



## A Welcome Step Into Spring

Spring has finally sprung (for most of us!) and we're all grateful to be leaving this particularly bad winter behind. The harsher temperatures have meant we've seen a big rise in requests for assistance with heating to stay warm, dry and prevent respiratory infections. Thanks to the generosity of our donors we have been able to meet these needs by providing firewood and assistance with heating bills.

A huge thank you to the supporters that help make this possible and allow us to continue supporting and advocating on behalf of our community. We hope you enjoy this September roundup and have a great October.



### From The Board Table

Following each meeting a Board member gives us insight into the strategic direction of CFNZ. This month Chair Jane Drumm shares her view from the Board table.



**Kalydeco Campaign Goes Live**

"Our August meeting focused on our agreed key priorities; advocacy, a strong CFNZ and a strong CF community. As Chair I find it heartening to hear that our new website has had 38,000 'engagements' and that people are engaged for longer than ever before. Along with this, we have already had almost \$10,000 in donations through our new website since the beginning of July. Advocacy and the strengthening of our CF community was also evident as we welcomed Eddie Porter to our meeting where the board discussed with him the work he and his wife Emma have started with the Kalydeco for Kiwis cause. As an outcome of these discussions, we as a board left...

[Read full Board update >](#)

The campaign to get Kalydeco publicly funded in New Zealand is officially underway, with CFNZ and Kalydeco for Kiwis working together to achieve this huge goal.

In early September PHARMAC called for applications from suppliers of medicines for rare disorders. Vertex, Kalydeco's manufacturer put in an application for Kalydeco and an announcement is scheduled for early 2019.

CFNZ engaged experienced advocate Lisa Woods to work alongside Eddie Porter from Kalydeco for Kiwis, to spearhead the campaign.

Get involved today by:

[Downloading our advocacy toolkit >](#)

[Visiting the advocacy hub >](#)

[Keep up to date on Facebook >](#)



## Fundraising Superstars

September has been absolutely brimming with exciting fundraising!

CE Jane and Marketing & Fundraising Coordinator Laura were thrilled to be invited to the Streetwise Conference where they accepted a massive cheque for \$6476.30 - thanks to the whole team who continue to work hard to support the CF community.

Canterbury Branch held an awesome fundraising talk featuring Nigel Latta, and netted \$15,000! Chair Melissa is pictured above left with Nigel. [Read more >](#)

It was black & white just how much fun the Hawkes Bay Casino Fundraiser was, check out the photo above right! The annual event raised a healthy amount with its black & white theme.

Last but not least, a huge thank you to Choice Hotels NZ for raising \$10,000 through its \$2 donation per bed night promotion during CF Awareness Week.



### Call For Scholarship Applicants

The Mark Ashford Scholarship (\$3,000) rewards excellence in tertiary education and tenacity to overcome the trials of CF while studying. It is generously sponsored by [Pink Batts](#). The last day to submit your application is Wed 17 October. [Apply online >](#)



### Rare Disease Day 2019

NZORD is calling for everyone, of any age, to share their story for Rare Disease Day 2019, taking place 28 Feb.

Up to four stories will be selected to feature on the Rare Disease Day website and associated materials. Deadline to submit your story is 12 October 2018.

[Share your story >](#)



### People With CF Encouraged To Get Their Genes Tested

As more precision medicines are developed that target specific faulty genes, it's becoming increasingly important to know your genetic typing. From the PORT CF data we hold, we can see that not all CFers know their genetic type. Jan Tate, CF Nurse at Starship, recommends "I encourage all CFers to ask their consultants for another blood test when they have their annual blood taken. This can be done through the clinic you attend".

[Read more >](#)

# OurEco Clean Helps Families Stay Healthy

The generous bunch over at OurEco Clean are offering 20% off web orders of their gorgeous eco cleaning products when you use the code 'CFNZ2018'. They're also donating 10% of their profits taken at the Allergy Free and Healthy Living Show. Thanks Sarah and Simon!

[Visit website >](#)

## Adult Workshop

We are inviting adults with CF to participate in an online workshop facilitated by Elizabeth Goodwin, Connect and Co, and Jane Bollard, CFNZ CE on Tuesday 16 October at 7-8.30pm. The workshop will discuss the findings from the recent interviews carried out by Connect and Co and also what CFNZ is planning to do. Input and discussion welcomed. A huge thank you to Mylan, makers of Creon, for making this workshop possible.

[Sign up for the online workshop >](#)



### Crusaders VS All Stars

Join us at this special, family-friendly charity cricket match on Saturday 15 December 2018 at Hagley Oval in Christchurch.

[Read more >](#)



### Templeton Golf Tournament

Annual Canterbury golf fundraiser on Friday 2 November 2018. Teams of 4, \$140 per team. Free BBQ!

[Learn more >](#)

# Worldwide Survey To Promote Physical Activity For People With CF

Sarah Denford, a research fellow at the University of Exeter recently got in touch with us to share the news that she's working on a Cystic Fibrosis Trust funded project aiming to promote physical activity for young people with CF.

They are asking young people with CF, their parents/carers, and members of multidisciplinary CF teams to complete the survey to help build up the best possible picture. This data will inform the development of toolkits and interventions to better support young people to be active without limits. The more people that are able to take part the better!

[Take the survey >](#)

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