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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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 All Postings

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 All Postings

RSS Feed

Category list

- ▶ Angela Mulholland's Postings (66)
- ▶ Avis Favaro's Postings (37)
- ▶ Dr. Grant Lum's Postings (14)
- ▶ Dr. Katy Kamkar's Postings (11)
- ▶ Dr. Lorne Brandes' Postings (51)
- ▶ Dr. Marla Shapiro's Postings (130)
- ▶ Dr. Neil Rau's Postings (7)
- ▶ Dr. Yoni Freedhoff's Postings (57)
- ▶ Karen Owen's Postings (18)
- ▶ Marni Kuhlmann's Postings (3)
- ▶ Monica Matys' Postings (49)

Tag cloud

Adhd Aging Aglukkaa Agriculture...  
 Aids Alberta Alcohol Allergies Als...  
 Alzheimer's Disease Alzheimer's...  
 Alzheimer's Disease Amyloid...  
 Anemia Antibacterial Antibiotic...  
 Resistance Antibiotics...  
 Antimicrobial-Resistant Anxiety...  
 Arthritis Asa Aspirin Assault...  
 Asthma Autism Babies Back Back...  
 Pain Backpacks Bacteria...  
 Barbecue Bariatric Surgery Bath...  
 Birth Blood Clots Blood Pressure...  
 Blood Sugar Bmi Bone Cancer...  
 Bones Books Brain Brain Injury...  
 Brca Breakfast Breast Cancer...  
 Caenor Cafeteria Calories...

The science and politics of CCSVI and Multiple Sclerosis

February 12, 2010 08:55 By **Dr. Lorne Brandes**



The headline over the Feb. 10, 2010 news release from the University of Buffalo, "First blinded study of venous insufficiency prevalence in MS shows promising results" seemed straightforward and encouraging. The statement went on to explain that, in the initial phase of the 500-patient trial, ultrasound (Doppler) examinations unequivocally showed narrowed neck or chest veins in 62% of patients with MS compared to 26% of normal volunteers. Complete data on these subjects will be presented at the American Academy of Neurology meeting in April.

Describing himself as "cautiously optimistic and excited", the study's principle investigator, Dr. Robert Zivadinov, went on to say "[the data] show that narrowing of the extracranial veins, at the very least, is an important association in multiple sclerosis."

To most observers, Zivadinov's preliminary results lend a significant degree of credence to Dr. Paolo Zamboni's as-yet unproven hypothesis that multiple sclerosis is primarily a vascular, rather than an auto-immune disease. Zamboni has coined the term CCSVI (chronic cerebrospinal venous insufficiency) to describe the toxic backup and leakage of iron-containing blood into the brain resulting from obstructive vein abnormalities in the neck or chest, that he believes is at the root of MS lesions or "plaques".

Yet, the "spin" on the significance of Zivadinov's findings depends on which news source reported them. For example, *The Globe and Mail* story header read, "Second MS study finds high rate of blocked veins", while that in the *National Post* stated, "Research casts doubt on new MS theory".

Like other major news media, including the BBC, London's *Daily Telegraph*, and the *Canadian Press*, *The Globe and Mail* report, written by Caroline Alphonso, limited itself to a factual report on the Buffalo results, and included comments on the inherent weaknesses in the studies to date.

On the other hand, the *National Post* story, by Tom Blackwell seemed to display a distinctly negative tone. Yet, that should not come as a total surprise as it was consistent with a previous piece Blackwell wrote in the NP, entitled, "Is new MS research the real thing, or a media-driven frenzy?" It was accompanied by an article, "A cure in sight? Not so fast", with the sub-heading "Media coverage reeks of typical hope-mongering", authored by *Financial Post* editor, Terence Corcoran.

What is going on here?

All journalists have their expert "sources". For example, over the years, I have advised CTV's Avis Favaro, among others. Similarly, readers of Tom Blackwell may conclude that one of his expert sources is Dr. Mark Freedman, head of U. of Ottawa's MS program. Dr. Freedman's mainstream orthodoxy in the immunological treatment of MS, and his negative opinion of Dr. Zamboni and CCSVI is well documented. "I think there are going to be millions of dollars spent now to follow a hoax.... If I thought for one instant there was substance to this, I'd be all over it," Freedman told Blackwell in January, before the interim results came out of Buffalo.

