

# The First Fatality of the Liberation War

Ashton Embry, November 23<sup>rd</sup>, 2010

I was greatly saddened by the death of Mahir Mostic due to complications following CCSVI treatment. My children are about the same age as Mr Mostic and I can only imagine the devastating grief his loved ones must be experiencing. My deepest sympathies go out to his family and friends.

There has been a great deal of publicity surrounding this tragedy and, not surprisingly, there has been a lot of blame thrown around. I thought it would be worthwhile to examine the facts of the case in order to see what went wrong and how we might reduce the chances of another fatality related to CCSVI treatment occurring.

I have tried to construct a sequence of the main events from the various news stories and I must emphasize that they might not be completely accurate given the source materials. Mr Mostic was treated for venous blockages in Costa Rica in June, 2010 and, as part of his treatment, he had a stent emplaced in a jugular vein. He experienced some clotting problems before returning to Canada and had them resolved at the clinic with blood thinners. A few months after his return to Canada, he started feeling badly and assumed it was due to a venous problem related to his CCSVI treatment. He sought medical help in Canada, including at least one visit to an emergency department at a St Catharines, Ontario hospital but unfortunately did not receive any treatment, in part (perhaps mainly) due to the fact he had an unsanctioned procedure outside of Canada. In October, he flew back to the vascular clinic in Costa Rica and he was treated with blood thinners. This resulted in uncontrollable haemorrhaging and Mr Mostic died.

The big question is not “who is to blame” but rather it is “how might have Mr Mostic’s death been prevented”. Clearly, if he had not sought CCSVI treatment, he would not have died in the way he did. However, it is easy to understand why Mr Mostic sought such a treatment given that his MS was progressing and his neurologist had no worthwhile treatment to offer him. There is no doubt that CCSVI treatment has significantly helped thousands of persons with MS and there have been almost no serious adverse effects from the treatment after over 12,000 procedures. Thus, Mr Mostic understandably chose to have an established, very safe and potentially beneficial procedure in an effort to relieve some of the progressing symptoms of MS.

I have no doubt that tens of thousands of persons with MS will make exactly the same decision in the coming 12 months for the very same reasons. From a purely logical and scientific point of view, seeking CCSVI treatment is the best decision a person with MS

can make, especially given the ineffectiveness of the current drugs for slowing MS progression and the potentially lethal side effects of some of them (e.g. Tysabri, Gilenia).

Given what we know about the events leading up to Mr Mostik's death, it would appear that the largest problem was the lack of any treatment by Ontario physicians. It is not known at this time if they outright refused to provide any assistance or simply did not know how to treat a blood clot associated with a venous stent. Regardless, the failure of the Canadian health care system to properly treat Mr Mostik is undoubtedly the largest factor in his death and thus this is the one that needs to be addressed if future deaths associated with very rare, adverse side effects of CCSVI treatment are to be prevented or at least minimized.

The most reasonable solution is for MS neurologists to take their heads out of the sand and to accept reality. They need to feel fine about their patients undergoing a potentially very beneficial treatment and, most importantly, they need to ensure their patients get good medical care following their return from CCSVI treatment. The current attitude and actions of many MS neurologists who denigrate both venous angioplasty and persons who get such treatment are completely unacceptable and are materially contributing to the current situation of inadequate follow up care for persons with MS who get CCSVI treatment. MS neurologists need to do some soul searching about their professionalism when it comes to CCSVI and need to remember that they are expected to put the health of their patients ahead of their personal prejudices.

I am sure some neurologists will use this devastating death to try to convince their MS patients not to seek CCSVI treatment. Along these lines, it was not surprising to see the most vilified neurologist in the world, Mark 'it's a hoax' Freedman, callously use Mr Mostik's death as a soapbox for baseless fear-mongering ("the risks, we've been saying, are significant", "the treatment is..dangerous") and adolescent mocking of persons with MS ("the things they used to do, like pour ointments on themselves and wear bracelets, didn't really hurt them"). There is no doubt he is beyond any hope when it comes to a rational, caring attitude towards persons with MS who have had CCSVI treatment. However, I am optimistic that other MS neurologists in Canada will do what is best for their MS patients now that the problem of the lack of adequate follow up care for CCSVI treatment has turned deadly.

In summary, it is most unfortunate that the Liberation War, which is being fought between persons with MS and MS neurologists/MS societies, has resulted in a fatality. Mr Mostic's death was a preventable tragedy which hopefully will raise the awareness of

MS neurologists that they must ensure their MS patients get good health care following their return from CCSVI treatment.

I realize the Liberation War will continue for the foreseeable future because, when it comes to CCSVI, it is not in the best financial interests of MS neurologists and MS societies, and their pharmaceutical masters, to act in the best interests of those with MS. Thus they disparage CCSVI treatment, falsely claim such treatment is dangerous, and work hard to delay the necessary CCSVI treatment trial research for as long as possible (truth is the first casualty of any war). From a purely monetary point of view, there are ten billion reasons why such actions are understandable. However, it is critical that MS neurologists draw the line at supporting MS patients following CCSVI treatment because, as we have just witnessed, it is a matter of life and death.