Multiple Sclerosis and the Australian Parliament - Time to Stand up and be Counted

The Hon Bill Shorten
Party Leader, Australian Labor Party
Parliament House, Canberra (original via email – copies to – see Footnotes)
Associated Correspondence http://www.msnetwork.org/bookmarks/advocacy-parliament.htm

Dear Bill

Clarification of ALP Policy Position
Cardiovascular issues and Multiple Sclerosis

With the approach of 2016 World Multiple Sclerosis Day with its theme ‘Independence’ we are reminded that it is almost 5 years since the then member for Page, Janelle Saffin first alerted the Australian Parliament (Hansard of 30 May 2011) on behalf of the Australian MS community, that the majority of those living with Multiple Sclerosis are being found to have serious cardiovascular irregularities of a type not previously detected - a condition called Chronic Cerebrospinal Venous Insufficiency (CCSVI).

Janelle referenced the experiences of many who found that treatment of this condition via venoplasty, a long standing day surgery cardiovascular procedure, achieved dramatic relief from many of the most common symptoms of MS. Shortly thereafter it was agreed to progress Parliament's role in this matter on a bipartisan basis including priority in fast tracking a related clinical trial being undertaken at the Alfred Hospital in Melbourne.

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. A recent communication with the Hon Wyatt Roy, (Assistant Minister for Innovations) said “No new medical procedures are involved – it’s all about the rights of people with MS to access long established and proven medical interventions”

The stakeholders who benefit most are:

1. The MS community itself through dramatic drug free relief from many of the most common symptoms MS
2. The Australian Government through significant reductions in expenditures including pharmaceuticals, income support and NDIS.
3. The broader Australian economy through the return of several thousand highly talented Australians to the workforce.
The Australian MS community itself is already making significant financial investments in bringing about all of these changes. We had been given to understand that the Australian Government would similarly invest on a bipartisan basis.

**What is needed by way of Parliamentary Interventions?**

In July 2015 a submission to the Australian Parliament titled "Treatment Delayed is Treatment Lost" consolidated wide ranging parliamentary dialogue since 2011. Shortly stated it identified the overall aim for Parliament as “accelerating the processes whereby what is being learnt is better translated into benefits for patients and reduced government outlays”. The scope of associated policy and program interventions being:

1. Funding support (on a dollar for dollar basis up to a maximum of $250,000) for the already commenced trial at the Alfred Hospital in Melbourne. Described by MS Australia as "vital research" this trial has since received international recognition and endorsement.

   Apart from the specific research associated this trial, the expertise being attracted to what is being learnt is positioning Australia well for the diffusion of knowledge of this type across the broader Australian (and International) medical professions. Based upon what has already been demonstrated it deserves far better strategic understanding and support at the highest political levels.

2. Encouraging additional clinical trials, with a specific focus on the role of Percutaneous Venoplasty in addressing vascular irregularities, and the consequential relief of most common CCSVI symptoms frequently experienced by many diagnosed with MS.

3. The implementation of an Australian National Monitoring System (ANMS) that includes retrospective opportunities for the registration/recognition of those that have/are being treated and captures relevant information. This recommendation has also been flagged by HealthPACT.

4. Ensuring the availability of Medicare rebates for all recognised CCSVI related procedures.

5. The ANMS to also enable screening and treatment to be offered to those who may so benefit from symptom relief – over and above those participating in more comprehensive clinical trials.

6. Screening for possible vascular irregularities to be undertaken, during the diagnostic stages of MS, as a prerequisite to qualifying for immunotherapy subsidies. Also flagged by HealthPACT.

**OUR QUESTION**

We ask, to what extent, if at all, Australian Labor Party policies, both short and long term, support progressing each of these 6 long standing interventions that underpin the overall aim. This question is also being asked of all Parliamentary Parties and a growing number of elected representatives - with all responses becoming publicly available from 15 May 2016.

