








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
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
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[Email](#)
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Treating CCSVI: What can we learn from coronary angioplasty?

May 07, 2010 09:02 By [Dr. Lorne Brandes](#)

As I write this blog, hundreds of MS patients have just rallied at legislatures across the country, asking the provinces to pay for immediate CCSVI testing and treatment.

And, in what can only be described as a stunning turnaround from its initial negative response to Dr. Paolo Zamboni's paradigm-shifting hypothesis that multiple sclerosis may be primarily vascular in origin, the Canadian MS Society, supported by the federal Liberal Party, is now lobbying Ottawa for \$10 million to help kick-start CCSVI clinical trials and research. It is a tacit, but welcome, admission that the \$200,000 to be awarded next month to successful applicants in the organization's special CCSVI grant competition falls far short of the mark.

"The MS community has spoken. They want access to diagnostics and treatment for CCSVI in Canada. The MS Society has already committed to funding CCSVI research and now we are calling on the Government of Canada to do its part," commented MS Society board chair, Linda Lumsden.

While lobbying the federal government is not guaranteed to quickly produce results, let alone be successful, I believe I know a groundswell of public support when I see one. So do politicians, bless their hearts. The CCSVI train has definitely left the station, piloted by thousands of brave patients with MS who, enabled by the incredible power of the Internet, have refused to take "no" for an answer.

As all of this unfolds in Canada, a new report from doctors in Jordan has just been published. While their ultrasound tests to assess blood flow in the internal jugular (neck) veins were not blinded to prevent "observer bias", they found that 21 of 25 patients with MS had CCSVI, as compared to none of 25 healthy controls.

Assuming that a highly significant association between CCSVI and MS continues to be shown, let us turn to treatment (happily mentioned in Ms. Lumsden's statement): the procedure of balloon venoplasty is currently thought to be safer than the use of stents to open up narrowed or blocked veins. Although simply a variation of balloon angioplasty, a relatively safe procedure used in hundreds of thousands of patients every year to treat blocked coronary and other arteries, opponents of treating CCSVI outside of clinical trials continue to raise the issue of safety if this method is applied to thin neck veins in MS patients. Are there not bound to be serious adverse events associated with such treatment?

In fact, there is no easy answer to that question. Why not? Because, with the exception of Zamboni's published studies in MS, there appear to be no previous reports, let alone clinical trials, of balloon venoplasty on jugular veins in the entire medical literature! In other words, until Dr. Zamboni linked jugular vein blockage to MS, it seems that nobody paid attention to the existence of "asymptomatic" anomalies in neck veins, much less their treatment.

Then what about angioplasty? Here the literature is very revealing, but in a completely (to me) unanticipated way.

In a comprehensive 1995 review of the subject in the *American Heart Journal*, Mueller and Sanborn wrote: "The history of angioplasty... has been marked by a steady stream of intellectual and technological advances. The promise of non-surgical revascularization has led to unbridled enthusiasm for these devices despite the relative lack of long-term or randomized data on safety and efficacy." [The italics are mine].

Believe it or not, Andreas Gruentzig, the "father" of the modern double-lumen balloon catheter to treat clogged arteries, perfected and made his devices on his kitchen table in 1975. After conducting a few animal and human cadaver experiments, he performed his first coronary angioplasty using a "kitchen catheter" on a living person in 1977!

After presenting the results of his first four angioplasty cases at a meeting of the American Heart Association that same year, it is reported that his colleagues burst into applause, recognizing this breakthrough with a standing ovation. Thereafter, Gruentzig travelled the country, teaching his method to scores of other doctors.

Soon, angioplasty was in widespread use without having gone through (up to that time) a proper clinical trial!

One would have to be forgiven, then, for suggesting that, had Dr. Zamboni made his discovery in 1977, patients with MS likely would have had their "liberation procedure" performed, probably with little or no hesitation, by the eager Gruentzig disciples of that era, and certainly without the stringent time-consuming clinical trials required in the 21st century.

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Am I advocating a return to the past? No. But it is certainly sobering to learn that balloon angioplasty, a highly effective, often life-saving procedure in wide use today, went through considerably less investigation prior to its adoption than Dr. Zamboni's balloon venoplasty for the treatment of CCSVI... an important consideration for those who argue against treating blocked neck veins without years of further study.