And what did Dr. Freedman think of Zivadinov's new findings? Commenting in Blackwell's latest NP story on the Buffalo data showing that abnormal veins were between 2 and 3 times more common in MS patients as compared to the nine-to-one ratio reported by Dr. Zamboni, he stated, "The whole notion of cause and effect is out the window."

Now, this is a free country where Mark Freedman, Tom Blackwell and Terence Corcoran, are entitled to their opinions. But, should not everyone, especially physicians and scientists, maintain an open mind to new and provocative information? As I noted in a previous posting, history provides us with some very sad examples attendant on the reflexive rejection of new ideas without any thought or inquiry as to their validity. Should we not learn from the past? And if we do not, how will progress be made, especially in science and the treatment of disease?

Before giving you my personal thoughts on where we currently stand with CCSVI, it is important to remember that I am an oncologist, not a neurologist, and certainly not an MS expert like Dr. Freedman. However, especially when judging the merit of new theories, sometimes outsiders to a specialty can see the "big picture" with more clarity (and perhaps less bias) than those who are "up close and personal". And as one who, for over 35 years, has been heavily involved in laboratory and clinical research, I believe I know a thing or two about science and (sadly) the politics of science.

First, I continue to believe that the CCSVI theory of MS proposed by Dr.

Multiple Sclerosis

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Month List

- 2010
  - March (2)
  - February (10)
  - January (17)
- 2009
- 2008
- 2007



- [Camping](#) [Canada](#) [Canadian](#)
- [Obesity Network](#) [Cancer](#)
- [Cardiovascular](#) [Cardiovascular](#)
- [Drugs](#) [Cars](#) [Ccsvi](#) [Chemotherapy](#)
- [Chia](#) [Chicken](#) [Children](#)
- [Chiropractic](#) [Cholera](#) [Cholesterol](#)
- [Cold](#) [Colds](#) [Colorectal](#) [Coma](#)
- [Competition](#) [Concussion](#)
- [Consumers](#) [Contest](#)
- [Contraceptives](#) [Coopman](#) [Costs](#)
- [Cyclophosphamide](#) [Daycares](#)
- [Dehydration](#) [Deit](#) [Products](#)
- [Dementia](#) [Dengue](#) [Depression](#)
- [Diabetes](#) [Diagnosis](#) [Diet](#)
- [Dimebon](#) [Disability](#) [Disaster](#)
- [Disease](#) [Divorce](#) [Dna](#) [Doctors](#)
- [Donor](#) [Drugs](#) [Dubai](#) [Ear](#) [Candling](#)
- [Eating](#) [Economy](#) [Emergency](#)
- [Employees](#) [Engagement](#) [Estradiol](#)
- [Estrogen](#) [Exercise](#) [Exercises](#) [Fast](#)
- [Food](#) [Fat](#) [Fat](#) [Tax](#) [Fatigue](#) [Favaro](#)
- [Fingernails](#) [Fire](#) [Fitness](#) [Flu](#) [Flu](#)
- [Shot](#) [Flu](#) [Vaccine](#) [Flumist](#) [Folate](#)
- [Folic Acid](#) [Food](#) [Food](#) [Safety](#) [Food](#)
- [Tax](#) [Fracture](#) [Franklin](#) [Freedhoff](#)
- [Frogs](#) [Genes](#) [Germis](#) [Ginger](#)
- [Glaxosmithkline](#) [Google](#) [Grief](#)
- [H1n1](#) [H1n1](#) [Flu](#) [Haiti](#) [Handshake](#)
- [Handwashing](#) [Happiness](#) [Head](#)
- [Injuries](#) [Headache](#) [Headaches](#)
- [Health](#) [Health](#) [Canada](#) [Health](#) [Care](#)
- [Health](#) [Care](#) [Providers](#) [Healthy](#)
- [Food](#) [Heart](#) [Heart](#) [Disease](#) [Heat](#)
- [Healthcare](#) [Heatstroke](#) [Hedgehog](#)
