



Re: Proposal to fund Inotuzumab ozogamicin for the treatment of relapsed or refractory acute lymphoblastic leukaemia/lymphoma

To: consult@pharmac.govt.nz

Date of Submission: 23 January 2025

Submitted by: Rare Disorders NZ

Contact person: Chris Higgins (CE)

Email: Chris@raredisorders.org.nz

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 Inotuzumab ozogamicin for the treatment of relapsed or refractory acute lymphoblastic leukaemia/lymphoma

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

Rare Disorders NZ endorses the submission on this consultation from Leukaemia & Blood Cancer New Zealand (LBC).

We particularly wish to emphasise LBC's point that this proposal does not negate the need to fund additional treatment options, such as blinatumomab, which was also identified in the Cancer Control Agency's *Understanding Blood Cancer Medicine Availability* report as a critical gap in the curative treatment setting for ALL.

While we are pleased to see this proposal to fund Inotuzumab, Rare Disorders NZ also shares LBC's concern that for years leading up to this, resources that could have been allocated to modern treatments were instead diverted to managing the toxicities of older ones.

It is an all too familiar story for rare disorders to see a lack of investment in medicine and instead resources used managing preventable morbidity for our community which has wide ranging effects both within and beyond the health system.

ENDS

Rare Disorders NZ

23 January 2025