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5/7/2010 10:37:35 AM #

Dr. Zamboni's research reminds me of a famous Canadian Doctor, **Sir Fredrick Banting**. In the fall of 1920 Dr. Frederick Banting had an idea that would unlock the mystery of the dreaded diabetes disorder. Before this, for thousands of years, a diabetes diagnosis meant wasting away to a certain death. Working at a University of Toronto laboratory in the very hot summer of 1921 Fred Banting and Charles Best were able to make a pancreatic extract which had anti diabetic characteristics. They were successful in testing their extract on diabetic dogs. Within months Professor J. J. R. MacLeod, who provided the lab space and general scientific direction to Banting and Best, put his entire research team to work on the production and purification of insulin. J.B. Collip joined the team and with his technical expertise the four discoverers were able to purify insulin for use on diabetic patients. The first tests were conducted on Leonard Thompson early in 1922. These were a spectacular success. Word of this spread quickly around the world giving immediate hope to many diabetic persons who were near death. A frenzied quest for insulin followed. Some patients in a diabetic coma made miraculous recoveries. While insulin is not a cure, this medical discovery has and continues to save millions of lives world-wide. The production of insulin has changed a great deal since 1922. Modern science and technology has made high quality insulin and delivery systems available to diabetic persons. When I was reading about Sir Fredrick Banting on the internet I was very intrigued about the following note because it jumped out at me as being so applicable today in our search to solve the mystery of MS. The following represents an entry into Dr. Banting's diary, March 21, 1931: *It occurred to me when we were puffing up the hill and the train was speeding along away below that the engine with all its power could not go up that slushy, soft, snowy road as fast as we could. Power is useless unless directed in the proper channel. People have different powers and the big question in life must be-"Are we on the right road for travel ?" We will certainly not get far in our given time unless we have chosen the road that is fitted to our particular locomotive.* **It took only two years for the discovery of insulin to be used on diabetic patients, why will it take 5 – 10 years to research CCSVI when so many patients, who have already been treated, report improvements?** I truly hope the MS Society will be investing and investigating in this ground breaking research and that vascular doctors and researchers will be supported, in the hopes of discovering if venous insufficiency is part of my MS.

Barb Bridger 

5/7/2010 10:43:28 AM #

The difference is that there is a very clear link between cardiac disease and blocked blood vessels, but that link does not exist between MS and venous blockages. Prelim reports out of Buffalo suggest 2/3 MS pts have blockages (why do the other 1/3 have MS?) and 50% of people without MS have blockages (the prevalence of MS is no where near 50%).

Also, if you read Dr. Zamboni's original studies, lots of questions are raised as to how he came to his conclusions regarding outcomes - how did he establish baselines for relapse rates (seems to be based on patient self-reporting, not to mention significant referral bias), the single physician assessing outcomes was unblinded, etc.

I wonder if you have read the original studies with a critical eye and recognize their deficits, or if you are using W5 for your medical education?

Does this treatment have potential - absolutely! Is it a slam dunk that is worthy of avoiding all the scientific study that we subject modern treatments to in order to ensure safety and efficacy, as well as efficiency in health care? Not so clear.

In the end, would you be willing to treat the thousands of MS pts in the country with a treatment that may prove to be ineffective and/or dangerous, wasting health dollars and possibly increasing morbidity, instead of waiting for the process to proceed in the same manner it does for every other new treatment.

As the King once said, "Only fools rush in..."

neurodoc 

5/7/2010 11:07:33 AM #

Neurodoc, the alternative to NOT fast tracking CCSVI diagnosis and treatment means MS continues to be a billion-dollar drain on the Canadian economy and health care system. People continue with their \$20,000 - \$40,000 per year drug therapies that may or may not slow the progression. Meantime, people with MS diagnosis who have their blocked veins fixed continue to improve and perhaps have a chance to remain, or regain, their independence and productivity. So who's wasting money?

We're not talking about baboon heart transplants here. It's looking at veins, looking at blood flow, and fixing it if it's impaired. If it were any other organ that had refluxing blood due to stenosis, we would not even be having this conversation because it would be a done deal.

