



THE UNIVERSITY  
OF AUCKLAND  
NEW ZEALAND  
Te Whare Wānanga o Tāmaki Makaurau

Tuesday, 4 July 2023

**Rt Hon Chris Hipkins**  
Prime Minister  
Parliament Buildings  
Wellington 6160

**cc. Hon Dr Ayesha Verrall**  
Minister of Health  
Parliament Buildings  
Wellington 6160

Dear Prime Minister,

We are writing to inform you of an appalling gulf which has arisen between Aotearoa New Zealand and other western countries in the funding of modern Haematology-oncology drugs, which has snowballed over the past decade into a substantive failing in this important component of our healthcare system. We ask for your help in remedying the situation.

The Government's medicines purchasing agency, Pharmac, has fallen seriously behind in its strategic objective of delivering equitable medicines access for Kiwis. The current state of affairs is undermining Haematology-oncology care in New Zealand and is preventing the reasonable pursuit of wellbeing by cancer patients in this country. Delays in the funding of new haematology-oncology drugs have reached such a crisis point that we feel that we must now advocate on our patients' behalf and ask that they be afforded justice by the Government, and be enabled to receive modern cancer treatments that are widely regarded as a standard of care across the Western world.

Lengthy delays in new drug access are negatively impacting the care of New Zealanders with a wide variety of malignant haematology disorders, such as acute myeloid leukemia (venetoclax, azacitidine, midostaurin), acute lymphocytic leukemia (inotuzumab), chronic lymphocytic leukemia (ibrutinib), Hodgkins lymphoma (Pembrolizumab) and multiple myeloma (daratumumab, pomalidomide, carfilzomib).

However, amongst these numerous concerns, delayed funding of 'new' treatments for patients with multiple myeloma perhaps represents the most egregious failing and epitomizes Pharmac's quiet neglect of Kiwis living with haematologic cancer. Ignoring actual *new* treatments for multiple myeloma, such as CAR-T cells (ide-cel, cilta-cel) and bispecific antibodies (teclistimab), which are currently being rolled out in the USA and elsewhere, New Zealanders with this cancer continue to be denied access to three '*less-than-new*' but effective and well-tolerated drugs (daratumumab, pomalidomide, carfilzomib) that are routinely used for the treatment of multiple myeloma in many other countries. Pharmac is reportedly considering their funding but has made no meaningful movement in a number of years. Consequently, Kiwis living with multiple myeloma in 2023 have not benefited at all from the considerable global progress that has been made over the past decade in treating this cancer and are still being offered a level of care that is limited to that provided circa 2014 in Canada or the UK.

To focus on the single most pressing priority, we ask for your help in ending an unconscionable five-and-a-half year delay by Pharmac in deciding whether to fund daratumumab, a highly efficacious modern medicine that is desperately needed to treat New Zealanders suffering with multiple myeloma. We appreciate that the Government expects Pharmac to be independent in its decision-making. However, after waiting for due process for many years to no avail, after corresponding with Pharmac representatives, and with no other effective avenue, we appeal to you, Prime Minister, to initiate improvements in Pharmac practices that have proven manifestly unfair to New Zealand's myeloma community. By international comparisons, Pharmac's protracted funding deliberation on daratumumab has become indefensible. Indeed, Pharmac's half-decade delay in providing a funding decision are also completely at odds with the Pharmac Review Panel's recommendations on drug funding transparency and timeliness, and with Pharmac's own undertaking to action this panel's recommendations.

To summarize the facts:

- Daratumumab is a monoclonal antibody that was developed for the treatment of patients with relapsed/refractory multiple myeloma who have received previous therapies. When first developed a decade ago it was regarded as a major breakthrough in the treatment of this deadly cancer, and evidence from clinical trials has substantiated that.
- It was granted breakthrough drug status in 2013 and was approved by the U.S. FDA under its accelerated approval program in 2015
- In two randomized phase III studies, reported in 2016, daratumumab reduced the risk of myeloma disease progression or death by 60%.
- The average overall survival gain produced by daratumumab is estimated to be approximately 3 years (37.8 months).
- Daratumumab was registered in NZ by Medsafe 5-and-a-half years ago in November 2017
- The manufacturer, Janssen, applied to Pharmac for funding in November 2017
- There have since been a total of 9 Pharmac Committee meetings to assess this treatment.
- A significant survival benefit was acknowledged by PTAC in 2019
- Daratumumab was recommended by CaTSoP as high priority for funding in November 2021.
- NZ myeloma patients have strongly advocated directly to PTAC in 2022 for funding of daratumumab but it appears (from meeting minutes) that their efforts made no difference.
- Although daratumumab offers the highest survival gain of any of the oncology treatments on Pharmac's options for investment list, and has been recommended with high priority for funding, as of May 2023 it remains unfunded in this country
- Recently, in April 2023, Pharmac communicated to daratumumab's manufacturer, Janssen, that it lacks the resources to assess the most recent daratumumab proposal and is deferring its funding decision yet again.
- Daratumumab is funded in 49 other countries.

