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**In this issue:** Awareness Week Wrap, CF on Shorty St, Board Elections, Call for Clinicians, Cystic Sister's Transplant, Max - the Little Ripper, CF Voting at The Warehouse, CF Hub & HB Casino Night



Panui



## Amazing Awareness Week of 2017

Awareness Week got off to a fine start with plenty of media coverage - including an article in the [New Zealand Herald](#) on collection day about the exciting research and game BreatheHero to improve rates of physiotherapy that's under development - definitely a big win for CF awareness.

Big thanks to Rachel Elliott and her son Luke (pictured above), and Starship Associate Professor Cass Byrnes for helping make this newspaper feature happen. A number of other people shared their experiences with CF during the Week. [Mark Passey](#) revealed his plans to launch a new scholarship scheme for Kiwis with CF in the Bay of Plenty Times on collection day and [Damien Bell](#) spoke about his lung transplant the day before.

Other media stories include [Erana Soper](#) in the Northern Advocate, [Raupunawaiariki](#) in the Taranaki Daily News, and [Claire Fisher and Amber](#) in Hawke's Bay Today. It was wonderful to see collectors out in force in many areas last Friday and Saturday.

Even the New Zealand Symphony Orchestra got into the swing of it by having a string quartet playing during the collection at Wellington International Airport - and drew quite a number of donations.

Thanks again to **Choice Hotels** for donating \$2 from every night stayed during

Awareness Week to CFNZ and also **Streetwise Coffee** which were selling chocolate fish and providing donation boxes at all their coffee carts around NZ.

Sincere thanks to all the volunteers and schools which ran fundraisers, coin trails and also the popular sausage sizzles. See photos below, including a cool one on Instagram of some of the NZ Rowing Team waving chocolate fish and the lovely Rosmini College boys in Auckland collecting yet again!



## Update from the Board

CFNZ had another full and productive Board meeting at the end of July. We welcomed Ed Campion from CF Christchurch to our Board meeting who is considering standing for the CFNZ Board. We are looking for three Board members in September as we had a resignation earlier this year. Some of the skills involved in Board membership include governance and leadership skills to assist the strategic leadership of CFNZ (such as ability and experience working strategically within a governance framework), financial and business management (especially from a governance perspective), fundraising strategising, understanding or experience with advocacy, medical/clinical knowledge of CF or networks within that area that may be advantageous to CFNZ. Please contact CFNZ Chair [Jane Drumm](#) or Chief Executive [Jane Bollard](#) for more information. Nominations close on 1 September.

The Board is also seeking a new Adult with CF representative for the Board and those interested can contact Jane or Jane for more information about this position. The Adult Rep will work closely with Lisa Borkus, Chair of the Adults Advisory Group, which provides feedback and advice to CFNZ Board and management.

As we are nearing the end of our three-year Strategic Plan, the Board with the CE are now working on a community survey and establishing focus groups to inform our next Strategic Plan. This will be our guiding document that will help us prioritise what we would like to achieve over the next three years. We encourage you all to take part

and let us know where you would like to see CFNZ in three years time. The terms of reference for the Clinical Advisory Panel (CAP) have now been approved by the Board and we are now calling for expressions of interest from our CF medical and allied health community - see more details below. This group of clinicians will provide advice to CFNZ on medical and scientific issues, and also help CFNZ establish its priorities for improved care of people with CF in NZ. We have also been researching to support a review of the CFNZ cross infection policy to make sure we are aligned with other CF organisations around the world. CF Australia has a new policy coming out towards the end of the year and we have decided to wait until the CAP is up and running before approving a new policy. Finalising this important aspect of our policy will be one of the first projects they work on.

By the time you receive this Panui, CF Awareness Week will be over for another year. On behalf of the CFNZ Board, I would like to acknowledge the CF team (both staff and volunteers) who have put in endless hours to make this week a success. Plans are already underway for next year's 50th celebration so please watch this space (and all CFNZ communications) for opportunities to get involved.

