



## Cardiovascular Issues and Multiple Sclerosis



Turn**On**the Tap

Deidre Mackechnie

CEO, MS Australia

(original via email – copies to – [see Footnotes](#))

Associated Correspondence <http://www.msnetwork.org/bookmarks/advocacy-parliament.htm>

12 May 2016

Ref RM2309MS

Dear Deidre

### **Open Letter to the Australian Parliament**

Our MS News update to MS Australia of 1 March titled “What's New in the world of Multiple Sclerosis - Cautionary Guidance for Service Providers’ – referenced cautions about the presence (frequently undetected) of cardiovascular disorders in many people diagnosed with Multiple Sclerosis. An upgraded edition of this Guidance is at <http://www.msnetwork.org/caution.htm>

Ongoing feedback about this issue subsequently prompted the development of an Open Letter to the Australian Parliament on behalf of more than 2,700 Australian Families who expressed written concerns about difficulties in accessing appropriate cardiovascular assessments. This process is being facilitated by the Multiple Sclerosis Network of Care Australia and CCSVI Australia.

No feedback was received from organisations operating under the MSA banner. This is possibly because it is not a function of MSA to provide individual medical advice - that being a matter entirely between an individual and their medical advisers. Your predecessor, Debra Cerasa, made that point when MSA stepped back from its commitment of 16 August 2012 to "raise awareness of this important issue” – about this commitment <http://www.msnetwork.org/library/CCSVI-Follow-up-letter-PFMS.pdf>

Notwithstanding, much has since transpired and it is not our intention to revisit old ground. Our primary reason for now contacting you relates to feedback received about MSA’s 5 May 2016 Parliamentary submission relating to better support for families living with MS. Unfortunately we have yet to see this submission, Could you kindly provide a reference as to where it is available from your web site.

Our particular interest is to what extent, if at all, MSA has specifically advocated in relation to the cardiovascular issues highlighted by the aforementioned Families. It is important, especially in an election year, for Parliamentary Representatives to have opportunities to hear first-hand from wide cross sections of any community. That is what our Open Letter and its many components are all about. Shortly stated the Open Letter seeks;

Bipartisan support of the Parliament "to assist in accelerating the processes whereby what is being learnt regarding cardiovascular irregularities and MS is better translated into benefits for patients and reduced government outlays"

Details of broadly based recommended policies and programs are also referenced – To access the Open Letter and also learn heaps more about what is happening in the field of neurovascular issues as related to multiple sclerosis click here - <http://www.msnetwork.org/news>

We look forward to your support of our endeavours to ensure that the voices of this very significant number of Australian Families living with a Multiple Sclerosis diagnosis are heard, respected and acted upon.

*Peter Sullivan and Kerri Cassidy,*

on behalf of CCSVI Australia Reference Group

<http://www.msnetwork.org/trials.htm>

Email [election@msnetwork.org](mailto:election@msnetwork.org)

Footnotes

Copied to MS Australia Network and Parliamentary Friends of People with MS

**Cc:** Senator Deborah O'Neill <[senator.o'neill@aph.gov.au](mailto:senator.o'neill@aph.gov.au)>; Senator David Bushby

<[senator.bushby@aph.gov.au](mailto:senator.bushby@aph.gov.au)>; Kerri Cassidy CEO CCSVI Australia <[kerric@ccsviaustralia.com.au](mailto:kerric@ccsviaustralia.com.au)>

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**From:** Deidre Mackechnie [<mailto:Deidre.Mackechnie@msaustralia.org.au>]

**Sent:** Thursday, 19 May 2016 4:54 PM

**To:** Eva and Peter Sullivan <[sullys452@bigpond.com](mailto:sullys452@bigpond.com)>

**Cc:** [kerric@ccsviaustralia.com.au](mailto:kerric@ccsviaustralia.com.au)

**Subject:** RE: MSA's 5 May 2016 Parliamentary submission regarding Multiple Sclerosis

Dear Peter and Kerri,

Thank you for your email and the attached letter.

A copy of MSA's 2016 Election Submission is available from the MSA web-site:

<https://www.msaustralia.org.au/about-us/what-we-do>

In summary, you will see that within the 10 issues that we are asking each party to commit to, there are three related to research and seven related to improving the lives of people affected by MS. These 10 issues were determined through a lengthy process involving advice from our National Advocates team (all of whom are people living with MS or carers), the state MS societies, MS researchers and the MSA Board.

We have not included any specific advocacy regarding cardiovascular issues, though we suggest Commitments 1 and 2, given they are broad and encompass a range of research activities aimed at

finding a cure and improving brain health, are in line with your cause. MSA continues to be guided by MS Research Australia regarding developments in MS research both in Australia and internationally.

Best wishes,  
Deidre Mackechnie

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Response 21 June 2016

To: Deidre Mackechnie  
CEO, MS Australia  
bcc: MSA network

**Subject:** Open Letter to the Australian Parliament

**Topic:** Cardiovascular disorders in people diagnosed with Multiple Sclerosis.  
Our correspondence of 12 May 2016. Your reply 19 May 2016

Dear Deidre

You will be pleased to hear that Parliamentary feedback about the issues highlighted through the Open Letter has enabled important key issues to be identified and the strengthening of associated communication channels. Details are overviewed in our 19 June update on this topic – see <http://www.msnetwork.org/news/June-2016.htm>

We continue to look forward to your support (and that of the broader MSA environment) of our endeavours to ensure that the voices of a very significant number of Australian Families living with a Multiple Sclerosis diagnosis are heard, respected and acted upon.

Very best regards

Peter Sullivan and Kerri Cassidy  
RM2320MS also refers

<http://www.msnetwork.org/voting/About-Kerri-Cassidy.htm>  
<http://www.msnetwork.org/voting/About-Peter-Sullivan.htm>

On behalf of more than 2,000 Australian Families living with an MS diagnosis.

See Open Letter at <http://www.msnetwork.org/electorates/openletter.htm>  
Email [election@msnetwork.org](mailto:election@msnetwork.org)

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Coalition response of 29 June 2016 (Abridged)

### **Coalition response to cardiovascular risk factors to multiple sclerosis**

On 29 June 2016 the Coalition (Tony Nutt - National Campaign Director) acknowledged the importance of cardiovascular risk factors to multiple sclerosis (MS). It confirmed its commitment to supporting Australians with MS through access to medicines and research into new treatments. It

said “we believe Australian patients should have timely access to innovative new treatments that have been independently assessed as safe, effective and cost-effective”

Full text

<http://www.msnetwork.org/advocacy/Coalition-CCSVI-Policy-2016.pdf>

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