

Dear Member of Parliament.

New Zealand patients with Rare Diseases need treatment too

- ❖ It has taken more than 10 years of advocacy to get acceptance of the needs of rare disease patients as deserving fair attention.
- ❖ Pharmac shifted their policy in 2014 and brought in a special fund for treatments for rare diseases.
- ❖ **But** progress has been painfully slow and 2 ½ years later only a fraction of these diseases have had their treatment funded.
- ❖ It is clear that Pharmac have been denied the funds they need to make these treatments available to NZ patients.
- ❖ It is also clear that the process being followed by Pharmac does not respond to the urgency of these patients' needs.
- ❖ We have launched a petition calling for adequate funding for rare disease treatments, and urgency in providing access. Up to 10 years+ is too long to wait.
- ❖ Check out the petition, linked from our website at www.ldnz.org.nz Please support us by signing on and sharing it with your networks. Share your concerns with the Health Minister.

We want no patient left behind - no family forgotten.

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

John Key, Prime Minister's Statement. Hansard P16498, 8 February 2011

Society is judging:

- Just because a disease is not common does not mean that the person with the disease should not receive treatment that could reduce their suffering or prolong their life (as they would if their disease was more common). Come on NZ, why are we lagging behind other countries!!! **Emma Grant, Auckland, New Zealand.**
- I am signing this because my entire family suffers the effects of living with a rare disease. Fabry disease runs in our family and half of us are progressing through various stages of this disease. It is a terrible shock when you are diagnosed with a progressive and rare disease and it is even more horrible to be told that because we live in New Zealand we cannot access the one treatment that is funded in all the other developed countries. We may be a small number but we are human beings too, doesn't every life count? Why should I have to tell my ten year old he needs to just sit and wait out the pain because the government won't help us access the one life saving treatment available, the one treatment that will slow

down the progression and allow us to live a better and more productive quality of life.

Carol-Anne Tate, Dunedin, New Zealand.

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