For New Zealanders living with cancer, treatment delayed is treatment denied. Pharmac's quiet foot-dragging with respect to the funding of new cancer treatments is difficult to reconcile with the way the Government values life. It is depriving Kiwis of years of lifespan, and it is denying our communities of the contribution that such individuals could make. People's lives are being needlessly sacrificed, and the accompanying anguish is vast. By one careful estimate, delays in daratumumab funding in New Zealand by Pharmac since 2017 have cost 1,410 Kiwis an average of 3 years of life each (>4,000 life years lost).

Compounding this pain, New Zealand patients with multiple myeloma are no longer able to participate in international clinical studies of highly effective new drugs such as CAR-T cells. This is a departure from the past and reflects the fact that, from an international perspective, New Zealand myeloma patients no longer receive the treatments that are recognized as a basic standard of care, and are thus considered ineligible to enrol on studies of newer experimental therapies. Therefore Kiwi myeloma patients miss out twice as a result of delayed governmental funding.

It is noteworthy that the incidence of multiple myeloma is higher amongst Māori and people of the Pacific Islands, who also have worse outcomes than their fellow New Zealanders. As daratumumab treatment is currently only available in our country to those with money or private insurance the present situation is contributing to the health outcome inequities in our nation and fails to live up to the goals of the Treaty of Waitangi.

Myeloma patients and their families live in dread of the next relapse. At the same time, for clinicians it is deeply distressing to have to tell cancer patients that there are effective treatments available in many other countries, but not in New Zealand. Sadly, we in New Zealand have become inured to the huge delays in accessing modern medicines. Since its inception Pharmac has promoted and dehumanized this situation with arguments of fiscal responsibility, but critically the delays have become longer and are having increasing impacts on patients.

The delay in daratumumab access for Kiwi myeloma patients in particular is beyond fair, and the latest communication from Pharmac describing its intention to further defer its review of this drug, let alone its funding, cannot possibly be seen as reasonable. This view is strongly held by virtually all New Zealand haematologists, myeloma patients and by The Haematology Society of Australia and New Zealand (HSANZ), Leukemia & Blood Cancer (LBC) New Zealand and by Myeloma New Zealand. We therefore ask you to urgently examine the situation and determine whether or not the Government regards Pharmac's functioning in this matter as fair and reasonable, particularly in the light of the Pharmac Review Panel's report.

In asking your attention, we are not asking for Daratumumab to be treated as a special case. Instead, the case for providing daratumumab access is very strong and already established. Yet New Zealanders continue to be let down by undue delays at the Government's drug-funding agency. Indeed, it appears that if Daratumumab is not being funded, either Pharmac is not meeting its guidance on funding or its budget is inadequate. We ask therefore that the Government review Pharmac's indefensible delay in delivering access to new cancer drugs such as daratumumab; and ask that the Government ensure that a fair and expedient medicines funding process is pursued to provide justice, relief and hope for Kiwi patients suffering from multiple myeloma and other devastating human cancers.

Yours sincerely,



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**This letter is Endorsed by the Haematology Society  
of Australia and New Zealand**

**On behalf on HSANZ: Dr Annette Neylon MB BS,  
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Disclosure: HSANZ has received sponsorship from Janssen, the  
manufacturer of daratumumab, to support educational  
scholarships and indirectly through the annual Blood conference.

**Endorsed by Myeloma New Zealand**

Mrs Barbara Horne  
**Chair and Trustee**

**Leukaemia & Blood Cancer New Zealand**

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[leukaemia.org.nz](http://leukaemia.org.nz) | [shaveforacure.co.nz](http://shaveforacure.co.nz) | [facebook.com/LBCNZ](https://facebook.com/LBCNZ)

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### **Myeloma patients & families**

Although a nationwide petition of myeloma patients or the public was not sought, the following individuals reached out to endorse this letter after becoming aware of its existence following its circulation to medical staff:

**Mr L Snape, FRCS(Edin) FRCS(Eng) FFDRCSI FRACDS**  
**Maxillofacial Surgeon**  
Christchurch  
Myeloma patient

Nichola & Andrew Oakenfull  
**Trustee of Myeloma New Zealand**  
Myeloma patient & husband

