

Comments on the National Post articles on Dr Zamboni and CCSVI by Blackwell and Corcoran

Dr Ashton Embry, Direct-MS (www.direct-ms.org)

A few weeks ago, two articles on Dr Zamboni's research on chronic cerebrospinal venous insufficiency (CCSVI) and its implications for treating multiple sclerosis were published in the National Post. One was by Tom Blackwell and was entitled "Is new MS research the real thing, or a media-driven frenzy?" Mr Blackwell tried to be somewhat objective on Dr Zamboni's work but frequently lapsed into negativity. The second article by Terrance Corcoran, the editor of the Financial Post, was entitled "A cure in sight? Not so fast". It did not pretend to have any objectivity and was pure vitriol from start to finish.

To understand the motivation behind these two "anti-CCSVI" articles, one has to be aware of "media politics" in Canada. There are two main newspaper chains and each has a national newspaper as well as numerous local ones. The National Post, which was founded by Conrad Black, is the national newspaper of CanWest Global Media and it represents the conservative voice in Canada. The national newspaper of Bell Canada Media, a somewhat more liberal voice, is the Globe and Mail, and it published the original story on Dr Zamboni's research on its front page in late November. Bell Media also owns the CTV network which produced the riveting documentary on Dr Zamboni's revolutionary work by Avis Favaro and Elizabeth St Philip. Needless to say there is a lot of rivalry between the two media chains and I am told that CanWest Global executives were most displeased that Bell Media scooped them on the Zamboni story. Thus, the Post articles are basically a "sour grapes" response by CanWest Global Media. However, that does not mean they potentially do not have some value.

I thoroughly enjoyed the CTV documentary and I thought it did a good job of addressing both the science involved with CCSVI and what such science means for understanding and treating MS. However, I am always interested in opposite views regarding Dr Zamboni's work, mainly as a check to see if I am missing some critical points or logic which would demand that I reconsider my position. Both Blackwell and Corcoran were not impressed by the content of the CTV documentary. Consequently, I saw their articles as a good way to see if those who are opposed to Dr Zamboni's work are able to provide new data or persuasive arguments to support their position. I have written this piece to comment on the content of the Blackwell and Corcoran articles and on whether or not they contain any worthwhile information regarding CCSVI.

Mr Blackwell's article did not provide any new data regarding CCSVI research and focused on responses to CCSVI from neurologists who lead the MS Clinics in Calgary, Winnipeg and Ottawa. I found the quoted comments of the neurologists to be quite revealing about the general reaction of the neurological

community to CCSVI. In a previous article (<http://www.direct-ms.org/magazines/Hope%20and%20Elation.pdf>), I predicted that the neurologists would have likely have a negative reaction mainly because CCSVI would have negative implications for their practices. The comments of the neurologists provided in Mr Blackwell's article certainly support my prediction.

Let's start with Dr Mark Freedman who heads the Ottawa MS Clinic. I found it quite shocking that he is quoted as calling Dr Zamboni's work "a hoax". First of all Dr Zamboni is a highly respected vascular surgeon and researcher who has practiced for many years and has published over 100 research papers in scientific journals. Secondly, he has published a number of peer-reviewed papers on CCSVI over the past three years and his results have been confirmed by studies at other centres. No one except Mark Freedman doubts the scientific integrity of Dr Zamboni's research.

For Dr Freedman to call Dr Zamboni's CCSVI work a hoax, and by implication, Dr Zamboni a fraud, without any supporting evidence, is unprofessional and basically slanderous. Dr Freedman should be censured for this completely unwarranted, personal attack on Dr Zamboni and I hope a formal complaint will be lodged with the Ontario Medical Association. Given this unacceptable action by Dr Freedman, there is also cause for concern regarding his membership on the MS Society of Canada's research committee and his capacity as the medical advisor to the MSSOC Ottawa chapter. I suggest he be relieved of any responsibilities regarding the MS Society of Canada as soon as possible. If this is the type of person MSSOC wants influencing their programs, then the MS patient community in Canada has to take a long look at the values of MSSOC and to ask whether or not such an organization should be supported.

Next up is Dr Luanne Metz, the head of the Calgary MS Clinic. Her main concern was that following the CTV broadcast her clinic was deluged by calls asking for information about Dr Zamboni's work. To me, such a flood of calls was to be expected because Dr Metz and the other neurologists at her clinic had never mentioned Dr Zamboni's important work to any of their patients before the CTV broadcast. Given that Dr Zamboni has been publishing his research on CCSVI since 2006, Dr Metz and her colleagues had adequate time to provide their clients with appropriate information on CCSVI over the last few years.

One has to assume either the neurologists at the Calgary MS Clinic do not keep up with the scientific literature or, alternatively, they do not let their clients know about important, new information as it becomes available. Thus, she and the other neurologists at the Calgary MS Clinic have no one to blame but themselves for the problematic deluge of phone calls to the Clinic when the news of Dr Zamboni's important research findings finally broke. I hope they have learned a valuable lesson and that from now on they will keep their patients properly informed of important new MS research findings so as to prevent a future tidal wave of phone calls.

