

Doctor who believes MS linked to blocked neck veins preaching caution

By Sheryl Ubelacker Health Reporter (CP) – 4 days ago

TORONTO — An Italian doctor who believes multiple sclerosis may be triggered by blocked neck veins defended his theory at a meeting of international neurologists Wednesday, but at the same time sounded a cautionary note to patients desperate for a cure. Dr. Paolo Zamboni's theory that narrowed neck veins cause blood-borne iron deposits to build up and damage brain cells has created a tidal wave of interest within the MS community, with patients around the world scrambling for a treatment the vascular specialist pioneered.

Neither that link nor the therapy - an unblocking of veins with balloon angioplasty that Zamboni has dubbed the "liberation treatment" - has been proven in testing on large numbers of subjects, a process that has long been the hallmark of evidence-based medical care.

But that hasn't stopped MS patients worldwide from travelling to clinics in countries such as Poland, which have popped up offering to diagnose chronic cerebrospinal venous insufficiency, or CCSVI, and to provide the controversial treatment for those willing to fork out thousands of dollars.

"This is really a work in progress," conceded Zamboni, speaking to a roomful of journalists and neurologists at the Toronto meeting, as well as more than 4,000 people hooked up to the proceedings online.

"We have proved the association," asserted Zamboni, who conducted a study on a small number of MS patients in Italy.

Still, he cautioned MS patients online for the webinar that it's important that the liberation treatment be rigorously tested by many groups of scientists around the world to prove that it is safe and effective.

Yet despite leaning towards prudence, Zamboni suggested that doctors might consider offering his procedure on "compassionate grounds" for patients with severe symptoms who haven't responded to conventional treatments.

He also said he is against the use by some clinics of stents - mesh cylinders that prop open blood vessels to prevent re-narrowing - because there is a risk they may dislodge and migrate through the bloodstream, and their long-term effects inside veins are unknown.

Zamboni, who has moved in a short time from obscure researcher to a medical superstar within the international MS community, urged people with the disease to follow his advice - and not that of "blogger patients."

Getting that message across could present a Herculean challenge, as every nuance of the CCSVI story is scrutinized and chewed over by so-called MSers - bloggers, Facebook and Twitter users - looking for answers about the often-devastating disease. A case in point: more than 7,000 online questions were posted by webinar viewers; only about four were answered because of time constraints.

Zamboni's theory challenges the long-held belief that multiple sclerosis is an autoimmune disease, caused by the immune system attacking the myelin sheath that covers nerve tissue.

An estimated 2.5 million people worldwide, including 55,000 to 75,000 Canadians, have the disease, a degenerative condition that can cause loss of balance, heat sensitivity, impaired speech, extreme fatigue, double vision and paralysis.

Dr. Robert Zivadinov, a neurologist at the University of Buffalo, N.Y., who is heading several studies to help determine what role, if any, blocked neck veins play in MS, said it's crucial that his scientific team and others follow a rigorous and ethical research process so patient safety is protected.

And he bluntly discouraged MS patients from becoming medical tourists to obtain the liberation treatment at overseas clinics, even though he understands how desperate they are for help to stop the progressively neurodegenerative disease in its tracks.

"I think they should not do it until we have data that this is helpful," Zivadinov said.

"That's my very short answer. I think that we don't have data at this moment to determine whether this is useful. I support initiation of more safety studies and hopefully more efficacy studies."

Dr. Aaron Miller, chief medical officer of the National MS Society in the United States, called the early findings about CCSVI "surprising and intriguing," but stressed far more research is needed to determine if neck vein blockages actually play a role in the nervous system damage seen in MS.

"In order for the MS world to understand the long-term benefits and the risks of procedures related to CCSVI, it's very important to balance the need for due speed with the important understanding that we must apply rigorous scientific investigation which can only come about through the conduct of properly controlled trials to understand this phenomenon," Miller said.

"We want to make sure that we provide the best information for all people with MS so they can make informed decisions about their future."

Other neurologists attending the webinar session also urged restraint in interpreting the early data, which they said are far from definitive.

"There is no evidence that 1, this exists at all and 2, if it exists that it isn't a result of the disease," said Dr. Robert Lisak, neurologist-in-chief at Wayne State School of Medicine in Detroit.

Until there are results from randomized-controlled trials, "you're talking about testimony, you're not talking about evidence," he said of anecdotal reports that unblocking neck veins can improve MS symptoms.

"I don't think you can criticize the patients. They're desperate."

Dr. Bruce Cohen, director of the MS program at Northwestern University in Chicago, credited Zamboni for his ingenuity for investigating the blocked vein phenomenon and Zivadinov for taking it to the initial levels of clinical research.

But he seemed to suggest that researchers, doctors and patients all need to take a deep breath and slow down.

"I think the proper way to consider this is it's preliminary," he said, citing a saying that "absence of evidence is proof of nothing."

"Just because it's possible to do a procedure doesn't mean that we should do the procedure."

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