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MS Research Australia Submission to the Senate Community Affairs Legislation Committee

***Inquiry into the Medical Research Future Fund Bill 2015 and the Medical Research Future Fund
(Consequential Amendments) Bill 2015***

In support of the submission by Medical Research Future Fund Action Group

Thank you for providing MS Research Australia with the opportunity to comment.

MS Research Australia endorses the submission from Medical Research Future Fund Action Group regarding the Medical Research Future Fund Bill 2015 and the Medical Research Future Fund (Consequential Amendments) Bill 2015.

MS Research Australia is the research arm of MS Australia. Its mission is to accelerate research toward the prevention, better treatments and a cure for multiple sclerosis (MS). MS Research Australia partners with relevant medical research institutes and scientists around Australia, to directly fund research as well as coordinating national and international collaborations in areas of research priority to MS. MS Research Australia also partners with other medical research funding bodies where relevant, including the NHMRC, to provide research grants.

MS is the most common acquired chronic neurological disease affecting young adults. There are 23,000 people living with MS in Australia and this number increasing. People are more likely to be diagnosed in early adulthood and three quarters are women. This has profound effects on an individual's ability to fulfil expected life roles at a stage when careers, relationships, and adult life in the community are consolidating, with resulting impacts on work, family, and social life.

MS is caused by an autoimmune process directed against myelin, which provides the insulating layer of nerve fibres in the brain and spinal cord. The medical research sector in MS is very strong and basic research has identified many of the genetic and environmental triggers of MS as well as a number of the disease processes involved. This past research has resulted in improvements to management and therapies for the most common form of MS, relapsing remitting MS, which translates to earlier diagnosis, less hospitalisations and slower disability accumulation compared to a decade ago.

For patients with primary progressive MS or those entering the secondary progressive phase of relapsing remitting MS, there is a very limited response to these therapies. Further research and drug development is vital to offer hope to these patients. A cure does not exist for any form of MS.

Therefore, MS Research Australia strongly supports the establishment of an ongoing, stable source of funds to be dedicated to medical research in Australia. However, the current Bill requires some minor amendments to ensure that the wording of the Bill maximises the potential for genuine innovation and research progress.

In particular, we would like to highlight our support for the following points made in the submission by the Medical Research Future Fund Action Group.



The definition of medical innovation is too narrow in the current form. We endorse the proposed wording changes suggested by the Medical Research Future Fund Action Group to include any *new or better ways to improve the health and wellbeing of individuals and the community*. As mentioned above, the mission of MS Research Australia includes the acceleration of research into better treatments for MS, but we also target prevention and research towards a cure. This broader approach allows MS Research Australia to fund a range of research priorities to improve the lives of people with MS and suggest a similar approach is warranted with the Medical Research Future Fund to ensure maximum utility.

We agree with the importance of the Australian Medical Research Advisory Board and the inclusion of the NHMRC CEO on the Board. This Board offers a significant opportunity to refine the goals and directions of the Medical Research Future Fund, not only in the short term, but also ensuring the long-term success of the Fund. This initiative mirrors the MS Research Australia International Research Review Board, which identifies promising areas of Australian research that complements and communicates with the worldwide effort. This develops the MS Research Australia strategic direction and focus for the allocation of funding for Australian research, thereby ensuring research funding is applied relevantly and efficiently. The Australian Medical Research Advisory Board would be in an ideal position to perform a similar function for the Medical Research Future Fund.

Further, the inclusion of community and consumer representation on the Australian Medical Research Advisory Board is important to ensure that this voice is captured. While a rigorous appointment process would need to apply to all members of this panel, community consultation is an important pillar of the research strategy for MS Research Australia moving forward and we agree this is also necessary for the Medical Research Future Fund. Members of the MS Research Australia and MS Australia executive teams would welcome the opportunity to represent the MS community on such a panel.

It is vital that the Medical Research Future Fund is a sustainable resource and of a suitable magnitude to achieve its funding goals. MS Research Australia supports the suggestions made by the Medical Research Future Fund Action Group regarding the reporting lines and other provisions for financial assistance as well as preserving the real value of the Medical Research Future Fund. Investment to support medical innovation, with the limitations outlined in the Medical Research Future Fund Action Group submission, would also provide a mechanism to improve funding for a current gap in the research translational pipeline.

Once again, we would like to thank you for undertaking this consultation and for providing us with the opportunity for comment.

Yours sincerely,

Dr Matthew Miles
Chief Executive Officer, MS Research Australia