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
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
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Treating CCSVI in MS patients: A reality check

March 05, 2010 06:52 By [Dr. Lorne Brandes](#)

Readers of my postings know that I have followed with interest, and (hopefully) reported objectively, on Dr. Paolo Zamboni's [hypothesis](#) that multiple sclerosis may be triggered by blocked neck or chest veins, resulting in a back-flow of blood into, and leakage from, the brain's venous system, a condition that he has called chronic cerebrospinal insufficiency (CCSVI).

A vascular surgeon by training, Zamboni's CCSVI theory evolved from his years of [research](#) on patients with chronic venous obstruction in the extremities, and the eventual realization that the tissue inflammation and iron deposition he observed in the legs of severely affected individuals was very similar to that reported in the brains of patients with MS.

Although completely "outside the box" of conventional wisdom, the suggestion that MS may have a vascular cause is not incompatible with the widely-held view that it is an autoimmune disorder: in patients with CCSVI, the immune response could be triggered by iron, and possibly, other inflammation-promoting blood constituents that leak from damaged veins into brain tissue.

Zamboni's postulate also jibes remarkably with the decades-old [anatomical](#) finding that MS lesions (or "plaques") tend to cluster along the brain's venous system and usually progress in a "backwards" direction. Indeed, new [MRI](#) studies indicate that most, if not all, MS plaques have a vein in their centre, and contain significant amounts of [iron](#).

Although some critics have suggested that any neck (jugular) or chest (azygous) vein abnormalities may result from, rather than cause, MS, a recent panel of international experts has concluded that the anomalies associated with CCSVI are [congenital](#) in origin, resulting from abnormal development in the fetus. Therefore, while much remains to be learned, it is conceivable that, as has been found in many cases of MS, developmental vein defects could be familial.

Furthermore, while we don't know whether vitamin D plays a role in the normal development of veins, research shows that it is certainly [important](#) for cardiovascular health. Is it not reasonable, therefore, to wonder whether, like MS, abnormal vein development could be more frequent in northern latitudes where pregnant mothers have decreased exposure to sunshine vitamin D? Lots of food for thought here!

Spurred on by excitement over the Zamboni hypothesis, and recent [confirmatory data](#) from the University of Buffalo that blocked neck and chest veins are two to three times more common in patients with MS than normal people, thousands of MS patients, dissatisfied with currently-available immunosuppressive treatment, have asked their neurologists to test them for CCSVI. Based on the reaction of [Winnipeg](#) neurologists, along with what I have gleaned from [online chat groups](#), the response to that request has been overwhelmingly negative. Why? Most neurologists want definite proof that treating CCSVI will help patients with MS before they carry out such investigations.

Patients argue that if their doctors are not at least prepared to test for CCSVI, no progress will be made. It's clearly a catch-22 situation, totally unacceptable to many MS sufferers and their advocates.

One such person is geologist Dr. Ashton Embry, a Canadian MS activist with his own [website](#). Extrapolating from the Buffalo data, which suggested that 80% of patients with progressive MS have venous blockage, Embry has gone so far as to develop and post an "integrated" hypothesis (unproven) that MS is primarily an autoimmune disease but that, when present, CCSVI potentially accelerates its downhill course. Moreover, concerned that time is running out for many patients, especially those with progressive forms of the disease, Embry is [advising](#) them to be tested for CCSVI now and seek treatment if blocked veins are found.

However, before proceeding, I would suggest that Dr. Embry, and those he advises, read a [news report](#), just published in the Annals of Neurology, on [two patients](#) with CCSVI who had what are called serious adverse events (SAEs) following stenting procedures to unblock their veins at California's Stanford University. A stent is a tiny metal mesh tube that is placed in blood vessels to keep them from closing back up again. It's designed to stay in the blood vessel permanently to improve blood flow.

One of the patients, a 51 year-old woman named Holly Shean, had the most serious of all SAEs: she suffered a sudden brain hemorrhage and died a few days after being treated.

