



Welcome To The May Panui!

Kia Ora <<First Name>>,

These last months will be etched in the history books as when the coronavirus took the world by storm, and in our hearts as the time we all realised again what is important to us.

We have also come to understand that home-schooling isn't for everyone, that baking cakes for 6 weeks solid now means we won't be able to fit out of our bubble (we have been exercising- yes, really), that the cat just recruited a slave to lead her to her bowl, and that the closet is the only quiet place for the Zoom meeting.

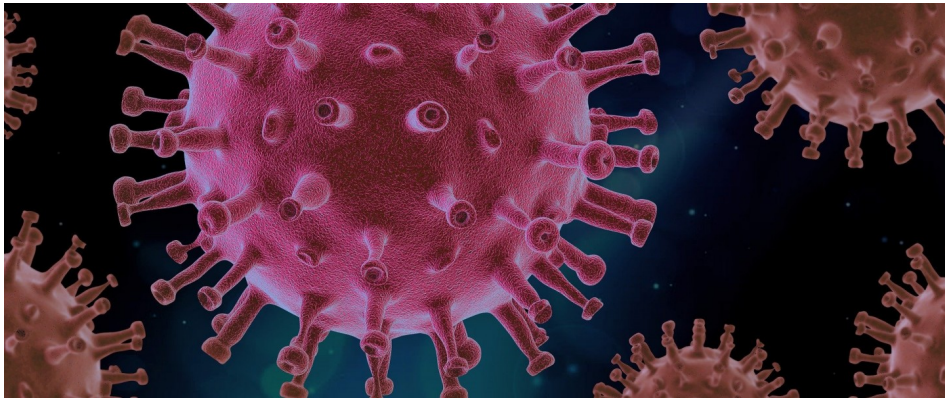
Despite these distractions, we bring to you this month's Panui – check out our wonderful compassion badges, the latest on advocacy, and the best hand sanitiser deal in town, plus lots more..

Also congratulations to Georgie Northcoat, our Mark Ashford Scholarship recipient. We raise our virtual glasses of bubbles to celebrate your success!

Cheers.

Jane Bollard
Chief Executive

**PS If The Layout Of This Email Doesn't Look Quite Right, Open
It In Your Browser For A Better View.**



COVID-19 Update

We're now in our second week of COVID-19 Alert Level 3 so we're working on some guidelines to help people with CF and their families plan for life during Alert Level 2.

The Ministry of Health is releasing more detailed Alert Level 2 guidelines on Thursday and we're talking with clinicians for specific recommendations and advice.

We'll keep you up-to-date on our [website](#) and [Facebook page](#) once we have more information.

[Read the rolling updates for the CF community](#)

[Read the COVID-19 Q&A](#)



Emergency Appeal Launched

The Coronavirus emergency has meant an increase in the demand for our welfare and mental health support, and the number of interventions carried out by our CF Fieldworkers has doubled. We are also entering the time of year when our usual support services are in highest demand.

We want to make sure that we can help every single person who needs us, but we

are facing tough choices. Last month we launched our [emergency appeal](#) – and have raised just shy of \$11,000! We are so grateful to each person who donated, big or small. Every donation really adds up to make a big difference for Kiwis with CF ❤️

We are aware this is a lot to ask at this time of national crisis, but now more than ever we really need you. If you can, please help support the CF community with a donation today: www.cfnz.org.nz/emergency-appeal/

Congratulations, Georgie!

We are delighted to announce the 2020 recipient of the Mark Ashford Scholarship - Georgie Northcoat.

After finishing her degree in December, Georgie is now pursuing postgraduate studies in ICT. Georgie is interested in new product development and innovation, and passionate about entrepreneurship and sustainability.

We are looking forward sharing more about Georgie and her achievements in the next CF News.



This Years Scholarship Is Made Possible Through A Generous Anonymous Donation

We are now looking for a sponsor for 2021 so we can continue to reward people living with cystic fibrosis, who show tenacity in overcoming the trials of their condition while studying.

Learn more about becoming a sponsor for the Mark Ashford Scholarship, [here >](#)

Advocacy Update

Advocating for people with CF still remains one of our top priorities, even during COVID-19.

Here is the latest advocacy update which includes information on CFNZ's engagements with both PHAMAC and Vertex, with the need for funding of Trikafta being top of discussion.

This update also covers the collaborative efforts with Patient Voice Aotearoa, focused on developing an action plan for the PHARMAC petition (which you can sign [here](#), if you haven't already!) And information about our letter of support to PHARMAC for the funding of Creon Micro.

[Read The Full Advocacy Update](#)

Compassion Pins

A reminder that we have these 'Compassion Pins' available for CFers, to help minimise situations where the persistent 'CF cough' is misunderstood. There's eight different badges with general messaging about CF, compromised immune systems, invisible conditions etc.

If you'd like a badge or two, please email comms@cfnz.org.nz with your name, address and which badge(s) you'd like.

