

Victoria mom goes to Poland for new MS treatment

She says waiting for the procedure to be allowed in Canada simply 'isn't an option'

By Damian Inwood, The Province June 20, 2010 [Comments \(9\)](#)

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**Valerie MacNeil
hopes a new MS
treatment will allow
her to be an active**

mother to her daughter, Bhreagh, again. She will travel to Poland later this month to undergo an experimental treatment to unblock her veins.

Photograph by: Bruce Stotesbury, Times Colonist, The Province

Victoria mom Valerie MacNeil had only been in her dream job as an addictions counsellor for a few months when she started feeling the symptoms of multiple sclerosis.

Now she prays that going to Poland next week for a controversial MS treatment will transform her from an invalid into the active mother of her 11-year-old daughter.

"If I can just take my daughter Bhreagh to the beach this summer whenever she wants to go, I'm going to be happy, because I've missed out on so much," she said.

MacNeil said she first started getting MS symptoms in January 2008.

"I had numbness on one side of my torso and my hands and arms were getting a bit numb," she remembers. She went to a specialist, who couldn't find anything wrong.

"Then at work, I began to drop cups of coffee or pencils, which would slip out of my hand," she said. "I started not being able to write very well or to type very well. Then, one day at work, I lost control of my bladder -- and I called the specialist right away and said, 'Look, something is happening to me.'"

In June 2008, she had an MRI. The results showed she had MS lesions on her brain.

"I can't do my work, and that was my dream job," she said. "The main thing, though, is I can't be an active mom."

MacNeil is leaving for Tychy, Poland, on Sunday to undergo an experimental "liberation" treatment that was pioneered in Italy but which isn't available in Canada.

MacNeil will undergo a Doppler ultrasound test and a magnetic resonance venogram (MRV,) which costs between \$500 and \$600.

Those tests are not allowed for MS patients in Canada, she said, but if they were, they would cost \$2,350. (MacNeil plans to be part of a class-action complaint to the B.C. Human Rights Tribunal, claiming discrimination because the testing is not allowed here.)

MacNeil will then undergo a neurological consultation on June 26 and, if needed, will pay about \$4,400 for the "liberation" vein treatment.

It was developed by Italian doctor Paolo Zamboni and involves an angioplasty-style treatment to unblock veins. It's used to treat a condition known as chronic cerebrospinal venous insufficiency, or CCSVI, which Zamboni says can cause a buildup of blood and iron deposits in the brain.

The treatment, which can also involve inserting stents to keep the veins open, has had immediate and beneficial results in some patients.

Researchers from the University of B.C. are part of a \$2.4-million study, involving 200 people, announced Friday to look into Zamboni's theory. She said that when her tests for MS came back positive, it seemed like a mixed blessing.

"It was a shock, in a way. But it was also a relief, because I was starting to worry I had some kind of brain tumour or something where I'd be told I only had a few months to live."

She said she's read about the positives and negatives associated with Zamboni's treatment.

"I'm going in with hope," she said. "Even if I can get 20 per cent of my energy back, it will be worth it."

- Valerie MacNeil will receive her treatment in Poland on June 27. She'll be back in Victoria July 7 and The Province will catch up with her then, to see how effective the treatment has been.

dinwood@theprovince.com

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