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## W5: Why MS patients aren't waiting for proof



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W5 Staff  
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A fascinating medical drama is unfolding on the Internet among patients and scientists – who are struggling to study a new theory and experimental treatment for multiple sclerosis.

W5 caused a huge stir among MS patients last November, when it broadcast a report about the new theory, which suggested that blocked veins in the neck and chest could be contributing to the disease.

Since then, patients have scrambled to learn more about the theory, promoted by Italy's Dr. Paolo Zamboni.

Zamboni believes that malformed veins cause blood from their brain to drain improperly, sending it back to their brain, and potentially setting off the immune response that marks MS.

In a preliminary study published last November, Zamboni found that opening these veins with a balloon improved MS symptoms and reduced new attacks. He dubbed the procedure the Liberation Treatment.

With many of Zamboni's patients reporting relief from some of their MS symptoms (for as long as the veins remain opened), MS patients from all over the world have been rushing to find someone willing to offer them the experimental treatment.

One of them was Steve Garvie.

He was diagnosed 10 years ago with secondary progressive MS. The disease left him using a walker most of the time, suffering profound fatigue and living in supportive housing.

Garvie had few options since there are no drug treatments for secondary progressive MS. "The clock is ticking. People die. People with MS commit suicide at an alarming rate. There is no hope. So why don't we give them hope?" he wondered.

But his neurologist told him to wait for more studies. So, Steve went to see vascular surgeon Dr. Sandy McDonald, who runs an imaging clinic in Barrie, Ont.

McDonald decided to test Steve's blood flow with ultrasound, using money from his own pocket.

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When the ultrasound scan showed signs of blood flowing backward into Garvie's brain, McDonald sent Steve for a venogram, in which dye was injected into his veins to look for problems.

Just as the Chronic Cerebrospinal Venous Insufficiency (CCSVI) theory suggested, Garvie had abnormal blood drainage from his brain, because of a narrowed left jugular vein.

Dr. McDonald and his colleagues decided to unblock the vein with a small balloon, a procedure called a venoplasty.

"I had to tell Steve very specifically: I don't treat MS. I have no idea what effect the balloon angioplasty would have on MS, but I knew from studies that had been done that the abnormal flow characteristics warranted further investigation," Mc Donald says.

Steve says as soon as the vein was opened, he immediately felt warmth in the left side of his face and he could wiggle his toes.

"One of the nurses came over and said 'Are you alright?' I said, 'Yes, shake my hand.' She shook my left hand which was useless before," remembers Garvie.

"It was quite remarkable," remembers McDonald.

**'The link has not been made'**

"The question as a physician, though, was: is it a placebo effect or is it real?," McDonald wonders. "I mean, when a patient really wants to get better, sometimes when you do something, they seem to feel better and it comes down, over time, to assessing whether or not his improvements are real or lasting."

All over the world, MS patients are seeking out physicians who will test and treat them. They are then posting the results online.

But many doctors who treat MS, such as Dr. Mark Freedman, the director of the MS research unit at the Ottawa Hospital, say the rush to test and treat vein problems bypasses the normal route of science.

Freedman says theories have to be proven before patients are treated.

"The link has not been made. The association has been made. But no one has convincingly shown this has anything to do with the disease," Freedman says. "Why would you fix something that may not have anything to do with the disease?"

Garvie was one of five Canadian patients treated by Dr. McDonald's team. Another was Lianne Webb, who was diagnosed with MS almost 20 years ago. She has relapsing-remitting MS, had been taking the drug copaxone, but still suffered MS symptoms and the occasional attack.

"At one point, I didn't have any movement in my right side," she remembers.

Ultrasound testing found she also fit the theory, with a venogram showing a narrowed left jugular vein. McDonald opened the vein a month ago. She says she feels better than she has the last five years or six years. "It's not a miracle, but if it stops progression, I'm all for it."

Matt Maltese, 26, has suffered relapsing-remitting MS for a decade. His whole right side would often go numb. He couldn't go up and down stairs, and his family had installed an elevator into the house.

When doctors performed the venogram in February, they discovered blockages in one of his jugular veins and the azygos vein in his chest. Both were opened with a balloon. The next day, Maltese was able to up and down the stairs with relative ease.

Dr. Christopher Guest, an interventional radiologist who performed some of the procedures on Dr. McDonald's five patients, says venoplasty is a technique that has been used for years in veins in other parts of the body. He doesn't think performing it in the neck is much different.

"If this were a risky procedure and there was poor data to support it, this would be a little more questionable. But these patients are severely debilitated, and the procedure is exceedingly safe," he says.

Many neurologists, such as Dr. Freedman, have been confronted by anxious, sometimes angry, patients, who demand testing and treatment. His message to MS patients is: slow down.

"It's an idea. All ideas on the table are important but we don't have the answers, and until we have all the answers you need to have a wide scope of understanding and belief."

**Balloons vs Stents**

Dr. Freedman and some colleagues wrote an article that appeared in the Annals of Neurology that urged doctors and patients not to test or treat vein problems until the theory has been proven in clinical trials.

They also highlighted the dangers of a modified form of the Liberation Treatment, in which some clinics used metal stents to prop open the veins, which are prone to re-narrowing.