While her family has publicly stated that the placement of two stents in her right jugular vein by Dr. Michael Dake, chief of Stanford's Catheterization and Angiography Center, had nothing to do with her death, the article notes that Ms. Shean had been placed on [coumadin](#), a blood thinner, following the procedure (although this is standard practice after [arterial stenting](#), there is much less published literature about the use of coumadin following venous

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stenting). While an autopsy did not reveal an anatomical cause of the hemorrhage, there can be no doubt that being on coumadin following insertion of the stents caused, or contributed to, the fatal bleeding.

The second patient, also treated for CCSVI by Dr. Dake, required open heart surgery after the stent became dislodged from the wall of the vein in the neck and travelled to the right ventricle of his heart.

As a result of these very serious complications, as well as pressure to stop from colleagues, Dr. Dake cancelled all further procedures until an approved clinical trial was in place "sometime in early 2010". However, Paul Costello, a spokesman for Stanford Medical Center, was somewhat less definite, stating, "... Dr. Dake and Stanford have determined that the initiation of a clinical development program leading to a possible clinical trial will be the next step, as we examine the possible risks and benefits of the procedure for patients with multiple sclerosis."

What I believe everyone should focus on here is that two SAEs occurred in a total of only 35 patients in Dake's study. If a highly eminent and qualified expert like Dr. Michael Dake has an almost 6% rate of serious complications associated with treating CCSVI, what would the rate be among vascular surgeons of lesser ability?

But that's not all there is to consider. How many know that fully 50% of patients whose neck veins were "liberated" by Dr. Zamboni suffered a restenosis (recurrent vein blockage) in the first year after the procedure? Dr. Zamboni views that as a real stumbling block; he also feels that stents, in their current form, should not be used. What that tells me is that not even the experts know for sure how to treat the blocked veins, let alone whether the procedure really benefits patients with the disease. After all, placebos are as effective as treatment of any type in one-third of people! That's pretty sobering, isn't it?

Finally, Dr. Zamboni's preliminary human study did not show a benefit of unblocking veins in patients with progressive forms of MS. That is not to say that better-designed, larger studies might not show a benefit, only that there are no current data demonstrating one. From my point of view as an oncologist, once any disease passes a point of "no return", be it cancer or progressive MS, it is unrealistic to think that any therapy, no matter how effective in earlier stages of disease, will help those in advanced stages.


So listen-up Dr. Embry and all those who want immediate action: for the sake of everyone (including me) who hopes that the diagnosis and treatment of CCSVI will be a very important step forward in MS, recognize that the scientific method demands the utmost scrutiny and proper testing of any new hypothesis. As exemplified by the unfortunate Stanford experience, running before we can crawl is more likely to set a good cause back than move it forward.


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Comments

3/5/2010 12:43:20 PM #
 I'm thinking that instead of taking YOUR attitude, that we might just NOT have stents put in or have new improved versions if needed.
 I'll be going ahead with it as I ACTUALLY HAVE MS and live with this degeneration of my body and life every day!!!!
 If you did, YOU would be just as keen on it too methinks - losing your ability to do anything and retain the respect of ignorant people (the majority of the able-bodied population) and continue to live the same full life as you did prior to diagnosis.
 Please reassess your opinion a tad with looking at the situation from another perspective.
 Rachael
 Rachael 

3/5/2010 1:40:44 PM #
 This article reaffirms that the puzzle that is MS, and more specifically the role that CCSVI plays, certainly warrants further thorough and careful study. In order for patients to be able to make informed decisions on what could be life-altering investigations/treatments, all sides of the issue (the good, the bad, and the ugly) must be presented. I would hope that those afflicted with MS would agree.
 Lee 

3/5/2010 2:34:11 PM #
 Lorne, you state, " Is it not reasonable, therefore, to wonder whether, like MS, abnormal vein development could be more frequent in northern latitudes where pregnant mothers have decreased exposure to sunshine vitamin D? Lots of food for thought here! "
 This is the implication of a study recently released from Scotland "Timing of Birth and Risk of Multiple Sclerosis in the Scottish Population" published in European Neurology. This study found that MS patients were much more likely to be born in the spring. Specifically males with MS had 48% more birthdays in April than healthy controls. Vitamin D deficiency in pregnant mothers would explain this, as well as the latitude factor.
 Randall 

3/5/2010 3:57:44 PM #

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 Injury Zamboni

"From my point of view as an oncologist, once any disease passes a point of "no return", be it cancer or progressive MS, it is unrealistic to think that any therapy, no matter how effective in earlier stages of disease, will help those in advanced stages."

