



Welcome To The June Panui!

Kia Ora <<First Name>>

Now that we're at Alert Level 1 life returns to being close to normal. Most restrictions have been lifted and many of us will return to work, school, church, sport and seeing friends, family and whānau. But going down alert levels can also bring up a range of emotions, and it's okay to feel anxious or worried.

Although the lockdown and physical distancing period is over, we will continue to provide Covid-19 related assistance to the CF community. During Level 2 our team of CF Fieldworkers started seeing people with CF in outpatient clinics (in line with DHB guidelines), and now in Level 1 they will return to visiting people in the community and in hospital. Please reach out to them if you need a listening ear, or need emotional or practical help.

As with many charities our usual fundraising was heavily disrupted during lockdown, and the future looked uncertain. We were overwhelmed with the generosity of New Zealanders when we launched our Covid-19 Emergency Appeal. Thank you for ensuring the CF community could continue to receive support and information through the pandemic and beyond.

During lockdown we also welcomed new families and whānau to the community, whose newborns were diagnosed during the difficult Covid-19 conditions. We're sending you aroha, please let us know if we can connect you with any extra support at the moment.

We're also humbled by the way people with CF and their families have reached out to each other via social media – asking and answering questions, sharing advice, offering support – all during a challenging time.

Our Auckland and Christchurch offices will reopen next week and our staff are dusting off their work clothes, putting away their slippers and looking forward to being back in the office.

Like you, we hope the path to Covid-19 elimination continues to move only forward, and we will continue to do all that we can to make a difference.

Arohanui.



Congratulations, Sir Professor Bob Elliott!

When the Queen's Birthday Honours were announced last week, we were thrilled to see Professor Bob Elliott receive the deserving accolade of a Knighthood.

Sir Bob Elliott was already royalty in the cystic fibrosis world, notably for his work on the newborn screening method, and his huge passion for research into childhood illnesses, along with co-founding what became Cure Kids.

In the late 70's Sir Bob Elliott made a major worldwide breakthrough in how to easily and quickly diagnose cystic fibrosis. He used old Guthrie cards and determined his new blood test was 100% effective in diagnosing cystic fibrosis.

"My informed guess [of the impact] of newborn screening is that it has added 30 years of life for people with CF, and hopefully more [years] to come," Sir Bob Elliott said in a 2019 interview with CFNZ.

Congratulations Sir Bob Elliott, thank you for the difference you've made to the lives of not only Kiwis, but people living with CF worldwide 💙

Read The Full Story [Here >](#)

Read CFNZ's 2019 Interview With Sir Bob Elliott [Here >](#)

Feedback On Your Covid-19 Experience

As we adjust to life with more freedom and reflect on the past few months, we'd like to get your feedback on what Covid-19 was like for you and your family, and if we made a difference during this time.

To say thank you, each person that provides feedback will be entered into a draw to win a My Food Bag voucher worth \$170.

You can reply to this newsletter, send an email to comms@cfnz.org.nz, DM us on Facebook, or speak to your fieldworker and let them know you would like to be entered into the food bag draw.

Draw takes place Wednesday 17 June at noon.

We'd be interested to know feedback such as:

- How did Alert Level 2, 3 and 4 make you feel, what was the experience like?
- What were your main concerns or worries?
- Where there any positives, or things that made it easier?
- Was there enough CF-relevant information available?
- Did you receive support from CFNZ during this time?
- Examples of what CFNZ did well, or could have done better
- Anything else you'd like to share with us 😊

Visit www.cfnz.org.nz/covid to read our Covid-19 updates and information.



Creon Micro Funding Approved

At the end of May, we were excited to share the news that PHARMAC would be funding Creon Micro from Monday 1 June 2020, through an agreement with [Mylan](#).

Creon Micro is a modified-release granule formulation of pancreatic enzymes. This formulation allows for smaller doses of the medicine to be administered.

Cystic Fibrosis NZ submitted a letter of support earlier in the year, outlining the benefits that access to Creon Micro would have on our young Kiwis with CF and their family.

“CFNZ is delighted to support the funding of Mylan’s Creon Micro. The first years following diagnosis of CF are a stressful time for new parents and anything that can ease the load on families and whānau is most welcome,” says CFNZ Chief Executive Jane Bollard.

Read The Full Story And Press Release [Here >](#)



Compassion Pins

It's been so nice seeing CFNZ's new Compassion Pins out in the community.

"Quite often in our time when we head out into public - the supermarket, the shopping mall or even mingling in social environments, we get an uncomfortable stare following Tailen's cough, as it is his everyday cough even when he is well."

This is exactly why we've made these pins available – to help limit the funny looks and



remarks. Turns out, they do the job AND they look cute.

Check Out The Pins And Request Them [Here >](#)

Access For Aotearoa

The new triple combination therapy, known as Trikafta, could be truly life changing for up to 90 per cent of people with cystic fibrosis. We have been working hard to stress to all relevant bodies the importance of funding this medication in New Zealand.

Our Chief Executive, Jane Bollard, has met with Logan Heyes, the new respiratory portfolio holder at Pharmac, and will be meeting Heyes again in mid-June with a representative from Vertex.

These meetings are to seek clarity on any plans Vertex and Pharmac have with regard to the funding of Trikafta, Orkambi and Symdeko. We look forward to sharing the outcome of these meetings with you.

Join our **Access for Aotearoa** Facebook Group [here >](#)

Help Inform A New Medicines Strategy

Medicines NZ has been working with the New Zealand Institute of Economic Research to develop a future-proofed Medicines Strategy and Policy. It is seeking input from patient groups, professionals, policy makers and the medicines industry.

This is our chance to have a say on policy that will ultimately impact on the funding of innovative medicines. [Register to take part](#) on the online consultation or download the draft policy, have a read and let Jane know what you think at ceo@cfnz.org.nz as CFNZ will be providing feedback. Consultation closes with MNZ on 6 July.

Have You Signed Up For RewardHub?

We shared last month that we'd become a 'cause' partner of [RewardHub](#).

This is a simple and free way to raise money for CFNZ. All you have to do is sign up

([here](#)) and do your everyday online shopping via the RewardHub website. The stores you shop on will donate a percentage of your total to CFNZ.

We posted a video showing how to sign up on our Facebook page [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.

- Johnsonville Charitable Trust and the Wellington Children's Foundation for funding equipment
- Central Lakes Trust and The Community Trust of Mid & South Canterbury for South Island services
- Roy Owen Dixey Charitable Trust for the Canterbury physio support

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



Get involved

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