

Panui - May: Big Win for CF Student, Update from the Board, New CFNZ Logos, New CFNZ Admin Manager, Pharmac News, Farewell to Anna & Breath4CF Reminder [View this email in your browser](#)



15K Scholarship for CF Student!

Congratulations to Kelcie Mills who has won a \$15,000 scholarship for her health and safety studies at Massey University.

Kelcie, who is studying online from her home in Hamilton, is the first recipient of the Zespri Scholarship which aims to support future occupational health and safety leaders.

The kiwifruit company is offering the Scholarship as part of an agreement Zespri reached with WorkSafe NZ as an alternative to prosecution for a workplace accident involving a quad bike at a Tauranga orchard in 2016. It will voluntarily pay a total of \$250,000 towards health and safety measures.

Kelcie (19) and her fellow students were advised to apply for the Scholarship which required an essay on health and safety - and last week she was excited to hear she had won!

Kelcie did not mention her health condition as part of the process and believes her youth helped her selection.

"I think my age helped because you don't find many young people studying health and safety."

She plans to use most of the Scholarship for her three-year course, but may treat herself a little..."I might do some shopping but 90 percent of it will go on the course," she says.

Kelcie originally enrolled in business studies at Waikato University last year but decided to switch to a bachelor of health science at Massey University that she is doing online - which she finds is better for her own health and future career.

"It's quite nice being able to stay home and warm. I got quite sick attending University last year. And I found business studies a bit boring," says Kelcie, who is enjoying all the aspects involved in health and safety.

"Health is now being identified as more than just physical," she says in an [article on the Massey University website](#). "You can't cover emotions with a hard hat and earmuffs and hope for the best."

Update from the Board

The CFNZ Board met on 19 May in Auckland with apologies from Denis, our President, who's off travelling the world. We welcomed Irene Vanderlaan, CFNZ's new Office Manager and our Board Secretary, having previously farewelled and thanked Emma for her great support over the past couple of years.

The Board was very pleased to see the results from the recent **CF Insight Survey** of people with CF and their families. This feedback is hugely important to inform us about how we can best meet our community's needs so we were really pleased to see the great response – 52%. There was good alignment between these results, the results of the empathetic interviews and the focus of our draft strategic plan which will be coming out soon. Notable priorities for people were support for advocacy, building a strong organisation and supporting CF research. Point Research which undertook the survey, provided us with some

useful performance indicators that we will now use to monitor how well we are doing in meeting the needs of people with CF and the Board is keen to explore some of the key themes further to get a better understanding of how we can better serve and support our community.

Jane Bollard, CE, will be travelling around the branches over July to present the survey results and to chat about the draft strategic plan. This is a great opportunity to find out about what is going on and to have input into the plan. Also for discussion will be how we fund our ambitious programme of work and as such the Board had a great discussion on the draft Fundraising and Marketing Plan. This is a key bit of work for us as it will shape our approach to generating revenue and will determine how many of those things in our strategic plan we can afford to do. A key objective is to widen our income base and it is pleasing to see that we are already making good progress with this, particularly in growing our grants revenue. The Board is grateful for the financial support central branches have provided over the last two years towards the costs of the central fieldworker. While this funding model was necessary, it is inequitable and the Board has been considering a more equitable model of support going forward. The Board has asked Jane to discuss this as she travels around the branches.

Finances are, of course, the bread and butter of Board business so it was great to see the steady improvement in the quality of the financial information provided. It was also good to see that the accounts are still looking healthy and that we are still tracking towards a small surplus for the current financial year. Moving to the Xero accounting system has improved financial reporting. We heard that Canterbury Branch is now using Xero and they're very pleased with how this is working for them. Wellington, Waikato and Hawke's Bay are in the process of moving across now. This will certainly make life easier for National Office in aggregating financial data for required reporting but if Canterbury's experience is anything to go by, it will also make things easier for branches.

As part of our regular review of policy, we also had a look at the People and Culture Policy; a great omnibus document that covers all things to do with our staff, people with CF and our wider community. One of its more debated bits is the cross infection policy. Before this is finalised, we want to see CF Australia's policy which has yet to be finalised.

Finally, the Board agreed not to hold a conference in 2019 and to put aside some funding to support branches in sending representatives to the Australasian CF Conference scheduled for August in Perth. It is a long way to go and not cheap but the quality of speakers is always great as are the potential learnings. So we feel the investment is well worth it.

- **CFNZ Board Member, Warwick Murray**



Introducing CFNZ's New Logos and Branding

CFNZ has introduced new logos and branding as part of our 50th anniversary. These Cystic Fibrosis NZ logos are easier to work with and it was decided CFNZ does not need a tagline because "Cystic Fibrosis New Zealand" is self explanatory, meaning people understand the organisation's aim is to support people with CF.

