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cf CYSTIC FIBROSIS NZ
Creating Better Tomorrows

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CF news

BRANCH NEWS

from around the country

Highlights from the
**CHAIRPERSONS'
CONFERENCE**

Auckland Marathon
BREAKS RECORD

TRAVEL TALK
with Lizzie McKay

MEET SINEAD

NZ's first Kalydeco kid



Update from the Chair

MAY, AUGUST AND SEPTEMBER BOARD MEETINGS

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As part of our plan to keep the CF community better informed about the Board's activities we have introduced new updates to be published in CF News.

This is where we will bring you highlights about any important happenings or new developments, so hopefully you will feel more involved with the Association and where we are headed. Here are some key items from the Board meetings in May, August and September.

At Belinda Burnett's first Board meeting held in May the new CEO, presented her interpretation of CFNZ Strengths, Weaknesses and Opportunities, and identified the following:

STRENGTHS:

- Passionate, knowledgeable and committed staff
- Dedicated funds for strategic programmes
- High level of clinical care being received in most regions

WEAKNESSES:

- Split loyalties – a regional v national vibe
- Uneven representation on Board (no South Island people on Board, Adult rep position(s) not outlined in the constitution)
- Somewhat confused identity – Auckland branch website, National office/National website, CF News and Branch newsletters

Belinda's discussion with the Board showed that some small branches are people-poor and cash-rich (based on per capita of PWCF in the branch area) whereas large branches tend to be cash poor and people rich. The Board feel some members may feel disconnected with the Association for a variety of reasons and this may be a possible reason behind the lower numbers attending conferences in the past few years.

Opportunities for CFNZ growth that were discussed included pursuing new funding streams and centralising managed services and communication to ensure all branches are kept well informed and that the community is engaged and active. The Board agree the critical importance of focusing on equitable treatment for all PWCF and their families regardless of where they live.

At our August Board meeting I accepted the resignation of a long-time Board member John Elliott. John has been a valued member of the Board team and we are all very appreciative of the energy and enthusiasm and robust discussion that John has brought to his role on the Board. On behalf of the Board and our CFNZ membership, I thank John and warn him that we will still be picking his brain and asking for his help at times.

The good news is there will be a Cystic Fibrosis National Conference next year. It will be held in Wellington in May 2015. It would be wonderful to see as many people as possible attending. As most branches are very successful with grant applications that pay for conference attendance, the cost of attending should not be a barrier. The conference speaker programme will be planned by a small committee and we hope it will have content that has high interest to as many people as possible.

In September, the Shares In Life Trustees met. Shares in Life was originally established to help fund NZ scientific and medical research into CF. The SiLF Trustees discussed methods to attract more research applications, and updates with regard to PORT CF and Quality of Life initiatives. Following John Elliott's resignation as a SiLF Trustee, the Board will be looking to appoint a new Trustee.

The lack of progress getting decent paediatric services in Wellington was noted as a major concern at our September Board meeting. Belinda reported that she had met with Capital Coast Health and had been told that a paediatric CF service was a priority within three years but that they aimed to achieve it in one year. We, as an Association, are committed to keep pressure on the DHB to make sure Wellington gets the service it deserves and equity with other CF Clinics around NZ

JANE DRUMM, CHAIRPERSON


 SNIPPETS


UPDATE from the CEO

My first update to you will be brief as we have such an action-packed issue this month!

Welcome to the branches who have elected to use the National CF Newsletter to communicate with their members – hopefully before too long all 12 branches will join in and the CF news will be representative of all our regions.

The progress I have made in the eight months since I started may not be immediately evident. However, I can report that the meetings I have had so far with Capital Coast DHB, the Ministry of Health and various pharmaceutical companies are a stepping stone to advancing the cause of CF on all fronts.

I have also worked with the Canterbury and Auckland branches on fundraising events that are shared between the branches and National. This is an initiative that I hope will soon become the norm for all the CF Branches.

I have also had the great honour to meet many of you in person. I am proud to represent such a committed and knowledgeable bunch of people. I look forward to working with and for you in the years ahead.

Enjoy this magazine in its new format – we would appreciate any feedback about the new look to the Editor.

Merry Christmas and a happy and safe New Year!

BELINDA BURNETT, CEO

Join our E-Newsletter Panui

An electronic update with the latest news and updates from the Association, called Panui, is being produced by Vicky (the National Information Coordinator) and emailed out on the last Friday of every month. It is currently being emailed to office bearers for the 12 branches. CFNZ want all our members to sign up to receive the Panui.

To sign up email Vicky at comms@cfnz.org.nz.

President's baby granddaughter

CFNZ Denis Currie's son, Cameron, has his hands full with a new addition to his family. Baby Georgia Elizabeth, pictured here at just 6 days old, is a brother for Patrick aged 6. Denis is thrilled for his son Cameron who at 41 has been fortunate to enjoy a healthy family and a rewarding career as a senior IT executive at NAB Bank in Melbourne.

"He's done well and both kids are great. The little boy is great and Georgia is a beautiful baby. She has a good set of lungs," he smiles.



Spring for donations

A funding partnership with Springfree Trampolines will see CFNZ getting \$140 for every trampoline sold.

Trampolines are considered an easy and effective form of physiotherapy and Springfree Trampolines were judged to be the safest trampoline out of five tested in New Zealand.

If you are buying a Springfree Tramp, please quote our unique code NZRP101 to ensure donations come through to the Association.

Choice donation from Choice Hotels

Choice Hotels has raised an impressive \$12,000 with their first Take a Breath for CF fundraising week held in support of the CFANZ.

To support us as their chosen charity partner, Kiwis were encouraged to take a 'breather' and stay at a NZ Choice Hotel between 8-14 June. From every stay during the week, \$2 was donated directly to CFANZ.

'We're delighted with the result from the campaign,' says CFANZ chief executive Belinda Burnett.

"The money raised will go towards supporting our field workers and the fantastic work they do travelling the country to help people with Cystic Fibrosis."

Choice Hotels recently announced a two-year extension of their partnership with the Association and will continue to substantially lower travel costs for CFNZ by providing free room nights at their properties around New Zealand.

The Choice Hotels website: www.choicehotels.co.nz, also features a prominent banner advertisement to help raise awareness about CF.

"It's great to see a large hotel chain provide us with so much support," she says.

www.choicehotels.co.nz



If you ask Sinead what's the worst thing about having CF, she'll tell you it's the isolation and exclusion – exclusion from the community, exclusion at school and isolation from other teenagers who have CF.

MEET SINEAD

NZ's first Kalydeco kid

Now Sinead (13) is finally pleased to have something to be singled out for. She's the only person in New Zealand getting funding for the medication to treat her rare genetic type of cystic fibrosis, G551D. But Pharmac isn't paying for it, Sinead is getting access to Kalydeco on compassionate grounds through the pharmaceutical company, Vertex. And it's already made a big difference, with Sinead's lung function almost doubling in just 12 days.

To date Pharmac has deferred a decision on funding the medication. Pharmac has also refused an application to pay for Kalydeco (ivacaftor) for Sinead on a named-patient basis because of her other health issues. Sinead has a kidney condition and complications from being born at 29 weeks gestation.

Getting access to Kalydeco is a victory for Sinead and her mother Andrea Neame who have been fighting for it ever since it was still under development seven years ago. Kalydeco has recently received government funding in Australia.

Andrea and Sinead are still committed to

fighting for government funding in New Zealand because they want all the other PWCF who have the G511D gene to have access to Kalydeco. Also, there's no guarantee that the compassionate supply through Vertex will continue indefinitely.

"If we go into another global financial recession that's the end of Sinead's Kalydeco. So while I'm eternally grateful to Vertex, there's no security," Andrea explains.

Sinead is happy to be a figurehead for the campaign to get funding for Kalydeco. She knows how lucky she is. It's definitely the most expensive tablet Sinead has ever taken.

"Mum told me 'don't you ever lose one. They cost \$500 US each!'" she says.

Sinead only started taking the medicine in November and the results after 12 days of treatment speak for themselves. Her lung function (FEV1) has gone from 38 percent to 77 percent and she has put on 2.1kgs.

"That is a huge response to Kalydeco," says Andrea.

Sinead is among the most serious cases of CF

in New Zealand for her age.

“Without Kalydeco Sinead doesn’t have much chance. We also still don’t know how she is going to respond to Kalydeco long term,” Andrea says.

“Sinead’s lung function has been very poor. She has huge problems with breathlessness and fatigue. She has CF-related diabetes and uses an insulin pump, has severe sinus disease, and must have night feeds. Sinead misses a lot of school.”

Andrea is keen to stress that Kalydeco is not a miracle drug and must be used in conjunction with the usual CF regime.

