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Scientists Call for “Ethical Consciousness” Around CCSVI Treatment and Research

Wednesday April 14, 2010

In a live web forum entitled, "What Do We Know About CCSVI?" sponsored by the National Multiple Sclerosis Society (NMSS) and the American Academy of Neurology on April 14th, people with MS were able to join researchers and journalists in hearing about chronic cerebrospinal insufficiency (CCSVI) and multiple sclerosis straight from the people who developed the theory and conducted initial research around the MS-CCSVI link. (Read the summary from the NMSS here: Web Forum Focuses on What We Know and Don't Know About CCSVI and MS)

Dr. Robert Zivadinov, Associate Professor of Neurology at SUNY Buffalo, was the principle investigator for the first CCSVI study in the US. (Read more about preliminary results here: What Do The Results of the "Buffalo CCSVI Study" Mean, Anyway?). While Dr. Zivadinov spent some time going over the details of what his findings were in his phase I study and what his plans were going forward, he devoted much of his time to emphasizing his concerns and approach to the ethical aspects of CCSVI research and treatment.

Dr. Zivadinov said that there was an enormous amount of international attention on this theory and that people with MS are now engaged in the conversation in a way they never could be before. However, this comes with challenges - as he mentioned, there is a classical ethical tension between rigorous scientific research and the respect for the needs and rights of patients.

To paraphrase, there are people with MS who believe in the CCSVI theory and treatment approaches that are demanding immediate evaluation for CCSVI and moving forward to get treated. Meanwhile, the scientists (including Dr. Zamboni and Dr. Zivadinov) who worked to develop this theory and figure out the best way to treat the condition are saying, "Slow down! Wait for us to work out a couple of the details!"

Among the points made by Dr. Zivadinov:

- Patients should NOT stop disease-modifying therapies at this time, even if they undergo angioplasty for CCSVI.
- At this time, patients should NOT get angioplasty for CCSVI outside of a rigorous clinical trial setting. At this point, there is not enough data - here is more safety and efficacy studies.
- There is a need to look at the impact of CCSVI treatment on MRI images and objective clinical measures.
- *The dialog between patients and researchers should be kept going.

Dr. Zamboni seems to support the cautious approach proposed by Dr. Zivadinov. He did mention that he believes there should be "compassionate grounds" for providing CCSVI treatment to people with rapidly-progressing MS under stringent guidelines and oversight. This would limit the potential harm that could be done by "unethical" doctors. However, recognizing that there were many people receiving CCSVI treatment outside of a research setting, he called for the formation of a registry that would allow people to be followed after a CCSVI procedure.

So, here are the very scientists who brought the CCSVI-MS theory into the light begging people with MS to slow down in their quests to undergo procedures to open their veins. While they realize people with MS want answers NOW, they say there is still much work to be done before this can be safely offered to all who want it (or even if it should be offered at all). What do you think?

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Comments

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(1) Roberta says: April 14, 2010 at 8:29 pm

I watched the entire panel discussion and felt it didn’t yield much new info for me, and offered precious little hope. I have had M.S. for 30 years. For the past 8 or so I have progressed from relapsing/remitting (RR) to secondary progressive(SPMS). There are no “disease modifying” drugs on the market for me. I am deteriorating daily and was a little disappointed in recommendations of the panel. Dr. Zivadinov is a dedicated researcher who has a broad interest in the wide effect of CCSVI on all neurological illnesses, the interventional radiologist seemed willing to open blocked veins if called upon to do so, though his colleague, Dake, at Stanford ran into difficulty placing stents in veins and was “asked to stop.” The neurologist on the panel was clearly the most cautious or uninformed or afraid. Only Dr. Zamboni, whose own wife suffers from M.S., and who has benefited from the “Liberation procedure” which he developed demonstrated true understanding and compassion. I would go to see him in Italy in a heartbeat, as he seems to get it…just what my long life living with this devastating illness has been. What if I could walk again?

(2) Melissa says: April 15, 2010 at 12:15 am

I also watched the entire web forum and my take-away was much different than Julie’s. I don’t think anyone was “begging” MS suffers to slow down. Instead, I think they are saying researchers need to work faster. We need to continue to aggressively study the amazing coorelations they have discovered between MS and CCSVI. I still don’t get why people are so afraid of this. Angioplasty is an extremely safe a proven procedure.

(3) Jennifer says: April 15, 2010 at 9:43 am

I think the worry and caution displayed is because of the almost ‘hysterical’ reaction of people with MS who were demanding a treatment that is not available yet.

Why is it not available, because it is entirely new and there are no testing protocols, no one trained to do the scans yet and it’s not proven yet to work, so there is no government that is going to pay for something in a universal health care plan unless it is proven. That just makes sense, otherwise every new theory for every disease would be demanded to be tried to help patients and it would bankrupt the system – not to mention- be completely unethical.

When MS patients are threatening neurologists and blaming them for being in bed with pharma companies and calling people at the MS Society’s liars and incompetent crooks — then some people get offended by that. Having worked their whole lives for the betterment of others and being slammed for “keeping”something from people with MS brings a rather sore spot into the conversation. Especially when members of your own family have MS and that’s why you do that kind of work.

(4) trion says: April 15, 2010 at 3:28 pm

ms really stinks. Caretakers are overwhelmed and patients are suffering. I for one am a suffering patient. I think it is irresponsible for any Dr to not appreciate in some respect the fact that CCSVI is real and that it could every well and has very well changed lives. I would challenge that guy from wayne state that fired at Zamboni to switch bodies with me for just one day. Believe me his perspective would change.

(5) Barbie says: April 15, 2010 at 8:47 pm

Thanks for posting this summary, Amelie. Very interesting, and somewhat as expected with them telling us to “wait for more research”. I am.

@ Roberta – Novantrone is approved for SPMS.

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