The other neurologist interviewed was Ruth Marrie, the new head of the MS Clinic in Winnipeg. She had a similar complaint to that of Dr Metz in that her patients disrupted the Clinic's activities by asking for information on Dr Zamboni's findings. All I can say to Dr Marrie is to keep your patients informed by periodic newsletters and such a problem can be readily avoided. I was somewhat surprised that Dr Marrie seemed also to be upset that Dr Zamboni's discoveries generated hope for her patients. I address this important "anti-hope" issue later in this article.

Finally, Dr Marrie thought it was unethical for Dr Zamboni to have his colleagues unplug his wife's blocked veins. I would stress that Dr Zamboni did not do the procedure himself but simply referred his wife to doctors who did what was required. I would hope if one of Dr Marrie's close relatives has a medical problem she will refer them to an appropriate specialist even if the specialist happens to be one of her colleagues. Overall, I found it strange that Dr Marrie would focus on the irrelevant detail of Dr Zamboni's wife having her venous blood flow restored and not bother to even comment on the importance of the Zamboni research.

Overall the quoted comments of the neurologists do not inspire confidence in MS care in Canada. One might have thought the neurologists would have been excited and enthusiastic about Dr Zamboni's discoveries, especially given the sad fact that the current drugs they prescribe only slightly delay disease progression for most. However, as clearly shown by the quotes in Mr Blackwell's article, their main reaction to news about a revolutionary, potentially effective treatment for MS was petty whining and baseless, mean-spirited attacks. I am saddened by this physician-centred, knee-jerk negativity which may have its roots in the fact that CCSVI has the potential to negatively impact their practices which focus on drug prescriptions.

Mr Blackwell also tried to blacken Dr Zamboni's discoveries by asking a bio-ethicist, Dr Ian Mitchell, his opinion on this matter. Dr Mitchell's only complaint was that Dr Zamboni had called the use of angioplasty to open blocked veins, the Liberation treatment. I expect Mr Blackwell had hoped for a more damning assessment than a trivial comment on an informal, and somewhat appropriate, nickname for a treatment which liberates blood flow from the brain.

Mr Blackwell's last kick at the cat was to discuss the results of Dr Zamboni's preliminary clinical trial. Mr Blackwell tries to disparage the study by noting it was not controlled or blinded. Unfortunately Mr Blackwell is unaware that almost all initial trials of a new treatment are not blinded or controlled. They are done to test safety and to see if there is any indication of positive results which would justify larger trials that would be controlled and blinded.

Dr Zamboni was able to demonstrate safety and the results provide a clear indication that the treatment may well have positive effects. On this latter point, it is worth noting that all the subjects whose veins remained unblocked did not have any further attacks over the two year study period. Mr Blackwell was able to find one naysayer, Dr Pierre Duquette of Montreal, who embarrasses himself by erroneously stating Dr Zamboni's results were negative.

It was nice to see Mr Blackwell concluded his article on a somewhat positive note by pointing out that the MS researchers at UBC are taking Dr Zamboni's research seriously and are organizing a clinical trial to confirm and extend his initial results. I will bet the UBC researchers will not have to coax and cajole their patients into participating in the CCSVI trial as they have to do with drug trials. They will be inundated by requests to be included in the trial because, unlike Tom Blackwell, MS patients know a good thing when they see it.

Now let's have a look at Mr Corcoran's article which, in contrast to Mr Blackwell's piece, did not bother with any facts or quotes. Instead, it was a no-holds-barred, bare knuckle assault on both Dr Zamboni and the CTV team that produced the documentary. I had predicted that Dr Zamboni's work would result in nasty, ad hominem attacks but Mr Corcoran exceeded my expectations on how ridiculous and spiteful the low blow accusations would be. In the first few paragraphs, Dr Zamboni is compared to a TV evangelist and his work is classified as junk science. With such absurd comments, Mr Corcoran establishes his complete lack of credibility on this matter and I refer you to Joan Beal's methodical, fact-based dissection of the Corcoran article (<http://www.facebook.com/notes/ccsvi-in-multiple-sclerosis/a-public-response-to-terence-corcoran-and-the-national-post/267753807210>).

There is no need to repeat all the valid points in Joan's masterful rebuttal, and I am going to concentrate on one interesting aspect of Mr Corcoran's article. This is his view on what he termed "hope-mongering". He described it as the media's "exaggeration of benefits and results, pandering to people's constant and often desperate search for cures to conditions and diseases". I reluctantly have to agree with Mr Corcoran on this one point in his article and I also see media "hope-mongering" as a problem.

At least once a month, a press release announces the latest research finding for MS and it seems such releases always include a line that states the finding will perhaps one day lead to an effective treatment for MS. I would certainly classify such press releases as hope-mongering because invariably the new findings are very minor and have, at best, a very obscure relevance for a new treatment. I might note that few, if any, persons with MS take these hope-mongering media reports seriously and I can assure you they do not generate any calls to the MS Clinics.

