

Panui - April: Dancing with the Stars, CF Achievers' Awards, NZ First Dates CF contestant, Pharmac Update - From Pharmac, CF Insight Survey, Good in the Hood, Lumino Day [View this email in your browser](#)

CF Panui



Dancing with the Stars' CF Heroes!

An incredible \$9250 was raised for cystic fibrosis when Dancing with the Stars' contestants appeared on All Star Family Feud on Monday.

DWTS winning contestants Jessica Quinn, Shavaughn Ruakere, Zac Franich and Suzy Cato were playing for CFNZ up against Robert Rakete, Gilda Kirkpatrick, David Seymour and Naz Khanjani who were supporting the Starship Foundation.

It turns out we have Suzy Cato to thank for nominating CFNZ as the charity for her team to support. She knows someone with CF who has thrived - helped with the assistance of CFNZ.

The show came down to a nail biting finish, and All Star Family Feud pledging \$10 for every point helped push Suzy Cato's team over the \$9000 mark.

It was exciting hearing the news that a DWTS team would be playing for CFNZ for the first time, and the announcement on our Facebook Page received a record number of 469 likes.

Some CFNZ staff and Auckland Branch committee members got the chance to attend the recording, with Anthea, Kelly and Niall pictured above with our favourite Dancing with the Stars.

And this isn't the only exciting television news to report this week! Shane Hill (pictured right) of the Wellington CF community appears on **First Dates NZ at 8.30 tonight** on TV2 where he reveals information about his health condition to his date.

Shane has a four-year-old daughter, is a PE and Tech teacher and he wants to show other young people with CF that you can lead a good life.

Congratulations to Five CF Achievers!

CFNZ congratulates these amazing CF Achievers - living their lives to the full in spite of a serious health condition!

Claire Schofield – CF Achiever, Education

After having to leave her nursing studies due a serious lung infection, Claire (29) decided to retrain and study horticultural science at Massey University. After completing her degree she forged a successful career at Plant and Food Research in Otago. She's been asked to present at a number of conferences and is now embarking on a Master of Science while still working full-time and managing the demands of CF.

Vaughan Somerville – CF Achiever, Sport

Vaughan (25) was named the Auckland University Sportsman of the Year in 2017 after his Futsal team won nationals in Christchurch. His Auckland University team are now off to Kazakhstan for the 2018 University Games, and Vaughan has earned the privilege to captain the team. He will use his Achiever's Award to help fund the trip.

Caleb Skene – CF Achiever, Education

Caleb (21) is in his final year of studying Architectural Design. He received an A-grade average for both year 1 and year 2, finishing in the top section of his class. He is planning to continue and study for his Master's degree.

George Blyth – CF Achiever, Leadership

George (18) has gained a number of leadership roles over the past year, particularly in the sporting field where he's been the captain of the school rugby team and vice captain of the cricket team. He was awarded the leadership medal for the Rangiora High School 1st XV, and was also a House Leader at Rangiora High School last year.

Note: Another CF Achiever who wishes to remain anonymous received a CF Achiever's Award for Sport for being named in one of New Zealand's Under 19 teams.

Update from Pharmac - by New Chief Executive

"I'm delighted to lead PHARMAC as it continues its work for New Zealand. Our broader funding work continues with work in community medicines, vaccines, hospital medicines, and medical devices used in DHB hospitals. In line with our strategic goals, we have a strong interest in activities to eliminate inequities in access to medicines.

We are currently considering a funding application from CFNZ for the TOBI Podhaler and this will be given full consideration by our clinical experts and economic advisers. We will first be seeking advice from our expert Respiratory Subcommittee, who will in turn provide their advice to our main clinical committee, PTAC. Should the recommendation be positive, PHARMAC would rank the funding proposal alongside other medicines seeking funding. We always have more options to fund than we can afford, so careful choices need to be made.

Some recent funding changes include the shingles vaccine being funded from 1 April, for people aged 65, with a catch-up programme for people up to 80. We're also funding an influenza vaccine this year that, for the first time, offers protection against four strains of influenza. People with CF are eligible for a funded vaccine, and we encourage people to



use the opportunity to prevent influenza infection.