MSriotgrl 

5/7/2010 11:31:29 AM #

Watching and hearing the providers egos get in the way is nearly comical. Neurologists claiming these vascular docs don't understand MS is a neurological issue is too common. Talking down to the folks who found this correlatin without vetting their background and body of work is further making the detractors look foolish.

Thanks pfor looking out for us (MS'ers) but please help us be tested to see, on a grand scale--the MS population, if this bears fruit, if it seems to not, then stop, but postponing when folks see hope is not a viable option in these days of the web.

If anyone has a blocked vein, should it be known, evaluated, and fixed? I believe the answer rarely will be no . . .

Roy 

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 Vegetables Veins Venoplasty
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 Times Walking Warfarin Water
 Watson Weight Weight Loss
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 Willow Winter Women Work
 Work-Life Balance Workplace
 Injury Yasmin Zamboni

5/7/2010 12:01:14 PM #

Thanks once again, Dr. Brandes- for your intelligent discussion of the history of angioplasty and how little will really understand about the importance of venous return of the jugular veins. Dr. Dake said the same thing to me and my husband Jeff, after he saw the severe stenosis and malformation of my husband's jugular veins--"I can't believe we've never studied this before!"

As you know, Kuwait has adopted early intervention, due to the advocacy of an interventional radiologist. A curiosity has been why the increase of MS rates in Kuwait. I stumbled on an interesting article this morning, and wanted to bring it to your attention. Obesity rates in Kuwait are now off the charts. My initial theory (which brought me to Stanford and the endothelial researchers there) was that endothelial disruption was contributing to rising rates of MS and autoimmune disease around the globe. Dr. Zamboni's discovery fit into that paradigm, which is how I was put in touch with Dr. Dake. I truly believe endothelial disruptors (saturated fats, low vitamin D, lack of exercise, heavy metals and toxins) are contributing to the nitric oxide disruption and higher levels of C-reactive protein found in those with heart disease AND venous stenosis. We have a world-wide epidemic of vasoconstriction.
<http://www.cnn.com/2010/WORLD/meast/05/06/kuwait.fast.food.obesity/index.html>
 hpt-Mid

I believe there is a strong correlation to stroke, heart disease, and what we are finding in venous stenosis...and it's all in the lining of the blood vessels- the endothelium. Thank you for continuing to make these connections for people. The more doctors that can help explain this paradigm shift, the better!

Joan Beal 

5/7/2010 12:25:46 PM #

For those who insist treat now, worry about the long term effects later, I would like to remind you of the Vioux story (<http://oss.mcgill.ca/everyday/vioux.x.pdf>).

All the proper procedures were followed, large trials instituted, clearance given millions of prescriptions written, then, disaster. Billion dollar lawsuits. "How could this happen?" cried patients and governments.

Now, patients expect physicians to go ahead with an unproven, under-investigated treatment. If it works, Dr. Zamboni is a legend and likely nobel prize winner. If not, who will pay for the poor outcomes. Will patients understand that physicians were forced to procede without the needed evidence by gov't and lobby groups? Not likely. Every physician that performed or recommended the treatment will be sued and cast into ruin. Who would like to volunteer to be in that group?

Remember "cold fusion?" Cover of TIME magazine in the late 80's - our energy needs were solved forever. But wait, no one could get the same results, and here we are 20+ years later and still no cold fusion.

As a physician who treats lots of patients with MS, I am excited about the treatment for the sub-group of MS patients it works on (only helps relapsing remitting in Dr. Zamboni's article) and hope this is the solution to this horrible disease. It could very well be the paradigm shift we need to solve the problem. But, without solid science to back it up, I will not recommend it to my patients.

neurodoc 

5/7/2010 4:51:43 PM #


Your scientific process and desire to study and test this potentially life-saving procedure is time-wasting and pointless. You want to study it, and I want my life back! I say sign me up and I will gladly be a guinea pig for this study! I want to stop feeling electric shocks in my arms and legs, I want to give back my walker that I shouldn't have to use at 43. I want to be able to go back to work and play with my 7 year-old daughter. If it gives me even a few weeks of some semblance of normalcy in my life, I will happily accept any consequences that arise in the future!!!! I have RRMS, so I am in the category that can potentially benefit from this procedure; why can I not have it done if I want it and am willing to sign a waiver absolving anyone other than myself of any blame if anything goes wrong??