One patient, treated in California last year, required surgery after the stent fell into his heart. Another patient died from bleeding linked to medications prescribed following treatment.

The five Canadian patients were not treated with stents, only with balloon angioplasty, as per the Italian protocol, which has showed no serious reactions from the procedure.

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"I don't think it's a dangerous procedure," says Dr. Guest. "If you look at the complications that have been reported, they are related to stents, rather than the actual angioplasty. And we would certainly never place a stent until there was data to support doing that."

#### **Impatient patients question, 'why the wait?'**

While patients agree that more study is needed, many aren't willing to wait several years for answers. Webb says the damage that could be done while waiting two or three years for clinical trials may not be reversible. "So why would you wait," he wonders.

Matt Maltese's father Vito says some patients and their families are willing to assume some risks. "Let us know what our risks are, let us know what our choices are, let us make the choice," he says.

Another patient, Sandra Black, remains disabled by her MS, despite the treatment in Barrie two weeks earlier. She also has secondary progressive MS, and uses a walker and a wheelchair. While she can't walk, she says the circulation to her feet has improved. They're no longer blue, and she feels more energetic.

"I am happy to stay awake all day, get up earlier and warm feet when I go to bed," she says.

Steve Garvie has had some of the most noticeable improvements. He can now walk where once he used a walker. He also was able to vacation with his partner Donna in the Dominican Republic, where for the first time, they danced.

But Garvie wouldn't call it a cure.

"No, I don't think so. There are some things I may never get back. But I am about 75 per cent better than I was before. That would be a fair statement."

These cases are anecdotal reports. They don't add up to much the scientific world, where only carefully controlled large studies will prove if this theory has merit.

That's why Dr. McDonald and his colleagues are no longer treating patients and instead are planning a formal study.

"We have to look at the rationale of doing venoplasty in MS patients aggressively. We need to study a lot of patients, done with neurologists, in a multi-specialty focus," says McDonald.

At the same time, McDonald is continuing to monitor patients with ultrasound to see if their vein narrowings recur, something reported in 47 per cent of patients treated in the initial Italian treatment study.

#### **Canadian teams take training in Italy**

The drive to learn more drew scientists to the San Giorgio Hospital in Ferrara, Italy, where Zamboni and his team are teaching researchers how to test for vein abnormalities using ultrasound. There are now some 100 other doctors and ultrasound technicians lined up for future classes in Italy -- and there are plans to open up training programs in North America.

"Interest is really exploding and we are moving really faster because I have continuous contact with colleagues all over the world," says Zamboni.

Canadian vascular surgeon Dr. Sandy McDonald and his technician, Angela, joined the s first international training program in Ferrara.

Also there, were teams from the University of Saskatchewan and the University of British Columbia, including radiologist Lindsay Machan. He says the CCSVI theory is intriguing because it means that balloon venoplasty might lessen symptoms of a disease that is now treated only with expensive medications that carry heavy side effects.

"If you think of the societal cost of MS young people, think of what we can accomplish for a relatively simple procedure. So we don't want this to languish and go on for a long period. We really want to get to the bottom of this," Machan says.

Scientists are now seeking research dollars, through donations, or through scientific grants and from MS societies.

Yves Savoie, the president of the Canadian MS Society, says 80 per cent of the phone calls the society now receives are about CCSVI. A one-time funding call was announced November. Grants for studies on CCSVI will be announced in June. The researchers selected will receive a maximum grant of \$200,000 for a two-year study. But there have no details on how many centres have applied for funding.

"I am quite convinced as a result of the excitement, the mobilization, the media attention, the process of discovery is going to be much accelerated," he says.

But neurologist Dr. Freedman, who has spent much of his career testing other promising MS treatments, including stem cell therapy, worries the MS Society could be diverting funds away from other promising leads.

"It's being forced, I think, to head down that road because patients are the main drivers of funds supporting the Society's work. And basically, they are looking at this and saying 'Stop everything else. Redirect your funding to this project because it's worth it. And I don't think that's the truth over many other projects that may have more scientific rationale to move forward."

Still, Freedman says his Ottawa team has submitted a bid to study the theory.

Yet studies could take years. Patients such as Christopher Alchenbrack have already learned he has problems with his neck veins, and is in a hurry to get them opened.

So the Wolfville, N.S. father of two, is funding his "study of one," spending more than \$10,000 from his retirement fund to get the experimental treatment at a private clinic in Poland.

"The reason I am so insistent on this procedure is that I have secondary progressive MS and nothing, none of the medicines I have used over the years, have worked to stop my ms. I've still progressed nonetheless."

Countless MS patients are travelling to new clinics opening up in eastern Europe and India that are charging thousands of dollars for testing and treatment with metal stents, rather than balloons, and claiming Dr. Zamboni trained them, when he did not.

"I understand that they are desperate and they can be attracted by this. I do not recommend this, because I do not know the quality. And probably this can be dangerous for the patients," says Zamboni.

He insists the best way of protecting patients is by convincing established medical communities with hard scientific data from more studies that test and treat patients.

"My position is to stand and respond with scientists and to tell the patients to give patience, because we are really running very, very fast."

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