

Calgarian opts for MS surgery in India

Longtime MS sufferer going overseas

BY SHERRI ZICKEFOOSE, CALGARY HERALD MARCH 11, 2010



Steve Zanini and Michelle Zanini in their home on Monday March 08 in Calgary. Michelle Zanini has MS and is travelling to India for controversial treatment not offered in Canada. Their goal is that Michelle will better and they will be able to go dancing together by Christmas.

Photograph by: Dean Bicknell, Calgary Herald

A Calgary woman suffering from multiple sclerosis is heading to India for a controversial surgery because she says she doesn't have time to wait for Canada to approve it.

Michelle Zanini has been living with the debilitating and puzzling neurological disease since being diagnosed in 1992.

But after recently reading about a hotly debated Italian doctor's suggestion that MS is linked to poor blood drainage from the brain, and that an angioplasty surgery to open veins may help, Zanini became optimistic.

The procedure is not yet offered in Canada.

The controversy over whether the surgery that removes jugular vein blockages gets results has medical experts and MS specialists asking for more testing.

Zanini says she simply doesn't want to wait.

The early findings offer a glimmer of hope to her and the thousands of MS sufferers in the province.

"We have nothing to lose right now. There are no drugs to treat secondary progressives," said Zanini, 51, who is in a secondary progressive stage of the disease.

"What's to lose? I'm not going to get any stronger, no matter how many weights I lift or how far I pedal my recumbent bike. I'm ready. We will go wherever we have to."

She leaves for India on March 24.

"It's exciting, it's scary and nerve-racking. It's an emotional alphabet soup."

Zanini is a married mother of two grown daughters.

"We want to do it sooner rather than later, and if we can bring back good news to the MS community, it would be great to see things speed up in Canada."

"We live in a beautiful, safe place that doesn't put its citizens at risk. We don't want people to take any drugs that aren't tested. I'm ready."

The treatment itself is expected to cost between \$9,000 and \$12,000. Along with flights and accommodations, the final tab will likely be closer to \$35,000 to \$50,000.

Friends and family are raising money to help offset costs by holding a silent auction at the Calgary Winter Club.

While Zanini knows the procedure is not a cure for MS, she and her husband Steve are anxious to see what results are possible.

"We understand the MS clinic is being cautious and judicious, but when we look at Michelle's MS, we're not willing to wait any longer," said Steve.

"We're looking to lower the pain in her movement and hopefully we can be dancing by Christmas."

MS is a debilitating disease that most often strikes people between the ages of 15 and 40, many of whom live daily with paralysis, impaired speech, loss of balance and even blindness.

The procedure and theory hails from Italian surgeon Dr. Paolo Zamboni.

Experts in the medical community who believe the condition is an autoimmune disorder caused by immune cells that attack the brain and spinal cord say it's too soon to draw any conclusions about the controversial theory.

"Our primary concern when anyone leaves the country for care is the quality of care they'll receive," said Darrel Gregory, spokesman for the MS Society in Alberta.

"I know that people are anxious for a cure with CCSVI issue, but you if go to another country and come back, if there are complications you can get into trouble," he said.

"Medical standards may not be the same as ours. We're always very careful and cautious about that."

The MS Society is looking into funding further research into Zamboni's theory, having received overwhelming interest from patients interested in signing up for any future studies.

"There's reason to study it more, we're not 100 per cent sure it's a cause. We do think there's enough evidence there to do some more research," said Gregory.

Experts in the medical community say more investigation is needed into the theory.

A recent University of Buffalo study of 500 people appears to partly lend support to Zamboni's argument. It found a condition called chronic cerebrospinal venous insufficiency, or CCSVI, is more than twice as likely to occur in MS patients than healthy people.

The preliminary findings have not been peer-reviewed.

Skeptics of Zamboni's theory suggest a larger sample size of patients monitored over time to see how the vein blockage progresses is key to determining if an association exists between the two conditions.

It might turn out that a venous blockage does not play any role at all in the progression of multiple sclerosis.

Zanini is one of eight Canadians heading to India for the procedure.

They've been undergoing testing at Vancouver's False Creek Surgical Centre and have been referred to another group to go to India.

The medical clinic is sending doctors to meet with Zamboni and others to learn more.

szickefoose@theherald.canwest.com

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