



10 June 2019

Times Running Out

There are no do-overs in life. We get one chance to act and then we live with it. Shakespeare said "Better three hours too soon than a minute too late" and he was right, because some things just are that urgent and clear cut.

"On the 24th of October last year me and my partner Michael welcomed our perfect little angel Evie into the world. Little did we know 12 days later one phone call would change our lives forever. Evie was diagnosed with CF with two F508del mutations, it truly was the most heartbreaking thing I have ever been through discovering this, and to this day it hurts to even think about it."
- Chelsea Hare

Our stories are the stories of real people. They are asking you for help in a specific and actionable way and the deadline on this assistance is coming up rapidly.

On Wednesday the 12th of June the PBAC will cease accepting public comments on Orkambi for infants aged 2-5. By that time, we need the CF community and their networks to submit recommendations emphasising the crucial role that Orkambi plays in CF treatment.

Unless the PBAC understands that this drug is indispensable they will not recommend it for reimbursement to the Government because it is extremely expensive.

"Worrying about Pippa's future keeps me up at night. When she starts school how will she take her enzymes, will she be teased for being different? If Orkambi could allow Pippa not to have to take enzymes anymore that would be such a huge weight lifted for us."
- Cassie Warwick

We have been very singular about this issue lately, and that is for the simple reason that the lives of Australian children are at stake.

"In his short 19 months, we have had 3 hospitalisations. Lachlan was not gaining weight and continually having oily bowel motions - malabsorption. It took until around 9 months of age before he even made it onto the growth chart for national averages. We are aware that many that take ORKAMBI gain weight. This would reduce the chances of him needing a food peg later on in life."
- Nola and Sarah

There is no higher call and no fight more pressing than the one that culminates on June 12th. We can't speak for the community this time, it must speak for itself. One by one. Adults, teenagers, family members - anyone who can lend their own voice on behalf of sick Australian children barely old enough to speak at all. They get one chance at life, and we get one chance to be there with them.

Here is the link to the PBAC portal <https://bit.ly/31jlo8r> and all the key facts are on the CFA website <https://www.cysticfibrosis.org.au/advocacy/campaigns>. Please take a few minutes to support our little Aussies with CF. You can literally change their lives.

Kind regards

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