I know there is some interest in our rare disorders work from people with CF and their families, as there are some sub-types of CF that could be considered rare.

At the end of 2017 we announced the formalisation of a process for considering medicines for rare disorders, which includes establishing a new clinical advisory subcommittee, to specifically consider funding of medicines for rare disorders. This work will begin in May, and we hope the committee will be able to have its first meeting before the end of the year. Later in 2018, we will call for funding applications from suppliers of medicines for rare disorders. This process could lead to even better access to medicines for people with rare disorders.

Our earlier contestable funding process led to decisions to list 10 medicines for rare disorders on the Schedule."

- **Pharmac Chief Executive, Sarah Fitt**

CF Insight Survey

Our CFNZ Insight Survey will be soon be emailed to the parents of children with CF and people with CF over the age of 15. We are extremely keen to receive feedback to help with planning of the future of CFNZ. Those who complete the survey can be in to win a \$500 prize kindly donated by TelferYoung Tauranga. If you don't receive an email please email info@cfnz.org.nz and we will send you the survey link.

Gene Editing Workshop

CFNZ attended the Royal Society Te Te Apārangi's Gene Editing in Healthcare workshop in April, which covered some of the ethics involved in gene editing and the new CRISPR technology that promises a cure for CF. The Royal Society discussion paper seeks to hear views on gene editing that will change the DNA of future generations which is what would happen for gene editing to cure CF and could have unknown effects. This is currently prohibited in NZ law.

The Royal Society discussion paper is also seeking views on gene therapy, which is currently being researched as a treatment for CF, which would only make genetic changes in a particular organ (such as the lungs) and wouldn't change human DNA of future generations - this therapy would be legal under



Mum Helps Campaign for Paid-Carer Support

Waikato mum Shannon who cares for one-year-old son, Tailen, with CF is one of the faces of the *She Cares* campaign to improve practical help available for people who care for elderly, ill or disabled friends or family members.

Shannon had to give up her job and works long hours caring for her son and his health needs. She says paid-carer assistance should be available to the parents of children with cystic fibrosis.

Her story appears on the [She Cares website](#) and has also told her story

existing laws.

However, new legislation is still likely to be recommended to cover all the issues involved with new gene editing technology.

Many participants raised concerns about access to treatment like gene therapy because it was likely to be hugely expensive.

[The Royal Society has produced a video explaining gene editing, which is also available from it's website.](#)



Pari T-Shirt Challenge

Yes! that's our Chief Executive Jane Bollard in the middle taking part in the Pari T-shirt Challenge along with some friends. Jane (3rd right) and her Nordic Walking Group took part in the Tauranga Half Marathon and supported CFNZ wearing PARI t-shirts.

The t-shirt challenge is to mark PARI's 50th anniversary by donating 10 Euro (NZ\$17) to CFNZ for anyone who completes a personal challenge wearing a PARI shirt and posts a photo on the [PARI BOY 50th Facebook Page](#).

[Order your t-shirts through the PARI website](#) - limit two per order.

There is a bit of a delay with orders at the moment. The next batch is expected to be delivered in May/June.

Researchers Seeking Volunteers

for the new CFNZ website to support the parents of other babies with CF. Shannon also has a [Facebook Page](#) documenting her and Tailen's CF journey.

Meanwhile, **Lumino Day** that provides family carers with free dental visits across NZ is being held on 5 May. [Register on the website.](#)

Great Hair Day for CF Nelson

Shampoo Plus in Nelson has named CFNZ Nelson/Marlborough Branch one of their charities of choice. Every bottle of Wella product sold will see \$1 going to eight chosen charities, including the Nelson/Marlborough Branch. A number of other hairstyling companies are supporting the initiative by donating goods to sell or raffle, and the local branch is delighted with the support.

Facebook Voting

The CF community love a good Facebook vote and this month was no exception. When KILT clothing store offered \$1116 for the charity with the most votes, the CF community swung into action with a heartening lead of 50 percent of the votes.

