



14 May 2019

DO WE HAVE YOUR SUPPORT?

Hello, it is Cystic Fibrosis Australia (CFA) yet again and yet again we are asking for your support. Working from the 'leave no one behind premise' we are embarking on a community advocacy campaign to secure access to ORKAMBI for young children.

What now? Well, it's not the time to rest on our laurels.

We didn't go quiet when Kalydeco was approved almost five years ago. In 2016, 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. For three years we advocated for ORKAMBI for children and adults 6 years and over and now in 2019 our toddlers and young kids need our help – and we can't let them down!

In July 2019, the PBAC will meet to consider recommending ORKAMBI for infants with two copies of the F508 cystic fibrosis gene mutation between the ages of 2 and 5 years. There are approximately 185 CF young ones in Australia who need ORKAMBI.

We know there are some powerful tools at our disposal and the PBAC Consumer Portal is one of them. CFA has prepared all the 'arguments' and they are listed on our website so go to <https://www.cysticfibrosis.org.au/advocacy/campaigns>. Take these 'arguments' and send them through to the PBAC at http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form

Parents, grandparents, siblings and carers ... we need your stories. Please email Nicki at CFA nickim@cfa.org.au if you want to be part of the campaign. Family, friends, colleagues and kindred spirits all make good advocates so share the CFA and PBAC links and encourage everyone to have their say.

Once the election is over write to your local member, your Health Minister and your Prime Minister. CFA has prepared some letters for you to edit at will <https://www.cysticfibrosis.org.au/advocacy/campaigns>.

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

1. 1 May 2019 – PBAC Agenda published and Consumer Portal opens for comment. CFA has briefing document on our website to support your submissions so go to <https://www.cysticfibrosis.org.au/advocacy/campaigns>.
2. 12 June 2019 – Consumer Portal Closes for comment.
3. 10-12 July 2018 – PBAC Meeting in Canberra.
4. 23 August 2018 – PBAC Announcement.

It is time to fire up your networks and get them involved in this very important advocacy. Call CFA any time if you need assistance.

Kind regards

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