

Sample letter to politicians

As Our Elected Official ... Make Things Right

ORKAMBI is back on the PBAC Agenda and it's now that the cystic fibrosis (CF) community needs you, as our elected official, to fight for what is right. Australians with CF need access to the best drugs and treatments and the prevarication by Government and Vertex are putting lives at risk.

Our community's voice will not be ignored and Vertex and the Government must understand that we expect them to negotiate in good faith, come to the PBAC table with a willingness to find a financial solution and work towards achieving access to ORKAMBI for our community.

Knock back after knock back because of price has embattled everyone in the our community but it has not weakened our resolve to eliminate suffering for those with CF and the tribulations for their families and carers. People with CF who have two copies of the F508del gene mutation have been denied a drug that has been available in the US for more than two years.

On July 3rd it will be the fourth time ORKAMBI goes under review for reimbursement by the PBAC and Cystic Fibrosis Australia (CFA) fears that this could be the last submission by Vertex. If Vertex pulls out of Australia we don't just lose access to drugs - the Vertex clinical trials here in Australia may cease as well.

As our representative in Canberra we are resolutely focused on your efforts to support people with CF because the seemingly perennial delay of ORKAMBI is cruel and unconscionable. You can't equate "rare" or "small numbers" with "insignificant".

Australia is a country that prides itself on an equitable and fair health system but sadly 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 it 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. ORKAMBI has been approved in the United States, Germany, Greece and Ireland and CFA believes Australian should be granted the same access.

Have you forgotten a key tenet of our national anthem ... **With courage let us all combine to Advance Australia Fair.**

With a Federal Election not too far away you must understand and embrace what our community, your electorate and the entire Australian community wants and needs ... access to the best healthcare to ensure people can live a full and valuable life.

If you have the time I would love to share my story.

Kind Regards