

12 January 2021

CLOSE ENOUGH TO TASTE IT

The fight for Trikafta has been underway at Cystic Fibrosis Australia (CFA) for some time now. We have been getting amazing feedback from the community, from active and vocal individuals who have made it their mission to contact local MP's or use the Pharmaceutical Benefits Advisory Committee (PBAC) consumer feedback channels in an effort to get the word out on Trikafta.

It is a tough campaign to mount, but the arguments speak for themselves.

- 1. Trikafta is a 3rd generation cystic fibrosis (CF) multi-drug, it is one of a kind.
- 2. This new medicine combines elexacaftor, tezacaftor and ivacaftor into a treatment of unprecedented efficiency and impact.
- 3. 90% of trial patients showed a decline or halt in lung damage.
- 4. Exacerbations, hospitalisations and antibiotic use were dramatically lower in the trial group.
- 5. Nutrition, BMI and mental health outcomes were all positively affected.
- 6. Incidents of CF-related diabetes were supressed and less frequent overall.

This is the future of CF in Australia, and we are close enough to taste it. We just need to keep the pressure on decision makers to make sure that Trikafta is on everybody's minds going into the March 2021 PBAC Meeting.

All of us would benefit in some way from this landmark in the fight for CF lives. Halting lung damage with early intervention is the number one way to stave off transplants and hospitalisation. It saves, extends and enriches lives and give people with CF a future.

In addition to a positive PBAC decision that will give general access to Trikafta for the 90% of CF gene profiles, I do not think that it is too much to demand immediate Compassionate Access for all eligible patients following a PBAC recommendation and prior to commercial negotiations. Why should people with CF continue to suffer while corporate imperatives take precedence, especially when it is estimated that Vertex will generate \$6.6 billion from Trikafta in just five years?

Everything you need to know about Trikafta and the PBAC comments process can be found on CFA's website <u>HERE</u>.

Now is the time to write to the PBAC and share your story – <u>Letter to PBAC</u>.

Trikafta may be the future of CF medicine, but CF lives are simply the future.

Kind regards

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