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8 October 2025

Pharmac
Via email to: Matt.McKenzie@pharmac.govt.nz
Copy to: CTAC members, Natalie McMurtry

Dear Pharmac

Submission regarding belantamab mafodotin for relapsed/refractory multiple myeloma

Myeloma New Zealand is a charitable organisation representing New Zealanders living with myeloma. We write to support the application to Pharmac for belantamab mafodotin (belantamab) to be funded for patients with relapsed/refractory disease from second line onwards.

Myeloma is a relapsing, remitting blood cancer for which there is currently no prevention, screening, or cure. Patients rely on drug therapies. With the exception of expanded access to already funded drugs (lenalidomide maintenance post-transplant and bortezomib unrestricted), pomalidomide remains the only new investment in myeloma treatment in New Zealand since 2014. In contrast, the number of myeloma treatments available internationally has surged ahead. A myeloma patient in England, for example, has eight more myeloma treatments funded on the NHS than Pharmac funds for myeloma patients in New Zealand. Modern drug therapies, not available to New Zealanders, are prompting open talk of a cure for this relentless blood cancer.

The impact of belantamab on patients

In the two letters attached, patients describe, in their words, the experience of being on belantamab. Key quotes include:

> ***Patient S:***
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> *In 2022 I began to relapse. Fortunately I was accepted on the DREAMM8 trial. After only three 28-day cycles of treatment I achieved a complete response/remission. This continues as I begin cycle 44 (40 months), confirmed by regular tests including bone marrow aspiration.* ***I feel that belantamab mafodotin has saved my life.***
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> *Infusions of belantamab mafodotin are given in the clinic, requiring about half an hour. Infusions have been given only when blood results are satisfactory, and my vision has reached the required level of acuity. In my case infusions have been given every five cycles.*
>
> *Keratopathy/blurry vision is a known side effect of belantamab mafodotin. However it is not permanent; visual acuity slowly declines and then improves between infusions. I've found this manageable.*
>
> ***Patient J***
>
> *In December 2022, with myeloma blood markers increasing and limited options available, I was very fortunate to be accepted for the DREAMM8 drug trial, drawing the Belantamab, Pomalidomide and Dexamethasone arm.* ***I am still participating in the trial today and have maintained a stringent complete response for the past eighteen months.***

The trial drug combination of Belantamab, Pom and Dex have given me the opportunity to be more independent, to carry out my many roles. ***For much of the time I feel "normal"*** *and as a result can participate in numerous activities, including my outdoor experiences that I love e.g. cycling, walking, pilates and golf, although they often require some preparation. As an example,* ***this year my husband and I went to Europe for seven weeks.***

I receive Belantamab 4-6 monthly, since it is only administered when my corneal microcysts have healed, and my blurred vision has returned to normal. I receive the drug intravenously in the Cancer Day Ward, taking approximately 3hrs. I return to most activities after a couple of restful days.

Without the opportunity to join this trial, I am not sure where I would be. *Probably rolling the dice and seeking Daratumumab treatment in Australia or selling our home to fund my treatment in New Zealand.*

About Myeloma New Zealand

Myeloma New Zealand is a charitable trust established in 2016 by leading New Zealand Haematologist, the late Dr Ken Romeril. Our purpose is to focus specifically on myeloma and to improve the quality of life and survival of New Zealanders living with it. We seek to empower patients with information, research, and support; to advocate with government to allow myeloma patients access to the remarkable treatments that are transforming lives and survival in other comparable countries; and to raise awareness and understanding of myeloma among the general public.

Dr Romeril understood that the goal of improving quality of life and survival would require advocating for better treatment options - there was desperate need for better treatments for New Zealand myeloma patients at the time he established Myeloma New Zealand. What was a desperate need in 2016 is even more so in 2025, given the many more options for myeloma patients available outside New Zealand.

