

Attention: Professor Wilson  
c/o Cystic Fibrosis Australia  
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Dear Professor Wilson

I would like to thank you and the Pharmaceutical Benefits Advisory Committee (PBAC) for recent recommendations relating to cystic fibrosis (CF) CFTR modulator drugs.

Our community now has an amazing opportunity through KALYDECO, ORKAMBI and SYMDEKO to stay well for longer and live a life like any other.

'Regular' is wonderful for those living with a disease like CF that restricts every part of your existence.

And now we are back again to ask for a favourable recommendation for ORKAMBI for our young Australians between the ages of 2 and 5 years old from the July meeting this year.

Every day of delay shortens the lives of our young people with cystic fibrosis and clinical trials here in Australia and overseas have proved ORKAMBI's medical effectiveness and safety.

The drug was seen to not only improve health outcomes but also quality of life for the whole family.

Australia has a fair and supportive health system so it is reasonable to ask that 185 little ones are given access to ORKAMBI.

Other countries including USA, Ireland, Germany, Austria, and Denmark have access to ORKAMBI and Australia should be next on the list.

Please think of the 180+ families living with the stress and unexpected nature of CF every day. They are part of our community who would be happy to share their stories at a consumer hearing.

Lived experience is a compelling argument and we are keen to make our case.

Kind regards

Person living with CF

Person supporting a person with CF.