



A U S T R A L I A
Giving life back



16 August 2012

Parliamentary Friends of MS

C/- Senators Lundy and Humphries

Parliament House

Canberra ACT 2600

Dear Senators Lundy and Humphries,

Chronic Cerebrospinal Venous Insufficiency (CCSVI) and multiple sclerosis (MS)

Thank you for facilitating our recent Parliamentary briefing on CCSVI and MS. We are grateful for being given the opportunity to share the latest information about this area and tell the real life stories of people living MS whose lives have changed after vascular treatment.

As discussed at the briefing, this letter is to confirm the actions we are actively pursuing; for which we seek your advice and support.

The CCSVI trial at the Alfred Hospital

A trial of the balloon angioplasty procedure in 160 patients has been proposed by The Alfred in Melbourne. The trial has ethics approval and has been reviewed and approved by Multiple Sclerosis Research Australia. The trial has received funding of \$95,000 thus far, given by MS Australia from money raised by the MS community and CCSVI Australia for this specific purpose. In total the funds contributed include \$15,000 from the CCSVI Australia community, \$73,000 from MS Australia and \$7,000 interest accrued during the period that the money was held in trust by MS Australia.

The total cost of the trial, however, is in excess of \$450,000, leaving a significant shortfall of \$335,000 to complete the research.

MS Australia will actively work with the Alfred Hospital to engage funds to complete this vital research. In addition we ask for your support in advocating for funding support of the trial to

the National Health and Medical Research Council and the Minister for Health to ensure the future of this vital research.

The need for a balloon angioplasty Medicare item number

As covered at the Parliamentary briefing, while the diagnosis of CCSVI by Doppler ultrasound can be accessed under the Medicare Benefits Scheme, the most common form of treatment – balloon angioplasty – cannot. Angioplasty is available under the scheme for various conditions involving venous abnormalities, but it is not available for treatment of venous abnormalities if patients have multiple sclerosis.

We will be working with representatives of the phlebological community to progress a campaign to rectify this issue, and would warmly welcome any advice or support from our Parliamentary friends.

In addition to these two pressing matters, we will endeavour to raise awareness of this important issue and will shortly be seeking briefing meetings with the Department of Health and Ageing to appraise them of our activities and the latest research.

As always, we are truly grateful for your continued support of issues faced by people living with the effects of multiple sclerosis across Australia. We hope we can continue working together to improve the quality of life of thousands of people living with this unpredictable disease every day.

Please contact me if you require any further information, or would like to discuss the above.

Yours sincerely,



Rob Hubbard

President

MS Australia



Kerri Cassidy

CCSVI Australia