**Template letter is below**

You can write to:

|  |  |  |
| --- | --- | --- |
| Dr Ayesha Verrall  | Associate Minister of Heath | a.verrall@ministers.govt.nz |
| Aupito William Sio | Associate Minister of Heath | a.sio@ministers.govt.nz |
| Dr Shane Reti  | National Health spokesperson | shane.reti@parliament.govt.nz |
| Jacinda Ardern  | Prime Minister | j.ardern@ministers.govt.nz |
| Andrew Little  | Minister of Health | a.little@ministers.govt.nz  |
| [Your MP or the MP of your loved one with myeloma](https://www.govt.nz/browse/engaging-with-government/members-of-parliament/)  | Find their contact details at this link | <https://www.govt.nz/browse/engaging-with-government/members-of-parliament/>  |

Copy and paste the message below into the body of an email. The only parts you need to adjust are who it is to at the beginning, the second sentence about who has myeloma, and your name at the end.

\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*\*

Dear (name)

I am writing to you regarding the Pharmac funding of treatments for multiple myeloma. I have multiple myeloma **OR** /my (relationship to you, eg mum, husband) has multiple myeloma.

I’m getting behind Myeloma New Zealand’s Keep Us Living campaign to advocate for better treatments, including daratumumab which is currently being consider by Pharmac. If you’d like to read their submission to Pharmac you can find it here <https://www.multiplemyeloma.org.nz/wp-content/uploads/2022/09/Pharmac-Submission-September-2022.pdf>

Multiple myeloma is a blood cancer of the plasma cells, found in the bone marrow. Myeloma is not a rare disease. Approximately 2500 New Zealanders, of whom 60% are male, are currently living with myeloma. Around 400 new cases are reported each year, and 180 deaths.

Myeloma is a relapsing remitting disease, requiring a new combination of treatments to be used at each relapse, or when serious side effects mean different treatments are needed. Myeloma is not curable, but with treatment innovations over recent years, it is now being seen and treated as more like a chronic disease in many counties, where patients are able to remain on treatment and keep well for increasingly longer.

There are currently Pharmac applications in for daratumumab, carfilzomib, pomalidomide and lenalidomide which are all on the Options for Investment list. We are concerned that there is no incentive for pharmaceutical companies to put in applications for the other treatments needed when there are already so many other applications which haven’t progressed.

Pharmac have said:

*“There are a number of multiple myeloma treatments on our Options for Investment list which means they are medicines we would like to fund when we have the budget available”*

The pomalidomide application has been in since 2015, lenalidomide first line application since 2016, daratumumab since 2017 and the carfilzomib since 2018. Being on the Options for Investment list means these treatments make economic and medical sense, the stumbling block is funding.

While Pharmac had an increase this year, it was a drop in the ocean for the amount they need. There is a large number of treatments on the Options for Investment list and without more funding, this will only grow.

Out of 20 OECD countries, New Zealand ranked last for the number of publicly funded modern medicines registered and launched between 2011 and 2020. Of the medicines registered here, only 26% were then publicly funded.

If we come back to the myeloma environment, there is a desperate need for better myeloma treatments in New Zealand. Thalidomide is currently the second and last line of treatment for those who have had a stem cell transplant. Those who do not qualify for a stem cell transplant have to wait until they have had the older and more toxic thalidomide before they are able to have the newer and easier to tolerate lenalidomide. We desperately need better treatments like daratumumab, carfilzomib and pomalidomide, and need lenalidomide in front line treatment. These treatments are Medsafe approved and available privately, but out of reach for most.

These treatments are not new but are more modern ways of treating cancer and provide meaningful survival and quality of life benefits, allowing patients to live a more normal life, with longer times between relapse.

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. We need better treatments, so these patients are able to live longer on each treatment, with less taxing side effects.

Patients with other chronic diseases like diabetes are treated for their entire life. Myeloma patients’ lives should not be limited by the number of funded treatments available: they should be able to continue to access treatments as needed.

I ask that you do what you can to support this cause to increase Pharmac funding and draw attention to the desperate need to fund more myeloma treatments like daratumumab.

Regards

**Name**