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News Sections

- Top Stories
- Canada
- World
- Entertainment
- Sports
- Business
- Sci-Tech
- Health
- Politics
- Weather

News Programs

- CTV National News with Lloyd Robertson
- Canada AM
- W5
- Power Play
- Question Period

Features

- Autos
- Consumer

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- Galleries
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Home : Top Stories : Clinic to test for controversial condition linked to MS

Clinic to test for controversial condition linked to MS



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CTV.ca News Staff
Date: Mon. Feb. 8 2010 9:39 PM ET

One of the first clinics in North America devoted to testing for a vascular condition that some experts believe is linked to multiple sclerosis is set to open later this month in Buffalo, just as scientists are to release more findings on the controversial theory.

The Buffalo Neuroimaging Analysis Center (BNAC) has announced that it will begin to offer testing for the newly discovered condition, called chronic cerebro-spinal venous insufficiency (CCSVI), in mid-February due to overwhelming demand from MS patients.

Italian scientist Dr. Paolo Zamboni believes that CCSVI causes veins in the neck and upper chest to twist, narrow or become blocked; in some cases, these veins never form at all. The result is poor blood drainage from the brain.

Zamboni has found that more than 90 per cent of patients with MS have these malformed veins, and improper blood flow from the brain.

Due to the overwhelming response to Zamboni's research and to its own study on the condition, the BNAC said it will begin offering diagnostic venous testing to patients beginning in mid-February 2010.

Testing will include:

- An MRI of the brain to measure the level of iron deposits
- An MRI of the neck to study the jugular, vertebral and other collateral veins
- A Doppler exam of the head and neck to determine blood flow
- A follow-up visit with a doctor to discuss the findings

News of the clinic opening comes days before scientists from the BNAC release data from their study that includes 500 MS patients who were tested for CCSVI.

"What I can tell you today is that the preliminary results are exciting scientifically and will generate a great deal of discussion among our colleagues, the worldwide press, and individuals like you who are following very closely any developments about CCSVI," Dr. Robert Zivadinov said in the BNAC newsletter.

Zivadinov said the second phase of the study will include another 500 patients and will "pose new and provocative questions about the CCSVI theory."

Scientist welcomes scepticism

Zamboni told CTV's Canada AM Monday that he welcomes skepticism about his findings.

"This is normal when there is a new finding in science," Zamboni said. "I think that this is positive because it stimulates debate."

Zamboni was in Hamilton, Ont., Sunday for a scientific workshop looking into the relationship between MS and CCSVI. Scientists from the United States, Europe and the Middle East reported that they had found CCSVI in more than 95 per cent of MS patients.

"The meeting yesterday was quite successful because we met a lot of colleagues from all

CTV News Video

CTV National News: Avis Favaro on the meeting
Scientists from around the world met in Hamilton, Ont., over the weekend to discuss the latest research and to launch new studies in the fight against Multiple Sclerosis. CTV National News: Avis Favaro on the meeting

Canada AM: Dr. Paolo Zamboni, medical professor
An Italian medical professor discusses his groundbreaking medical theory and procedure that could potentially cure patients who suffer from Multiple Sclerosis.

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over the world that are actually working on our theory," said Zamboni, who is a professor of medicine at the University of Ferrara in Italy.

According to Zamboni, a surgical procedure to restore proper blood flow, which he dubbed the "Liberation treatment," can reduce MS symptoms.

In a study of 65 patients who underwent the procedure, released in the *Journal of Vascular Surgery*, Zamboni says that 50 per cent of patients with the most common form of MS were relapse-free for at least 18 months. In a control group of MS patients who did not undergo the procedure, only 27 per cent went 18 months without an MS attack. Additionally, only 12 per cent of patients in the surgery group had brain lesions -- a sign of active disease -- compared to 50 per cent in the control group.

Research will take time

Dr. Mark Haacke, director of the imaging division in the school of biomedical engineering at McMaster University, organized the weekend conference and said "no one is claiming it's a cure."

"It's a cardiovascular problem first, it may be related to MS, it may cause MS -- but we don't know all those answers yet," he told CTV.ca. "That's going to take time to do very careful research to evaluate those MS patients that do get the operation."

"Do they get better? Do they stay the same? Do their lesions go away? Or do they at least not get worse. (It) may take years and years to really determine the effectiveness of this surgery."

MS societies around the world have responded with funding for research into CCSVI. The Italian Multiple Sclerosis Foundation has allocated up to \$4.5 million for research and the MS Society of Canada has called for applications for grants for those studying Zamboni's findings.

Charity Intelligence Canada, a group that provides donors with research and information, called for additional research and funding into Zamboni's findings on Monday. The group said Canadians donated \$62 million to MS-related charities in 2009, and said "supporting CCSVI research presents an opportunity for donors to have high impact in their giving."

"Donors wanting to support CCSVI research in Canada should donate directly to St. Joseph's Healthcare and McMaster University in Hamilton, Ontario and University of British Columbia, designating their donations to CCSVI research," the group said in a statement.

However, experts have warned that the findings are far from being validated and those with MS should continue with their current treatment.

