



Contributors

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 Email
 All Postings

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 All Postings

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 Email
 All Postings

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 Email
 All Postings

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 Email
 All Postings

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 Email
 All Postings

Dr. Neil Rau
 Email
 All Postings

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 Email
 All Postings



RSS Feed

Share |

Category list

- ▶ Angela Mulholland's Postings (93)
- ▶ Avis Favaro's Postings (40)
- ▶ Dr. Grant Lum's Postings (15)
- ▶ Dr. Katy Kamkar's Postings (16)
- ▶ Dr. Lorne Brandes' Postings (73)
- ▶ Dr. Marla Shapiro's Postings (167)
- ▶ Dr. Neil Rau's Postings (10)
- ▶ Dr. Yoni Freedhoff's Postings (76)
- ▶ Karen Owen's Postings (18)
- ▶ Mami Kuhlmann's Postings (3)
- ▶ Monica Matys' Postings (49)

Tag cloud

- Adhd Aging Alcohol Allergies Als Alzheimer's Alzheimer's Disease Antibiotics Anxiety Arthritis Asa Aspirin Asthma Autism Babies Back Barbecue Bariatric Blood Blood Clots Blood Pressure Bmi Bones Brain Brandes Breast Cancer Calories Cancer Ccsvg Chemotherapy Chicken Children Cholera Cholesterol Costs Dementia Depression Diabetes Diet Disability Doctors Dogs Dr. Marla Eating Epilepsy

CCSVI one tumultuous year later: Where do we go from here?

November 17, 2010 09:13 By **Dr. Lorne Brandes**

It is now a year since CTV's [W5 report](#) on Dr. Paolo Zamboni and his [CCSVI](#) (chronic cerebrospinal venous insufficiency) theory of multiple sclerosis sent shock waves through the scientific and lay communities. Would "tumultuous" be an appropriate adjective to describe the events of the ensuing twelve months? I think so.

And if one had to identify the most important aspects of this story, in what realm what would they lie? Medical? Political? Social? Behavioral? Adversarial?

Ultimately, there are books to be written here! But for now, allow me, like [Janus](#), to look back over the year that was, and ahead to the year that (hopefully) will be.

To begin, it is no understatement that Zamboni's theory of MS came out of left field, evoking both an ill-informed, [reflexive](#) dismissal of his hypothesis, and derogatory comments about him (it did not help that the venoplasty treatment he developed to open blocked veins was dubbed the "liberation procedure" by one of his colleagues).

"Who is this guy? Some obscure Italian? A vascular surgeon? Not a neurologist? What does he know about MS? He treated his own wife? His name is Zamboni? Ha ha ha!!"

Given the extremely icy reception Paolo Zamboni received from the medical establishment, his was an apt surname.

Within days of the W5 story, neurologists and MS Society officials, longtime subscribers to the premise that MS is an autoimmune disease, gave a unanimous thumbs-down to the possibility that obstruction of venous drainage in the neck and/or chest caused blood to back up and leak [toxic iron](#) from damaged thin-walled veins deep in the brain, killing nerve cells.

Some even went so far as to call CCSVI a [hoax](#). Never mind that other researchers had shown that [iron-rich](#) MS plaques consistently form around [veins](#) and that the disease progresses in a "[backwards](#)" fashion (compatible with retrograde blood flow) in tissues bordering the venous system of the brain. It had to be a hoax. Period.

Then a remarkable thing happened. Patients pushed back hard. Internet chat rooms on MS websites and Facebook lit up with blistering comments aimed not only at neurologists, but at drug companies and MS Societies as well. Given the marginal, or even [negative](#), results of current drug therapies, how dare they dismiss Zamboni's hypothesis without a shred of contrary evidence?

Soon, despite [safety](#) warnings, and a lack of hard evidence that venoplasty worked, hundreds of desperate MS patients, unable to get treatment in Canada, paid to go to clinics abroad to have their veins "liberated". Many [reported](#) a rapid decrease in symptoms such as fatigue, headache, brain fog and cold extremities. Others posted "before and after" [videos](#) on YouTube, showing dramatic improvements in balance and walking. Had there ever been anything like this? Not that I could remember.

Realizing that they were rapidly falling out of step (not to mention out of favour) with their constituency, the Canadian and American MS Societies quickly changed course, becoming more conciliatory and responsive. A call went out for CCSVI research proposals, with the promise to fund successful applicants by June, 2010.

True to their word, seven grants, totaling \$2.4 million, were [awarded](#) to four Canadian and three American research teams. But there was a problem: the studies would only assess vein anatomy; none would offer treatment if blockage was found. Any future decision on funding clinical trials would be put off until the findings of the first studies were in.

But knowing that obtaining an answer could take up to three years, and unwilling to wait for fear that, by then, their symptoms could be much worse, angry and dissatisfied patients cranked up the volume, demanding more immediate action.

