



23 April 2021

A Tough Pill to Swallow ... ACCESS DEFERRED

The Cystic Fibrosis Community is devastated today. Trikafta was not recommended for reimbursement by the Pharmaceutical Benefits Advisory Committee (PBAC). Having seen the outstanding clinical trial data we can only surmise that once again 'money' is the stumbling block.

Lives are lost, families destroyed, and futures put on hold while protracted negotiations play out.

Cystic Fibrosis Australia (CFA) is not suggesting the exorbitant list price of \$410,000 per person per year is paid, however we do believe that Vertex is capable of providing Compassionate Access to all eligible Australians while negotiations continue.

ICER* has stated publicly that Trikafta is 'well above commonly-accepted cost-effectiveness thresholds' and at \$1120 per day pp we have to agree. ICER estimates that Vertex will earn US\$6.6 billion from Trikafta alone by 2023.

CF lives should not be lost because of this craven commercialism. A few months of Compassionate Access should not be too big a pill to swallow for a company whose share price currently sits at around AUS\$278.

CFA will be requesting access to Vertex's PBAC Submission, the PBAC Minutes and any other relevant correspondence. When lives are at stake the power players must be held to account. We will also be holding a stakeholder meeting to get all critical protagonists at the table to share their dealbreakers and demands.

Please enlist the support of your local Federal Government Member [LINK](#) and your local media outlet. This is a community campaign and if we are to get the desired outcome, we must all pull in the same direction.

We can keep it simple as we have one 'ask' ... ***immediate Compassionate Access for all eligible Australians while commercial negotiations continue.***

Kind regards

A handwritten signature in black ink that reads "Nettie Burke".

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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>