About Multiple Myeloma in New Zealand

Data available up to 2022 shows that over 450 New Zealanders are diagnosed with myeloma each year and the rate is increasing (Te Whatu Ora 2025). There are currently 2500 (estimated) individuals with myeloma in New Zealand (Milne, Boyd et al. 2019) and data available up to 2020 shows that approximately 200 New Zealanders die each year from myeloma (Te Whatu Ora 2025).

Inequity exists in myeloma with Māori and Pasifika reporting a higher rate of diagnosis and a lower rate of survival (Milne, Boyd et al. 2019).

A significant focus of Te Aho o Te Kahu (Cancer Control Agency) is to reduce cancer incidence by preventing cancers in the first place. Myeloma is not a cancer that can be knowingly prevented. Myeloma patients are currently disadvantaged because they have no ability to reduce or avoid their cancer burden.

Significant impact of previous PHARMAC approvals

A significant improvement in survival was observed following Pharmac's funding of bortezomib in 2011 and lenalidomide in 2014. Post Pharmac approval of bortezomib and lenalidomide, the five year survival rates increased to 45% (from 36% in the previous time period which was prior to these two medicines being funded) (Milne, Boyd et al. 2019).

We believe that Pharmac approving funding for belantamab will also provide life changing benefits for myeloma patients in New Zealand.

Addressing unmet health need in relapsed/refractory myeloma

Myeloma patients have been affected by a lack of investment over the past eleven years. Patients who have relapsed following their initial treatment are currently able to receive funded treatment with pomalidomide, cyclophosphamide, or thalidomide.

These medicines continue to have their place in the myeloma world and are still needed, but in 2025 New Zealanders need, and should be able to expect, much better for second or third line treatment.

Other treatment considerations impacting myeloma patients

- The absence of publicly-funded daratumumab is affecting the ability for myeloma patients in New Zealand to access clinical trials. New Zealand haematologists have been forced to turn down trial participation recently because of lack of access to daratumumab. This is extremely concerning - in the past, trials have been an enabling pathway for NZ patients to access newer treatments. It also demonstrates how far New Zealand's treatment of myeloma has fallen behind the rest of the developed world, where daratumumab is the standard of care against which newer innovations are measured.

- Myeloma is a highly individual cancer. Patients have a wide variation in experiences and responses to treatment. Not every drug works for every patient. Patients may have reactions to one drug, not be able to tolerate another, and get positive results from a third. Together with the relapsing remitting nature of myeloma, this heterogenicity of disease emphasises the urgent need for more and new treatments.

- Māori and Pasifika (who are already over-represented in the myeloma population) are less likely to have a stem cell transplant and their overall survival is worse (Milne, Boyd et al. 2019). Better treatments, like belantamab, represent an opportunity for these patients to live longer on each treatment, with fewer side effects.

- Patients have moved to Australia and the United Kingdom because they can access better treatments for their myeloma in those countries. New Zealanders should not have to move overseas to access treatment.

- With the modern treatments available internationally, myeloma can be considered more like a chronic disease. New Zealand patients are not getting that opportunity.

- Private insurance is not the answer – patients are still limited in their options. Only carfilzomib, daratumumab, and isatuximab are Medsafe approved. Given both daratumumab and isatuximab are anti-CD38 monoclonal antibodies, patients with insurance are realistically only two options better off than those relying on Pharmac-funded treatments. The stark reality is that a public patient in Australia is better off than a patient going private with insurance in New Zealand. A patient on the NHS in England has four times as many treatment options as a patient with insurance in New Zealand. Pharmac's lack of investment in funded treatments has created a disincentive for pharmaceutical companies to register medicines with Medsafe.

Current myeloma funding in New Zealand compared to Australia and England

The 2019 Myeloma New Zealand Burden of Disease report states that New Zealand had a five-year survival of 45%. This is compared to the Cancer Council Australia reporting in 2018 that Australia's

five year survival was 51%. A difference of 6% means that of the 450 New Zealanders who will be diagnosed with myeloma this year, 27 more of them would still be alive in five years if they were diagnosed and treated in Australia instead of New Zealand.

