



14 May 2019

Media Release

## **HOLD YOUR HORSES ... WE ARE AT IT AGAIN**

One of Cystic Fibrosis Australia's (CFA) most important duties is ensuring that people with cystic fibrosis (CF) are given access to the lifesaving treatment they need.

In July 2019 the Pharmaceutical Benefits Advisory Committee (PBAC) will meet to consider recommending ORKAMBI for infants 2-5 years old. There are approximately 185 CF young ones in Australia who need ORKAMBI now.

These potent CFTR modulators must be made available to CF Australians of all ages, especially young children, for whom quality of life depends on early intervention.

We are hot off the heels of our last advocacy triumph, and it is true that taking a moment to recharge and celebrate success is important. The champagne has been raised and the toasting done. Now our focus on tomorrow and it's Game Day once again.

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 and Symdeko be reimbursed for those with two copies of F508del gene mutation or one F508del and one of almost 30 residual mutations. Both the current Government and Opposition have committed to funding the PBAC recommendations so this submission is extremely significant.

It's not the time to rest on our laurels.

In 2015, after securing funding for Kalydeco (2-5 year olds), we didn't sit on our hands and we did not waste our momentum. We kept the energy up and the pressure on because we knew there was more to do. CFA has prepared a briefing suite for the media and the community. Go to <https://www.cysticfibrosis.org.au/advocacy/campaigns>.

We hope to involve parents, grandparents, siblings and carers of 2-year olds with CF in our campaign and if you would like to hear their stories contact Nicki at CFA [nickim@cfa.org.au](mailto:nickim@cfa.org.au).

There are a few key dates to add to your diary and these include:

1. 12 June 2019 – Consumer Portal Closes for comment.
2. 10-12 July 2018 – PBAC Meeting in Canberra.
3. 23 August 2018 – PBAC Announcement.

I realise it may seem like 'Ground Hog Day' but 185 very young children need our support so they get access to a drug that will change their life. I hope your media outlet will be able to support our efforts. Call anytime if you would like an interview or to meet a member of our outstanding community.

For further information:

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