

# MS patients want access to new surgery

*Last Updated: Monday, April 12, 2010 | 10:17 AM ET* [Comments 17](#) [Recommend 16](#)  
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Hundreds of Canadians who have multiple sclerosis are demanding access to a new procedure that MS specialists warn is at best experimental and at worst dangerous.

More than 20 Canadians have gone to a private clinic in Poland in the past two months alone. It is one of a handful of locations worldwide offering an operation to remove blockages in neck veins that drain blood from the brain back to the heart.



*Rebecca Cooney wants to promote research and testing of CCSVI. (CBC)*

Dr. Paolo Zamboni of Ferrara, Italy, describes the condition as chronic cerebrospinal venous insufficiency or CCSVI. His research suggests the narrowed or blocked veins lead blood to move backwards or reflux back into the brain and spine, causing damage.

The hypothesis is unproven and studies are underway to show how common CCSVI is in MS patients, those with other neurological conditions and healthy people, as well as to explore its potential role as a major risk factor in MS.

While studies in Canada get underway, some patients are travelling overseas, paying for tests and surgery out of their own pocket. Others are lobbying for the Canadian health-care system to cover the diagnostic tests to look for blocked veins in people with MS.

"Even the Doppler testing is not covered by OHIP, for example," said Andrew Katz of Ottawa, who has MS and uses a wheelchair. Katz was willing to pay \$500 out of pocket for Doppler ultrasound testing in Montreal.

Katz and his friends are also putting together posters and signs to carry in a march planned for May 5 on Parliament Hill.

"The point of the rally is to demonstrate and voice our opinions about the way the government is handling the CCSVI situation," said Katz. "It's not moving fast enough."

## Tears of hope

Katz's fellow campaigner Rebecca Cooney has secondary progressive MS, which means she never has periods where she can function normally.

## CCSVI explained

Chronic cerebrospinal venous insufficiency is a chronic problem in which blood from the brain has

difficulty returning to the heart. It is caused by a narrowing or "stenosis" in the veins that drain the brain.

The MS Society describes CCSVI as "a hypothetical disruption of blood flow in which the venous system is not able to efficiently remove blood from the central nervous system, resulting in increased pressure in the veins of the brain and spinal cord, which in turn results in damage to these areas."

Small studies on people with MS suggest the blockages lead to different patterns of blood flow back to the heart. Blood leaves the central nervous system differently than normal. For example, it may flow more slowly, leading to swelling, or may move backwards or "reflux" into the brain.

In November 2009, Dr. Robert Zivadinov of the neuroimaging analysis centre in Buffalo, N.Y., presented his preliminary results trying to confirm the link between blocked veins and MS. Zivadinov said a combination of being born with narrow veins in the neck or thorax, along with environmental and genetic factors such as vitamin D deficiency or exposure to the Epstein Barr virus, may play a role in causing MS, an autoimmune disorder.

Different tests are used to diagnose CCSVI. Doppler ultrasound of the neck and skull may show if blood is refluxing. Venography, which involves injecting a dye into the veins to watch blood flow and possible stenosis in the azygous vein in the chest and the two internal jugular veins, is also used.

Doctors may also turn to more sophisticated tests using magnetic resonance venography and magnetic resonance imaging to look for abnormalities. Researchers are still investigating the best protocols and tests to use. People doing the tests need to be trained to do it effectively.

Treating the condition is more controversial. Zamboni's angioplasty-like procedure involves a small incision in the groin to insert a catheter into the blocked vein that is opened with a small balloon. In his small study, most of the 65 patients who had the procedure had fewer MS attacks and brain lesions, although the improvement was temporary for about half.

One U.S. clinic that started doing Zamboni's procedure stopped after a metal stent put into a patient's vein went into his heart. Another patient died of a cerebral hemorrhage after the procedure, said Dr. Jock Murray, an expert on multiple sclerosis who helped found the Dalhousie MS Research Unit in Halifax.

A review article in the *Annals of Neurology* challenged the role of CCSVI in MS and discouraged people with MS from having invasive procedures until the benefits are demonstrated more conclusively.

The findings need to be repeated in more patients and controls with consistent MRI protocols, the reviewers concluded. Further studies also need to be blinded, that is, researchers can't know which subjects have the disease and which don't, to help prevent bias. Given ethical concerns, MS patients who have the treatment are told to continue taking their disease modifying medications, which makes it harder to determine the effectiveness of the surgical treatment.

Over almost 18 years, Cooney's condition has worsened and she is losing the use of her legs. Cooney walks with a cane and worries that within a year she will be in a wheelchair. She has already moved to a house with fewer stairs.

"I was with my family and my daughters," Cooney recalled of first hearing news about the surgery. "I started to cry because I felt it was finally something tangible that can be done, that can be fixed."

