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Making Myeloma Manageable

MEDIA RELEASE

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FOR IMMEDIATE RELEASE

**BLOOD CANCER PATIENTS IMPLORE PHARMAC TO FUND DESPERATELY NEEDED MEDICINE**

New Zealanders living with multiple myeloma, a deadly, relapsing/remitting blood cancer, are mounting a major, evidence-based campaign to press Pharmac into funding a transformative treatment that has been standard-of-care throughout the OECD for more than 5 years.

Myeloma patient and trustee of Myeloma NZ Nichola Oakenfull says patients who’ve had one line of treatment live in dread of the next inevitable, more aggressive relapse, for which there are no modern treatment options in New Zealand.

“We’re not talking about just prolonging people’s lives; we’re talking about restoring quality of life, keeping people well and able to continue to be a parent, a grandparent, a productive, contributing member of society, or anyone who simply wants to continue to enjoy life.

“There have been amazing advances internationally in myeloma treatments in recent years that are turning this into a manageable disease that is practically a chronic illness, and steadily moving us towards a cure. But not in New Zealand.

“There have literally been no new myeloma treatments funded in New Zealand for 8 years, and people are dying unnecessarily because of that.

The treatment patients are desperately calling for is daratumumab, a monoclonal antibody that activates the patient’s immune system to attack and kill cancer cells. Pharmac is currently considering funding this.

Ms Oakenfull, a young mother, wife and fulltime worker, says in theory Pharmac has been weighing up this medicine for the past 5 years, despite there being extensive, compelling evidence of its significant impact on survival rates.

“Pharmac has just released a response to the Pharmac Review Panel’s report and says it plans to do more to achieve health equity. We hope that means they will treat every life as worth the same. “Because currently they don’t. Compare not funding this treatment for us with telling a diabetic that they’re not allowed any more treatment. No one would dream of doing that but that's essentially what's happening to us.

“We think it’s desperately unfair that we’re so limited in treatment options and treatments like daratumumab remain unfunded by Pharmac. These fantastic medicines are available, but we can't access them.

“So we’ve put together a very substantial submission [here](https://www.multiplemyeloma.org.nz/wp-content/uploads/2022/09/Pharmac-Submission-September-2022.pdf) setting out the clinical evidence for funding this treatment. It also includes a compelling volume of evidence from 17 patients of the impact of myeloma on their lives.

“The Pharmac Review Panel’s recent report called for much greater consumer consultation and meaningful involvement in Pharmac’s funding decisions, so we are asking them to hear the voice of those whose lives depend on their decisions,” said Ms Oakenfull.

In the same vein Ms Oakenfull is asking Pharmac to allow Myeloma NZ to present the submission to Pharmac in person, to give patients a chance to be heard.

She said the submission is the first of a number of initiatives designed to maintain the pressure until this medicine is funded.

Around 2500 New Zealanders live with myeloma. About 450 are diagnosed with myeloma each year, and 180 die.

ENDS

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