The family have moved from Invercargill to Auckland to help get access to Kalydeco and during her fight for the medication Andrea actually visited Pharmac in Wellington to get a meeting with the Chief Executive. But the news was not good.

“They told me in no uncertain terms that Sinead would never be funded for Kalydeco in this country. She wasn’t a candidate for transplant. I felt like the Pharmac executives were telling me that Sinead was too sick to waste money on. The wording in the letter says ‘the cost benefit outcome is poor’.”

The medicine costs about \$NZ350,000 a year. Vertex says it can’t comment on individual cases.

Andrea is naturally thrilled her daughter is now receiving it, but wants others to know their fight is not over yet. Her guess is that Pharmac will not fund Kalydeco until that and another drug, lumacaftor is approved as a combination therapy to treat the more common genetic type – DeltaF508.

But Andrea knew that she didn’t have time to wait. “I needed to secure funding to help Sinead as quickly as possible. If we can help Vertex get Kalydeco available in New Zealand it will be better for many more people with CF when the combined therapy becomes available.”

You can follow Sinead’s progress as “the Kiwi Kalydeco Kid” on Facebook.
www.facebook.com/kalydeco4sinead

ABOUT THE PHOTOGRAPHER:

Spiros Poros is an Auckland-based professional photographer who volunteered his time to take Sinead’s photo. We offer a sincere thanks to him and assistant Ben Blair for helping to make our new cover look great. Once based in New York, other stars he has photographed included J.Lo and Keira Knightley. He also has experience with fashion and documentary photography.

To book Spiros visit: <http://spirosporos.com>

Kalydeco overview

Kalydeco (ivacaftor) is considered a breakthrough in the science of genetics and drug development.



It is the first medicine which operates to directly affect the protein (CFTR) for a specific gene that causes the cystic fibrosis. It potentially could help about 30 New Zealanders with CF that have that specific gene. Significant benefits have been demonstrated in the trials done here and overseas in these individuals. Kalydeco is also a triumph for the Cystic Fibrosis Foundation in America, which contributed to funding its early development at Vertex.

What is it?

Kalydeco is a pill taken twice a day with fat-containing food. It helps the protein function better improving its action as a working chloride channel by semi-correcting the defect in the protein caused by this particular gene. This helps to normalise airway secretions helping to clear mucus from the airways resulting in improved lung function, less chest infections, and it also has benefits on other aspects of cystic fibrosis such as increasing weight.

Who will it help?

There are many different strains of the cystic fibrosis gene, but it’s only those with the defective gene called “G551D”, which the New Zealand Medicines’ Authority, Medsafe, has approved Kalydeco for – and only for those aged six and over. About 30 people in New Zealand have the defective G551D gene according to cystic fibrosis registry data.

How effective is Kalydeco?

Two major studies, one of which was published in the prestigious New England Journal of Medicine, concluded that Kalydeco significantly improved lung function after two weeks and the benefits continued during the trial for almost a year.

Will Kalydeco help others in future?

More studies are needed to determine whether people with other cystic fibrosis genetic disorders may benefit from the medicine. It may be that it will also have a good effect on other genes that cause faults similar to G155D. It has recently been shown that alone it will have no effect on the defects caused by the DeltaF508 gene.

Will it be funded in NZ?

Like other drugs for very rare diseases, its price is very high, about \$NZ350,000 a year. It is funded in 19 countries around the world including Australia, the UK and the USA. The company which makes Kalydeco, Vertex, has made a submission to the NZ drug funding body, PHARMAC, but so far a decision is still pending.

Rachael Ward tells her story of falling in love and marrying John Ward who has CF.

"I met John at his work when I bought a cell phone off him and we discovered that we went to the same church but had never met. We found that we had many similar interests including our love of Sci Fi and music and after a few months of seeing each other around we started hanging out as friends.

On the second time we hung out I discovered that he had CF because he left a medical letter lying around. It didn't faze me as I had grown up with a brother who has autism and as a firm believer in Jesus Christ I have faith in healing.

Hanging out turned into dating and dating turned into a serious relationship and after a year and a half of being together John proposed to me on my 23rd Birthday at the lookout point in Riverton. I cried and hysterically said yes and then called my parents straight away.

We got married on the 27th of September in our church Invercargill Christian Centre, my bridesmaids and I walked into a Star Trek Enterprise theme song Faith of the Heart which was made even more special because John did his own cover version of it and recorded it all himself.

My dad officiated the service with John's dad's assistance and we shared our own personal vows that were a secret from each other until now. We had a Star Wars cake especially made for us which was cut after the ceremony and our bridal party shots were taken in Riverton as where our reception was held. It was so windy that day that during the photos which were taken outside, one of the groomsmen started tearing up because of the wind and my dress came unhooked at one point.



Rachael & John's SCI-FI WEDDING



Before reception I surprised John by changing into a second wedding dress but he didn't even notice that I had got changed until I really prompted him!

Our reception was in the Riverton RSA where we had dinner and dancing and the traditional embarrassing but heart-warming speeches of course. It was a great day surrounded by the people that we love but more importantly God had his hand on it because the day went so smooth and everyone had such a great time.

I am so stoked to be married to such a great man and I know that God isn't finished with us yet, he has great plans for us and has promised us hope and a future."



HIGHLIGHTS FROM THE CHAIRPERSONS' CONFERENCE

The annual CFNZ Chairpersons' Conference saw Board members and branch representatives gathering in September to discuss some of the current issues facing the Association and the best direction for the future.

The shrinking charity dollar and a tight fundraising environment has seen the Association look to new methods of funding, which is one of the reasons it has appointed Kiwifirst to fundraise on behalf of CFNZ.

Kiwifirst presentation

Kiwifirst is currently the direct marketing service for the Haemophilia Foundations, Make A Wish Foundation, Jigsaw and Riding for the Disabled.

Kiwifirst founder Steve Waring, who has haemophilia, told the conference that the service is committed to ringing every household every 12 months on behalf of CFNZ, offering to send them a marketing pamphlet with a view to making donations. No payments are taken over the phone and the service aims to develop a long-term relationship with donors and build knowledge and understanding of cystic fibrosis throughout the wider community.

It was estimated that around \$80,000 would come to CF in the first year of operation.

Branches voted unanimously for Kiwifirst to become official fundraisers for CFNZ with donations to be split 50/50 between head office and the branches – on a population basis, and to review the relationship after the first year. Money raised will be spent both locally and nationally and always for the benefit of people with CF.



CEO's bit

Chief Executive Belinda Burnett's presentation to the conference centred on improved communication

between branches and seeking equality of care around the country.

The Auckland Branch grants team have identified grants that National Office and branches can apply for and have offered to help them. Belinda has asked for branches to provide positive stories to support these applications. Showing the difference a funding grant has made to someone's life is a great way to get a repeat grant! These stories will be made non-identifiable.

Workshop session for the CFNZ Strategic Plan

A new strategic plan for the Association is being developed. Aly McNicholl who is a director of the NZ Coaching and Mentoring Centre and lectures at UNITEC in Not For Profit Management, headed the session to help representatives provide feedback to help the Board plan for new influences expected to impact on CFNZ and PWCF in the future.

Some of the major issues identified included:

- Problems with PORT CF buy-in
- Lacking of funding for medication
- Few NZ specialists

Some suggestions for improvements included:

- Branch education updates
- Shared sense of urgency with medical teams
- CF nurse consistency

Chairpersons will consult with their branch committees and feedback any comments or suggestions in preparation for the new blueprint.

Branch business

Access to Pulmozyme trials was discussed and branches have been asked to provide feedback about what is happening in their area, especially as the criteria for Pulmozyme has been relaxed and more people are able to be put forward for the trial.

There are also issues related to the DHB funding of nebulisers and physio equipment. It is a major task for our branch committees when these items are not funded by a DHB. Pharmac decisions on equipment are due in 2017.

Concern was raised about the level of the funeral grant limit of \$1,000 and inequality of access to financial support because of different funding levels around the country between the branches. There will be a review of the welfare policies by the board and staff of CFNZ, and will be presented at the next Chair's Conference.

The development of a plan for newly diagnosed families to be put in touch with the Association and branches was called for because there are also wide variations in how this is being achieved around the country with the possible effect that new families are not very aware of what the Association does and how to get involved if they should wish to.

Golden boy Joe CLAIMS SILVER

It's hard to believe that Dunedin man Joe Voyce was once an underweight adolescent.

Joe (23) has not only transformed his body, he's also achieved his goal of becoming an award-winning bodybuilder after placing second in a Dunedin Bodybuilding competition.

Joe, who was diagnosed with CF as a baby, has managed a weight gain of 26 kilos after taking up bodybuilding two years ago.

