



9<sup>th</sup> May 2019

## HOLD YOUR HORSES

One of our most important duties here at Cystic Fibrosis Australia (CFA) is ensuring that people with cystic fibrosis (CF) are given access to the lifesaving treatment they need. This would be impossible without Government funding.

Recently the CF community celebrated two big advocacy victories. On the 27th April the Pharmaceutical Benefits Advisory Committee (PBAC) recommended that Kalydeco be reimbursed for babies 12 -24 months old and Symdeko be reimbursed for those with two copies of F508del gene mutation or one F508del and one of almost 30 residual mutations. The current Government and Opposition have both committed to funding the PBAC recommendations so this listing is extremely significant.

In July 2019 the PBAC will meet to consider recommending ORKAMBI for infants 2-5 years old. There are approximately 185 CF kids in Australia who need ORKAMBI.

We need to get these potent CF modulators out there to CF Australians of all ages, especially young children, for whom quality of life depends on early intervention.

We are still enjoying the flow on effects of our last advocacy triumph and it is true that taking a moment to recharge and celebrate your successes is important. The champagne has been raised and the toasting done, so let's remember that tomorrow is Game Day once again.

With a Federal Election less than two weeks away we must continue to put pressure on all sides of the political divide. Politicians must understand and embrace what our community, their electorate and the entire Australian community wants and needs ... access to the best healthcare to ensure people can live a full and valuable life.

Here is how you can get involved ...

1. Parents, grandparents, siblings and carers of 2-year old with CF ... we need your stories. Get in contact with Nicki at CFA [nickim@cfa.org.au](mailto:nickim@cfa.org.au)
2. Ask your family and friends to make their feelings known on the PBAC Consumer Portal. This is a very important weapon in our armoury.  
[http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC\\_online\\_submission\\_form](http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form)
3. Like and share our posts and communiqués with your networks ... social media is a powerful tool

4. Write to the PBAC and Vertex. All the information you need can be found at <https://www.cysticfibrosis.org.au/advocacy/campaigns>
5. Stay tuned into the CFA and spread the word about ORKAMBI access in the run up to the PBAC Meeting
6. Contact your local media and share your story. CFA has produced a media release and this too can be found on our website

I realise it may seem like 'Ground Hog Day' but 185 young children need our support so they get access to a drug that will change their life.

Call me anytime if you have an idea about how we can further support our cause and finally please get involved.

Kind regards

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