



Welcome To The September Panui!

Kia Ora <<First Name>>,

In August, Eddie Porter (Kalydeco for Kiwis) launched a petition for the funding of Kalydeco for kiwis living with cystic fibrosis with the G551D mutation. We urge you to support this campaign, along with Malcolm Mulholland's petition for Pharmac's budget to be doubled.

August also saw a very exciting CF Week! Read all about the success of the Give a F* for CF campaign, and view the stories that were generously shared by families in our community throughout the month.

All the best for September,

Jane Bollard
Chief Executive

We Need Your Signature!

Our very own Eddie Porter launched a petition to get Kalydeco publicly funded for those with G551D Cystic Fibrosis. Malcolm Mulholland has also started a petition asking for Pharmac's budget to double.

Please add your voice to these two important campaigns by signing the online petitions, and please share them far and wide and encourage your family and friends to sign as well.

Head over to our website to read more about Kalydeco, and the petition, [here >](#)

Sign The Kalydeco Petition, [Here >](#)

Sign The Pharmac Petition, [Here >](#)



New Zealand Gives A F* For CF

Wow – a huge thank you to all those who gave a Few hours, a Few bucks, a Future, Full life, Fighting chance.... etc etc last month!

If you missed it, we asked the public to Give a F* for CF with a tongue-in-cheek campaign for our 2019 Annual Appeal. Activity included digital advertising, a giant billboard in New Zealand's most coveted positions, billposters across Auckland and Christchurch, Facebook activity, and street collections across the country. There was definitely a 'buzz' with lots of conversation and news coverage raising awareness of CF.

The CFNZ website had 43.5% more visitors this CF Week compared with last year, with many of these being new visitors. This also translated into an increase in donations, with several new regular gift sign ups and new donors. We thank them from the bottom of our hearts for giving a better future for people with CF.

A huge thank you to all the volunteers who participated, whether it was a few hours collecting, helping to organise the collection, recruiting volunteers, selling chocolate fish, sharing your story, running their own fundraisers etc... it all makes a big difference.

CF Week 2020 runs from 17 – 23 August, with collections on the 21st and 22nd. Sign up to volunteer [here](#) >

Don't forget, you can still text FUTURE to 4462 to make a \$3 donation or visit cfnz.org.nz to sign up as a regular donor or make a one-off donation.



CF In The Media

CF gained great coverage in the media, over Awareness Week and the lead up. We are very grateful for those who shared their experiences of life with CF. Catch up on all the stories below.

Read Tony Stewart's story, [here >](#)
Read Tailen's story [here >](#)
Read Trudy's story, [here >](#)
See Hayden and Pip on Breakfast, [here >](#)
Listen to Georgie on The Hits Dunedin, [here >](#)
Listen to Pip on More FM Rodney, [here >](#)
Read Makena's story, [here >](#)
Read Hanna Meates' story, [here >](#)
Read Lisa's story, [here >](#)

If you'd like to share your story in the future, email Lizzie at comms@cfnz.org.nz.

A Big Thank You To Our CF Week Sponsors

Mylan, EBOS Healthcare and PARI all generously sponsored CF Week 2019, helping to cover the costs of promotional material, information leaflets, and campaign costs in our effort to raise awareness and funds. Thanks ever so much for your commitment to CFNZ and the CF community!



Straight From The Lungs – Podcast Review

Are you into podcasts? CFNZ's Information Coordinator, Sarah Cahill, stumbled a podcast by 24 year old CFer, William Marler. Based in the UK, William has been working on a 14 episode podcast. Each episode focuses on

I was going to be
so much to that dude.

I was the first
to have child
still a day later

start list
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end of
mber
get
heart list

she was a brave, inspirational
little warrior. If you think the
world's against you, just think
about Elle and how she got on
with it. She had everything
against her, but she still
embraced life and enjoyed it.

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back

**straight from
the lungs**

a cystic fibrosis podcast

missed someone to hear that must
but I actually have been less
all the activities I need to take

I climbed Mount Everest

one CF-related topic, featuring different people of different ages, health professionals, friends and family. [Read Sarah's review](#), have a listen yourself, and let us know what you think! Do you know of any other podcasts focusing on life with CF? We'd love to know about it.



Christmas Tree Festival

The Christmas Tree Festival held at Wellington Airport is back for 2019! Are you interested in promoting your brand/organization, or know anyone who would? From 26 November – 6 January, you can light up a Christmas Tree with your business-branded decorations, and support kiwis living with CF, at the same time. You'd be showcasing your brand to up to 20,000 potential customers each day. Keen to [learn more?](#)



Casino Night Success

The sixth annual Hawke's Bay Casino Night was held on 24th August. This year the theme was Masquerade; many masks were donned, and a fabulous time was had. Guest speaker, Nick Laing also shared his experience of life with CF. A bit of gambling, eating and auctioning, what more could you want! Read more about the evening, including auction items, and a few more photos, [here >](#)

Raffle Results

We saw great success with the Winter Raffle Appeal this year, raising over \$16,000!

A massive thank you to all who bought and sold tickets, and especially thanks to our sponsors who donated prizes.

Noel Leeming | AIG | Choice Hotel Asia-Pac | EBOS Healthcare | Bike Barn | Dilmah | OurEco Clean | Burger King

View the winning tickets, [here >](#)



Get Your Scripts Delivered To Your Door

ZOOM Pharmacy is a nationwide service that delivers your prescription medicines direct to you, and coordinates your repeats before you run out. They're a NZ trained pharmacy team aiming to improve medicine adherence. They've got a great app to coordinate your scripts and repeats, and you can also set up a daily reminder to take your meds. If apps aren't your thing, just give them a call or drop them an email.

All patients need to do next time they are sitting at home or work, and about to organise their repeat prescriptions, call their GP clinic, and ask the receptionist or nurse to fax their prescription to ZOOM Pharmacy. It's as simple as that.

Added bonus, your first delivery is FREE!
Find out more, [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.

Community Trust of Mid & South Canterbury | COGS | Central Lakes Trust | Eastern & Central Community Trust | Milestone Foundation | Four Regions Trust

A Note From The Board

During the latest board meeting in August, we welcomed two new members, Rachel Harris, an independent director, and Jaggar Bootten, a third year med school student.

We covered many aspects which included: what the next twelve months will look like for the board, the agenda for the up-coming Chairs Conference and AGM, and a great report on CF Awareness Week from the Chief Executive and Marketing and Fundraising team.

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



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