- [Helmets](#) [Hepatitis](#) [Her2](#) [Herceptin](#)
- [High](#) [Blood](#) [Pressure](#) [Hip](#)
- [Replacement](#) [Hiv](#) [Holidays](#) [Home](#)
- [Birth](#) [Honey](#) [Hormone](#)
- [Replacement](#) [Hospital](#) [Hospitals](#)
- [Hrt](#) [Hypertension](#) [Immunization](#)
- [Infection](#) [Infectious](#) [Disease](#)
- [Infectious](#) [Diseases](#) [Influenza](#)
- [Ingredients](#) [Injuries](#) [Injury](#)
- [Prevention](#) [Insomnia](#) [Intellectual](#)
- [Disability](#) [Internet](#) [Intimacy](#) [Iron](#)
- [Jewish](#) [Job](#) [Security](#) [Juice](#) [Junk](#)
- [Food](#) [Kandel](#) [Kidney](#) [Disease](#)
- [Kidney](#) [Stones](#) [Kidneys](#) [Kids](#)
- [Knee](#) [Knee](#) [Injuries](#) [Knee](#) [Surgery](#)
- [Knees](#) [Lancet](#) [Lawnmower](#)
- [Layoffs](#) [Lead](#) [Leukemia](#) [Liver](#)
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- [Loneliness](#) [Losortan](#) [Lou](#) [Gehrig's](#)
- [Lung](#) [Disease](#) [Lungs](#) [Magnetic](#)
- [Stimulation](#) [Malaria](#) [Malnutrition](#)
- [Mammogram](#) [Mammograms](#)
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- [Medicine](#) [Memory](#) [Menopause](#)
- [Mental](#) [Health](#) [Mental](#) [Illness](#)
- [Mentally](#) [Retarded](#) [Menus](#)
- [Metastasis](#) [Metastasis](#) [Metformin](#)
- [Mice](#) [Microorganisms](#) [Midwife](#)
- [Migraine](#) [Milk](#) [Mmr](#) [Moles](#) [Mri](#)
- [Mrsa](#) [Ms](#) [Ms](#) [Multiple](#) [Sclerosis](#)
- [Ms](#) [Multiples](#) [Sclerosis](#) [Multiple](#)
- [Myeloma](#) [Muscle](#) [Nannies](#) [Natural](#)
- [Health](#) [Products](#) [Directorate](#)
- [Nausea](#) [Newman](#) [Nitrates](#)
- [Nitroglycerine](#) [Nobel](#) [Nurses](#)
- [Obesity](#) [Ontario](#) [Organ](#) [Donation](#)
- [Organ](#) [Donor](#) [Orthopaedic](#)
- [Osteoporosis](#) [Outbreak](#) [Ovarian](#)
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- [Pandemic](#) [Parents](#) [Parp](#) [Inhibitor](#)
- [Patients](#) [Pesticides](#) [Pertussis](#)
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- [Pharmacies](#) [Pharmacists](#) [Phelps](#)
- [Physical](#) [Plumpped](#) [Pollution](#) [Post](#)
- [Traumatic](#) [Stress](#) [Disorder](#) [Poverty](#)
- [Pregnancy](#) [Pregnant](#) [Prenarin](#)
- [Prescription](#) [Prescriptions](#) [Prices](#)
- [Procrastination](#) [Progestins](#)
- [Prostate](#) [Prostate](#) [Cancer](#)
- [Prosthetics](#) [Psa](#) [Psychiatric](#)
- [Disorder](#) [Psychiatry](#) [Psychology](#)
- [Ptsd](#) [Puttilitary](#) [Quarantine](#)
- [Radiation](#) [Recession](#) [Rehab](#)
- [Research](#) [Restaurants](#) [Rethink](#)
- [Breast](#) [Cancer](#) [Ribavirin](#) [Sad](#)
- [Safety](#) [Salba](#) [Salmonella](#) [Salt](#)
- [Sars](#) [School](#) [Schools](#) [Screening](#)
- [Seniors](#) [Sex](#) [Sexual](#) [Health](#)
- [Showers](#) [Skiing](#) [Skin](#) [Skin](#) [Cancer](#)
- [Sleep](#) [Smog](#) [Smoking](#) [Sodium](#)
- [Soft](#) [Drinks](#) [Soium](#) [Spice](#) [Sports](#)
- [Statins](#) [Stem](#) [Cells](#) [Stigma](#) [Stress](#)
- [Stroke](#) [Studies](#) [Suburbs](#) [Sugar](#)
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Zamboni is scientifically plausible and deserving of serious and intensive investigation. Those health professionals, and others who, for whatever reason, remain in denial should get over it and commit to finding the answer rather than obstructing progress.