"Although the early data are of great interest, it is important to acknowledge that the concept of CCSVI as a cause of MS and the use of stents or balloons to widen veins as treatments, are ideas that are far from being accepted by most researchers in the field," the MS Society of Canada says on its website.

Experts have expressed concern that the initial excitement over the new procedure was leading some to drop their current treatment.

"To people with MS we say: don't abandon the course of treatment that you have started," Yves Savoie, the president and CEO of the MS Society of Canada told CTV News in November.

"Those treatments have been proven in large trials to be effective in reducing the burden of disability that comes with MS."

Haacke says that since most MS patients have MR scans performed, clinicians should consider performing additional scans for CCSVI.

"It's important for clinicians to begin to realize that they should be taking some time clinically -- not on the research side -- to scan their patients and find out if this is a problem," he said.

Canada has one of the highest rates of MS in the world, affecting between 44,000 to 78,000 in the country.

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Betty Ann Vivian said
This is great for all of us! Great except us stay at homes because we are so limited! All funding should go to this as imagine how much money governments could save. Take care and get us well! Betty Ann from North Vancouver

Vancouver, BC said
I have MS and have been on a new treatment for MS (Fingolimod). I have shown good improvement (rather than decline) on this new drug that is soon to file for approval in the US. However, fatigue continues to be a factor. I think that this shows that the immune system is a factor in MS. However, I think there is also something to the veinous theory. Somehow, I think the two are linked, and one might feed off of the other. We don't yet know for sure what the cause is, but any insight helps. There are other quite certain things which need to be examined which need to be explained, such as the environmental factors, such as the link between lack of Vitamin D in the early years of life and MS. Could the lack of vitamin D also affect formation of veins? I am not a doctor, but everyone should keep an open mind. What I want to say is that we should not take the either/or approach of MS being an autoimmune disease vs. a veinous symptom. It could be both/and plus maybe even other factors. I am encouraged by the veinous theory-- it would be very nice to get my energy back. By the way, I am big on on how serotonin affects the brain and MS. I read yesterday that eating nuts before bedtime helps with sleep disturbance because it helps in the production of serotonin (often a very low levels in people with MS). Low serotonin levels have also been linked to MS. After eating nuts before going to sleep, I had my best sleep in a long time, and I have more energy too. Best of wishes, Vancouver

Stan Bailey said	I watched the program on CTV back in November last year with great interest. This doctor had great personal motivation to think "outside the box" and did so, with results that are quite obvious to anyone who watched the program . I would dare say that there are people and companies with vested interests in research and drugs that would not be impressed by an effective, inexpensive treatment, with a procedure that could be performed in just about any hospital, and giving very good results to boot. It would make some very highly "qualified " people look ...well really bad.
Michelle said	As a person who has lived with MS all her life (mother has it) and who also has MS, am in the secondary progressive stage , which means very little treatments available. I think this is a great "breakthrough" in MS research and could provide results to help those who are newly diagnosed or still in the early stage(s) of this chronic disease. As I'm in the later stage of this disease I am still willing to help in any kind of research that may be done for this , especially if the results can help someone else or for the researchers to determine which stage it would be beneficial to. The Dr's I have spoken with have all had mixed reactions to this procedure that Dr. Zamboni has found, which bothers me as I thought that they would keep an open mind about learning about something new. I've always been told that a Dr. never stops learning after he's/she's left medical school , so why is this so different? From Petawawa
Geraldine murphy said	In my 14 years of hoping that I could wake up to something that made a lot of sense about a treatment for MS, finally that time is now. If this gives a better quality of life to those who have already had the treatment, then it can do the same for others. I also have a sister with chronic progressive and much worse than mine. That is my hope that we can both be treated with success and get to enjoy the life we once had.
Dale Woolsey said	I agree whole heartedly with Stan's comments. As a person with PPMS diagnosed in 1985, I have followed all MS Society news and research on MS while donating hundreds of dollars over the years & seeing no progress in treatment for my type of MS. Dr. Zamboni has found what I & many other MS sufferers believe to be the most likely contributor to the excess iron in the brain causing the CNS to attack itself. There are drug companies with a vested interest definitely not wanting Dr. Zamboni's theory proven correct.
Colin Rose said	Zamboni is not a scientist. He is a varicose vein surgeon who tried to apply what he knows about veins to his wife's MS. What he does is not science. He only welcomes skepticism from real scientists because it legitimizes his creation.
Allan in Healthcare said	Skepticism is healthy, and even though I very much hope that this treatment yields results I'm worried about people jumping on the bandwagon too enthusiastically. As for funding, this research could end up as a treatment, or it could end up as a dead-end, wasting time and money that could have gone to other research projects looking for other treatments. Potentially worst of all is that so many people affected by MS are desperately seeking a cure, and overhyping this research as some sort of miracle cure could get many vulnerable people's hopes up. Let's go slow, steady, and scientific.
Nancy in Saskatchewan said	My husband is 39 yrs old and has MS. We too, watched Dr. Zamboni's interview with CTV and while we have had our fair share of "ups & downs" with this disease in the past few years, I definitely have to say that day in November was by far our "highest up!" If this procedure can help any MS patient, even if its a short term result, if they can have a better quality of life for that amount of time, its definitely better than nothing. Knowing there's a realistic procedure that can be done in most local cities of MS patients is a real blessing to look forward to! MS patients know that drugs are very costly, therefore of course these drug companies and some professionals are skeptical of Dr. Zamboni's findings because, where does that leave them? Perhaps they could think of those who would be benefited by being able to walk again, not having numbness in arms or legs, those that struggle with some memory loss or by finding some balance in their life to get through the day. Come on Canada, lets get working on this and applaud Dr. Zamboni for such a wonderful discovery!!
Valerie...Sault Ste Marie said	I have had PPMS for the last 12 years and have been very patient as well as many others with ms. As the disease worsens their seems to be no drug that can help. Dr.

