

Hon Dr Ayesha Verrall

Minister of Health
Minister of Research, Science and Innovation



5 JUL 2023

Chris Higgins
CEO Rare Disorders NZ

Lewanna Pentecost
Navigator, Rare Disorders NZ
lewanna@raredisorders.org.nz

Ref. AVC2023-2715

Tēnā korua

Spinal muscular atrophy screening

Thank you for writing on 1 June 2023 about including screening for spinal muscular atrophy (SMA) in New Zealand's newborn screening criteria. Thank you also for including the letter from the Paediatric Neurologists.

I appreciate your sense of urgency on wanting to ensure SMA is included in the National Metabolic Screening Programme (NMSP) screening panel. Both Te Whatu Ora – Health New Zealand and I, understand that this rare disease has a significant impact on whānau.

In principle, Te Whatu Ora has advised me that it believes there is a strong case for adding SMA screening to the NMSP to gain maximum benefit from the Government's investment in treatment funding. However, the addition of SMA to the NMSP requires substantial investment.

Te Whatu Ora is working through the clinical, operational, and financial requirements to add SMA to the screening panel. As you will appreciate, it is critical to ensure there are resources to support the inclusion of SMA in the NMSP over the long term.

Te Whatu Ora is expecting a final decision on including SMA in the NMSP will be made in the near future.

Thank you again for writing. I hope this information is useful.

Nāku noa, nā

A handwritten signature in black ink, appearing to read 'Ayesha Verrall'.

Hon Dr Ayesha Verrall
Minister of Health