Second, I believe that the preliminary findings of Dr. Zivadinov and his colleagues in Buffalo are significant and support a link between MS and CCSVI. However, their early data are not as robust as Dr. Zamboni's and their study raises many new questions. For example, what is the true incidence of vein abnormalities in MS patients and normal controls? Does MS only occur or progress in people with more severe types of venous obstruction?

While we do not yet know, it is important to understand that Dr. Zamboni used both ultrasound and the direct injection of dye into veins (called venography) to obtain his results. The first phase of the Buffalo study employed only ultrasound. Of the two tests, venography is more sensitive and definitive in demonstrating anatomical abnormalities and blockage in veins, akin to angiograms being the "gold standard" in diagnosing coronary artery disease in the heart. In acknowledging this important difference, Dr. Zivadinov has **stated** that more "advanced diagnostic tools" (including, I suspect, venography) will be used to test the next 500 subjects in his study.

Finally, taking into account Dr. Zamboni's preliminary results, there is no "level 1" evidence that unblocking veins is an effective treatment for any type of MS. As Paolo Zamboni himself has stated, the answer to that most important question will require further independent assessment and will take time, probably 3 to 5 years at a minimum, to answer. Until then, I strongly advise that patients wishing to have their veins tested, and an unblocking procedure performed, should do so only in approved clinical trials that are properly designed to insure their safety and provide an accurate assessment of efficacy.

In this respect, Canadian MS patients are especially fortunate that centres at McMaster and UBC already have teams of neurologists, radiologists and vascular surgeons who are committed to carrying out these complex studies. While they have our thanks and best wishes for success, they also desperately need our **donations**. Please be generous and help if you can.

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### Comments

2/12/2010 6:04:37 PM #

Dr. Brandes Thank you for your support in this area (why I don't know CCSVI should be treated as controversial) We Ms'ers are on an uphill battle and why should that be when the most revolutionary possible research in 70 years for MS has to be fought tooth and nail with our MS Societies in various provinces. They decide to offer \$100,000 for ... See Moredresearch when I see places around the world offering MILLIONS to aid in this breakthrough research. Your Network and Reporters have contributed more in my opinion than our MS Society for which we volunteer our time to help in Walks Bike rides, Various fund raising activities. You are right as this has now become a political fight and should the science and Doctor Zamboni's not be in the headlines. I went to my local chapter this morning and there is nothing they could provide me on CCSVI in print all they could do was refer me to the internet or their Toronto Office.

Places like Poland and Bulgaria are taking the lead on CCSVI and people are running to these countries to spend their hard earned money to be Liberated of this crippling disease and all our Ms Society can hand over is \$100,000. To me as an MS patient that has contributed to the MS Society of Canada, this hurts and I applaud You and Avis Favro and all other health professionals for sticking up for us. Thank you.  
 Jamie

Jamie Chalmers

2/13/2010 6:05:40 AM #

Thank you so much for being open and fair in your article/blog. My focus for my MS is to have my Azygos vein investigated and I noticed there isnt as much focus on this thoracic vein drainage stenosis as there is on the jugular investigations. ALL my MS legions and nerve plaques are along the T zone of my spine and NONE on my brain whatsoever. So, I feel I am justified in thinking my Azygos vein is severely compromised. Who will test this for me here in Australia? Probably nobody. I am tired of the severe spasms and am on a waiting list to get Intrathecal baclofen pump - YES, it's come to that! medications dont work and I cannot sleep. If someone could help me or guide me to getting my azygos vein tested and opened/liberated in a trial setting here in Australia, i PLEAD you to help steer me in that direction. Limited funds but i'll take out a loan, i've had enough. i dont expect to walk anymore, just need urgent help with spasms.

Friday

2/13/2010 8:51:21 AM #

My focus for MS is to have my neck veins and Azygos veins scanned. Having this for 14 years and know that opening the jugular veins as well the azygos vein can give me a better quality of life. Yes, there May BE complications along the way, I'm ready to take that chance. This is Canada where casution is taken no matter what. Like the comment before me I want this treatment now. I can't wait two years for the studies to end only to be told it's ok. I've never had pain, incontnence or fatigue that others talk about. I simply can't walk but have pins & needles and inflammation in my lower limbs for 14 years what is that if it isn't poor blood fow. My family is as excited as I am.. Please help me.

