



Welcome To The December Panui!

Kia ora,

The sun is (mostly) shining, the days are longer and hotter, and Christmas is fast approaching...

We are very grateful to finally be sending a Panui while not being in a Level 3 / 4 lockdown! 🙌

As life and activities around us start to have fewer restrictions, we know that there will still be some hesitancy, but we do hope you are able to be out and about enjoying the sunshine, while we ease ourselves out of 2021.

In this issue of the Panui, you'll read all about our Christmas Appeal, where we are raising funds to support our people with CF and their families with the day-to-day challenges and financial stresses of life with CF.

Read about the sparkling success that is the CF Christmas Tree Festival, an update on all things advocacy, and more stories from the community.

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

Ngā mihi,
CFNZ Team



Our Community Knows It Well – CF Doesn't Take A Break For Christmas 🎄

CF doesn't go away just because its Christmas – in fact, it can intensify over the holiday period. Too many of our families have experienced being in hospital, recovering from surgery, on home IVs, or waiting for new lungs for Christmas, on top of the financial stress that the end of the year can bring.

This festive season we're asking the New Zealand public to support our Christmas Appeal and ensure families living with CF can access vital, practical support when they need it most. Funds raised go straight into welfare support and Breath4CF exercise grants, and supporters can choose a specific region to support if they wish.

A huge thank you to Brett and Penny for sharing how life with CF impacts families on the daily as part of the appeal 💖

To find out more about the appeal or make a contribution, head to www.cfnz.org.nz/christmas



Advocacy Update

Release Of Pharmac Review – Interim Report

In March this year, the Government announced an independent review of Pharmac - New Zealand's medicines buying agency. They were tasked with considering how well Pharmac performed and whether its performance could be improved.

On 2 December, the Minister of Health released the Pharmac Review Panel's Interim Report. The Panel concludes, amongst other things, that Pharmac is underperforming in helping to remove inequitable health outcomes, and its prioritisation approach appears to disadvantage Māori, Pacific people, disabled people, and those with rare disorders. Sadly, this will come as no surprise to the CF community.

Read our full update, and the interim report [here >](#)

NZ Herald – CFNZ Advocacy Advisor's Opinion Piece

Ahead of the PTAC meeting a couple of weeks ago, our Advocacy Advisor Christine Perrins who has been instrumental in the campaign, wrote an opinion piece on the critical need to fund Trikafta for all eligible Kiwis with CF.

CFNZ also urges Pharmac and Vertex to progress their commercial negotiations as quickly as possible to agree a fair and reasonable price for Trikafta – and make sure that Kiwis with CF have a future to look forward to.

Read Christine's opinion piece [here >](#)

Updated Trikafta Campaign Messages

As we are now in the next stage of the campaign, where the application for Trikafta is with Pharmac, we have updated our messaging accordingly. If you'd like to read them, and check out our new Trikafta page on the website, you can view it [here >](#)



Making Wellington International Airport Shine This Christmas!

The annual CF Christmas Tree Festival at Wellington International Airport is underway, giving travellers a shiny end to what has been a far from smooth 2021.

Nearly 50 businesses, organisations, schools, and community groups have sponsored and beautifully decorated trees, making the airport terminal sparkle.

We'd like to say a huge thank you to all involved, from our coordinator, Wellington Branch, Wellington International Airport, to all the companies who've decorated trees, to the team who transport the trees to the airport. You all play a vital role in making this event the success that it is, and we are so very grateful.

The Gala, which launched the festival took place last week, and the winning tree was judged and announced! Congratulations to Sam's Art House for taking out the top prize, and Naylor Love who came 2nd, and Bay Plaza in 3rd place.

People's Choice – Vote Online

The People's Choice Prize is still up for grabs, and this year you can take a look at the trees and vote for your favourite online, [here >](#)

The winning business will receive \$5000 advertising package at Wellington Airport, and everyone who votes goes into the draw to win \$500 to spend in any shop at the terminal.

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 2021 recipient, Emma, [here >](#)

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

Find out more info and apply here:

👉 [Mark Ashford Scholarship](#)

👉 [CF Achievers' Awards](#)



CF News Callout

The next issue of the CF News is just around the corner, and we'd love to tell your story!

Have you recently graduated? Finished school with some pretty cool plans for next year? Would you like to tell us about your child's first year at kindy / school and how you dealt with CF? Have you set and achieved some goals that you'd like to tell us about?

We would love to hear from you... Please either reply to this email, or email Lizzie on comms@cfnz.org.nz, - lets get you featured in the next issue!

Do Your Christmas Shopping Through Rewardhub And Get FREE Donations For CFNZ

If you're anything like us in Level 3, there's been a bit of online shopping going on... Don't forget to do your shopping via Rewardhub - its free and a percentage of your purchase will be donated to CFNZ, if you're signed up [here >](#)

With Christmas fast approaching, get your shopping sorted via Rewardhub; you'll find shops like Countdown, Onceit, TheMarket, Mighty Ape, Cotton On, My Food Bag, The Iconic, Hello Fresh, Lego, and hundreds of others.

Sweatember - A Finalist!

A couple of months ago, we were thrilled to hear our 2020 Sweat4CF campaign was a finalist in the not-for-profit sector of the TVNZ Marketing Awards 😊

This week we watched the virtual awards ceremony.

We'd like to congratulate Women's Refuge New Zealand on taking the win – your Safe Nights campaign is world class, it inspired us all, and has been a life-changing for women and families across the country. It was a privilege being in the list of finalists alongside you 💙



Putting For A Good Cause

Another successful golf tournament for Cystic Fibrosis Canterbury! This tournament is now in its 34th year, and we are very grateful for the support Templeton Golf Club has given us over many years.

This year we fielded 21 teams, which is a step up from previous years, the weather was great and the day was thoroughly enjoyed.

We are astounded each year with the kind donation of prizes and auction items. This year was no different, some to mention would be the motorised chilly bin (pictured above with Sandy Champion), signed Crusaders Jersey, Canterbury Rams Singlet, Nespresso Coffee Machine, a trailer load of firewood, and some lovely alcohol gift packs. We raised approx. \$7000! Huge thank you to all involved.

New Face On The CFNZ Board

Introducing Zac, the newest member of the CFNZ Board.

“I am thrilled to join the CFNZ board. I have just returned from the UK. While I was there, I spent two years on the board of Action Duchenne, a UK based charity working with the Duchenne Muscular Dystrophy community. It was such a fabulous experience, and I hope I can use some of that to contribute to CFNZ’s continued success. I have some great friends in the CF community in NZ and can’t wait to get more involved.”

Welcome aboard, Zac!



Happy Volunteer Day!

Over the weekend, it was International Volunteer’s Day.

We would like to take this opportunity to say a big THANK YOU to all our volunteers across New Zealand. We could not do what we do, without you.

We are always very grateful for new volunteers, especially around Awareness Month. If you’d like to sign up to volunteer for Cystic Fibrosis New Zealand, head over to our sign-up page on the website [here >](#)

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 – for support with operating costs
- Taranaki Foundation – equipment for Taranaki branch
- TG Macarthy Trust – for support funding the Fieldworker service
- Geyser Community Foundation – support for Rotorua
- Trust Waikato – equipment for Waikato
- Lindsay Foundation – for funding portable spirometers

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