



Welcome This Month's CF Panui!

Kia ora,

As we move into a new month and reflect on February, it's inspiring to see that progress on some key focus areas are being achieved from the help of many.

Kalydeco for Kiwis and CFNZ have been working together for several months to campaign for the first of the innovative medicines, Kalydeco, to be government funded. We were blown away by the number of people who took the time to write to Pharmac telling them how important this is to them. Read the full update below.

After over three years of work, the paediatric clinical review group's work on clinical guidelines for children and young adults with CF is nearing completion. As you might imagine with a national multidisciplinary team on the job the guidelines have been well debated. It's great that CFNZ has been an integral and welcome member of this group. CF research has also had a great kickstart with the first phase of the National CF Research Strategy being co-funded by CFNZ and Cure Kids.

We very much look forward to sharing the achievements that March brings.

Jane Bollard
Chief Executive

Movement On Kalydeco

In February we received the fantastic news that PHARMAC'S Rare Disorders Subcommittee had reviewed the submission for Kalydeco, and had put forward a recommendation for funding in NZ. Last week PHARMAC's Pharmacology and Therapeutics Committee (PTAC) met to discuss the recommendation, and they will make a recommendation about whether to fund Kalydeco to the PHARMAC Board, who will make the final decision.

To keep the pressure on, CFNZ developed a [template email](#) in support of Kalydeco, and asked as many people as possible to email PTAC ahead of its meeting. We were copied in to just under an incredible 170 emails from friends, families, medical professionals, supporters, and many other walks of life. It may be a couple of months before we know what PTAC have recommended, but we're in a strong position and we'll let you know once we hear. A huge thank you to everyone who helped make this possible.

It was also encouraging to see PORT CF, New Zealand's data registry owned by CFNZ, mentioned in the [Rare Disorders Subcommittee Minutes](#) as part of its

recommendation. This registry helps us to analyse CF trends and has become an important tool in our lobbying efforts. Thank you to the people with CF who kindly agreed to anonymously share their health data and to the health professionals for helping to administer this registry.

More information: www.cfnz.org.nz/advocacy

Keep connected: www.facebook.com/KalydecoForKiwis



Full House At Nelson Fundraiser

The CF Nelson team kicked off 2019 with a sell-out quiz night held at the Brightwater Sprig and Fern, raising an awesome \$616 to help support local people with CF. Over 20 individuals and businesses donated raffle prizes thanks to the hard-working team of the CF Nelson branch. [Read full story >](#)

We Need A Film Star!

Now that we've released our two new school guides, we're looking for a child aged 5–7 who would like to star in a short video. We'd like to show other children with CF who are about to start school, and their parents, how much fun school is and how CF is managed during a school day. If you think your child would like to be a star for a day, please contact Laura: laura@cfnz.org.nz.

Download the school guides:

[Guide for parents and caregivers of children with cystic fibrosis](#)

[Guide to cystic fibrosis for primary schools and teachers](#)

Would You Like To Feature In One Of Our New Guides?

We've received a great response from adults with CF who have helped us develop the soon to be released Employer's Guide. We'd love to hear from adults all over the country who are happy to be photographed at work to be used in the guide. We're keen to feature people working in a diverse range of professions, so if you'd like to be involved please contact Sarah: sarah@sayline.co.nz.

Showing Gratitude To Our Funders

We rely on the generosity of grant funders to support the CF community. Thank you to the following funders who have provided support ranging from salaries, operating costs, and equipment for CFNZ branches.

Procure Charitable Foundation; Grumitt Sisters Charitable Trust; Winton & Margaret Bear Charitable Trust; Redwood Trust Inc; Dragon Community Trust; Mainland Foundation; and First Light Community Foundation.

If any CFNZ branches need assistance with grant funding please contact our Grants Coordinator Jeanette: grants@cfnz.org.nz.

End Of Tax Year Receipts

31 March is the end of the tax year and CFNZ will be sending all our amazing donors an end of year donation summary for tax purposes so you can claim your rebate. If you've not donated this this tax year, you can do so here: www.cfnz.org.nz/donate

Can You Help?

The 2019 CF National Raffle goes live early April and we're looking to raise an awesome \$20,000 so we can continue supporting the CF community. But a great raffle starts with great prizes! Can you or your business donate something to our national raffle?

