Hon G. A. Hunt MP/Ms Catherine King MP
Minister for Health/Shadow Minister for Health & Medicare
Member for Flinders/Member for Ballarat
Parliament House
CANBERRA ACT 2600

June 2019

Dear Minister

Congratulations on the recent election result and now that the excitement has abated I thought it was time to reinvigorate our very important and life changing advocacy again.

The cystic fibrosis (CF) community is extremely grateful for the access to KALYDECO, ORKAMBI and SYMDEKO the Pharmaceutical Benefits Advisory Committee (PBAC) has recommended and the government has funded over the past four years.

Cystic Fibrosis Australia (CFA) is heartened that your Government has agreed to fund all medications recommended by the PBAC. I hope that all parties come to the table and negotiate in good faith and access is provided in a timely manner.

These drugs currently make lives liveable again for half of the CF population in Australia. We have more to do as it is unfair that many children and adults still have no solution to their pain and health decline.

In July the PBAC will meet to assess ORKAMBI for children with two copies of the F508del gene mutation who are between the ages of 2 and 5 years old.

The sooner young children have access to ORKAMBI the sooner their lung disease will halt and the better their long-term prognosis will be.

The trial results are in. They showed that ORKAMBI was safe and well tolerated for 24 weeks, with children ages 2 to 5 demonstrating a similar safety profile to those who were 6 and older.

One secondary endpoint of the study, the levels of sweat chloride - a parameter commonly used to diagnose the disease - improved after 24 weeks of treatment. Other secondary endpoints, including growth parameters, also improved with the medication.

This drug works and 185 young Australians need access to it asap.

Thanks for your previous support and I hope it continues.

Kind regards

Community Member