Geraldine Murphy

2/13/2010 11:11:12 AM #

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The number of Buffalo are not well presented, they did took in their experience people with not definite diagnosis... so if we count only people with definite MS the number are much the same than the Zamboni one's .... it is 80 % .  
80% of the people with a definite diagnosis of ms did have pathological veins.

Barbara Gagne 

2/13/2010 8:39:23 PM #

I have been tested 2 times and yes the correct way, which if I hear one more time are you sure I think I will scream. I do not have any stenosed veins at all. The numbers in the Buffalo study do speak in favor of not all MS patients have stenosed veins, which leads me to believe the stenosed veins are a result of MS and not the cause of MS. I say this because I an newly diagnosed and again, yes I was tested for Lupus, Lyme's Disease and every other gosh darn disease under the sun. Also, what about the 25% of patients who had stenosed veins and did not have MS, when I think of this I have to say that stenosed veins are neither the cause or effect of MS. I guess in 3 to 5 years someone will really know and I would actually like a big name university such as Harvard, UPenn, Mayo, or Johns Hopkins to be active in this study, this is the only way it will be heard full force in the US media. Because big name universities are not involved it leads me to believe that they don't feel this is credible, but again as I said, only time will tell.

Rather Not Say 

2/13/2010 8:49:02 PM #

The Buffalo study did not appear to address any imaging of the Azygos vein. I want to know: In the patients Zamboni studied, what was the ratio of CCSVI found in the Internal Jugular Veins (IJV) vs. the Azygous (AZY) vein?

I wondered if this might account for some of the "discrepancy" between the 90% ratio from Dr. Zamboni's initial study, vs the 55% found in the Buffalo study. It seems to me that stenosis in the AZY would be a critical factor (my MS was diagnosed on the basis of spinal lesions). How do we know that one third of MS patients don't have AZY stenosis? If that were true, then the numbers could end up being very similar.

Freedman et al seem to criticise lack of data in Zamboni's small "un" controlled study, but sure have jumped all over the preliminary Buffalo data, where there is still so much more analysis of the data required! They are happy spending millions to do risky immune system re-boots in a study of only a dozen patients, but only want to offer a couple hundred thousand for CCSVI studies. Come on... a > 50% association between CCSVI and MS shows a VERY significant association, let's spend some money and figure out WHY!

PS: To Dr. Brandes and CTV, thank you for adding a "rational" voice to this discussion!

James Mossman 

2/13/2010 10:56:40 PM #

I primarily want to offer my thanks. So thank you for your words.

I too do not understand why researching this is a problem. I do not believe that pharmaceutical companies could influence to this extent as I get the feeling that professional snobbery is at work here.

I live in the UK where we are having to campaign to even get research done here.

I would like to see the results from Poland, are these published/available?

Jarrold Robinson 

2/14/2010 12:21:06 AM #

When I saw the W5 program about Zamboni, I got my church group praying and went looking for someone to treat my wife of 34 years. Thankfully Dr. Simka of Poland offered to treat her and on December 29, 2009 she had her left jugular vein unblocked. Since then she is like a new person, no more double vision, no blurred vision, full bladder control, no more extreme tiredness. All the folks urging caution, more study, not proven etc. none of them suffer from MS but all of them directly live off the suffering of MS patients. When my wife's suffering is at stake or the caregivers' pocket book, it seems that pocket book talks. Besides the financial downside, the decades spent in futile research must also impact the ego. Of course this is nothing new. When Jesus gave the blind man back his sight the Pharisees were not overjoyed either. It is unfortunate that we can not be masters of our own health management and we have to head to Poland and Cuba to get treatments that are available locally. MS patients are being victimized by the MS establishments. We need to unite and remove the control that these people have over our lives.

Steven Simonyi-Gindele 

2/14/2010 1:01:12 AM #

Its a great discovery, all thanks to Dr. Zamboni for his wonderful efforts, we need to utilise his efforts positively and leave the one aside who are critique to his findings (MS society and neuro's). Anyway this is gathering momentum, people dont agree to this findings sooner or later will come to terms with it.

