



## Welcome To The July CF Panui!

Kia ora,

This issue of the Panui contains important information around our recently updated cross infection policy, which we urge all families to be aware of, news about what we are getting up to advocacy-wise, an update on the success of the Winter Raffle Appeal so far, a thank you to our volunteers, and a shout out to our Instagram star, Georgie Northcoat.

We are pleased to be helping with a study on the needs of siblings of children with CF, and one on the impact having a complex medical condition has on social relationships. We'd appreciate your contribution to these studies by, where appropriate, taking the short, anonymous surveys linked below. We are excited to be supporting both studies as part of our commitment to research and working towards a better quality of life for people with CF and their families.

This time next month we will be gearing up for a busy and exciting CF Awareness Week!

Arohanui,

Jane Bollard  
Chief Executive

---

## Cross Infection Policy Update

With help from its Clinical Advisory Panel, CFNZ has released revised guidelines on infection prevention and control in non-healthcare settings. The position statement is designed to educate people with CF, their caregivers and families about the risks of person-to-person infection from respiratory pathogens of any kind. The statement outlines general hygiene guidelines for people with CF, as well as particular policies relating to households, schools, workplaces, sports, pools, gardening, pets and animals, and events organised by CFNZ.

Read more, including the key elements of the new policy [here >](#)

---

## It's Survey Time!



### Sibling Survey

Are you 16+ years old, have a sibling, or someone like a sibling to you (cousin, whāngai) who was diagnosed with cystic fibrosis at least one year ago, and were living with them when they were diagnosed?

We'd love you to take part in this survey (run by Katie Armstrong through Massey University) which aims to figure out how needs of siblings of kids with cf can be met. The results will be valuable in the development of services which protect the wellbeing of healthy siblings.

Click [here](#) to take the survey, or for more info.



### Keeping Socially Connected, With CF, Survey

A research team at Auckland University of Technology is exploring the impact having a complex medical condition has on social relationships.

Have you: got CF, are aged between 18 and 65 years old, and live in NZ?

If the answer is yes to all of those, you could be the perfect participant for this anonymous online survey.

Your involvement in these surveys is a huge help and is very much appreciated.

The survey will be open until 11th August.

Take the survey, [here](#).

---

## CF Awareness Week

CF Awareness Week is fast approaching! Held every year in August (12<sup>th</sup> – 18<sup>th</sup>), we aim to build awareness around CF, what it is and how it affects people. Several events are held around the country, and we encourage you to get involved too! If you'd like to chip in, hold an event, do some fundraising, check out our fundraising page, [here](#), or contact your local branch. We are always looking for volunteers to help out with our street collection too.

For general fundraising enquiries or to order promotional material, contact Laura at [laura@cfnz.co.nz](mailto:laura@cfnz.co.nz).

# Keen To Volunteer For CFNZ?

[Sign up here >](#)

---

## Winter Raffle Appeal Update

The raffle is in full swing, with only a few weeks to go! We've had a fantastic response this year, raising well over half of our goal of \$20,000 already. A big thank you to our CF community for yet again, getting behind this appeal, with some of you ordering books, selling them and ordering more! Thank you also to our corporate sponsors for donating some really great prizes.

To buy your raffle tickets, download an [order form](#), fill it in and post it back to us with details of your payment. If you'd like to help us reach more people by selling tickets to friends, family and colleagues, please send your request to [laura@cfnz.org.nz](mailto:laura@cfnz.org.nz) and we'll send you out your requested number of books to sell. You can either pay for the books upfront or pay after you've sold them. For more info, visit [www.cfnz.org.nz/raffle](http://www.cfnz.org.nz/raffle). Good luck!



---

## Advocacy

### Equipment

In June and July last year, CFNZ advised DHBs of our intent to exit the supply of vital equipment for people with CF ie nebuliser compressors. We are now following up with each DHB to ensure they have acknowledged this, and understand the role they will now be playing and that they are ready to take on equipment supply.

At our discretion, CFNZ may continue to fundraise for equipment not supplied by DHBs, or where DHBs provide limited or no access to equipment that enhances treatment and quality of life.

We were recently asked to submit feedback to Pharmac about them managing devices, this submission has been entered. Our submission stated that we supported the move to ensure equity of access to devices across New Zealand but expressed concerns around the limit of funding, the lack of consumer representation in the process and Pharmac criteria not usually meeting the needs of rare disorders. We also identified the need to ensure that if a medication is funded the equipment to administer it is also funded.

## Ministry Of Education

We have written to the Minister of Education and the Ministry identifying the health and safety risk around having more than one child with CF attending each school and the need to have a strict management plan in place. So they are well aware of the risks, we have sent them the new informational guidelines around cross infection developed by CAP (find our cross infection position statement [here >](#)) and our [Guide to cystic fibrosis for primary schools and teachers](#). We are happy to write letters to individual schools as well.

## Work And Income NZ

Feedback from our CFNZ Adult interviews conducted last year showed a struggle that many adults with CF face, is dealing with WINZ. We are meeting with the Carmel Sepuloni, Minister of Social Development, this week to identify these concerns and see how we can work together to improve WINZ interactions for people with CF.

## A Better Model For Funding Medications?

Jane, Chief Executive CFNZ, recently went to a seminar to hear Sir Andrew Dillon, CEO of the UK drug agency NICE, speak. They have an impressive model with regard to getting medicines funded. NICE have no waiting list, approve more than 80% of the applications to fund new medicine, and they do this all very quickly, with an aim of getting a signal out the door within 90 days. You can listen to Sir Andrew's very interesting chat with Guyon Espiner, [here >](#)



## Mask Up For CF

Hawke's Bay friends, SAVE THE DATE for the annual Casino Night Fundraiser. Date: 24 August. This year's theme is Masquerade, so don your best mask, and join us for a fun evening supporting the Hawke's Bay branch. Keep an eye on our facebook page or website for ticketing details, coming soon.



