

23 March 2021



FIGHT HARD ... IT IS WORTH IT

People who make history rarely realise what it is that they are doing. The feuding feudal barons of 1215 could not foresee the social impact of Magna Carta when they signed it. Great discoveries like Penicillin and Radioactivity nevertheless owe a great deal to accident.

But although momentous things have been known to happen by accident they very rarely happen in quiet neighbourhoods. Great things happen where there is already a powder keg of energy and struggle and activity.

At Cystic Fibrosis Australia (CFA) we fight hard because we know that great things are only possible if we do. There are never guarantees, we can never ask for a refund of our hard efforts if a decision does not go the way we want.

Advocacy is sometimes a thankless job and you can pay up front for a product that is never delivered.

In recent years we have been lucky. We have scored a few wins on important issues like funding for Orkambi and Symdeko and Kalydeco. But this year the stakes are high because cutting edge CFTR Modulators with a second corrector are almost within our grasp.

The Pharmaceutical Benefits Advisory Committee (PBAC) is currently deliberating whether or not it will recommend Trikafta for government funding. We need to make ourselves part of this closed-door conversation and the only way to do it is to make some real noise.

Immediate Compassionate Access is a major priority, and one that we will have to fight for. But we will also have to fight to get recognition for the amazing patient responses to this drug and to avoid letting things boil down to a clinical commercial level.

The decision to reimburse will be announced on 23 April 2021. Three options are on the table – approval, deferment and rejection. If Trikafta is approved CFA is asking for immediate Compassionate Access for all eligible people as this will alleviate months of suffering and save lives.

It is estimated that Vertex will earn \$6.6 billion from Trikafta over the next five years. 1200 doses over a few months while a price is set won't break the Vertex Bank. Help us make sure Vertex is aware of our needs by sending them a letter regarding immediate Compassionate Access following a positive PBAC recommendation. This has not been done before but where there is a will there is a way. [LINK to Vertex Letter](#)

The time has come already for you to fight hard with CFA for Trikafta. That means sharing the Trikafta message on socials and going the extra mile, like drafting a letter to our Health Minister, Greg Hunt about the importance of Trikafta to Australians with cystic fibrosis (CF). Local media and local members are a great resource and letters and contact details can be found [HERE](#).

When we fight hard we still do so blindly, without the comfort of guarantees. But the history of the world and the history of our own plucky community shows that at these times of struggle great things can happen.

Kind regards

A handwritten signature in black ink, appearing to read "Nettie Burke". The signature is fluid and cursive, with the first name "Nettie" being more prominent than the last name "Burke".

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