



Welcome The June CF Panui!

Kia ora,

Last month we received the news that the Pharmacology and Therapeutics Advisory Committee (PTAC) of PHARMAC recommended Kalydeco be funded with a low priority for the treatment of cystic fibrosis with the G551D mutation. This is a positive step forward and one which we should take time to celebrate.

We continue to work closely with Eddie Porter, Kalydeco for Kiwis, to plan the next steps in our Kalydeco campaign. We've met with PHARMAC to ensure we have a clear understanding of its decision and the process going forward. We will share any updates with our community and supporters.

As the beginning of the new financial year approaches we have been busy working on our 2020 Annual Plan, including how we measure our success and ensure our work continues to focus on improving the lives of people with CF and their families.

And lastly, tickets are now on sale for our winter CF raffle with great prizes up for grabs. You can buy or sell tickets; find out more information in this newsletter.

Stay warm and stay well.

Arohanui

Jane Bollard
Chief Executive

CF On The Radio

Last month two adults with CF gave fantastic radio interviews on their experience with CF, helping to raise much needed awareness.

On 3 May, Alana (pictured right) spoke with Jesse Mulligan on Radio New Zealand about life before and after her lung transplant. [Listen to the interview >](#)

Then on 16 May Jenna and her sister Lisa joined breakfast show hosts Sarah and Martin on the The Breeze Hawkes Bay 97.5FM. [Listen to the interview>](#)

A huge thank you to Alana and Jenna for sharing their stories, and to RNZ and The Breeze HB for making this happen!



Kalydeco Recommended For Funding

As part of the announcement that the Pharmacology and Therapeutics Advisory Committee (PTAC) of PHARMAC recommends Kalydeco to be funded, PHARMAC has ranked Kalydeco against other funding applications. It's not known how long Kalydeco will have to wait on the list to be funded and become available. Kalydeco for Kiwis, CFNZ and the CF community will continue to put the pressure on until Kalydeco is not only funded, but accessible to all who need it. Following the announcement, PHARMAC has offered to speak with CFNZ so we have a clear understanding of its decision and the process going forward. We will share any updates with our community and supporters. [Read more >](#)



Noel Leeming Friends & Family Deal Running 10 - 23 June

Get some great deals whilst supporting Cystic Fibrosis NZ, starting Monday. Download the flyer or show it on your mobile and get cost + 10% storewide, with 2.5% of total sales going towards CF research, advocacy, information and support. How awesome is that?
[Download flyer >](#)

CF Research News

New Research Development Manager Appointed

We've appointed a new Research Development Manager in partnership with Cure Kids to kick-start a national research strategy, following a workshop held last year to explore research priorities and opportunities. Dana Felbab, who has a background in molecular biology (genetics and pathology), works one day a week at the CF office in Auckland. She has experience as a medical laboratory scientist, first in New Zealand and then the United Kingdom. Soon after returning from the UK, she joined Roche Diagnostics NZ as a product specialist and after five years there, moved to Auckland UniServices as a business development manager, securing funding for innovative research at the University of Auckland. Dana is passionate about translating New Zealand research into real world outcomes that can improve people's lives. Welcome Dana.

Mānuka honey kills drug resistant bacteria found in cystic fibrosis

A study carried out by Swansea University Researchers has revealed a potential breakthrough in treating antimicrobial resistant respiratory infections, particularly ones found in people with CF. The results showed that mānuka honey was effective in killing antimicrobial resistant bacteria by 39 per cent compared to 29 per cent for antibiotics. [Read full article >](#)

Nelson Marlborough Branch Make A Run For It

Setting a good example for her son was the motivation for Sadie to compete in this year's St Clair Half Marathon in Marlborough. After sharing with friends and family the news she was training for the event, 17 other people joined the team and together they raised over \$7,500 for the CF Nelson Marlborough branch. "Since leaving school I haven't been very sporty, but my four-year-old son has CF and I know one of the most important things is being active. It made me think, how can I preach this and not be setting an example," Sadie says. [Read more >](#)