**KEEPING IT SIMPLE**

By May 2016 our Election 2016 campaign evolved into one simple question whereby Candidates and Party Leaders were asked "Given hat no new medical procedures or new medications are involved will you undertake to use your best endeavours to advocate for the Australian Parliament to assist in accelerating what is being learnt regarding cardiovascular disorders and multiple
sclerosis into benefits for patients and reduced government outlays." Here is a link that also enables a response to this question - http://www.msnetwork.org/voting

REFERENCES

Time to Stand up and be counted http://www.msnetwork.org/caution-parliament.htm
Treatment Delayed is Treatment Lost http://www.msnetwork.org/advocacy/reps-healthcommittee.pdf
Ministerial Innovation Update http://www.msnetwork.org/advocacy/Hon%20Wyatt%20Roy.pdf

Peter Sullivan and Kerri Cassidy,
on behalf of CCSVI Australia Reference Group
Email election@msnetwork.org

Facebook Update of 26 May 2016

Hi Bill - in terms of remarkable people please don’t forget to also better support those living with a Multiple Sclerosis Diagnosis who have serious but untreated cardiovascular disorders, Here is an update.

Digital Democracy – Enhancing the Political Process

With a focus on the “Independence” theme of 2016 world MS day, and in parallel with the lead up to the 2 July Australian election the extended Australian MS Community is seeking to better understand where each parliamentary party, and those seeking election/re-election, stand in relation to the impact of cardiovascular problems on MS progression.

Polytrak is a novel new resource that helps to keep track of ongoing progress thereby assisting this Community to join in to advance this important conversation - especially with Party Leaders and Candidates in individual States and Electorates. A handy shortcut is http://www.msnetwork.org/polytrak

The community is using #StrongerThanMS and #neurovascular, #CCSVI and/or #HeartBrainConnection and #democracy to help bring this innovation to the world’s attention.

Reference Facts Sheet RM2223MS

Footnotes

Copied To '(MinisterforHealthandAgeing@health.sa.gov.au)'; 'Amanda. Rishworth. MP (Amanda.Rishworth.MP@aph.gov.au)'; 'Janelle Saffin (jasaffin@nor.com.au)'; 'Janet Hasall - for Jason Wood MP (Janet.halsall@aph.gov.au)'; 'Jason Clare MP (Jason.Clarie.MP@aph.gov.au)'; 'Jason Wood - MP (Jason.wood.mp@aph.gov.au)'; 'Kelly. Odwyer. mp (kelly.odwyer.mp@aph.gov.au)'; Kevin Hogan MP Member for Page (kevin.hogan.mp@aph.gov.au); MP Catherine King - Ballarat
(Catherine.King.MP@aph.gov.au); 'MP Chris Hartcher - Terrigal (terrigal@parliament.nsw.gov.au)'; 'MP David Davis - Victoria (david.davis@parliament.vic.gov.au)'; 'MP David Hodgett MP - Victoria (david.hodgett@parliament.vic.gov.au)'; 'MP Jennifer Rankine - SA (wright@parliament.sa.gov.au)'; 'MP John D Hill - SA (minister.health@health.sa.gov.au)'; 'MP Julie Bishop (Julie.Bishop.MP@aph.gov.au)'; 'MP Kelly Vincent (Kelly.Vincent@parliament.sa.gov.au)'; 'MP Tanya Plibersek (tanya.plibersek.mp@aph.gov.au)'; 'MP Thomas George (thomas.george@parliament.nsw.gov.au)'; 'MP Tony Abbott (Tony.Abbott.MP@aph.gov.au)'; 'MP Tony Smith (Tony.Smith.MP@aph.gov.au)'; Senator Deborah O'Neill (senator.o'neill@aph.gov.au); Tony Burke MP (Tony.Burke.MP@aph.gov.au); Tony Zappia MP (Tony.Zappia.MP@aph.gov.au)

Additional Recipients