



Welcome To The March Panui!

Kia Ora <<First Name>>,

Check out our March edition for some wonderful success stories from our CF community, both as individuals and together - go Kalydeco! We are so excited to see the change that the funding of this drug will make to the lives of our Kiwis with CF.

Also find some useful information on COVID - 19 and what we can do to limit its impact.

Take care out there,

Jane Bollard
Chief Executive.

COVID-19 Update For Our CF Community

On Friday 28 February the New Zealand Ministry of Health confirmed its first case of COVID-19 (novel coronavirus), followed by confirmation of additional cases.

This has prompted many questions from our CF community about the risk for people with cystic fibrosis and advice about staying well.

We encourage you to read our full update which answers CF related questions, and contains key information and basic hygiene tips, [here >](#)

The Ministry of Health is posting factual, NZ specific updates to their website, daily, [here >](#)

We will also publish any important updates for our CF community on our website and Facebook page.



On 26 February, PHARMAC announced their decision to fund Kalydeco for people with cystic fibrosis (G551D mutation) – a huge cause for celebration and a positive step forward for kiwis with CF.

As Kalydeco (ivacaftor) is yet to receive Medsafe approval and until Kalydeco is listed on the Pharmaceutical Schedule, PHARMAC has set up an easily navigable 'exceptional circumstances' application process from 1 March so that people who are eligible can access Kalydeco.

Read the full story [here >](#)



Meet Chani

We are delighted to welcome Chani Venter to the wonderful CFNZ Fieldworker team. Chani is based in Hamilton and is covering the Waikato and Bay of Plenty regions.

You'll get to know Chani a little more in the latest issue of the CF News. We are incredibly grateful to the Lighthouse Foundation for funding this role ❤️

Auckland Workshop To Inspire Empathy And Connection Open To CF Parents

A one-day taster workshop on the principles of Nonviolent Communication (NVC) is being hosted for the general public and parents in the CF community this April with proceeds going to CFNZ. NVC, sometimes known as Compassionate Communication, aims to strengthen our ability to inspire compassion and to respond compassionately to others as well as ourselves.

Facilitator Wayne, who has a 19-year-old son with CF, explained, “The communication skills gained from NVC have been such a huge support to us when it comes to supporting Ben on his journey that we have decided to offer this day to support others who may also be in a similar position to us”.

The workshop will be held on Saturday 4th April 2020, 8:45am – 5pm in Northcote, Auckland.

Read the full story and find event and ticket info, [here >](#)



Anahera's Amazing Award

Anahera recently completed year 8 at Breens Intermediate, and was awarded the values trophy for the student that most embodies BRAVE. Make the right choice, taking risks, kia kaha, know when to walk away, be humble and tell the truth. We are very proud of her achievements over the last few years and the amount she managed to fit into her busy days. It was lovely to have this recognised at prizegiving.

Anahera even recently spent a few weeks in hospital, her CF has been completely under the radar of her school peers and friends.

Well done Anahera, a well-deserved accolade ❤️



Optimistic On Orkambi

Australian mum, Sonia Marshall, whose daughter Evie has experienced spectacular improvements in her health since starting the CF medication 'Orkambi,' spoke at the CFNZ



Fair For Rare

Rare Disorders NZ launched their Fair for Rare campaign at Parliament on 28 February. Jane Bollard attended the event in support of RDNZ's call for recognition and awareness of

office in December 2019.

“Its life changing. There are no words, really. We are so incredibly lucky,” said Sonia.

You can watch Sonia’s inspiring talk, which included ways they advocated for the CF modulator drugs in Australia, on our website.

Read the full story and watch the video [here >](#)

the challenges faced by people with a rare disease, and for the development of a national framework.

“With 1 in 17 people living with a rare disorder RDNZ’s support is not only invaluable but vital”, says Jane.

Seen with Lisa Foster, RDNZ’s chief executive, at the event which also celebrated 20 years of support to families.

Read more about RDNZ’s Fair for Rare campaign [here >](#)

Talking About Research

Do You Know About Reporting Medicine Side Effects?

Medsafe is conducting a survey about reporting side effects to medicines, for New Zealand consumers and patients to complete. The aim of this survey is to explore how much you know about reporting side effects to medicines, and how you find out about how well a medicine works or its side effects.

The survey is open until Friday 24 April, and will take five to ten minutes to complete. Take the survey, [here >](#)

The Social And Economic Cost Of CF

We’d like to extend a big thank you to all who participated in our Cost of CF survey over the last couple of months. The responses are now with Deloitte and will be an important part of the report they are preparing. We are looking forward to seeing the results and to finally have evidence-based data available.



Tandem With Coffin In Tow

We are incredibly proud of our CF community members Camilla and Julian (www.rip.kiwi) for their epic tandem ride from Dunedin to Parliament, demanding for a PHARMAC funding boost.

CFNZ would like to express our sincere thanks and admiration to you both for putting yourself out there and for making such a statement to politicians and the NZ public on this important issue.

Read the full story and access all the media coverage [here >](#)

If you're yet to sign the petition to double the PHARMAC budget, you can do so, [here >](#)

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.

- Hutt Mana Charitable Trust for supporting the Hutt Valley area fieldworker service
- Mainland Foundation for funds towards operational costs in Christchurch
- Community Trust South and W. Duncan Bickley Trust fund for supporting the South Island fieldworker service
- Lion Foundation and Foundation North for significant support with operating costs

CF Awareness Week 2020

CF Awareness Week will be
10 – 16 August, with street collections taking



place on Friday 14th and Sat 15th.

We are always on the lookout for volunteers, street collectors, chocolate fish sales-people...

We'd love you to get involved!

Sign up on our website, [here >](#)

From The Board Table

The CFNZ Board had their first meeting for the year on Sunday 3 March, which followed a strategic day on the Saturday.

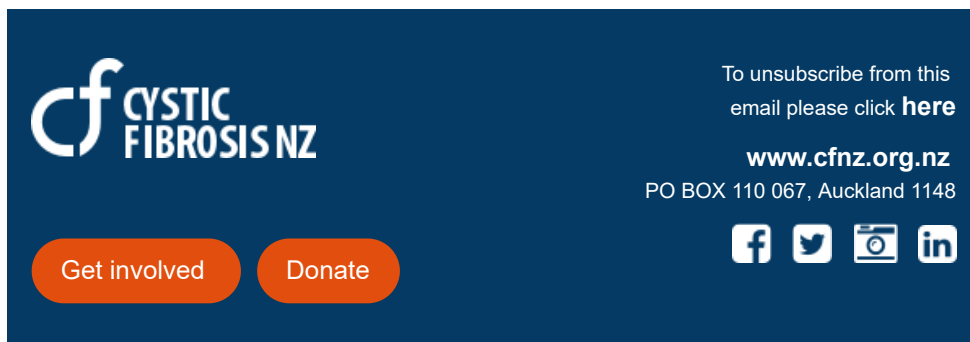
The latest update farewells two board members, introduces Andrew Cameron, acknowledges the exciting Kalydeco news and a look into the next phase of our advocacy plan. The update also includes information about the research being carried out by Deloitte about the cost of living with CF.

Read the full Board Update, [here >](#)

Keep An Eye Out For The CF News Magazine...

The summer issue of the CF News is on its way to a letterbox near you! Get in touch if you have any feedback, or would like to have your story featured in the next issue.

Email [Lizzie comms@cfnz.org.nz](mailto:Lizzie_comms@cfnz.org.nz)



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