And that's exactly why MS patients want to be tested, and if CCSVI is found, treated now. Not all of us have the luxury of waiting 5 or 10 years. For some of us the disease is progressing and it may be too late in 5 years for the treatment to help. Would you tell somebody dying of cancer and for which no current treatments had worked that they shouldn't give some promising new treatment a try? Really? If it were you or somebody you loved? Well, what about somebody who is quickly becoming disabled from MS? I'm an adult. If I want to take a risk with a therapy (as if Tyasabi isn't a risk?) then it should be up to me. I get so tired of the condescension of doctors who think they have to protect me from myself. I may have MS, but I'm perfectly capable of making a rational decision based on my own personal situation and the information before me.

Juli 

3/5/2010 4:54:18 PM #

Everything described is appropriate and logical. However, I am sitting here typing this in my wheelchair, having just gone on long-term disability insurance because I can no longer work. What now? One thing I know, financially this will lower my and my family's standard of living dramatically. The risk/return of proceeding with a CCSVI intervention is a no brainer.

Andrew Katz 

3/5/2010 6:07:17 PM #

I think that we should have the opportunity to decide to get this treatment ourselves. I don't think it should be up to all the skeptical population to use "fear tactics" to stop us from getting CCSVI if we have the opportunity. MS sucks and I for one am willing to get my veins scanned and have the procedure done if stenosis is found.

C Amyotte 

3/5/2010 6:25:29 PM #

Last year when I met my neurologist, we discussed many treatment options. One option was to go to Ottawa and have a bone marrow transplant. As a father of two great children, and a husband to the most wonderful woman in the world, I decided against it when my neurologist informed me that the risk of death is 10-11 %. I decided to start a course of chemotherapy (mitoxantrone) instead, with the unique goal of stopping the progression of my disease. The neurologist told me that I could stave off the wheelchair for up to 10 years with chemo, but that I would eventually progress anyway; it was all a matter of time.

Well, I've already been tested for CCSVI, and found to have a completely blocked right jugular vein. If I have the chance of having the "liberation procedure" and there is only a 6% chance of something to happen to me with something that has not yet been tested and perfected, or a 10-11% chance of death through something that HAS BEEN TESTED.....well, if I take statistics, I'm better off with the stent procedure. Doesn't take a rocket-scientist to figure out that one !

My heart has already been slightly damaged from the chemo, so I'm Poland bound for the surgery. Why would I wait ? I have nothing more to lose....what's the worst thing that could happen....I'll end up in a wheelchair ? Or worse, disabled ? Already there folks.....and as an INFORMED, person, I know the risks. Just like when I decided to do the chemo....I knew the risks, and it damaged my heart function.

I find this article more of the negative propoganda that we are seeing more frequently in the media. This will not sway people into putting off the treatment because we can read through the real intentions of what is being said here. If anything, it is just pushing people to act faster before they totally block all possibility of having this treatment done.

One last point....why would I take advice from an oncologist (cancer doc) on venous problems ? Why would I even go and see a neurologist ? We need to be dealing with interventional radiologists, vascular surgeons, and other people who operate on venous systems..... In the words of Dr. Brian Hardy, an interventional radiologist from Winnipeg, Manitoba, he says about performing the procedure: "« Again, getting back to the basic technique, the basic principal of doing it, we do that, we do it already, we have the capability of it here. It's a question of which patients to do it in, which balloons, etc. Those are all things that we will hopefully get answers for. In principal, to do a jugular vein angioplasty, I do it for other reasons already. So it's not as if we don't know the technique. We are approaching this cautiously to make sure we are doing it for the right reasons, in the right place. »


SO FOLKS, THIS IS ALREADY BEING DONE IN CANADA, JUST NOT ON PEOPLE WITH THE MARK OF THE MS BEAST ! They know the risks already, but pressure from groups of neurologists is being used to scare the ill-informed.