MSsufferer 

5/7/2010 5:28:05 PM #

I once again thank you very much for your support in our fight. I am realizing that CCSVI is so much simpler than it is being made out by the Multiple Sclerosis Society. They have NO business to insert themselves to a procedure that like you say has been around for decades. The MSS theories have no credibility any more. I have been misled for 20 years and now I am being DENIED a simple ultrasound to get confirmation of something I KNOW I HAVE. CCSVI is now being proven daily and if you have been diagnosed properly and have the correct test YOU WILL HAVE CCSVI. My body works on my blood circulation. I do not have this luxury that all nay sayers have. I KNOW when I get liberated I will have the tight burning, tingling and needle pins throughout my body gone. Why? Because my body will be getting the correct blood flow that all other non MSers have and take for granted. I know it will relieve my Lymphedema, my bladder and bowel problems and hopefully other symptoms that I am sure you do not want to hear about! The only thing I will not be expecting is to walk again. And I am OK with that. Just to get relief and a better quality of life is all I want.

I do go back and read other comments and for those thumbs down people you have no compassion and you do not have CCSVI. If you are worried that the money you will be paying for this it should not be a concern. If I have to pay to have treatment in Canada I most certainly will pay my share. Not to put the burden on people who do not agree. My choice.

Shirley Renshaw 


5/7/2010 5:29:54 PM #

this is not a drug therefore what clinical trial or research needs to be done? if this wasn't labeled MS NOBODY WOULD CARE !!! it would be a quick and simple angioplasty on your veins and then you get on with life...and neurodoc, shut up we all know who you are and quite frankly you should put your sorry ass in my shoes so i can watch you cry...you have no business spouting your negative misinformed crap at hope. mom used to tell us "if you have nothing good to say dont say anything." stop being a barnacle on the ass of progress...

crazylegs 

5/7/2010 5:30:23 PM #

I wish fools would stop writing about the Buffalo study. It is usually neurologist who quote it. Fact is the numbers from this study are tainted by the use of M.S. patients relatives as the none M.S. people. No wonder veins are blocked! Also , where were these people trained to do the ultra sound test? Italy....I think not. Try again with professionally trained people to do the testing and do not use related people as the none M.S. testing . And finally stop the none sense 100% are stenosis

steve garvie 

5/7/2010 5:40:49 PM #

Dear Dr. Brandes,

Thank you so very much, once again, for your eye-opening blog and for staying with us on the CCSVI. issue We very much appreciate an unbiased medical profession

who cares about us, our health and well-being which is at risk as we continue to fight (with what little energy we have and our wide-ranging disabilities and challenges) for immediate CCSVI testing and treatment here in Canada.

In my nearly 16 years of MS, my own neurologists have constantly warned me about the harmful effects of stress on MS and how they can exacerbate my symptoms - and yet, here we are in a most stressful situation where our right to appropriate health care for a vascular condition is being denied simply because we have MS.

Neurodoc, are you not concerned about protecting your MS patients from having relapses with all the overwhelming stress imposed by "recommendations" that are keeping us from accessing CCSVI testing and treatment here in Canada?

How are you dealing with the following results of solid science? The March 29th report from Stanford studies showed that certain MS drug treatments (which have been dispensed to patients for years!!) were helpful to some MS patients while harmful to other MS patients, actually causing their conditions to worsen.

Clearly, more solid science is needed on this new revelation. More solid science is needed to establish a test that can identify which MS drug treatment will be effective for which patients. So, what are you doing in the meantime? Are you still prescribing these drugs to newly diagnosed patients - not knowing whether they will be helped or harmed? Have you disclosed this information to MS patients already on these drug treatments?

You wrote: "In the end, would you be willing to treat the thousands of MS pts in the country with a treatment that may prove to be ineffective and/or dangerous, wasting health dollars and possibly increasing morbidity, instead of waiting for the process to proceed in the same manner it does for every other new treatment."

