



Welcome To The September Panui!

Kia Ora <<First Name>>,

Well, when we sent out the last Panui, we couldn't have predicted the next would be sent from within our bubbles in lockdown once again!

We hope being in Alert Level 4 has been ok for you all: that you've done some baking, watched plenty of Netflix, and that you've taken time to relax too. Although we know what we have to do as a community, and nation, it doesn't make it any easier – please reach out if you need support, our Fieldworkers are working from home but are only a text away.

See our COVID-19 Update here >

Today marks the first day of SWEATEMBER (read about it below). We have over 230 people registered to sweat, and they've raised over \$35k already.

Lockdown has given us the perfect opportunity to set a sweaty goal! Its not too late to sign up! 🖔

You'll read that there are some changes ahead, while we sadly say goodbye to our current Chief Executive, Jane Bollard.

Find out about the latest in advocacy, and more.

Look after one another, stay warm.

Nga mihi, CFNZ Team



SWEATEMBER Is Back!

And just like that, Sweatember is here! Join hundreds of New Zealanders as they take on a sweaty challenge of their choice during September and raise money for a better future for Kiwis with cystic fibrosis.

A big shout out to everyone who has already signed up \heartsuit Your decision to become a sweating superstar is soooo appreciated.

And for those of you still thinking about getting involved, don't be shy! You can choose to support an already registered superstar or register your own activity at any point during September. Any sweaty activity qualifies and you can participate as either an individual or team – it's entirely up to you.

Looking for some inspiration? Here's a few of our top sweaters so far...

- Lorrae_rae "I'm sweating for CF for my nephew Mr Lincoln who has CF. Mr Lincoln is 2 years old and full of energy with the cheekiest smile. He loves sports and is always running round with his big sister so I figured I'd run 300km in 30 days to sweat for him."
- Reeses 100km in 30 days "I was born with CF and have always loved physical activity and sport since I was little! I'm sweating to help spread awareness and raise money towards the miracle drug Trikafta, and to show that CF cannot hold me back!"
- Shelleyrob "Because my beautiful daughter has CF and I want to do what I
 can to support her and all people living with CF in NZ. I'm going to walk
 150km in September!"
- Reclaim Team Dean "In July 2021, Dean passed away after 19 years of living life to the fullest. If we can help save one life, it'd be worth it. She was one of the rare ones. So effortlessly herself, and the world loved her for it."
- Teagan's 200 km "My partner George has CF along with many others! I am
 playing my part this Sweatember to support the CF community & raise \$\$ to
 help support George and our fellow CF friends live long and happy lives."
- Lizzie Blades 50k Lizzie both works at CFNZ and lives with CF. "Every \$ we raise goes straight into giving Kiwis living with CF a bigger and better future.

 I'll blade to that!"

However you get involved, you can feel great knowing that all donations raised will make a tangible difference to the CF community.

Visit www.sweatember.org.nz to sign up.

Snag Yourself Some SWEATEMBER Sweatbands And Headbands

Look the part and be a walking / running / roller-blading billboard with our Sweatember sweatbands!

SHOP online here >

They will be on their way to you as soon as covidly possible



Changes Ahead For CFNZ

Farewell, Jane Bollard ♥

Last month, we informed our CF families and supporters that Jane Bollard has sadly resigned from her position as Chief Executive.

Work has already started on recruiting a new Chief Executive. "The organisation's priorities will not be changing, so the focus will be on finding someone committed to the cause, a strong leader and a great communicator and advocate. We will be doing everything we can to get the right person," says Warwick.

We thank Jane for all the time and energy she has put into CFNZ, and wish her all the very best for the future.

Read the full story here >

Introducing our Acting Chief Executive, Christine Perrins

Christine, who has a 26 year old daughter with CF, has been generously volunteering her time as our Advocacy Advisor for the last 18 months, with the Trikafta Campaign being her key focus. We are thrilled that Christine will shortly be stepping into the Acting Chief Executive role while we are recruiting for our new Chief Executive. Christine will be supporting the CFNZ team, while maintaining her focus on advocacy.

