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Doctors who believe MS linked to damaged veins urge more testing

By Carly Weeks

From Thursday's Globe and Mail

Demand by patients for surgery prompts researchers to advise caution and safety

The researchers behind a controversial theory that multiple sclerosis may be cured with simple surgery are now urging patients demanding immediate access to the treatment to wait until it is properly tested.

Doctors who are already offering to perform the procedure are acting irresponsibly and may risk harming patients, the researchers said during a forum at a major neurology conference in Toronto this week.

It is a cautious message coming from Paolo Zamboni and Robert Zivadinov, two researchers who helped propel the notion that MS is linked to blocked blood vessels leading from the brain, rather than the conventional thinking that it is an autoimmune condition. But it illustrates how little scientific research examining the theory has been done - and how many important questions remain unanswered.

"I think that the steps should be respected of scientific research," said Dr. Zivadinov, associate professor of neurology at the University of Buffalo who is conducting research on the new theory, which was developed by Dr. Zamboni. "We need to first find whether something is safe, then whether it might be effective."

But some members of the medical community say unjustified risks have already been run as MS patients around the world invest their money and fly to foreign destinations in hopes the unproven treatment will eliminate their often-debilitating symptoms.

"We've seen over and over again in the history of medicine claims for other surgical procedures, other kinds of interventions that come out with great hype and then, if they're ever studied adequately, turn out not to be valid," said Aaron Miller, who was part of Wednesday's panel. He is professor of neurology and director of the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at New York's Mount Sinai School of Medicine.

At the heart of the debate is a theory developed by Dr. Zamboni, director of the Vascular Diseases Center at the University of Ferrara in Italy. He believes multiple sclerosis is a vascular condition caused by blocked or malformed veins responsible for draining blood from the brain, and that it can be treated with surgery to reopen the veins. After news of his research was published, patients flooded doctors' offices with phone calls and some have travelled to such countries as Poland to get the controversial treatment.

Research conducted by Dr. Zamboni and published last year showed that nearly three-quarters of a group of 65 patients had no MS symptoms two years after they had surgery to repair the brain drainage problem.

However, critics say the study had serious limitations, such as the fact that results may have been biased because patients and doctors knew what the treatment was designed to do.

Another major issue is the fact that Dr. Zivadinov, who is also the director of the Buffalo Neuroimaging Analysis Center, wasn't able to identify a vein problem in nearly half of the 500 MS patients involved in a study he is conducting. Furthermore, 22 per cent of the healthy control group involved in the study had the vein blockage problem.

Some members of the medical community say those kinds of facts cast doubt on Dr. Zamboni's research. They also say it's impossible at this stage to judge whether the vein drainage problem triggers MS, contributes to its progress, or is simply a secondary issue common to some people with the disorder.

"I think that a lot of people aren't getting the full picture," said Katherine Knox, director of the MS clinic at Saskatoon City Hospital. "We have to be very careful that we don't conclude that association equals causation.... We cannot make those conclusions at this time."

Dr. Knox is planning a study to determine whether the vein problem is present in people with symptoms of MS, as well as those at high risk of developing the disorder.

But Dr. Zamboni says his research clearly shows there is a link between vein blockage or malformation and multiple sclerosis. Now, it's up to researchers to determine the extent of the link, how it might be related to the progression or onset of MS, and whether it's associated with other neurodegenerative diseases.

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