And he placed second in his Novice Physique category at the Dunedin Bodybuilding Champs, NABBA, in September this year – the first time he has entered the amateur competition.

"I wanted to do really well but I wasn't expecting to come second. I was over the moon," Joe says.

When Joe decided to start pumping iron he weighed 55kgs, but managed to gain 26kgs after consuming a whopping 6000 calories a day, which included eight eggs, and five protein shakes.

"I made sure I ate as much as possible. I also had to hit the gym six or seven times a week," he explains.

"I was really skinny. I always bought small size clothes. It's harder to buy clothes now because I fit XL and kept outgrowing them."

From the ages of 10 to 16, Joe struggled with his health and ongoing complications from cystic fibrosis.

"I was often getting sick. I was in hospital quite a few times. When I was 12 I had dropped down to

27kgs. I was skin and bones," he recalls.

"It's been a hard road keeping weight on," says Joe who would recommend weight lifting to others with CF, but adds it's not for everyone.

"People with CF can't always breathe easily so running can be difficult. Although you do still need a decent amount of breath for bodybuilding.

"It doesn't happen overnight. It's a massive lifestyle choice," says Joe who was lifting 120kg on the bench press and 46kgs on dumb bells.

Joe, who manages a supplement store, has had exacerbations a few times since he started training.

But because Joe was keen to keep up with the body building he followed the advice of his doctor and went straight into treatment each time.

Although Joe is aware of some people injecting steroids to build muscle, Joe says that's absolutely not for him.

"It's just been a lot of hard work. I'm just trying to get as far as I can as who I am."



While training Joe's typical daily diet consists of:

Breakfast

1 cup oats
4 eggs
2 x toast
Protein shake

Mid-morning snack

Chicken + rice

Lunch

Chicken + rice
Protein shake

After lunch

Beef + salad wrap

Before gym

1 cup oats
Protein shake

After gym

1 Tbspn of Nutella
1 Tbspn peanut butter
Protein shake

Dinner

Roast or fried rice

Supper

Protein shake
4 x eggs
2 x toast

MEDICAL OPINION

Dr Richard Laing, the lead physician responsible for the Christchurch Adult CF Team, says any exercise is favourable for PWCF but any sporting activity or the use of supplements should be run past their CF medical team to make sure the PWCF makes the right decisions for their own individual health.

"They should work closely with their dietitian to make sure their nutritional approach is sensible. Some of the supplements that are used can be counterproductive," he says.



Pepster breathing therapy

Move over Minecraft and Flappy Bird, a new video game is under development and it's just aimed at children with cystic fibrosis.

The new game **Pepster**, invented by an Australian university student, makes breathing therapy for children more fun because they have to use their breath as a game controller.

Engineering student, Elliot Smith, has won two technology awards worth \$10,000 and \$5000 for his mobile app called Pepster which includes two games, including one where a person's breath controls a spaceship and also records how well the child is doing so doctors can monitor their progress and make adjustments if necessary.

Elliot says Pepster is essentially a digital version of medical devices but connected to a mobile or tablet.

It is aimed at children from four to 14 most of who find chest physiotherapy a chore.

"This gives them an incentive to do their physiotherapy more regularly and also allows us to record the information and send it back to doctors."

But it's not available yet. A clinical trial involving 30

patients is underway and once that's finished the inventors will seek approval from medical authorities in Australian and the US to put it on the market.

Although he couldn't comment on the medical trial, Elliot said things were looking positive as many patients were using the device regularly.

"From the parents, the feedback is that their children are genuinely enjoying the experience and it's stopped being almost a chore."

Elliot has no personal connection with CF but realised he could do something to improve people's lives.

"After talking to families and specialists at the hospital we felt it was a great cause to devote our time towards."

"I thought I could sit there and write Flappy Bird 2 or I could devote myself to something like this and I thought this was the best use of my skills and the resources I have at hand, and it's a really rewarding thing to spend your own time on I guess."

RECIPE ROUND-UP



Sausage Meatballs

This is a great starter or snack that kids can make. It can easily be frozen into individual servings that can be reheated at a later time.

Prep time: 30 minutes

Ingredients:

- 500gm pork sausage, raw
- ¾ cup all purpose baking mix
- 2 cup grated cheddar cheese
- ½ cup onion, chopped finely

Directions:

1. Preheat oven to 375°F (190°C).
2. Combine all ingredients in a large bowl and mix well.
3. Form mixture into 2-3 cm balls.
4. Place on cookie sheet and bake for 15 to 20 minutes or until cooked through. Center temperature of the sausage balls must exceed 165°F (73°C).

Serves: 12

Serving size: 3 sausage balls

Nutritional analysis: (PER SERVING)

234 calories
11 g protein
18 g fat
485 mg sodium
168 mg calcium

Note: Nutritional analysis may vary depending on ingredient brands used.

Variations and suggestions:

This dish can easily be frozen before or after you cook it. Make some today and freeze half of the batch to serve at a later date.

This recipe is thanks to the website **Kidshealth.org** which has lots of great recipes for kids with CF: kidshealth.org/parent/recipes/cf_recipes/cf_sausage_meatballs.html

Christchurch nurses CELEBRATE CONFERENCE WIN

Appendicitis may be rare in children with CF, but studies show when it does occur it's much more serious.

The most recent studies into appendicitis in CF was presented at the Cystic Fibrosis Nurses Conference in Melbourne in September 2014 by Christchurch Hospital nurses Alison Duggan, Bridie Callaghan, Margy Wanty and Jo Hall, whose insightful research won the best abstract presentation at the conference.

The research into perforated appendix and appendiceal abscess in children and young people with cystic fibrosis was also presented by Alison at a National Office staff meeting in October.

The study identified a 1.2 percent rate of appendicitis in PWCF over a 16 year period at the Canterbury DHB, below a rate of 1.5 percent determined by international research. There is an incidence of seven percent in the general population.

They found that appendicitis is difficult to diagnose in children with CF as they don't always experience classic symptoms, such as centralised abdominal pain which can spread to the right lower abdomen, fever, vomiting, and nausea, loss of appetite, constipation or diarrhoea.

"Kids with CF tend to get tummy aches and there are lots of reasons for it. Children with CF are given regular

antibiotics and steroids which can mask the inflammatory symptoms, which can make appendicitis present as very similar to DIOS (blockage of the intestines)," Alison explains.

"Diagnosis is further complicated because in people with CF the appendix is usually large and distended and full of mucous – so even people with CF without appendicitis tend to have an abnormal looking appendix and this can be a cause of chronic rumbling abdominal pain, but that's a completely separate thing to acute appendicitis," Alison explains.

"It has been suggested that the thick and sticky mucous in the appendix of a person with CF may actually have a protective action in that nothing can get in and infect it."

However, the perforation rate and abscess formation in CF is over double than the general population.

Two patients were presented as case studies at the CF Nurses Conference. One was a six-year-old who was admitted with a perforated appendix and abscess, and the other a 16-year-old who had passed out at a clinic appointment and was found to have an appendiceal abscess.

Both patients required surgery



I-R: Jo Hall, Alison Duggan, Bridie Callaghan, Margy Wanty

and high dependency unit or intensive care unit admissions. The six-year-old's recovery was described as "virtually miraculous" for a child with CF, and she was discharged after six days.

The 16-year-old had a much more prolonged and complicated recovery with several surgeries over a period of months, however he eventually made a full recovery without major lung complications.

Along with carefully-planned pain management, Alison says the keys to recovery with CF patients are to get them on their feet mobilising, and to begin chest and breathing therapy as soon as possible after surgery to prevent lung complications, and to manage bowel function to prevent DIOS.

"With all children, but particularly children with CF, abdominal pain – particularly new or sharp pain – should always be reported to their doctor," Alison says.

When Alison's group was presented with their award of an iPad mini at the conference, they decided to give it to their 16-year-old case study subject, who was thrilled with the gesture.



Aden aged 4 and Thomas aged 10 years

YOUNG ENTREPRENEUR supports CF

Hi I'm Thomas - Back in April I went to the National Young Leaders Day in Rotorua where there were inspirational speakers who talked about what they did to help people. When I got back home I decided that I would sell chocolates for Cystic Fibrosis. Aden lives just down the road and he has Cystic Fibrosis so I went online and bought chocolates with the money I had earned from catching goats and plucking possums.

I sold them all at Pony Club so I put a notice in the school newsletter to say I would be selling chocolate bars at school. I bought Picnics, Crunchies and Chocolate bars from The Warehouse for \$1 and sold them at school for \$2. My two best mates Ethan and George helped me. We sold them at morning tea and lunch time for two weeks. We raised \$257.50 for a great cause.

