



Australian Orkambi Success A Huge Opportunity For New Zealand

After a long, passionate campaign for Orkambi by the Australian CF community, on Friday 18 August they received the incredible news that the medicine would finally be funded for 1,500 people with CF in Australia. A huge congratulations to CF Australia and its community for the successful campaign.

At Cystic Fibrosis New Zealand we are not only happy for our friends across the Tasman, but happy for what this could mean for New Zealand. We see this is a huge opportunity - Vertex, manufacturers of Kalydeco and Orkambi, will now be entrenched in the South Pacific and its time for Vertex to work with Pharmac to see Kalydeco and Orkambi funded in New Zealand. We need these life-changing medications here.

As part of our commitment to advocacy, Lisa Woods has recently joined the CFNZ team to focus our advocacy efforts and the time has never been better to harness our collective energies to get the results we deserve. We strongly encourage the New Zealand CF community to throw their full weight behind both CFNZ and the [Kalydeco for Kiwis Facebook](#) page and the campaign that we will together undertake for precision medicines.

We'll be providing updates and information on how you can be involved through the CF Panui, our [website](#), and [CFNZ Facebook](#) page.

Awesome Awareness Week

August kicked off with an awesome amount of awareness and fundraising activity across New Zealand. The campaign 'Cystic Fibrosis is a race against time' featured

11-year-old Tayler and his family, who were all incredibly generous in sharing their story with the world. You can watch the video we filmed by visiting cfnz.org.nz/tayler.

A huge thank you also to the volunteers who helped shake buckets, run mufti days and bake sales, and talk to the public about CF during the week. And of course, a huge thank you to those kind and generous souls who took the time to visit the website and donate, send a text donation, or pop some notes into a collection bucket. You are all amazing.

Race Against Time

Dollars are still being counted, but this year is proving to be awesome! Activity on the Facebook netted us almost 200 new 'likes' and there was a significant rise in online donations. Digital advertising will continue for the next two weeks, as will our text to donate campaign. If you haven't done so already, you can still donate \$3 by texting 'help' to 4462.

A huge thank you to [Mylan](#), makers of Creon, for sponsoring CF Awareness Week.

'He doesn't want to be labelled the sick child' – the young boy not letting cystic fibrosis get in the way of his love of sports

TUE, AUG 21
TAGATA PASIFIKA
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Meeting Bruno Cettina it would be hard to tell this 12-year-old who loves sport is suffering from a chronic illness.



Tagata Pasifika met Auckland boy Bruno Cettina, who is battling cystic fibrosis. Source: Tagata Pasifika

Bruno suffers from cystic fibrosis, a life-threatening disorder that damages the lungs and digestive system.

Bruno In The Spotlight

Gorgeous Bruno and his family have been speaking to TVNZ 1 as part of Cystic Fibrosis Awareness Week. In this great video, Bruno shares what it's like living with CF, how he doesn't let it get in the way of his love of sport, and what we do to help shape a brighter future for children like Bruno.

[Watch video >](#)



Planning Behind The Strategy

Throughout July and August, Chief Executive Jane Bollard has been visiting the 12 CFNZ branches to discuss the next strategic plan and direction. A huge thank you to [Choice Hotels NZ](#) who generously provided bed nights for Jane while she was out in the community. A webinar for CF adults to contribute to the plan will follow shortly.



A Choice Video From Choice Hotels

As part of its ongoing commitment to helping people with cystic fibrosis, this year Choice Hotels created a fantastic awareness video that was seen by thousands of people online, and is displayed in several of the hotels across the country. Thanks, Choice Hotels!

[Watch video >](#)



Printed CF Resources Are Here!

A couple of weeks ago we received the VERY exciting package full of new printed CF resources and presentation folders. These new resources were developed collaboratively and are full of quotes and experiences from fellow parents and friends. They are available to everyone and can be requested direct from us, or you can see the online copy on our website. Let us know what you think of them!

[Request printed resources >](#)



Last Chance To Have Your Say

A working group on antimicrobial resistance in cystic fibrosis is asking people with CF and their families to help them understand current knowledge, concerns, and what they want to learn and change regarding antimicrobial resistance. The results will be used to make recommendations to keep CF care moving forward. The survey is anonymous, and takes about 5-10 minutes.

[Take the survey >](#)