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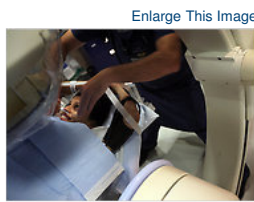
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From M.S. Patients, Outcry for Unproved Treatment

Published: June 28, 2010

(Page 2 of 3)

Meanwhile, researchers are trying to answer basic questions. On June 29, the team in Buffalo is to begin the first treatment study to include a control group. The controls will be given a sham procedure, and compared with others who get the real thing. Initially, 30 patients — only those with an early form of the disease — will be enrolled. Thousands of people applied.



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A PATIENT DOES HER HOMEWORK
Neelima Raval, 38, who has had multiple sclerosis for 13 years, had researched Dr. Paolo Zamboni's vascular treatment before approaching Dr. Daniel Simon in Edison, N.J., about trying it.

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RUTH'S STORY

SPLINTER GROUP The Reformed Multiple Sclerosis Society formed to increase the availability of vein treatment. Its Web site features video testimonials.

about the procedure “in the near future.”

The Multiple Sclerosis Societies in the United States and Canada will spend \$2.4 million over the next two years on studies at seven centers. Researchers will study veins in patients with different stages of multiple sclerosis, in healthy people and in those with other neurological diseases. The studies will not test the balloon treatment, but are meant only to find out if the narrowings really exist, if they are related to the disease and if they are a cause or an effect.

Some patients complain that the society has been too slow to consider the new idea. A splinter group — the [Reformed Multiple Sclerosis Society](#) — has formed to increase the availability of the vein treatment.

Joyce Nelson, the president of the [Multiple Sclerosis Society](#) in the United States, said, “I wasn’t aware how thin the veneer was and how close to the surface the frustration was.”

“‘We can’t wait’ has resounded,” Ms. Nelson said. But she added, “There isn’t a way to rush the work that needs to be done.”

As the procedure has caught on in some places, few serious complications have been reported. But at [Stanford University](#), a woman, 50, treated with [stents](#) (wire-mesh tubes used to hold blood vessels open) and blood-thinning drugs, died of a [brain hemorrhage](#) after returning home, and another patient needed heart surgery after a [stent](#) placed in a neck vein came loose and was swept into the heart. The procedures were stopped.

Dr. Michael Dake, who treated the patients, declined several requests for an interview, but said by e-mail that he hoped to discuss “a number of exciting developments”

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Dr. Philip Pizzo, the dean of Stanford’s medical school, said the vein theory “deserves to be explored” — but only in studies. A study with a control group is being planned.

About 400,000 people in the United States have multiple sclerosis; worldwide, there are 2.1 million. (The disease is more common in temperate zones than in the tropics, and affects more women than men and more Caucasians than members of other groups.) It usually begins in young adults, with fatigue, [vision problems](#), numbness, bladder trouble and difficulty with walking, balance and coordination. The disease eats away a fatty substance, myelin, that coats nerves, and gradually scars the nerves. The damage is thought to occur because the immune system, for unknown reasons, mistakenly attacks myelin.

Most patients, 85 percent, start out with a form called relapsing-remitting. In about half of those the disease becomes progressive, harder to treat and more disabling. Ms. Raval, who is 38 and has had multiple sclerosis for 13 years, implored Dr. Simon to test her for narrowed veins and, if he found any, to open them.

Dr. Simon regularly uses balloons and stents to open bile ducts and blood vessels. He was impressed with Ms. Raval’s determination, her trove of information and her background. She has a degree in toxicology and works for a drug company. But he was also familiar with Dr. Zamboni’s work—and deeply skeptical of it.

“My initial take was, it doesn’t make any sense,” Dr. Simon said.

But Ms. Raval had high hopes. She said she believed that the balloon treatment would be “the next best thing to a cure.” The usual drugs have not worked for her. Her 5-year-old son is eagerly awaiting the day when she can run with him, but she is finding it harder and harder even to walk. **Theory Born of Experience**

Dr. Zamboni, 53, (no relation to the inventor of the ice-rink machine) began studying the medical literature on multiple sclerosis in 1995 when his wife learned she had the disease.

“What I found was like a detective story,” he said.

He discovered reports of vein abnormalities and of brain lesions forming around veins. But the research had been abandoned. Vein disorders are his specialty; he has been studying them for 25 years. He began using [ultrasound](#) and other imaging techniques to examine veins, and found narrowings in the neck and chest veins in people with the disease, but not in healthy ones. He suspected that abnormal blood flow and pressure in the veins— not just narrowing alone — might cause minute amounts of bleeding in the brain, leading to an immune reaction and inflammation that damaged myelin and nerves. Iron deposits could also form, and add to the damage. He wondered if opening the narrowed areas might help.

In 2006 he began using balloons to treat patients, including his wife, whose symptoms went away and, he says, have not come back. Other patients who, like his wife, had relapsing-remitting disease, also recovered fully, he said; but some did not respond at all. In those with progressive disease, fatigue improved, but not mobility problems, according to a [pilot study](#) he published in December in The Journal of Vascular Surgery. And in half the treated patients, the neck veins closed up again. The study did not have a control group, and the patients were also taking drugs to treat multiple sclerosis . More rigorous trials will start in Italy this summer, Dr. Zamboni said.

Another doctor, Marian Simka, who has been performing the procedure in Pszczyna, Poland, has reported that it has made symptoms worse in some patients.

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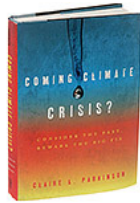


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