"We hear you," the Canadian MS Society replied. Despite [spending](#) only 22% of their \$33.7 million budget to fund research, MSS officials announced that they would join the federal Liberal Party in lobbying Ottawa for \$10 million to pay for treatment trials. In response, the federal health minister, Leona Aglukkaq, convened a late-summer meeting of "experts", selected by officials of the Canadian Institute of Health Research and MS Society. Their mandate: to reach a consensus and advise her.

But when that time came, the panel, which did not include a single physician or scientist involved in the research, diagnosis or treatment of CCSVI, [recommended against](#) clinical trials until the results of the anatomy



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- ▶ CCSVI One Tumultuous Year Later: Where Do We From Here?
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- ▶ Drug Companies And Doctors: Redefining The Relationship
- ▶ Smoking Linked To Alzheimer's Disease And Other Dementias

Month List

- 2010
- November (7)
 - October (14)
 - September (16)
 - August (10)
 - July (13)
 - June (16)
 - May (13)
 - April (15)
 - March (15)
 - February (10)
 - January (17)
- 2009
- 2008
- 2007

[Estrogen](#) [Exercise](#) [Fast Food](#) [Fat](#)
[Fatigue](#) [Favaro](#) [Fda](#) [Fitness](#) [Flu](#)
[Flu Shot](#) [Flu Vaccine](#) [Food](#)
[Freedhoff](#) [H1n1](#) [Haiti](#) [Health](#)
[Health Canada](#) [Heart](#) [Heart](#)
[Disease](#) [Heat](#) [Heat Stroke](#)
[Hepatitis](#) [Herceptin](#) [Hiv](#) [Hormones](#)
[Hospital](#) [Hrt](#) [Infants](#) [Infection](#)
[Influenza](#) [Injuries](#) [Insomnia](#)
[Internet](#) [Iron](#) [Junk Food](#) [Kids](#)
[Liberation](#) [Liver](#) [Lou Gehrig's](#)
[Malaria](#) [Meat](#) [Medication](#)
[Medications](#) [Medicine](#) [Memory](#)
[Menopause](#) [Mental Health](#) [Mental](#)
[Illness](#) [Metastasis](#) [Mrsa](#) [Ms](#)
[Mulholland](#) [Multiple Sclerosis](#)
[Nausea](#) [Nutrition](#) [Obesity](#) [Ontario](#)
[Osteoporosis](#) [Outbreak](#)
[Overweight](#) [Pain](#) [Pandemic](#)
[Parents](#) [Patients](#) [Personality](#)
[Pregnancy](#) [Premarin](#) [Prices](#)
[Prostate Cancer](#) [Psychiatry](#)
[Psychology](#) [Ptsd](#) [Quarantine](#) [Rau](#)
[Restaurants](#) [Safety](#) [Salt](#) [School](#)
[Seniors](#) [Shapiro](#) [Skin Cancer](#)
[Sleep](#) [Smoking](#) [Sodium](#) [Soft](#)
[Drinks](#) [Sports](#) [Stent](#) [Stigma](#)
[Stress](#) [Stroke](#) [Sugar](#) [Sun](#)
[Surgery](#) [Sweeteners](#) [Swine Flu](#)
[Tamoxifen](#) [Teens](#) [Trans Fat](#)
[Tumour](#) [Tv](#) [Vaccination](#)
[Vaccine](#) [Vegetables](#) [Veins](#) [Virus](#)
[Vitamin D](#) [Vitamins](#) [Waist](#) [Wait](#)
[Times](#) [Water](#) [Weight](#) [Weight Loss](#)
[Winter](#) [Women](#) [Work](#) [Zamboni](#)

studies were known. The [optics](#) were plainly bad....so bad that a Globe and Mail [editorial](#) encouraged the health minister to ignore the panel's recommendation.

Luckily, there was already a plan B in the wings. A month earlier, Saskatchewan's premier, Brad Wall, had stepped up to the plate. With the highest rate of MS in the country (and among the highest in the world), he [announced](#) that his province would fund a properly-designed clinical trial to answer the question of whether unblocking veins is of benefit to patients with the disease. Undeterred by the panel's negative report, Mr. Wall soon appointed his own group of expert advisors and pledged \$5 million for an approved study to begin sometime in 2011.

Yet, even before the Saskatchewan study was announced, clinical trials of CCSVI treatment had begun in the United States. The University of Buffalo treated the first 10 patients in its new [PREMiSe](#) (Prospective Randomized Endovascular therapy in Multiple Sclerosis) study and is currently awaiting its institutional review board (IRB) assessment before proceeding to the next twenty. A second IRB-approved treatment [study](#), involving vascular specialists associated with Albany Medical College, has recently commenced in Albany, NY.

The importance of these properly-designed clinical trials of balloon venoplasty, with careful follow-up of patients, cannot be overemphasized. Many worry about some of the out-of-country physicians and centres that offer CCSVI treatment. What are their qualifications? What do they really know? We generally hear about people who have had a good outcome. How many have not? The latest reports of [serious complications](#) following stenting in foreign clinics should cause us alarm. Indeed, Dr. Zamboni himself has long warned against using stents, as well as seeking treatment outside of clinical trials.