We will be using these logos on the new website and for all fundraising materials, so please let us know if you see our "*creating better tomorrows*" logo still in use. It will probably take a while to fully adopt the new logo.

Ask Laura at laura@cfnz.org.nz if you need the new logos for fundraisers, events or posters and she can send you them.

She has also developed a handy guide [50 ways to kick-start your fundraising](#) available on the website, which is a helpful guide for volunteers wanting to support the CF community.



Farewell to a Friend

Last month CFNZ received the very sad news about Anna Scoullar-Jones from the Central Districts Branch passing away. This was a big blow because Anna was always one of CFNZ's greatest champions.

Anna's son Lockie has CF and she joined Central Districts Branch as Co-Chair not long after he was born 18 years ago. Initially she co-chaired the Branch with her childhood friend Erin Bartrum who had CF. When Erin passed away, Anna ran the Branch on her own until deciding to step down as Chair last year.

Anna, who also had a younger daughter Bella (13), was instrumental in organising the local Ballentynes Fashion



Hello Irene, Goodbye Emma

Welcome to Irene Vanderlaan who started with CFNZ as our new Office Manager this month. Irene has a background in medical research and most recently worked for a multiple sclerosis drug trial, managing a Compassionate Use programme for ex-trial patients across New Zealand and Australia who had been on the drug and wished to continue using it. Based at the CFNZ Auckland office, Irene will process Breath4CF grants and other CFNZ grants, along with taking minutes at CFNZ Board meetings and all administrative tasks related to the office.

Be nice to her she's new.

Sadly, it is farewell to Emma Nielsen who is leaving us for higher learning at Auckland University. We wish her all the very best for the future.

Show with everyday women modelling latest fashions – she even managed to talk the Whanganui Mayor into modelling on a few occasions.

Anna (48) was farewelled at her funeral with the help of her husband, Frazer's band, The Noodles, playing the soulful Crowded House song *Always Take the Weather*.

Frazer has asked us to express the following message: "Please pass on to the CF community how blessed we've been with the love and generosity we have received from you over this difficult time."

Rest in peace with all our love Anna.



CF Achiever Finds Love

Just weeks after receiving a CF Achiever's Award, Claire Scofield had another happy occasion to celebrate - her engagement to boyfriend Dan, who proposed at the top of a cliff they had just climbed in Australia. Congratulations Claire and Dan!

Pharmac News

Pharmac is seeking applications for its new Rare Disorders Subcommittee and is also consulting with a view to improve patient representation.

Pharmac is seeking nominations for its Rare Disorders Subcommittee of PTAC which advises about the funding of new medicines. It is looking for applications and nominations for health professionals with the following attributes:

Lumino Day Lucky for Some

Big thanks to Lumino for Lumino Day which provides free dental treatment for caregivers around NZ. We know of one Canterbury mum who received a free check-up and a free filling!

Breath4CF Deadline

Applications for the Breath4CF grant need to be in by 15 June to allow processing before 30 June, which is the end of the financial year. The Breath4CF activity grant is available for all people with CF (\$300 for

- Vocationally registered health practitioners with a special interest in the management of rare disorders
- An ability to evaluate clinical evidence and make recommendations that will determine medicines funding
- A commitment to making the best recommendations for New Zealanders

[See the Pharmac website for more details.](#)

Pharmac has also launched a public consultation process about how it incorporates the consumer voice in funding decisions. Public meetings are being held across NZ which are open to everyone.

[See the Pharmac website for meeting dates.](#)

adults and \$150 for under 6s each financial year). The aim of the grant is to remove cost barriers for physical exercise which improves lung health for people with CF. [Application form available here.](#)

Good Links:

- [Possible cure for common cold](#)
- [What to eat post-transplant](#)
- [Romantic novel about love affair between two CF parents wins award](#)
- [Travelling with CF - US blog](#)
- [NZ Herald Racing Columnist Hails CF Jockey a Hero](#)
- [Latest Kalydeco data looks very positive](#)
- [Tobi safe for under 6s - study](#)

[Panui - sign up here](#)

Last day for Good in the Hood & Torpedo7 Discount

Today is the final day for both Good in the Hood and the Torpedo 7 discount deal for CF. There are CF voting boxes at Z Energy Hastings, Broadway in Wellington and Newton, Auckland.

Also, [Torpedo7 has been running a](#)

[discount for CF](#) on outdoor gear which ends today.

Quote of the Month: *"I am thankful every day to be included in the CF community, and be surrounded with beautiful, inspirational people that are grabbing life and running with it."* - **Claire Scofield, CF Achiever, based in Otago**



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