Also once a week Mum drops me off at the Bradcocks house before school and I help Aden with his nebuliser and I would really like to help raise money for CF again.

Tributes flow for Win

CFNZ has farewelled dedicated supporter Win Beattie who died suddenly after a short illness. She was 88 years old and had been committed to caring for children with cystic fibrosis since starting work as a paediatric nurse in Hutt Hospital in 1970.

National Board member Margaret Nicholls paid tribute to Win at her funeral in July, describing her as a person who was widely respected for care and knowledge.

"Win was a rare medical person who not only had a professional interest in a group of her patients, but also a care and concern that went above the call of duty."

Win had worked at the Hutt Hospital on the children and adolescents ward from 1970 to 1988. She developed a special interest in working with CF children and their parents, alongside paediatrician Dr Archie Kerr.

"Win organised the local Christmas parties for the children for many years," recalls Margaret, who has two sons with CF.



"Nowadays it's a tragedy for PWCF that they cannot get together with their peers because of the dangers of cross infection."

When a group of young CF women began a national adult group with monthly newsletters, Win took over when illness interfered with their work.

The Cystic Fibrosis Association of New Zealand granted Win a Life Membership in 1995 in recognition of her service – a privilege that's only ever been awarded to five people.

"Win was also brave," says Margaret. "She attended the funerals of the young people and over this last decade would say that she wished it could be her and not them losing the struggle."

At Win's funeral Margaret thanked Win for loving our children, for fighting the good fight and keeping the faith.

NEED A FUN WAY TO RAISE FUNDS FOR CF?

Hawke's Bay Branch has got a recipe for a fun night which managed to raise over \$10,000 our first time using it - see page 17 for more details. Like all recipes, the more you use it, the better at it you get. We'll refine it each year but here's the basic recipe.

INGREDIENTS

- 1 enthusiastic team of 3 or 4 volunteers from your local branch
- 1 centrally located venue with a bar and great catering
- 1 supportive supplier of Casino Equipment
- LOTS of generous donators of prizes/auction items
- All your friends, family and acquaintances available on the night dressed to impress...

METHOD

1. Pick a date which avoids major conflicts (e.g. All Blacks games, School holidays, Cricket World Cup etc)
2. Book the casino equipment, location, caterer and major sponsors.
3. Tell everyone!!
4. Assign several folks to go forth and secure auction items.
5. Tell everyone again – sell tickets
6. Get your good duds on and get ready for a night of laughs and harmless gambling. Winners are Grinners!
7. Feel incredible at the end of the night when all things are tallied and you've all had a great night AND made lots of money for CF!!

If your branch is interested in running a Casino Party as a fundraiser, contact Catherine Rusby by email (cathrusby@hotmail.com) and she'll help you with putting the night together.



FUNDRAISING MODELS

Central Districts Branch dressed to impress for Bubbles Week at its annual Ballentynes Fashion Show.

Six volunteer models, including a Wanganui District Councillor and a Ballentynes staff member, showcased summer trends at Ballentynes Fashion Central during CF Awareness Week in October. Branch Chairperson Anna Scoullar-Jones says they each brought their own special flair and style to the runway, with a small but enthusiastic crowd of women looking on.

There were spot prizes, an Avon raffle and supper to follow, along with much shopping. This was the 4th annual collaboration between Ballentynes Wanganui and Central Districts CF Branch, and raised several hundred dollars to benefit the branch members. This was in lieu of a street collection.

Wendy Ballentynes' staffer
Bery Nugent Radio Network
Jenny Duncan Wanganui District Councillor
Sarah Hird Pharmacist
Deb Paton Ministry of Health
Stephanie Bishop Driving Miss Daisy



A special thank you must be extended to Russell McVeagh, the law firm which had 32 people registered for the event. They made a total of almost \$10,000. We wouldn't have achieved such an outstanding result if it wasn't for them. They also kindly allowed us to enjoy the food and refreshments

CFNZ breaks Auckland Marathon record

It was a record-breaking result for this year's Auckland Marathon fundraising efforts. We made a total of \$33,500 thanks to all the athletes that chose CF as their charity.

offered in their corporate tent after the race.

Last year \$22,000 was raised from the Auckland Marathon. This year we decided to invest in a Gold ticket for the event, which meant we were one of Auckland Marathon's listed charities on their website, and volunteers could also register to raise money for the designated charities.

We even had a few CF athletes competing, including eight year old Amy from Waikato who entered the Kids Marathon.

Despite two sprained ankles Leonard Thompson (pictured left) decided to continue to carry on for the sake of his wife Huia who has CF, and to honour the donations of his friends and family who had raised

\$1270 for his effort for CF. However, Leonard decided to power walk the course instead.

"He was going to give up," Huia explains. "But as sore as he was he was determined to go ahead."

Leonard (52) only decided to enter the event one month before, but he tagged all his and friends on Facebook, and soon the donations were flowing in.

"We've got a big family. We weren't expecting such a good result. Tagging is a good option for athletes who are running for charities," Huia explains.

Huia (51) was only diagnosed with CF in 2006 and her health has been stable until recently.

"Just lately it's got worse. But hey, I am lucky I got to see over 50!"

SPECTATOR'S REPORT

Anthea Wendelborn and Jo Ringer were on the side lines to support our runners. Anthea reports on the excitement in the air:

"As we parked the car at Smales Farm and chose our cheering position at the side of the road we knew the marathon runners were on their way. Armed with makeshift CF signs on badminton racquets we were ready to cheer our fabulous runners on as they passed us at the 10km mark. Fortunately, we found ourselves beside two of the most vivacious and positive women out there on the side lines at 6.30am in the morning. It didn't take us long to chat with these fabulous strangers who religiously cheer runners of all kinds every year at the same spot. Their enthusiasm made up for the lack of coffee intake (thanks to Columbus being firmly shut at that time) and soon we were buzzing with excitement

(and a few emotional tears) as the first runners came by. We had such a blast cheering our team of runners (and many others taking on the full and half marathon challenge), receiving the unexpected smiles, and "that's our charity", and cheers for us in response to reading our swaying racquets swinging above our heads. Some of the runners "dress-up" outfits were also "out there" and entertaining. Are there any keen cheerleaders for next year keen to get wild and wacky with our outfits?! Could be fun.

Well done to each and every one of you who ran and raised money for our cause "Cystic Fibrosis"



this year. We applaud you and thank you sincerely for your efforts.

Jo and Anthea (CF Mums).

CF AWARENESS (BUBBLES) WEEK 13th – 19th October

We approached this year's CF Awareness Week with a bit of uncertainty as the branch have had a tumultuous year with losing our office space, scrambling to find a new one and then moving into our flash new office. Needless to say the willingness was there but there was very little lead in time to get things organised. Then just as the dust began to settle we lost our valuable Branch Coordinator Wendy! We did however manage to pick ourselves up and secured our new Branch Coordinator Shelley Oliver.

So with that all behind us, we decided to go full-steam ahead and give Awareness Week preparations everything we had and to make it as successful as possible. Nothing like throwing Shelley in at the deep end of the pool!

Our first glimmer of light came when Robyn Somerville, Committee Member, put up her hand and said that she would hold a "High Tea Fundraiser" for friends and family. The original plan was to invite about 30 people but when word got out about how fabulous it was going to be, the guest list exploded and at least 50 people attended. Robyn, with the help of her daughter Nicole, was fortunate enough to secure sponsors who were able

to fill goodie bags and provide many prizes for auction. The High Tea was a great success. We are grateful to Robyn and Nicole for all their efforts in making this Awareness Week event such a success.

Our next stroke of luck happened when Jo and Anthea confirmed an arrangement to have TWO sausage sizzles at Mitre 10 Albany, a week apart. Both days were fun and Jo and Anthea's families teamed up to make these events successful making a whopping \$700 for the branch.

Shelley managed to secure permissions from the Auckland Council for street collecting in 16 different venues – just in the nick of time. We were so lucky that the weather was perfect and so lots of donations were collected from generous shoppers all around Auckland.

Unfortunately, there was a very disappointing incident where Lions Club Pukekohe members were doing a bucket collection for us at the Pukekohe Countdown and a person snatched a bucket and ran off. Another man attempted to steal the other bucket but fortunately one of the Lions Club Members managed to hang onto it. The volunteer was much shaken and we are grateful that no serious harm had come to her.



We send out a HUGE thank you to all the Branch Committee Members, the Auckland Branch community and all the generous volunteers that contributed to the success of our CF Awareness Week events. With all your hard work we raised over \$10,000. It was a huge effort, with a very short lead-in time and we are so grateful to you all.

Having your help (and the help of your family and friends) enables this annual CF Street Appeal to take place. Please diary right now the dates for next year's CF Awareness Week, 17-23 August 2015.

