

CFNZ announces less than a month until eligible Kiwis with CF can access Trikafta.

In less than a month, people with cystic fibrosis (CF) over the age of 6 who meet the eligibility criteria, will have access to funded Trikafta. From 1 April 2023 New Zealand will join the more than 30 countries where Trikafta is publicly funded.

Pharmac has confirmed to Cystic Fibrosis NZ (CFNZ) that formal approval has now been given to fund elexacaftor with tezacaftor and ivacaftor (brand name Trikafta) for people aged 6 years and above with CF, subject to eligibility criteria.

Lisa Burns, Chief Executive of CFNZ said, "This decision is nothing less than monumental, it's a significant announcement that will dramatically change the lives, and life expectancy, of so many Kiwis with CF. The last two years have been tough, with the months since the preliminary announcement being especially difficult. Emotions and anxiety have been running high for our families and we're delighted that they now have certainty."

Pharmac has confirmed that no changes have been made to the proposal that was put out for consultation on 4 December 2022. That proposal provided for wide eligibility for Trikafta, including rare mutations that are responsive to Trikafta in vitro. New Zealand is one of the few countries in the world to provide such extensive access to Trikafta.

In August 2022, Pharmac acknowledged that Trikafta could give people with CF benefits equivalent to 27 more years of full health when compared to current treatments. While it is wonderful news for those who are eligible to receive Trikafta, CFNZ acknowledges that there is a period of transition that will need to take place.

Many Kiwis with CF will be facing a new reality. Until now, many people with CF were not able to make big life decisions about their education, career, relationships, buying a house, or retirement. Instead, they have lived with the anticipation that their future would be cut short. Support will be needed to help them adjust as they transition to a life of opportunities that they didn't think were possible.

A Waikato mum whose 6-year-old son will be eligible for Trikafta said "Being on Trikafta will give my boy hope, it will give him a life. He will be able to go to school. My family will be able to breathe. The psychological health of all will improve. We will be able to have a life outside of medical care in hospitals and at home. This is our lifeline."

"New CFNZ support programmes focused on wellbeing, mental health, education, and connection are already being developed so that we can respond. Understanding the changing needs of our community is important so we can provide meaningful, tailored support that makes a difference." says Lisa.

"For some, this announcement doesn't change their reality, and we will continue providing support for quality of life and wellbeing.

There is a small percentage of people with CF who will not be able to take Trikafta or who will not be eligible. There are also those for whom Trikafta has come too late. We honour them and send our aroha to those families who may have lost a loved one, and those who have been through a transplant or are in end stage care."

Rebekah, mother of a young man with CF who is one of those not eligible for Trikafta said, "The approval of Trikafta for the eligible CF community felt like a double-edged sword. Thrilled to know the future is brighter for most with CF while feeling waves of intense grief at the loss of my son's quality of life and future. I do not wish this pain on anyone else and only wished this medicine had come 10 years ago for Matthew."

"CFNZ would again like to acknowledge the tremendous efforts made over the last two years by the CF community. We are grateful for their support, generosity, and kindness and the support of the wider NZ public. So many people bravely shared their deeply personal stories in the hope of raising awareness and making a difference. CFNZ would also like to thank Pharmac, Vertex, and the Government for making this happen."

With the widening of access to Kalydeco not included in the Trikafta decision, it will continue to be part of the ongoing advocacy work for CFNZ. Pharmac already funds Kalydeco for some people with CF, and its expert advisors have recommended a high priority for widening access.

Lisa said "CFNZ is encouraged by Pharmac's understanding that there is a strong desire for all people with CF to have a funded CFTR therapy, and that they are committed to continue working towards this. We urge them to widen access to Kalydeco and provide access to other CFTR therapies to everyone who would benefit, as quickly as possible. There is no equity until everyone who could benefit from a CFTR therapy has access to one."

"An exciting time is ahead for those eligible to access Trikafta, and we are full of anticipation as they start to live lives that once appeared impossible. We cannot wait to see the lives of our families transformed through this historic announcement."

"CF is a condition for whole of life, and we are committed to walking beside our community for all of it. As their needs evolve, so do we." said Lisa.

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If you would like to speak to someone local in the community, please get in touch.

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