

In this issue: Wellington Xmas Tree Festival, Crusaders Charity Cricket, Update from the Chief Executive, Marathon Effort in Auckland + Queenstown, CFNZ Raffle closes next week [View this email in your browser](#)



Wellington Xmas Tree Festival Best Yet!

The Wellington Christmas Tree Festival is now bringing a touch of Christmas magic to Wellington Airport. More than 25 trees sponsored by local sports teams and businesses went up this week - making the Festival the biggest yet. This year the Airport has donated a huge indoor billboard which features the above image to help raise awareness of CF. It is also displayed on a digital rotating advertising board in the Terminal and we are extremely thankful to the Airport for its generosity.

CF Wellington organiser Michele Wilson is particularly impressed with the level of support from Airport Chief Executive Steve Sanderson and the marketing team. If you're travelling through Wellington Airport keep a look out for trees decorated by the All Blacks, the Hurricanes, Wellington Phoenix, Weta Workshop, David Jones, Whittaker's, CFNZ and more! The NZ Symphony Orchestra and Chamber Music New Zealand have volunteered to play during the Festival so you might get hear some soothing sounds as well.

Caleb Conquers Marathon

Caleb Skene has run the Queenstown Half Marathon after being given a ticket for his 20th birthday from friends at the beginning of the year. At the time Caleb, who has CF, was looking for a new challenge. He had 10 months to train but after putting it off for many months he started training hard including a two-hour run around around Hagley Park which unfortunately left him with severe blisters just one week before the



Queenstown Marathon. Luckily his feet healed enough for him to complete the half marathon in 1:49min - a very impressive result! Also, thank you to the runners from Willis Towers Watson, which ran the **Auckland Marathon** a month ago, raising \$7000 for CF Auckland.



35 years of Canterbury Charity Cricket!

For 35 years the BNZ Crusaders have sacrificed their love of rugby to switch codes to play in CFNZ's annual Charity Cricket match.

This year the Crusaders will be taking on an All Star team including former All Black and Crusaders star Andrew Mehrtens in the friendly 20/20 match on Sunday 10 December at Christchurch Boys High School. The All Stars are hoping they can break the Crusaders winning streak for Charity Cricket. The free family day out is expected to be the best event yet. Along with a Children's Cricket Academy to start the day, a new feature will be a market marquee which will feature artwork on sale by local artists to help raise funds for CFNZ including a portrait of the late cricket legend Martin Crowe by Ira Mitchell and also artwork by former TV presenter Erin Simpson. Artwork by Svetlana Orinko inspired by 65 roses, which is a worldwide symbol of cystic fibrosis, will also be auctioned at the Charity Cricket match. We also welcome the return of Harry Ensor (pictured on the banner above) as the event poster boy.

Update from the Chief Executive

Good On You Capital & Coast DHB!

Our recent interviews and discussions with families living in Wellington show that the employment of a CF Specialist Nurse at the hospital has made a huge impact on the ease and access to treatment for their children:

"I cannot tell you how excited I was (with the organisation of the annual review) and what an amazing job the CF nurse is doing.

She has taken a lot of stress away from us as a CF family.

What usually takes three days of trips to the hospital was done in a day."

- Wellington mum

After many years of lobbying by CFNZ and the Wellington Branch, Tricia Martin's appointment has made the world of difference. While the role was initially for a year, we are delighted that this position has now been made permanent.

Also, I have been impressed with the willingness of the project team to engage with both CFNZ and the Branch regarding the new Children's Hospital build. We have been able to be involved from the outset in this exciting project. The Wellington Branch Committee and I received a guided tour of the concept clinical rooms this month.



Pictured here: DHB's Consumer Engagement Lead Ava Gibson with Wellington Committee - Nicci Hughson, Kim McGuinness and Paula Richards.

- Jane Bollard, CFNZ Chief Executive

Pole-Tober-Fest Party Pics

We received some amazing photos from the Pole-Tober-Fest show (see below) which raised a record total of \$4500 for CF Canterbury. You can see from these photos what a great show it was. It featured burlesque, dancing, acrobatics, the CFNZ bucket on stage, and also two people who were invited on stage to try breathing through a straw to get a taste of what having CF is like. Thanks again to Juliet Hubbard and Liv Allchurch from Liberate Pole Dance and Exercise for organising.







Pharmac Changes Rare Disorder Medicine Application Process

Pharmac has established a number of new measures which hope to improve access to rare disorders medicines in NZ. A Pharmacology and Therapeutics Advisory Committee (PTAC) rare disorders subcommittee will be established, Pharmac will regularly call for rare disorder funding applications and engage with suppliers before doing so. It will also drop the requirement for Medsafe approval (drug licensing) before a funding application can be considered. (So far Orkambi has not be registered with Medsafe in NZ).

