Online submission to PBAC regarding Gilenya® (fingolimod) for Relapsing Remitting MS (RRMS) for patients who weigh 40kg or less including paediatric patients

Submissions to be lodged by 12 June at:
https://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form

Medicine:	**Gilenya®** (fingolimod)
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Declaration of interest:

MS Australia is making this submission as we have an interest in the health and well-being of all people with MS. MS Australia is the national peak body for people living with MS in Australia. We work with governments at all levels, engaging on the issues that concern the lives of people living with MS, their families and carers, the community and the economy. We declare that we have in the past received funding support from Novartis and from other pharmaceutical companies with an interest in MS in the form of grants for projects.

Consumer input:

MS Australia is writing to support the inclusion of the medication fingolimod (brand name Gilenya®) to the Pharmaceutical Benefits Scheme (PBS) for people with relapsing remitting MS (RRMS) who weigh 40kg or less, including paediatric patients. As the national peak body for people with MS we are proud to advocate on behalf of our member organisations and the MS community. One area we are particularly passionate about is the provision of more affordable and accessible treatments that can improve the lives of people with MS.

There are currently more than 25,600 people living with MS across the country and over 7.6 million Australians know or have a loved one with this potentially debilitating disease. MS can be particularly debilitating and has an unpredictable disease course. No two cases of MS are the same. There is no one-size fits all treatment for people living with MS and to date, there is no known cure.

The challenges faced by people with MS can be significant and can have a devastating impact on their families and the wider community. Relapses can result in short term or long term disability, resulting in the need for physical and/or psychological care and support, medical investigations, treatments and hospitalisation.

Being able to better manage and limit the frequency and impact of relapses can help alleviate the burden of MS on the community and the individual.

To date, there have been no disease-modifying therapies available to people diagnosed with MS for children or adolescents under 18 years of age, including paediatric patients.

It is estimated that there are less than 350 people diagnosed with MS in Australia aged under 25 years of age, so there will be a limited financial impact of including this medication on the PBS for paediatric patients.

Including this medication on the PBS will, however, make a valuable addition to the repertoire of medications available to people with MS and their neurologists. It will allow for an appropriate treatment choice to be made according to the efficacy and possible side-effects in relation to an individual's circumstances and will help to alleviate the economic cost of MS to individuals, their families and the broader community.

Our colleagues at MS Research Australia will be making a submission that includes research information regarding this change to the existing listing of fingolimod.

We appreciate you considering this treatment for inclusion on the PBS.

How did you learn about this consumer submission process?

From PBAC web-site.

SUBMIT (BUTTON)