Stanford's results have now shown that for years, these drug treatments have now been proven to be "ineffective and/or dangerous to some patients, wasting health dollars...."

Have you prescribed any of these MS drug treatments to MS patients since March 29th, 2010, even though you don't know if the patient will be harmed or helped?

Dr. Brandes, I thank you again, for caring about us MS patients.


God Bless,
Chrystal

Chrystal 

5/7/2010 5:40:49 PM #

Mr/Ms neurodoc

You really don't get it. You have no clue. You have to get some compassion working. This is not new. I have been deceived and now you deny me a simple test. That is what we all want to prove to you that this is not your concern but the Vascular Community expertise. As Steve Garvie said "don't send an electrician to fix a plumbing problem!!". In case you do not know Steve Garvie is, he has been Liberated and his quote hits home in a great way.

Shirley Renshaw 

5/7/2010 6:10:45 PM #

I strongly support the compassionate treatment of CCSVI sufferers now.

Reading the contrary views of Neurodoc, I think there is a basic flaw in his logic. The wait for "more research" alternative he advocates as a no loss approach. This is NOT true, for the people with infirmity and suffering, it represents a great loss including very many lives and the chance of recovery for many more. This is a simple case of risk management and the "treat now" alternative is vastly superior.

Although Neurodoc does not say it, his position sounds like, if I have to do full clinical trials and jump through hoops to prove my new drug treatments, I want CCSVI to suffer the same fate. This does not consider the people who are ones that medical sciences are supposed to be concerned about.

Comparing CCSVI to Merck's VIOXX scandal is ludicrous. Just think about it for a second, enough said. Comparing it to cold fusion is also pretty weak. CCSVI treatment has been replicated hundreds if not thousands of times already with excellent results. That is why people are screaming for it.

Conrad Greer 

5/7/2010 6:17:50 PM #

Steve, these "fools" prefer to spew incorrect information about CCSVI, the Buffalo studies, etc., because that is the only thing that strengthens their weak case.

They obviously lack any conscience - and yet they claim to be protecting MS patients with their recommendations/advice/interference.

It's wonderful to know that there are wonderful, caring doctors like Dr. Brandes, who care not only about patients, but also about accurate information.

Chrystal 

5/7/2010 6:21:54 PM #

Your own words mock you, neuro-doc.

"All the proper procedures were followed, large trials instituted, clearance given..." then, disaster. Billion dollar lawsuits."

So, even if they take your advice and wait 5-10 years for CCSVI treatment trials, there are still possibilities of failure or disappointment. Meanwhile, ten years of further brain damage has occurred for the huge MS patient population which would have had the opportunity for a better quality of life.

"If it works, Dr. Zamboni is a legend and likely nobel prize winner. If not, who will pay for the poor outcomes." I can guarantee you, the line of patients willing to sign a waiver would be long.

Julie Way 

5/7/2010 6:37:19 PM #

Neurodoc

I certainly hope that you know the difference between a drug and a medical procedure? May I assume your caution also applies to the use of all drugs that are used today for Multiple Sclerosis? None of the drugs cure MS. The ones that are not off-label only claim to slow down the progression. My question is if I cannot be told how fast or slow the progression of MS will be - then how can anyone know if it could be slowed down?

I did take avonex for 8 years. I was terribly sick every week. When I progressed anyway to SPMS, I stopped. Side effects of the other drugs that I have taken have also made me terribly sick. I now have days when getting dressed is too overwhelming. Do you really prescribe that I just sit back and wait?

I suggest that you do a little more research, papers have been written on this topic for over 100 years. Dr. Zamboni was now able to have medical equipment that was able to provide some answers to these theories. He did not just pull things out of thin air.

The questions that should be raised today is how can we improve the diagnosis of CCSVI. How can we better treat CCSVI.

At the very least have some compassion and allow me to decide if I want to have a

procedure done that has very little risk and a tremendous potential to improve the quality of my life. And yes, this procedure has helped many with SPMS.

Jane Mescon 

5/7/2010 6:44:44 PM #

Neurodoc, I had an MRV on Tuesday that showed that my left jugular vein is "almost completely closed". Notwithstanding any other health conditions or symptoms I might have, do you recommend that I let that go untreated? Or should I have been denied the MRV in the first place, because then the blockage would not exist?

