



Welcome To The August CF Panui

Kia Ora <<First Name>>,

On Tuesday night the Government confirmed community transmission of COVID-19. Auckland was moved to COVID-19 Alert Level 3 and the rest of New Zealand, to Alert Level 2. Tonight, it was announced that Auckland would stay in Alert Level 3 and the rest of the country, Level 2, for a further 12 days.

It's not the news we were hoping for, but we got through this together before, and we'll do it again.

It's okay to feel worried, anxious, overwhelmed, scared and/or angry. CFNZ is right here alongside you, and we will do our best to keep you informed and supported.

The Covid section of our website is still available, and we continue to post updates as things change. Visit it here: www.cfnz.org.nz/covid. If you have any questions that come to mind, get in touch and we'll try to get them answered by our brilliant CF Clinical Advisory Panel.

We're thrilled with how our new fundraising campaign, SWEAT4CF and SWEATEMBER is taking off. We've raised almost \$17,000 to date, and we've not even got into September! If you haven't checked it out yet, read more below or visit www.sweat4cf.org.nz

In early August Trikafta was thrust into the national spotlight with a public plea for Trikafta by CFNZ Patron Sir Bob Elliott on Newshub.

Read the latest Advocacy Update, including a comment from Vertex, below.
Kia kaha to all our community in Auckland and around the country ♥

The CFNZ team



Get SWEATY For CF This September!

SWEATEMBER challenges Kiwis to commit to any sweaty activity throughout September to get fit and raise money to support New Zealanders living with CF.

Get your walking club on board, set a new personal best, agree a challenge for your Zumba class... even see if you can get your school, workplace or gym involved. Make your sweat count by sweating for CF.

Campaign proceeds will be used to advocate for access to medications, provide information, counselling, transplant and hospital support, and fund research.

- Meet our SWEAT4CF [Champions](#)
- Download the [fundraising guide](#)
- Check out this fun [Sweatember calendar of challenges](#)
- Get yourself a retro [Sweat4CF Sweatband](#)
- Visit www.sweat4cf.org.nz for more information!

Don't worry if you've already got plans this September, you can SWEAT4CF any time of the year!

Reminder About Changes To CF Week

As we shared in July, Cystic Fibrosis NZ 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. Our next street collections will take place 28 and 29 May 2021.

Access For Aotearoa

Advocacy Update

Thanks to Sir Bob Elliot, and Bella, we have had a huge amount of publicity for Trikafta over recent weeks. This has resulted in Vertex publicly stating that they plan to apply to the appropriate government agencies, using their available pathways, to achieve Pharmac-funded access in the fastest possible way.

In a meeting yesterday, Vertex reiterated that they are fully committed to exploring access for people with CF in New Zealand to future Vertex medications. As a next step they plan to engage with the appropriate government agencies to gain their feedback into this process. This is great news, a big step forward and we anticipate an update as soon as the process is determined.

CFNZ is excited to be working on the Trikafta campaign with Trikafta for Kiwis, a group led by Carmen Shanks and supported by Eddie Porter, set up to advocate for Trikafta.

You can access their updates on the Trikafta for Kiwis Facebook page, [here >](#)

We're also thrilled to be working closely with Christine Perrins around our advocacy strategy, with a big focus on developing the Trikafta campaign strategy in conjunction with Trikafta for Kiwis.

Read the full Advocacy Update to learn more about Medicines NZ and their panel discussion on Medicines Inequity, and our continued work with PVA, [here >](#)

The petition calling for a reform of PHARMAC and to double their budget, closes 22 August, [sign here >](#)

Trikafta In The Media

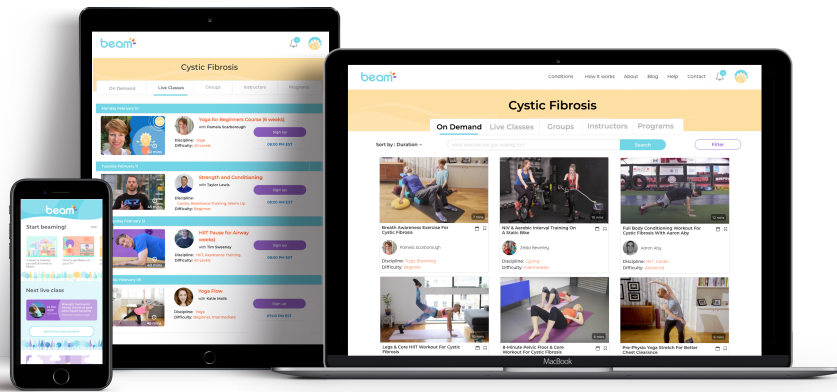
You can view Sir Bob Elliot and Bella's Newshub story [here >](#)

Watch extended coverage by Patrick Gower on The Project, [here >](#)

Watch Bella and her mum Alley on The AM Show [here >](#)

Watch Carmen Shanks' story on Newshub [here >](#)


Hear Jane Bollard's interview on More FM Manawatu, [here >](#)



We're Investing In Your Well-Being

Get **FREE** access to the Beam Team online exercise program

CFNZ has been very fortunate to receive a grant from Te Hiringa Hauora – the Health Promotion Agency in NZ, to enable all people aged 16 years or over with CF in New Zealand and new mums of babies with CF to engage with the **Beam** online exercise platform for a 3 month pilot programme, with the aim to make it easier for you to be more active, achieve your goals and make some positive connections. If you are younger than 16 but would still like to participate, talk to your Fieldworker – we will allow some flexibility on this.