Dr Maroussia Koptcheva-Petzirova,  
**MD FRACGP**  
Myeloma patient

Dr Timo Pecirov, MD  
**Orthopaedic surgeon**  
Husband of myeloma patient

Maureen & Tony Hutchinson  
Parents of myeloma patient

Wendy and Liam McEntegart  
Spouse and myeloma patient

Elizabeth Leavins  
**CT radiographer/MRT**  
**Mother of 3 daughters.**  
Myeloma patient

Sandra Russell  
Psychotherapist & myeloma patient

Scott and Katrina Harris  
Myeloma and Amyloidosis patient, and spouse

Kathleen Hutchison  
Myeloma patient

Clive & Vivienne Brumby  
Whenuapai, Auckland  
Myeloma patient & spouse

Erica Wills  
Hobson Point, Auckland  
Daughter of myeloma patient

Susan Ross  
Schnapper Rock  
North Shore  
Myeloma patient

Sandra Plummer  
**Dispute Resolution Specialist, Barrister & Solicitor,**  
**Legal Educator (retired)**  
Auckland  
Myeloma patient

Annise Raea  
Remuera, Auckland  
Daughter of myeloma patient

Anna Thompson  
Myeloma patient

Bruce Matheson  
Tauranga  
Myeloma patient

Mark Dodson  
Avalon, Lower Hutt  
Myeloma patient

Barry Johnston  
Wanaka  
Myeloma patient

Caroline and Matt Dodson  
Lyll Bay, Wellington  
Sister & brother of Mark, myeloma patient

Antonia Wright  
North Shore  
Myeloma patient

Veronica and John Dodson  
Rolleston  
Uncle & Aunt of myeloma patient

Sandra, Eleni and Michaela Psaltis,  
Myeloma patient & 2 daughters

Michelle Krause  
Daughter of myeloma patient

Janice Rapana  
Myeloma patient

Louise Macdonald  
Wife of myeloma patient

Jacq Dwyer  
**Chair, South Taranaki District Council's Pātea  
Community Board**  
**President of the Pātea Historical Society**  
Myeloma patient

Judy Morrison  
Melbourne, Australia  
**Kiwi myeloma patient.**  
**Moved to Australia to receive Daratumumab**

Eleanor Fairhall  
Myeloma patient

Philip Harward  
Principal, Project Management, Aurecon  
Brother-in-law of myeloma patient

Roslyn Norrie  
Registered Dietitian  
Whangarei  
Partner of Myeloma patient

Regina Worle,  
Myeloma patient

Kirsty Sweeney & Dermott Sweeney  
Daughter & daughter-in-law of myeloma patient

Jan Macpherson  
Fairlie NZ  
Mother of myeloma & amyloid patient

Nicole F Vipond  
Maungatautari  
Cambridge  
Myeloma patient

Linda Salvidge  
Sister-in-law of myeloma patient

Sandra & Wilson James  
Friends & supporters of myeloma patient

Michelle Warshawsky  
Titahi Bay, Porirua  
Family of myeloma patient

Sonia & Geoffrey Welham  
Myeloma patient & wife  
Two children aged 8 & 13.

John Harward and Penelope Anderson  
Family of myeloma patient

Richard Taggart  
Son of myeloma patient  
Wellington

Fiona Jones  
Myeloma patient

Claire Taggart  
Myeloma patient supporter

Kimberley Ross-Guilford  
Queenstown  
Daughter of myeloma patient

James Brown  
Work and Income Case Manager  
Myeloma patient

Rebecca Dodson  
Auckland  
Sister of myeloma patient

Paul Crosbie  
**Pilot**  
Auckland  
Myeloma patient

**Major General (Retired) Maurice Dodson**  
**Commander of the British Empire (CBE)**  
**Military Cross (MC)**  
Wellington

Marion Watson & Ronald Edge  
Auckland  
Myeloma patient and spouse

Joyce & Jessica Chin  
Myeloma patient & daughter

Jill Gwynne  
Dunedin  
Myeloma patient

Dianne Moffatt  
Myeloma patient

Toby Fuller  
Dunedin  
Myeloma patient

Jo Clarke  
Witby, Porirua  
Supporter

Geoffrey Marshall  
Auckland  
Myeloma patient

Geoff Dawson  
Auckland  
**Myeloma patient**  
**Has self-funding daratumumab for 2 years**

Stacey Ross-Duncan  
Registered Nurse  
Relative of a myeloma patient

Noeleen Dodson  
Paraparaumu  
Relative of a myeloma patient

Alexander Brown  
Myeloma patient

Alice Joan Delaney  
Relative of a myeloma patient

Anne-Marie Mills  
Sister of a myeloma patient  
Sandra Harward  
Sister of myeloma patient

Wendy Sanderson  
Friend of myeloma patient

Jill Dodson  
Relatives of myeloma patient

Megan Frewin  
Auckland  
Myeloma patient