



Welcome To The May Panui!

Kia Ora <<First Name>>,

Happy cystic fibrosis awareness month!

In this issue of the Panui, you will read all about CF Month and the ways you can be involved in giving Kiwis with CF a brighter future. The 2021 raffle is now live, with over 30 prizes to be won.

Read about the success of our 2019 Insight Survey, and keep an eye out on the 2021 Insight Survey that will be sent out to the community in the coming weeks.

We cover all things advocacy in the latest update, including the good news that Vertex has submitted an application for Symdeko.

Have a great May 😊

Nga mihi,
CFNZ Team



May Is Cystic Fibrosis Awareness Month!

Cystic fibrosis impacts every individual differently. But we all want the same thing; access to life-changing medications, support throughout the ups and downs, and a brighter future ahead.

Throughout the month of May we'll be educating the public on the impact of CF, sharing your personal stories, and asking people to help "give a future" for Kiwis with CF by getting involved.

There are so many ways you can help give a brighter future:

- Visit giveafuture.org.nz to make a donation or text FUTURE to 4462 to make a \$3 donation
 - Follow our [Facebook](#) and [Instagram](#) pages and share our content
 - Search for "CFNZ" to add a frame to your Facebook profile picture
 - Sign the petition for Trikafta [here >](#)
 - Order raffle tickets to sell, or purchase tickets for yourself – www.cfnz.org.nz/raffle
 - Raise money by hosting a collection box, create your own fundraiser, or selling chocolate fish – contact your local branch or email laura@cfnz.org.nz
 - Get in touch if you'd like to share your story on our Facebook, Instagram or website - email Lizzie comms@cfnz.org.nz
 - Participate in or donate to the Auckland, Wellington and Christchurch street collections (28th and 29th)
 - Order yourself a 'Give a F* for CF t-shirt and wear it with pride! Shop online [here >](#)
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Win One Of 33 Great Prizes With The CF Raffle

The annual CF Raffle is a great way to help raise funds towards advocacy and support services! It's easy - buy tickets for just \$5 each, or \$20 for a book of five (get one ticket free!). Or, order tickets to sell on to friends and family and maximise your impact. It's truly a win-win! Visit www.cfnz.org.nz/raffle for the full list of prizes plus how to enter.

2021 Insight Survey On Its Way...

In 2018, CFNZ undertook the first CF Insight Survey of people with CF and their families.

You can read about it [here >](#)

The survey findings helped us to provide a more targeted service delivery focused on meeting the needs and aspirations of people with CF.

The information has been used extensively to make a case for better care and treatment, for seeking funding of our services, and most recently in our Trikafta campaign where survey info, together with Port CF data, was shared with key stakeholders to describe the unmet health need of kiwis with CF.

This year we are broadening our survey to include people with CF, all family/whanau members, key stakeholders and CF clinicians. There's also a \$500 cash prize up for grabs!

Watch out for the survey and please give us your feedback.

Advocacy Update

Good News - First Step in Vertex NZ Application Process

Earlier this year, Vertex announced it would be submitting applications to Medsafe for three different treatments for cystic fibrosis – the three CF modulator therapies registered in Australia as Orkambi, Symdeko and Trikafta. This is so it can have the widest coverage of the CF community by mutation and age group.

On 22 April, Vertex took the first step in its New Zealand approval and funding process by submitting its application for Symdeko to Medsafe.

Symdeko (tezacaftor/ivacaftor and ivacaftor) is available in countries such as the US, the UK, and Australia, and works for people with CF with two copies of the F508del mutation or at least one other mutation that is responsive to Symdeko.

PHARMAC has invited Vertex to concurrently apply to Medsafe for marketing approval and to PHARMAC for funding of its modulator therapies. Medsafe and PHARMAC have agreed to consider the applications in parallel. CFNZ is actively lobbying for Trikafta to be publicly funded as soon as possible.

While there's still a long way to go, this is good news and an important step forward in the process of securing essential medicines for Kiwis with CF.

It's important to note that while Trikafta has a potentially wide coverage, Symdeko will be needed for some people with CF.