## Got Instagram? So Do We!

Meet Georgie, living and studying in Dunedin, and in her spare time, showering our CFNZ Instagram account with all sorts of inspiration and daily CF happenings.

Follow us over at @cysticfibrosisnz to watch Georgie's day-in-the-life stories and her own life and cf updates.

Make sure you tag #CFNZ so we can see what you're up to, and feature you on our account too!

## Thank You, Volunteers

June saw National Volunteer Week, which was a timely reminder for us to express our absolute gratitude for our amazing volunteers. You're all over the country, and we couldn't do what we do, without you. Although you've got this dedicated time in the spotlight, we don't just appreciate you for a week, we appreciate all you do, every day.

Thank you!

---

# Research Update

## The Social And Economic Cost Of CF

We are halfway there, but another \$50,000 is needed for CFNZ to be able to go ahead with a major study into the social and economic impact of cystic fibrosis. This research could see significant changes required for CF management in the health and education systems, and would be a useful tool in CFNZ's advocacy for new drugs, healthcare provision and support services to improve the lives of everyone with CF.

"It's a significant and valuable piece of work for us that represents an investment in the future of our community".

We are looking for more funders and donors so that we can get started with this research. If you'd like to hear more information, or find out how your contribution could help, please contact Jane at [ceo@cfnz.org.nz](mailto:ceo@cfnz.org.nz).



## Hawke's Bay Concert Supports CFNZ

A memorial concert for Byron Middleton aka “DJ Byza” is being held at Smiths & Aroha in Napier on Saturday 20<sup>th</sup> July. Headlined by Tropical Downbeat Orchestra, a fun loving family with a passion for music, and featuring Byron’s good friends, Paul Lowe and Joe Bicknell with an all acoustic set, it is a guaranteed great night, with \$2 of each ticket purchase, going to CFNZ. For the full story and ticket details, [click here >](#)

---

## Meet The Sponsors



### Streetwise Coffee

Introducing Streetwise Coffee, one of our wonderful corporate sponsors.

Streetwise Coffee are well known for making exceptional takeaway coffee, day in and day out. Ethically sourced Havana coffee beans, outstanding service and genuinely recyclable coffee cups means Streetwise Coffee is quickly growing to become New Zealand’s most recognised takeaway coffee brand.

What is not so well known is their ongoing support for Cystic Fibrosis. For years they have promoted CF Awareness Week by decorating their coffee carts, donning t-shirts and donating all profits from the sale of chocolate fish back to Cystic Fibrosis. And this year will be no different, with 22 carts nationwide selling custom-made scented car fresheners, they hope to raise even more funds for our worthy cause. They’re open as early as 5am, 7 days a week, so if you don’t already get your coffee fix from a locally owned coffee company, check them out!

A big thank you to Luke, Stace and the team at Streetwise Coffee, for your ongoing support of CFNZ. We look forward to seeing your decorated carts in August!

### OurEco Home

We’d like to introduce you to another one of our fabulous corporate sponsors, OurEco Home.

OurEco Home is in the business of handmade cleaning products, without any nasty chemicals, and is owned and operated right here in NZ.

If you shop on their online store ([www.ourecohome.co.nz](http://www.ourecohome.co.nz)), and use the code CFNZ2015, 15% of the value of your order will be donated to CFNZ. Thanks,

## OurEco Home!

Owner, Sarah Fisher talks about how OurEco Home began, and how their products have benefited her family, [here >](#)

---



### Support From London

We were delighted when we heard that Crystal Banks, who is living in London, chose to get in the ring to support CFNZ. Crystal's sister Tiffany's partner Chris lives with CF and underwent a lung transplant last November. "Tiffany and Chris received incredible support from Cystic Fibrosis New Zealand including regular contact with the fieldworkers, grocery vouchers and lots of other practical support. Chris is now working and goes to the gym, I'm incredibly happy for them both." Thanks to her hard work, determination, and the support of friends and family, Crystal managed to raise \$3000 for CFNZ! We are so very grateful.

[Read full story >](#)

---



### Chocolate Fish Champ

Christchurch chocolate fish champ, Tyler Yorke-Thompson (brother of Ayden) recently spent his Sunday raising money for the CF Canterbury Branch. He expertly devised a plan, made a sign and set up a stall outside his house and managed to sell a whopping 200 chocolate fish! He even received an \$80 donation from a man who had driven by in the morning and saw him still sitting there in the afternoon. That is dedication right there. Thank you, Tyler, for your hard work – we might have to get some hot chocolate-fish-selling tips from you! Think you could sell as well as Tyler? Get in touch with your local branch for more chocolate fish related information!

---



## CF News

Keep an eye on your letterbox because the latest edition of the CF News will be on its way to you soon.

## Need More Information?

Visit the CFNZ website for latest news, resources, information, apply for grants, find contact details and more. Go to [www.cfnz.org.nz](http://www.cfnz.org.nz) >



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

[www.cfnz.org.nz](http://www.cfnz.org.nz)

PO BOX 110 067, Auckland 1148

Get involved

Donate



This email was sent to [comms@cfnz.org.nz](mailto:comms@cfnz.org.nz)

[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)

Cystic Fibrosis New Zealand · PO Box 110067 · Suite 2 79 Grafton Road · Auckland, 1010 · New Zealand

