



Welcome To The October Panui!

Kia Ora <<First Name>>,

Last month the Chairperson's Conference and CFNZ AGM was held in Christchurch and was a great success.

A main discussion point was around the petition Malcolm Mulholland launched, asking for an external reform of Pharmac and to double the budget Pharmac currently receives. We have since put a strategy in place around gaining as many signatures as we can, hoping to push the current total from just over 10,600 to 25,000.

We weould really appreciate you adding your voice by signing the petition and sharing it far and wide. You can learn more about it below and on our website.

Wishing you a happy and healthy October,

Jane Bollard Chief Executive

Help get life changing medicines funded in NZ

The funding of critical medicine to enable people to live long and prosperous lives is something that should concern all of us. We want NZ to be a place where people who need it can access life-saving medications.

Funding for medicine is just 5% of the NZ health budget, compared to the OECD average of 16%. Kiwis are missing out on life-saving medications, including those

living with CF.

Please help by signing the below petition (share it with your network, friends and families) and let the government hear your voice \Box

Sign Pharmac Petition Here

If you'd like a printable document to collect written signatures, email comms@cfnz.org.nz and we will send it through.
You can find more about this petition and how you can help, here >

Update From The Conference

The branch Chairperson's Conference and CFNZ's AGM took place in Christchurch last month. While the weather wasn't the warmest for the soft Northerners, the welcome from hospitable Cantabrians certainly was. A big thanks to Melissa and her team for playing host. The sessions were a mix of presentations, facilitated discussions on key issues and of course, the formal AGM. You can read a full update and main take-aways from the weekend from our newly appointed Chair of the CFNZ Board, Warwick Murray, here >

Meet Alex, Our New Adult Rep On The CFNZ Board

We are very excited to introduce our newly appointed CF adult representative on the CFNZ Board, Alex McKay. Alex works as a management consultant, he's a keen golfer, and has perfected the art of espresso martini making.

We are very lucky to have Alex on board, with some great skills, and experience both in the business world, and of course life with CF.

Read more about Alex, and his role on the Board, here >





Good In The Hood

September was Z Energy's Good in the Hood month, where each station across the country gives \$4,000 to neighbourhood groups in need.

We managed to get a spot in several Z Energy stations, and we wait in anticipation for results! Thank you to those who have supported by visiting and dropping your tokens CF's way!



Sponsor A Christmas Tree!

Do you have a business, or know one that would love some exposure over the silly season? Well, what a coincidence! The Christmas Tree Festival held at Wellington Airport is back for 2019. Sponsor a Christmas Tree, decorate it with your branding, and have a potential 20,000 people see it every day. Find out how to get involved, here >

KILT - Get Your Totes!

We were so pleased to find out that CFNZ will be the lucky recipients of the proceeds for October sales of NZ designer store Kilt's, Tote Bags - thanks to all your votes!

These are \$15 each in-store or \$5 with any purchase in-store or online. Head over to their website, here >

Would make for a great little Christmas present!

Thank you Kilt, for running such a kind promotion.



Research Update

How Do You Clean Your Nebs?

Members of the Cystic Fibrosis NZ Otago Branch and the University of Otago are undertaking a survey to learn more about the types of nebulisers used by people

with cystic fibrosis for inhaling antibiotics, and how those nebulisers are cleaned after use. This will help in their research that aims to inform best practice guidelines for the CF community about safe and appropriate disposal of nebulised antibiotic residue, to minimise the chance of creating antibiotic resistant bacteria in the environment.

We'd love for any nebuliser users, or parents of children who nebulise antibiotics, to read through the information on our website, and take the survey, here >

CF Research Questions

We are keen to hear what you think are the most important research questions when it comes to Cystic Fibrosis.

As a starting point, we would appreciate if you could fill in a simple 4 question survey. It will ask you to identify top 10 questions that you believe should be researched to provide answers which can be translated into reducing the biggest/ most important challenges you face as the CF community. You can be as specific or as broad as you like.

The survey is anonymous, and all responses will be reviewed by the Research Development Manager at CFNZ who will analyse and consolidate the answers. These will then be used to create a second Prioritisation Survey to allow you to prioritise the top questions.

To begin the survey, please click here > Help us reach everyone by sharing the link with your family and friends. Thank you!



31 Times In 31 Days

For the month of October, Hannah, Hutch, Aaron and Chelsey are going to walk (climb!) up Puketapu every day to help raise awareness for CF and fundraise for Breath4CF for those living with CF in Otago. Hannah and Hutch have two daughters, Sophie and Lucy. Sophie lives with CF. They've shared their view of life with a child with CF, and exactly why they were inspired to fundraise and exercise, at the same time.

Read more here >

Check out their Facebook page for updates here >

Have you got a great fundraising idea like Hannah and Hutch, or want us to think one up? Get in touch and we can help you with exactly that, and support you the whole way.

Advocacy

In the last 12 months, Pharmac called for submissions regarding managing fairer access to hospital medical devices. CFNZ provided feedback from a CF perspective, in support of Pharmac managing the funding and supply of medical devices. We were one of three patient groups to do so.

Pharmac are considering all feedback received during this consultation period as they determine the next steps. We will keep you updated with any decisions made.

You can read the feedback summary, here >





The great people at CLM The Bays, introduced to us by Jamie Archibold, have a cool event happening on the 1st November. They'll be running 24 gym classes in 24 hours, supporting kiwis with Cystic Fibrosis. We are on the lookout for businesses to sponsor each hour, at \$100 each. If you sponsor a class, your business will be welcome to hand out flyers, have promotional material at the gym and on their TVs. If this sounds like something you'd like to be involved in, please get in touch! Email comms@cfnz.org.nz



Canterbury Golf Tournament

The Annual CF Canterbury Branch Charity
Golf Tournament is back for 2019! Held at
Templeton Golf Club, teams of 4, \$140 per
team on 1st November.
Want to enter a team for this Ambrose event,
or donate a prize for the players?
Get in touch with Nicky on 021 515 767 or
doug.nick@orcon.net.nz.
Spaces are limited!





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