	<p>Zamboni is a blessing and at least his reasoning sounds founded. I wish Canada would jump on board with this and let us living with the disease decide where the money goes and if we want to have this treatment. If the doctors are skeptical....oh well, we are the ones living this. I have two petitions going right now with almost 300 signatures. I plan on handing it to our MP with the hopes the government will realize that the people are behind this 100%. To support the petition go on facebook groups and join us. (petition for funding)</p>
<p>Kate Bahen said</p>	<p>CCSVI is a legitimate medical theory that merits funding. To get CCSVI going in Canada is expected to cost \$1.5 million. St. Joe's could start-up in 2 weeks if it receives \$400,000. We can wait for governments to fund, we can wait for other organizations, we can wait for other countries to proceed, or we can donate today to get CCSVI underway now. This power is in the hands of Canadian donors. Please donate to St. Joe's, McMaster or UBC and make sure you designate your gift clearly for CCSVI research.</p>
<p>emmett said</p>	<p>just having some hope from a discovery such as this has already motivated me to keep things working through exercise & healthy diet. it gives me a whole new outlook on my future. so happy to see the millions donated to help further our knowledge of this procedure. waiting to maybe get better is better than waiting for overwhelming deterioration.</p>
<p>Grace Grigg Hamilton said</p>	<p>My mother has MS and hasn't walked in 22 yrs. My sister has it as well. I have never seen both of them so optimistic in my life. My mother may not be a candidate for this treatment but as she says "it's good to have hope, it costs nothing." I think that the Pharmaceutical companies are against this theory because they will lose a lot of money. I pray for all those who suffer from this terrible disease that this theory and procedure will help each and every MS patient.</p>
<p>David Sawkiw [saskatchewan farmer] said</p>	<p>Something that was left out of the above article is the iron... I heard iron build up in the brain is part of the problem. This article DOES mention Canada as being a hot spot for MS, and I've heard Saskatchewan is the worst.. Here is something to think about., MOST roads here are gravel surface and the clouds of dust we breathe everyday is loaded with iron. Also MOST of our water we drink is VERY high in iron (so high that it sometimes VOIDS the warranty on domestic hot water heaters). I would like to see some research in this area too</p>
<p>Barb Schermann said</p>	<p>I was very happy to read through the comments and finally see from someone else that is living with PPMS . I was so excited when I watched the special on CTV regarding The Liberation Treatment, I think because it's logical! Hopefully there will now be research into this breakthrough that will help all of us. KEEP STRONG !!!!!!!!!!!!!!!</p>
<p>Maxine David said</p>	<p>Canadians donated \$62 million to MS-related charities in 2009! wonder if they feel like they got their money's worth? There is still no cure. They still do not know what causes MS. Drugs that can help stop the progression of MS are only some-what effective for only some people with MS in the early stages. Some of these drugs are very dangerous, they can cause permanent heart damage or cause cancer. I can understand Mr. Savole's concern about people abandoning treatment but what if there are no disease modifying drugs like in my case after only 13 years. CCSVI is congenital and precedes MS lesions. Dr. Zamboni has found that more than 90 per cent of patients with MS have these malformed veins, which causes improper blood flow from the brain. When these veins were repaired, dramatic improvements resulted in the health of these patients. The budget for the grants for CCSVI study offered by MS Society of Canada are \$100 000 per year. July 1, 2010 is the anticipated start of funding. For us in MS community; this is already a case of too little too late. Maxine LeBlanc-David D'Escousse, Nova Scotia</p>
<p>Tom Hennessy said</p>	<p>Zamboni is not a scientist. He is a varicose vein surgeon who tried to apply what he knows about veins to his wife's MS. What he does is not science. Of course what YOU do is .. Sceptics abound and IF he HAS shown this kind of recovery in people who HAVE BEEN DIAGNOSED with MS by OTHER DOCTORS then UNLESS you are going to call him a liar to his face I suggest you keep YOUR unwarranted scepticism to yourself. Imho .. I believe others may concur ..</p>
<p>M said</p>	<p>This is so exciting. I will be donating tomorrow. I wonder if anyone has contacted the Gates foundation. They donate heavily to health care causes. It's worth a try. Good Luck!</p>



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