Chris 

3/5/2010 6:52:16 PM #

So, I am going blind, puking, cannot walk very well and you think the less than 1 % chance that the doctor will make a mistake should deter me from having a simple two hour angioplasty operation that requires two stiches

Give me a break. who do you work for Biogen.??

gsandisc@gmail.com 

3/5/2010 7:07:56 PM #

I don't have 5-10 years to wait either, stents aren't what Dr. Zamboni used, he did angioplasty and if my veins are occluded or malformed that it what I will request.

Bridget 

3/5/2010 7:09:48 PM #

The drugs gave me nothing but nearly bankrupted me. The CCSVI treatment offers a chance I am more than willing to take - a simple procedure (no, no surgery is simple) that has helped others like me with MS. I don't have the luxury of time to wait until the drug companies have exhausted their options to block this (they will never exhaust their options because they have MONEY). The procedure should be allowed immediately in Canada. We don't HAVE to opt for the procedure if we don't want it, but if we do want it, we should have it available to us.

If you could imagine the freedom from this broken down body I've been living in for more than 16 years, you'd understand. If any other vein or artery in the body had a blockage or was twisted, there would be something medical done about it. We are asking for no more, neither should we accept less.

Jeanine Baker 

3/5/2010 7:10:55 PM #

interventional radiologists are really the only ones who have the expertise to deal with ccsvi. neurologists are used to owning MS. they need to collaborate. hospital directors need to teach them how to work together for the benefit of MS patients. cardiologists and geologists and oncologists can kibbitz all they want--it's just talk, lets get the experts we need to stop their fighting, kiss and make up. get to work do the science together. we are suffering every day.

carol 

3/5/2010 7:58:12 PM #


I like to hear views from both sides of the fence about CCSVI especially when they are medically sound. I respect Dr. Brandes opinion and after reading this article these are my thoughts: CCSVI is the most promising treatment for MS EVER. We need our health care practitioners, namely interventional radiologists and venous surgeons to start studies on how best to unblock these veins. Another point that nobody has addressed so far is tracking the patients who have had the liberation surgeries. Research for CCSVI is starting to occur all around the world but are we just all duplicating the same studies? I know UBC wants to find and treat blockages as part of their study which I applaud. I still feel that everyone with MS should get scanned ASAP. This way it will be known how many of us actually have the blockages. I was scanned and have an irregularity in my right jugular. I have sent the MRI Institute in Detroit a copy of scans as they will be the world's largest repository of CCSVI MS patient information. If I am told I need stent(s) on March 30 in Poland I will say "GO FOR IT." I understand the risk and am willing to deal with them.

Ginger 

3/5/2010 9:26:53 PM #

"From my point of view as an oncologist, once any disease passes a point of "no return", be it cancer or progressive MS, it is unrealistic to think that any therapy, no matter how effective in earlier stages of disease, will help those in advanced stages."


What an irresponsible statement, comparing cancer to ms is ridiculous. The cause of glial death in MS is unknown, CCSVI offers a theory of cause. Remove the cause of destruction and the body has a chance to heal itself. This should be first and foremost the point of view of any physician. Isn't this the reason tumors are removed?

gwen valentic morrison 

3/5/2010 9:38:12 PM #

i believe, sir, that you are correct. Dr Zamboni's hypothesis is valid and a 6% chance in that small of a study, is NOTHING!!!! When I had chemo, mitrozantrone, i had a higher risk of getting cancer because of this treatment!! And a higher risk of my heart valves not working poperly, just from taking small doses of chemo. That is a treatment that has been around for 20years!!!! what kind of numbers are we going to see when they actually have the MILLIONS of ms patients whom, i believe after test are done, will have a blockage. Now that we know that these blockages are happening, we need to know the proper way to fix it. I have hope again, and I acredit Dr Zamboni with this. Please stop this negative blabber, and let these specialists keep trying to figure out a way to fix our veins...to let us be able to WALK with our loved ones again....to not just sit/lay and watch as other nations bypass our doctors....

can you imagine how much the pharmecudical companies stand to lose? hahaha!!!!!!! as if they really need all the money from us people who are so physically incapable of making a decent wage.....MWHHAHAHA

Kim Janzen 

3/5/2010 9:42:08 PM #

"From my point of view as an oncologist, once any disease passes a point of "no return", be it cancer or progressive MS, it is unrealistic to think that any therapy, no matter how effective in earlier stages of disease, will help those in advanced stages."

