



Welcome To The December Panui!

Kia Ora Comms

With the opportunity for up to 90% of people with CF to be able to benefit from the new drug Trikafta, CFNZ has restated its commitment to advocacy and to working with Patient Voice Aotearoa, Rare Disorders NZ, Pharmac and Vertex to get these drugs publicly funded in NZ.

We acknowledge the tireless efforts of Eddie and Emma Porter (Kalydeco for Kiwis petition) and Waverley and Peter Brett (Double the Pharmac budget petition) and thank everyone who has thrown their support behind these two petitions.

I hope you enjoy reading about our other advocacy and research projects in this edition of the CF Panui.

We will be in touch one final time before Christmas, however as an advance warning please note that the CFNZ office will be closed from midday 24 December and reopens Friday 3 January.

Jane

Advocacy Update

Pharmac Petition Biggest Opportunity For CF Medicine Funding

CFNZ has committed to ramping up its advocacy programme to get more public support for the doubling of Pharmac's budget – an essential prerequisite for the funding of new drugs like Kalydeco, and ultimately the new Trikafta.

“This programme will aim to significantly increase the number of signatories to the petition but also to directly target politicians and build political support for a budget increase,” says Warwick Murray, CFNZ Board Chair. If you've not yet signed, you can do so, [here >](#)

As a related initiative, it is great to see the Kalydeco petition being presented to Parliament with

just under 11,000 signatures. A huge thanks to Eddie and Emma Porter (of the [Kalydeco for Kiwis](#) campaign group) for their efforts to get this going and to the wider community for encouraging others to sign.

CFNZ Presses For Constructive Talks Between Vertex And Pharmac

CFNZ and Kalydeco for Kiwis have been working hard behind the scenes to get Vertex and Pharmac talking. With the announcement of Trikafta some members of the New Zealand CF community have questioned why CFNZ doesn't skip straight to Trikafta.

"We have over a decade worth of strong irrefutable Kalydeco data and still Pharmac have not got Kalydeco sorted", explains Eilis Quinn, Vertex Country Manager for Australia and New Zealand. "There is no way we will be prioritising Trikafta for submission to the New Zealand Authorities as the Kalydeco experience would strongly indicate that Pharmac would not consider Trikafta seriously with its limited years of clinical data."

Later this week CFNZ Chief Executive Jane Bollard and Eddie Porter will be talking with Pharmac representatives to ascertain why it's taking so long for Pharmac to engage in a meaningful way with Vertex.

Understanding The Cost Of Care For CF

Meanwhile, CFNZ has given Deloitte New Zealand the green light to begin collecting information for the Social and Economic Cost of CF report.

"The research will provide a significant and valuable tool in our efforts to secure Kalydeco, Orkambi, Symdeko, and eventually Trikafta in New Zealand," says Jane Bollard, CFNZ Chief Executive. "To date there has been no economic or social cost data to provide to Pharmac or the Government, so the ability to present this powerful argument could be a game-changer.

"We will be asking the CF community to help us collect information on the impact of CF on your lives in a survey that will be coming out soon. Watch out for the email or click to the link on Facebook. If there is one survey that you want to do this year- this is it." says Jane.



Equipment Update

Majority Of DHBs Now Providing Nebulisers

Following 18 months of behind the scenes work with DHBs, Pharmac and EBOS, CFNZ is pleased to report that most DHBs are now funding and supplying the PARI BOY SX nebuliser and consumables to people with CF. We're still working with Canterbury DHB to ensure a smooth transition of provision of equipment for everybody seen by the Canterbury DHB team. Read the [full update >](#)

Make Sure You're Covered For Christmas

If you need a new PARI BOY SX nebuliser or related consumables, please contact your usual CF team for DHBs funding equipment or Sue Lovelock, Fieldworker for those DHB areas where equipment is not yet managed by them. With Christmas fast approaching NOW is a good time to check your equipment and make sure you have everything you need over the holiday period.

