

Sarah Fitt
CEO
PHARMAC
PO Box 10-254
Wellington 6143



Copy to: Hon Steve Maharey (Pharmac Chair) and Adrienne Martin (Therapeutic Group Manager)

27th May 2019

Dear Ms Fitt

RE: Urgent clinical need for Ocrelizumab PHARMAC funding for people with Relapsing Multiple Sclerosis (PwRMS)

The Multiple Sclerosis Society of New Zealand (MSNZ) is writing to urge you to fund Ocrelizumab (Ocrevus) with immediate effect due to the imminent life-threatening risks that delays in Pharmac's processes are putting on people with MS.

At the PTACs November meeting, Ocrelizumab was given a positive recommendation if cost neutral with the other MS treatments. As per email correspondence we have received from Pharmac in April 2019 this process has not yet begun. We have also been in contact with Roche who are aware that Ocrelizumab is currently more expensive but intend to make this cost-neutral. They are awaiting Pharmac to begin the negotiation process. As it has been over 6 months we ask you to advise us:

- When will this negotiation process begin?
- What is the delay?

I attach with this letter a previous communication written in April. We received the full support from leading neurologists across the country in submitting this.

Many patients who are on Tysabri are JCV positive and risk contracting progressive multifocal leukoencephalopathy (PML). This is a deadly and fast acting condition so time is of the essence. With each monthly infusion this risk increases.

An example of the impacts of Pharmac's slow processes are:

Anne a person with MS in Auckland is JCV positive but the most highly effective treatment for her was agreed to be Tysabri. Anne is currently working and able to maintain this due to the benefits that Tysabri provides in managing her condition. When Anne started on Tysabri, she had a 1:10000 risk of contracting PML. As the risks increase with each infusion, at her last appointment she was advised her risk is now 1:333. Anne has been advised that before long her risk will be 1:125, an untenable danger to her life. Anne is currently having to weigh up whether to discontinue treatment, which keeps her in employment and her condition under control, versus an ever-increasing risk of contracting a potentially life-threatening brain disease. The former option is becoming the most likely which may lead to a progression in her condition and disqualification from future treatment access.

These risks are very real and Anne is not alone. With these risks, and PTAC's support of the evidence to fund Ocrelizumab, we ask why the continued delay? The delays in your process are putting people with MS at risk of the very the dangers Pharmac's funding review processes propose to mitigate.

Multiple Sclerosis Society of New Zealand Inc.

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Given the important information highlighted above we ask PHARMAC to urgently fund ocrelizumab as a treatment option for all people with relapsing MS in New Zealand.

Yours faithfully



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