Even if the angioplasty or stent surgery doesn't reverse anything, Cooney is optimistic the decline could be stopped. So far, she has spent \$4,000 for tests in the U.S. that showed two severely

narrowed internal jugular veins.

Cooney's objective is to help promote research and testing of CCSVI. She laments the lack of standard protocols and training to diagnose the condition.

### **Doctor urges patience**

To that end, Cooney and other members of the MS Liberation Group are trying to raise money, awareness and build partnerships to facilitate training of technicians performing the diagnostic tests in Canada.

"People with MS have such a difficult time anyway," Cooney said. "To have them go through all of that and then give them results that aren't accurate I think is immoral."

There are indications that the treatment might only work for certain kinds of MS or for only a while, and there can be complications, said Dr. Jock Murray, an expert on multiple sclerosis who helped found the Dalhousie MS Research Unit in Halifax. Murray urges Canadians with MS to have patience.

"I don't want to discourage or remove hope, but I think it's important that people understand what we currently know," said Murray. "It's not a lot. And I think one of the difficulties is it does take time to get the answers."

### **Brisk business overseas**

Cooney and Katz say many MS patients don't have the time for science to weigh in on the unproven treatment that is not available in Canada.

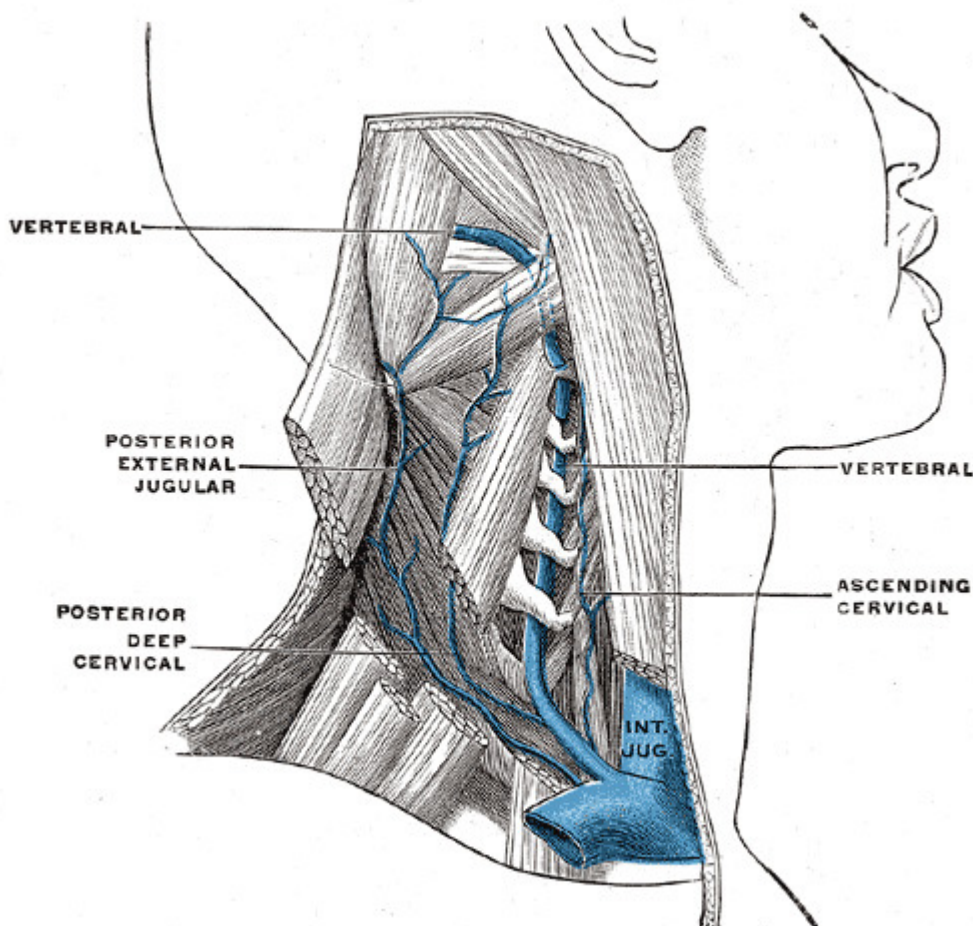
"Anybody that has had MS is perfectly happy to be led down the garden path just for the chance that maybe having a shot at this," said Katz. "And that's the fact."

Experts with the International Union of Phlebology, which investigates and manages vein disorders, agreed CCSVI is a condition that should be looked at and taken care of, Katz said. He thinks the hesitation of Canadian vascular surgeons may reflect "the Canadian culture that needs to be so cautious that we need to validate everything we do."

