



## Welcome To The October CF Panui!

In the October issue of the CF Panui you can help us keep up the momentum of our campaign for Kalydeco and other precision medicines, find out the date for one of our biggest events in our calendar and learn what we're doing to fund strategic CF research.

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## Keep Up The Letter Writing!

The PHARMAC rare disorder subcommittee is due to meet very soon, so it's important we keep the letter writing going. If you haven't already, please show your support. A template letter is in our [advocacy kit](#) and you can order stickers from the CFNZ website. We're also gathering stories about people who will benefit from Kalydeco, please get in touch if this is something you can help with.

[Read more](#)



# A 60 Year Voyage In Cystic Fibrosis

By Emeritus Professor R. B. Elliott

I made my first diagnosis of cystic fibrosis in 1958. Rocco Barbaro, from an Italian immigrant family, was admitted to the Adelaide Children's Hospital during a summer heat wave of over 40°C with heat exhaustion – he was dehydrated and seriously ill.

He did not respond well to the usual measures of intravenous hydration and cooling and went on to develop serious pneumonia. In the light of this, I asked for the newly invented sweat test which came back positive. It should be remembered that cystic fibrosis had only been clearly separated out from other causes of failure to thrive in 1939.

[Read more](#)

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## CFA Mental Health Roadshow

The mental health roadshow is kicking off in Brisbane in November, helping to educate the medical and CF community about mental health with a chronic condition. The sessions will be filmed and made available at a later date. We're very lucky that field workers Gretchen and Sue will be attending the roadshow in Melbourne, with flights paid for by Air NZ. Thanks for the support!

[Read more about the roadshow](#)

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**Save The Date!**

**CF Awareness Week 2019  
12- 18 August**

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## Spotlight On Research

We've been working with Cure Kids to organise a workshop for next month that will bring together CF researchers, clinicians and stakeholders to explore CF research priorities. The process will identify how NZ can best contribute to global CF research and what research could have the greatest impact for people with CF.

CFNZ - Auckland Branch hosted a research presentation this week, with updates from Cass Byrnes and Rebecca Scoones. A video recording will be made available soon.

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## PARI Proving Popular

Our joint campaign with PARI is proving to be very popular! The Auckland Marathon last weekend saw many of the t-shirts going the distance. Here's Eddie from [Kalydeco for Kiwis](#) in his shirt! On top of that, some of the CFNZ team and friends spent the afternoon learning archery, all wearing our blue shirts. Keep an eye out on Facebook for the pictures! Don't forget, you can still [order a t-shirt](#) and wear to a sports challenge of your own (big or small!), and PARI will donate approximately \$16 to CFNZ.





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## Employers Guide To CF On The Cards

Following on from the insights on what matters to adults with CF, having support if they choose to tell their employer about their CF was identified. We're now looking to speak with adults who've broached the subject with their employer and can share their experiences and advice for other CFers. We're also looking to speak to employers on how they support their staff member. If you'd like to be involved please email [sarah@sayline.co.nz](mailto:sarah@sayline.co.nz).



### Amazing Anaheira

Check out this gorgeous picture of CFer Anaheira recently playing netball and keeping active. She's becoming quite the star! Keep up the great work Anaheira.

Don't forget, we provide grants to help keep people with CF active. Each person with CF has an allowance of up to \$300 each year. To find out more, email our [grants administrator](#).

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## Rachael's Lipstick Here To Stay

We are absolutely bowled over with the support from Karen Murrell, who recently let us know that the make up manufacturer has decided to keep the gorgeous Rachael's Colour as a stock colour! To date the lipstick has raised almost \$10,000 for the charity, which is just amazing. You can [watch the video](#) about CFer Rachael and her amazing Make-a-Wish journey or buy your own lipstick on the [Karen Murrell website](#).

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### Order Your Kalydeco Stickers And Support The Campaign

[Order stickers](#)

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