Today, New Zealand myeloma patients are worse off for treatments than Australian myeloma patients were in 2016. Since 2016, Australia has added daratumumab, carfilzomib, pomalidomide, elotuzumab (removed in December 2024 from funding for commercial reasons), and selinexor to the PBS. Ciltacabtagene autoleucel (CAR T-cell therapy) is recommended for funding but still under negotiation on price.

Given this, it is reasonable to assume the survival gap between New Zealand and our closest neighbours will continue to widen.

In England the gap is even wider. Daratumumab, carfilzomib, elotuzumab, selinexor, ixatuximab, belantamab mafodotin, teclistamab and elranatamab are all available on the NHS - a heartbreaking gap of eight medicines ahead of New Zealand.

Side effects of belantamab mafodotin

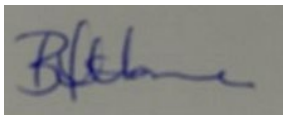
While initial trials of belantamab had higher rates of ocular side effects and the possible additional costs of specialist checks, anecdotally we understand that real world use of belantamab is seeing these being less of an impact. While we would not usually reference a podcast, this podcast (run by haematologists) with Professor Hang Quach, is a great summary of her experience with belantamab mafodotin and how the side effects are manageable https://youtu.be/q6jvR4U-lDI?si=91m0Y2IV4C70XpPc

In summary

Since its formation in 2016, Myeloma New Zealand has been advocating for more and better myeloma treatments to be funded for New Zealanders. We are seriously behind the rest of the world and patients are dying because they cannot access good treatment options.

Please fund belantamab mafodotin.

Yours sincerely



Barbara Horne
Chair
Myeloma New Zealand

Nichola Oakenfull
Trustee
Myeloma New Zealand

Patient letters in their own words

Patient S:

A Belantamab Success Story

Multiple myeloma entered my life in 2016 when I was diagnosed with smouldering myeloma. In 2019 it became active. As I was too old for the preferred treatment (a stem cell transplant) I had nine months of drug combinations: cyclophosphamide, bortezomib and dexamethasone for five cycles, followed by four cycles of thalidomide, bortezomib and dexamethasone. I had a very good

response with this regime. At the end of this treatment lenalidomide was recommended for maintenance therapy. It was not funded for patients who hadn't had a transplant, but I was able to fund lenalidomide myself for two years.

In 2022 I began to relapse. Fortunately I was accepted on the DREAMM8 trial, which is comparing the effectiveness and safety of belantamab mafodotin, pomalidomide and dexamethasone against bortezomib, pomalidomide and dexamethasone; more fortunately I was randomly selected to receive the belantamab combination. After only three 28-day cycles of treatment I achieved a complete response/remission. This continues as I begin cycle 44 (40 months), confirmed by regular tests including bone marrow aspiration. I feel that belantamab mafodotin has saved my life.

As part of the trial I have monthly clinic appointments for review and dispensing of pomalidomide and dexamethasone, which are tablets taken at home. Infusions of belantamab mafodotin are given in the clinic, requiring about half an hour. Infusions have been given only when blood results are satisfactory, and my vision has reached the required level of acuity. In my case infusions have been given every five cycles.

Keratopathy/blurry vision is a known side effect of belantamab mafodotin. However it is not permanent; visual acuity slowly declines and then improves between infusions. I've found this manageable, but acknowledge that it may be more difficult for patients whose employment or lifestyle requires consistently better vision. There have been other side effects, including neutropenia, fatigue and some loss of balance, which are more likely to be attributed to pomalidomide and dexamethasone. Although life with side effects has resulted in a "new normal" I consider this a fair exchange for a living longer.

It's my hope that Pharmac will add a happy ending to my story by providing funded access to belantamab mafodotin to my fellow myeloma patients. All of us deserve another option to keep us living.