We will be reaching out to you to help us, so feel free to get your thinking cap on now as to how you can be involved. We reckon that 2015 will be bigger and bubblier than ever before.

CF Auckland Branch 2015 Meeting dates

- 10 February 7.30pm Committee meeting
- 14 February 9am–12pm Planning meeting
- 10 March 7.30pm
- 14 April 7.30pm
- 12 May 7.30pm
- 9 June 7.30pm

Contact: auckadmin@cfnz.org.nz



Farewell to Wendy

The Auckland Branch would like to thank and acknowledge Wendy Edmonson our Branch Coordinator for the last two years. Wendy finished up with the branch in early September to allow herself more time with family and pursuing her many interests. The branch acknowledged Wendy's exemplary service with a presentation at the opening of the new CF Auckland Office. Wendy outlined how she would miss the contact with families and PWCF who she had built up great rapport with during her two years in the employ of the Auckland branch. Wendy has always gone the extra mile especially with branch events and fundraisers like Round the Bays, the Parent "Hot Tips" evening and of course our annual Awareness Week Appeal. We wish Wendy all the very best for the future.

THE SHIFT

On the 9th of May this year the CF Auckland office went mobile. Our three CFNZ Fieldworkers and the Auckland Branch Coordinator set up work spaces at home as we ended our more than 15 year shared work space relationship with the Parent and Family Resource Centre. Although leaving the people was sad, moving from the Onehunga building was not. The building had survived several floods, a fire and more recently had been overtaken by a “forest” of fungi. Our accommodation needs had also mushroomed so it was time to go! The search for a new “home” had already been in progress for about eight weeks with several “nearly there” moments. “Never mind”, said we. “Kiwis are adaptable and resourceful and lucky!” we thought, as we crossed our fingers and toes and put most of our furniture



into storage.

Fortunately, kindly KinderCare came to our rescue and we were able to store our operation day-to-day requirements in an extremely serviceable temporary office within the Mt Wellington KinderCare building.

Six weeks later, signed, sealed and delivered, we moved again into our fabulous newly decorated #79 Grafton Road space. There have been many changes this year and we acknowledge that at times it has not been easy. Staff have had to be particularly patient and amazingly adaptable, Branch Committee Members have seen more office spaces than they have had lattes and, in the middle of all of this there have been;

retirements, resignations and reallocation of responsibilities. (Pardon the appalling alliteration!) Now we are settled, stable and smiley and still have our fingers and toes crossed that #79 Grafton Road will be the CF Auckland Office for a long, long time.

WELCOME TO Shelley and Vicky

Although Vicky works for CFNZ (National) and Shelley works for CFNZ (Auckland Branch) as they started within a week of each other and are both based at the new Auckland Office, it seemed very appropriate to welcome them together and introduce them to the NZ CF community together.

Shelley is the Branch coordinator for the Auckland Branch and will likely be the person you first talk with when you phone the office. Shelley works Monday -Thursday from 9.30am and 3.30pm and is the first point of contact for all things to do with the branch. It has already been a very busy time at CF Auckland Branch for Shelley, even though she is used to a very full and eventful work environment in her previous positions; Office Administrator and PA for MS Auckland and as an Admin Advisor for the Northern Region Presbyterian Support. Shelley has organised our Awareness Week

appeal, coordinated the Auckland Marathon (CF as a Gold charity), recruited volunteers, updated the branch website and even attended and taken minutes for two branch committee meetings – all in the 10-short weeks she has been with CF. All this on top of keeping up with equipment requests, and hospital pack and voucher requirements from our CF Fieldworker, and getting the new office space operational... Whew I feel tired just thinking of it all!

Vicky our National Information Coordinator has also had a “baptism of fire”. Employed Monday-Friday 9.30 to 3pm to take on the communications and information “brief” for CFNZ, Vicky has in her short 11 weeks with CF taken on the production and coordination of our CFNZ Annual Report, the underwriting of the new e newsletter-CF Panui, Awareness Week publicity and press releases, note taking for the Board meeting and Chairpersons



Conference, CF News and much more. We are fortunate to have secured Vicky as her past work as a senior writer with NZ Women's Weekly, a writer for New Idea and her previous role for Family Doctor as the website editor make her a terrific and experienced resource for CFNZ in this newly developed role.

It has been my pleasure to have been involved with both of these appointments and I know you will all enjoy getting to know both Shelley and Vicky better and hearing more about what they are getting up to in their respective roles.

Jane Drumm, CFNZ Chair



12 days of Christmas

We were fortunate to be the recipients of a grant from Auckland Airport - 12 Days of Christmas.

This was used in our CF Community with a variety of items being purchased for our young people to get 'active' - running shoes, balls, hoops, bikes, racquets... the list was endless. Many thanks to Auckland Airport for making this possible for our community. Elliot and Kelea loved their new bikes!

AUCKLAND BRANCH NEWSLETTERS

The Auckland Branch has decided to produce monthly e-newsletters and to have several pages in the CF News, which is regularly distributed nationwide, as opposed to publishing our own separate newsletter twice a year.

The monthly e-newsletters are to be sent out to our existing database and any AWCF (who are not currently on this data base) would need to "opt-in" by contacting the Branch Coordinator Shelley Oliver at auckadmin@cfnz.org.nz. If in doubt, and you would like to remain in contact with the branch, please call text or email Shelley 021 820 566 to check if you are on our database, that way you will remain informed about branch "happenings".

THE MIDDLE YEARS Parents Toolbox Course

MONDAY NIGHTS, 7pm-9pm
23rd FEBRUARY - 30th MARCH 2015

CF Auckland has secured FREE courses at The Parenting Place that are specifically designed for parents of children with CF.

Only 15 spots available. Please register your interest with Shelley and we will update you with more information in the New Year.

6-12 years - *Make the most of these years while your children still want to be part of your team!*

The Middle Years covers:

- Parent types
- Building character and self-esteem
- Emotional resilience
- Discipline
- Creating traditions and memories
- Capitalising on the 'tween-age years'

Small group course with a trained facilitator

- Six sessions per course
- Tailored to your needs
- Tea, coffee, refreshments and nibbles provided

CYSTIC FIBROSIS OFFICES - 79 Grafton Road, Grafton, Auckland

Contact: SHELLEY OLIVER

Ph: 09 379 0374, Mob: 021 820 566, Email: auckadmin@cfnz.org.nz

Thanks Auckland Branch

With a donation that was raised "In Memory" the Auckland Branch has purchased steam sterilisers for all PWCF in the Auckland Branch catchment. Here is Angus pictured right with his new electric steriliser.



The branch purchased both electric and microwave sterilisers and people will have the choice of which kind works best for their situation (as the electric ones are bigger and perhaps a bit harder to store). The great aspect of this wonderful and generous gift is that keeping those ever so important nebuliser parts clean and bacteria/mould free is now so easy. Thanks so much Auckland Branch, Rangitoto College and the Perry family.

New flatscreens

Auckland Branch and another charity, Lung Health, bought 21 new TVs with DVD players for the respiratory wards at Auckland City Hospital this year. The ADHB was changing to a digital system so it was the perfect time to get new ones, especially as many of the old ones had not been working for some time.



MEETING REPORT

Jane Drumm reports on the meeting between the CF Adults Team and Auckland Branch committee representatives:

In the last Auckland Branch newsletter we outlined a new initiative where branch representatives meet twice a year with the Adult CF Multi-disciplinary Team. The purpose of this meeting is to express and work on any identified issues or concerns or queries as put forward by adults with CF, the branch or the CF Team.

The group have established that reporting back to the adult CF community via the CF News is a sound way to share any developments, new initiatives or changes to the CF hospital services (both In and Outpatients).

At our last meeting the CF Team outlined that as part of the AWCF annual review process/appointment the team will be encouraging people to identify personal goals that they would like to work on with regard to their CF care and wellness.

The agreed goals would be discussed at the annual review and would be recorded in the annual review letter that is sent out post appointment. AWCF will be asked to come to their annual review appointment prepared with some ideas for possible goals.

The team pointed out that it is advisable to have annual review tests done 2-3 weeks prior to the annual review and to bring in all CF treatment related equipment to annual review for checking to ensure everything is in great working order. The branch gave feedback to the CF Team that the AWCF they had talked with had noticed some positive changes with regard to the streamlining and reduced wait times at the Outpatients clinic.

A patient experienced a problem contacting the CF Nurse Specialist and found phone "tag" can be frustrating. Cath Lamont explained

that she is available by text, email and phone and that most AWCF prefer contact via text.