Welcome, Christine!





Giveaway With B.Bold!

Our friends at B.BOLD have generously given us one of their combo packs of award winning, all natural, highly effective cream deodorants to give away \heartsuit

Whilst powering through your sweaty challenge, know that B. Bold has got your back (and your pitts!)

To be in to win, simply FOLLOW B.BOLD Natural and CFNZ on Facebook / Instagram, like the giveaway post, and TAG a friend who might want to smell nice too ③

☆DISCOUNT CODE ☆

B.BOLD have also extended a special 15% online discount when you purchase direct from their website (www.bbold.co.nz) during the promotional period. Simply use the code SWEATEMBER at checkout.

This promotion runs from August 26th – September 12th with the winner being drawn September 13th. Giveaway is not in association with Facebook or Instagram.

Advocacy Update

Let's give the petition calling the government to publicly fund Trikafta for all eligible Kiwis living with CF, a big push to the finish line \bigcirc Strength in numbers!

Sign here if you haven't already, and please share the petition link with your friends and whanau.

Trikafta application with Pharmac

The application process is progressing. Pharmac's respiratory sub-committee was considering Trikafta at its meeting on 26 August.

Pharmac Review

The Independent review panel reviewing Pharmac was expected to provide its interim report to the minister of health by 20 August. CFNZ is keen to see the report released publicly to understand how the panel has considered the concerns raised, and the approach it is likely to take in its final report in December.



Lizzie McKay On Brodie Kane's Podcast - Kiwi Yarns

We're kicking off SWEATEMBER by sharing an extra special podcast - Kiwi Yarns with Brodie Kane - featuring our very own Lizzie McKay ♥

Listen here, or on any podcast platform:

✓⊋ Apple podcasts here

Spotify here



Being Me: OJ

Attitude had the privilege of following the ever-resilient OJ and his whānau around recently, creating this moving documentary ♥

Its raw, open, heartwarming, and heartbreaking.
It highlights exactly why we need Trikafta to be funded for all Kiwis like OJ, living with cystic fibrosis.

Thank you for sharing your story with us, Daniels family

Watch the full documentary here >



Thank You, Liberate Pole Dance & Exercise!

Earlier this year, Liberate put together and sold a calendar in honour of the beautiful Juliet Hubbard.

"Thank you to Juliet Hubbard (RIP) for always being an inspiration for so many people and being our beautiful poster girl and friend... We have had a ball fundraising for CF and will continue to support the cause where and when we can," – Olivia Allchurch from Liberate.

They were able to handover the proceeds to Melissa Skene recently. Thank you, Liberate \bigcirc

Gastro Services Survey: Final Notice

The research team in Christchurch are running the survey study "Gastroenterology services within Cystic Fibrosis Clinics across New Zealand" for one more week (closing 7th September).

If you have not completed it yet, and are an adult with CF, or carer of an adult or child with CF, they would be very interested in what you think on this subject!

The survey takes about five minutes to complete - please click on the link below for further information, and to access the survey here >

Lockdown Recs! §

We've all be sharing what we've been watching (other than season 3 of the 1pm briefing!) and listening to in the calmer hours...

Here's some tv show recommendations across Netflix, Neon, and OnDemand for the adults:

- Mare of Easttown
- · The White Lotus
- Smother
- Unknown
- Clickbait
- · The Queen's Gambit
- The Office (UK and US)
- Gossip Girl Reboot
- The Fall
- Wentworth
- Marcella
- Mindhunter
- Snowpiecer
- Love Island (if you're anything like Lizzie!!)
- Unbelievable

If you're into podcasts, have you tried these ones?

- What The CF! (Of course)
- · Kiwi Yarns with Brodie Kane
- The Deep
- · The Shrink Next Door
- True Crime New Zealand

Showing Grantitude

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

- Mainland Foundation, Four Regions Trust and K.D. Kirkby Charitable Trust have supported us in purchasing nebulisers, Freestyle Libre sensors and sterilisers.
- COGS committees all around the country have supported us for operating costs, as has the Eastern & Central Community Trust.

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

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



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