CYSTIC
FIBROSIS NZ

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06/21

Welcome To The June Panui!

Kia Ora <<First Name>>,

Well, what an incredible month May was for cystic fibrosis awareness in New Zealand!

We'd like to say a huge, heartfelt thank you to all who shared their story with the media or on social media, those who held fundraisers, sold chocky fish, shook buckets during the street collection, those who wore their Give a F* t-shirts… We appreciate every single thing our wonderful community did to raise awareness and funds in the month of May.

In this issue of the Panui, you'll read about the success of CF Month, find out how to purchase / sell raffle tickets, see and add to our Trikafta Wall of Wishes, and read about some cool community fundraisers.

We've included a detailed advocacy update covering the Pharmac funding announcement, Pharmac review, and the Medicines Landscape. We also shine a light on what CFNZ Taranaki is doing to promote the Trikafta Campaign.

Thanks again for your support during May – lets have a fab June!

Stay warm,

CFNZ Team

New Zealand Gives A Future For Kiwis With CF

How awesome was May?! If you missed it, CFNZ took over May with the CF Month “Give a Future” appeal, shining a light on life with CF, access to medications, daily treatment and more.

Thanks to the wonderful CFers and their families who put their hand up to be interviewed we managed a phenomenal amount of TV, radio, newspaper, and online coverage, helping to raise awareness and educate the NZ public about CF. You can view / read the iincredible coverage by scrolling to 'Campaign Feed' here >

As a result, almost 71% of the people on the CFNZ website during May were new visitors, with What is CF, Trikafta advocacy, CF care, and CF Genetics being the most popular pages for new visitors.

The NZ public responded by donating over $45,000 via the CFNZ website and ‘Give a Future’ appeal page. T-shirt sales and community fundraisers raised a further $15,000 and continues to grow.

A huge thank you too to the volunteers who gave a few hours at our street collections in Auckland, Wellington, and Christchurch. The amount raised at street collections is being finalised and is not included in the above totals.

We are incredibly grateful for the support shown for the CF cause and CF Month this year. If you would like to give a few bucks to the campaign (it all helps!) visit www.giveafuture.org.nz, or text the word FUTURE to 4462 to make a $3 donation.

CF Raffle – It’s A Win-Win!

Tickets for the CF Raffle 2021 are selling like hot cakes… email laura@cfnz.org.nz to buy tickets or request tickets to sell if you haven't done so already. Each ticket puts you in to win one of 33 great prizes and raises funds to help give a brighter future for Kiwis with CF.

Visit www.cfnz.org.nz/raffle for more information.

Advocacy Update

Since the last edition of Panui there have been some significant ups and downs in the campaign for Trikafta for Kiwis with CF.

A major up has been CF Awareness Month - a success with coverage on TV and in media across the country. Thank you to all of those who shared their stories and made sure that CF and the urgent need for Trikafta remains a high-profile issue.

Tales of Trikafta from Taranaki

The awareness and fund-raising effort by the Taranaki Branch of Cystic Fibrosis NZ is just one example of the enormous effort that the CF community is putting into this campaign. They organised a sold-out movie night and put together an amazing booklet, Tales of Trikafta from Taranaki, that tells the stories of CF in the region. They achieved media coverage, support from local MPs, and 11-year-old Brett Holdcroft made the front page telling his CF story to Stuff.
The Taranaki Branch's booklet provides an extremely useful resource for everyone involved in raising awareness of CF and the urgent need for Trikafta and can be found here >

Pharmac Funding

A major down came with announcement of Pharmac funding, which saw $200 million allocated over 4 years with only $40 million for next year. In making this decision, the Government ignored the 100,000 people who signed Patient Voice Aotearoa's petition to double the Pharmac budget, and Pharmac's own advice that it needed $420 million just to catch up let alone fund new medicines coming through the system. A deeply disappointing decision.

Medicines Landscape 2020/21

Analysis Aotearoa spent only 5 per cent of its health budget on medicines compared with 12 per cent in the UK and 15 per cent in Australia.
You can read more about access to medicines in New Zealand here >

Pharmac Review

The Prime Minister Jacinda Ardern responded to criticism of Pharmac's funding allocation as part of an interview with The Hui concerning CF and access to

Trikafta (watch here >) The PM advised that the current review of Pharmac will address how new medicines for smaller groups and rare disorders should be provided.
However, the requirement for this to be dealt with is not clear in the Terms of Refence for the Review and Cystic Fibrosis NZ will be seeking formal confirmation that this issue will be addressed. Cystic Fibrosis NZ has already had an initial meeting with the Chair of the Review Panel, Sue Chetwin, and will be attending a workshop with medical charities and the wider Panel on 25 June to discuss this and other key issues. An interim paper is due in August and there will be the opportunity for written submissions prior to the final report in December.

CF Modulators in New Zealand
As advised in the last Panui, Vertex has submitted its application to Medsafe for approval of Symdeko, with applications for the remaining two CF modulators yet to follow.