Cath's hours of contact are; 8am- 4.30pm Monday- Friday but during this time may not be able to answer her phone, e.g. performing a sterile dressing, with unwell inpatients. If you can't get hold of Cath please leave a message on answerphone/text or follow the instructions on the answerphone. When Cath is away someone else will be monitoring her phone and this may cause delays in a response.

Cath outlined the appointment process for CF clinics as some people are happy with their time and the notice period they get prior to an appointment and others would like much more notice. All clinic appointments (including annual review letter and test forms) are posted 3-4 weeks prior to the appointment.

The capacity of the CF clinic does reduce if someone is away. It is really important that AWCF contact Cath as soon as possible if you are unable to attend a scheduled clinic appointment or if you need to change the time. When people are late to clinic the schedule tends to get thrown out.

It is also important that any changes in details (address/email address/phone numbers) are passed on as incorrect details can lead to delays with receiving appointment letters, annual review letters and forms.

Post-clinic letters are available as a summary of the appointment. AWCF can receive these letters either each time or only after annual review time. It is up to you how often, some people like lots of information some people just like a little information.

The team would encourage each person to talk with the doctor

on what suits you best. Letters summarising clinic appointments can be sent by mail or electronically (i.e. via email) - once again please request whatever suits you best.

There was a query about transplant clinics as some AWCF have expressed concern that at times they feel that their CF-related questions are not being addressed by the lung transplant team they see in clinic.

Dr Mark O'Carroll explained that he is not always present at the transplant clinic. Mark expressed that transplant clinic is the best place for an AWCF who has had a transplant to be seen for many reasons including, but not limited to the fact, that the spectrum of possible clinical problems for an AWCF post-lung transplant is different from that pre-lung transplant and the transplant team are best placed to manage that.

Mark will put together a brief article that will clarify this for all AWCF who have had a transplant and live in NZ. This will be discussed with the Transplant Team so that they are aware of people's concerns about CF care and transplants.

The group also discussed antibiotic use and acknowledged that it is a fine line to tread with regard to administering antibiotics in order to find the right balance between current and future benefits, and the risks of antibiotic treatment of CF-related infections.

The team asks all AWCF who have concerns, queries, or issues about antibiotics to bring their questions to their annual review as part of the "goals" process, so that they can talk about it and make an informed decision to determine together the most appropriate approach.

YOU'VE GOT TO KNOW WHEN TO HOLD 'EM...

The highlight for our branch in 2014 has to have been the Monte Carlo Casino.

Members of our committee have wanted to get a successful evening fundraising event off the ground for a few years now, and are extremely grateful to the lovely Cath Rusby for making this happen. We are all looking forward to the next one in 2015.



- **We also held our AGM in August**, and had a great turnout – this showed us that although we only have a small committee we do have a supportive wider community and it would be great to find an easy way to reach out to them more often.
- **A local 'crafty' grandmother and her friends** put their skills to good use during the winter months and held a stall at an annual knitting market. Despite the main visitors being crafty people themselves (looking for craft supplies), Joan managed to raise almost \$200 for cystic fibrosis and still has many handmade items that she'll keep for fundraising at a later date.

- **Our Physio Caregiver System** is still going well. The families using the system are finding it very beneficial. Currently, it is being used by families with primary school age children. Having a DHB-trained caregiver come into their homes and ensure that physio is being performed regularly and adequately, has taken a lot of pressure off parents. We are grateful to be able to support our local families in this way.



CLAIRE'S CAPE CHALLENGE

The Staples Rodway Cape Challenge is an annual 32km event starting and finishing at Clifton Bay.

The course is mainly on private land and includes windswept beaches, native forest, waterfalls, river gorges and stunning coastal farmland.

Each year a nominated charity receives the surplus funds raised (a few thousand dollars) and one of our committee members is keen for Cystic Fibrosis to become the official charity one year.

To show her commitment to seeing this through Claire Fisher entered the 2014 Cape Challenge, despite not being a runner (of any description)!

She raised almost \$1500 for Breath4CF along the way and has our branch's application, to be the 2015 official Cape Challenge charity, in at Staples Rodway already.



MA'A NONU



BRUCE LUXFORD

ZOO CHIMPS
SAM & MALIKASTEPH
WOODMAN

OUR ANNUAL CHRISTMAS TREE FESTIVAL

This has been a high point. Held at the St James and sponsored by local businesses, it's wonderful to see families coming to visit the display to vote for their favourite tree.

Getting Kiwi celebrities, sports people and artists to decorate a Xmas Tree bauble to be auctioned on Trade Me has proved to be a winner. We had some amazing donations including one from All Black coach Steve Hansen, Ma'a Nonu, artists Steph Woodman and Bruce Luxford. And a surprisingly good one from Wellington Zoo chimps Sam and Malika.

We were also able to use the Festival as a platform to help lobby for Kalydeco in a press release issued in Wellington.

The musical Mama Mia has been performing at the same time and concert promoters allowed CF Wellington to collect before and at half time during every performance.

- **A big thank you** to everyone that helped during Awareness Week. We had collection points at six sites across the city, with the Railway Station the most lucrative spot (total \$1423.20). We also had a Mad Butcher BBQ, and Streetwise Coffee sold chocolate fish with all the proceeds going to the branch.

- We are also grateful to **Nga Tawa School Council** which held a bake sale and to **CQ Hotel** staff who braved the rain to help collect.

The Freemasons Taia-Raukawa Lodge

donated \$600 to Cystic Fibrosis Wellington for the purchase of two nebulisers. Nicole attended their monthly meeting to accept the nebulisers and gave a presentation on Cystic Fibrosis.

The Freemasons are also donating the proceeds of their Clay Bird Shoot on 22 March at Martinborough to CF Wellington.

Please contact Co-Chair Kim McGuinness if you would like to join the CF clay shooting team.



THE WELLYS

WELLINGTONIAN OF THE YEAR AWARD

Congratulations to Wellington Branch Co-Chair Nicole Doriguzzi on being nominated as a finalist in the *Dominion Post Wellingtonian of the Year Awards*.

She was one of four finalists in the Community Service category because of the work she does as a volunteer animal therapist, regularly visiting rest homes to share the love and joy that puppies and kittens bring.

As a finalist it was reported that “Nicole doesn’t let having Cystic Fibrosis stop her. She also volunteers as Chairperson of the Wellington Cystic Fibrosis Branch and fosters animals in need.”

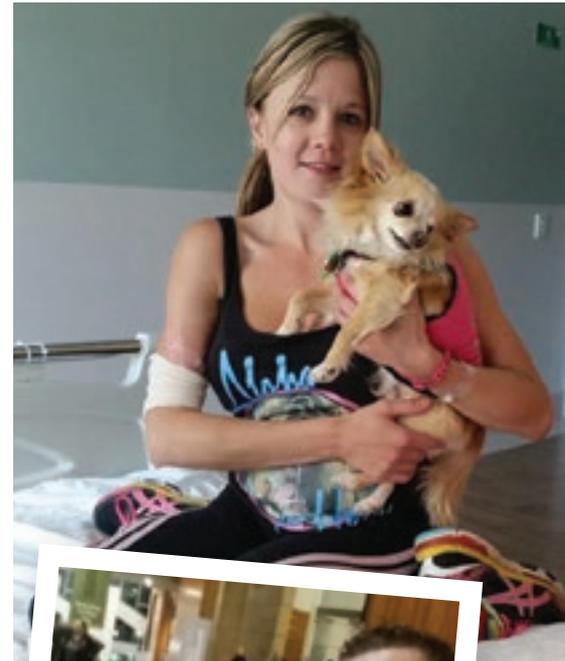
Each week Nicole takes puppies and kittens to visit Te Hopai rest home, which she says is especially helpful for those with dementia and communication difficulties.

“There are some residents that are unable to talk or communicate but when they pat that puppy their eyes

light up and they smile, and you know that you are making a difference. Some residents with dementia who aren’t even able to remember their names are able to recount stories of their pets during their childhoods and how much they loved them. Seeing how animals can bring such joy is worth more than anything in the world to me.”

In the last year alone, Nicole has been admitted to hospital three times, and despite having a PICC line for intravenous antibiotics in her arm, she never missed a visit to the elderly.

Her own Chihuahua Princess Sachi was smuggled into Wellington Hospital for a visit when Nicole was admitted two months ago.



CHRISTMAS DINNER

Christmas came early for our branch. We subsidised the dinner on 14 November at CQ Hotel to celebrate the past year with our CF community in the lead up to our Christmas Tree Festival.