So where do we go from here? While I don't claim to have a crystal ball, I suspect that the next 12 months will bring heightened attention to some of the controversies surrounding CCSVI.

For example, the interpretation of the data in a recent, [widely-reported](#) negative ultrasound [study](#) by Doepp and his colleagues, appears to have been effectively challenged by Dr. Zamboni. In a letter just [published](#) in the Annals of Neurology, he pointed out that, as measured by the German researchers, the change in blood flow through the neck veins when going from the lying to upright position was 50% less in the 20 MS patients than in the 56 normal controls tested.

In Zamboni's opinion, this difference supported the presence of CCSVI in the MS group. Using a Doppler ultrasound image for illustration, he went on to note that, in his experience, abnormal membranes (septa) and/or malformed valves inside neck veins were more common than stenosis (narrowing) as a cause of obstructed blood flow.

"Clearly a complete understanding of the system is required before drawing conclusions about the lack of venous abnormalities, and this requires ultrasound, MRI and catheter venography. This underscores the urgency of establishing an internationally accepted protocol. In the attempt to achieve this...my group is available to travel to Berlin and rescan with German colleagues the entire series [using] the proposed methodology," he wrote. Touché.

Will Dr. Doepp accept Zamboni's offer? I suspect that [Dr. Sandy McDonald](#), a Barrie, Ontario, cardiovascular surgeon who runs a private imaging clinic, would urge him to do so. Before he and his colleagues traveled to Ferrara last year to learn Dr. Zamboni's ultrasound technique, they "missed a lot of pathology," he told me a few months ago.

Dr. McDonald's group has since scanned approximately 400 MS patients. Cautious by nature, he nonetheless believes that a very high percentage appear to have significant, and often complex, vein anomalies. As for normal subjects: "We also have done normals and find they are indeed normal," he wrote in an e-mail last August. He is currently reviewing all his data to confirm the findings in the hope of publishing them.

Clearly, with the commitment of people like Sandy McDonald and Brad Wall, each determined to find honest answers, the next year should bring us closer to an understanding of CCSVI and how it may be related to MS.

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Comments

11/17/2010 12:59:56 PM #

Thanks for this comprehensive overview. One year of news flashes, blogs, controversial scientific evaluations summarized in one article. On a personal note: as a PPMS patient and being treated for CCSVI (two malfunctioning valves in jugulars) I am now able to run and squash again. Quite a progress in three months. My neurologist has no good explanation as he can not support the CCSVI theory.

On another note; it has become clear that Canada's medical community, although excellent in care and research, is extremely conservative in receiving new ideas. Yet innovation is not only a matter of step by step incremental change (as current, traditional research does) it is also about more 'radical' innovation. Other industries (especially electronics) understand this very well. This proves that the time for the medical community to revise its innovation process is NOW!

job rutgers 

11/17/2010 1:08:44 PM #

Thank you Dr. Brandes for a comprehensive outline of this past year.....so many memories with frustrations and hard work and yet still there is HOPE. Now if we can only get follow up care along with ER care in Canada. 2011 will be better, only because 100's more of us Canadians will get treated away from home and 1000's of us Canadians will continue to fight. Thank you for being a great advocate for all of us!!

Bev 

11/17/2010 2:04:09 PM #

Thank you Dr. Brandes for the overview. Sadly, it has been almost a year and we've got nothing to show for here in Canada. I watched W5 and 8 months later, I was treated and I am feeling so much healthier. Unfortunately, the corruption and narrow mindedness is keeping many others from seeking treatment at home. I believe this goes beyond being a conservative nation as my previous sentence states. We will keep pushing until this discrimination is lifted and is treated here at home.

CCSVI Treat 

11/17/2010 2:30:04 PM #

12 months on and we are still in the dark ages here in Canada, pushing ineffective disease modifying drugs and ignoring a simple procedure to correct the anatomy of the veins. Until a Doctor can explain to me why the brain, our most important and delicate organ, is immune to blood circulation deficiencies, I have no choice but to take everything they say against CCSVI and the Liberation Treatment as complete rubbish motivated by money. How dare they say Zamboni is a fraud and the procedure is nothing more than placebo when the very drugs they push have not been held to the same standard they demand of CCSVI and the Liberation Treatment? Also, the drugs have never shown any efficacy beyond 1/3, which is considered placebo effect. Who do these people think they are fooling?

Ernie 

11/17/2010 2:38:41 PM #

Thanks so much for this comprehensive and accurate report. It is very much appreciated. I can only hope that many others will read this

Thanks 

11/17/2010 2:57:10 PM #

21st November was that day that HOPE came knocking at my door. Since that time I have been an advocate of this procedure, preferring to call it angioplasty rather than the liberation treatment. I actually received my procedure in July which included the installation of two stents to keep my vein open. I also stenosis in my right jugular and my azygous vein. I have been fortunate in that I have wonderful recovery and only have minor difficulties now.

