



Welcome To The November CF Panui!

Phew - November seems like it's been a crazy month! It's been a busy time at Cystic Fibrosis NZ pushing along advocacy efforts, kick-starting some exciting CF research initiatives, coordinating our first Blue Shirt Week with the help of PARI, setting up the Christmas Tree Festival in Wellington, and securing a spot as Charity of Choice at the Parker V Flores fight next month! Read on to find out more, and of course [get in touch with us](#) if there's anything you'd like us to include in the December roundup.

Blue Shirt Week 18

Next week marks the start of our Blue Shirt Week! PARI will donate 10 Euros (approx \$17) to CFNZ for every person who wears a PARI t-shirt at a sports event or personal challenge and posts a photo on the [PARI BOY 50 Jahre / Years](#) Facebook page. Easy peasy! Please note photos need to be posted by end Dec to be eligible. [Read more >](#)



Parker V Flores Supporting The Fight Against Cystic Fibrosis

We are incredibly grateful to be the Parker V Flores Official Charity Partner, helping to raise both money and profile of CF. The partnership includes e-direct mail to the Duco Boxing mailing list, advertising in the corporate programme, an auction on the night, plus a meet & greet with Parker for a member of the



CF community. Keep your eyes peeled for a special message on our Facebook in the next few days too! What's more, book a table of 10 in row 4, and as a supporter you'll receive 10% off the total cost and CF will also receive 10% kickback of this total value. [Find out more >](#)

CF Shining Bright At Wellington Airport

The CF Christmas Tree Festival is in full swing with dozens of beautiful, twinkling Christmas trees from local and national sponsors. Last year we raised a record total of \$40,000; this year we've aimed even higher, and thanks to Wellington International Airport and everyone taking part, it looks like this year will be our best yet! [Read more >](#)

Right: The Streetwise Coffee tree

[Watch the festival promo video!](#)



Advocacy Update

The Rare Disorders Subcommittee has now met to discuss Kalydeco, though we don't expect to hear from the committee until the new year. A huge thank you to everyone who took the time to write to Sarah Fitt, CEO of Pharmac and to David Clark, Minister of Health. The CFNZ Board signed off on the CF advocacy strategy at their meeting on 27 October. Lisa Woods, advocacy consultant, had the opportunity to present at the recent Chairpersons conference and will be getting in touch with the branches to discuss local advocacy issues.

Pole-Tober-Fest 2018

This is the fifth year of the Liberate Pole Dance and Exercise Cystic Fibrosis Canterbury Fundraiser Show that Olivia Allchurch has put together (owner of Liberate Pole Dance and Exercise) with the help from myself and Liv's students. Olivia has done such a great job producing yet again another great show fundraiser for Canterbury branch. [Read more >](#)

Pictured below: Juliet (left) and Liv at the fundraiser.



Upskilling In Mental Health

CFNZ were recently invited by CF Australia to a Mental Health Roadshow presented by Alexandra Quittner Phd and Anna Georgiopolous MD. Sue and Gretchen were fortunate to get flights funded by [Air NZ](#) so were able to attend these valuable workshops. Alexandra has been involved in CF research for 30 years and spoke about the background around testing for anxiety and depression of people with CF over 12 years old and of carers, and the findings that depression and anxiety were two to three times higher than reported in the general community. Anna is a psychiatrist from Boston and spoke about assessing anxiety and suicidality, psychopharmacology, ADHD and substance misuse, CFTR modulators and transplant psychiatry. Lots of information to take in!



CF Research Kick-Start

On Wednesday 21 November CFNZ and Cure Kids gathered a cross section of researchers, clinicians and community together to kick-start the development of a single vision for CF research for NZ. Five key themes became apparent as being crucial for building a research vision for CF for New Zealand. An action plan and timeline is currently being developed for presentation to the Cure Kids and CFNZ Boards this side of Christmas.

Successful Chairies

The Board, CE and Branch chairs met for the CFNZ Chairpersons Conference in late October to reflect on last year's progress and to develop their thinking around important issues facing the organisation and PWCF. Topics for discussion included branch health, community support, marketing, fundraising and advocacy to name a few. The AGM was also held over the weekend where Warwick Murray was reappointed to the Board and one vacancy remained. Following the AGM the Board elected Jane Drumm as chair of the board.

Cross Infection Policy Update

The Clinical Advisory Panel, established to provide CFNZ with professional support from CF clinicians, will be meeting in December to discuss and confirm the revised Cross Infection Policy. We will publish the policy on the CFNZ website when approved.

Improvements In Lung Function In Phase 3 Studies

Exciting news – Vertex has announced that studies involving a triple combination treatment significantly improved lung function in people with the ddf508 mutation (the most common mutation). This has massive implications for many people with cystic fibrosis, and we'll be following the continued development of the treatment closely. [Read full announcement >](#)

Otago Cricketers Take The Bait

Dunedin CF fishing legend Dylan Booth recently spent a day out on the water with players from the Otago Volts Cricket Team. He shares with CFNZ how the cricketers fared swapping cricket bat for fishing rod. "My health hasn't been very good lately as I've been in and out of hospital for the past few months, so I thought of a brilliant idea to do a fishing outing with the Otago Volts Cricket Team. [Read more >](#)

Right: Cricketer Mark Craig with his rainbow trout



Golfing Success For Canterbury

Golfers were treated to some good weather and a lot of laughs at the annual Charity Golf Tournament held at the Templeton Golf Club on 2 November. A field of 68 players competed in this year's event. The Ambrose format of play with a shotgun start added to the fun and each team finished about the same time, apart from the usual stragglers. [Read full story >](#)

Pictured below: (left) Fieldworker Sue, Canterbury Chair Melissa, and new committee member and BBQ star Allister on the day! Loving the groovy CF apron too :)



Stuck On Christmas Shopping?

If, like us, you're preparing to face the crowds to get the Christmas shopping done... don't forget you can order the beautiful Rachael's Lipstick direct from the Karen Murrell website! This gorgeous pink colour was chosen by Otago CFer Rachael and has now been confirmed as a permanent addition to the range. Plus, 50/50 of the proceeds go to Cystic Fibrosis NZ and Make a Wish NZ. A gift most certainly in the Christmas spirit! [Find out more >](#)



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