**By CFNZ Board Member Kim McGuinness**

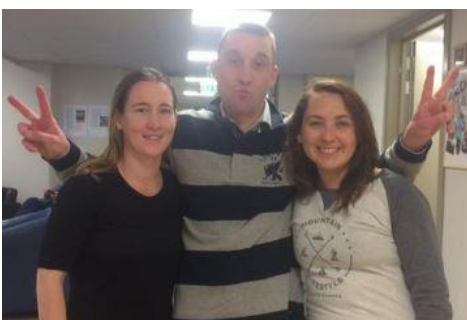


## Shortland Street Features Cystic Fibrosis

For the first time, TV's Shortland Street has featured a main character affected by cystic fibrosis. This month it was revealed that Sass's love interest, Dr Hawk's Logan (pictured above) has the cystic fibrosis gene. A previous partner also had the CF gene and they had a son with the disorder who passed away.

TVNZ tells us that this is not going to be an extended story line but it was featured the week before Cystic Fibrosis Awareness Week which was great for awareness of the disorder and hopefully encouraged more people to donate.

It was also CFNZ's most successful Facebook Post, with 283 "Likes".



## Cystic Sister on the Mend

Isn't this picture a sight to behold! Kristie Purton is recovering well after her lung transplant and for the first time can safely hang out with other CFers who've had lung transplants such as Rupert and Alana (right) pictured here at Hearty Towers in Auckland. Kristie's also able to hang out with her own sister Nikki now which is yet another advantage of her transplant which gives her heaps more energy to keep up with her three children. Kristie was also the lucky winner of a \$20,000 More FM Home Facelift competition thanks to a huge number of votes so life is definitely on the up.



## One to Watch!

CF legend Max was named Most Valuable Player of the Year for Riversdale Rippa Rugby in Southland. Not that surprising since he got Player of the Day for his first match ever!

## CFNZ Call for Clinicians

CFNZ is now calling for expressions of interest from clinicians to be involved in CFNZ's new Clinical Advisory Panel, which is being established to provide CFNZ with honest and impartial advice on clinical aspects of the activities of CFNZ. The Panel will include two CF paediatricians and one CF adult chest physician, one paediatric CF Nurse and one adult CF nurse, a physiotherapist and dietitian. Additional specialists will be consulted as required. Email Chief Executive Jane Bollard: [ceo@cfnz.org.nz](mailto:ceo@cfnz.org.nz) to request the specific terms of reference for the new CAP.



## Casino Night Next Week

It's the Hawke's Bay Casino Night next Saturday in Havelock North which will bring flashbacks to the psychedelic 60s as gamblers get into the spirit of the 60s theme.

The annual Casino Night

## CF Hub

Kiwis with CF are being invited to join the Australian-based network, CF Hub, which is a members-only online community for people aged over 16.

[The CF Hub website](#) is aimed at improving social isolation associated with CF and also provides fresh information for the CF community.

There's worldwide news, personal stories from others with CF and topics related to equipment, CF cooking and also a meditation room.

## Warehouse CF Voting Stores

Warehouse stores are continuing their support of local CF groups through their Bags for Good voting programme. Customers can vote for CF if they ask for a token at the following stores when they buy a shopping bag (remember to ask for a token).

- Auckland's Atrium
- Sylvia Park, Auckland
- Morrinsville
- Te Awamutu
- Matamata

is Hawke's Bay Branch's main fundraising event of the year and always a fun night of irresponsible gambling - all in the aid of raising funds for CF. [Buy tickets online.](#)



### Yaam is a TV Good Sort

Wairoa teenager Yaam was honoured with a visit from the [1 News Good Sort](#) programme for what turned out to be a moving segment. Yaam was nominated as a Good Sort after his wish to plant 300 olive trees was granted by the Make a Wish Foundation. Yaam (15) is pictured here with his dad and CFNZ Fieldworker Jude Kelly who paid a visit to Yaam's Farm.

Branches are thankful for the success of CF at a number of stores in the past six months. Auckland Branch received over \$2000 from one store, the CF token boxes at Whanganui and Palmerston North were always the most popular and Taranaki Branch has formed positive connections with the New Plymouth store.

### Panui Thursdays

For almost three years the Panui has been delivered on the last Friday of every month but from now on it will come out on the last Thursday of every month. So look out for the next edition on Thursday 28 September.

### Good Links

- [Lung transplant survival rates study](#)
- [Virus-eating superbug research](#)
- [Funding of Orkambi rejected in Australia](#)
- [Animated characters highlight long-term health conditions](#)
- [Life hacks for chronic illness](#)
- [Marvel supports CF Captain America campaign](#)

[Panui - click here to sign up](#)



Facebook Website

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