

www.multiplemyeloma.org.nz
nichola@multiplemyeloma.org.nz

5 March 2023

Tracey McLellan
Health Committee Chair

Dear Ms McLellan

Therapeutic Products Bill

Myeloma New Zealand is a charitable organisation representing New Zealanders living with myeloma or multiple myeloma), New Zealand's second most common blood cancer.

There is no prevention or screening programme for this relapsing, remitting blood cancer and, while there is no cure, it is treatable. With modern treatments, myeloma can be a chronic but manageable disease but that manageability relies on a combination of modern drug therapies and, for those with sufficient health status, stem cell transplants.

However, New Zealand myeloma patients do not have access, in New Zealand, to those modern treatments.

With the exception of expanded access to already funded drugs (lenalidomide maintenance post-transplant and bortezomib unrestricted), there has been no new investment in myeloma treatment since 2014 (Pharmac.govt.nz 2022). There are a number of myeloma treatments approved by Medsafe and appearing on the Pharmac Options for Investment list (Pharmac 2022). These, and more options, are available for myeloma patients outside of New Zealand.

Currently, with the support of and a prescription from a specialist, myeloma patients in New Zealand are able to access these modern treatments in other countries and self-import to New Zealand. The self-importation of generic medicines enables patients to access treatments they would not otherwise accessible.

As drafted, the Therapeutic Products Bill cuts off this access to crucial life-extending medicines – unless the patient goes to the source and returns to New Zealand with medication in their luggage and repeats every three months.

In addition, it cuts off access to future medicines. There is a proliferation of myeloma medicines on the horizon internationally – and this Bill will deprive New Zealand patients of access to options of new lines of treatment required when their myeloma inevitably relapses or a line of treatment is no longer effective.

About Myeloma New Zealand

Myeloma New Zealand is a charitable trust established in 2016 by leading New Zealand haematologist Dr Ken Romeril. Our focus is to make myeloma manageable, improving the quality of life and survival of New Zealanders living with the disease. We are primarily a patient advocacy organisation, seeking to empower patients with information, research and support; to advocate for access to the remarkable treatments that are transforming lives and survival in other comparable countries; and to raise awareness and understanding of myeloma in New Zealand.

Dr Romeril understood that the goal of improving quality of life and survival required advocating for better treatment options as there was desperate need for modern medicines at the time Myeloma New Zealand was established. Since then, no new drugs have been funded. What was a desperate need in 2016 is now even more so.

About Multiple Myeloma

Multiple myeloma (myeloma) is a blood cancer that resides in the bone marrow. It affects multiple sites in the body where bone marrow is normally active in adults, including the spine, skull, pelvis, ribs, shoulders and hips. Sufferers of myeloma experience serious complications including bone and kidney disease, serious infections, and excessive levels of calcium which can lead to confusion, disorientation and weakness (Milne, Boyd et al. 2019).

Each year, approximately 450 New Zealanders are diagnosed with myeloma and the rate is increasing – currently an estimated 2500 New Zealanders are living with myeloma and approximately 150 die annually.

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).

Although myeloma is currently incurable, in countries where modern medicines and treatments are available it is becoming a chronic but manageable disease.

Our goal is for New Zealand patients to live longer – self-importation of medicines not funded here is a critical step for many patients, providing extended or new lines of treatment.

We note that a significant focus of Te Aho o Te Kahu (Cancer Control Agency) is to reduce cancer incidence by prevention. Myeloma is not a cancer that can be knowingly prevented.

Draft Bill

We note that a concern of the Impact Summary at <https://www.health.govt.nz/system/files/documents/pages/impact-summary-personal-imports-dec18.pdf> is around the quality and safety of medicines imported. We agree this is a potential risk, but we are not aware of any specific New Zealand cases where this has happened - the Impact Summary references only international cases.

There are legitimate websites e.g www.fixrx.com, which source all medicines strictly from government and pharmaceutical companies' authorized distributors, and use only manufacturers who have US FDA cGMP (current good manufacturing practice) certification.

We would like to see patients able to continue to self-import medicines from overseas with a prescription. The Bill allows imports by pharmacists under section 80 and health practitioners under section 88, both for a specific patient – this places an unnecessarily onerous burden on already extremely busy pharmacists and health practitioners. They will not bring in medicines for one patient, and patients will miss out.

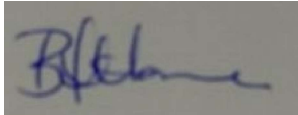
Cancer medicines are significantly underfunded New Zealand. Removing the ability to self-import cancer medicines will result in patients dying sooner than they should.

Changes to the Bill

We ask that subsection 105(6)(a) is removed from the Bill so patients are able to import prescription medicines by delivery, not just by luggage. In the event there are other sections that are relevant, we ask they are also removed or amended so patients can self-import prescription medicines.

We are hoping the Bill's consequence of depriving myeloma patients of access to life-extending treatments is unintended and that this can be reversed.

Yours sincerely

A rectangular box containing a handwritten signature in blue ink, which appears to read 'Barbara Horne'.

Barbara Horne
Chair
Myeloma New Zealand