Email: laura@cfnz.org.nz.



Fieldworkers Take Time To Be Mindful

Gretchen, our northern fieldworker, and Jude, our central fieldworker, attended a mindfulness workshop in February. Gretchen shares some of her thoughts: " Research shows that mindfulness practice can be effective in working through the stressors, anxieties and challenges we face on a daily basis. Incorporating mindfulness can be as simple as taking a few minutes a day to engage in exercises designed to encourage calmness, clarity and wellbeing".

[Read more >](#)

CF Science And Research Online Event

The Cystic Fibrosis Foundation (CFF) is hosting its first virtual event dedicated to CF science and research. ResearchCon is a free online event to share the latest infection research with the CF community, held on Friday 1 March from 1pm (Thurs 28 February 7pm EST). Topics include the role of inflammation in CF lungs, bacterial infections and antimicrobial resistance and chronic infections and their impact on the gut. During registration you can select the topics you're interested in. Please note, as this is a US event some of the information may not be relevant to

our New Zealand CF community. [Find out more >](#)

New Zealand CF Research Gets A Kickstart

The CF Insight Survey we ran last year showed that the CF community wanted CFNZ to have a greater contribution to CF research, and we're pleased to report that there have been some exciting developments happening behind the scenes. Cure Kids and CFNZ are now co-funding the first step of the National CF Research Strategy to move CF research forwards. This first phase is aimed at connecting the CF clinical and research communities both locally and internationally, determining how NZ fits the global research scene and identifying the research priorities of our CF community, in order to deliver real benefits for people with CF.

Have Your Say

The CFNZ Board oversees the charity's strategic direction and acts as a voice for the CF community, and we actively encourage people to have their say. The next Board meeting takes place on 24 March and if there are any items for the Board to consider, please email them to admin@cfnz.org.nz by Monday 4 March.

Expressions Of Interest - Australasian CF Conference

Cystic Fibrosis NZ would like to offer conference grants to assist with the costs of traveling and attending the Australasian CF Conference, 3-6 August 2019, at the Crown Towers Hotel in Perth. We have some limited funding and would like to hear from those who are considering attending so we can gauge interest. Please email admin@cfnz.org.nz.

Mark Ashford Scholarship Applications Close 15 March 2019

Sponsored by TeflerYoung, the Mark Ashford Scholarship is awarded each year to a person with CF who has shown excellence in their studies. [Find out more and apply >](#)

Position Statement For Healthcare Workers With CF

A new position statement about the work environment risks for healthcare workers with cystic fibrosis has been published. A multidisciplinary team of Australian and New Zealand CF and infectious disease clinicians, infection prevention and control practitioners, healthcare workers with CF, academic experts in medical ethics and representatives from universities appraised the available evidence on the risk posed to and by healthcare workers with CF. Specific recommendations were made for healthcare workers with CF, CF healthcare teams, hospitals and universities to support the safe practice and appropriate support of healthcare workers with CF. [Read the position statement >](#)

CF No Barrier To Achievement

It's been a double success for last year's Mark Ashford Scholarship recipient Damien Bell. Damien, an adult with CF from Te Awamutu, has been announced as the recipient of the Wintec Gordon Chesterman Scholarship. Damien is halfway through his three year degree, studying towards a Bachelor of Applied Technology at Wintec in Hamilton. The scholarship is awarded based on academic merit, personal character and community involvement. You can read more about Damien's win on the [Wintec website](#). Congratulations Damien, we wish you all the best for the rest of your studies.



Hairs To A Fundraising Superstar!

CF Auckland branch received a special donation thanks to four-year-old Mila from Gisborne. Mila donated 45cm of her long hair to Freedom Wigs, an organisation who makes wigs for people with long-term hair loss conditions. Mila asked for the money she would have been paid for her hair to be donated to Cystic Fibrosis Auckland, to show her support for her one-year-old cousin Otis who has CF and lives in Auckland. You can read more about Mila in the [Gisborne Herald](#). Thank you Mila! We think you're a rock star for supporting people in NZ with CF!

Need More Information?

Visit the CFNZ website for latest news, resources, information, apply for grants, find contact details and more. Go to www.cfnz.org.nz >



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www.cfnz.org.nz

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