



2016 Australian Election - An Open Letter to the Australian Parliament regarding Multiple Sclerosis



To: Key Australian Parliamentary Health Care Decision Makers
Parliament House, Canberra (original via email – copies to – [see Footnotes](#))
Associated Correspondence <http://www.msnetwork.org/bookmarks/advocacy-parliament.htm>

11 April 2016

Ref RM2227MS

In March 2016 the Leaders of Australia's Political Parties were asked to clarify the ways in which their Party's Policy Platforms for the 2016 Election address Cardiovascular issues experienced by significant numbers of people diagnosed with Multiple Sclerosis. As part of this process a number of key Health Care decision maker have since been invited to participate in the following consultative processes aimed at providing better safeguards for such people (estimated at around 24,000 across Australia).

Breakthrough research consistently identifies (treatable) vascular irregularities as contributing to many of the most common symptoms of Multiple Sclerosis. Despite this, access to appropriate vascular screening and associated Medicare coverage is not routinely available. Something is seriously wrong. – could you please try to assist in fixing this

Clarification of Bipartisan Policy Position Cardiovascular issues and Multiple Sclerosis



We are writing to advise of your nomination (as an elected representative see [Figure 1](#)) to participate in a consultative process aimed at providing better safeguards for people diagnosed with Multiple Sclerosis who may also have chronic cardiovascular disorders

This process was initiated in March 2016 when the leaders of all of Australia's major political parties (and all independents) were invited to clarify their party's position regarding a bipartisan approach to implementing policies and programs that **"assist in accelerating what is being learnt regarding Cardiovascular Issues and Multiple Sclerosis into benefits for patients and reduced government outlays"**. See <http://www.msnetwork.org/caution-parliament.htm#leadership>

Protecting the Vulnerable

Of significance, and perhaps contrary to popular belief, Multiple Sclerosis Australia does not provide medical or legal advice. It says that “people must seek their own advice as may be appropriate”. This is cold comfort for seriously ill people trying to come to grips with an MS diagnoses. Processes need to be in place to protect the vulnerable. See <http://www.msnetwork.org/action/protecting-the-vulnerable.htm>

Our Interactive Open Letter



A highly successful ‘***must watch, read and comment***’ interactive Open Letter is also provided in order to generate ongoing consumer focussed feedback. The first stage of which involved the identification of the Decision Makers considered best able to give effect to the desired outcomes.

While a large body of *quantitative* evidence is now available this consumer focused *qualitative* feedback helps the broader community to better appreciate the consequences of systemic failures in properly addressing cardiovascular problems experienced by people living with MS. Something is seriously wrong.

It is our view, especially in the light of the forthcoming Federal Election, that the Parliament needs to take ownership of its own shortfalls in this area by effectively addressing these issues including urgently working towards implementing the recommended patient centred solutions. Three suggested steps in this rebuilding process follow.

Establishing Effective Communication Channels



First, we recommend accessing the Open Letter and its associated options. It will also enable you to communicate directly with the MS community through constructive comment and support. Be aware that each year an estimated 1000 Australians are diagnosed with MS.

Up to 80% will have underlying (and undetected) potentially treatable serious cardiovascular disorders. The majority will be fast tracked onto expensive immunotherapies unrelated to cardiovascular issues. There is currently no mandated safeguard to ensure people are made aware of these underlying conditions – treatment delayed is treatment lost. . Commence your journey at: <http://www.msnetwork.org/electorates/openletter.htm>



Second, we emphasise how important it is to us to receive advice from individual Party Leaders that clearly explains the ways in which their Policy Platforms for the 2016 Election address these important issues. This advice can be sent to email election@msnetwork.org

During May 2016, we will be passing this information, along with details of past performance, onto the broader MS community.



Third, communication may well improve were we able to communicate directly with specific Representative/s with ongoing responsibility for the parliamentary carriage of the issues referenced in the Open Letter. No new medications or medical procedures are involved. The issues are exclusively about access and protecting the vulnerable. If this can be arranged please let us know at email leadership@msnetwork.org

5 Years is a Long Time

5 years down the track and notwithstanding significant advances in understandings, including warnings about the consequences of a failure to identify cardiovascular disorders in pwMS, we hold the view that the Australian Government has not yet honoured its undertakings to assist in fast tracking progress.