Research

There has been a lot of research requiring our community's participation in the last six months. We'd like to say a big THANK YOU to those who have generously spent time taking part in the surveys; your input is an integral element of these research studies, which aim to improve life with CF.

In July we asked you to complete a survey about 'social connectedness' in people with complex medical conditions, for a study happening at Auckland University of Technology. Keep an eye out early next year, as these results will be available in February.

Q & A

In the recent CF Research Survey where we asked for people's top questions about CF they'd like to be answered by research, we received some great questions for which we already have answers. Over the next few issues of the Panui, we will endeavour to answer them for you.

Can Babies Be Gene Tested During Gestation?

If both parents are carriers then they will be offered genetic counselling to discuss their reproductive options. One of the options is to have prenatal testing which is genetic testing of an established pregnancy at about 11–12 weeks gestation via CVS or 15–16 weeks gestation via amniocentesis.

Read More About Cystic Fibrosis Carrier Screening [Here >](#)



Celebrating A New-Born Screening Test Milestone

For over 50 years the lives of thousands of babies have been improved through a simple blood test. The newborn heel-prick test, or Guthrie test, is now used all over the world, and 2019 marks 50 years of its use in New Zealand. The test is used to screen newborn babies for over 20 rare conditions, including cystic fibrosis.

In the late 70's CFNZ patron Professor Bob Elliot made a major worldwide breakthrough in how to easily and quickly diagnose cystic fibrosis. He used old Guthrie cards and determined his new blood test was 100% effective in diagnosing CF. This meant vital early treatment could be started before irreversible scarring of the lungs occurred.

Learn more about the history of the new-born heel-prick test, and read Sarah Cahill's interview with Professor Bob Elliot [here >](#)



Meet Warwick

Introducing our newly appointed Chair of the CFNZ Board, Warwick Murray. Warwick has been a board member for over two years, so we're very excited that he has stepped into his new role as Chair. Warwick lives with his wife Yvonne and youngest daughter, Charlie, in the Bay of Plenty.

Warwick says, "like most fathers of people with CF, I wish I could magically find a cure", so he's proud to be part of the board, doing what he can to help improve the lives of people living with CF and their families.

Read the full story, [here >](#)

Read Warwick's recent Board report, [here >](#)



Happy Volunteer Day!

Thursday 5th December is Volunteer Day. We would like to take this opportunity to say a big THANK YOU to all our volunteers across New Zealand. We could not do what we do, without you.

We are always very grateful for new volunteers, especially around Awareness Week. If you'd like to sign up to volunteer, head over to our [sign-up page](#).

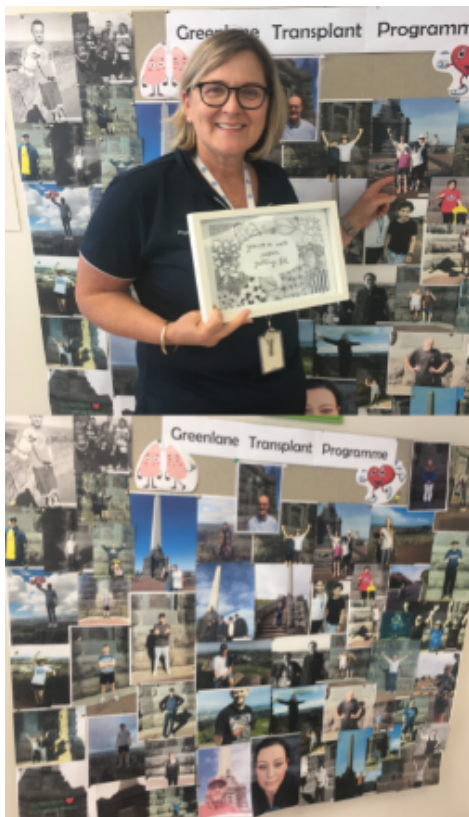


Scholarship Applications For 2020 Now Open

The Mark Ashford Scholarship and CF Achievers' Award applications are now open.

