

**In this issue:** Casino Night Record Win, Update from the Board + New Board Members, CF Rides Again, Canterbury's 30th Golf Tournament + Gene Editing Lectures [View this email in your browser](#)



## Hawke's Bay Casino Night Gives Peace a Chance

The CF Hawke's Bay Casino Night took a trip back to the psychedelic 60s for their popular annual fundraising event.

The gambling on blackjack and roulette wheels was all in the aid of local people with CF - this year raising a record total of \$17,000 thanks to some generous auction bids including Cape Kidnappers luxury accommodation that sold for \$2000.

The 60s theme proved popular with everyone dressing up for the occasion. There were hippies, go-go girls, minis, maxis, headbands and high boots. Elvis Presley also joined in the fun.

## Update from the Board

The September Board Meeting was an interesting day addressing important aspects of CFNZ's business and with the support of CFNZ's Chief Executive we agreed these actions/decisions:

- The strategic planning process for the 2019-2021 Strategic Plan was agreed and will be assisted with input from information provided by early diagnosed families, branch chairs and members, our Adult Advisory Group, overseas learnings, researchers and clinicians, comprehensive surveys of adults and families with CF children, environmental scans, global research on charity best practice and so on. It will be a very well-informed strategy.
- Chief Executive Jane Bollard has many things on her to do list and the Board has helped her prioritise her top five activities to focus on and these priorities will be what drives her budget. Jane reports regularly on her key priorities.
- The Board has agreed we will not have an Annual Conference in 2018. There are a few reasons for this, such as dwindling attendance and the large expense that a conference involves and predominantly a commitment to the 50th year anniversary activities which would be competing for resource and time.
- We were delighted to hear the progress and success of Port CF, with 98 percent of available data completed and reports for 2015 and 2016 available by the end of the year. Most importantly, with strong data CF clinicians are in a better position to be developing trials which will likely help improve clinical practice and improve the outcomes of PWCF. Accurate data also helps in our advocacy for bringing new and better drugs to New Zealand.

- We continue to seek grants and support which will help in refreshing and redesigning our website - this will offer exciting new functionality to the CF community.
- The Board is evolving and growing our governance capabilities. We have now established a Risk Committee which will look at how we minimise operational and strategic risks before they happen. This committee has already drafted a Fraud Risk Management policy which states a ZERO tolerance for fraud in any area of the organisation.
- Who knew? CFNZ does fund research. We have a ring-fenced fund that is specifically for research. Some know it as the Shares in Life Foundation (SiLF) and we will now be promoting it as CF Research so that it is clear to the wider community. It is another aspect of CFNZ that donors can choose to contribute to. Our most recent research project is a joint project with Cure Kids. Together we now have more money and resources to assist research projects that will make a difference to CF lives. SiLF (now CF Research) also contributes \$20K every year to CFNZ to support immediate needs and that is distributed in the form of many types of assistance that we call "Quality of Life".
- CFNZ have now completed our move to consolidated accounts and we continue to aim for a single system for financial management. The Board approved last year's financials (subject to audit) and this was approved by the Branch Membership at the recent AGM. We continue to manage our finances closely. We are aware of income uncertainty (nature of a charity) and welcome all suggestions for fundraising and donations.
- Wellington is getting a new Children's Hospital and construction will start very soon. The Wellington Branch has asked for CFNZ's support to outline the requirements for the new building and future proofing it as a single location for CF treatment for the greater Wellington region. The Board recognise that the best care for PWCF in the Wellington region will most likely come from a single location with state-of-the-art treatment and care facilities, which will have the potential to become a regional centre, therefore the Board are putting their support behind a Children's Hospital that will provide that level of service and is future proofed for PWCF in the greater Wellington region.
- Expressions of interest for both the Clinical Advisory Panel (CAP) and the Board representative for the AWCF have been received and reviewed. Appointments will be made as soon as possible. For the CAP, once appointments are made a meeting schedule will be set. The AWCF Board Rep will be invited to the next CFNZ Board meeting in November.

As a member of your Board, I can assure you that we are working with the CFNZ management team to grow our organisation into an even stronger and more effective organisation, delivering best practice services to our CF community and stakeholders.

**- Catherine Rusby, CFNZ Board Member**

## **Warm Welcome to New CFNZ Board Members**

At CFNZ's Annual General Meeting this month two new Board Members were elected to the Board - Ed Champion of Christchurch and Michele Wilson of Wellington. Long-serving Board Chair Jane Drumm was also re-elected. The new members replace outgoing Board Member Kim McGuinness and former Board Member Cheryl Moffatt, and join current Board Members Warwick Murray and Catherine Rusby. CFNZ extends a huge thank you to those who have served on the Board and extends a warm welcome to our new Members.



