Cystic Fibrosis Briefing for NZ Parliamentarians – February 2018

Cystic fibrosis

Cystic fibrosis is New Zealand's most common life-threatening genetic disorder. One in 25 Kiwis carry the gene that causes cystic fibrosis (CF), often without knowing. There are around 500 Kiwis living with the condition.

CF causes persistent lung infections and limits the ability to breathe over time. It causes mucus to block the airways, causing chronic lung infections, and also blocks other organs such as the liver, seminal ducts and pancreas. This prevents vital enzymes being released to digest food, leading to problems with weight gain. Before the disorder was recognised in 1938, children with the condition were classed as 'failing to thrive'.

These days life expectancy is much better – especially overseas where people with the condition have access to high precision medicines and all the latest treatments for the condition. In New Zealand, it's believed life expectancy for a child born with CF today is about 37. While we have no firm figures on NZ life expectancy at this stage, the estimated age is significantly below countries such as the US, Canada and the UK which report 45+.

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Estimated life expectancy

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The biggest issues

For many years cystic fibrosis has been left out of government policy, which is disappointing given that it is New Zealand's most common inherited condition that shortens life expectancy.

People living with cystic fibrosis have fallen into a pharmaceutical gap where they do not qualify for the rare medicines fund under the existing criteria, nor do they qualify under the general medicine budget that aims to benefit a large percentage of the population. For families who can benefit from precision medicines, this is a heart-breaking and vulnerable position.

Limited access to effective medicines

Our role is to advocate on behalf of the New Zealand cystic fibrosis community. Cystic Fibrosis New Zealand is lobbying for progress in the following areas:

- **Kalydeco** – New Zealand is the only country in the OCED (with a high incidence of CF) that does not fund Kalydeco for people who have the G551D gene (approx. 32). This medicine has transformed the lives of people with this genetic type of CF. Clinical results show that hospital admissions are drastically reduced, lung function deterioration is effectively stopped, and there are high hopes it will also improve life expectancy.

- **Vital equipment** – CFNZ is probably the only charity in New Zealand that funds medical devices for patients. In July we met with Pharmac to see if they could take over the funding of nebulisers and compressors which are not funded by many DHBs. We have been informed that we will need to approach each DHB individually to ask them to take over the funding of these devices. This is an incredibly time consuming and difficult task for a small charity.

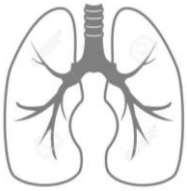
- **Wellington Hospital** - this is also part of CFNZ's advocacy efforts. The new children's hospital needs safe clinics for children with CF who are very prone to serious infections.

- **Funding** – traditionally the Ministry of Health has provided $65,000 annually towards our social workers who visit hospital clinics, and families in their home, to help them cope with the demands of CF. The MOH wants

DHBs to take over the funding of this service and we are eager to ensure a smooth transition to the new system. CFNZ's other services are covered entirely by grants and donations but funding is always tight.

- **Tobi Podhaler** - this is a product that delivers the antibiotic tobramycin by aerosol. It takes CF patients just 1 minute to inhale this compared to around 20 on the conventional nebulisers. This is available in Australia and the United Kingdom and people with CF returning to New Zealand are distressed to find it is unavailable here – Tobi Pods would dramatically reduce treatment burden and improve people's lives.

- **Orkambi** -is another medicine that has been effective for treating patients with the common F508del gene (approx. 162 people). This medicine has not even been registered in NZ due to the cost of manufacturers submitting an application versus the likelihood of Pharmac funding.



500 kiwis live with cystic fibrosis

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How you can help

CFNZ has written to all MPs to brief them about some of the issues facing people with CF. We request that you work towards improving the lives of people with CF in New Zealand by keeping their needs in mind for the formation of new health policies and supporting improvements to funding medicines in New Zealand. Your support is key to improving the life expectancy of people with cystic fibrosis in New Zealand.

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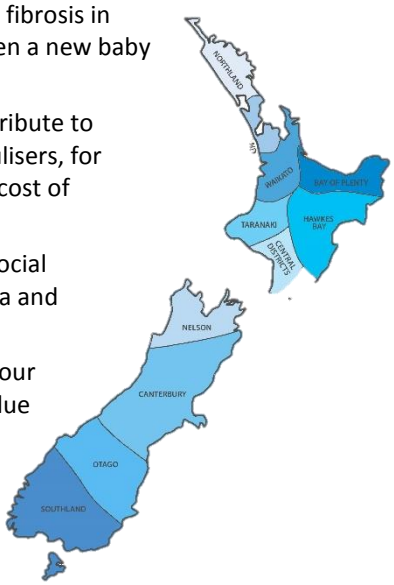
Cystic Fibrosis New Zealand

Cystic Fibrosis New Zealand (CFNZ) supports the 500 people living with cystic fibrosis in New Zealand. We provide social workers who are there for families from when a new baby is diagnosed right throughout the rest of their lives.

We provide a number of grants to help people improve their health, we contribute to research, and in many regions we fund vital medical equipment such as nebulisers, for people with CF to take their medicine, because some DHBs do not cover the cost of this.

We also provide regular communication through newsletters, conferences, social media and the CFNZ website, promoting public awareness of CF via the media and fundraising events.

There are 12 local CFNZ branches (locations, right) around New Zealand and our representatives have regular contact with families with CF. However, sadly, due to infection risks, people with cystic fibrosis are unable to socialise together due to the chance of contracting life-threatening lung infections.



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