems and the underlying anti-CCSVI prejudice of members of the research teams, I am expecting the worst in terms of objective and accurate results.

I would note this research, when it is all done and published, will not bring us any notable understanding that we don't already have today. This is classic "stall research" and it will significantly delay urgently needed research which will test the efficacy of CCSVI treatment. The value of CCSVI relief is the BIG question at hand, not the already answered question of whether or not most persons with MS have CCSVI (they have!).

As I have always said, it will be at least a decade, if not longer, before the needed research is done to determine the efficacy of CSSVI relief. Given the fact that CCSVI treatment is potentially very harmful to the long term financial health of neurologists and MSSOC, such a delay is understandable .

The bottom line is the MSSOC miniscule grants for projects which address questions for which we already have the answer will ensure nothing of any significance will get accomplished over the next 2-3 years. I leave it to the reader to try to fathom why MSSOC would do this.

Furthermore, MSSOC and the neurologists will undoubtedly continue to piously preach that persons with MS should not be tested or treated for CCSVI until they have done the proper research. Given the type of research and funding amounts for CCSVI MSSOC believes in, it will be a very, very long time before the "proper" research is done.

At least MSSOC didn't disappoint me and they maintained their dedication to ensuring no real action on CCSVI. The sad thing is many people will be fooled into thinking that MSSOC is acting in the best interests of persons with this totally inadequate and almost worthless research program. The truth of the matter is that MSSOC is doing great harm to persons with MS by lobbying against CCSVI testing and treatment and by not funding any research on the value of CCSVI relief for MS. I can only hope persons with MS will see the real situation and start supporting CCSVI research projects which will benefit persons with MS rather than those which only benefit the neurologists.