Charles 

5/7/2010 6:52:15 PM #

If the Neuro's are so concerned about the welfare of MS patients and their care, why are they not lobbying the Government and the College of Physicians and Surgeons to express their desire to do the proper testing. I'm sure every Canadian MS'er would be willing to volunteer for proper testing and if required Angioplast procedure. The Neuro's could follow them for years and report on their finding. Would this not satisfy their quest for proven or unproven results, similar to how they procede with all the drug trials which carry numerous risks.

The Neuro's cannot tell us what causes MS (no one can) and why the symptom's vary from person to person. The MS disease was regarded as the catch all for which they could not explain so maybe we need to redefine the MS disease.

Lets remove the patients that suffer from CCSVI as I believe they have been misdiagnosed by the Neuro's and never did have MS. The CCSVI patients should be referred to Vascular specialist and the Vascular surgeons can determine their best treatment. The remaining patients that do not have CCSVI can stay with the Neuro's and they can continue their research as they always have and hopefully they will get better results with their drug trials with all the CCSVI patients removed. Put your money and concern where your mouth is and allow the Testing to determine once and for all if this is a hoax.

Carol Prest 

5/7/2010 7:09:35 PM #

Neurodoc,
I feel you have quite the ego as a Neurologist. I mean seriously how does your head fit through the door? Maybe it needs to be known then who you really are so that the patients you treat everyday can see your "true" colors. If you were my neuro and I heard you talk like this about CCSVI I would hit you with my cane and never come back (and say oops that was a muscle spasm) Whether or not you think CCSVI works is really irrelevant because we MS'er's are not asking for the Neuros to treat us we want the ones who know how to perform the angioplasty to. Does that hurt your ego? Well too damn bad!
Once again why get an electrician to fix your plumbing problem. So go away and quit pissing on whatever hope we have. This is the first time in my life (19 years) since I was diagnosed with MS at the young age of 18 and I believe we might see the light at the end of a dark tunnel in regards to this awful disease. I have many friends come back from Poland and I have seen for my own eyes how much better they are doing now. So where ever I have to go I will get my life back idiot! Now go crawl back under your rock you crawled out from and quit emailing us on work time!

flygal 

5/7/2010 7:17:17 PM #

When I began doing Inclined Bed Therapy (IBT) 4 months ago it became clear that for me at least the issue is related to kinked veins. In fact, I can diagnose it now myself without the doppler or medical lingo because I can feel it in my body. The kink is most apparent in my right vein that runs from about an inch in from my right ear and down through my back into my lower body. When I lay down on my left side (and only raised with pillows fm my waist up about 45 degrees) I can feel the warmth of blood begin to flow from my right cheek/side of face down into thru my neck down into my right side and somewhat move in towards the middle of my back..... It becomes a visual in my mind "Not" that I am using imagery, but that I am literally seeing the river of my large vein on my right side split off into little streams as the kink is undone when I lie this way.

And: Cog for is now gone - I can see more clearly than I have been able to do in 3 years, my sweat smells differently, I fall asleep within 5 minutes of the set up, etc. etc. It is very much like the post-Zamboni procedure reports I am reading on www.thisisms.com

Just a note 😊 Food for thought,
Yours,
Anne

AnneAnne 


5/7/2010 7:17:54 PM #

I have been suffering with this progression of "MS" for 10 years now. My family lost my sister on Christmas Eve 2009 due to complications of MS... I refuse to end up where my sister did. If this procedure has ANY indications of help I will be the first one in line.