This procedure is no hoax, Dr Zamboni is no heretic and the results are not a placebo. If Dr Mark Freedman wants mouse work completed, he need look no further than those of us who have be so fortunate to become medical tourists to get our lives back at our own expense. What kind of country with one of the best medical systems in the world would allow such treatment of their citizens.

But this is not the answer. We need this treatment done now and in Canada. The cost to our taxpayers are minimal when compared to the present costs to keep people on drugs that don't work and in assisted living. No one is doing the comparative costs. Who is gaining by this delay - certainly not the citizens of Canada.

Judy Filipkowski 

11/17/2010 2:59:29 PM #

It's not the fault of physicians for not buying into a process with little to no evidence behind it. There are thousands of treatments with the "evidence" of testimonials behind them. It's not my job to believe them, and send people for a surgical procedure that could kill them. Real outcomes measured properly in well powered randomized and blinded trials must be shown before we subscribe to CCSVI. So do your trials and then get back to us. Don't blame the scientific community for not listening to your emotional arguments. Talk to scientists with science.

thedocsquawk 

11/17/2010 3:04:40 PM #

Thank you 2.5 million times over Dr. Brandes. As those here previous to me have said your comments for the past year are very much appreciated. I am confused as to why you did not use the terms that NO SAYERS have been using. I am pleased and no complaints from me that is for sure. I thank you for making this a clear and very understandable article. As long as the MS Neurologists do not interfere with this cutting edge hypothesis we will have a new and very accepted course of treatment. for CCSVI. The hypothesis is very understandable and makes so much sense. It is too bad that the CMSS (Canadian Multiple Sclerosis Society) did not come up with this AMAZING find. AND it is too bad they ignored the theory for at least the past 30 years where this could have been co-discovered the Angioplasty and the Venography at the same time. This is their loss and it is up to the proper specialists to do their job. The CMSS is determined not to budge on helping those who would get a better quality of life as others have and in some cases is taken for granted. It is the money that is holding this back and I would love to see a dispute on just that fact. It is too late there are so many conflicts of interest with BIG Pharma and these Neurologist and the CMSS it is mind boggling. Disclosures that are provided by Neurologists in the United States and Canada are proof alone that their ties are very strong. Too bad we have to suffer because of the all mighty dollar. Too bad there is no ethics being used either. Let alone compassion. I just hope this strangle hold they have will finally be broken. It has taken 62 years and billions of dollars wasted and for what? NOTHING. They have NOT EVEN COME CLOSE TO CCSVI. It is not theirs to hold back. THIS IS A VASCULAR ISSUE FIRST. NOT A NEUROLOGICAL ISSUE. Unless we are denied the Vascular route/Angioplasty then we WILL develop MS symptoms. Very avoidable. BUT for now very cruel.

Shirley Renshaw 

11/17/2010 3:08:43 PM #

Thank you so very much for your thoughtful and thorough report. I have advanced secondary progressive MS and am hoping that Canadian officials I once believed in will come to realize that, like charity, compassion begins at home. If similar human rights violations occurred elsewhere in the world I know Canada would intercede. That's one of the reasons I love this great nation. Now I'm afraid a new term will have to be coined to describe government decreed withholding of a common medical procedure from a specific group ONLY because of a pre-existing medical condition. MS-ocide? I am trying to go somewhere for the procedure. I will spend the money and risk traveling under extremely difficult circumstances. I will come home to a country unwilling to give me follow-up care should I need it. I am one of the lucky few who can afford to do this without selling

everything I own. I am disgusted that politicians and physicians are so blasé about human life and suffering that they feel they can hide their inflexibility, fear and/or ignorance behind a smokescreen of ethical posturing and one-sided debate. For tens of thousands of Canadians there is no debate, only a choice: CCSVI angioplasty or death.

Heather 

11/17/2010 4:26:17 PM #

Thanks a lot for the report. Certain MS specialists have been given so much power over the course of the time that it is so hard for them to let go. There are exactly acting similar to the mom who has recently drowned her two daughters for fear of losing them over the custody battle. So if they cannot have it, no one can, and they are killing the MS patients and surprisingly, unlike the mom case, Government of Canada, along with Ms. Aglukka is supporting them.

Dr. Mark Freedman who is testing chemo therapy and in his study of ten MS patients, 1 died, 1 got symptom free and the rest are suffering they way they had been suffering, is calling this procedure dangerous! Yeah Dr. Josef Mengelel, ops, I meant Freedman, it is so hard to lose your ginny pigs, isn't it?

Dr. Paul O'Connor calls this procedure unrelated to the disease instead he insisted for me to go on medications which their side effects are more severe than my MS symptoms. But on one way he was right, MS drugs help, they kill you and put you out of the misery of this dreadful disease.

