

07/20



## Welcome To The July Panui!

Kia Ora <<First Name>>,

This month we are thrilled to be launching our new fundraiser, SWEAT4CF. With a focus on exercise, sweaty activities, and education, you'll be sweating for your own health, and the health of Kiwis with CF - it's a win-win!

Chocky Fish selling is fast approaching - make sure you place your orders with your local branch, in time to sweat, and treat yourself 😨

Read on to learn about the exciting developments for CF Awareness Week going forward, and advocacy update for July.

Arohanui, Cystic Fibrosis NZ Team



# Get Sweaty With SWEAT4CF.... And Extra Sweaty During SWEATEMBER!

Introducing you to our newest fundraiser.... SWEAT4CF!

We're asking everyday Kiwis like you to take on the SWEAT4CF challenge and help bring lifesaving medicines such as Trikafta to New Zealand, provide support and information through our CF Social Workers, and fund research for a life unlimited.

During the month of September take your sweating for CF to the next level by getting extra sweaty for our national SWEATEMBER campaign.

Go for a walk or run every day, dance classes, train for a marathon, cycling, even climb a mountain every day! Commit to an activity or challenge that breaks a SWEAT and ask your friends, whānau and followers to sponsor you.

Make your sweat count and make a difference for Kiwis with CF. Visit www.sweat4cf.org.nz to get started today.

Learn More About SWEAT4CF Here >

## CF Week Moves To May

#### Grab Your Pen And Diary And Put A Big Circle Around May 2021!

CFNZ has taken the decision to align our annual awareness drive with our counterparts in Australia and America by moving CF Awareness Week to May. 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 May with CF Month. Street collections will take place 28 and 29 May 2021 and we'll be sharing insights on CF throughout the month. Let us know if you're interested in sharing your story as part of this by emailing comms@cfnz.org.nz

This year we are focusing on SWEATEMBER, and we look forward to all things CF Awareness Month related, in 2021. Read the full update here >



## Alert Level 1 - Keeping Up-To-Date

While we're all enjoying the freedom of Alert Level 1, here at CFNZ we're continuing to keep up-to-date with the pandemic both in New Zealand and overseas  $\heartsuit$ 

Read our latest update and information on FluTracking here >

## **Advocacy Update**

In our latest Advocacy Update, we look at the exciting Trikafta news for England and Europe. There's an update on Cystic Fibrosis NZ's recent meetings with both Vertex and PHARMAC, where Jane stressed the importance of having Trikafta publicly funded in New Zealand.

CFNZ also submitted a paper in response to Medicines NZ's request for feedback on the development of a new generation medicines policy, and we've included Medicine NZ's latest report.

Read the full update, here >

#### **Rare Disorders Petition**

A new petition needs more signatures to help ensure New Zealanders with a rare disorder have access to the best healthcare.

The Petition of Sue Haldane for Rare Disorders NZ: Develop a National Rare Disorder Framework, urges the Government to acknowledge the universal challenges faced by people living with a rare disease, and the unfairness within the current system, by committing to the development of a New Zealand National Rare Disorder Framework.

Read more and sign the petition here >



Nebulised Antibiotics Residue And Resistance Research Enters Phase 2



Research Highlights Unmet Needs Of Siblings

Cystic Fibrosis Otago is working with the University of Otago to investigate how people with CF are cleaning antibiotic residue from their nebulisers and how this might impact antibiotic resistance. Last year, members of the community were surveyed (thank you!) about their discarding of antibiotic residue and cleaning practices, which contributed to the research findings for phase 1. Funding for phase 2 of the project has been confirmed.

You can read about phase 1 findings, and the objectives for phase 2, here >

Last year we put out a request for siblings of people with CF to participate in a research survey.

This research was led by Katie Armstrong of Massey University and focused on the unmet needs of siblings of children with cancer and serious chronic health conditions (including CF) in New Zealand. Katie has published her findings which found siblings have very high levels of unmet needs. Further research is taking place which builds on these findings.

Read the full story here >

# MarketFest With Rewardhub

One of Rewardhub's partnering stores, TheMarket is running a 'MarketFest' for the next 5 days. There will be site-wide discounts, and you can use the code Fest15 for an extra 15% off. You will also go in the draw to win a \$1000 shopping spree, and 5% of all TheMarket purchases made through Rewardhub will be donated to CFNZ.\*

If you haven't already, you can sign up (here) then complete your online shopping via the Rewardhub website.

If you use desktop, there's also a cool new feature on Google Chrome that will let you know when you've searched for a shop that is in the Rewardhub programme! Check that out here >

\*T&Cs: During the MarketFest campaign period, transactions involving any MarketFest 15% discount coupon from any source will be limited to a maximum of 3 per customer. There is no limit on the number of transactions per customer where a



See full T&Cs on Rewardhub's website.





# It's Chocky Fish Time

Ready to sell and eat some Chocky Fish? Us too!

There's 50 fish in a box, sell the fish for \$1 each, minimum order of 1x box.

Get in touch with your local CFNZ Branch to get your orders in.

Need the contact details for your branch? Find them here >

## Donation From Property Listing

One of the families in our community recently sold their house which resulted in a lovely donation for CFNZ Nelson. Ollie Klotz and Sera's property was listed with Tracy Beer at Mike Pero Real Estate, who generously made the \$500 donation.

Tracy says, 'Giving is not just about "make a donation" it's about making a difference.' A big thank you to Ollie and family, and Tracy, for supporting CFNZ.



### **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.

- Bendigo Valley Sports & Charity Foundation, AD Hally Trust and Stewart Family Charitable Trust for equipment
- Otago Community Trust Covid Response Fund for operating costs
- Community Trust of Mid & South Canterbury for Fieldworker support

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



This email was sent to <<Email>> why did I get this? unsubscribe from this list update subscription preferences Cystic Fibrosis New Zealand · PO Box 110067 · Suite 2 79 Grafton Road · Auckland, 1010 · New Zealand