

Political party commitments on Myozyme and orphan drugs

NZ First

- Thank you for your 25 Oct e-mail. A civilised society should and could afford this. That is NZ First's view.
Winston Peters

NZ Labour Party

- “ The Labour Party believes that sufferers of rare diseases deserve fair and equitable treatment when it comes access to orphan drugs. As I said when I met with Pompe sufferers recently Labour does not believe that politicians should make decisions about the availability of specific drugs. What we can do, and what Labour will do, is set the criteria and funding for such decisions so that there is fair and equitable treatment. Treating orphan medicines the same way as other medicines is not fair or equitable. We will urgently review the criteria for access to highly specialised medicines. New Zealanders pride themselves on being caring and fair, we need to translate that into reality for sufferers of rare diseases.”

Grant Robertson, Labour Health Spokesperson.

Green Party

- "If there is a right to good healthcare, and we believe there is, then there is no reason that people living with Pompe should somehow be exempted from this right. Certainly the treatments are expensive compared to other pharmaceuticals, but no more expensive than quite a number of the non-pharmaceutical therapies that are funded. People living with Pompe and their families deserve a better deal. In fact they deserve the better deal intended by the NZ Medicines Strategy. It's time to deliver that now. "

Kevin Hague
Green Party MP

ACT Party

- The ACT party is dedicated to improving our economy and the efficiency of our Government services. Without a strong economy and business growth, New Zealand cannot afford a first class health system. In such circumstances New Zealand will continue to see cases like this where other countries are able to fund appropriate healthcare and New Zealand cannot. For this reason we are seeking ACT party votes in the coming election. It is time for change.

Robyn Stent Health Spokesperson

Mana Party

- No response

United Future Party

- I am committed to ensuring that those aspects of the medicine strategy that have not been implemented would be worked on as a priority by the new government. Peter Dunne

Maori Party

- There is a profound injustice at play, when simply due to the rarity of the diseases in question, that some families are placed at considerable disadvantage when it comes to the consideration of the most appropriate treatment. The Maori Party want our whanau to be the best that they can be and to be supported by an equitable, sustainable health system. In this capacity, we are calling for an evaluation of the Exceptional Circumstances funding process which governs the management of diseases like Pompe disease that need highly specialised treatments. We would like to encourage support for a robust orphan drugs access programme that will ensure treatment for our Pompe patients and other rare diseases. Our major argument is that no-one in New Zealand that is ill should not have support to treat the disease. Everyone must have a right to treatment.

Tariana Turia

National Party

- The High Costs Highly Specialised Medicines Review - a National promise – recommended PHARMAC review its Exceptional Circumstances process. PHARMAC did that and the result is a new scheme – to replace the old one called "Named Patient Pharmaceutical Assessment". It starts next March and its budget is expected to go up from \$4 million to \$8 million in the first year. Patients previously declined will be able to apply to have their application reconsidered after 1 March 2012. I encourage them to take advantage of the new clearer, more transparent criteria. I understand why patients with lysosomal storage disorders see some of the treatments now becoming available as offering them hope. I am advised PHARMAC is seeking further evidence. They've issued a request for information to manufacturers and other organisations around the world seeking data on patient outcomes from using Myozyme and other enzyme replacement therapies. PHARMAC would like to review that information as it would significantly assist their ability to make a better-informed funding decision. We appreciate, and as I said, empathise with your situation. We'll never be able to afford everything we would like. But I am pleased that PHARMAC is continuing to look for information that could support applications for the kinds of drugs you are seeking.

Jackie Blue

“I say that one should judge a society by how it looks after the sick and the vulnerable”

John Key, Prime Minister's Statement. Hansard, p16498, 8 February 2011

This phrase was repeated in very similar words by John Key on TV One's Sunday programme the day after the 2011 General Election