



***Hope and Elation - Frustration and Anger – Fear and Loathing:
The Contrasting Emotional Responses to the Revolutionary
Discoveries in MS Made by Dr Zamboni***

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The beautifully crafted, CTV documentary on the astounding findings of Dr Zamboni and his team for multiple sclerosis has hit the MS community like a tidal wave and has evoked a variety of emotional responses. Most people with MS see CCSVI as a huge breakthrough for understanding and treating MS and had an initial feeling of unbridled elation that finally there was some real hope for an effective treatment on the horizon. I expect most people with MS thought “I have to get my veins checked out!”, even before the credits rolled on the Zamboni documentary.

Such a reaction is completely understandable. Dr Zamboni’s research leaves very little doubt that most people with MS have impaired venous flow from the brain and that such a problem is caused by narrowings and outright blockages in the main veins which drain the brain. To anyone with a semblance of objectivity, this is a “no drainer”. I might note that small studies in Poland and at both Stanford and the University of Buffalo in the USA have already confirmed these findings. The University of Buffalo is now doing a very large study to add further confirmation. I would be willing to bet the farm that this study will validate Dr Zamboni’s findings and, most importantly, it will silence the vocal skeptics, many of whom are neurologists with a blatant conflict of interest regarding the emergence of a potentially effective, non-drug treatment.

I have noticed from discussions with numerous persons with MS over the past few weeks that the initial feelings of excitement and hope have been replaced in many cases by anger and frustration. This has come about because everyone is finding it impossible to get an MRV to determine if they indeed have venous blockages. In Calgary, one person I was speaking with called every private imaging clinic and got no where. The receptionist at each clinic simply read a prepared response they had gotten from Alberta Health that there is not enough evidence to warrant such a scan. I quote from a November 26th email from the manager of one clinic “*Until we get further instruction ... we don't feel that ethically we can institute these scans for patients*”. Always nice to know the Alberta government is out there making sure persons with MS do not find out if they have a serious venous problem or not.

I have spoken to a few dozen persons with MS and each one expressed their burning desire to find out if CCSVI affects them and if so, how badly. And each one was very angry and frustrated that there was no way they could get such an important test done. The fact that the government substantially contributed to the problem only made them angrier.

When it comes to fear and loathing, I expect these feelings are being harboured by other constituencies of the MS community, namely the MS clinicians, researchers, drug

companies and charities. Why would such pillars of medicine fear and hate CCSVI? Regarding the clinicians, I have no doubt that they quickly realized that, if relief of CCSVI is an effective treatment, especially for the newly diagnosed, then they would essentially be cut out of the action when it comes to treating MS patients. Once a person was diagnosed with MS they would be immediately referred to a vascular specialist who would then oversee the person's treatments. It would be "diagnose and adios" for the neurologists, a somewhat ironic development given that is how the neurologists used to treat MS patients before the advent of MS drugs in the mid-90s .

As far as the MS researchers go, I can definitely empathize with them. I have been involved in research for over 40 years and I know, if someone suddenly demonstrated that I had spent the last 40 years barking up the wrong tree, I would have a variety of intense, negative feelings. One thing that has never been mentioned is how the Zamboni results demonstrate that the EAE animal model, which is widely used in MS research and upon which 10s of millions of dollars are spent every year, is clearly not suitable and is almost worthless. The mice do not develop CCSVI and thus the EAE model is no better than an animal model in which the mice developed CCSVI but no CNS lesions. A viable animal model for MS needs to exhibit both phenomena – end of story. Such a realization will cause great gnashing of teeth in the wide world of MS research.

It is also not a stretch to predict that fear and loathing in the MS research community will turn to anger and I hope Dr Zamboni is prepared for some blistering attacks on both his work and his character. Hell hath no fury like a researcher proven wrong or disenfranchised. Finally, I won't belabour the fears and anger of both the clinicians and the researchers regarding the potential loss of all that drug company largesse and research money which has been a bonanza over the past 15 years.

That brings us to the drug companies that supply the drugs that currently are used to treat MS or are in development. I have no doubt these companies must be having hand-wringing meetings these days to discuss the threat of a potentially effective, non-drug treatment for MS. The boardrooms must reek of fear and loathing when the obvious implications of the Zamboni discoveries are discussed. The bottom line is that there are tens and possibly hundreds of billions of dollars at stake in the foreseeable future and the drug companies are not going to let that kind of serious cash simply disappear without a fight. It is impossible to predict how the companies will deal with this real threat to their bottom lines and stock prices but you know it is not going to be pretty.

Finally, I suspect there is a lot of fear and loathing going on at the national MS societies in the countries with high rates of MS (e.g. Canada). For the MS Society of Canada this has been a public relations disaster which potentially will translate into a loss of revenue. The most obvious, embarrassing aspect of this fiasco is the fact that MSSOC wasn't even aware of the Zamboni research until mid October when they put up on their website a few, pathetic paragraphs on CCSVI that were cribbed from NMSS. They had absolutely no plans to fund any research on CCSVI until the CTV documentary put a gun to their head and they then hastily cobbled together a press release (in which Dr Zamboni's name was mis-spelt) and issued a call for CCSVI research proposals.

The big question is why, with their blue-ribbon scientific advisory board, did MSSOC have no clue about CCSVI when papers on the subject began appearing in 2006 and major contributions were publicly available in late 2008 and early 2009. Were all their scientific advisors asleep at the switch? Assuming these renowned researchers read the scientific literature, do they have they the ability to recognize a watershed contribution when it crosses their desk? The fact CCSVI went unnoticed by MSSOC for more than a year is cause for serious concern about the competency of the organization in terms of providing reliable and timely scientific information to their members. What other important information is currently out there going unnoticed by MSSOC and its scientific advisors?

To sum up, Dr Zamboni's amazing and groundbreaking discoveries have induced a wide variety of emotions in the different factions of the MS community. Such emotions are going to make it even harder for his findings to be properly tested and, if proven to be correct, to be incorporated into clinical practice. Regardless, it is important to realize that such strong emotions exist and to be cognizant of the different and somewhat antagonistic views and goals of the two groups that comprise the MS family – those that live with MS and those that live off MS.