

Health 

Controversial approach to treating MS

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SAN FRANCISCO (KGO) -- There's a radical new theory developing on the cause of multiple sclerosis. MS has long been considered an auto-immune disorder, in which the body attacks itself.

But new research points to a vascular problem and early studies show it might be stopped or even reversed through surgery. It is generating excitement and words of caution from doctors who say the science doesn't yet back it up.

Sammy Jo Wilkinson was just turning 30 when her body went through a dramatic change. The diagnosis was multiple sclerosis, an incurable, often disabling disease that attacks the nervous system, and there's no known cause.

Now 15 years later, she sees herself similar to a stroke patient in recovery.

"I've had this uncontrolled micro-stroke going on all over my brain, iron deposits from the reflux of blood hitting the blockage and coming back into the brain and lack of oxygen in the brain, so this has been going on in my head for 15 years, leaving all kinds of scarring and damage," Sammy Jo said.

What Sammy Jo describes is a radical new theory developed by Doctor Paolo Zamboni of Italy. He's not a neurologist but a vascular surgeon. His research began when his wife was diagnosed with MS. He calls it CCSVI -- Chronic Cerebrospinal Venous Insufficiency.

"Three major pathways are frequently blocked by narrowing in patients affected by multiple sclerosis," he said.

Zamboni believes the blockage in these veins in the neck area causes a reverse flow of blood back into the brain, damaging the nervous system. He found the condition in 90 percent of Italian MS patients he studied.

His solution is opening the jugular veins with balloon angioplasty or stents, techniques originally developed for opening blocked arteries.

"We found for example, patients with early disease, we have full recovery of symptoms. Patients with severe disabilities certainly did not recover but were less fatigued, less tired, more positive," Zamboni said.

And as word spread on line about a possible new cause of MS and a treatment for it, patients started pushing for the surgery now, including Sammy Jo.

"It does have risks, but it was a risk I was willing take, especially with the outcomes I was hearing about from some patients," she said.

Sammy Jo's web research led her to the one doctor believed to be performing the operation in the U.S. -- Dr. Michael Dake, professor of cardiothoracic surgery at Stanford.

After confirming a severe narrowing of her jugular veins, Dr. Dake inserted three stents in October. But in December, he stopped performing the procedure.

The university won't say why and prohibits him from speaking with ABC7, but released this statement: "As interest in the CCSVI procedure has grown, Dr. Dake and Stanford have determined that the initiation of a clinical development program leading to a possible clinical trial will be the next step."

In fact, the National Multiple Sclerosis Society is coordinating a worldwide effort to conduct and evaluate research on CCSVI -- grant money will be awarded in June. Still, the Society's VP of research characterizes the Zamboni hypothesis as a long shot and cautions patients should only undergo the procedure as part of a clinical

trial.

"Currently, there is not enough evidence for me to recommend it to my patients," Dr. Ari Green from UCSF said.

Green is assistant director of the Multiple Sclerosis Center at UCSF. He believes CCSVI is an intriguing theory, though very preliminary and in need of replication.

"What we don't want to do is hurt people. In this instance, there have already been two cases of people who had stents placed who had serious consequences, one death, one person who needed surgery in which they had to open up the patient's chest to fish out a stent that had migrated away from the site at which it was placed," he said.

"There are things that could cause worry, but I'm a lot less worried than I was just about becoming disabled from MS," Sammy Jo said.

Now two months post surgery, Sammy Jo says the muscle spasms that kept her awake at night are gone. Her husband noticed an immediate change in her appearance.

"The thing that really struck my attention was that her complexion came back, from a jaundiced look to pink and healthier looking skin, that was almost immediate," Sammy Jo's husband Doug Flomer said.

Critics point to the placebo effect -- the power of the mind to affect dramatic change in the body -- which is why randomized clinical trials of the CCSVI diagnosis and procedure are critical.

Zamboni agrees.

"We are on the way to solve a puzzle," he said.

Scientists at the University of Buffalo just announced preliminary results of their research into the link between CCSVI and MS patients.

Using Doppler ultrasound they found more than 55 percent of patients with MS had the narrowing of the veins, compared to just 22 percent of the health controls.

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