How the branch can help you:

- \$300 Breath4CF top-ups for physical activity such as gym membership
- Equipment costs that are not covered by the DHB. If you require a nebuliser please let the branch know and we can purchase a new one
- Babysitting expenses to attend branch meetings and events
- Counselling fees
- Winter power bills, and in some cases, firewood
- 50 percent off parking at Wellington Hospital and extra parking assistance for lengthy hospital stays
- CFNZ funeral grant top up

Contact: Nicole Doriguzzi on email:
nicole@cfwellington.org.nz



BLOWN AWAY on Bubbles Day

Our Bubbles Week created a few new stars from our region who have helped raise awareness for CF. Anahera (8) enjoyed being interviewed on CTV - live TV is always an interesting experience! It was excellent to see Nicky Murphy's story make into The Press during Appeal week as well.



Thank you to all who supported Bubbles Week especially Kathryn Parker for her collection efforts and organising a successful bubble blowing fundraiser at Heathcote Valley School. Rochelle Pope for raising awareness and collecting in the Hanmer community and Paula Thompson for her swim-a-thon and street appeal collection in Timaru. All your collective efforts managed to raise a total of approximately \$2,500 for the branch.

Our Bubbles Week was somewhat quieter this year. Unfortunately, we had to cancel a few organised events due to lack of volunteers and next year we will have to try something different.

ANNUAL GOLF TOURNAMENT

We held our annual golf tournament at Templeton Golf Club on the 31st of October.

Templeton Golf Club have fully supported us with this event for over two decades and once again delivered a beautifully well-maintained course. We appreciate all the Club do for us each year, by charging no green fees for the day, organising the draw and helping us with fine tuning.

This year we only fielded 48 players

– numbers were down by half and the feedback we got was the 31st is not a good day being the end of the month. We were missing 11 teams in total made up of people we personally know who have played most years before and will be back next year. This was nerve racking to say the least; it was so unusually quiet and felt quite relaxed as organisers.

We had amazing prizes, raffles and auction items all that had been donated and a big thank you goes out to our main prize gatherers Liz Rhodes, Deidre Wright, Kaye

Stuart and Heather Robertson, who help us out every year with this task, always coming up trumps.

Our Auctioneer from Harcourts

Grenadier Ned Allison, who kindly donated his time, ran a very successful Auction making us \$2300.

The weather was very threatening but spared us as it moved around, providing us with an amazing lightning storm but with little to no rain in our area.

At the end of the day we proved you do not need a lot of people to make a good profit, the golfers we had dug deep, had an enjoyable game of golf, sausages, refreshments a lot of laughs and provided us with a profit of approx \$6000.

For next year we have learnt to stay away from the end of the month!

Apart from the CF mothers who gather prizes that I mentioned above who also help on the day, special mention needs to go to our committee members Nicky Churton, Sandy Champion, Joan Leighton and Sue Lovelock who every year help out tremendously with this event.



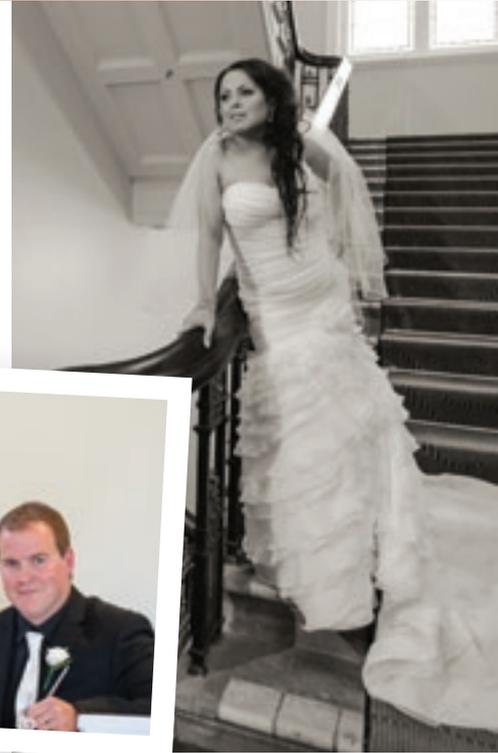
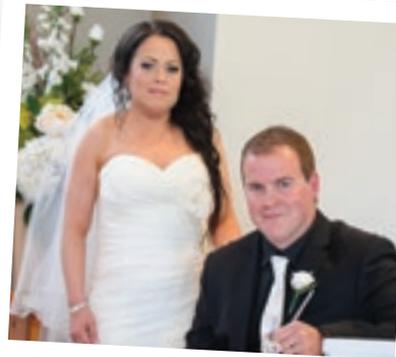
KRIS & JULIET'S wedding

It was third year lucky for Juliet and Kris Hubbard who tied the knot on the anniversary of their third year as a couple.

They married on 10.10.14 at Rosburn Receptions in Rangiora after being engaged for about 17 months. Their wedding celebration included a big bridal party - six bridesmaids plus a flower girl, and four groomsmen. The proceedings took a little longer than planned as Juliet was one hour late to make it down the aisle, but the important thing is that she did make it!

Juliet, a PWCF, and Kris enjoyed a fantastic 10 day honeymoon in the Gold Coast Australia, including a trip to Sea World to "meet a dolphin", which Juliet loved.

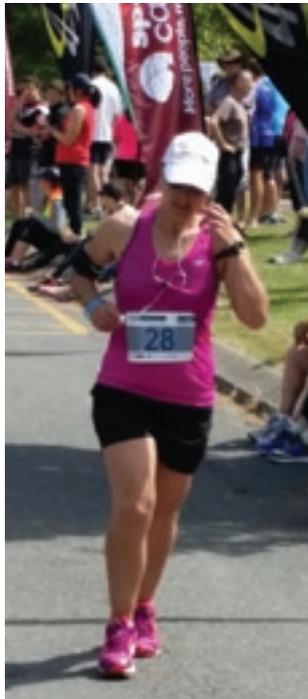
"It's been such a busy time lately but at the same time very enjoyable. I'm looking forward to our married life ahead and being the best wife I can be. But I won't lie - I'm secretly looking forward to sleeping in our new room having managed to twist Kris's arm into letting me have a hot pink feature wall in the new place," Juliet says.



Cecileah's MARATHON EFFORT

Cecileah Inns achieved her goal of running in the Lay Associates Half Marathon, which is part of the Selwyn Running Festival, to raise money for CF - and inspired her daughter with CF along the way:

"Well I did it. I ran my first half marathon (on a HOT day with a dodgy knee) and managed to raise some money for CF Canterbury in the process (around \$2,000).



One of the coolest aspects of the training journey for me was seeing the impact my rejuvenated focus on fitness had on the family, especially Anahera. She is a keen runner and one day wants to follow in my footsteps and run a half marathon, or - who knows - a full marathon!"

Canterbury branch community physiotherapist

Our community physiotherapist Hilaire O'Dea can be contacted on: 021 133 5194 or hilairecommunitycfphysio@gmail.com

Hanmer holiday house

Wanting a break away that won't break the bank?

CF Canterbury has a house available for rent on the outskirts of the lovely village of Hanmer Springs. If you have a family member with Cystic Fibrosis, you can book the house for only \$25 per night!

You can view details of house online at: <http://tinyurl.com/k5espm6> Check the online calendar or call Hanmer Holiday Homes (03 315 7336) to see which days the house is available and then contact Jo Haar to make your booking - Phone 03 351 8779 or jo_haar@hotmail.com

Even without the CF member discount, this is very reasonably priced accommodation in a popular holiday place, and it has the advantage that you are supporting CF Canterbury.

Charity Cricket Match

If anyone can volunteer to help at the Crusaders Charity Cricket Match on Sunday 7th December please contact national office.

Calendar - Punting on Avon 2015

Canterbury Branch with National Association are selling calendars "Punting on the Avon 2015". These will retail at \$20 each with Canterbury Branch and National receiving 50% of profits.

Email addresses

Canterbury Branch members, please send an email to cfcantebury@gmail.com with your name in the subject line to be added to our email database. We will be communicating more via email now. Please contact us so you do not miss out on important news and opportunities. This is also a great way to get involved and volunteer when we put an email call out for support.



Tell us a little bit about yourself...

I'm 23 and living in Auckland with my parents – Andrea & Philip and both of my brothers – Andrew & my twin Alex (PWCF).

I am currently working part time in an admin job and really enjoying it! I've never really had a job before this year, as my health always took the front seat and so working wasn't really a priority.

I love spending time with family and friends, spending time at our beach house, going for walks and exercising (while being able to breathe at the same time!).

What was your health like before your transplant?

Before 2011 my health was quite manageable, thanks to three monthly courses of IV antibiotics, which were generally done at home.

However, my health (particularly my lungs) deteriorated dramatically in 2011 & 2012, so I was assessed for a lung transplant and put on the waiting list in June 2012.

By 2012 I was on full-time oxygen. I received the "gift of life" in January 2013 and I am so incredibly grateful! I have always been a very positive person, but even I had never imagined that life could be this amazing!