Read more info and apply here:

- [Mark Ashford Scholarship Application](#)
- [CF Achievers' Award Application](#)



Shout Out To The Transplant Physios

Our wonderful Office Manager, Irene, recently underwent a knee replacement. She is back on board (hooray!) after six weeks of recovery. During Irene's recovery, she had physio appointments at Greenlane Clinical Centre. Irene wore her 'Give a F*' t-shirt one day, and Jan, her physio, had a family connection with CF, so it started a great conversation, and an introduction to one of the special physios that looks after our CFers post lung transplant, Anita Jackson.

Anita showed Irene a drawing that Lizzie McKay had done for the gym after her transplant in 2013 - 'You're a well person getting fit'. She is pictured here, pointing to all the photos of post-transplant patients who've conquered One Tree Hill.

Orkambi Experience

We've been lucky enough to have been contacted by a CF mum from Australia, Sonia, whose daughter Evie has seen an incredible improvement from being on Orkambi.

Sonia Marshall will be talking about Evie's very positive experience with Orkambi in both Wellington and Auckland this month. It will be an informative meeting where you can ask questions and have a general chat about the impact that Orkambi has had on Evie's health.

- **12 or 13 December** - VENUE TBC, Wellington at a time TBC
- **17 December** - CFNZ office (79 Grafton Road), Auckland at 10am

If you are interested in the Wellington date, please contact the Wellington team at wellington@cfnz.org.nz.

For those of you that can't make the Auckland meeting, it will be live-streamed on Facebook, and will be uploaded onto the CFNZ website for later viewing. If you have questions you'd like to ask Sonia, please email them to Sarah - auckadmin@cfnz.org.nz.

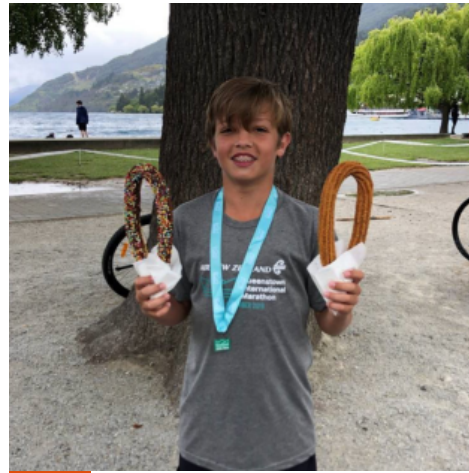


Canterbury Raffle Success

The Cystic Fibrosis Canterbury Branch ran their very first raffle recently and was a great success. So successful, that they've decided this will run as an annual event.

Their first prize was a \$4000 pharmacy gift basket, won by Jo Donaldson (pictured).

We will keep you updated as to when the 2020



Running For Churros

Bruno competed in the Queenstown Kids Marathon, a 2.8km event. Bruno crossed the finish line in 11 minutes and 5 seconds, taking over a minute off his time from his 2017 efforts!

"The experience was and always is awesome and the best part was the HUGE Nutella churros afterwards, equating to 5 enzymes." –

CF Canterbury Branch Raffle will take place.

love your work, Bruno, and excellent creon counting!



School Starter

Have you got a little one starting school in the new year?

Check out the [CF at School webpage](#) for resources and support.

Our team of CF Fieldworkers are also available to help ensure your child has a positive start to school-life (and you too!)

Need A Laptop?

We recently received a generous donation of refurbished laptops to hand out to people living with CF in NZ. We have four left in our hot little hands, that we'd love to give out before Christmas! Please get in touch with Sarah, Auckland Branch Co-ordinator, if you'd like to put your name down for one. Email:

auckadmin@cfnz.org.nz

We Want Your Stories!

Get in touch with Lizzie (comms@cfnz.org.nz) with any of your good news stories, things you'd like to share, cool pictures, helpful hints... anything!

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