

27 May 2022

Feedback from Multiple Sclerosis New Zealand regarding the proposal to fund treatment earlier for relapsing multiple sclerosis



Dear Pharmac Board Representatives,

I am writing on behalf of Multiple Sclerosis New Zealand (MSNZ), our members and the multiple sclerosis (MS) community regarding the current proposal to widen the access to MS treatments. MSNZ strongly supports the recommended changes, and we welcome the proposal. We have no recommended changes to make to the proposed criteria. These changes will bring treatment access in line with international guidelines and is a huge step forward for New Zealanders yet to be diagnosed with MS or awaiting access to treatment.

Accepting the 2017 McDonald Diagnostic Criteria with these proposed changes will have a profound effect on the long-term physical and brain health of those yet to be diagnosed with MS. It will also have a huge impact on the mental health of those going through diagnosis, reducing the stress and fear of having to wait for a second event, risking unnecessary disability and disease progression.

Early intervention with a therapeutic strategy of treatment and lifestyle modifications helps to preserve brain health, provide the best opportunity to successfully manage the condition by reducing the risk of premature disability and disease progression. This means people with MS can continue to live long, healthy lives.

In 2014, when Pharmac approved the funding of Tysabri and Gilenya, MSNZ argued at the time the access criteria were too restrictive. This was confirmed to us by treating Neurologists domestically and internationally who advised they were able to diagnose MS much earlier than treatment access was allowed under NZ rules.

We note, for the record, that while Pharmac's application tracker indicates that an application for change was only made in 2020, this is incorrect. While the *latest* application was made by a clinician in 2020, in May 2018, MSNZ, with the help of Professor Helmut Butzkeuven from Monash University and Alfred Health in Melbourne, a lead specialist at MS Brain Health and Managing Director of MSBase Foundation, made a presentation and subsequent submission of the necessary evidence to support changing the criteria to Pharmac 7 days later in June. However, mistakes with Pharmac's processes delayed the review of the data and our new evidence was only presented to PTAC in late 2019.

It is disappointing that the time it has taken for Pharmac to accept these internationally recognised diagnostic criteria, many New Zealanders with MS have experienced delayed access to treatments. These delays will have a long-term impact on their MS and overall health and disability.

That said, we are optimistic about the positive outcomes these changes will now have on those to be diagnosed in the future. Thank you for approving these changes to the access criteria for MS treatments. We hope there is no further delay in these being officially approved and funded.

Kind Regards,



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