Pierre Bouvrette of Montreal said he can't wait for treatment in Canada. Bouvrette went to a private clinic in Katowice, Poland, and paid \$10,000 for surgery to open up his neck veins. The fee also buys five days at a hotel and breakfast.

"It is not totally proven, there are some chances to take, but I am willing to take them," said Bouvrette. "If I don't do it, I'm going down the hill [to] wheelchair and eventually bedridden."

The Polish clinic is doing brisk business, performing five operations a day. It is booked well into next year.



*Veins of the neck*

*including internal jugular shown in blue. (Gray's Anatomy)*

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**[Tedicho](#) wrote:**Posted 2010/04/12

at 11:16 AM ETHello everybody, I watched and listened every sides and got most important ideas, I know that everything takes time but there is no enough explanation why CCSVI ocured in MS patients and why don't need to get fixed timely? The journalists have to ask these questions to get a resonable answer. I am very interesred in this issue because I diagonessed three years ago and I don't want to see it just progressed with out any solutions. I believe that God will reavel all secrets of the diseases which mens hid it knowingly ir unnowingly. Things are going fast at this time & need to be more faster than now. People pray, fight for your rights by being reasonable, just be relaxed & see what is going to be tomorrow.

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**[gumhead](#) wrote:**Posted 2010/04/12

at 11:12 AM ETLow Dose Naltrexone isn't a cure for any disease. Neither is it a mood alterer or a pain killer. However, it may make your symptoms seem less intense, make you feel better and take

away some of your pain.

Low Dose Naltrexone is a drug that was originally prescribed for drug addicts. At 50 mg doses, it fills the cell's natural opiate receptors, thus preventing addicts from feeling high. That is why it can't be taken with any opiate-type drug.

Then it was discovered that at doses of 1.5 mg to 4.5 mg it causes the body to produce endorphins. These not only make people feel good but they help to boost the immune system and lower pain levels.

Low Dose Naltrexone can help people with autoimmune diseases such as Multiple Sclerosis, Crohns, Rheumatoid Arthritis, and Lupus as well as HIV/AIDS, Cancer and children with Autism. Also, because of the way it works to lower pain levels and boost the immune system, it is being used to treat people with Fibromyalgia and Chronic Fatigue Syndrome.

This low dose drug can be used in conjunction with CCSVI surgery or before you have this surgery to greatly improve your immune system. It is being used world wide by approx. 100,000 patients with the above autoimmune diseases. Please Google it as it is life changing. There are also Yahoo chat groups with information.

I can attest to it working for Rheumatoid Arthritis and Fibromaylgia. It has lessened pain, improved mood, lessened cognitive difficulties, increased energy. Truly life changing.

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[knotalone](#) wrote:Posted 2010/04/12

at 11:09 AM ETThere are indications that the treatment might only work for certain kinds of MS or for only a while, and there can be complications, said Dr. Jock Murray, an expert on multiple sclerosis who helped found the Dalhousie MS Research Unit in Halifax. Murray urges Canadians with MS to have patience.

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My brother has lived with MS for the past 20 years. I have seen him go from an active individual to a person confined to a wheel chair, he tried drugs and at best they may have slowed it down in the early stages.

Dr. Murray says it may only work for certain types of MS. and that there may be complications.

I am here to tell you that the risks and side effects from some of the drugs they give to these patients are a hell of a lot worse than angioplasty.

I know of several people that have had angioplasty operations related to heart conditions. I have not heard of any of them having side effects from it.

The biggest problem I see with this treatment is that it would cut out the drug companies.

You can bet they will be lobbying hard against any research involving this procedure.

If they want to do research why not have willing participants take part in trials. MS patients know the risks, they also know there options.

Let them make the decision it is there life and if it works can you imagine the health care dollars it would save, and the quality of life these individuals would gain.

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[AlbertaBoy111](#) wrote:Posted 2010/04/12

at 11:07 AM ET This is so ridiculous. It is obviously just pressure from big pharmacy to keep this from happening. They make millions every year selling EXPERIMENTAL drugs to MS patients that have much much lower success rates than that claimed by this treatment. This treatment works better the earlier it is given. Give it to them now, look at the numbers after. Even if this has a 1% success rate it is worth it is it not? That is higher than the rate any of these other treatments (whos symptoms are almost endless and nearly as bad as the disease itself). Give them the treatment now. I mean it is one of the most simple surgeries available.

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**[PDBadibus](#) wrote:** Posted 2010/04/12

at 11:05 AM ET ""Anybody that has had MS is perfectly happy to be led down the garden path just for the chance that maybe having a shot at this," said Katz. "And that's the fact."

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And that's fine. But you can't expect that Canadian taxpayers to fund your 'garden path' treatments until their efficacy can be proven. That's what clinical trials are for. Science is a process, and it isn't always as fast as we'd like it to be.

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