



## Welcome To The November Panui!

Kia Ora Comms,

Over the past few weeks, international cystic fibrosis organisations have celebrated more milestones in their mission to improve the lives of people with cystic fibrosis (CF). This includes FDA approval of Trikafta, increased access to Orkambi (ivacaftor/lumacaftor) and access to Symdeko. Read the update below for further detail.

While Cystic Fibrosis NZ is delighted by the success overseas, it once again highlights just how far behind New Zealand is with securing these vital medications, for people with CF in New Zealand. The impact these medicines have on improving the quality of life of people with CF has been proved time and again.

I have written to Vertex to congratulate them on their success and to urge them to engage with PHARMAC and we will continue to put pressure on the Government to ensure our voice is heard. New Zealand cannot continue to be left behind.

I encourage everyone to sign the two petitions; [to double the PHARMAC budget](#), and for [Kalydeco to be publicly funded](#). Please share with your networks to show the Government how important access to these life-saving medications is for us.

Arohanui,

Jane Bollard  
Chief Executive

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## International News

On 21 October, the US Food and Drug Administration (FDA) approved the use of the triple combination CFTR modulator Trikafta (elexacaftor/ivacaftor/tezacaftor) for people with cystic fibrosis aged 12 and over who have at least one F508del mutation in the CFTR gene.

Clinical trials of Trikafta have shown dramatic improvements in key measures of CF, and in time more than 90% of people with CF could benefit from this highly effective therapy.

Australia also announced increased access to Orkambi (ivacaftor/lumacaftor) and access to Symdeko (tezacaftor/ivacaftor) for people with CF aged 12 and older who have two copies of the F508del mutation or who have one of 26 specified mutations, even if they don't have a copy of the F508del mutation.

Also last month, the National Health Service (NHS) England announced a two-year managed access agreement with Vertex for Orkambi and Symdeko, with agreement that Trikafta would be submitted to the National Institute of Health Care Excellence (NICE) for appraisal. This follows the announcement of a similar five-year deal in Scotland.

### Emily Writes

We are very grateful for our CF community's continued support of these petitions for access to modern medicine in NZ. Recently a parent shared the PHARMAC petition with [Emily Writes](#) who then shared the message with her 37k strong fan base on Facebook. This, along with our drive for signatures has pushed us over the 15k mark!

As the [petition](#) has now been extended until 26 March 2020, we encourage everyone to keep sharing and continue to get the word out there.

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## Research Updates

Huge progress has been made in the development of precision medications for people with cystic fibrosis over the last few years. While CFNZ remains committed to continuing the fight for access to new medications, we also firmly believe we can positively impact the quality of life of people with CF by continuing our research into other areas of CF care.

Find out more about the national research strategy [here >](#)

### CF Research Questions

We are keen to hear what you think are the most important research questions when it comes to Cystic Fibrosis.

The aim is to identify research priorities for our CF community, connect the CF clinical and research communities locally and internationally and determine how New Zealand can contribute to the global scene.

The survey is anonymous, and all responses will be reviewed by the Research Development Manager at CFNZ who will analyse and consolidate the answers. These will then be used to create a second Prioritisation Survey to allow you to prioritise the top questions.

To begin the survey, please [click here >](#)  
Help us reach everyone by sharing the link with your family and friends.

### **Nebuliser Survey**

Cystic Fibrosis Otago branch and the University of Otago invite you to take part in a survey about how people with CF, or their carers, rinse and clean nebulisers after they've been used for treatment with inhaled antibiotics.

Knowing more about the best way to clean nebulisers after use is important to help prevent antibiotic resistance, and keep antibiotics working effectively for people with CF.

Read through the information on our website [here](#), and take the survey, [here >](#)

### **Port CF Update**

We have been working hard to improve the quality of the data we collect in our CF data registry – PORT CF.

