



## It's CF Awareness Month!

This August we're asking the public to 'Give a F--\* for CF' by donating to the Cystic Fibrosis annual appeal, which officially runs from 12 - 18 August 2019, including street collections on the Friday and Saturday.

There is some tongue-in-cheek humour to it, and we believe in this day and age, more so than genuine offence. In fact, when we pair the 'F' to a genuine way of helping (funding, few hours of volunteer time etc) it actually removes the power of the 'F word' as a swear and replaces it with an act of generosity.

Each 'F' allows us to highlight an aspect of what it means to live with cystic fibrosis, educating people about the condition and the work that CFNZ does. A digital, social and out of home advertising campaign will support the usual street appeal to spread the word and fundraising resources are now available. There are several ways you can get involved:

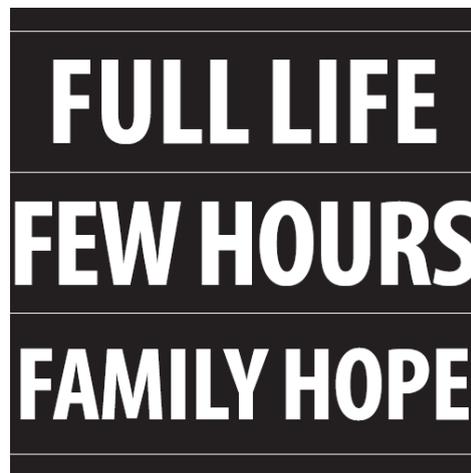
- Sign up to volunteer in the street collections or sell chocolate fish [here >](#)
- Get fundraising materials ([here >](#)) and host a fundraiser
- Text the word 'FUTURE' to 4462 to make a \$3 donation
- Donate online or pop some money into the collector's buckets when you see them!

Visit [cfnz.org.nz/future](http://cfnz.org.nz/future) for further information on the campaign.

We are also incredibly thankful to [Mylan](#), [EBOS](#) and [PARI](#) for their generous contribution towards this CF Awareness Week, helping to cover the cost of the awareness resources.

Have a great month.  
The CFNZ team

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## Research For Siblings – We Would Love To Hear Your Voice

We want to offer better support to siblings of children with chronic illness in New Zealand but to do this, we need to hear your voice.

If you answer yes, yip or yeah to the following questions, we want you!

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 you living with them when they were diagnosed? (It is also fine if you weren't born when your sibling was diagnosed).

If you meet the criteria, we would like to encourage you to take this 5-10 minute survey run through Massey University, (or pass it on to your sibling, child etc who fits the bill).

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.

Thank you to those siblings who took this survey last month, the information collected is so very valuable in Katie Armstrong's research into the needs of siblings of children with CF.

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# Raffle Drawn 9 August

The Winter Raffle Appeal has ended – and you’ve helped raise a whopping \$16,300 towards essential services! We didn’t quite make our \$18k target, but we’ve been amazed with all the awesome buyers and sellers this year. Thank you so much! If you haven’t banked your money yet, please do so before 9 August, when the raffle will be drawn, and winners announced.

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## Meet Sophia, Our School Video Super Star!

We recently produced resources on starting school with CF for both parents and caregivers, and schools and teachers. To accompany those resources, Sophia allowed us to visit her school, and she answered some questions, very knowledgeably for a five year old, might we add! You can find the resources, watch the video, and meet cute little Sophia, [here >](#) .

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## Bows For Maddy

Zoe, owner of bellabowtiquenz, has an item up for sale on her website called "Maddy's Rainbow", in memory of Maddy Stuart. They are donating \$5 from every sale of Maddy's Rainbow bow set to CFNZ. A beautiful way to honour Maddy, thank you Zoe. You can purchase Maddy's Rainbow bow set, [here >](#)

## Grabaseat With Caleb

It was pretty cool to see Caleb, this year's Mark Ashford Scholarship recipient, on our facebook feed thanks to grabaseat's #GrabARandom campaign! Caleb and Simon spent the weekend cruising around, showing us all that Invercargill has to offer. Check out the video [here >](#)



## More Needles, Thanks Pharmac!

We were very pleased to see that Pharmac has increased the quantity of funded insulin needles permitted per prescription, from 100 to 200. "Repeat prescriptions will allow patients who need more than 100 needles to access these without needing an additional prescription". CFNZ put forward a submission in support of this proposal.

The fewer trips to the GP or hospital for extra scripts the better, we say!

It is also exciting to see that there is an application for funding of the Freestyle Libre monitor under assessment at the moment. This system means no more finger pricks, the ability to be more aware of what your sugars are doing, therefore encouraging better diabetic control.

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## Update From The CFNZ Board

The July Board meeting saw a great discussion around the organisational review report from Craig Fisher, looking at the structure of CFNZ and how it aligns with the newly developed strategic delivery pillars, governance aspects, along with several

positive “shout outs”.

Along with some exciting new developments, comes a few changes, with board members stepping down, including Jane Drumm (CFNZ chair), Melissa Skene and Michele Wilson.

We are seeking new board members, and nominations for a new adult rep – a two year appointment that has been carried out most recently by Mark Passey. You can download the nomination forms in the full Board Report, [here >](#).

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## Showing Gratitude

A big thank you to the following sponsors who have provided funding for equipment (Eflows, Mobile S nebulisers, oxygen concentrators etc) for various branches around the country over the last couple of months.

New Zealand Community Trust | Mainland Foundation | Hazlett Trust administered by Perpetual Guardian | AD Hally Trust | The Lion Foundation | Estate of Gordon and Lindsey Isaacs administered by Perpetual Guardian | Bendigo Valley Sports & Charitable Foundation | Stewart Family Charitable Trust administered by Perpetual Guardian | One Foundation | Roy Owen Dixey Charitable Trust | Otago Community Trust | Youhtown Inc | Redwood Trust Inc

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## Do You Love To Write?

Well, we'd love to showcase your blogs or opinion pieces on our website! We are keen to get real life stories, from our real life CFers, caregivers and supporters. Anything from the journey of a new diagnosis, to starting out in the workforce, daily routines, coping strategies, you name it, we'd like to hear it.

Get in touch with Lizzie at

[comms@cfnz.org.nz](mailto:comms@cfnz.org.nz) to get involved.



## Your Story Matters

Your story is important – whether you have CF yourself, or are the parent of a child with CF, or another family member. We'd love to hear from anyone who is affected by CF and would like to tell their story for the benefit of other.

Personal stories help put a human face and voice to the work we do. They help raise

awareness and encourage others to become involved in improving the quality of life for people with CF.

The stories page of our website features five people who have shared their experience of CF and the impact it's had on their own life or the life of someone they know. Have a read of these [here](#) >, and let us help you tell your own!

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