

## Cystic Fibrosis New Zealand Briefing for Parliamentarians

### To all Members of Parliament

I am writing to you on behalf of Cystic Fibrosis New Zealand to highlight the challenges faced by the more than 540 people living with cystic fibrosis in New Zealand. We ask that you do all you can to improve their lives by supporting:

- ***Our campaign to have Trikafta publicly funded so that the immediate and significant benefits for people with cystic fibrosis, their families and the health system can be realised as soon as possible.***
- ***An urgent and substantial increase in public funding for medicines and improvements to speed up access to life-saving drugs.***

### What is Cystic Fibrosis (CF)

Cystic fibrosis (CF) is a serious and ultimately terminal inherited genetic condition affecting more than 540 people in New Zealand (NZ). Around 1 in 25 New Zealanders carry the faulty gene that causes CF and 12 babies were born with CF in New Zealand in 2019. CF causes the body to produce thick sticky mucus which damages the lungs, digestive system and other parts of the body. CF imposes a heavy burden throughout life with significant quality of life, social and economic impacts on people with CF, their families and communities.

**540+ PEOPLE  
WITH CYSTIC  
FIBROSIS IN NZ**

Current treatment for CF involves a demanding and time-consuming daily regime of lung clearance and medication, together with regular medical check-ups and, over time, increasingly frequent hospitalisations. For a number of those with CF, a lung transplant may be the only remaining option. CF cuts short the lives of those with condition, with only half of those with CF reaching 31 years of age.

### Cystic Fibrosis NZ (CFNZ)

Cystic Fibrosis New Zealand (CFNZ) was established in 1968 and is the only charity in NZ dedicated to supporting and improving quality of life for people with CF and their families. CFNZ advocates for better access to treatment and medication for people with CF and invests in research. CFNZ's team of social workers support families in their homes and in medical settings. CFNZ also facilitates parent to parent support, provides vouchers and allowances during hospitalisations, exercise grants, welfare assistance during hardship, assistance towards organ transplant costs and, when necessary, end of life support.

**ONLY 50% OF  
PEOPLE WITH CF IN  
NZ REACH 31 YEARS  
OF AGE**

### Public Funding of Trikafta

Current treatments for the majority of people with CF in New Zealand treat only their symptoms. CF modulators, such as Kalydeco and Trikafta, provide the first treatments to address the underlying cause of CF. Kalydeco is funded in New Zealand but works for only approximately 5% of those with CF. Approved by Pharmac in early 2020, it is already providing significant improvement in health and well-being for the 30+ eligible NZ patients.

**Cystic Fibrosis NZ Supporting Kiwis with cystic fibrosis to live a life unlimited**

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**TRIKAFTA WORKS  
FOR 90% OF PEOPLE  
WITH CF**

Trikafta works for approximately 90% of those with CF and provides immediate and significant benefits. These benefits include increased lung function and weight gain, reduced treatment burden, improved quality of life and increased life expectancy. Trikafta not only benefits those with CF and their families. Trikafta would also provide immediate and longer-term

benefits for the New Zealand health system, though reduced hospitalisations, decreased treatment burden, and deferred or avoided lung transplants.

Trikafta is now available to people with CF in the UK, Republic of Ireland, the USA, Denmark, Germany and Switzerland. It is currently being considered for funding in Australia with a decision to be announced in April 2021. Several New Zealanders are self-funding Trikafta and, as a result, have experienced life-changing improvements in their health, well-being and ability to fully participate in life. CFNZ wants to see Trikafta publicly funded in New Zealand, so that the immediate and significant benefits for people with CF, their families and the NZ health system can be realised as soon as possible.

CFNZ supports the petition of Trikafta for Kiwis to the Health Select Committee seeking public funding for Trikafta.

[https://www.parliament.nz/en/pb/petitions/document/PET\\_99952/petition-of-carmen-shanks-publicly-fund-trikafta-medication](https://www.parliament.nz/en/pb/petitions/document/PET_99952/petition-of-carmen-shanks-publicly-fund-trikafta-medication)

***Medicines Funding***

CFNZ wants to see an urgent and substantial increase in public funding for medicines and improvements to speed up access to life saving drugs. Current arrangements mean that New Zealand continues to fall further behind other developed countries and now ranks last of 20 OECD countries for market access to modern medicines.

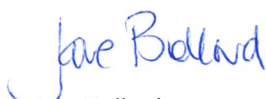
New Zealand's medicines' budget has been significantly underfunded and is failing to keep pace with population growth and inflation. The waiting list for funding of medicines has grown from 92 in 2015 to 110 in 2019, while the average waiting time for approval has increased from 2.7 years to 4.8 years over the same period. New Zealand has publicly funded only 23 of the 403 medicines launched elsewhere in the OECD between 2011 and 2018.<sup>1</sup>

Pharmac urgently needs a substantial increase in funding to enable it to clear the growing backlog of medicines awaiting funding and provide for life saving new medicines. Improvements are also needed to speed up access to life-saving medicines.

CFNZ supports the petition from Patient Voice Aotearoa to the Health Select Committee seeking the reform of Pharmac and the doubling of Pharmac's budget.

[https://www.parliament.nz/en/pb/petitions/document/PET\\_91080/petition-of-malcolm-mulholland-for-patient-voice-aotearoa](https://www.parliament.nz/en/pb/petitions/document/PET_91080/petition-of-malcolm-mulholland-for-patient-voice-aotearoa)

Thank you for your support.



Jane Bollard  
Chief Executive

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<sup>1</sup> NZ's Medicines Landscape 2019/20, Medicines New Zealand