Re: Proposed guidelines on pre-implantation genetic testing for cases involving specialist disagreement

To: ACART (ACART@health.govt.nz)
Date of Submission: 22 October 2026
Submitted by: Rare Disorders NZ
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Declaration of interest

Rare Disorders NZ works with clinicians, researchers, allied health professionals, academia, government and industry to achieve better outcomes for people with a rare disorder in New Zealand and their whānau. We are funded by grants, donations, fundraising events, Pharma roundtable and a small Te Whatu Ora contract. This submission is in regard to the proposed guidelines on pre-implantation genetic testing (PGT)for cases involving specialist disagreement

Rare Disorders NZ

Rare Disorders New Zealand (RDNZ) is the respected voice of rare disorders in Aotearoa. We are the national peak body organisation, supporting the 300,000 New Zealanders with rare disorders and the people who care for them. We help those living with rare disorders to navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

Our vision is for New Zealand/Aotearoa to become a country where people and whānau living with a rare disorder experience best possible health and wellbeing. We seek to achieve this by enabling and empowering people with rare disorders to best benefit from services and therapies available in New Zealand, and by championing their collective voice, advocating for provision of world leading evidence based health, disability, education and other services.

A rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 2,000 people in Aotearoa New Zealand. Rare disorders include, but are not limited to, rare conditions among genetic disorders, cancers, infectious disorders, poisonings, immune-related disorders, idiopathic disorders and various other rare undetermined conditions. An ultra-rare disorder is a medical condition with a specific pattern of clinical signs, symptoms and findings that affects fewer than or equal to 1 in 50,000 people in Aotearoa New Zealand

Submission

Rare Disorders NZ appreciates the opportunity to consult on this document. As a non-clinical organisation we will not comment on the questions regarding the guidelines outside of saying that it is imperative that patient and whānau voice is considered in both the process of considering an application under these guidelines and in designing how the approach would work in practice.

In response to the questions regarding PGT more broadly and the foreshadowed wider review of the regulatory settings for ART in New Zealand, including PGT, Rare Disorders NZ would like to take the opportunity to signal that we would like to be involved in future consultation.

RDNZ strongly recommends that ACART ensure meaningful and ongoing consumer involvement, including representation from people living with rare disorders and their whānau, across any review process. This aligns with Priority 4 of the Ministry of Health's 2024 Aotearoa New Zealand Rare Disorders Strategy, "Giving voice to people and their whānau living with rare disorders", which recognises the importance of ensuring that lived-experience perspectives are reflected across the health system.

The Strategy states that the voices of people and whānau living with rare disorders should be evident in consumer forums, advisory groups, committees, and other decision-making bodies, and that these perspectives should inform service evaluation, policy development, business cases, and investment decisions.

The Strategy further acknowledges that meaningful progress depends on partnership with people who have lived experience, noting that it is only through "real-life insights" that opportunities to improve outcomes can be fully understood and acted upon. RDNZ therefore encourages ACART to embed consumer and lived-experience representation as a core component of this piece of work, alongside clinical, ethical, and technical expertise.