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Ask for scans, says MS pioneer

Urges patients to ask for MRIs to check neck veins for blockages

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February 09, 2010

JOANNA FRKETICH
THE HAMILTON SPECTATOR
(Feb 9, 2010)

MS patients are being told to seek MRI scans and treatment by an Italian doctor pioneering a radical and unproven theory that the disease is vascular.

But it will be next to impossible to get the tests and surgery in Ontario, leaving thousands of patients vying for 100 spots in a Hamilton study testing the theory.



Dr. Paolo Zamboni urged doctors to be more open to his ideas during a media conference at St. Joseph's Hospital yesterday -- his first North American appearance since his theory of "chronic cerebrospinal venous insufficiency" started gaining worldwide attention in the fall.

"If I should be a neurologist and read similar reports ... the first thing I should do is to investigate the neck veins of my patients," said Zamboni. "My suggestion is to investigate patients as soon as we can, not to simply criticize."

He said the test to find out if veins draining blood from the brain are blocked and the procedure to improve the blood flow are already known to be safe and effective and should be available to MS patients.

"We think treatment of CCSVI can be done," he said. "CCSVI is a vascular disease, probably congenital, with guidelines in diagnosis and treatment."

However, the Ministry of Health made it clear yesterday it won't fund the scans or balloon angioplasty to treat it because it considers Zamboni's theory to be "experimental."

Canada has one of the highest rates of MS in the world -- about one in 1,000 people have the disease -- so doctors say scanning them would overwhelm the health-care system.

"We'd swamp MRI capacity," said Dr. John Paulseth, director of the MS clinic at McMaster University Medical Centre.

He said there isn't enough proof yet to use so many health resources to do the scans and surgery.

"I think his hypothesis is very worthy of further study," said Paulseth. "But it needs to be corroborated."

That leaves MS patients with only one option in Ontario -- trying to get into the study being launched by St. Joseph's Healthcare, McMaster University and Hamilton Health Sciences. It is putting in a proposal to the MS Society of Canada today to scan the veins in the brains and neck of 100 MS patients with varying degrees of the disease and compare it to the veins of 100 similar healthy people. They're looking to see if the veins of people with MS are blocked while healthy people's are not.

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The researchers have already had more than 22,000 MS patients from around the world try to get into the study. They are looking for other funders so they can test more people.

Only the University of British Columbia is doing similar testing in Canada.

Patients can pay to get the scans in the United States but it costs about \$4,500.

It has left MS patients feeling hopeless just as the potential of a new treatment is coming to light. The mystery neurological disease was believed until now to be an auto-immune reaction, where the body attacks itself, with no cure or effective treatments.

"I'm trying to stay positive," said Jennifer Dennis, who lives in Whitby and is trying to get into the St. Joseph's study. "I have hope (about the theory) but I don't know if I particularly have hope for me."

The 26-year-old single mom pleaded with health professionals to no avail to use the study protocols when they did a regularly-scheduled MRI in December.

"It's very frustrating," she said. "Here is a potential medical breakthrough for a crippling disease and they don't want to do it. It only takes one person to take the chance but right now no one is willing to take the chance."

She worries by the time CCSVI is rigorously studied that it will be too late for her.

"This would be huge for me," she said. "My case hasn't progressed very far yet."

Dr. Mark Haacke, who works out of both McMaster and Detroit, says he thinks Canada is missing out on the opportunity to create a national database of MRI scans on MS patients.

"My personal opinion is that ... patients should be getting these images," he said.

Both Haacke and Zamboni acknowledge more study needs to be done, although they say early research out of Poland and Jordan is backing up Zamboni's theory.

Tomorrow, the Buffalo Neuroimaging Analysis Center is expected to release the first results from its CCSVI study of 500 patients. The results are predicted to back up Zamboni considering it is now moving forward from studying the MRI scans to testing the treatment.

"The preliminary results are exciting scientifically and will generate a great deal of discussion," stated the center's director Dr. Robert Zivadinov in a newsletter last week. "This particular research is having an impact like no other we have known."

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