MEDIA RELEASE **20 August 2021**

THE DOMINO EFFECT

Today Trikafta was recommended for reimbursement for people 12+ years with one F508del gene mutation and one minimal function mutation and this is great news for 390+ Australians who have not had a CFTR modulator prior to Trikafta.

However, Trikafta was not recommended for reimbursement for people F508del homozygous and F508del heterozygous with a Residual or Gating mutation.

Nettie Burke, CEO at Cystic Fibrosis Australia (CFA) said today that Australians with CF and their families have been waiting for Trikafta since it became available in the US in October 2019.

"This partial PBAC recommendation is a step in the right direction, we commend the PBAC for a smart decision and they have confirmed what we all know … Trikafta is an outstanding treatment" she said.

"We are told the dispute continues over the numbers of eligible patients, onboarding rates, discontinuation and long term data but our considered position here at CFA is that both sides are just jockeying for the right price. That means the conversation is still stuck on Vertex shareholder value and Government budgets, not saving CF lives." she added.

To help speed things along, the Australian Cystic Fibrosis Data Registry, managed by Monash University and CFA, has already provided critical data and is poised to despatch more on request.

"The CF community would like to see Trikafta contracts promptly signed for people with one F508del gene mutation and one minimal function mutation, but we have no assurances that this will happen. We fear that access may be delayed until a 'Trikafta Deal' is done for the entire F/any CF population" Nettie added.

Minister Hunt said today that he welcomed the PBAC recommendation for Trikafta and that he was heartened that the PBAC had recommended a PBS listing for people with cystic fibrosis with one F508del mutation and a minimal mutation and added " We have written to Vertex to outline our clear intent to list this medicine on the PBS as soon as possible and have called on the global executive of Vertex to work in partnership with the Government and the Australian community."

"We will continue to work towards broadening access to promising new treatments for Australians with CF. Our Government has provided access to Kalydeco, Orkambi and Symdeko and we are committed to fund all new CF treatments once recommended by the PBAC," Minister Hunt said.

Sadly CF lives will still be lost, and families destroyed if protracted negotiation continue for the remainder of the CF community. The solution is clear:

- The PBAC recommends Trikafta for reimbursement for the whole CF community 12+
- The ACFDR provides the Dept of Health with quarterly data relating to the number of patients on Trikafta and those who have discontinued treatment
- The Government reimburses Vertex for all patients taking Trikafta during that period.

"Now is the time for common sense to prevail and if we are to believe that all parties want a solution, maybe they need some level-headed consumers at the table to get a resolution. CFA is ready and willing to participate and we know that our community will step forward as well," said Nettie Burke.

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FOR FURTHER INFORMATION
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