Three cheers for Dr. Zamboni.....Sunny

Manoj Agrawal 

2/14/2010 1:32:42 AM #

I echo Jamie Chalmers thoughts above.  
Thank you CTV for being on the story.

Michelle Pearson 

2/14/2010 1:20:25 PM #

Thank you CTV -- and to all others pursuing CCSVI and its treatment.

M. Addison 

2/14/2010 2:42:28 PM #

I was diagnoses with MS in 2005, and am a second generation individual with MS (my maternal grandmother also had it), so I have been watching research into MS with interest for 30 years. I'm hopeful that CCSVI will bring some relief to the many symptoms I suffer, but am concerned about the treatment methods. Is there any chance that the narrowing of the jugular views is a natural defence against MS by restricting the blood flow into the central nervous system..albeit a poor one. Is there any chance that by opening the veins up through stents may lead to a faster progression of MS or the shift from RRMS to SPMS be accelerated? Is there a possibility that the jugular veins may be weak and unable to support normal blood flows and may rupture a few years after the stent procedure? I look forward to some real science being bought to this terrible illness on this issue and hope that at some point in the next 5-10 years a new treatment method arise as a result.

Peter Tutty 

2/14/2010 2:58:32 PM #

Don't under estimate the power of the Pharmaceutical companies, most (maybe all) are heavily funded by the Pharma's and some of the Neurologists with in the MS Clinics are actual paid consultants for these companies to promote their drugs relating to MS. If it is proven to be a vascular issue (not neuro) then MS patients will have no need for the current

structure of the MS Clinics, but rather will be patients of Vascular surgeons. This will not be taken lightly...I think this is the big story and maybe worthy of media attention to expose this road block.

Carol Prest 

2/14/2010 10:39:36 PM #

Dr. Brandes, thank you so very much for addressing the "politics of science" issue and for writing in support of the "CCSVI in MS" theory receiving due consideration with full and proper investigation. Thank you also for challenging the callous and biased media and neurologists who are trying to brush this theory aside at such an early stage.

I am so grateful to CTV and W5 reporters for bringing to light a discovery that the world (and certainly Canada, with one of the highest rates of MS) needed and had every right to hear about. Surely our MS Clinics and advocate agencies are members of the various international MS Consortiums and attend Conferences, etc...did they not hear of Dr. Zamboni's theory 3 years ago when he first invited the medical community to join him in his research?

If these groups were unaware, why? Why were they and their people not hearing rumblings of any and all possible theories about MS right from the beginning - or at least at some point in the last 3+ years? Maybe all this current uproar could have taken place years before, followed by research and studies running concurrently with Dr. Zamboni's research and studies into the "CCSVI in MS" theory...and we would have had a more timely and conclusive answer as to whether or not this theory is unfounded and whether or not the liberation procedure is a valid treatment. Time is not on an MS patient's side. Thank God that Dr. Haacke was aware - and has been working to help CCSVI studies move forward. Hopefully other specialists will remember their conscience and their calling, and join in the work to resolve this issue one way or another in an honest and unbiased way.

No stone should be left unturned. Any and all plausible theories and procedures should be investigated fully. As much as I would caution fellow MSers not to rush for any treatment/procedure until it has been studied and improved, living with an illness that has already taken so much from me, I cannot fault any patient that has gone ahead and had the procedure. I definitely would not tell patients to hold off in getting tested for vein blockages.

Over the years, we have heard other theories bandied about but never had the same gut reaction to them as we did to this theory. We are not gullible simpletons as implied in NP articles. We haven't dug deep into our pockets to purchase the miraculous magnets, potions, juices, etc. that have been dangled before our eyes. Why, some of us have even resisted the obscenely-expensive drug treatments dangled before our eyes by specialists, when our own research determined the drug could cause us more harm than good (as others had experienced), would not help our current symptoms, and didn't come with any guarantees.

As we listened and watched the W5 story unfold, what we heard made so much sense and we felt in our hearts that this was an answer that MSers and our loved ones have been praying for. It may not be "the" answer, but it certainly appears to be "an" answer with significant effects.

All that MS patients want is for this new discovery to be given full airing in order to ascertain its merits, rather than being ruled out at the very outset. We are prepared for science to either support or refute Dr. Zamboni's findings - that is why we want proper testing soon.