Meanwhile, the New Zealand Institute of Economic Research has released a [report into funding of medicines in NZ](#) which shows a drop in the proportion of the health budget devoted to pharmaceutical purchasing. The report shows that inflation, population growth and a widening of purchase responsibility means that Pharmac has effectively a little more than half the portion of the health budget it had a decade ago for community pharmaceuticals.

CF Survey and CFNZ Publications Project



Paul's Prestigious Award

New Zealander Paul Fowler has earned recognition for his extraordinary fundraising efforts, cycling 4000kms around Europe, raising \$20,000 for Cystic Fibrosis Western Australia. He was jointly named the Patron's Awards Community Fundraiser of the Year and was presented with his award by Australian Governor-General Sir Peter Cosgrove (pictured right) this month who is also the Patron of CF Australia. Paul grew up in Rotorua with CF then moved to Australia. He's now living in Germany.

Terry's Trek for Maddy

Terry Wilson is back from his pilgrimage to walk the Camino in memory of his granddaughter, and featured in an [article on Stuff](#) which has also led to more media interest. Terry raised over \$5000 on his [Givealittle Page](#) for Cure Kids and CFNZ during

A survey of the CF community is planned for early next year which will help in forming CFNZ's new strategic plan and future priorities. We'd love to know the kind of information that is important to you for the development of this survey which will be carried out by an experienced health researcher.

Email us your input:

info@cfnz.org.nz.

We are also in the process of updating our information guides and would like to hear from the families of newly diagnosed children and families of children who have recently started school for their input and ideas. We've contracted Sarah Cahill, former Starship nurse and professional writer to help us with this project. If you'd like to make any contribution

email: sarahcahill14@gmail.com.



Raffle Draw Next Week!

Last chance to buy tickets for the CFNZ annual raffle. There's an autographed 2017 All Blacks jersey up for grabs, Choice Hotels accommodation and also two tickets to the WOMAD Festival which is almost sold out. The raffle is drawn 13 December. Raffle tickets and money need to be in by 6 December. Good luck to all in the draw. [See all prizes on the CFNZ website.](#) [And order here.](#)

Ahoy Students!

There are still a few spots left for female students for the Spirit of New Zealand's Inspirational Sailing Experience in February when 30 physically challenged young people from around NZ will embark on a 5-day subsidised sailing voyage from Princes Wharf in Auckland. Travel to

his pilgrimage and although it was a lot more strenuous than he anticipated, Terry's now got the walking bug and is considering more CF charity treks.

Makena's Keeping it Real

Aucklander Makena Houston made headlines after she was featured in a lingerie modelling campaign for Lonely Lingerie which likes to use "real women" as models. Makena's modelling photo with her oxygen tubes went viral on Facebook and the story featured in a number of newspapers including [The Daily Mail](#).

CF News Update

There's a bit of a delay on the next issue of the CF News. Normally it would be published in December but CFNZ is waiting on a grant to print the magazine - fingers crossed it will come through soon and we can publish early next year.

In the meantime, the last CFNZ Panui of 2017 will be emailed on Thursday, 21 December.

Anyone not signed up to the Panui should get on the list because it's a great way to keep up with the latest CF-related news. Email:

comms@cfnz.org.nz.

Update your Email

People with a Vodafone email address have had to switch providers.

Email addresses that are affected:

- clear.net.nz
- es.co.nz
- ihug.co.nz
- paradise.net.nz
- pccconnect.co.nz
- quik.co.nz
- vodafone.co.nz
- vodafone.net.nz
- wave.co.nz

Auckland is included in the cost. Applications need to be in 6 December. [Inspirational Application Form](#) - [Inspirational Medical Form](#).



Dreadlock Holiday

Glen hasn't had a haircut for over 10 years but that's all about to change when Glen's dreads get the chop in support of CFNZ and his nephew with the condition. Glen's kindly set up a [Givealittle Page](#) to raise funds. Donate before 30 December which is D-day for Glen's dreads.

People with these email addresses can set up automatic forwarding to their new email addresses but please update us at admin@cfnz.org.nz with your new email if it's changed - we don't want to lose anyone.

Good Links:

- [MS drug can kill Pseudomonas](#)
- [Gene therapy blog from Cystic Fibrosis Foundation conference in the US](#)
- [Latest trial data for upcoming CF therapies](#)
- [Phone and video monitoring for CF patients](#)
- [Nasal cells may determine if precision medicines will work](#)
- [Virtual reality used during CF treatments overseas](#)

Panui - sign up here

Quote of the Month: *"I'm very proud of myself - as you all should be proud of yourselves for how you handled the year. I think we should all get one small present - even a chocolate bar - wrap it up and on the card you write your name and the message 'I am so proud of you' - sign it and stick it under the Christmas tree - go on do it."*
- Terry Wilson, who walked the Camino in memory of his granddaughter Maddy



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