Pharmac and Medsafe have indicated that they will consider the application for the triple therapy combination (registered as Trikafta in Australia) at the same time. While Medsafe will assess the safety and efficacy of the medicine, Pharmac will assess the case for public funding. Pharmac’s assessment includes review by expert advisory committees, an economic assessment and comparison with, and ranking against, other medicines using its Factors for Consideration decision-making framework. Final approval by Pharmac is subject to funding availability.

Trikafta in Australia
There is no word yet on when Trikafta will be listed on the Pharmaceutical Benefits Schedule in Australia. The listing was not declined but was deferred in late April to enable further engagement with Vertex over a number of issues.

Are You On Kalydeco?

As part of the campaign for Trikafta in New Zealand, we are collating stories about the positive impacts that Kalydeco and Trikafta have had on those Kiwis lucky enough to be receiving these life-changing treatments.

We would love to hear from willing members of the community who are taking Kalydeco / Trikafta about how things have changed for them, and the impact that the treatment has had on their day to day life, physically and mentally.

This information won’t be shared publicly. Contact us if you’d like more detail on how this will be used.

If you are happy to share your story and be involved, can you please email Lizzie comms@cfnz.org.nz

Food Worth Making II - Sam Mannering

We are pleased to share that CFNZ is the charitable partner for Sam Mannering's new cookbook: **Food Worth Making Volume II**. This means that $5 per book will go to CFNZ with a goal of $25,000 by Christmas. Sam is looking to do an initial print run of 5000 copies, arriving in September, with hopefully as many of them presold as possible.

Sam is an Auckland-based food writer and mostly writes for Stuff, with a weekly food column in the Sunday Star Times. He also owns the Homestead Café at Pah Homestead in Hillsborough.
If you'd like to grab yourself a copy, and support CFNZ at the same time, pre-sales are here >

We're On The Lookout For SWEATY Champions!

Last year we ran our first ever SWEATEMBER campaign and raised a whopping $130k to support and advocate for the CF community. We're on the lookout for new SWEATY Champions for this years' campaign… CFers, mums, dads, grandparents, friends, supporters, of all ages…

Send an email to comms@cfnz.org.nz to express interest.
Check out last years' champions www.sweat4cf.org.nz/champions

For the last week of CF Month “Give a Future” appeal we raised awareness of the real lives being impacted by Aotearoa’s lack of access to modern medications. We built the 'Trikafta Wall of Wishes.'

View the Wall of Wishes here >

Help grow our Wall of Wishes by emailing your photo and wish to Lizzie at comms@cfnz.org.nz

Thanks to those who have already added their wishes to the wall 💙

Friendly Reminder About Breath4CF

Breath4CF is a physical activity grant aimed at promoting exercise for Kiwis with CF. The applications close on **25 June 2021**.

To apply for a Breath4CF grant please fill out the application form and provide either a receipt as proof of your purchase, or an invoice to be paid.
Find the application form here >

Thank You Marineland Street Rod And Kustom Klub!

As part of Hawkes Bay’s Awareness Month activities the Marineland Street Rod and Kustom Klub came to visit Amber’s grandfather’s car collection. They donated $1,000 and Amber’s mum, Claire, got to educate a relatively large group of people about life with CF and the CF community’s desire to get Trikafta available in NZ. Members of the HB Vintage Car Club also recently had a similar experience and donated $275. Claire has followed up with both clubs, asking them to send out the Trikafta Petition to their members.

We all have different avenues that we can use to fundraise and create awareness of CF. It is great to see so many people with CF and their families throughout NZ using their strengths and opportunities to share their stories during Awareness Month.

Drink Beer, Do Good!

For the month of June Shining Peak Brewing in Taranaki are raising their glasses and contributing their 5% Project funds to CFNZ Taranaki.
Read more here >

Head along to Shining Peak Brewing for a brew or two this month! 🍻

To coincide with supporting CFNZ Taranaki, they're proud to be a sponsor of Shane Kidby and his Walking with Wings challenge where he's aiming to walk 15,000km of Aotearoa's coastline to raise funds and awareness for Cystic Fibrosis and mental health.

Thanks Shining Peak Brewing! 🤍

CF Gastro Survey

A team of researchers in Christchurch are running a brief survey study called: *"Gastroenterology services within Cystic Fibrosis Clinics across New Zealand".* If you are an adult with CF, or carer of an adult or child with CF, they would be interested in what you think on this subject. They are exploring the provision of Gastroenterology services to CF Clinics across New Zealand. They aim to identify any issues or gaps and use this to advocate for future service planning.

The survey it takes about five minutes to complete. Please take the time to click on the link below and read the information sheet.
For more info, and to take the survey, click here >

Many thanks from the research team:
Dr Angharad Hurley (Researcher) and Professor Andrew Day

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.

- The Lighthouse Foundation and Air Rescue Services Ltd for supporting our Fieldworker service and CFNZ operations,
- Milestone Foundation and David Ellison Charitable Trust for operating costs,
- Wellington Children's Foundation for equipment.

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

Thank you for helping Kiwis with
CF to live a life unlimited.

www.cfnz.org.nz
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Get involved Donate