This may be true, but considering that it is not known what causes MS progression and what can stop it, this comment is hardly evidence-based. It sounds more like a layman's observation than that of a scientist.

I agree what has been said above. When considering risk-benefit, few, other than patients, take into account the risk of accumulating disability vs the risk of angioplasty. This risk of angioplasty is relatively low, and the potential for benefits looks encouraging, even if they appear minor. Let MS patients decide whether they will accept the risk, including the risk that no benefits will be seen.

Theresa 

3/5/2010 9:56:23 PM #

Oh how quickly you were persuaded... did it take much money to get you to go so far from your previous posts? No worries because I have made up my mind to get tested and, if necessary treated.

I have even sent my neurologist a letter firing him! I wrote this and sent it before I read your mindless blubber. We aren't stupid and not going to be fooled by scare tactics.

This is a copy of the letter:

Dr. M. *****
MS Research Clinic
Ottawa Hospital General Campus
Room 6310, 501 Smyth Rd
Ottawa, ON K1H 8L6

Dear Dr. *****,

Re: Termination of Services

Please regard this as written notice that after much consideration I have decided to terminate our doctor-patient relationship. My decision to remove you as my neurologist has not been taken lightly. It is my opinion that you have failed to adhere to the Hippocratic Oath:

"I swear to fulfill, to the best of my ability and judgment, this covenant: I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow. I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism. I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug. I will not be ashamed to say "I know not," nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery. I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God. I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick. I will prevent disease whenever I can, for prevention is preferable to cure. I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm. If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help".

Or, in simple terms - I will prescribe regimens for the good of my patients according to the best of my ability and my judgment and never do harm to anyone. Although the oath is not a legally binding agreement, it has traditionally directed the actions of doctors for many years.

I feel your cumulative behaviours in my past treatment and your recent decision to withhold your approval and direction for testing of the CCSVI theory violate my rights and also violate the physicians' oath to ethically practice medicine and to keep the good of the patient above all as the highest priority.

It is not possible for individual physicians to maintain expertise in every area of medicine.

Contrary to your opinion, it may be the case that my problem is vascular. There is no way of telling this without "testing". I firmly believe that it is in my best interest that I seek alternate care options that will provide me with optimum care. I wish to pursue this as a vascular issue and be tested by a specialist in that area. Furthermore, I feel it is against my rights for any doctor to withhold the opportunity for the CCSVI testing and treatment. I should not have to "beg" just to be tested. I have the right to be tested in Canada at the closest facility, now.

Based on your recent public actions against the introduction of the CCSVI testing and treatment, it appears that you are unwilling to explore any of the recent studies which lie outside your realm of research (studies which if proved reliable might harm your relationship with pharmaceutical companies). You appear to adamantly oppose suggestions from other legitimate areas of MS research.

Your main focus appears to be on a drug cure for MS which is all well and good but I feel your main focus should be on the patients who come to you for care – for attention to their symptoms, for how current research can be applied to their condition and, if there is nothing at present that would be of help, at the very least for some consideration, compassion, encouragement, regular follow-up and, the most important thing – hope!

If I am tested and it is found that the CCSVI treatment will not help me – WELL AT LEAST I TRIED! I don't think you realize what it is like when your "specialist" takes away what is likely the last "glimmer of hope" I have for possible improvement in my MS condition. When I first began treatment with you, I was under the understanding that you were a leader in multiple sclerosis (MS) research. I completed a reasonably lengthy clinical trial under your care. I duly attended all scheduled procedures and appointments but when my "follow-up" period ended, I suddenly became of no use to you. I was made increasingly more aware of this when our scheduled appointments became vague, repetitive and not "routinely scheduled". There was a definite disinterest on your part when I enquired about other drug treatments and therapies and you showed no interest in guiding me at all.