I wish I knew what dope Mr. Beaute was on when he was recruiting the team of "experts", for sure it would have ease some of our symptoms.

maria090 

11/17/2010 5:41:01 PM #

When will people finally get it? This is a minimally invasive procedure that has been performed for upwards of 30 years. When the only options are 1) Die or 2) Over 90% chance of maybe getting better. Please let me choose my own destiny. Sarcastic "thank you" to the MS Society of Canada and the Canadian Institute for Health Research for not allowing any Doctors with any direct experience a chance to speak to their committee before they basically decided not to even move forward with a trial. Smells fishy, doesn't it Minister Aglukak? Anyone happen to see where many members of this joint committee get their funding? Oh? Big Pharma? And how about MS Clinics? Right... Anyone wishing any back up info on this, let me know.

Wendy Ireland 

11/17/2010 5:41:45 PM #

Thank you to Dr Zamboni for thinking "outside the box" with MS. This procedure is already done all the time in Canada called Venous Angioplasty(or venoplasty) for blocked veins has helped give back some MS Patients some quality of life. Of course many of us who have went abroad would have liked to have this at home on our own soil in Canada but there are those powers higher up who are blocking this. Since the MS Society who says they represent MS patients has not once stood up for my rights in being discriminated against since last Nov they ahve not nor will not recieve another dime from me for support. I am very thankful for Dr Sandy McDonald he is a hero to MS patients because he said a long time ago "Set the MS aside and let me help my patients with a "vascular issue" because that is what this is.

The science will find out exactly in the years to come how this all ties into MS but for myself going to Sofia, Bulgaria this July and being treated by Vascular Specialists gave me back proper blood flow and some quality of life and I don't care how Dr Mark Freedman twists this he is wrong and the truth always comes out in the end.

I am glad I went abroad and had proper blood flow restored so I can see my two young children grow up and can still feel their kisses on my once completly numb cheek since the day I came home from Bulgaria 4 months ago.

Thank you Dr Brandes.

The Province of Saskatchewan does have a TRUE LEADER and I am so very thankful this is where I live in Canada now more than ever!

Michelle Walsh 

11/17/2010 6:58:10 PM #

Thank you so much for being a part of the conversation.

Your perspective adds tremendously to our understanding of this new area of medical discovery.

If only all physicians were as thoughtful and deliberative as you, we might avoid the knee-jerks and resulting backlash altogether; we could work together with the medical community to figure this out. We'd be a lot further ahead if everyone was working towards the same goal, figuring this thing out and its significance in MS, rather than vested interests taking up defensive positions and being immediately resistant to the possibility of a paradigm shift.

Thank you for being a beacon in the tumultuous sea this past year. We needed a life guard, and we got one in your advocacy and voice.

Sue 

11/17/2010 7:01:01 PM #

Though not Canadian, I appreciate the overview. Conspicuously missing are the offensive remarks made by the detractors of CCSVI, notably your own Dr. Mark Freedman. I have secondary progressive MS. From life in a power wheelchair, balance bars, and transfer tables I am free from all but trace symptoms of Multiple Sclerosis. Although we don't have the angst of our Northern neighbors, things are tough for those of us seeking the angioplasty procedure in the US also. As you said, the next twelve months will focus on the complications of the procedure. If those who stand to lose money and peer honor could get over themselves, this would no longer be considered an experimental procedure. I am one of those Youtube wonders you spoke of and one of the people with very remarkable improvements. I have 15 grandchildren who I can spend amazing time with, impossible before this life saving option. I have my life back and it is very sweet. That is my twelve month observation. A solid plus for me was making many new friends from a beautiful country I am determined to visit.

Linda Rousay 

11/17/2010 8:59:10 PM #

I went and had the procedure on July 15th in Poland. I no longer need a cane to walk, I walk with a limp now not a leg drag . I went for a bike ride with my eight year old daughter this summer. " FOR THE FIRST TIME". I played ball hockey this weekend and was able to stand and be the goalie, My long term goal. to jog before the procedure, it was not to get worse and maintain the quality of life I had left.

I have four months in and it has changed life!!!!

Melissa Robertson 

11/17/2010 9:36:20 PM #

Thanks for everything. Without family having heard of this procedure from Canadians, I may not have known!

Jennie 

11/17/2010 10:45:10 PM #

I will soon have the Liberation Procedure for CCSVI here in the US. I almost pity the

medical communities of both Canada and the US when history marks what is unfolding regarding the blatant disregard of innovation in the treatment of MS. Do I think the procedure is a cure, I have no idea. Is it a means to a better quality of life.....without doubt. Let history take note of the cold hearted nay sayers and mjay they rue the words.