The MS Community is Committed

Through its close involvement with leading Australian Vascular Specialists (with strong international linkages) the Australian MS community itself is already making significant commitments, including financial, in bringing about all of these changes. We had been given to understand that the Australian Government would similarly invest on a bipartisan basis. Learn more about these developments

<http://www.msnetwork.org/advocacy/questions.htm>

Peter Sullivan and Kerri Cassidy,
on behalf of CCSVI Australia Reference Group

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

PO Box 10, Blackburn, VIC, 3130

Email election@msnetwork.org

Subsequent Developments

Since the early 1990's neurologists have underpinned the management of Multiple Sclerosis on the belief that it is strongly associated with an overactive immune system. Treatment invariably involves "dampening down" the immune system via a diverse range of immuno suppressant drugs. The global market for these drugs is approaching \$20 billion p.a. - much of which is achieved through government subsidies.

On 6 April 2016 , the highly respected National MS Society (USA) drew an important line in the sand in relation to these drugs when it issued a press release that emphasised "there are FDA-approved therapies that can impact the underlying disease course in people with the more common forms of MS. **However, none of these can stop progression or reverse the damage to restore function.** See

<http://www.msnetwork.org/caution-parliament.htm#progression>

Footnotes



Our Election Scorecard

Figure 1

Health Minister, Susan Ley,
 Leader, Australian Liberal Party. The Hon
 Malcolm Turnbull

Deputy Leader, Australian Liberal Party, The
 Hon Julie Bishop MP

Leader, Australian Labor Party, The Hon Bill
 Shorten MP

Deputy Leader, Australian Labor Party, The
 Hon Tanya Plibersek

Leader, Australian Nationals, The Hon
 Barnaby Joyce MP

 Deputy Leader, Australian National Party,
 Senator Fiona Nash

Leader, Australian Greens, Senator Richard
 Di Natalie

Deputy Leader, Australian Greens, Senator
 Larissa Waters

Bipartisan Decision Making

Committees

Chair, Senate Health Committee Senator Deborah
 O'Neill

Chair, House of Representatives Health
 Committee, Mr Steve Irons MP

Innovation Influence

 Assistant Minister for Innovation, Hon Wyatt
 Roy

Consumer Focused Advocacy

 CEO CCSVI Australia, Kerri Cassidy

 Convenor, Multiple Sclerosis Network of
 Care Australia, Peter Sullivan

Parliamentary Friends of people with MS, Senator
 David Bushby

Age and Disability Human Rights Commissioner,
 Hon Susan Ryan AO

REFERENCES

About Innovation Management <http://www.msnetwork.org/innovation.htm>

Bipartisan Open Letter/Petition <http://www.msnetwork.org/electorates/openletter.htm>

Time to Stand up and be counted <http://www.msnetwork.org/caution-parliament.htm>

Treatment Delayed is Treatment Lost <http://www.msnetwork.org/advocacy/rep-healthcommittee.pdf>

Ministerial Innovation Update <http://www.msnetwork.org/advocacy/Hon%20Wyatt%20Roy.pdf>

RECIPIENTS

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 Cassidy CEO CCSVI Australia (kerric@ccsviaustralia.com.au); Malcolm Turnbull MP - Liberal Party Leader
 (libadm@liberal.org.au); MP Julie Bishop (Julie.Bishop.MP@aph.gov.au); MP Sussan Ley Health Minister
 (minister.ley@health.gov.au); MP Tanya Plibersek (tanya.plibersek.mp@aph.gov.au); Peter Sullivan

Convenor MS Network of Care (Aust) (election@msnetwork.org); Senator David Bushby (senator.bushby@aph.gov.au); Senator Deborah O'Neill (senator.o'neill@aph.gov.au); Senator Di Natalie - Greens (senator.dinatale@aph.gov.au); Senator Fiona Nash - Asst Health Minister (senator.nash@aph.gov.au); Senator Larissa Waters (senator.waters@aph.gov.au); Steve Irons MP . Health Committee (Steve.Irons.MP@aph.gov.au); Susan Ryan - Disability Human Rights Commissioner (infoservice@humanrights.gov.au); Wyatt Roy MP (wyatt.roy.mp@aph.gov.au)