Rachel 

5/7/2010 9:27:14 PM #

The unbridled enthusiasm of multiple sclerosis sufferers for new strongly and reliably efficacious therapies is entirely understandable but needs to be tempered by the unbiased and thoughtful analysis of the evidence by neurologists and researchers. The breathless enthusiasm with which some members of the lay media echo in unfiltered fashion Paolo Zamboni's theories and claims is less excusable, however. It is incumbent on members of the media, who claim to be "medical correspondents", to exercise some degree of judgement and discretion in presenting Paolo Zamboni's claims. I find it somewhat implausible that the thousands of neurologists and researchers who have been investigating the causes and potential treatments of multiple sclerosis, and who have invested tens or hundreds of thousands of person-hours of effort into unlocking the incredibly complex and interrelated autoimmune-genetic-environmental-infectious factors underlying the disease, actually missed out on the fact that it was just some blocked veins under the head that were actually responsible for the disease. Boy oh boy, don't all those people look stupid now? People should be reminded of previous cases where apparently effective therapies for complex diseases (that lack truly effective conventional therapy) which ended up being shown to be ineffective or possibly dangerous. In many of these cases, one or only a few investigators were the pioneers and enthusiastic advocates for the therapies and in all cases these individuals initially presented observational data that was remarkably positive. These therapies include bone marrow transplantation for metastatic breast cancer, bone marrow transplantation for amyloidosis, transmyocardial laser revascularization for refractory angina, Batista procedure (reduction left ventriculoplasty) for dilated cardiomyopathy, lung volume reduction surgery for emphysema. More "fringe" therapies have included Di Bella multitherapy for advanced cancer, sodium bicarbonate infusion for cancer (based on Tullio Simoncini's claim that cancer is caused by a fungus), and chelation therapy for advanced coronary artery disease. The question I would like to pose to the medical community and to the public is the following: Should medical professionals and government agencies allow patients to pursue whatever therapy they want, irrespective of the presence or absence of quality evidence? What if such therapies are later found to actually harm patients? Who would then be held responsible? And, of course, is the government obliged to pay for whatever therapy patients want to pursue, irrespective of the available evidence and the involved costs?
ZJE.

Zoltan Egri 

5/7/2010 9:50:57 PM #

To AnneAnne-

Thank you for the information about your success with IBT (inclined bed therapy). This at least can be a partial fix until the medical community finishes embarassing themselves as they have obviously been doing for decades. But, let's move forward.

In part, I have to support one teeny tiny thing neurodoc has said. Very careful monitoring of this procedure needs to be assured, when it is approved. Funny, how so many things doctors prescribe and implant are not actually FDA approved, but I digress. The fact that Dr. Zamboni is correct on his medical re-discovery brings forth the point that the entire explanation of the MS disease has to be re-evaluated. The medical system has not been aware that MS is a vascular condition (odd since they recognize Alzheimer's and Parkinson's is vascular) so this embarassing moment means they are back at square one. Since neurodoc has suggested that research is necessary before implementation, I wish he could think of at least one meaningful piece of research that he would want. Yeah, he doesn't know of one. That's what I thought. OK, here's one for you. And think hard about this guys, because this should start TODAY. The clinical evaluation of MS, especial new onset and relapse should include a differential diagnosis for cerebral venous thrombus. Well, they never do that do they? However, the CCSVI could be the after effects of a tendency to form blood clots in the venous sytem out of the brain. Did you catch that Dr. Dake at Stanford had a fatal bleed on one of his patients? That's why there was the screeching halt on the procedures. Whoah, a bleed. Could it mean there was a clot up there, and active bleeding process? A platelet propelled coagulopathy? From now on, diffusion wighted MRI to rule out CVT on relapse or active progression. WHETHER OR NOT THERE'S GOING TO BE ANY balloon angioplasty. And while you're at it, might as well learn your platelet cytokines, because they are potent white cell recruiters. Activated platelets are known to be circulating in MS and there have been platelet associated deaths due to thrombocytopenia. Could it have been consumptive thrombocytopenia? The face of MS understanding just changed and the docs have a lot of catching up to do. BTW, in cases of ischemia of the brain, (low blood flow) it is well known that antioxidants are effective in reducing axonal death. Big pharma won't tell you that!!!!

Nanobot 

5/8/2010 9:45:28 AM #

<http://www.facebook.com/#!/group.php?gid=371923465195>

is where we are posting all non pharma methods of relief from ms symptoms...we call it the cosvi society...ms'rs standing together helping each other talking with each other and providing support and encouragement...we know your pain because we have it too. neurodoc feel free to come see how ms'rs want to be treated because your manners and attitude suck towards the people you claim to help.


crazylegs 

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