

26 April 2021

## **Patients V's Patience – Never the Twain Shall Meet**

The word **patient** is popularly defined as a person who quietly suffers, someone lying patiently in a bed waiting for interventions from outside experts. The concept of **patience** is an acceptance or tolerance of delays, problems, or suffering without becoming annoyed or anxious.

The ambiguities of Health Technology Assessment system and the English language are at play here and I choose to believe that the CF community neither should have to lie patiently nor tolerate delays in care.

The announcement last Friday that the PBAC will not be recommending Trikafta for reimbursement heralds the end of and **patients** with **patience**. We cannot sit idly by while Big Pharma and Government play 'holdout' with people's lives.

We know that every day of delay is a day of lung damage, mental anguish, isolation and progression towards end of life.

The solution is clear, and it is not new ... ***immediate Compassionate Access for all eligible Australians while commercial negotiations continue.***

The vanguard of HIV advocates campaigned on the same platform in the 1980s and in recent years some responsible pharmaceutical companies have generously offered this feature as part of negotiations. Compassionate Access is a norm not a privilege, and lives are on the line here.

CFA is aware that R&D cost must be met otherwise drug development would cease to exist. However, let's see those costs come out of finalised contracts. Let's see these pharma companies show some heart. ICER\* estimate that Vertex will see Trikafta revenues of US\$6.6 by 2023. Compassionate Access to Trikafta will NOT break the bank for Vertex.

Time to call on your local media, local polities and local communities to support our 'Have a Heart' campaign. Simply put the image on your emails, on your socials, on other people socials, on the windows of your car, send CFA photos of your best 'Have a Heart' stance for circulation and use hashtag #haveAheart.

While resubmission and price negotiations continue behind closed doors we need all our stakeholders to know that we are watching, waiting, and hoping they will 'Have a Heart'.

Kind regards



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\*ICER is a group of independent experts who would review and analyse of the clinical trial evidence, listen to patient testimony, and deliberate over the clinical and economic value of health interventions.

<https://www.cysticfibrosis.org.au/advocacy/trikafta-advocacy-plan>

# Have a Heart for CF



**Have a Heart  
for CF**



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