MEDIA RELEASE
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Trikafta – positive news but progress still painfully slow

Pharmac has now published a partial record of the Respiratory Advisory Committee's April 2022 meeting, covering the Committee's reconsideration of Vertex's application for funding of Trikafta. The release of this excerpt is the latest step in the ongoing battle to get Trikafta funded for Kiwis with cystic fibrosis (CF).

The Respiratory Advisory Committee, which includes experts who understand the complexity of CF, has restated its original recommendation that Trikafta is a **high priority** for funding for all those **aged six years and older** who would benefit.

The Committee considered the evidence it had received to be of "high strength and quality" demonstrating that Trikafta has a "significant and consistent clinical benefit". The Committee also noted that "results were consistent across multiple trials, case studies, and real-world studies, and considered that the results were robust despite the heterogeneity of CF, a disease in which positive outcomes have been very difficult to demonstrate." [1]

Cystic Fibrosis NZ Chief Executive Lisa Burns says, "We are relieved and reassured that the latest record reflects and reinforces what the respiratory experts told Pharmac last August. We can only hope that Pharmac is listening this time.

Hope is all our families have left, with the health and quality of life of their loved ones rapidly deteriorating and the ability to do anything out of their hands."

Almost a year after the Committee's original assessment of Trikafta, ongoing delays with meetings and long waits for recommendations and records to be published continue to cause frustration for CF families, exacerbated by announcements of further Government spending.

CFNZ believes the Government and Pharmac are out of step with the rest of the world where more innovative progress is being made with access to modern medicines. The estimated annual cost of less than $60m to fund Trikafta for the 400 people with CF who would benefit, would require only 6% of the nearly $1 billion it is costing the Government to temporarily reduce fuel taxes.[2]

"The issue is not how we can afford to fund modern medicines like Trikafta in New Zealand, it is how can we not do it. We need a significant change in our approach to funding modern medicines that is based on prevention not treatment. Medicines like Trikafta are an investment rather than a cost," said Lisa.

Independent work commissioned by CFNZ for 2019/20, and shared with Pharmac, calculated the approximate annual social, economic, and financial cost of CF to be $116m.

In contrast, the estimated investment of less than $60m on Trikafta would provide significant economic and financial benefits, keep people out of hospital, lower the number of infections requiring intervention, reduce lung transplants, and improve quality of life overall, reducing the burden on New Zealand's healthcare system which is already under pressure particularly with respiratory illnesses.

“Only 0.8% of Pharmac’s budget is spent on medicines for rare disorders like CF. Decision making to get medicines funded is complex, opaque and has unnecessary delays that are just not good enough. There are 10 medicines for rare disorders on the options for investment list including Trikafta, waiting an average of 5.74 years, with one medicine on the list for 13 years,” says Lisa.

CFNZ is aware of many families who are now medical refugees. With no other options left, they have been pushed to leave New Zealand, making the difficult decision to uproot their lives, leaving family, friends, and careers to keep their loved ones alive. Those who have been able to access CF modulators overseas are now unable to return to NZ because they are not funded here.

“We know Trikafta is a good investment, we know it works. There is so much evidence from overseas and from Kiwis whose lives have been completely changed by having access to Trikafta. Why do you have to be fighting for your life before you can be given this wonder drug?”

OJ Daniels from Rotorua has bravely shared his CF journey to raise awareness, documenting recently getting access to Trikafta through Vertex’ s Managed Access Programme. “Only 10 weeks ago I found myself in ICU fighting for my life. I had to search deep inside to find the strength and courage to keep fighting. The battle to find the will to live versus the urge to let go. I was between two worlds: the living and the dying. Now I have been on Trikafta for 6 weeks and I am doing great. All I ever wanted was to know what it’s like to truly live.”

The next milestone for the CF community will be the release of the Pharmaceutical and Therapeutics Advisory Committee (PTAC) record from May which is due out in mid-August, followed by Pharmac’s quarterly ranking of medicines in September. CFNZ is hopeful that the Respiratory Advisory Committee has finally been heard and that Trikafta will be fairly prioritised and funded based on the advice of the experts.

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For more detailed information please refer to the Cystic Fibrosis NZ media kit.

1. https://pharmac.govt.nz/assets/Excerpt-from-Record-of-the-Respiratory-Advisory-Committee-meeting-27-May-2022.pdf
2. https://www.beehive.govt.nz/release/government-cuts-25c-litre-fuel-excise-cost-living-relief-package
   https://www.beehive.govt.nz/release/govt-provides-more-cost-living-support