

22 May 2019

LOUDER THAN A RALLY CRY

This letter doesn't have a happy ending, yet. The stories you are about to read drive us every day. CF kids are our kids, and your kids. CF kids are Luke and Bianca's kid.

Asher is 3 ½, he has two copies of the F508del CF gene mutations and his FEV1 has not yet been tested.

Asher's parents Luke and Bianca shared their story with CFA ...

'There are things that we notice, such as him saying he has a sore tummy or saying 'something feels wrong in my tummy', diarrhoea or constipation.'

'When he's sick I find it harder to sleep, listening out for his breathing or coughing and hoping he is going to wake up better not worse in the morning.'

ORKAMBI [means] less sickness, less hospital admissions, less treatments for Asher.



CF kids are Rebecca and Jason's kids

"Our names are Rebecca and Jason, and our identical twin girls, Abi and Ella, have cystic fibrosis. They have just turned 4.

What keeps us up at night... Anxieties about their weight gain, their uncomfortable tummies

with oily poos that happen at 4 in the morning on occasion, worries about any slight sniffle and whether it will turn into a major infection requiring oxygen support

I have slowly come to terms with the expectations and effects of CF and plan for Abi and Ella to have full and active lives. However, the fact is that the median age of survival is still 37 in Australia and perhaps 50 at the latest estimates for Canada. I am still blindsided by this at times."

So now you know what drives us. And you won't be surprised to be hearing from us. A lot.

We need your voices too.

The PBAC sits in July to decide the fate of Orkambi for 2-5 year olds. When they do they will hear us alongside our community, alongside Rebecca, Bianca, Abi, Ella, Asher. Alongside CF babies.

We need consumer portal submissions in by 12 June ... Louder than a rally cry.

[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)

Kind regards

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