



Welcome To The November Panui!

Kia Ora friend,

There's only 51 days until Christmas, and a summer we hope brings with it a little more freedom...

We hope you're keeping well and happy wherever you are in NZ; but especially those in Alert Level 3 areas. It's been a tough slog – we take our hats off to you all.

This week, we welcomed our new Chief Executive, Lisa Burns onto the team. We are so looking forward to working with Lisa, and navigating this new phase together!

In this issue of the Panui, we're updating you on the latest Trikafta news, introduce you to some new faces, provide information about this year's Christmas Tree Festival, the Triple P Parenting Programmes, and reminder about Compassion Pins.

Take care, and make sure you get a dose of vit-d outdoors!

Nga mihi,
CFNZ Team

Thank You, Christine!

We'd like to acknowledge Christine Perrins, who seamlessly stepped into the role of Acting CE over the last couple of months. It's a big, busy role; Christine led the team entirely from home. She supported us every step of the way, held important conversations, and had our CF community in the forefront of all she did. We are truly grateful! Christine continues to generously volunteer her time as our passionate, professional and intelligent Advocacy Advisor, as she has since early 2020.

Advocacy Update

Major Step Forward For Trikafta

We were delighted to announce that Vertex's triple combination therapy Trikafta has been added to the priority list of medicines that Pharmac would like to fund.

Pharmac's respiratory experts considered Trikafta in late August and recommended that it be funded with a high priority. Based on this advice, and an economic health assessment, Pharmac has determined that Trikafta is a medicine it would like to fund.

The Respiratory Subcommittee report advised that Trikafta "could allow patients with CF to live a nearly normal life" - an incredible thought for our Kiwis with CF



Read the full story [here >](#)

CFNZ is grateful to Pharmac for undertaking the assessment process so rapidly. Trikafta will bring life-changing benefits to the health and well-being of the majority of people with CF in New Zealand. We look forward to Pharmac working quickly through the next steps and making Trikafta available as soon as possible.

Read the Pharmac [media release >](#)

Trikafta In The News - Thank You Paddy!

Following this exciting Trikafta announcement, Patrick Gower did an incredible story on Newshub. It's amazing to hear PHARMAC acknowledge that Trikafta is a 'paradigm shift' – the move from treating the symptoms of CF to treating the underlying cause.

Thank you as always, Bella, Ed and Izaeah, for being willing to get in front of the camera and show NZ some of the faces of those living with CF, and showing us the real impact Trikafta has had on your lives 💖

Paddy – we are so grateful to have you throwing your energy CF's way – we so appreciate the strong, vocal and passionate advocate we have in you.

Watch the story [here >](#)

Meet Raki!

The lovely Raki has joined CFNZ as our Fundraising and Marketing Coordinator.

Raki has a background in population health and experience in fundraising within the not-for-profit sector. In her role, she will be coordinating the implementation of programs to grow support for CFNZ. She will also assist the wider team with digital marketing, managing web content, and advocacy communication. Raki is passionate about seeing health equity achieved and is committed to conduct her practice in a culturally safe manner, and we are so happy to have her on our team!





Let's Get Kat's Name On Paige's Birth Certificate

Hopefully you will have seen that recently, Paddy Gower, Newshub and More FM have been sharing the story of the gorgeous little Paige, who is the only child in NZ whose birth certificate reads 'not recorded' where her Mum's name should be 💕

Paige's mum, Katherine, lived with CF; she had a lung transplant which gave her many extra years, and dreams of becoming a mother. As she was unable to carry a baby herself, she and her husband Kyle went through the surrogate process with Renee and Josh. Unfortunately, Kat's health began to seriously decline, and a few months before Paige was born, we lost our amazing Kat. A friend and inspiration to many in our community 💕

New Zealand's out-of-date surrogacy and adoption laws are standing in the way of acknowledging Katherine Harris as a mum, because she passed away before Paige's birth.

All Kat wanted was to be a Mum, and she should be honoured as a Mum, Paige's Mum 💕 Let's get behind Paige and Kyle, please sign this petition to help Kat's legacy continue through Paige. Add your voice [here >](#)

Rare Disorders Survey – Have Your Say

Rare Disorders have announced the launch of their 2021 Voice of Rare Disorders survey - and we need your help to make it a success.

"In 2019 we launched our first ever Voice of Rare Disorders survey, and the data we collected has been vital for our advocacy directly with the Minister of Health, health officials, Pharmac and MPs for people living with rare disorders, and through all areas of our work. The survey offers the voice of all people with a rare disorder to show the true impact and barriers faced and guides the focus on our ongoing Fair for Rare Campaign."

Anyone living with a rare disorder in NZ, as well their whānau and carers are strongly encouraged to take this survey.

Take the survey [here >](#)

Read more about survey [here >](#)



We are pleased to announce that the Cystic Fibrosis Christmas Tree Festival will once again be a festive display throughout Wellington International Airport despite Covid-19. The festival is about fundraising, but it is also about building a community that knows about our people, their needs and our goals.

If you or anyone you know has a business or organisation who would like to be involved in this years' Christmas Tree Festival, please get in touch with Mary Tapp - cfchristmastreefestival@gmail.com

Triple P – Positive Parenting Program

Additional funding from the Ministry of Health and support from Whāraurau (as part of their COVID-19 response) enables whānau to now have free access to the Triple P online parenting programmes.

Triple P programmes are developed for ages 0 – 16 years so guaranteed something for everyone.

The website is: www.triplep-parenting.net.nz

When on the website, you can click on the “GET STARTED” icon where a bunch of resources are available, such as a parenting guide, parenting in Covid-19, top tips for schooling during Covid-19

“Positive parenting helps you feel more confident and less stressed about raising children”

For the amazing free online courses - click on the “FIND HELP” icon where you'll find resources for teenagers, support with confidence in kids, and Fear-Less Triple P Online which is a programme parents and caregivers can do to support young people with anxiety.

Speak to your Fieldworker if you'd like support navigating the Triple P Programmes.

Rewardhub – 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.

A Note From The Board

The October CFNZ board meeting was an opportunity to reflect and celebrate our recent achievements to date but also to welcome some new faces including our incoming CE.

Read the Board update, which includes a Sweatember celebration, the exciting Trikafta developments – including our gratitude for those happy to share their stories, and more.

Read the full report [here](#) >



Torpedo 7 Friends And Family Sale

That time of the year again (right before Christmas!) where Torpedo 7 hold their

Friends and Family Event. From the 3rd to the 16th November you can get up to 50% off a huge range of gear.

Use the code on the flyer when shopping online, or take the flyer in store with you.

Download the flyer [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.

- Lottery Grant Board, for support with operating costs
- Hutt Mana Charitable Trust, for support funding our CFNZ Fieldworkers
- Hugo Charitable Trust, for support with our advocacy and research projects.

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