Press Release from Lysosomal Diseases New Zealand - Another medicine funding petition launched

New Zealand Rare Disease Patients Need Treatment Too.

Samantha, Freda and Yakuta, a mother, a grandmother, and a young woman with her life ahead of her, have launched a petition to Parliament aimed at ensuring Pharmac have enough funding to implement its new policy on medicines for rare diseases, which was announced back in April 2014, and to give urgency to doing so.

Samantha Lenik, Freda Evans, and Yakuta Moiyadi are all affected by Pompe disease, a rare Lysosomal disease that affects just eight other New Zealanders. It is a fatal disease which leads to progressive muscle weakness, wheelchair dependence and breathing assistance, and ultimately less time with their families.

This frightening outlook can be prevented with treatment. An enzyme replacement therapy called Myozyme can stabilise the disease and prevent deterioration. This treatment was first approved ten years ago by the FDA, the US medicine regulator, and is funded for patients in 76 countries around the world, but not in New Zealand.

Samantha Lenik, who is leading the petition, is asking Parliament to urgently review the funding Pharmac has available so it can fully implement its policy on medicines for rare diseases. "We have worked hard over many years to get Pharmac to change its attitude to funding treatments for rare diseases," says Samantha, "and the 2014 policy showed they were finally responding to our voices. But it is clear that two and a half years later, very little progress has been made in funding the treatments signalled as likely candidates under this new policy".

Samantha and her support network say that restrictions on Pharmac's budget is the major reason for the delays, with a lack of any urgency on Pharmac's part being another significant factor.

The trio are also concerned about other rare disease patients in the same situation. Yes, they need their own treatment funded, but they also want all eight treatments that are candidates under this policy, to be funded. These include treatments for several Lysosomal diseases like Pompe disease, plus Cystic Fibrosis, PNH and atypical-HUS disease - treatments that are all available to patients in most developed countries, but not in New Zealand.

Samantha asks all who support them to sign the petition on change.org<https://www.change.org/p/the-house-of-representatives-of-new-zealand-and-minister-of-health-dr-jonathan-coleman-new-zealand-patients-with-rare-diseases-need-treatment-to> which can also be accessed via the home page of Lysosomal Diseases New Zealand www.ldnz.org.nz<http://www.ldnz.org.nz/> Copies of a paper petition for gathering signatures can also be downloaded from the LDNZ website.

"We need to get treated so we can get on with living our lives," she says. "We want no patient left behind - no family forgotten."

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