For example, the recent, glowing press releases for new oral drug treatments for MS did not cause a ripple in the MS community or any annoying disturbances at Dr Metz' and Dr Marrie's clinics for that matter. The reason for this is persons with MS are quite capable of distinguishing between an announcement that offers no realistic hope for an effective treatment for MS and one that does. Everyone knows the new oral drugs are just more of the same "off the shelf" cancer drugs that cause immune suppression, a lot of nasty side effects including death, and do little for stopping disease progression. The hope-mongering, MS drug researchers have falsely "cried wolf" so many times that they have lost all credibility when it comes to finding an effective treatment for MS.

Given the pervasive hope-mongering in the media, it is reasonable to ask if there are any media stories that generate what might be called realistic hope for MS patients. To answer this, we have to differentiate between hope-mongering which hypes findings that have little chance of helping persons with MS in the near future, and realistic hope that is associated with a finding that has a good chance of being of significant value for treating MS in the short term.

To me, realistic hope must be based on a fact-based assessment of how given findings relate to the basic cause of MS. Once a theoretically reasonable, empirically supported cause for a disease is formulated, then a realistic hope for an effective treatment is born. For example, once it was discovered that AIDS was closely associated with a specific virus, then, and only then, could there any realistic hope that an effective treatment could be developed. The same logic applies to all past diseases from celiac disease (gluten ingestion) to stomach ulcers (bacterial infection) for which a reasonable, evidence-based hypothesis for cause was put forward and an effective treatment based on that hypothesis was then developed. It is important to understand that realistic hope is born when a reasonable, well supported hypothesis for cause is proposed and not when the hypothesis is proven correct.

For the past 150 years, medical researchers have not been able to offer a reasonable explanation for the cause of MS. There have certainly been numerous hypotheses put forward, from a bacterial infection to autoimmunity, but not one of them could provide a good explanation of all the available data on MS. Thus, there has been no realistic hope for an effective treatment despite the endless, hope-mongering which has accompanied the introduction of MS drugs that address only effects of the MS disease process rather than the cause and do little to stop disease progression.

The sudden appearance of Dr Zamboni's astounding findings on this barren, hope-deprived wasteland has generated unprecedented excitement and hope (and phone calls) in the MS patient community. The reason for this complete change in the MS landscape is that the Zamboni discoveries have allowed the formulation of a comprehensive and theoretically satisfying explanation for the cause of MS.

The chain of thought which has ignited this realistic hope goes like this: 1) exciting new fact - almost all persons with MS have significant blockages in the veins that drain the brain and very few controls have such a pathology, 2) exciting new fact - such blockages lead to demonstrable back flow of blood into the brain, 3) exciting, fact-based explanation - the back flow of venous blood provides a solid understanding of the previously inexplicable venocentricity of all MS lesions and their ubiquitous association with iron deposits, 4) exciting, fact-based interpretation - such back flow and its effects on the blood-brain barrier (BBB) can lead to breaches in the BBB, the subsequent development of CNS inflammation, and the consequent symptoms which characterize MS.

For the first time, all we know about MS can be rationally and logically understood by seeing MS as primarily a vascular disease and secondarily an autoimmune one. Thus, it is entirely reasonable to hope that the repair of the venous blockages will be an effective treatment for MS, especially in its early stages. Only time and further research will determine if CCSVI relief is indeed an effective treatment but that has nothing to do with the reality of today's justifiable hope that has surged worldwide through the MS patient community. The bottom line is that there is a good chance that treatment of CCSVI will be an effective treatment for MS and that is all that is needed for realistic hope.

Unfortunately, Mr Corcoran does not have the scientific background or the empathy to understand why Dr Zamboni's findings have generated realistic hope for the MS patient community. He simply cannot differentiate between the hope-mongering associated with an insignificant research finding or a drug that addresses only an effect, and the realistic hope that springs from a new and scientifically solid hypothesis for disease cause. Perhaps one day he will discover the critical difference between hope-mongering and the generation of realistic hope if he or a loved one contracts a serious disease of unknown cause.

In summary, the National Post articles have not provided any new data or sensible arguments that counter the opinion that Dr Zamboni's discoveries are a huge breakthrough for understanding and treating MS. The only positive contributions of the articles are that they have revealed the pettiness and/or vindictiveness of various neurologists and they have made us think about the important difference between hope-mongering and realistic hope.

Finally, these negative, "sour grapes" articles have done a disservice to persons with MS by relating a series of misconceptions, half truths and outright false statements and by trying to destroy justifiable and realistic hope that CCSVI relief will provide an effective therapy for MS. I expect these articles will not be the last attacks on Dr Zamboni and the implications of the CCSVI concept because various power centres in the MS community are dead set against any non-drug treatment for MS. The good news is that, despite such attacks, science will not be deterred or derailed and it will eventually determine beyond a reasonable

doubt if the relief of blocked veins is an effective treatment for MS. I certainly hope it is.