Dear Pharmac Board,

23 June 2023

I am very excited to hear that Pharmac is proposing to fund by special authority, Ocrelizumab for PPMS patients. As the committee has requested feedback from the public, I would like to take that opportunity.
I have a family member who has been very fortunate to receive Ocrelizumab via compassionate use directly from Roche, for several years now. It has been nothing short of life changing for him. He was diagnosed with PPMS in 2013 and due to this treatment and his commitment to exercise, he remains able to walk, climb stairs, drive, attend to his own personal hygiene, ride a bicycle and generally participate in life. Admittedly, these things are more difficult and painful than they were 10 years ago, but I have no doubt that had he not had access to this drug, he would be hugely more disabled than he is now.

PPMS is a cruel disease which causes severe pain and immense disability. Under the NZ health system, there is very little support for such patients. There is only a very infrequent visiting neurologist to the city where he lives, he receives no physiotherapy, no occupational therapy, no counselling service, no financial support, no support whatsoever from the health system for his disability. He largely relies on a good relationship with a GP who tries her absolute best, and the services of a very underfunded MS patient support group.

Given that Ocrelizumab has been shown to slow progression of disability, and that NZ has such poor supports for those with that disability, it is imperative that Ocrelizumab is funded for patients with PPMS who currently have such a great unmet need.

I would also encourage the committee to reconsider the EDSS criteria for funding and not to include an upper limit for this. There is no reason why the most disabled should face worsening disease when there is treatment available. Ocrelizumab slows progression, but it does not stop it. Increasing EDSS is not a sign that the drug is not working. The data from the open-label extension of the ORATORIO trial does not conclusively show waning of treatment effect and certainly there is no proven mechanism for this waning of efficacy. Given this collective uncertainty of this effect, it seems prudent to allow patients who, along with their treating specialist, believe they continue to receive benefit from the drug, to remain on it.

Thank you for your consideration.