

# Hon Dr Ayesha Verrall

Minister of Health  
Minister of Research, Science and Innovation



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Rare Disorders New Zealand  
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Tēnā kōrua

## Rare Disorders New Zealand

Thank you for your correspondence of 18 and 31 July 2023 regarding rare disorders. I appreciated our constructive meeting in July, and I note your request to meet me again to discuss the potential of a rare disorders centre of excellence. Unfortunately, I am unable to meet at this time.

I acknowledge Rare Disorders New Zealand's advocacy for establishing a rare disorder centre of excellence to provide oversight and expertise. I understand that Rare Disorders New Zealand is concerned about our health system's current ability to adequately support people with rare disorders and to appropriately diagnose and treat such conditions. I commend your advocacy for people living with rare disorders, and I assure you that I am committed to ensuring the health system is responsive to the health needs of all New Zealanders.

I recognise the partnership you have developed with Manatū Hauora towards developing a rare disorders strategy for New Zealand. Manatū Hauora officials advise me that the agency recognises the importance of addressing the challenges and systemic barriers that affect the rare disorders community and that they are taking into consideration all recommendations that are put forward.

I can confirm my intention that the *Therapeutic Products Act (2023)* (the Act) will continue to enable access to unauthorised medicines, including via pharmaceutical companies' compassionate access arrangements. As part of the work to implement the Act, Manatū Hauora officials will also explore regulatory options to ensure pharmaceutical companies continue to bring their new products to the New Zealand market. My expectation is that Manatū Hauora officials will engage with you directly on these issues.

As you will be aware, Pharmac is the government agency that decides which pharmaceuticals and medical devices will be publicly funded. Pharmac operates independently of me, as the Minister of Health, Associate Ministers of Health, and Manatū Hauora. This independence allows the public to have confidence in the impartiality of funding decisions, and it would not be appropriate for me, as Minister of Health, to intervene in the decision-making process.

Thank you again for writing. I hope this information is useful, and I wish you both well.

Nāku noa, nā



Hon Dr Ayesha Verrall  
**Minister of Health**