



Welcome To The April Panui!

Kia Ora <<First Name>>,

We hope this issue of the Panui finds you full of chocolate and hot cross buns, and relaxed after the long Easter weekend.

The beginning of 2021 has seen a large focus on progressing the campaign for Trikafta, and keeping up the momentum which gained much traction during the Newshub 'Because it matters' series. Last week, a facilitated meeting between PHARMAC, Medsafe, Vertex, Trikafta for Kiwis, CFNZ and CF clinicians took place, the first meeting of its kind between these groups. We made positive steps forward, with PHARMAC and Medsafe inviting Vertex to apply for the triple combination therapy concurrently.

Read PHARMAC and Vertex's statement about the meeting below.

While progress is happening on the advocacy-front, CFNZ sees and supports the continuing day-to-day needs of the CF community, with our wonderful CF Fieldworkers available to help, especially with the colder months fast approaching.

Thank you to those who applied for CF Achievers' Awards and the Mark Ashford Scholarship. We look forward to announcing the recipients soon.

Nga mihi,
CFNZ Team

Advocacy Update

Stakeholder Meeting

Last week, New Zealand edged a little closer to securing the latest CF modulator therapy, registered in other countries as Trikafta/Kaftrio.

In what is believed to be the first meeting of this type, PHARMAC, Medsafe, Vertex, Trikafta for Kiwis, and Cystic Fibrosis NZ met on Tuesday to discuss how we could work together to quickly get the triple combination therapy in the hands of people with CF.

Members of the CFNZ Clinical Advisory Panel presented a comprehensive picture of the urgent health needs of the CF community and the changes for those Kiwis already on the therapy.

Medsafe and PHARMAC spoke of their respective processes, and we are pleased to confirm that PHARMAC and Medsafe have agreed to consider applications concurrently to help shorten the time frame. Part of the meeting also included a private discussion between Vertex, PHARMAC and Medsafe.

We wish to thank all the participants for their willingness to attend and for the positive outcome of the meeting. CFNZ continues to urge Vertex to complete and submit its application to Medsafe and PHARMAC without further delay.

Read PHARMAC's [full media release](#) >

After PHARMAC's statement was released, Vertex responded, outlining that they are actively working on their documents for submission, and that they plan on requesting a priority review from Medsafe which could shorten the process.

Advice From CAP On The Covid Vaccine

With the Covid-19 vaccine due to be rolled out to high risk populations from May onwards, we asked the CFNZ Clinical Advisory Panel on their advice for the CF community.

The panel advised that all people with CF will be offered an appointment and that it strongly recommends you have the vaccination when it is offered. There is only vaccine product being offered in New Zealand, the Pfizer/BioNTech vaccine, and requires two doses. The second dose is given at least three weeks later. It's very important you get your second dose. You will have the best protection once you have both doses.

Be prepared to feel a little lousy afterwards, with fatigue, muscle aches, and headaches a commonly reported reaction. This should pass within a day or two.



CF Awareness Month - May 2021

CF Awareness Month is just around the corner, and it's a perfect time to get involved and make some noise about cystic fibrosis. We've always felt there are so many aspects to CF that it's hard to pin it to just one week – so we're taking over the whole of May!

This year we'll be focusing on four key themes;

- Access to medications / campaign for Trikafta
- Impact of CF on the body
- Daily treatment of CF
- Cross infection

We'll be discussing and raising awareness of the above topics through 'day in the life' video clips, photos, written words, news articles, radio, and any other way we can get the word out. If you'd like to share your story or experience, get in touch with Lizzie at comms@cfnz.org.nz

[Read more >](#)



Meet Chris Shanks, CFNZ Board Member

Early this year we welcomed Chris Shanks to the CFNZ Board. Chris is married to Carmen who lives with CF and runs the Trikafta for Kiwis advocacy group. Chris is also an active member of the Auckland Branch Committee, and brings to the Board financial, contract and management skills.

Read more about Chris [here >](#)

CF News Magazine Will Be Hitting Your Letterbox Soon!

Our latest edition of the CF News is almost on its way to you...

In a bid to reduce our printing costs and carbon footprint, we'd love to know if you'd be happy to receive the twice yearly magazine, digitally. All the same content straight to your inbox, ready to read anywhere, any time.

We'll still be doing a print run for those signed up to receive the printed magazine, but hope to move towards a more digital format. If you're happy to be taking off the printed mailing list, be sure to update your preferences [here >](#)



Welcome, Angela!

In February we welcomed Angela into the CFNZ fold. Based in the national office in Auckland, Angela is our go-to person for administration requirements, grant applications, and is who you'll hear from on the other end of CFNZ admin

emails.

Read more about Angela, [here >](#)

Wedding Wishing Well For CFNZ

Kagan and Anna, thank you so very much for choosing CFNZ to be the recipient of donations in lieu of wedding gifts at your recent nuptials. Every dollar is appreciated, and we're grateful that amongst the wedding madness, you thought to include CFNZ.

Congratulations, we wish you a very happy future! 



Charlotte's Triple Peaks Trail

Charlotte and Aiden met at a friend's 21st birthday party seven years ago. Aiden has cystic fibrosis (CF) but he hasn't ever let it limit his life. He describes his treatments as, "business as usual", is positive and upbeat, and very practical about his routine and how CF has impacted him. Charlotte became aware of the drug Trikafta a few years ago and thought, "ok, great that'll be there for Aiden later down the line", but as the last few years have shown, his health can become vulnerable pretty quickly so she became increasingly frustrated at the existence of such a life-changing drug not being available for people with CF in New Zealand.

As a couple, they wanted to raise awareness and encourage people to [sign the petition](#). Charlotte decided to embark on a 'Triple Peak Trail' during the month of March 2021. She managed to walk an incredible 22,002m elevation!

Well done Charlotte and Aiden, thank you for raising awareness for the need for Trikafta.

Read the [full story >](#)

CFNZ Zoono Code Still Works!

A little reminder that we still have a discount code with our friends at Zoono who have your hand sanitiser and surface sanitiser needs covered! Use the code CFNZ20 to receive 20% off any purchase online at zoono.co.nz



What The CF! A CF Podcast

Seasoned media professionals, and parents of a CFer, Ingrid and Ian, have started a brand-new podcast, with series one being all about CF diagnosis. Episodes include interviews with CF Mums, Dads, a genetic counsellor, one of our lovely CF Fieldworkers, Sue Lovelock, and more to come.

Find WTFC wherever you listen to your podcasts:

[Spotify >](#)

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Rewardhub - Now Includes Countdown!

The team at [Rewardhub](#) have now partnered with Countdown, meaning 1% of every Countdown shop via Rewardhub will go to CFNZ if we are your chosen charity. It's a great way to generate "free donations" and is easy to set up.

Sign up [here >](#)



Thank You Cox Partners Napier

Cox Partners Napier kindly donated \$500 to CFNZ Hawkes Bay. This donation was generated by the commission from a residential sale where the vendors chose CF as the recipient.

Malcolm Cox (pictured) was most interested in Kirsty's life with CF and the part CFNZ plays.

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.

- Community Trust South, LW Nelson Trust, Rata Foundation, Lion Foundation, Four Winds Foundation, W.Duncan Bickley Charitable Trust, Central Lakes Trust, Dragon Community Trust, BlueSky Community Trust, for operating costs
- Hugo Charitable Trust for research support

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.

www.cfnz.org.nz

PO Box 110 067, Auckland 1148

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