*Your address*

*MP’s address or email*

*Date*

Dear *(name)*

**Pharmac funding of multiple myeloma treatments**

I am writing to you regarding the funding of treatments for multiple myeloma. Myeloma New Zealand, which supports me through living with myeloma, is making a submission to Pharmac calling for more treatments to be funded. **I am asking you to support this cause OR I am asking to meet with you to discuss this further.**

I have attached my story so you can understand how personal this situation is to me. **(or you could write about your experience here).**

Multiple 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 innovations in treatment over recent years, in many counties it is now being seen and treated as more like a chronic disease, where patients are able to remain on treatment and keep well for increasingly longer.

In New Zealand, however, patients are limited (depending on whether or not they have had a stem cell transplant) to two or three lines of treatment, one of which is thalidomide, the old drug from the 1950s. And then that is the end of the line, unless the patient can afford to self-fund the next treatment, or move to another country where they’re funded (e.g. Australia).

Treatments like daratumumab, carfilzomib, pomalidomide, elotuzumab and ixazomib for relapsed and refractory myeloma, and lenalidomide in initial treatment are Medsafe approved and available privately in New Zealand. They are funded in 48 countries, including Australia, Canada, and the United Kingdom. These are not new drugs: they are used as standard of care overseas and in private treatment in New Zealand. **Despite all this, no new myeloma treatments have been funded in New Zealand for eight years.**

 Why we need these treatments funded:

* Daratumumab, carfilzomib, pomalidomide, elotuzumab, ixazomib and lenalidomide, provide meaningful survival and quality of life benefits.
* These treatments are easier to tolerate than older drugs like thalidomide and cyclophosphamide, provide effective treatment for longer, and allow patients to live a more normal life, with longer times between relapse.
* Patients who have severe side effects from a treatment have an urgent need for treatment options.
* Clinicians have been calling urgently for five years for daratumumab to be funded in NZ.
* Pharmac’s own expert committee accorded daratumumab high priority in December 2021.
* Better myeloma treatments will enable **us /people like me** to regain control of the disease as early as possible in its course, maintaining quality of life and giving **patients/ us** a chance to survive until the next new breakthrough line of therapy becomes available.
* 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.
* **Not funding effective treatments for myeloma is very unfair.** 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.

It is very distressing to know that good treatments are available in this country, but not accessible to those of us who are limited to publicly funded medications. **I ask that you do what you can to support this cause, and I would like to meet with you to discuss this further.**

Yours sincerely

**Signature
Name**