



Welcome To The July Panui!

Kia Ora <<First Name>>,

What an exciting few weeks it has been, full of good news for our CF community. We said goodbye to June with Vertex submitting its application to Medsafe for approval of Trikafta, and we welcomed July with the news that Vertex had put in place a Managed Access Programme for Trikafta in New Zealand. We've talked about what this means for Kiwis with CF, below.

This week we sent out the 2021 Insight Survey – which asks you what is important to you, to help shape the future of CFNZ. We'd appreciate your feedback, and there's a \$500 spot prize up for grabs!

The CF Raffle for 2021 was a success, thanks to those who purchased and sold tickets. The winners have been drawn and are in the process of being contacted.

Have a happy, healthy July.
Stay warm.

Ngā mihi,
CFNZ Team



Advocacy Update

Trikafta Managed Access Programme Announced

On Friday 2nd July, we were delighted to confirm that Vertex put in place a Managed Access Programme in New Zealand for the triple combination therapy (registered as Trikafta in Australia) for those in critical need.

CF clinicians are now able to make a formal request to Vertex for access for patients who meet a certain criteria and for whom access to the programme may be the only option remaining. Please note that people with CF or their families cannot apply direct to Vertex.

Cystic Fibrosis NZ is delighted that Vertex has established a Managed Access Programme for Kiwis with CF. The programme can provide access to Trikafta to individuals in urgent need, while regulatory and funding applications are worked through by Vertex with Medsafe and Pharmac.

But this Managed Access Programme is no substitute for publicly funded access. We will continue to work with all parties to secure Trikafta and Vertex's other CF modulators as soon as possible for our CF community.

Read the full update [here](#) >

Thank you Izaeah for sharing what this might mean for you with Newshub. Watch the full story [here](#) >

Thanks Ed for always being willing to share your Trikafta story. Read The Herald report [here](#) >

Medsafe Grants Trikafta Application Priority Status

On Monday 21st June, it was confirmed that Vertex had submitted its application to Medsafe for approval of Trikafta.

The application is for the treatment of CF in people 6 years and older. Medsafe has accepted the application and granted it priority status, enabling a shorter time for evaluation.

Cystic Fibrosis NZ is absolutely delighted that Vertex's application for Trikafta has been submitted to Medsafe and we look forward to an application to Pharmac in the very near future. Pharmac and Medsafe have already agreed to consider the applications in parallel.

Read the full update including a statement from Vertex [here >](#)

Help Shape The Future Of CF Support

CFNZ exists for you, the CF community. Tell us what is important to you, and help shape the future services of CFNZ. We'd appreciate your input into our 2021 Insight Survey: there's one for people with CF (over 15 years of age), and another for parents and care givers.

To start the surveys, click:

- [here](#) if you live with cystic fibrosis
- [here](#) if you are a parent / partner / whānau member

If you complete the survey before midnight Sunday 18th July 2021, and you share your name at the end of the survey, you will be entered into the draw for a \$500 spot prize.

Read more about the 2021 Insight Survey [here >](#)

A huge thank you to those who have already completed the survey 



Get Sweating For CF This SWEATEMBER!

Last year you helped raise a whopping \$140k for support, information, and advocacy by sweating throughout the month of September... Can we do it all over again?! We'll be kicking off the new campaign in around three weeks' time, so dust off the lycra, dig out the sweatbands, and start planning your sweaty activity!

We're also on the lookout for new champions to help promote the campaign. Have a look at last years' [champs >](#) . Get in touch with Laura (laura@cfnz.org.nz) to find out more.

Online Auction Raises Over \$20k For Cystic Fibrosis

Initiated by Josh and Kareena Sneddon of Tahau Jerseys, the auction ran on bidr on 21 June. Featuring 46 lots with a mix of live animals and straws on offer, alongside donated goods ranging from a day of digger hire to stays in luxury apartments, the auction attracted 79 registered buyers, with more than 120 others following it online. A huge thank you to the Sneddon family, Linked Livestock, and Bidr for making this awesome fundraiser happen.

Read the [full story >](#)



Bread4CF!

Alex and Matt set themselves the mammoth task of growing, making, and baking 31 sourdough loaves in the month of May. Every donation over \$20 received their very own handmade loaf wrapped in baking paper, tied up with string.

They perfected the art of sourdough during lockdown last year, and 31 households were able to reap the rewards!

Thanks Alex and Matt for raising just over \$1,350.00!



Thank You Shining Peak Brewing!

Every month **Shining Peak Brewing** donates 5% of their beer revenues to a different local Taranaki organisation. They kindly chose CFNZ Taranaki as their recipient organisation for the month of June. Shining Peak Brewing broke their 5% Project record by raising \$5,059.22! Massive thank you going out to the team, and all who purchased a brew in June.

Pictured receiving the cheque from Shining Peak Brewing above is Shane (**Walking with Wings**), Shelley – CFNZ Taranaki Branch Chair, and Evie – a fellow CFer from across the ditch!

Read more about **The 5% Project** >

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.

- The Kingdom Foundation for operating costs
- AD Hally Trust and Norah Howell Charitable Trust for equipment

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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