Steve 

11/17/2010 10:48:42 PM #

First I must say how much admiration and respect I have for what Dr. Lorne Brandes has attempted to do, through his blog, and through his personal efforts, to further the cause of CCSVI treatment, and thereby hopefully improving the lives of so many. While I do not have a personal connection to MS, I have been following this amazing story very closely, and reading the anecdotes of those who have experienced measurable relief of their symptoms, and more importantly, dramatic improvement in the quality of their lives, leaves me with a sense of awe. I believe that the only sensible, scientifically prudent, and humanitarian course of action would be to keep moving forward. I would also encourage all the provincial health ministers, and provincial premiers to step up to the plate, review their resources, and devise a plan to assist those researchers who are dedicated, through properly designed clinical trials, to investigating CCSVI.

Evie Elliott 

11/18/2010 3:27:25 AM #

"Dr. Mark Freedman who is testing chemo therapy and in his study of ten MS patients, 1 died. I got symptom free and the rest are suffering they way they had been suffering, is calling this procedure dangerous! Yeah xxxxxxxxxxxx, ops, I meant Freedman, it is so hard to lose your ginny pigs, isn't it?"

I'm sorry, this has been bothering me all night and I just cannot let this stand. Dr. Freedman has done some unpopular things, but he is a physician and cares about people. On the other hand, the individual he is being compared to was not human, was a murderous torturing beast, and should never have walked this earth. I should be the last person to defend him, but someone has to. Please remove this offensive writing and please let my request stand as the first in a full day who requested this.

We need to retain our humanity at all costs, and this is a tiny price to pay compared to that paid by the victims of the monster whose name I will not even use.

Please allow me pride in my citizenship. Shame.

Chris Sullivan 

11/18/2010 6:18:55 AM #

Hi All,
I have not read all the comments but we, who have MS, and those caregivers who provide daily assistance to us want to see action. I have been saying for a long time that checking for blockages and restrictions in the veins without treating them, if found, is USELESS. It is the procedure that needs to be tested and tracked for results. It is a Quality of Life issue for those affected d by MS.

As far as the CIHR not recommending studies, I say look at the head of the CIHR, Dr. Alain Beaudet. He is a Vice President of Pfizer. The same Pfizer that makes and benefits from the sale of Rebif, a very commonly used medication for control of MS Symptoms. Rebif costs about \$25,000 a year. Mmmm Conflict of Interest? I say YES!

I went to Costa Rica and had the Liberation Treatment. My results were Instantly recognized and significant. My brain fog is gone and daily I feel much more alert and alive. I see colour in left eye for the first time in 25 years. I no longer have to wear my leg brace as my drop foot has disappeared. I sweat again. Sounds disgusting but my body is trying to regulate his own temperature. My balance is improved. I can stand from a sitting position without the use of my hands. My balance is better. I can walk further, although still use a cane, but more so for when I need to rest.

This is not a Cure and no one ever has said it is. It is a Quality of Life Issue and we all deserve Quality of Life.

Michael Lortie,
Kingston, Ontario

Mike Lortie 

11/18/2010 4:34:30 PM #

As I posted earlier..... let history defend or condemn based on the facts..... whether the early '40's or the 2010's.....the facts will be the fact!!!

Steve 

11/18/2010 8:23:52 PM #

Dr. Brandes

In your post you make note of MS patients having "liberation" for CCSVI posting Youtube videos of their dramatic recoveries. You ask has this happened before. Yes, it has, there are many Youtube videos of MS patients show how well they can move after being treated by a faith healer. The testimony of these individuals appears to me as sincere and convincing as that of the liberation patients. One could ask since both therapies have the same effect should not provincial health departments fund research into faith based healing for MS (after all therapeutic touch was claimed by many to be effective at healing before Emily Rosa revealed the flaws in it).

In the past 12 months researchers have tried to replicate the hypothesis that CCSVI is connected to MS. Three recent papers, Florian Doepp, Peter Sundstrom and Mike Wattjes (see Colin Rose's blog for discussion) could not find any difference in venous anatomy between MS patients and healthy controls. This calls into question the physical reality of CCSVI. Also when looking on Pubmed for CCSVI research papers, one has difficulty finding any recent publications supporting CCSVI. Why this lack of follow up to support an exciting new paradigm?

What I find most interesting about Dr. Mike Wattje's paper (published in Journal of Neurology Neurosurgery and Psychiatry) is the interventional neuroradiologists state the cranial and cervical venous system is complex and variable in MS patients and control subjects. Additionally Gray's Anatomy states the Left and Right Internal Jugular veins are often unequal in size in the same patient. Is it possible Dr. Zamboni assumed the normal anatomical variants seen in the veins of MS patients was pathology and mistakenly linked MS to it?

Facts are inconvenient things and no amount of hopeful thinking will change them.