However, the charity Angel Casts, which supports grieving parents of babies who pass away, beat us to the top spot. Still it was nice to see the donation going to a small and deserving charity.

Good in the Hood at Auckland, Hastings and Christchurch

CF will have voting boxes at Z Energy stations at Auckland's Z Newton, Z Hastings and

Public health researchers at the Auckland University of Technology are studying the social impact of complex medical conditions like cystic fibrosis.

They are seeking face-to-face interviews with 30 Aucklanders about how they maintain social connections and the extent of social support. They are looking for people aged over 18 who see multiple specialists. A \$30 gift voucher will be provided for those taking part. Contact: Dr Asmita Patel, email: asmita.patel@aut.ac.nz or text: 021 02232031.

Meanwhile, a worldwide *Scientific Communication in CF* study has been launched by the Northern Ireland Microbiology Discussion Group.

The study was launched at CF Ireland's annual conference this month and aims to improve the communication of science-related topics to the CF community.

The researchers are keen to hear from people with CF, parents, carers, and friends and family. There are 40 questions and [the survey takes about 20 minutes to complete.](#)



Waihi Celebrates CF Trig Challenge

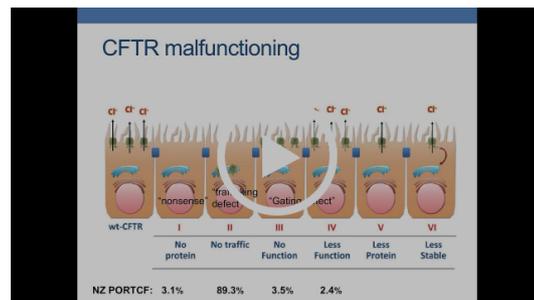
The Bay of Plenty Branch also had plenty to celebrate this month with the completion of the CF Trig Challenge and a celebration to mark

Christchurch's **Z Belfast**. Voting starts in May so be sure to pop a token in the CF box when you buy anything at these stations.

Meanwhile, there are CF voting token boxes at the following **Warehouse** stores for people who buy a carry bag at any of the following stores:

- Auckland Atrium
- Auckland St Lukes
- Auckland Sylvia Park
- Palmerston North
- Levin
- Feilding

Voting for this round finishes 1 July.



New Developments in CF Video

Starship Associate Professor Dr Cass Byrnes *New Developments in CF* presentation.

This is filmed in four parts. The first two videos feature Dr Byrnes' presentation and the second two feature the panel discussion with Dr Byrnes and Starship's Dr Mirjana Jaksic, CF Nurse Specialist Jan Tate and Physiotherapist Rebecca Scoones. It is also available to [view via the CFNZ website.](#)

the incredible total of over \$11,500 raised. The Challenge, launched by Sara and Emma of Beach Kids in Waihi, was held to help support their pre-school student Frankie-Lee. It involved walking the Waihi Beach Trig 48 times. Pictured above are Sara, Emma and Frankie-Lee's mum Kas.



Last Call for New Diagnosis Booklet

We would love some more feedback from parents about the *Newly Diagnosed* guide before the review stage closes. Please contact Laura at office@cfnz.org.nz if you are able to help review it before it goes to print.

CF's Ironwoman

Hugh thanks to Tania Dowie for her massive achievement completing Ironman and raising over \$2000 for CFNZ's Breath4CF fund. The 3.8k swim, 180k bike ride and 42k run weren't easy to say the least but Tania says it definitely helped having her son Jesse, who lives with CF, cheer his mum over the finish line.

Good Links:

- [Siblings and CF study - UK](#)
- [Positive response to lung functioning monitoring at home](#)
- [Liver enzyme interferes with Orkambi](#)
- [Preparing for a lung transplant](#)

Panui - sign up here

Quote of the Month: *"I advise the parents of other babies with CF to reach out for help – don't be afraid to ask questions. Keep an open mind and know that when you're having a bad patch you will get through it. I know my family have been great even though we are not that close. It's important to keep your immediate support small and rely on them."*

- Shannon, mum of 18 month old Tailen with CF





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