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Rare Disorders NZ Submission on the National Public Health Service Consultation Proposal

Rare Disorders NZ strongly opposes the National Public Health Service (NPHS) consultation proposal to significantly reduce the Antenatal and Childhood Screening team from nine roles to four.

This team plays a critical role in supporting three essential screening programmes that directly impact the diagnosis and management of rare disorders:

1. Antenatal screening
2. Newborn Metabolic Screening Programme
3. Universal Newborn Hearing Screening and Early Intervention Programme (UNHSEIP)

The proposed staff reductions are alarming, especially as advancements in newborn and antenatal screening are accelerating with genomic technologies enabling the detection of more conditions than ever before. Now is the time to expand and future-proof these critical programmes—an urgency recognised by the Australian Government, which is actively investing in the growth of its newborn screening initiatives[i].

It is widely acknowledged that success of screening programmes depends on their implementation and design, rather than the testing technology[ii,iii,iv]. Reducing staff resources at such a pivotal moment completely undermines New Zealand's ability to plan for, consult on and successfully implement these life-saving advancements.

The Ministry of Health's recently published *2024 Aotearoa New Zealand Rare Disorders Strategy*[v] identifies Health New Zealand – Te Whatu Ora as responsible for implementing and monitoring this Strategy. Reducing the size of the Antenatal and Childhood Screening team directly undermines Priority 1 of the Strategy: "Gearing the System for Quality Care."

Priority 1 explicitly states: "The capability and service infrastructure to support early testing and preventive care will be built over time."

Cutting the Antenatal and Childhood Screening team compromises New Zealand's only universal programs capable of identifying rare conditions in babies in time to allow early intervention – crucial to prevent the onset of disease symptoms or delay disease progression.

Priority 1 of the Strategy also emphasises that "the approach to making decisions on and prioritising system investments will improve over time so that it values and considers benefits for people and their whānau living with rare disorders."

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This change proposal disregards the needs of individuals and whānau who rely on robust screening services for early diagnosis and intervention, actively hindering equitable outcomes for the rare disorder community.

Rare Disorders NZ advocates for a comprehensive and well-resourced antenatal and newborn screening programme that aligns with international best practices, ensures early diagnosis, facilitates access to life-changing treatments, and supports Te Whatu Ora's obligations to implement the Rare Disorders Strategy

If Te Whatu Ora had engaged with the implementation of the government's Rare Disorders Strategy from the outset after it was published in July 2024 – as it should have done, but didn't – and if the workforce requirements for supporting people with rare disorders had been addressed in Te Whatu Ora's December 2024 Workforce Plan[vi] – as they should have been, but weren't – we very much doubt that this proposal would have materialised in the first place.

We strongly urge the NPHS to reconsider this proposal and prioritise the long-term development and future proofing of perinatal screening services to uphold the commitments outlined in the Rare Disorders Strategy.

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[i] https://www.health.gov.au/sites/default/files/2024-12/newborn-bloodspot-screening-nbs-delivering-consistency-and-expansion-fact-sheet.pdf

[ii] S. Gillner, G. Gumus, E. Gross, *et al.*
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[iii] B. Wilfond, S. Gollust
Policy issues for expanding newborn screening programmes: the cystic fibrosis newborn screening experience in the United States
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[v] Aotearoa New Zealand Rare Disorders Strategy. Te Rautaki o Aotearoa e Pā ana ki ngā Mate Mokorea. July 2024. https://www.health.govt.nz/publications/aotearoa-new-zealand-rare-disorders-strategy

[vi] Health Workforce Plan 2024. Health New Zealand/Te Whatu Ora December 2024.
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