The 2016 and 2017 reports have taken a bit longer than anticipated to produce as we have been adding more information to the reports from the data we collect so the information is comparable with overseas registries. Our PORT CF coordinator and DHB staff across the country have been working hard to get as much information on as many people with CF as possible into the database.

We anticipate that 2016 and 2017 reports will be out before the end of the year.



**Raise A Glass To Support CFNZ  
This Christmas**

Our friends at Giesen Wine Estate have put together a limited time special offer exclusively for the CF community. "Since 1981 the Giesen Brothers and their team have been creating wines that people love to drink, whatever the occasion there is a Giesen Wine for you to enjoy", says Olivia Giesen, who helped make this fundraiser possible. "The team at Giesen's are passionate about contributing to the wider community and could not miss the opportunity to work alongside Cystic Fibrosis NZ."

Purchase any case (6 bottles) of Giesen Estate wine for a little over \$12 per bottle before 5pm Friday 15<sup>th</sup> November, and they will ship it for FREE. Better still, Giesen will make a donation to Cystic Fibrosis NZ for every case sold. These are outstanding sets of wine and a deal not to be missed. Not only do they taste great, but they (with your help!) will make a difference to our CF community – so "cheers" to that!

**Use The Promo Code CFNZ**  
**Shop Online [Here >](#)**

*Offer ends 5pm Friday 15th November. Available for online purchases only, purchaser must be 18 years or over, ID will be required on delivery.*



## 24 Classes In 24 Hours

**CLM The Bays** held an event over the weekend to raise funds and awareness for Cystic Fibrosis. They ran 24 gym classes back-to-back in 24 hours. Each hour was kindly sponsored, and lucky gym-goers were treated to spot prizes throughout the classes. The event ran seamlessly, with all staff and attendees given a run down of why CF was such a great cause, and close to their hearts, thanks to Jamie Archibald.

It was such a privilege to work with the amazing team at CLM The Bays. They were all so kind and welcoming but most of all, excited for and believed wholeheartedly in the cause. A special mention to Sammy who kept the 24 hours running smoothly, made sure photos were taken in each class, and even dressed up in a unicorn onesie for the 1am session.

Donations are still being counted, but we are very pleased to announce that there has been over \$4,500 raised!

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## Good In The Hood Success!

Z Station's Good in the Hood was back for 2019, and Cystic Fibrosis Branches across NZ were some of the lucky recipients!

A big thank you to those who promoted the Z Stations supporting CF.

We managed to have success in these areas:

**Auckland** was awarded a total of \$2321 across three stations.

**Waikato** was awarded \$840.

**Hawkes Bay** was awarded \$456, and as a result of exposure from the Z Station, someone also donated \$400!

**Nelson** was awarded \$477, and then another two Z Stations awarded them \$100 from each!

**Canterbury** was awarded an amazing \$1016.



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## CF Achievers Award

Applications are open for next year's Cystic Fibrosis Achievers' Awards. [Mylan NZ Ltd](#) (brand owner of Creon) is very pleased to announce its continued support of the awards for 2020.

"As a company we value our ongoing partnership with CFNZ and welcome the opportunity to play a part in the recognition and celebration of the amazing achievements of people living with CF. Success comes down to attitude, drive and determined focus. The Mylan team look forward to hearing about these latest achievements and we've been truly inspired by your past success. We wish all applicants the very best of luck," says Sean Stewart, Country Manager.

Read more and apply, [here >](#)

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## Conquering The

## Bridge For CF

A huge thank you to all who participated in the Auckland Marathon for Cystic Fibrosis.

A particularly big thank you to Niall and the team at Willis Towers Watson, with over 30 runners / walkers, you raise the bar every year, and we are so very grateful!

We had two physios working their massage magic; thank you Sarah Diskin ([Optimise Movement](#)) and Freya Try (third year physio student).




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## Good News Stories!

Got a good news story?  
Want to share it with the CF community?  
Great! We'd love to hear and share it!

Email Lizzie at [comms@cfnz.org.nz](mailto:comms@cfnz.org.nz)

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