Following the clinical trial you classified me as a primary progressive MS patient and as a PPMS patient I was left "high & dry" to just slowly progress, without hope. As a PPMS patient I was no longer eligible for future clinical trials and, as I said, no longer useful to you. There was very little interest in following up on my health and my condition.

In January of 2009, I found out that I should have been seen by you 6 months before that time and then it took at least another 8 months to get in to see you. At the appointment prior to January of 2009, I was not told to call and set up a follow-up appointment for a certain length of time - or I would have.

With regard to the current CCSVI possibility many do not accept your clinical trial theories. A significant correlation between CCSVI and MS has been established by other researchers. By accepting clinical trials as a necessity prior to treatment, you are dooming large scale testing for ten years - and then treatment availability for another ten years. That is totally unacceptable!

I fail to see why you are so against the CCSVI testing. The testing and subsequent treatment, if required, are non-invasive and no way near as harmful as the application of some of the drug therapies tried in the past or stem cell treatment. If you can't support the current research I wish you would stop what appears to me to be throwing childish temper tantrums and step aside! The CCSVI testing can be done during the other types of treatment and no-one is recommending that current treatments be stopped while investigating this other hopeful avenue. What is the problem???? "When you are constipated you get a laxative or an enema not a clinical trial".

Through "specialist" designations, and I presume the years of research you and other like-minded doctors put in, you collectively tend to act "god-like" and act as though you "own" my life and my MS. I am not "owned" by anyone and I have a right to request and receive any legitimate non-harmful testing and treatment available even if it is against the current direction of your specific type of medicinal practice.

Denying access to the latest innovative testing and possible treatment is significantly prolonging the suffering of MS patients. It is unconscionable to deny MS sufferers access to testing and, if warranted, such a simple, non-drug treatment.

Currently we are only asking for exploration into the testing for CCSVI and that it is recognized by the healthcare system. This new research and treatment cannot be stopped. MS patients world-wide have spoken out and are being heard. We are human beings, not numbers or statistics, and we deserve to live life to our best advantage – not left to 'just exist'! Many MS sufferers believe that, as in many other cases in today's society, our "illness" and the drug treatment thereof is monetarily worth more to some elements of our society than our health. It is time to look out for the best interests of the public (individuals – you and me) and not the huge corporations.

Thankfully, to live with this disease, a person must be strong and determined. Those same qualities have pushed testing for CCSVI further and faster than if we left it solely up to the medical community.

Although you are indeed a powerful presence in the MS world, it is my very life at stake here and that makes me a lot more determined to be tested for CCSVI and possibly treated.

If you are not willing to reconsider your former position and provide the requisitions and directions for the CCSVI testing for me, then I feel you are not looking out for my best interests and I have no further need of your services and in which case I am hereby cancelling the appointment scheduled for August 16th, 2010 @ 3:00 pm.

Sincerely,

Ms. Christine B*****

CC: Canadian Medical Association
Office of Ethics, Professionalism and International Affairs
1867 Alta Vista Drive
Ottawa ON
K1G 5W8

Christin B. 

3/5/2010 10:00:51 PM #

all you doctors wake up...ccsvi works, once you get over that then we can concentrate on making it work even better.you should count on how many lives you can save and not count on how much money you can make.

tazz 


3/5/2010 10:25:32 PM #

Why why...is it so hard for people to understand the desperate nature of this disease? ... this article is completely void of compassion...." running before we can crawl " .. what were you thinking? We wake up every single morning wondering what the day might bring.. no...we are not uneducated and in need of hand holding.. we are 1.5 million strong and WE are shouting out to you.. THIS MAKES SENSE!!! .. all the symptoms we share that have, in the past, been ignored.. FIT!. the pieces of the puzzle are falling into place..please listen to us... !! CTV was pinnacle in bringing this research to us... please please do not close that door!! Objectivity can be relayed in a much more positive light. Simply pointing out that, yes, there are risks is enough. You might want to check the suicide rate in the MS community and compare this to your 6% math....and why did you not add those liberated elsewhere in this math? I look forward to the day that all this foolishness is behind us and like all those who have already commented.. I too will, not run or crawl, but LEAP at a chance to be liberated!

pCakes 


3/6/2010 12:55:02 AM #

I believe we will need to march on Ottawa and on every capital of every province. We will be heard. We need testing today, all of us suffering from MS. Then treatment. Doctors should be getting training, not doing studies. The proof and "studies" will happen as we are treated. Now that would be cost saving and time saving and producing miracles all at the same time!!!

