



## Welcome To The December Panui!

Kia Ora <<First Name>>,

We've decked the (Wellington Airport!) halls, there's Christmas music on the radio, and we're excited to have put together the final issue of the CF Panui for 2020.

At the end of November, a memorial service was held for Sir Bob Elliott. CFNZ President Denis Currie and CFNZ Board Chair Warwick Murray attended, representing the CF community. A beautiful service honouring a man whose life was dedicated to positively impacting the lives of others.

Tuesday night saw Minister of Health, Right Honourable Andrew Little, open the CF Christmas Tree Festival in Wellington Airport. We were grateful to have Ed Lee share his powerful story as well.

We have settled into our new CFNZ office, and had a lovely 'house warming' morning tea on Tuesday. Our new address is 64 Grafton Road, Grafton.

Wishing you all a safe and happy lead up to the festive season.

Nga mihi,  
CFNZ Team

PS The CFNZ office will be closed from 24th December, and will open again 5th January.

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## Ending The Year With A Sparkle At Wellington Airport

More than 30 businesses, community groups, and organisations are welcoming a better and brighter 2021 in a sparkly Christmas display at Wellington Airport.

The annual Christmas Tree Festival – a joint event between Wellington Airport and CFNZ – aims to support businesses and organisations whilst raising funds for support, advocacy, and research for people with cystic fibrosis.

This year CFNZ's two trees focused on advocacy and compassion, with a Trikafta tree featuring photos and stories from some of the Kiwis with CF who would benefit from the breakthrough medication. Next to the Trikafta Tree is a banner with a QR code linked to the Trikafta Petition. The second tree is covered in large-scale versions of the Compassion Pins we created earlier in the year. (Keep an eye out on Facebook - we will give some of these away next year!)

The Gala and launching of the festival took place on Tuesday 1st December - a lovely evening with Andrew Little opening the event. We'd like to extend a huge thank you to all who attended, and all the businesses who have supported the festival this year.

Thank you Mary, for excellent coordinating, Wellington Airport for giving us the opportunity and platform to once again raise awareness for CF, and Wellington Branch for all the effort put in all year round to make the festival so successful!



# CHRISTMAS TREE FESTIVAL 2020

## Award Applications Now Open

The Mark Ashford Scholarship and CF Achievers' Award applications for 2021 are now open.

Each year the Mark Ashford Scholarship is awarded to a person living with CF who has shown excellence in tertiary study and / or shown tenacity to overcome the challenges of CF while studying. Meet our 2020 recipient, Georgie, [here >](#)

The CF Achievers' Awards also celebrate people with CF who have achieved excellence in any of the four categories: leadership, the arts, sports or education.

Find out more info and apply here:

- [👉 Mark Ashford Scholarship](#)
- [👉 CF Achievers' Awards](#)

## Advocacy Update

### New Children's Hospital in Wellington

CCDHB called for consumer representatives to be a part of clinical design workshops for the New Children's Hospital in Wellington. We submitted three people to be part of this but unfortunately no one was selected for the group.

### PHARMAC stakeholder consultation

Jane Bollard, CE participated in a consultation process by PHARMAC to see how they can improve their relationship with their stakeholders. They sought insights into the type of relationship we have with them today and the type of relationship we need into the future. CFNZ was one of 20 initially consulted. A survey has now been developed and has been sent to all stakeholders.

### Trikafta Campaign

In this turbulent year of lockdowns it's great to know that Christmas festivities are still going ahead.

On Tuesday night the CFNZ Christmas Tree Festival, held in partnership with Wellington Airport, was opened by the Right Honourable Andrew Little, Minister

of Health.

Ed Lee, a Wellington based person with CF, gave an inspirational talk about how his life has changed with the new Vertex medication, Trikafta. Notable was that he didn't feel like he had CF anymore and that he could now plan his life rather than contemplating a lung transplant. Also his clinical results were greatly improved- his recent lung scans were so remarkable that the radiographer had to check it was the same person!

Jane Bollard, CE CFNZ who attended the opening commented 'If we didn't already know it, hearing Ed gives us a most compelling reason to unite in the campaign to have Trikafta publicly funded in NZ.'



### **PHARMAC decision improves access to Pulmozyme**

On 23 November, PHARMAC informed us of its decision to transition funded access of dornase alfa (Pulmozyme) to a standard Special Authority from 1 December 2020. We welcome this decision, which improves equity of access of Pulmozyme for people with CF and reduces the burden of access.

Find out what this means for people with CF and those with existing panel approvals, [here >](#)

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## **Study Of ARO-ENaC In Healthy Volunteers And In People With CF- Recruiting Now**

Arrowhead Pharmaceuticals have nearly completed enrollment in the first cohort of people with CF in New Zealand in their AROENaC1001 study.

If you are interested in finding out more about this trial please click [here >](#) or email [clinicaltrials@arrowheadpharma.com](mailto:clinicaltrials@arrowheadpharma.com).

Be sure to talk to your clinical team too if you are interested.

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## Hey Adults With CF!

You may remember a while ago we asked adults with CF for some input for a new resource that we are putting together; an Adults Guide. We'd now love some feedback on that resource before it is finalised.

If you'd be happy to help us out, please get in touch with Sarah via email: [sarah@sayline.co.nz](mailto:sarah@sayline.co.nz)

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## Zoono Giveaway!

Attention all users of hand sanitiser and surface sanitiser... We are excited to announce that we have teamed up with Zoono to do a Christmas giveaway!

Keep an eye out on the Cystic Fibrosis NZ Facebook page next week 📺

Don't forget to use the code CFNZ20 to receive a 20% discount when purchasing products online at [zoono.co.nz](https://www.zoono.co.nz)

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## Liberate Pole Dance And Exercise 2021 Calendar

Every year the studio works with other performers to bring a variety show together to raise funds. "With Juliet passing away this year and Covid causing restrictions to so many events. It made sense to take advantage of what seemed to be unfortunate circumstances, and produce a calendar including some of our performers from the last few years and honour Juliet's life by making it a memorial for friends and family alike." Funds raised from the sale of these calendars will be going to CF, thank you Liberate!

You can purchase these from Olivia at Unit 2/369 Wilson's Road, North Christchurch. \$25 cash or bank transfer. We are at studio 5:30 till 7:30pm Monday to Thursday guaranteed, otherwise we can organise a time.

Email [olivia.allchurch@xtra.co.nz](mailto:olivia.allchurch@xtra.co.nz) Or text 0211885201

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## Thanks, Choice Hotels!

We are excited to announce our long-term sponsor, Choice Hotels, has launched a new initiative which allows its members to turn their Choice Privileges points into charitable donations, to support Kiwis living with cystic fibrosis.

“The changes to the way we have all been able to travel this year have meant that the majority of our members were unable to take advantage of the Choice Privileges program like they would usually, however with restrictions easing it is a fantastic opportunity for members to take a break, earn points and then use those points for a good cause,” said Choice Hotels Asia-Pac CEO, Trent Fraser.

[Read the full story here >](#)

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## Showing Gratitude

A big thank you to the following sponsors who have provided funding over the last couple of months. We are so very grateful.

- Foundation North – operating costs
- Trust Waikato, Trillian Trust and TM Thompson Trust for equipment

If any Branches would like assistance with funding for specific things, you are welcome to get in touch.

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Thank you for helping Kiwis with  
CF to live a life unlimited.

[www.cfnz.org.nz](http://www.cfnz.org.nz)

PO Box 110 067, Auckland 1148

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