The Hon Greg Hunt MP
Minister for Health and Aged Care

Ref No: MC21-039194

Mr Ken O'Dowd MP
Chair
Standing Committee on Petitions
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Dear Chair

Thank you for your correspondence concerning Petition EN3224 that was presented in the House by the Deputy Chair of the Standing Committee on Health, Aged Care and Sport, the Dr Mike Freelander MP. I note that the petition has 35,815 signatures and relates to the listing of Trikafta® (elexacaftor/tezacaftor/ivacaftor and ivacaftor) on the Pharmaceutical Benefits Scheme (PBS) for cystic fibrosis (CF).

I am aware of the distress and difficulties faced by people living with this debilitating condition and the ongoing concern felt by their families and friends.

The Pharmaceutical Benefits Advisory Committee (PBAC) - an independent expert advisory body comprising doctors, other health professionals and consumer representatives – makes recommendations to the Australian Government about PBS listings. Under legislation, the Government cannot list a new medicine on the PBS unless the PBAC makes a recommendation in favour of its listing.

I have previously been delighted to announce a number of PBS listings that bring improved outcomes to many people with cystic fibrosis. Since 2014, the Government has invested over $1 billion in PBS subsidies to secure access to three modulator medicines listed on the PBS for the treatment of CF, namely: Kalydeco® (ivacaftor), Orkambi® (lumacaftor/ivacaftor) and Symdeko® (tezacaftor/ivacaftor).

At its July 2021 meeting, the PBAC recommended Trikafta® for the treatment of patients with CF aged 12 years and older who have one F508del mutation and one minimal function mutation in the CFTR gene (F/MF population), a patient population that does not current have access to PBS-subsidised treatment. However, the sponsor chose not to progress listing based on this recommendation, unfortunately delaying access to this treatment through the PBS.

The PBAC has recommended the PBS listing of Trikafta®, for the treatment of all patients with CF who are 12 years and older who have at least one F508del mutation on the CF transmembrane conductance regulator (CFTR) gene, at its December 2021 meeting.

If the company accepts the required terms, then the Government will be delighted to list this medicine as we have done with over 2,800 new and amended medicines to date.

I can confirm my Department is in advanced discussions with the company and subject to their final agreement I look forward to further announcements shortly. As has been the case with regards to Symdeko and Orkambi, this is a matter of deep personal passion.

The Medicine Status website enables you to search and monitor the status of medicines as they progress through the PBS listing process. The website is updated monthly and can be found at: www.pbs.gov.au/medicinestatus/home.html.

Thank you for writing on this matter.

Yours sincerely

Greg Hunt