

## MEDIA RELEASE

FOR IMMEDIATE RELEASE

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### CANCER AGENCY REPORT DUPLICATES PHARMAC ROLE

The Cancer Control Agency's analysis of the gap between Australia and New Zealand in funding 18 selected medicines with substantial clinical benefit is a welcome way of drawing attention to the plight of NZ cancer patients desperate for treatments that are funded across the Tasman, but not here, says Myeloma NZ Chief Executive Dr Ken Romeril.

"It's good to see the Agency weighing in on this issue, but their findings are not news to anyone involved in cancer treatment, and this kind of analysis is surely part of Pharmac's job in evaluating medicines.

Dr Romeril said the release of the report raises a number of important questions:

1. Why is it necessary for another government agency within the Ministry of Health to spend what must be a very large amount of money on work that should be done by Pharmac, and might have been better spent on funding medicines?
2. How does the release of this report fit with the withholding of the final report of the Independent Pharmac Review Panel?
3. What has become of the Review Panel's report, which must surely examine whether Pharmac's model and methodology is keeping NZ in step with the rest of the world in terms of access to modern medicines?
4. How does this list of 18 'gold standard' medicines line up with Pharmac's Options for Investment list of 78 medicines?

Dr Romeril said the most important question is what this report might mean for those NZ cancer patients who right now are struggling with desperate and severe unmet need for treatment.

"In that regard a further concern I have about this report is that it reinforces the idea that there are only two types of treatment: curative and life-extending. That is a crude distinction and sows the idea that funding a medicine that extends life by a short time is not worthwhile.

"In fact many cancers have been cured in our lifetime. And for a number of cancers there are cures on the horizon, with life-extending treatments often becoming the bridge that keeps the patient alive and well until the next breakthrough or the cure has arrived.

"Approaches to treating multiple myeloma are a good example of this point. Transformative, life-extending treatments have been available and funded throughout the Western world for several years. And a cure is in fact in sight. But in NZ myeloma is one of the most neglected

areas in terms of access to new treatments, with no new treatments having been funded for in NZ for the past 7 years”, said Dr Romeril.

Myeloma patient and young mother Nichola Oakenfull says seeing the Agency’s report just highlights the pain of her predicament.

“It’s pretty demoralising as a patient to read the report talking about curative and non-curative cancers. It feels like we are cast aside because there is no cure for us.

“There’s no cure for diabetes. But we accept the cost of continuing to treat diabetics as the right thing to do. Should we decide not to treat them because they are going to die anyway?

“Overseas, people with my cancer are living long and productive lives because they have access to drugs that manage their cancer for long periods, and when one drug stops working they move to the next option. Here in New Zealand we only have two lines of treatment for transplant eligible patients, and then it’s game over.

“As shown in the report, Australia has carfilzomib, daratumumab and pomalidomide funded for myeloma, while these three are not funded in New Zealand at all. These are not fancy, new, unproven drugs. They are standard of care overseas. People are shocked when I mention in international groups that we don’t have these medicines here in NZ.

“The Malaghan Institute in Wellington is doing amazing work with CAR T-cell trials. I want to be around for when they start using them for myeloma patients.

“I have an eight year old son I need to stay alive for, but I potentially won’t with the currently approved drugs. Knowing that it could all be so different if I lived across the Tasman is honestly heart-breaking, and so unfair”, said Ms Oakenfull.

Dr Romeril said Myeloma NZ was disappointed that blood cancers had not been included in the report, but noted that the Agency intended to produce a separate report on these.

“We will look forward to that with great interest,” said Dr Romeril.

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Myeloma New Zealand focuses specifically on multiple myeloma and improving the lives of patients affected by it. Our mission includes campaigning for the best patient care, gaining new, improved treatments, and enabling support for affected families.

Around 360 New Zealanders are diagnosed with this form of blood cancer every year. Myeloma New Zealand wants to provide support and information to help them and their families and loved ones to understand the myeloma 'journey' from diagnosis to treatment. We want to help them through the milestones they may encounter along the way and the likely options and choices they may have. But most importantly, we want to help beat this cancer by identifying and supporting strategies and research initiatives that will both improve the quality of life of those living with myeloma and extend their lives.

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