

## **MEDIA RELEASE**

Thursday 20 March 2025

### **Medsafe approval clears the way for expanded access to Trikafta for Kiwi's aged 2 to 5 years old.**

**Auckland, 20 March 2025** – The path is now clear for Pharmac to expand access to Trikafta for New Zealand children aged 2 to 5 years following Medsafe's approval of the treatment for this age group.

Cystic Fibrosis NZ (CFNZ) is urging Pharmac to act without delay, ensuring that our youngest and most vulnerable Kiwis with cystic fibrosis (CF) can benefit from this life-changing medicine. The evidence from those aged 6 and over clearly demonstrates that funding Trikafta leads to significantly improved health outcomes, fewer hospitalisations, and a transformative impact on wellbeing and quality of life.

Pharmac's expert advisers clearly recognised that damage occurs to children with CF very early in life. They concluded that the best way to prevent deterioration and long-term damage is to intervene early i.e. at 2 years of age.

**In the light of this evidence and with no regulatory barriers remaining, CFNZ is calling for a swift funding decision.**

Lisa Burns, Chief Executive for CFNZ said "Pharmac already funds Trikafta for those who are eligible aged 6 and over. New Zealand has some of the widest access in the world, covering many rare mutations. Now, with Medsafe approval, there is nothing standing in the way of expanding access to the approximately 60 children aged 2 to 5 living with CF who would be eligible."

"New Zealand has the opportunity to join 31 other countries—including Australia, Canada, and the UK who have recognised the overwhelming benefits of early intervention and have made this treatment available. It's time for us to do the same."

The case for early intervention is well established. The trajectory of CF is largely determined in early childhood, and delaying access to treatment can result in irreversible structural lung damage. International data shows that starting treatment as young as possible leads to better long-term outcomes, reducing the burden on the health system and pressure on families.

Lisa says "This is an opportunity for Pharmac to take a fresh approach to the assessment process using this as a case study for a fast-track funding decision. Clear evidence of benefit and cost savings along with evidence from comparable countries would avoid unnecessary delays and give children the best possible chance at a healthier future.

For families like the Rooney's who received a diagnosis of CF for their new son Luca at three weeks old it was one of the most difficult challenges they've had in their lives. The news was crippling for both Liam and Courtney who already had Beau (now 4 years old) and with no family history on either side. "All we want for him is to live a happy and healthy life doing whatever he wants to do. In the short term, we pray that Trikafta funding is brought forward to 2 years old, and his body reacts well to the drug. He and his brother are the lights of our lives." says Liam.

The inaugural **New Zealand Cystic Fibrosis Symposium**, taking place on **9-10 May 2025** in Auckland, will bring together clinical teams, researchers, and the CF community to explore the latest advancements in CF care.

As the first international symposium of its kind for CF in New Zealand, the event will feature leading global and local experts sharing insights on emerging treatments, research, and evolving models of care. This includes discussions on what to expect when Trikafta becomes available for children aged 2 to 5, ensuring the CF community and healthcare professionals are well-prepared to integrate this treatment. The symposium provides a vital platform for knowledge-sharing, collaboration, and innovation to improve outcomes and quality of life for people with CF in New Zealand. **For more information, visit [nzcfsconnect.nz](http://nzcfsconnect.nz).**

“The symposium will provide invaluable opportunities for healthcare professionals, researchers, and the CF community to connect with international experts. Together, we aim to foster collaboration and knowledge sharing that will prepare us for when Trikafta becomes available to this younger age group,” said Lisa.

CFNZ remains committed to advocating for timely and equitable access to modern CF treatments, ensuring all New Zealanders with CF have the opportunity to live well and thrive.

#### **ENDS**

For media inquiries or interview requests, please contact:

Imagery is available, attached.

#### **Supporting Resources:**

CFNZ Media Kit

End of Release

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#### **About Cystic Fibrosis NZ (CFNZ):**

Cystic Fibrosis New Zealand (CFNZ) was founded in 1968. It is a well-respected charity delivering a range of vital services. We support many of the more than 600 people and their families affected by cystic fibrosis (CF) in New Zealand.

We work with people of all ages from pre-school age to adults to change the trajectory of their lives. We are here to extend and improve the lives of those living with CF.

CFNZ relies on the generosity of donors and support from the philanthropic and business community. Our vision is that people with CF are thriving and living healthy lives. We are committed to ensuring that individualised and meaningful support is available at every part of their CF journey.