Sue Roylance
September 2025

Patient J:

Dear Pharmac

In relation to Pharmac consideration on funding Belantamab Mafodotin for multiple myeloma (MM) patients, I am submitting a personal submission.

I'm a 67 year-old grandmother living with Multiple Myeloma over the last five years. I have 4 grandchildren under 8 years old who I interact with as much as I can, and a 92 year-old mother who requires my continued support. When I was diagnosed with MM I reluctantly retired early. Following induction therapy, I had a successful Stem Cell Transplant (May 2021) with nine months remission using lenalidomide before relapsing. In December 2022, with myeloma blood markers increasing and limited options available, I was very fortunate to be accepted for the DREAMM8 drug trial, drawing the Belantamab, Pomalidomide and Dexamethasone arm. I am still participating in the trial today and have maintained a stringent complete response for the past eighteen months.

Like many people experiencing a form of cancer, Multiple Myeloma has changed our lives; my husband and I are experiencing a vastly different retirement to the one we had originally planned. We now live month to month monitoring my pathology results. Our plans are typically short-term,

e.g., weekly to monthly. My immune system is compromised, which requires careful planning; with reduced time when visiting our grandchildren to decrease the risk of exposure to viruses and diseases. My main support when out in the public is my N95 mask. I have some side effects from the trial drugs, however, fortunately these are relatively minor considering the 'big picture'.

The trial drug combination of Belantamab, Pom and Dex have given me the opportunity to be more independent, to carry out my many roles; grandmother, carer, mother, wife, friend… with community volunteering next on my list when time allows. The primary side effects I experience include lethargy/tiredness and blurry vision. For much of the time I feel "normal" and as a result can participate in numerous activities, including my outdoor experiences that I love e.g. cycling, walking, pilates and golf, although they often require some preparation. As an example, this year my husband and I went to Europe for seven weeks. Even so, it required an enormous effort, with careful planning going into organizing the trip. Ensuring it occurred between Belantamab cycles, I was given permission by GSK – noting I had been "stable" on my drugs for a considerable time.

I receive Belantamab 4-6 monthly, since it is only administered when my corneal microcysts have healed, and my blurred vision has returned to normal. I receive the drug intravenously in the Cancer Day Ward, taking approximately 3hrs. I return to most activities after a couple of restful days. My Pomalidomide doses are daily, on a monthly cycle (3 weeks on and 1 off) and Dex weekly. This year I have commenced monthly immunoglobulin transfusions. I definitely have benefited from the procedure having only experienced illness once this year compared to three times during the same period last year.

Belantamab trial participants are demonstrating a strong deep response to the drug. This has a significant impact on multiple myeloma patients' lives. It sounds like it is easier to tolerate compared to the **older drugs** presently used in our health system. It has allowed us to live as near a normal life as possible, with reduced side effects. With innovations in treatment over recent years, MM is now, elsewhere in the world, being seen and treated like a **chronic disease**, where patients on treatment keep well for a longer time, with fewer side effects and an improved "quality of life".

Without the opportunity to join this trial, I am not sure where I would be. Probably rolling the dice and seeking Daratumumab treatment in Australia or selling our home to fund my treatment in New Zealand. Self-funding Belantamab presents the same alternatives, initially selling our home that we have worked all our lives to enjoy in our retirement, and/or shifting to Australia away from family. I find it difficult to understand why government-Pharmac decisions are so short sighted. Seemingly more-heavily weighted on "financial" benefits rather than considering the potential savings for the broader health system and the benefits in providing greater quality of life, that in itself should generate enhanced opportunities for our community and nation. My understanding is that Multiple Myeloma research is cutting edge with an increasing range of new drugs being discovered. I urge Pharmac New Zealand to keep pace with these innovations, negotiating support from drug companies, to fund drugs like Belantamab that are vital in our fight against Multiple Myeloma.

Finally, thank you for the opportunity to make this submission on behalf of all those affected by Multiple Myeloma.

Yours faithfully,

Patient J
October 2025