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MS patients rally for experimental treatment

By CBC News
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Canadians with multiple sclerosis rally across the country to demand access to a controversial procedure not available in Canada or covered by provincial health insurance policies.

Canadians with multiple sclerosis rallied across the country Wednesday to demand access to a controversial procedure not available in Canada or covered by provincial health insurance policies.

The procedure, developed by Italian researcher Dr. Paolo Zamboni, involves angioplasty to help ease the flow in neck veins of blood from the brain to the heart. Zamboni believes narrowed or blocked veins force blood to move backwards or reflux back into the brain and spine, causing damage.

He's termed the condition chronic cerebrospinal venous insufficiency, or CCSVI.

Rallies were planned for Halifax, Ottawa, Toronto, Regina, Edmonton, Vancouver, Victoria and elsewhere.

"With this kind of an illness, there isn't time for them to take three years to find out something," said Jennifer Noriega of Edmonton, a 38-year-old mother of two who has been living with MS for 11 years.

Noriega, who can no longer walk, tried many different medications, including chemotherapy drugs, and now plans to travel to Bulgaria for the treatment.

"The risk might be that it works and then three months later it doesn't work," Noriega said. "But at least I'll have those three months."

More than 20 Canadians travelled to a clinic in Poland between February and April for the treatment.

Many MS specialists say Zamboni's procedure is experimental at best and could be dangerous.

Studies are underway to show how common CCSVI is in MS patients, those with other neurological conditions and healthy people, as well as to explore its potential role as a major risk factor in MS.

But despite the specialists' hesitation, some Canadian patients are travelling overseas, paying for tests and surgery out of their own pocket. Others are lobbying for the Canadian health-care system to cover the diagnostic tests to look for blocked veins in people with MS.

"I've been fixed," Steve Garvie, 53, told the crowd gathered at Queen's Park in Toronto. Garvie was one of five people who had the procedure at Royal Victoria Hospital in Barrie before the surgeon voluntarily stopped.

"What they're doing is criminal," Garvie added in an interview. "Every person that wants the operation should have it."

"With any new treatment, whether it's drugs or technology, we need to ensure that it is thoroughly researched before it is approved for use," said Andy Weiler, a spokesperson for Alberta Health. "It needs to be an evidence-based decision that it is a safe and effective treatment."

Likewise, Nova Scotia's Minister of Health, Maureen MacDonald, met with protest organizers in Halifax for about 30 minutes on Wednesday but was not swayed by their arguments.

"We still don't know what the risks or the evidence are of the treatment," MacDonald said. "At this stage, it would be premature to have kind of a mass testing process for a treatment that is still unproven."

MacDonald said no other province is funding this kind of testing or treatment for MS.

\$10 M in federal funding sought

In a release Wednesday, the Multiple Sclerosis Society of Canada called on the federal government to provide \$10 million for research into CCSVI and MS.

The MS Society proposes that the \$10 million be appropriated to the budget of the Canadian Institutes of Health Research and earmarked for CCSVI research.

MS Society representatives were to meet with MPs in Ottawa on Wednesday and Thursday to discuss other major issues:

- Creating a nationwide income security program for people affected by MS that would replace what the society calls "the current hodgepodge of disability pensions, social assistance programs and tax credits, some of which cannibalize each other, resulting in less money for people with disabilities."
- Increasing funding for health research with a focus on "innovative health research that can be translated rapidly into therapies that can benefit people with MS and other chronic conditions," including research into CCSVI.

Last month in Toronto, Zamboni and his collaborator, Dr. Robert Zivadinov, associate professor of neurology at State University of New York at Buffalo, cautioned people with multiple sclerosis to not rush to seek out the surgical procedure to unblock veins unless it was through official clinical studies.

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