



MEDIA RELEASE

5 November 2020

MILESTONES THAT MUST BE MET

Once again people with cystic fibrosis (CF) begin the long wait for life changing and life extending medicines. Vertex Pharmaceuticals submitted Trikafta to the Therapeutics Goods Administration (TGA) in February this year and best-case scenario will be that the Pharmaceutical Benefits Advisory Committee will (PBAC) review it in March 2021.

13 months for Step One in the Australian Health Technology Assessment (HTA) process is a milestone, but the journey getting there was way too long. Step Two involves the PBAC deciding whether to recommend Trikafta for reimbursement. A decision will be announced on 23 April 2021, however that is not the end of the journey.

A positive recommendation would be a great landmark however it's only then that the commercial negotiations begin. What is Australia prepared to pay for decades of life for 90% of the Australian CF population this drug?

This time around Cystic Fibrosis Australia (CFA) is taking a new approach to our advocacy. In the Trikafta debate we do not need to prove Trikafta's efficacy – clinical trials around the world have done that already.

Instead CFA is feeling positive about TGA approving Trikafta and the PBAC recommending it for reimbursement. With that in mind we are asking that Vertex provide immediate Compassionate Access to all eligible people following the PBAC decision.

"It is estimated that Vertex Trikafta revenue will be \$6.6 billion by 2025," said Nettie Burke, the CEO of Cystic Fibrosis Australia. "While this is great for shareholders, why should people with CF have to wait as commercial negotiations drag on, especially as we cannot impact this part of the process?"

"To achieve immediate Compassionate Access would be the greatest milestone of all and could change the HTA process and negotiations for all health conditions," she said.

Most journeys are measured by how close you are to home. Most journeys have a clearly defined end and that means milestones are something you can take comfort in. Not in the CF world.

The HTA process has previously taken up to three years to provide Australians with CF drugs that allow them to dream and plan and that is cruel and unacceptable.

Nettie's final say on the matter is a cogent call to action. "If we have learned nothing else from the turmoil of 2020, we know now is the time to embrace change – in an emergency break glass."

CFA has created a Trikafta Portal for the media and community

<https://www.cysticfibrosis.org.au/Advocacy/Trikafta>

About Cystic Fibrosis

<https://www.cysticfibrosis.org.au/getmedia/c9762f6b-03fa-4224-9156-7a45e0e910dc/ABOUT-CYSTIC-FIBROSIS.aspx>

#ENDS#

For Further Information:

Nettie Burke

CEO, Cystic Fibrosis Australia

0404 034 294

nettieb@cfa.org.au

For Further Information or to arrange an interview with CFA, or a person with CF, email or call

Nettie Burke nettieb@cfa.org.au

Mobile: 0404 034 294