Submission to Pharmac on Proposal to fund supplements for phenylketonuria and other inborn errors of metabolism

To: consult@pharmac.govt.nz
Date of Submission: 28 November 2023
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 response to Pharmac's proposal to fund supplements for phenylketonuria and other inborn errors of metabolism.

Rare Disorders NZ

Rare Disorders New Zealand 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 affected by rare disorders navigate the healthcare system, find information and resources, and connect with support groups specific to their condition.

We proudly advocate for public health policy and a future healthcare system that works for those with rare disorders – using a strong and unified voice to collaborate with Government, clinicians, researchers, and industry experts, to promote diagnosis, treatment, services, and research.

Our vision is for New Zealand to become a country where people living with a rare disorder are fully recognised and supported with equitable access to health and social care.

Our submission

We are pleased to see that people with phenylketonuria (PKU) are now having their unmet needs recognised, and New Zealand is making steps towards meeting internationally recognised standards of care.

Rare Disorders NZ support the changes proposed to the eligibility criteria for currently funded foods and supplements for inborn errors of metabolism in Section D and Part II Section H of the Pharmaceutical Schedule to simplify access for people with inborn errors of metabolism.

Rare Disorders NZ have been long-time advocates for access to medicines for Rare Disorders including phenylketonuria (PKU).

It is important to reference the advocacy as it has taken a significant toll on patients, their loved ones, and the rare disorder community in the time that it has taken to get to this point.

Support for Submission by the PKU NZ Facebook Support group

Rare Disorders NZ strongly supports the submission written by Malany Turner PKU NZ Facebook Support group, which you will find enclosed.

We particularly would like to draw attention to, and endorse, the following recommendations they have made:

1. The current range of supplements available poses significant hurdles for the PKU community. One of the primary challenges is the limited variety of supplements in terms of flavours and options. Often, individuals struggle with adherence to the prescribed diet due to personal taste preferences. Discontinuation or alteration of preferred supplements causes distress as we rely on these supplements for our nutritional needs. Regrettably, many of us consume these supplements out of necessity rather than enjoyment.
2. Furthermore, the storage and portability limitations of existing supplements compound these challenges. Large containers necessitate ample storage space, whereas newer options, such as the small 16g powder sachets proposed by Cortex and Vitaflo, offer greater convenience, especially for families and individuals on-the-go.
3. In support of the submissions made by Cortex and Vitaflo, we urge Pharmac to consider allowing these supplements to be accessible through 3-month pharmacy prescriptions. The current system's inconsistency in accessibility creates undue stress, with some individuals required to visit pharmacies monthly, while others receive three-month supplies. Standardizing access to a three-month supply with minimal contact between dietitians and pharmacies would significantly alleviate the burden and improve adherence to prescribed dietary regimes.
4. We strongly advocate for these changes, recognizing the immense impact they would have on our community's well-being. Additionally, we wish to express our support for Cortex Health's endeavor to introduce new low-protein/metabolic food choices in New Zealand, intending to submit further support should this funding application progress.

ENDS

Rare Disorders NZ

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