

In this issue: Charity Cricket, Update from the Board, Wellington Xmas Tree Festival, Claire's Mountain Climbing Expedition, Rylee Aces Sports Awards, CFNZ Raffle Draw, CFNZ Office Dates [View this email in your browser](#)



Crusaders Charity Cricket Big Hit!

Super Rugby Champions the BNZ Crusaders went into bat for CFNZ at the 35th annual Charity Cricket match, raising a big sum of over \$30K to support New Zealanders with CF.

The Crusaders were up against the All Stars Invitational team, led by Andrew Mehrtens, which was able to break the Crusaders five-year winning streak for the annual 20/20 Charity Cricket match.

It was particularly successful this year - the sunshine helped attract more people on the day which also featured a Kids' Cricket Academy in the morning, and a marquee with stunning art on sale.

A lot of people put in a huge amount of effort to make this day a success and we would like to thank the BNZ Crusaders, the Invitational team, Dan Vann for his Cricket Academy, The Rock for all the publicity, schools that ran mufti days to support the event, Poster Boy Harry, Jen Duncan for organising and all the amazing volunteers who gave up their time to support CF.

MC Chris Bond gave a moving talk about his personal experience with CF. "I have a cousin who has CF and have experienced first hand how important CFNZ are and the amazing work they do," he said.

Update from the Board - Ed Campion

After the recent election of a new board at the AGM, the December board meeting provided a chance for us all to get to know each other. Because it was the first time we had met, we spent some time working together to determine how we will function and behave as a board and looking at the governance role and particularly how this applies in a not-for-profit organisation.

There has been some great work done by the CFNZ team in applying for grants.

There have been 27 requests completed worth approximately \$90,000 in the past few months. Jeanette the CFNZ Grants Coordinator has done an amazing job - keep up the great work! Typically, Jane B (CE) has had to seek approval from the board prior to lodging grant requests. To aid the effectiveness of this process the board agreed to enable grant applications to be completed and submitted without prior board approval in the future - we are all of the opinion that unless this is a specific requirement by the particular funding body all funds to benefit PWCF are great and the more streamlined the better.

The 2018-2020 Strategic Plan is scheduled for development in February/March with the aim of getting this out to the branches for consultation shortly after. At the Chairpersons Conference in October some initial work was done which will be very useful in setting the strategic direction of CFNZ for the next three years.

We were delighted to hear of a significant grant obtained from S.K.I.P (Strategies with Kids, Information for Parents). This grant came about as a consequence of the empathetic interviewing that was recently done with young families of PWCF. The insights that were gained from this process clearly demonstrated a need for improved resources for parents. As a result this grant will enable further interviewing in Auckland and development of web-based parenting information.

The board received an update on the Clinical Advisory Panel (CAP). There has been some great interest in membership of this, with work being done to finalise the team so that they are ready to meet in the New Year.

It is pleasing to report that the financial position of CFNZ is strong with the predicted minor deficit at the AGM now looking like a small surplus for this financial year.

The board members determined membership of sub committees as below:

- Mark Passey – CF Adult Advisory Group (with Chair Lisa Borkus)
- Ed Campion and Jane Drumm – CF research/SiLF (Shares in Life Foundation)
- Catherine Rusby – Investment committee (with Chair John Parsons)
- Warwick Murray and Michele Wilson – Risk committee
- Jane Drumm and Jane Bollard – CAP

Finally the board would like to thank Jane Bollard and her team for all of their hard work this year and we would like to wish you all a safe, healthy and happy Christmas.

- CFNZ Board Member, Ed Campion



Merry Christmas Tree Festival!

CFNZ Wellington's amazing Cystic Fibrosis Christmas Tree Festival features some very original displays from local businesses and sports teams. At the gala opening this month, the Axe furniture store tree (pictured) was named the best Xmas tree because of its inspirational black and white photos of people meeting loved ones at Wellington Airport. It's wonderful to hear native birds singing in the Kiwibank tree and the Wellington Hospitality tree provides a handy guide about the bars and restaurants in the capital. CEO's from Wellington Airport, Air New Zealand, NZ Rugby and CFNZ all spoke at the gala. CFNZ is especially thankful to the Wellington Branch for the time they devoted to making this year's festival the biggest and brightest yet. We are delighted that Wellington Airport has confirmed the Xmas Tree Festival for 2018.