Paul 

11/18/2010 8:47:45 PM #

Thank you Dr. Brandes. For "docsquak" - there is credible science available on CCSVI and it has been available and studied since 1863 but has been ignored by the so-called MS specialists. These MS specialists have been chasing an unproven mouse study conducted after the Second World War that resulted in MS being labelled an autoimmune disorder. Chasing that unproven mouse study has led to absolutely nothing of benefit for MS sufferers. The only groups that have realized any benefit are the ones who live off MS. MS sufferers can, indeed, hold the Canadian medical community to account for its obstinate refusal to even consider a low risk treatment for a vascular problem that has been clearly linked to MS. I am on a waiting list to have treatment in the United States and I am grateful for that opportunity. I am thoroughly disgusted with the lack of action and dispection currently the norm in Canada as far as CCSVI is concerned. The "MS specialists" are making themselves irrelevant and it is a shame that they do not realize it. They have lost respect and trust and the recent "woe is me" story in the Toronto Star about the poor, misunderstood MS neurologists will not help them regain the ground they have thrown away.

Linda 

11/19/2010 1:50:14 AM #

Dear Dr. Brandes,

Thank you so very much for your objective review of the past year's happenings. We have very much appreciated your time and trouble in keeping CCSVI truths at the forefront, while naysayers have consistently trotted out inaccurate information.

Your concluding paragraph highlights a huge problem that has been paramount from the day after WS's first show about CCSVI aired.

"Clearly, with the commitment of people like Sandy McDonald and Brad Wall, each determined to find honest answers, the next year should bring us closer to an understanding of CCSVI and how it may be related to MS."

Honest answers. Honest statements, based on facts, truths. Was that too much for MSers to ask for and expect? And yet, throughout this past year, the amount of "BS" (pardon me for not spelling it out) that has been flung at us from the various people who suddenly claimed CCSVI - a vascular condition - as their territory although they have no vascular background and had ignored this plausible theory for years, is unbelievable, unforgivable, and utterly disgusting.

We MSers were not looking to be duped by either side - pro-CCSVI or anti-CCSVI. And yet, right from the get-go, one side has reigned with duplicity, questionable actions/inactions, dirty tactics, etc. We simply wanted the truth, and for this plausible theory to be given its due consideration. Up until now, it still has not, not in Canada.

For Dr. Sandy McDonald (an actual expert) to have been excluded from the panel selected by CIHR and the MS Society - is shameful, and reflective of the dubious agenda on the table at that meeting with the federal health minister. For our FH Minister to be seemingly blindly led astray by this carefully selected panel of puppets???

The sad and sickening reality is that in this last year, we MSers were denied honest answers from so many who had been treating our illness when we inquired about CCSVI (even a simple, "I don't know" would have been an honest and acceptable answer). We were denied honest information from those who claim one of their main roles is to provide timely and accurate information. We were denied real advocacy and representation by those earning a living in the name of our illness. We were denied compassionate care by our health system (for those in further stages of this disease who have no other options). We were denied our rights as human beings, to access vascular assessment and treatment, by our country.

Chrystal 

11/19/2010 2:22:27 AM #

BTW, for the naysayers - the plausible CCSVI "theory" is actually a "condition" recognized by 47 countries. While our Federal Health Minister continues to hold Canada (except for Saskatchewan - thanks to Brad Wall) back, waiting for a Canadian stamp on studies, etc., increasing numbers of Canadian patients will continue to seek treatment abroad...and so many other Canadian patients will continue to progress while waiting for Canada step up.

Where CCSVI is concerned, Canada: Not a leader. Not even a follower.

<http://csvg-ms.net/en/content/consensus-document-international-union-phlebology-iup-2009>

Consensus Document of the International Union of Phlebology (IUP) – 2009

Last modified: 11.04.2010 - 07:37 CET Created: 28.01.2010 - simplex A consensus conference on venous malformations[iup09] – headed by Prof. Byung B Lee from Georgetown – and experts from 47 countries – studied the evidence and unanimously voted in favour of officially including the stenosing lesions found in CCSVI in the new Consensus document and Guidelines.

[lee09a]

This paper can be brought to interventional radiologists and vascular surgeons. CCSVI lesions are classified as a truncular venous malformations - which means that vascular doctors have now classified this disease, CCSVI, as congenital- and preceding MS lesions.

Extracts:

The International Union of Phlebology (IUP), the largest international organization devoted to the investigation and management of venous disorders, established an expert panel to formulate guidelines for physicians and health care professionals around the world on the evaluation and treatment of venous malformations (VMs).

The aim of this document is to provide recommendations for the diagnosis and treatment of VMs based on the best currently available scientific evidence. When scientific evidence was lacking or weak, a consensus of opinions among expert members of the panel was reached to support the recommendations.

...

Truncular lesions of obstructive nature (webs, hypoplasia) may have different hemodynamic impacts on their relevant vascular systems depending upon their location, extent/severity, and natural compensation through collaterals. Chronic venous insufficiency develops in the territory drained by the truncular vein. Stenosing truncular lesions produce venous obstruction leading to a reduction in venous drainage. Membranous obstruction of the inferior vena cava in primary Budd-Chiari Syndrome is an example of a primary obstructive VM affecting a major vein.

