MEDIA RELEASE
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PHARMAC SAYS IT CAN'T PROGRESS TRIKAFTA

Is **"HOPE"** the new medicine strategy for NZ?

Yet again, Pharmac has raised the hopes of Kiwis with cystic fibrosis only to shatter them.

After months of what appeared to be encouraging progress, Cystic Fibrosis NZ (CFNZ) has been advised by Pharmac that, following its September medicines' ranking process, Trikafta[1] has not moved up the Options for Investment (OFI) List.

The outcome of this is that Pharmac is not **in a position to move forward with funding Trikafta at this time,** and that funding is **unlikely to occur without changes to the information at hand.**

Lisa Burns, Chief Executive for CFNZ says "We are shocked and outraged at this decision from Pharmac. This highlights our significant concerns about what is going on within Pharmac, their processes, decision criteria, and how these decisions are being communicated. We have been left confused and don't have the words to convey our deep disappointment for our CF community."

In August 2022, Pharmac released the record of advice from its Pharmacology and Therapeutics Advisory Committee (PTAC) and published a summary of its Technology Assessment Report (TAR)[2] containing its assessment of the cost-effectiveness of Trikafta.

As part of that release, Pharmac acknowledged the major benefits that Trikafta offers, not just to the health system but an extension to life expectancy and quality of life, estimating that Trikafta would provide benefits equivalent to **27 more years at full health when compared to current treatments**.

Pharmac also stated that it had already re-ranked Trikafta on its Options for Investment (OFI) List and was continuing commercial discussions with Trikafta's supplier, Vertex, to try and reach an agreement that would enable funding.

However, Pharmac has now advised CFNZ that Trikafta was re-ranked again in September, but it has not moved high enough up the OFI List for it to progress to funding at this time. Pharmac has advised CFNZ that changes would be needed to one or more of the factors for consideration before Trikafta could be re-ranked again and have the chance to move further up the OFI List.

These have been outlined as:

1. More information that could change Pharmac's Factors for Consideration
2. A change in the price offered by Vertex
3. Additional budget uplift.

Lisa said "The failure of Trikafta to move up the OFI List to progress funding makes it very clear that the Pharmac process does not work for modern medicines. Despite all available evidence, assessments and reassessments, validation by their Clinical Experts, we're going round in circles with unnecessary delays due to poor process, and decision making."

"We are utterly thrown by Pharmac's decision not to prioritise funding Trikafta. It defies logic that a medicine with such positive impact doesn't make it up the ranking list for funding. The current average life-expectancy in New Zealand is 31 yet Trikafta could give Kiwis with CF an additional 27 years, and quality of life. It doesn't make any sense."

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[1] Trikafta is a medicine that treats the cause of cystic fibrosis for around 90% of those with the condition.
[2] https://pharmac.govt.nz/news-and-resources/news/2022-08-15-media-release-pharmac-shares-update-on-its-assessment-of-trikafta/

Pharmac stated in its August release that they don't just look at how much, in dollar terms a medicine costs, that they also consider the health benefits to the person taking the medicine and what the benefits would be to the healthcare system. This is inconsistent with the decision advised to CFNZ where cost appears to be a barrier in moving the application forward.

"Trikafta is now available in more than 30 countries around the world. Pharmac has had access to the same information and evidence, in fact they've had the benefit of all the additional worldwide clinical data provided by Vertex, so are they implying that all those countries got it wrong?" said Lisa.

Trikafta would be a highly cost-effective investment. Independent work commissioned by CFNZ for 2019/20, calculated the approximate annual social, economic, and financial **cost of CF to be $116m** which was shared with Pharmac. The estimated annual cost to **fund Trikafta would be significantly less than $60m**.

Pharmac has advised CFNZ that "the door is not closed" and that "Trikafta is a medicine we want to fund". But, even if changes can be made to enable Trikafta to move up the OFI List, Pharmac has advised that this **will not happen before December 2022**.

"In the meantime, those who can will make the decision to leave NZ, their home, families, education, and careers to access Trikafta or another CFTR modulator overseas. Others will desperately seek access to Trikafta by any means they can or try to access unregulated alternatives, potentially putting their health at further risk while simply trying to stay alive," said Lisa.

New Zealand's current medicines funding system is out of step with the rest of the world, cost focused and obsessed with procuring cheap drugs at the expense of health outcomes. The perception that the Pharmac model is the envy of other countries, is simply not true, it's an example of what not to do and their model hasn't been adopted anywhere else in the world.

"This game of chance, playing with the lives of our CF community is unacceptable. We need a medicines framework that recognises funding medicines like Trikafta is an investment in the people of New Zealand and our health system. Until we do, thousands of sick and vulnerable Kiwis will continue to experience needless suffering and early death."

"CFNZ and our CF community remains relentless in our determination to get Trikafta funded in New Zealand. **Kiwis deserve better than this, HOPE shouldn't be our only option for a medicine's strategy**."

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