## Schools' CF Fundraising Super Stars

Pakowhai School in the Hawke's Bay (top) held a dress in blue day for CF. They raised \$50 for the local branch from the gold coin donations which was a great effort for a small rural school with less than 30 pupils there on the day. Students also made the most of the *Be a Star for CF* signs for the photos.

Macleans College (left) presented a \$5000 cheque to the Auckland Branch following their big fundraising efforts including three bake sales and selling chocolate fish. Westlake Forest Hill Kindergarten in Auckland (right) also came up with a healthy fundraising idea for CF. They asked children to bring vegetables from home and turned them into a nutritious soup to be sold back to parents for a donation to CF Auckland.

## CF Rides Again in Big Charity Bike Ride

Cystic Fibrosis Canterbury has been fortunate to be selected as one of the charities for next year's [Central South Island Charity Bike Ride](#). This race raises a lot of money for various charities and Canterbury Branch is delighted to be chosen as a recipient once again.



**Mercury Energy**

## That's Choice!

[Choice Hotels](#) made a huge donation of \$12,000 to CFNZ following their campaign during Awareness Week to donate \$2 from every night stayed at one of Choice Hotels NZ properties to CFNZ. A most welcome donation - thanks Choice!

## Marathon Effort in Auckland

Auckland Branch is getting set for the Auckland Marathon on Sunday 29 October and is keen for more runners to join them.

Insurance brokers, Willis Towers Watson, has a team of 20 at the starting line and is fundraising through [Givealittle](#).

Anyone who runs the half marathon or marathon for CF Auckland will get a well-deserved massage and bacon butties at the finish line.

## Gene Editing Lecture Series

The Royal Society of New Zealand held a lecture series around NZ about gene-editing (CRISPR) this month. The Auckland lecture, *Making babies: You, me and gene editing?* discussed what level of gene editing would be acceptable as a society. Currently, genetic embryo research is against the law in NZ. One of the speakers, Dr Mary Birdsall of Fertility Associates said at this stage NZ is watching to see how the research develops overseas. She said that couples worried about having a child with CF can have pre-natal diagnosis with an IVF cycle but gene editing would be helpful in cases where a couple's embryos all test positive for CF.

Interestingly, she is also asked about sex selection 4-5 times a week from couples undergoing IVF. Sex selection is against the law in NZ. We will include a full report about this lecture in the next issue of CF News.

## Generates Funds for CF

Anna Scoullar-Jones of Central Districts Branch has a sister Katy (left) who works for Mercury Energy in Auckland. So when Mercury announced it was giving \$10K donations to ten different charities nominated by their staff members, Katy instantly thought of Anna caring for a son who has CF. Her heartfelt submission pulled no punches about the plight of people with CF describing it an "often lonely situation".

It must have struck a chord with the selection committee because CFNZ is now \$10,000 better off! Huge thanks to Katy and Mercury for this donation.

## More Media

In the past month a few more CF-related articles have appeared. Two weeks ago the Sunday Star Times featured [12-year-old Tylah Davidson](#) about how Kalydeco remains unfunded in NZ.

Businessman [Mark Passey of Tauranga](#) revealed more of his plans to launch a new scholarship for the CF community in The Weekend Sun. And the Cystic Sisters told their amazing story in That's Life magazine this week with the excellent headline: *65 Days of Goodness*.

## Ahipupu Challenge

The third [Ahipupu Challenge](#) in Northland to support CFNZ is being held on 7 October. A record number of teams will be competing in the Challenge which sees them climbing Mt Parihaka, paddling 6km in a waka and swimming 20 lengths of the pool in the Whangarei Aquatic Centre. Good luck to all the athletes and a big thanks for the ongoing support!

## Good Links:

## Golf Tournament Turns 30!

It's Canterbury's Templeton Golf Tournament on Friday 3 November - an extra special occasion this year because it's the 30th anniversary of this annual fundraising event. The Ambrose tournament costs \$140 per team (four players per team). There's a free BBQ and food served during the tournament, plus prizes for every player. Golfers keen to mark this occasion and help raise funds for people with CF in Canterbury can contact Nicky for tickets. Email: [doug.nick@orcon.net.nz](mailto:doug.nick@orcon.net.nz) or phone 021 515 767.

- [Good Nutrition could slow progression](#)
- [Home iv's safe as hospital - study](#)
- [5 myths about CRISPR](#)
- [How to support a partner with a genetic disorder](#)
- [Yummy chicken for CF](#)
- [Fighting a war against CF - personal story](#)

**Panui - sign up here**

**Quote of the Month:** *"Of course it would be great not to have CF, but you can't afford to think like that. I have been dealing with this since I was six. And no, you can't live your life being scared of it."*

**- Mark Passey, Tauranga**



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