



January 2021

Attention: Professor Wilson and Ms Jo Watson
c/o Cystic Fibrosis Australia
nickim@cfa.org.au

Dear Professor Wilson and Ms Watson

I would like to thank you and the Pharmaceutical Benefits Advisory Committee (PBAC) for supporting the Cystic Fibrosis Community over the past recent seven years. We are grateful as we are sure you are proud that your recommendations relating to cystic fibrosis (CF) CFTR modulator drugs have saved many lives.

This embodies so much more than mere statistics because behind every one of them is a compelling tale to tell. I have cystic fibrosis/ my child has cystic fibrosis and this is my story ...

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We are once again asking for your assistance to get people with CF the best drugs and treatments in the fastest possible time. 90% of Australian need Trikafta now. A favourable recommendation following the March 2021 PBAC meeting will allow all people with CF to embark on a valuable and worthwhile life with all the benefits and joys of education, work, family and friends.

Every day of delay shortens the lives of people with cystic fibrosis and the evidence is there. Trikafta is medically effective and safe. The drug was seen to improve health outcomes by preventing permanent, irreversible lung damage and international clinical trials have shown Trikafta significantly reduces pulmonary exacerbations, hospitalisation and antibiotic use plus increases BMI.

Trikafta is highly effective for both adults and children with CF and has a positive effect on the mental health of the family unit by reducing stress, anxiety and depression. Other countries including England, Ireland, USA, Denmark and Germany have access to Trikafta and Australia should be next on the list. Please think of the CF families living with the stress and insidious nature of CF every day.

We are happy to share our stories at a consumer hearing and we hope that we will be granted this access to the PBAC. As you know, “lived experience” underscores a cogent argument and we are keen to make our case.

Kind regards

Person living with CF

Person supporting a person with CF