

January 26, 2011

Theresa Oswald, Minister of Health
Room 302 Legislative Building
450 Broadway
Winnipeg, Manitoba R3C 0V8

Dear Ms. Oswald,

On behalf of the Multiple Sclerosis Society of Canada, Manitoba Division, we once again thank you for your recent commitment to helping us end MS. Your allocation of \$500,000 towards chronic cerebrospinal venous insufficiency (CCSVI) pan-Canadian therapeutic clinical trials, your over \$500,000 additional investment in the MS Clinic at the Health Sciences Centre and the addition of Tysabri to the Drug Formulary are strong steps in enabling people affected by MS to enhance their quality of life.

We are interested in furthering the MS Society's mission, and are writing to request that the Government of Manitoba put in place a systematic approach to key issues relating to CCSVI.

As you are aware, the Multiple Sclerosis Society of Canada and the U.S. National MS Society have funded seven research projects that are examining the association between CCSVI and MS. We are currently in the first year of a two-year study and expect preliminary results to be released late next year. In addition, the MS Society has committed \$1 million toward a pan-Canadian therapeutic clinical trial, if and when warranted. We are getting closer to this realization since your government among others, has committed funds for further study of treatment therapies for CCSVI. We believe the Government of Manitoba can be part of other important initiatives in two additional ways:

1. Create a registry for patients who have treatment for CCSVI abroad, and work with the MS Society of Canada to advocate to the federal government to play a coordinating and funding role similar to registries across Canada. The tragic death of an Ontarian following treatment overseas for CCSVI makes compelling the need for systematic data about CCSVI, collected through a registry or through observational studies. This requires urgent action while we await more probing data on whether there is a correlation between MS and CCSVI sufficient to warrant a more definitive random controlled treatment trial of CCSVI.

2. Ensure that no one who undergoes treatment for CCSVI abroad, is denied the necessary post-treatment, follow-up medical care they require when they return home. Recent media coverage has demonstrated that growing numbers have experienced complications from receiving treatment abroad. By post-treatment follow-up medical care, we do not intend to mean that physicians in Manitoba should be compelled to perform the CCSVI treatment or to re-do treatments where the initial treatment has failed or the veins have become obstructed again. Rather, we want to ensure that residents of Manitoba have access to appropriate specialist care for follow-up and/or complications ensuing from CCSVI treatment obtained abroad.

We would welcome the opportunity to discuss these matters with you prior to April 1, 2011.

We hope that you will continue to lend your support to the MS cause. People with MS are our top priority, and we are taking initiative to ensure that adequate information is available and research is being done to provide this community with quality information for them to make informed decisions. We look forward to strengthening our partnership with you in investing in CCSVI research for residents in Manitoba living with multiple sclerosis.

Yours sincerely,



Wendy O'Malley
President, Manitoba Division



Brian Lerner
Chair, MS Society Board of Directors

cc: Yves Savoie, President & Chief Executive Officer, Multiple Sclerosis Society of Canada
Dr. Ruth Ann Marrie, Director, MS Clinic, Health Sciences Centre
Darell Hominuk – Director, Client Services and Government Relations, MS Society