Rylee's a Great Sport!

Rylee's taken out three big sports awards for 2017. She's been named Taradale Intermediate's Year 7 Athletics Champion, came 2nd in cross country and also received the MVP (most valuable player) award for her netball team. Her family say Rylee embraced her first year of intermediate with the school's great sports culture - helping to keep her well with all the exercise.

Reminder to check WINZ eligibility

CFNZ Fieldworkers are finding some CF families aren't getting the Disability Allowance costs they could be entitled to. [Check this link](#) to see what subsidies could be available for families who receive the Disability Allowance.



Raffle Winners

Congratulations to the winners in the CFNZ Annual Raffle. The winning names and numbers are on the [website](#). Thank you to Red Crayon raffle marketer Ross Ford (pictured



Claire's Mountain High!

Climbing The Remarkables in Otago is hard enough without CF - Claire Scofield's lung function is between just 43-46 percent but here she is making the most of her mountaineering boots bought with her Breath4CF grant. Claire starts to notice the low oxygen levels in the mountains from about 1500 metres and her climb in The Remarkables was about 2300 metres, and it took her about twice as long as other climbers. "But I just love the mountains so much, any chance to get high and I'll take it," she says.

Teen Transplant in Woman's Day

Emma Taylor's lung transplant at the age of just 18 has featured in Woman's Day. The story gives a moving account of the tragedies Emma and her family have faced and the life of someone waiting for a transplant. You can read the real life story on [Pressreader](#). Emma is back home after her successful operation, and planning to study interior design and go travelling. She's celebrating Christmas with her family but says she's already received her greatest gift - thanks to her lung donor.

CF News Out Soon

We are pleased to report that CFNZ has now received two grants to publish the summer edition of CF News (yes, Jeanette strikes again!). Due to the holiday season this issue will be mailed out in February.

right) for helping with the draw and to friendly chiropractor Kamal Merai who was our upstanding citizen for the raffle draw. Thanks to everyone for selling or buying all those tickets.



CF Canterbury's Kiwibank Hero

CFNZ Canterbury Chair Melissa Skene received her Kiwibank Hero medal at a presentation this month. The Kiwibank Local Hero Awards honour everyday people doing extraordinary things in their community. Melissa gave up a full-time career to help run Canterbury Branch 18 years ago and we are forever grateful for her efforts. She is pictured in white in the middle of the front row.

Respiratory Awards Open

The Asthma and Respiratory Foundation's Respiratory Awards are open for nominations for people who achieve their goals despite living with a respiratory condition. Achievements can cover sports, leadership, academic, cultural and community and include being able to manage a respiratory condition while living a full life. [See the website](#) for more information.

Update your Email

Please let us know if you have changed your email address after Vodafone stopped its email service. Email us at admin@cfnz.org.nz with your new email if it has changed. Thanks!

Merry Christmas and Happy New Year!

CFNZ staff are on deck until midday tomorrow. The office will be closed until 8 January 2018. During that time people are advised to contact their medical team in the first instance. Any fieldworker queries should be directed to Sue Lovelock who is the CFNZ Fieldworker who will be periodically checking messages. Email: sue@cfnz.org.nz. Mobile: 021 0222 1203.

CFNZ wishes the CF community a happy and safe holiday season. We have had a very strong year and couldn't have done it without the support of all our wonderful branch members and volunteers. Merry Christmas!

Good Links:

- [Researchers may have found link to organ transplant rejection](#)
- [Wristband can detect CF](#)
- [Mums carry extra burden of caring](#)
- [Happy life despite low lung function](#)
- [Proton pump inhibitors linked to hospitalisations](#)
- [Big Life Fix features a breathing therapy game for two brothers with CF. Watch on demand at TVNZ](#)
- [Kalydeco safe and effective for 1 and 2-year-olds](#)

Panui - sign up here

Quote of the Month: *"When I started raising \$ for the CFF in high school (1976), I never could have imagined the decades of fundraising, the amazing patients and parents I would*

meet, and the deep involvement with the CF science community that would become such a special blessing in my life. Thank you so much for your appreciation of my efforts and know that I will never stop until we have a one-time cure for everyone with cystic fibrosis!"

- Bob Emmelkamp, [Cystic Fibrosis Research News Facebook Page](#)



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