Pictured below left: Marian, Jackie, Aimee and Karen pre race

Below right: Marathon team members Hannah, Sandy, Karen, Jackie, Lisa, Robyn and Sadie



Sharing The Warmth

Winter is set to be warmer for one Christchurch family, thanks to a generous donation from Gavin Lowe Energy. Kimberley Swaney and her family, which includes Noah and Elijah who both have CF, were this year's recipient of a heat pump installed in their home on 14 May. "We're so grateful for the gift of warmth and good health for our family," Kimberley says. [Read more >](#)

Pictured left: Kimberley and Melissa with Mike Little from Gavin Lowe Energy

Breath4CF Grants

Breath4CF physical activity grant allowances run from 1 July to 30 June, in line with the CFNZ financial year. If you have not yet used your allowance (up to \$150 per child under 6 years, \$300 per child/adult 6 years and above) please ensure any remaining applications are received by June 26 to allow time for processing. Any applications received after this will be taken from your 2019/2020 allowance.

Visit www.cfnz.org.nz/breath4cf to apply

Support & Information News

New Resources On The CFNZ Website

We've added some new factsheets on our website that you can download and print out:

- Guidelines for nebulising hypertonic saline
- Guidelines for nebulising antibiotics

- Guidelines for the care and cleaning of airway clearance and nebulising equipment

[View resources >](#)

We have a range of resources available for our CF community and anyone who would like to know more about cystic fibrosis. If you'd like to provide feedback about any of our resources or know of a resource we should include, please email us at info@cfnz.org.nz.

Employer's Guide Ready For Publication

Thanks to a grant from the ANZ Staff Foundation our new guide: A guide to cystic fibrosis for employers is nearly ready for publication. A big thankyou to the many adults with CF who contributed to the development of this guide and we hope it provides PWCF and their employers with a useable resource. Once it's been finalised it will be available on the website to download or you can email admin@cfnz.org.nz to request a hard copy.

Video For Children With CF Starting School

Last month we visited 6-year-old Sophia (pictured below) and her family in Hamilton to film a video for children with CF starting school. We were blown away by Sophia who did an incredible job of being our film star for a couple of days and allowing us into her home and school. We look forward to sharing the video with our CF community soon, created especially for children with CF and their families.



Winter Raffle Appeal 2019 - Can You Help?

Grab your tickets for this year's winter raffle and a chance to win a host of amazing prizes. Tickets are \$5 each or you can buy a book for \$20 and get 5 tickets for the price of 4.

To buy your raffle tickets, download an [order form](#), fill it in and post it back to us with details of your payment. If you'd like to help us reach more people by selling tickets to friends, family and colleagues, please send your request to laura@cfnz.org.nz and we'll send you out your requested number of books to sell. You can either pay for the books upfront or pay after you've sold them.

Find out more at www.cfnz.org.nz/raffle. Good luck!



Annual Possum Day Out

Andrew Peter McCleary, or as he was more commonly known and loved by most as “Possum”, was again remembered at Pourerere Beach at the annual Possum Day Out fishing competition, a three day event which started on Thursday 21 February. What started as a get together for family and friends to remember a son, brother, uncle and friend six years ago has turned into an annual event to remember Possum, and raise much needed funds to support the local Hawke’s Bay branch of Cystic Fibrosis New Zealand. [Read more >](#)

Update From The CFNZ Board

After our March strategic day we hit our May Board meeting feeling invigorated. Discussion took place on the Proposed CFNZ Board Programme of Work 2019/20 where we looked at a list of priorities and topics to become our annual work plan over the next 12 months along with policy review. This looks like a big task but meeting by meeting we will be working hard on this. A working group has been formed to look at the up and coming Chairpersons Conference agenda in September. [Read the full board report >](#)

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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