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From M.S. Patients, Outcry for Unproved Treatment



Béatrice de Géa for The New York Times

By DENISE GRADY
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For her first appointment with Dr. Daniel Simon, Neelima Raval showed up with a rolling file cabinet full of documents. She had downloaded every word written by or about Dr. Paolo Zamboni, a vascular surgeon from Italy with a most unorthodox theory about [multiple sclerosis](#).

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Béatrice de Géa for The New York Times
A LOOK INSIDE Neelima Raval had her veins tested by Dr. Daniel Simon to see if they were narrow.

Dr. Zamboni believes that the disease, which damages the nervous system, may be caused by narrowed veins in the neck and chest that block the drainage of blood from the brain. He has reported in medical journals that opening those veins with the kind of balloons used to treat blocked heart arteries—an experimental treatment he calls the “liberation procedure”— can relieve symptoms.

The idea is a radical departure from the conventional belief that multiple sclerosis is caused by a malfunctioning immune system and inflammation.

The new theory has taken off on the Internet, inspiring hope among patients, interest from some researchers and scorn from others. Supporters consider it an outside-the-box idea that could transform the treatment of the disease. Critics call it an outlandish notion that will probably waste time and money, and may harm patients.

These critics warn that multiple sclerosis has unpredictable attacks and remissions that make it devilishly hard to know whether treatments are working — leaving patients vulnerable to purported “cures” that do not work.

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The controversy has exposed the deep frustration of many people with this incurable, disabling disease, who feel that research has let them down. It is a case study in the power of the Internet to inform and unite angry patients—which may be a double-edged sword. Pressure from activists helped persuade the [Multiple Sclerosis Society](#) to pay for studies of Dr. Zamboni’s theory, but the Internet buzz has also created an avid market for a therapy that is still unproved.

“It’s eye-opening the way this group of patients has grabbed hold of the social-networking technology,” said Dr. Simon, an interventional radiologist at JFK Medical Center in Edison, N.J. “They’ve taken this to a level I’ve not seen in other patients. Patients used to read an article or two. Now, they’re actually seeing procedures on YouTube. Is this the future of medicine?”

Scientifically, the jury is out: Dr. Zamboni’s hypothesis is being studied. It is not known whether narrowed veins are more common in people with multiple sclerosis than in others, and even if they are, whether the narrowings are a cause, or an effect, of the disease. There is no solid proof that opening the veins can help. There have been no studies with control groups — the only way to find out whether a treatment works.

“In my view the evidence is quite scanty and the biological plausibility is low,” said Dr. Stephen L. Hauser, the chairman of neurology at the [University of California, San Francisco](#). Many neurologists agree. Dr. Hauser said there was much stronger evidence that the disease arose from genetic variations affecting the immune system.

But Dr. Adnan H. Siddiqui, part of a team at the [University at Buffalo](#) that has been studying Dr. Zamboni’s theory, said that it made sense and that the data from Italy was encouraging. Still, he emphasized that more study was needed, and that patients should not be treated until the research was done.

In Demand

Despite the lack of proof, many patients are captivated by the idea that multiple sclerosis might turn out to be a vascular disease. They want to believe it can be fixed with a relatively simple procedure, and they want to be tested and treated. Now.

These patients say they cannot afford to wait for research results because they will wind up in wheelchairs before the studies are done. Their only option so far has been a lifelong course of drugs with limited benefits and harsh side effects. To some, balloon treatment seems no riskier than those drugs.

Dr. Zamboni himself has said that the procedure should not yet be done outside of studies. He said in an interview that he was conducting research only and had turned down thousands of requests from people wanting to go to his clinic at the University of Ferrara.

But other doctors have set up shop. A clinic in India with a toll-free American phone number has an online advertisement for a “liberation package.” Patients are posting testimonial videos and trading tips on clinics in Bulgaria, Poland and Jordan.

In the United States, where many [hospitals](#) forbid experimental treatments outside of studies, a “back alley” network of doctors willing to perform the procedure has begun to develop, said Dr. Salvatore J. A. Scalfani, chairman of radiology at Downstate Medical Center in Brooklyn. He said he knew of about a dozen. The doctors try to stay under the radar, and patients quietly pass their names to one another.

“It reminds me of [abortion](#) in 1968,” Dr. Scalfani said.

He said he had treated about 20 patients at [Kings County Hospital](#) before the hospital ordered him to stop in early April. He said he had a waiting list of 300 to 400 patients..

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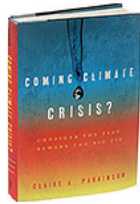


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