We encourage everyone to get involved, its such a unique opportunity that we'd love as many Kiwis living with CF as possible, be supported in this way 

Full details, and information on how to register can be found [here >](#)



Cystic Fibrosis In The News

We'd like to say a big **THANK YOU** to those who have shared their CF story with the media recently. In case you missed any of these pieces, we have linked them below.

- We kicked off with a humbling and special story shared by OJ and his Mum, Trish, as part of THREE's The Hui. You can view that [here >](#)

- Paula Thompson, one of our amazing Sweat4CF Champions, was interviewed by the Timaru Herald, [here >](#)

- Two of our wonderful parents, Sarah and Dave, were the well deserving recipients of ASB's Good As Gold Award. These guys go above and beyond for their community, and we are so glad they've been recognised in this way. [Watch here >](#)

- Dylan Booth and Maisy Millwater were featured in the Otago Daily Times, with a different twist, CF in numbers. Read [here >](#)

- The beautiful Chantelle de Kort (another one of our Sweat4CF Champions!) shared her story with Stuff, [here >](#)

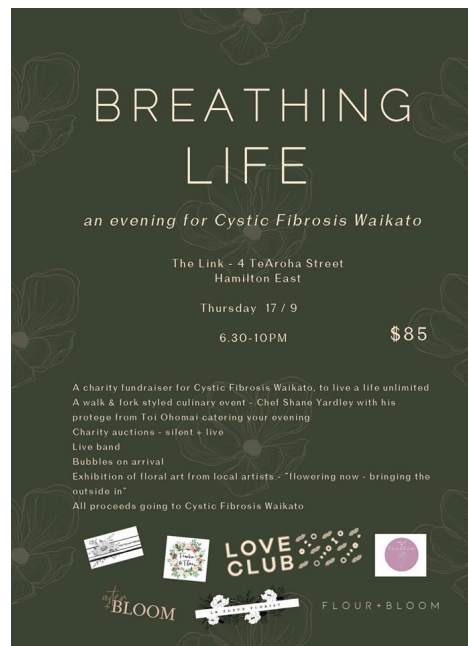
BREATHING LIFE

An Evening For CF Waikato

Together, Kelly Oliver and CFNZ Waikato, are holding an evening to fundraise for those in Waikato. The night will see a walk and fork style dining experience with top chefs, a silent and live auction, a live band, and much more.

Kelly was interviewed ([here](#)) by Stuff promoting the evening, and sharing the busy treatment regime people living with CF often have on their plates.

Find out more about the Breathing Life Event, [here >](#)



CFNZ Canterbury Branch Receives \$5,500 From Central South Island Charity Bike Ride

90 cyclists pedaled 385km over three days in February. from Timaru, to Tekapo, to Kurow and back!

A huge thank you to the participants for helping Kiwis with cystic fibrosis in the Canterbury region. Check out Canterbury Branch rep, Paula Thompson (in the red coat), collecting the giant cheque!

Read the full article [here >](#)



Mullet Growing Season A Success!

Mullet Over was a fundraiser for CF Waikato that kicked off on the 1st of November 2019 and finished on the 1st of May 2020 with heads being shaved. They raised a whopping \$4000!

A big thank you to those who put their hair on the line for CF 😊

Input Needed For Adult Wellbeing Guide

We're thrilled to have received a grant from the Health Promotion Agency/Te Hiringa Hauora to develop an Adult Wellbeing Guide ❤️

This guide is aimed at people with cystic fibrosis aged 15 and over and will include topics such as nutrition (including alcohol), travelling, mental and emotional wellbeing, exercise, sexual health and fertility/pregnancy/family planning.

We'll also use the guide to broaden our content for adults with CF on the website.

🗣️ Can you help? 🗣️

We need input from adults with CF to make sure this guide includes helpful, relevant information for New Zealanders.

We'd love to hear from you!

Find out full details [here >](#)

3D Printed Help For People With CFRD

A member of the community has been getting nifty with a 3D printer, and has worked his magic and created some holders for Dextro Glucose Tablets and Relion Glucose Tablets, which would be handy for those with CF related diabetes – a good way to keep the tablets together, and free from contamination in your bag or pocket! If you'd be interested in getting your hands one of these containers, please email comms@cfnz.org.nz and we take your order.



The containers would be around \$4-5 plus post.

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.

- Eastern & Central Community Trust for Fieldworker support
- Community Organisation Grants Scheme for salary support
- Mitsubishi New Zealand Ltd for a generous donation towards equipment

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

An Update From The Board

Our CF Adult rep on the Board, Alex, has reported back on their third scheduled meeting for 2020, but of course as we have navigated our way through COVID-19 as an organisation and as a community, the Board have met numerous additional times over the last four months.

In this update you'll read about the project of redefining and reinvigorating our core 'organisational values', how the organisation structure project is tracking, and more.

Read the full update [here >](#)



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