

Panui - January: Update from the Chief Executive, Gene Editing in NZ, CF Achievers' Awards Open, New CFNZ Publications Review, Running for CF and Climbing Everest for CF [View this email in your browser](#)



Happy All Black Shirt Raffle Winners!

The All Blacks have proved just as popular off the field as on as shown by our raffle winner's grandchildren who were happy to show off the family's new autographed rugby shirt at their bach in Twizel on holiday.

Donna Johnson won the 1st prize All Black shirt in the CFNZ annual raffle and has given it to her son Nick who is the new proud owner. But it looks like her grandchildren Aria, Toby (middle) and Bede also want a piece of the action.

The 2017 raffle raised \$17K to support people with CF which was up on last year - thanks to all the raffle ticket buyers and sellers.

Update from the Chief Executive

It's January 2018 and a great time to ponder on the year ahead and also to look back on what has been achieved. In fact what better time than in the month named after Janus, the God of beginnings and transitions, who is portrayed with two faces - one looking back to the past and one looking to the future?

This year we are taking the opportunity to reflect and honour 50 years of service of Cystic Fibrosis New Zealand and to also develop some bold audacious goals that will define the organisation's priorities for the next three years and beyond.

With initial input from branch chairpersons and staff last year, and a session scheduled for March with the Board, we will run an insight survey in March/April welcoming the CF community's thoughts as to how CFNZ should move forward. All feedback will be considered together with CFNZ's journey over 50 years, the NZ "not-for profit" landscape, what's happening on the global stage with our fellow CF Associations, our demographics (with better than ever information from our updated PORT CF), the political situation, and our ability to drive support and funding. A draft plan will be developed and circulated to branches and other stakeholders for comment with the aim of completion for July.

So everyone, put on your thinking caps and think about what is important to you, where you want to be in five years' time and what CFNZ's priorities should be. Meanwhile, a BIG goal that we decided to tackle over summer is the development of a new CFNZ website. We are pleased to be working on this with Transformer – a company who we feel really understands the organisation and is providing huge skill and expertise at a very competitive rate. We are indebted to an Auckland donor who is funding this work, to SKIP who is funding the development of online parent resources, to our willing group of Synergy volunteers who did a lot of the initial leg work for us and to Laura Huet, Marketing and Fundraising Coordinator, who is very ably project managing this. We cannot wait to share this with you.

Finally, I want to reflect on the passionate support we receive from so many individuals, groups and businesses who undertake their own challenges (marathons, team building exercises and alike) to raise funds in support people with CF. This month I was honoured to chat to the Streetwise Coffee staff as they handed over a big cheque and to be asked to attend the Birkenhead Rotary Bowls Tournament in Auckland in aid of the charity. I'm inspired to read in the Panui about the people who are putting in so much effort for a cause that is clearly important to them. Thank you to everyone whose New Year's resolutions include doing something in support of people with CF. Your effort makes a difference and your support is very much appreciated.

- **CFNZ Chief Executive Jane Bollard**

Royal Society Gene Editing Discussion Paper

The Royal Society of New Zealand is seeking feedback on its Gene Editing Discussion Paper released just before Christmas. The Society has considered four scenarios where gene editing could be used and weighed up the pros and cons. Cystic fibrosis comes under "scenario two" in the document, which uses the example of gene editing to prevent the inherited breast cancer BRCA1 gene. The paper states: "*Genetic manipulation of an embryo has to proceed with the understanding that the person who is affected cannot consent to the initiative. This concern sits at the core of the ethical prohibition on modification of the human germline (genetic material passed on in reproduction). Similarly their altered germline could impact on their reproductive health and could lead to the transmission of modified genes, some of which may have undefined biological effects.*"

The Discussion Paper supports the use of gene editing that is not inherited by future generations such as the case in sickle cell anaemia where gene editing could fix the gene as part of a bone marrow transplant. The report states: "*Sickle cell anaemia is a severe and debilitating disease. From that perspective, it would be hard to deny a family wanting to use non-inheritable gene editing to help affected people.*"

The Royal Society Te Aparangi Discussion Paper is available here and any feedback sent to Dr Marc Rands - mark.rands@royalsociety.org.nz

Calling all CF Achievers

The CF Achievers' Awards are now open for applications from anyone with CF who has achieved excellence in leadership, the arts, sport or education. The application form is [available here](#). They are open to all New Zealanders with CF who achieve their goals along with managing the high treatment burden with CF. We are extremely grateful to Mylan (makers of Creon) for their ongoing sponsorship of these inspirational awards.



CFNZ Publications Ready for Review

We've been working with parents across New Zealand to develop three new guides – *CF at School*, *Friends and Family Guide to CF* and *Newly Diagnosed*. We're excited to share that the *CF at School* and *Friends and Family* guides are now at the review stage, and we'd like to invite volunteers to review either (or both!) guides and provide feedback for us. Please contact Laura at office@cfnz.org.nz if you'd like to be involved. The *Newly Diagnosed* guide review process will follow at a later date.



Running for Max

Max was diagnosed with CF three months ago and already he's been teaching his parents a lot about strength and stamina. He's also got a great support team behind him including his cousin Chris who is running for Max in Wellington's Round the Bays next month and fundraising via [Everyday Hero](#) to help Max become whoever he wants to be.

CFNZ is also thankful to have two other runners leading fundraising for the CF community. Lucindajay and her family are running in Auckland's Round the Bays and fundraising with [Everyday Hero](#) to help support her little brother Hayden with CF. And Catrina Fisher has been inspired by a family affected by CF to run in the Rotorua Marathon and raise funds via [Givealittle](#).



Climb Everest for CF

The Waihi Beach community are getting behind a Climb Everest Challenge to raise funds for CFNZ Bay of Plenty and pre-schooler Frankie-Lee. Frankie-Lee (inset) and her family settled in Waihi after travelling around New Zealand looking for the perfect place to live. The family have embraced their new community with Frankie-Lee's preschool Beach Kids launching the [Everest Challenge fundraising through Givealittle](#) after learning all about her disorder when she enrolled. The challenge involves walking the Waihi Beach Trig 48 times between 20 February and 21 April. The story featured in the [Bay of Plenty Times](#) this week.

CF Bags for Good @The Warehouse

There are six Warehouse stores which are helping to raise money for CF in their Bags for Good initiative. You can vote for CF at the following stores when you buy a carry bag at the counter and you may need to ask for a token - Auckland Atrium, St Lukes and Sylvia Park, Palmerston North, Levin and Feilding.

Bay of Plenty Health Consumer Rep

The Bay of Plenty DHB is establishing a new Health Consumer Council and is looking for candidates who can provide input into how the health system operates. They have called for "good people who can see things from both sides of the fence." Application forms and Terms of Reference are [available here](#).

Good Links:

- [7 inspirational CF vloggers](#)
- [Organ donation upswing in NZ](#)
- [English actress has niece with CF](#)
- [Kiwi footballer's wife has surrogate baby for friend who had CF](#)
- [Lying or sitting inhalation times study](#)
- [Feeding tube blog - Cystic Fibrosis Foundation, US](#)

Panui - sign up here

Quote of the Month: *"The truth of it all is that as much as I wish and want to make CF disappear, It isn't going to, not until there is a cure. But you have me. I will **always** be there for you. We will fight this together."*

- [Open letter from sister of girl with CF](#)



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