Bev 


3/6/2010 12:57:26 AM #

Christin B., thank you for sharing your BRILLIANT LETTER!!! Just BRILLIANT!!! Bravo!! You have spoken for ALL of us!!! Thank you again.....b

Bev 

3/6/2010 1:08:18 AM #

Many people with MS are on the Drug Tysabri for MS. 15 people or more have died from a brain infection caused by this drug. People getting stem cell treatment for MS have a 10% chance of dying as a result of the procedure. People with MS are willing to take a risk to stop or slow down the deterioration of this horrible disease. This research is going to take forever because of lack of funds and the turf wars of doctors and the greed of pharmaceutical companies. People with MS don't have the luxury of time. I have read the honesty of the blogs of people who have had the liberation procedure. I spoke with one woman, her double vision went away, her bladder control came back and her fatigue lifted. Her left internal jugular vein was completely blocked by a membrane and her vein was liberated in Poland. The first two symptom changes cannot be described as placebo effects. Neither of the disease modifying drugs that I have been on ever reversed any symptoms.

LW 

3/6/2010 1:42:13 AM #

Recently I have been diagnosed with MS. I was shocked and in disbelief, had a very hard time adjusting to this new reality. Then the anger took over, I spend days and nights researching, studying the symptoms, forms of MS, drugs. Had a visit at the local MS clinic where I spent 6 hours mostly in hallways and waiting rooms to be told that to qualify for treatment I have to have another relapse, to confirm the severity of my case or....??? I was also told I needed MRI which the receptionist was going to arrange for me; have not heard from her yet. It is now 5 months since the diagnosis, and really if not my family doctor, I wouldn't have any help. As I mentioned before, I did lots of MS research and like most of MS-esers discovered Dr. Zamboni and his CCSVI theory. I told my doctor about the "new kid on the block" and supplied her with copies of my research. Having her on my side helped me tremendously, as not only that I felt very louse physically I also was an emotional mess. I knew she was leaving for 2 weeks vacation, but she ensured me if help needed I would be able to see a doctor who will cover her absence. UNFORTUNATELY FOR ME I WENT TO SEE THE "REPLACEMENT". I just found out that False Creek Surgical Clinic will be hosting Dr. Simka from Poland who like Dr. Zamboni specializes in CCSVI and "Liberation Treatment" He was here to observe the Doppler tests done on Canadian patients with MS. I begged the girls at the clinic to give me an appointment on that day (they were just wonderful, sympathetic and kind). The only thing I needed was a referral from my family doctor and a blood test before MRV. Feeling ecstatic I run to my doctor's office for a referral. I was booked with the "replacement" doctor, introduced myself, told her about my condition, asked for the referral; AND TO MY ASTONISHMENT I WAS REFUSED. DR. BEVERLEY LEE-CHAN gave me few very lame excuses like: she is not in a position to supply me with such referral because she was not sure who was going to follow up on the results (da, my family doctor would), and that the facility was a private clinic. She also refused to give me requisition for blood work. The stress was so severe that I got myself the MS Hug, could not bread or move, left the office crying and devastated. My Doppler test day was not going to happen because of a doctor who could not care less about me. I did have my Doppler and MRV only because my family doctor cared enough to help me to speed up the necessary blood test, and gave me the referral to take to the FC clinic on the day of my appointment. I know now that I have problems with my veins and would benefit from the treatment. I don't know when but I will go to Poland to help myself to live a better life. I think my biggest responsibility at the moment is to take care of myself to avoid being a burden on others. My wish is to have the Liberation Treatment done in Canada, but judging the local attitude and the lack of funds it will not happen soon, and I need help now before the life in a wheelchair happens.

Jenna M 

Add comment

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