Australia Trikafta decision deferred

It has been announced that the Australian Pharmaceutical Benefits Committee (PBAC) has deferred the listing of Trikafta on its Pharmaceutical Schedule (PBS).

Cystic Fibrosis NZ is very disappointed that Australians with CF and Cystic Fibrosis Australia did not get a resounding yes on 23 April.

But we know they won't give up fighting and we look forward to a positive decision as soon as possible.

PBAC's decision comes after more than 12 months of consideration, and approval for the use of Trikafta by the Australian Therapeutic Goods Administration (TGA).

Read the full update [here >](#)

Pharmac needs \$420 million just to catch up

On 29 April, Newshub revealed that Pharmac has a list of 73 medicines it would like to buy for Kiwis, but can't due to budget constraints. The total cost would be just over \$400 million - requiring a 40 percent increase in Pharmac's \$1 billion annual budget.

Read full story and comment [here >](#)



Sinus Rinses For All! (If You Have CF 😊)

Our friends at NeilMed have generously agreed to an ongoing donation of sinus rinse bottles for CFNZ to distribute for free, to the CF community. Sinus rinsing is a way of life for many in our community, and it comes with an expense. We hope this deal makes life a little easier, and more hygienic. Speak to your fieldworker or email admin@cfnz.org.nz to access.



A Successful 65 Hours Of Bowls

Dan took on the crazy goal of bowling for 65 hours to raise funds and awareness for CF. All inspired by his daughter who lives with CF. He raised a huge \$22,887.00 for CFNZ! Dan and his daughter Jessica were able to hand the cheque over to Melissa (CFNZ Canterbury Chair) over the weekend.

Thank you Dan, what a wonderful (back-breaking!) feat! We appreciate every last minute.

The Great Dargaville Bake-Off

The Great Dargaville Bake-Off was a great success, raising just over \$6020!

Bex, whose young boy with CF inspired the activities, said “Our community really came together and supported this event and the fight against CF. Biggest thanks to Goodlife Soap who came up with the idea and ran the event.”

The day saw a range of activities for the kids, from a bouncy castle to gingerbread-people art. A huge thank you to everyone involved – what an amazing community.

Read the article in the Kaipara Lifestyler [here >](#)

A Morning Tea Fundraiser

There are still tickets left for the Morning Tea, raising funds for CFNZ Auckland Branch, on 21 May!

Have a look at the details below, and contact Jill Thoratt on 0211714612 more info.

JOIN US FOR

MORNING TEA

RAISING FUNDS FOR
CFNZ AUCKLAND BRANCH

GUEST SPEAKER

MAGGIE BARRY ONZM

| | | |
|---------------|---|-------------------------------|
| Friday 21 May | : | 10.30am |
| Contact | : | Jill Thorrat 021 171 4612 |
| Address | : | 218 Lake Road Hauraki 0622 |
| Tickets | : | \$50 |

Baking and goods for sale
EFTPOS available

CFNZ AUCKLAND BRANCH
12-30080216256-00
Reference: Morning Tea

PLEASE PARK ON SIDE STREETS



Rose Soap Kit

Jo, a member of the CF community has created soap making kits to raise funds for CFNZ this CF Month.



Soap Kit - Community Fundraiser

Jo, a member of the CF community, has created soap making kits to raise funds for CFNZ this CF Month.

Each kit is \$25 including postage. They contain two reusable rose-shaped silicon moulds, and the ingredients to make a couple of soaps, including shea butter, jojoba & rose oil, and pink clay. Plus its vegan friendly!

Email Jo, knox.j.b.k@gmail.com to place an order.

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.

- Margaret & Huia Clarke Trust, Akarana Community Trust, Kingston Sedgfield Charitable Trust, Mainland Foundation, The Trusts Community Foundation, Bendigo Valley Sports & Charity Foundation, Stewart Family Charitable Trust, Roy Owen Dixey Charitable Trust, Trust Aoraki for funding equipment,
- Grumitt Sisters Charitable Trust, John Ilott Charitable Trust for funding the printing and distribution of the CF News,
- Robert & Barbara Stewart Charitable Trust, Redwood Trust, Blue Waters Community Trust for operating costs.

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



Get involved

Donate

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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