[See the full list of Compassion Pins, here >](#)

Sign up and get shopping, here >



Raise A Glass To Support People With CF

We've teamed up with Winefunder.co.nz to bring you a fun little fundraiser – with wine! For every six bottles purchased, \$10 goes straight to CFNZ towards advocacy, support, information and research. There's a great selection of wines at a budget to suit all. Cheers to that!

Visit: www.winefunder.co.nz to purchase

Limited time only – ends 8 June 2020.

Thanks, Zoono!

The lovely people at Zoono who make hand sanitiser and surface sanitiser, have offered the CF community a 20% discount, using the code CFNZ20 at checkout.

Zoono Hand & Surface Sanitiser have been successfully tested against the COVID-19 surrogate at >99.99% effectiveness. Zoono lasts for up to 24 hours on skin, and up to 30 days on surfaces.

Shop the sanitisers online here: <https://zoono.co.nz/collections/shop-all>

Learn how Zoono works, here: <https://zoono.co.nz/>

Use the code CFNZ20
and receive

20% off ZOONO

Hand and Surface Sanitisers



ZOONO®

cf CYSTIC FIBROSIS NZ



COVID-19 Survey

There's a new Rare Barometer survey on rare disease patients' experience of COVID-19.

The results of this survey will enable us to measure how the virus is affecting rare disease patients' lives and give us the possibility to communicate facts and figures to decision-makers, so that people living with a rare disease are not left behind when handling the crisis.

The survey should take no longer than 15 minutes, and all responses are anonymous.

You can take the survey [here >](#)

[More info about the survey >](#)



Clinical Trial In NZ

We were excited to hear that Arrowhead Pharmaceuticals Inc. recently announced that it has filed an application in New Zealand to carry out a clinical trial of their therapeutic, ARO-ENaC, which utilises the company's exclusive technology.

ARO-ENaC has the potential to be a therapy regardless of the CF mutation present, which may prove useful in combination with existing or new CFTR-targeted therapies.

Read the full story and press release [here>](#)

Socially-Driven Design And CF

Matt Law, a fourth year Visual Communication student at Massey University, is basing his full year Honours project on CF and socially-driven design.

"I am looking at how socially-driven design can encourage people living with cystic fibrosis to pursue a more aspiration approach to self-management."

Matt has created a short questionnaire for people with CF. The results and comments collected will be used to help inform his project.

Read the full story and take the survey, [here >](#)

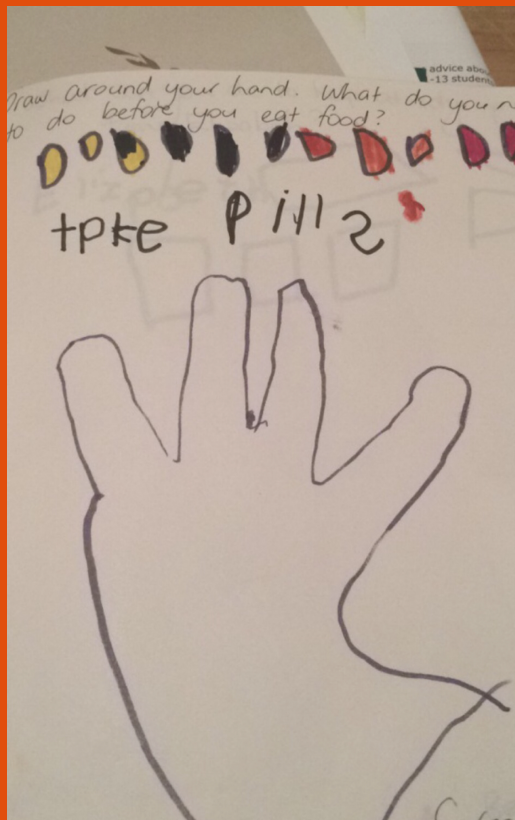
Drawing Challenge!

We all seem to have a little more time on our hands, and gaps to fill between remote learning lessons...

So, we want to challenge (CFers big and small!) to a little drawing competition! You could draw part of your daily routine e.g. pills, nebulisers, physio, exercise, the list goes on...

Send us a photo (comms@cfnz.org.nz) and we'll use them to show people a small part of what CF life includes.

I found this gem the other day from when I was at kindy... Creon taking was already well-ingrained! Pretty sure the answer was supposed to be 'wash your hands' - Lizzie



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.

- Robert & Barbara Stewart Charitable Trust, CERT, Central Lakes Trust and Rata Foundation – For South Island services
- Dragon Community Trust - Admin support
- Johnsonville Charitable Trust and Wellington Children's Foundation - For funding equipment
- Sir John Logan Campbell Residuary Estate - For Auckland Branch, funds towards parking vouchers

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



Get involved

Donate

To unsubscribe from this email please click [here](#)

www.cfnz.org.nz

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