From M.S. Patients, Outcry for Unproved Treatment

Published: June 28, 2010

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Researchers in Buffalo have confirmed (but not yet published) that narrowed veins and abnormal blood flow are more common in people with multiple sclerosis. But, while Dr. Zamboni found them in all patients and no healthy people, the Buffalo team found them in about 60 percent of patients and 15 percent of healthy controls.

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ADVOCATE Steven J. Simonyi-Gindele, of the Reformed Multiple Sclerosis Society, urges patients via video to be treated at a hospital in Bulgaria.

Granting a Patient's Wish

Dr. Simon sensed that Ms. Raval would have no peace unless she could learn whether she had narrowed veins, and he wanted to help her.

So he offered to perform a test to find out, a venogram. It involves passing a tube into a vein in the groin and up to the neck and chest, and then injecting dye to take X-rays of the veins. He felt sure there would be no blockages.

"And then she would be able to stop obsessing over this and move on with her life and get some kind of conventional treatment," he said.

But he was stunned to find narrowings, right where Dr. Zamboni's theory predicted: in the jugular vein in the neck, and the azygous, a vein in the right side of the chest.

Ms. Raval was elated. She felt certain that opening up those veins would solve her problems. Dr. Simon agreed to try.

Although it was, technically, an experimental procedure, Dr. Simon said he did not have to ask his hospital for permission to perform it. The details were similar to other procedures that interventional radiologists do every day. It is not uncommon for them to take a device approved for one purpose and use it for another, like putting a bile-duct stent into a blood vessel — a practice called "off-label" use, which the Food and Drug Administration allows. Interventional radiology, Dr. Simon said, is an "off-label specialty" that depends on innovation and adaptability.

On March 24, as Ms. Raval lay on a padded table in a treatment room, Dr. Simon passed balloons to the pinched spots in her right jugular and azygous, and dilated them.

The procedure took less than an hour. In the recovery room, Ms. Raval said she felt better already.

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Over the next days and weeks, she noticed remarkable improvements. Her fatigue went away. She walked and climbed stairs more easily, and the color in her face brightened. Her husband and co-workers saw the changes, too, she said.

Was it real, or just one giant, communal placebo effect? Ms. Raval posted exuberant Facebook messages naming her "most amazing doctor." Other patients began calling Dr. Simon.

Within a month, Ms. Raval again had trouble walking. She felt sure her veins had closed again. Another venogram showed they had. Dr. Simon reopened them.

Ms. Raval felt better — and then deteriorated again. On June 18, another venogram, her fourth invasive procedure in three months, suggested that the narrowings had recurred. She struggled over what to do. She could not keep having balloon procedures again and again. Dr. Simon consulted Dr. Dake, his former mentor, who recommended stents.

Initially, Ms. Raval and Dr. Simon had thought stents too risky. Unlike balloons, which are inserted briefly and removed, stents are permanent. They can migrate to somewhere they do not belong, like the heart, as occurred in Dr. Dake's patient. Or tissue growth can clog them.

But Dr. Simon and Ms. Raval could see no other option. On June 23, he implanted a stent in her two jugular veins.

"I really have a good feeling on this one," Ms. Raval said a few hours after the procedure. " I think this is the resolution, long-term. Let's wait and see."

In the meantime, Dr. Simon had conducted venograms on about 20 other patients with multiple sclerosis. He found narrowed veins in all but one. He said he was going to ask the hospital's ethics panel for permission to perform balloon procedures in those patients. But the hospital would have to figure out how to get paid: insurance might cover venograms, but not an experimental treatment. The total charge for the procedure, including both hospital and doctor fees, would be about $10,000, Dr. Simon said.

He and his partner, Dr. Noam Eshkar, said they knew many researchers thought patients should not be given unproven treatments outside of clinical trials. They said they did not disagree. But they also sympathized with patients who had progressive diseases and who felt they did not have the time to wait. "In the real world," Dr. Eshkar said, "things happen at the edge of scientific proof."

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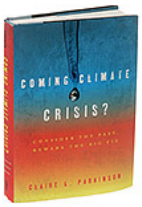

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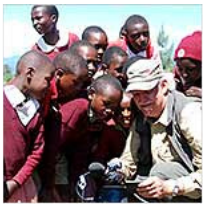

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