

Hon XXX MP
Member for XXXX
Parliament House
CANBERRA ACT 2600

May 2019

Dear Minister, MP or Senator

As Our Elected Official ... Leave No One Behind

ORKAMBI is back on the Pharmaceutical Benefits Advisory Committee (PBAC) Agenda and it's now that the cystic fibrosis (CF) community needs you, as our elected official, to fight for what is right.

Young Australians between the ages of 2 and 5 years with CF need access to the best drugs and treatments and any delay is putting lives at risk.

Our community's voice will not be ignored and we expect Vertex and the Government to come to the PBAC table with a willingness to find a financial solution and work towards achieving access to ORKAMBI for our community. Price continues to hold up access to life saving drugs and you know young children should not be punished in this way.

For the past five years we have battled on, but it has not weakened our resolve to eliminate suffering for those with CF and the tribulations for their families and carers.

ORKAMBI for 2 to 5 year olds has been available in the USA, Ireland, Germany, Austria, and Denmark for over a year and we believe Australian should be granted the same access.

As our representative in Canberra please support people with CF. It is not fair to equate "rare" or "small numbers" with "insignificant". Australia is a country that prides itself on an equitable and even compassionate health system but often people who need life changing drugs are refused access due to cost.

ORKAMBI is proven to improve lung function and reduce exacerbations, hospitalisation and antibiotic use. Trial participants report improved nutrition and subsequent BMI increases, both of which have the capacity to stave off diabetes. ORKAMBI had a positive effect on the mental health of people with CF leading to social inclusion and a reduction in personal and family stress.

This drug makes a difference to the length and quality of people's lives. For that reason alone, ORKAMBI needs to be reimbursed. Please let your party room know that you support the CF community and make sure they realise that every day a person is denied access to ORKAMBI is another day of potential life limiting - and irreversible - lung damage.

Please remember a key tenet of our national anthem ... **With courage let us all combine to Advance Australia Fair.**

If you have the time to really understand the burden of CF, I would love to share my story.

Kind Regards
Community Member