How has your health been since your transplant?

I haven't been hospitalised since last November, which is basically a lifetime record for me. My last admission was for surgery to stop reflux (Nissen fundoplication). It's quite a common procedure to have post transplant because if reflux spills into your beautiful CF-free lungs, it can cause rejection – so anything to avoid that is essential.

Are there any unexpected changes you had to make due to your transplant?

In 2012 when things became a lot

TRAVEL TALK

with Lizzie McKay



Lizzie is a very talented, beautiful and bubbly fellow Adult with CF who has just recently been on a trip of a lifetime - travelling around Europe for a month, after her double lung transplant in early 2013. She spoke to one of the Adult News editor's Chloe Mackie about how she managed her condition.

harder and more tiresome for me I had to leave my studies. I did almost three years at The University of Auckland, studying towards a Bachelor of Education majoring in Primary School Teaching.

Sadly I won't be going back to that because the anti-rejection drugs from my transplant mean that I am "immune compromised" and unfortunately it's a fact of life that kids get sick very easily. So it wouldn't be the smartest move for me to be in a room with them day in day out, as much as I enjoyed my studies and previous placements.

What inspired your trip to Europe?

When I wasn't feeling quite so flash, mum said to me "Lizzie, when you can breathe again, we are going to take you to Cinque Terre, Italy" and we made it there in October, which was an absolute dream come true (even though it rained the whole day we were there).

Tell us about your travels...

We traveled to London, Paris and all over Italy. I'd never done so much

exercise in my life, but I loved it so much. We even walked to the top of the Duomo at St Peter's Basilica – 320 steps!

I loved London – Buckingham Palace, The Tower of London, London Bridge, Oxford St shopping.

I was blown away by the sights in Paris! Family favourite being the Eiffel Tower, where we went to the very top – such a spectacular view.

Most of our trip was based in Italy though. We spent a day in Venice, where we went on a gondola down the canals – a once in a lifetime experience. We rented a car and drove from Venice to La Spezia, where we went to Cinque Terre then to Tuscany, where we spent the next week in a villa 30 minutes out of Florence. Each day we went to a different village or walled town – Lucca, Pisa, Florence, Sienna, and my favourite being San Gimignano. This week was spent with my beautiful cousin – Antonia, whom we hadn't seen for over a year.

Dad then drove us into the middle of Naples – wow, what an experience! No lanes, no lights, no



rules! Another gorgeous cousin, Gabrielle lives and runs a hostel there, so we had a great time being shown around by a “kiwi” local. We had a day trip to Amalfi and Sorrento. I would have to say that the Amalfi coast was the most beautifully, breath taking place – I would LOVE to go back there and stay much longer. The pizza in Naples was the best I have ever experienced in my life – I haven’t been able to bring myself to have Domino’s pizza again!

Our last stop was Rome – another indescribable place. We did a walking tour of Old Rome, getting to see all the Roman ruins – The Pantheon and The Colosseum were amazing. I found it so hard to comprehend how long all of the beautiful buildings and monuments had been around for, and that they had all been built without any of the technology we have today.

What was your favourite part?

Each day was my favourite day – I honestly couldn’t tell you, we made incredible memories everyday! But to experience it all with the two people who have worked so hard to keep me healthy, stood by my side for 23 years of clinic, hospital admissions and surgeries – that was the best part! Thank you Mum and Dad!

What was your diet like?

In Italy we ate a LOT of pasta! Great for someone on a CF diet, that’s for sure! My go-to dish was a Caprese salad (lettuce, tomato and fresh mozzarella).

Did you face any difficulties with your health while you were away?

I was lucky enough to not have too many “sick days” while we were away, apart from vomiting my way down Portobello Road Markets in London on our first day! I think that was my

body’s reaction to the long haul flight, as a similar thing happened the day after we got home too.

We made sure we didn’t jam pack our weeks

too much and planned to have some “rest” days and half days during the trip. We decided it was best to be able to enjoy the things we could do, rather than trying to fit everything in. There were many “we can do that next time” moments.

Did you have any issues while trying to plan your trip due to having CF?

Not really, as I was able to get travel insurance through Apex Insurance in conjunction with the CFANZ, an opportunity that the CFANZ secured for CFANZ members this time last year. But luckily I did not have to make use of it!

Did having CF restrict you while you were away? Or lead you to avoid anything?

We tried not to let CF stop me from experiencing anything while we were away! Being fit played a big role in this and being responsible with how much we set out to achieve each day.

The only thing I tried to avoid was being around people who were unwell (but that is the same as at home). I took masks on the plane just in case I was sitting near someone with a cold or flu.

Any preparation advice for other AWCf wanting to travel?

- Be as fit as you can before you go (being a tourist uses more energy than you think).
- Plan in some down time so you don’t over-do it.
- Take plenty of extra medication and carry it on board airplanes with you. Some good advice we were given – keep all medication in its original packaging, in case you are questioned by customs officials and also take your latest clinic letter or similar letter from your doctor.
- Ask your doctor for a week or so course of oral antibiotics to take in

your bag in case you pick something up in your travels.

- Get contact details of respiratory doctors or CF specialists in the cities you’re traveling to – just in case.
- You want to prepare for the worst, but hope for the best!

How did you get yourself so fit before you left?

In the first few months post-transplant, exercise is a huge thing and is pushed in a very positive and enjoyable way. I became passionate and excited about being fit, a feeling I’ve never had before – all thanks to my Physio Paul Birch. We started off at the gym an hour each week day, doing 30mins of cardio and 30mins of exercises with light weights (as I basically had no muscle at all), this programme got harder as I got fitter.

When I left the Greenlane gym and before going to Europe, I joined a gym closer to home and mostly did the same programme as post transplant, but with slightly bigger weights.

Since being home from Europe I’ve sat down with a personal trainer and got a new programme – incorporating some of the machines.

I’m trying to go to the gym at least three times a week with a walk or two with friends or family added in each week as well.

If you would like to learn more about travel insurance or travelling with CF, visit the www.cfnz.org.nz website where there is a “Travel Guide for People with Cystic Fibrosis” which goes into more detail. If you are planning on travelling and would like a quote for travel insurance (a number of conditions apply), please contact Julie Clemett – julie@cfnz.org.nz or 0800 651 122.

For more stories from the Adult News visit the CFNZ website: www.cfnz.org.nz

CF Adult Representatives:

CARMEN BRADSTREET

Email: carmyb_nz@hotmail.com

CHLOE MACKIE

Email: chloe.amanda@icloud.com

NATIONAL BOARD

Jane Drumm - Chairperson

Auckland
Phone: 09 817 4753 Mobile: 021 117 3621
Email: drumms@ihug.co.nz

John Parsons - Treasurer

Havelock North
Phone: 06 877 4062 Mobile: 021 215 3285
Email: john.parsons@xtra.co.nz

Margaret Nicholls

Wellington
Phone: 04 232 0972 Mobile: 027 248 3666
Email: margaret.nicholls@gmail.com

Cheryl Moffatt

Christchurch
Phone: 03 322 8563 Mobile: 027 491 4481
Email: taffom.c@gmail.com

Kim McGuinness

Wellington
Mobile: 022 684 8598
Email: kimmcguinness@hotmail.com

CF Adult Representatives

Carmen Shanks and Chloe Mackie
Email Carmen: carmyb_nz@hotmail.com

CF News correspondence to:

National Information

Coordinator

Email: comms@cfnz.org.nz

Patrons

Professor Bob Elliott
Andrew Ellis

President

Denis Currie
Email: deniscurie@xtra.co.nz

STAFF

CFANZ National Office

1st Floor, Broadway
62 Riccarton Road
PO Box 8241,
Christchurch 8440
Freephone: 0800 651 122
Website: www.cfnz.org.nz

Chief Executive

Belinda Burnett
National Office
Mobile: 021 283 0051
Email: belinda@cfnz.org.nz

Administration Manager

Julie Clemett
National Office
Phone: 03 341 8014
Freephone: 0800 651 122
(welfare inquiries)
Email: julie@cfnz.org.nz

North Island Fieldworker

Melinda Coombes
Auckland Office
Phone: 09 308 9161
Mobile: 029 773 1398
Suite 2, 79 Grafton Road,
Grafton, Auckland 1010
Email: melinda@cfnz.org.nz

South Island Fieldworker

Sue Lovelock
National Office
Phone: 03 341 8029
Freephone: 0800 651 122
Email: susan@cfnz.org.nz

National Information

Coordinator
Vicky Tyler
Auckland Office
Suite 2, 79 Grafton Road,
Grafton, Auckland 1010
Phone: 09 308 9161
Mobile: 021 818 750

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