Truncular VM lesions may also occur in veins with the same embryologic origin or draining the same territory (e.g., stenosing lesions of the extracranial jugular veins, superior vena cava, and azygos vein system along the main outflow pathways of the cerebro-spinal venous system as suspected cause of multiple sclerosis).96-99

...

98 = [zamboni09b]

Reference: CCSVI in Multiple Sclerosis: News from Dr. Zamboni- CCSVI lesions classified as congenital

Chrystal 

11/19/2010 8:57:30 AM #

"CCSVI" is junk science and "liberation" is dangerous charlatany. See blog for details.

<http://medicalmyths.wordpress.com/2009/11/24/the-zamboni-myth-ccsvi-surreal/>

Colin Rose 

11/19/2010 12:11:23 PM #

Sorry for not clarifying. We want honest answers from credible sources.

Some obviously prefer junk pharmacology. Certainly more dangerous than "liberation". Just ask mourning family members of those who died while being treated with certain MS drug treatments and run a tally...then track down the many more who have brain disease....and that's the track record of just one of the MS DMDs. Tragic.

Disease progression was not only worse than predicted by the model used by NICE,1 it was worse than that in the untreated control group.

http://www.bmj.com/cgi/content/full/340/jun03_1/c1672
http://www.eurekalert.org/pub_releases/2010-06/bmj-mds060310.php
<http://www.metro.co.uk/news/829242-ms-drugs-scheme-a-costly-failure>
<http://www.reuters.com/article/idUSLDE6520H520100603>

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[http://www.boston.com/business/healthcare/articles/2010/03/29/for\\_many\\_ms\\_drugs\\_not\\_helpful\\_study\\_shows/?p1=Well\\_MostPop\\_Emailed3](http://www.boston.com/business/healthcare/articles/2010/03/29/for_many_ms_drugs_not_helpful_study_shows/?p1=Well_MostPop_Emailed3)

For many, MS drugs not helpful, study shows  
 By Rob Waters , Bloomberg News / March 29, 2010  
 March 29, 2010  
 Scientists find there may be two forms of multiple sclerosis  
 Posted: 09:34 AM ET  
 By Val Willingham, CNN Medical Producer  
<http://pagingdrgupta.blogs.cnn.com/2010/03/>

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Chrysal 

11/19/2010 12:28:22 PM #

Chrysal, look no farther. The credible source is there - Colin Rose.

Linda 

11/19/2010 12:46:39 PM #

Linda, I trust you are joking 😊. Thanks for the chuckles.

I guess each one is entitled to their opinion, as is CR. I certainly am not seeking his opinions.

Chrysal 

11/19/2010 2:25:42 PM #

Chrysal, your trust is not misplaced. Indeed, I was joking. As everyone is entitled to an opinion and to express that opinion, I believe that each MS sufferer is entitled to seek whatever treatment they believe is appropriate and to make that choice in consultation with a physician who the MS sufferer can trust to provide sound, objective medical advice. I consider myself fortunate to have a family doctor who does exactly that and who does research to ensure that he is providing the advice required. My doctor did research, spoke to colleagues, etc., regarding CCSVI and is very supportive. I am fortunate, others are not so fortunate.

Linda 

11/19/2010 4:32:47 PM #

Linda, I agree with everything you wrote.

I'm so glad that you have such a wonderful physician. I wish there were more like him - will have to keep looking. Take care and keep well.

Chrysal 

11/19/2010 9:07:15 PM #

@ Linda : What would you expect a family doctor to say to a patient if s/he is absolutely convinced that some medically absurd treatment that cost her/him \$many thousands has cured her/him? If the doctor had said "You wasted your money on a hoax" you would probably have found another family doctor. So family doctors and neurologists treating MS patients who are Zamboni zealots have nothing to lose by making nice noises about "CCSVI" that keep those patients happy by "providing the advice required" and keep their real opinion of the scam to themselves. To my knowledge I am the only doctor with the professionalism to write a blog that says what most doctors think of "CCSVI" but won't risk losing patients if they said it publicly. If Zamboni zealots don't like it, too bad. If they want to get stents for their "restenosis" in Costa Rica and bleed to death that's their choice.

Colin Rose 

11/20/2010 12:59:46 AM #

CR, you write so callously of Mahir Motic, the young man who died tragically **BECAUSE he was not able to receive after care for his complications IN CANADA and he was forced to go back to Costa Rica.** You should be ashamed of yourself.

BTW, your blog is not on a professional site such as CTV MedNews Express Blog, is it?

"What most doctors think of CCSVI"...hmmm have you spoken personally with most doctors??"

To MY knowledge, most doctors' hands are tied and their mouths have been gagged by the "powers-that-be", but they will say - off the record - that they entered the medical profession to treat ill patients regardless of their pre-existing condition, and they wish they were not being prevented from doing so. **Why did you enter the medical profession, CR???**

I will not waste any further time reading your comments...not because you do not agree with CCSVI, but because I find it quite disturbing to read the rantings of such a hostile and heartless "physician".

Chrysal 

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