

9 June 2019

Everyday Struggle

Cystic fibrosis (CF) is a rare disease and varies so much. It can be easy to feel helpless or alone. Australians with CF tend to take the opposite approach. They band together, support each other - they even march together, because they know that action is what gets results.

But 'Everyday Life' can get in the way of all that. Rare disease advocacy is great but, really, who has the time? We all want the PBAC to approve ORKAMBI for 2-5 year olds this June, but how much should we *really* go out of our way to struggle for it?

Let's ask Kayla Morris:

"It wasn't until Asher was 4 weeks old, that we found out.



I don't really remember a lot of the 1st year of Asher's life... I was constantly stressed, anxious, angry and sad. Our world was all about learning as much as we could about CF and also making sure Asher was getting all of the medications...

He was unable to breathe properly while sleeping and his body was being starved of oxygen. His little body was fighting hard to work properly – he was really struggling to put on weight.



***ORKAMBI is the drug of hope for people like us – the CF Community.
ORKAMBI actually helps correct the underlying defect, not just mask the symptoms.***

Having a drug like ORKAMBI in our lives would mean EVERYTHING, potentially adding an extra 20 years + to Asher's lifespan. Asher starts Kindy next year."



ORKAMBI for 2-5 year olds is going up for consideration by the PBAC this month. That means the chips are down for Asher Williams, for Abi and Ella Edwards, for Asher Best, and they need their people to speak for them. We are all in this together.

Please let the PBAC know that you want the struggle to end and put your comments on the PBAC portal.

http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form. If you need inspiration, then go to CFA's website where we have listed all the facts. <https://www.cysticfibrosis.org.au/advocacy/campaigns>.

Thank you in anticipation for supporting these young Australians.

Kind regards

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