DR MONIQUE
RYAN
KOOYONG'S INDEPENDENT

16 March 2023

The Hon Mark Butler MP
Minister for Health and Aged Care
House of Representatives
Parliament House
CANBERRA ACT 2600

By email: minister.butler@health.gov.au

Dear Minister, Mark,

Re: Accelerating access to Trikafta for children with Cystic Fibrosis

I write to request clarification regarding the current delays in the approval process for the PBS listing of Trikafta for 6 -11 year-olds with cystic fibrosis (CF) and seek your commitment to do everything you can to accelerate those childrens' access to this drug.

There are 500 Australian children currently waiting for access to Trikafta. The drug, developed by Vertex Pharmaceuticals, was first added to the PBS on 01 April 2022 for Australians with cystic fibrosis aged 12 years and older, with at least one F508del mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene.

In December 2022, the Pharmaceutical Benefits Advisory Committee (PBAC), recommended approval for Trikafta for children aged 6-11 years old. Recently, however, Kooyong families have been informed that discussions with the Department of Health and Vertex regarding Trikafta for this age group have come to a standstill and have been referred back to PBAC, causing further delays for access to this drug.

I'd be grateful for your feedback on expediting access to this medication for those children, given its proven effect in reducing infection and , reduced hospitalisation, reduced scarring of the lungs and better quality of life for children with cystic fibrosis.

With all best regards,

Dr Monique Ryan MP

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