What we don't ever want is suppression and ridiculing of theories/discoveries before they have even been accurately investigated (with proper equipment, methods and protocols) and given due consideration. Who knows how important they may prove to be (to any degree) in solving the MS puzzle?

Chrystal Gomes 

2/16/2010 4:05:38 PM #

i just recieved a phone call informing me that our community access center will be going through some cut backs on funding. my wife has MS so this is a concern of coarse. i don't understand how we can fund a was in Atganistan, cancel parliament, help other countries and yet cut funding to our own people. this is a scar on our country. we say we are a country with one of the best health systems. i very much appreciate the help we have gotten but when we start cutting funds to our own poor and or feeble how can we be an example of a caring nation. i am not here to argue the politics. i am just a retired steel worker so i don't have the education to do so, but i see what i see, please forgive any errs in my spelling or grammer. thankyou for taking the time to read this

paulmacdonald 

2/25/2010 4:27:09 PM #

wether ms is caused by blockage of the veins or the blockage is caused by ms why would you not just clear them anyway

paulmacdonald 

2/26/2010 2:52:05 PM #

I have always been curious about functionality in websites and, well, the world in general. I read this article with great interest. It does seem to me that the reason we comment is to speak our minds so why not have the comment field first? However, as others have pointed out, one gets used to the conventions regardless of reason.

<a href="http://www.onlineuniversalwork.com">home programe </a>

jacob 

2/27/2010 8:52:09 AM #

CTV NEWS ARE A VERY HONEST, INFORMATIVE AND WELL RESEARCHED MEDIA. I FIRST HEARD ABOUT THIS TREATMENT THROUGH THEM. GREATEST THANKS. I HAVE HAD PPMS FOR NEARLY THIRTY YEARS. I HAVE HAD KNOW HOPE UNTIL NOW. BASICALLY THEY ARE TRYING TO TREAT THIS LIKE A WITCH DOCTOR FALLACY AND BASH IT DOWN AT EVERY TURN. LATELY I HAVE DONE NOTHING BUT RESEARCH ON THE INTERNET. IN THE U.S. IN 2007 8.2 BILLION WAS SPENT ON M.S. DRUGS. PHARMACEUTICAL COMPANIES MAKE SO MUCH MONEY ON US THEY WOULD RATHER JUST TREAT OUR SYMPTOMS IT IS SO PROFITABLE FOR THEM. A CURE WOULD BE CATASTROPHIC TO THEM. I BET IF 1000S OF MS SUFFERERS WERE TESTED AND THE COMPLETE TEST DOPPLER AND MRV WHICH BUFFALO DID NOT DO THE RESULTS WOULD BE ASTOUNDING. NATURALLY THIS IS UNLIKELY TO HAPPEN. I MYSELF AM GOING TO BULGARIA IN JUNE OR JULY. WE MSERS DO NOT HAVE THE BENEFIT OF YEARS OF RESEARCH TO SATISFY A MONETARILY CONTROLLED SOCIETY. WHY IS IT ALSO THAT A DRUG THAT CAUSES BRAIN INFECTIONS AND EVEN DEATHS. APARENTLY THAT IS LOW ENOUGH OF A PERCENTAGE TO ALLOW IT TO STILL BE MARKETED STILL BEING PUSHED. NATURALLY MONEY IS THE BOTTOM LINE.

HERE IS A LINK I HAVE FOUND FOR MS TESTS AND TREATMENTS IN THE WORLD  
<http://multiplesclerosisurgery.com/where-tested-ccsvi.html>

THANK HEAVENS FOR GOOD, HONEST, INVESTIGATIVE JOURNALISM

PLEASE PARDON CAPS IT IS HARD TYPING WITH ONE FINGER

JAYNE SPENCER=HILL 

3/4/2010 8:21:32 AM #

I agree with Paul MacDonald, whether or not a person has M.S. surely anyone with blocked veins should have treatment. Because we are labelled, is this why we get ignored and left to get on with it.

The sooner the U.K. gets its act together, the better. Awaiting results from other countries does not tell me if my veins are blocked, but does tell those who are tested. Common sense, don't you think.

I too don't want to have to wait a few years down the line and be told yes that is why you have M.S. I so want my health and strength back, and to be able to take my 20 month old grandson by the hand and take him for a walk. Not much to ask is it, better than winning the lottery

Linda Davies 

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