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cf CYSTIC FIBROSIS NZ
Creating Better Tomorrows

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CF news



TV Reward for **Sisters** **Good Deeds**

**Craw Family Hunt for Perfect Home | NZ Research News
CF Adult News: Joe Wins Love & Gold**



UPDATE FROM **THE CHAIR**

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One of the highlights of this job as Chair of the CFNZ Board is working with and getting to know such a dedicated and talented bunch of people. At our AGM this year we had two of our long standing Board members retiring by rotation. For me that was both sad and exciting. I will miss the organisational maturity, wisdom and institutional knowledge that both Margaret Nicholls and John Parsons have brought to their roles as CFNZ Board members. I will also miss them as true individuals with their own spin and take on the different situations and issues we as a Board have to address. As I have said many times I love to be surrounded by a Board of people who think differently to me. I am of the firm belief that great governance comes from diverse perspectives, robust discussion, finding consensus and making decisions as a group that are the best for the organisation. Having trust in the group and the group process is also key to a well-functioning Board and I am pretty proud of the way the CFNZ Board operates.

It is my honour to thank both Margaret and John for their service to CFNZ (although I do know that this will be ongoing in many other ways). I am delighted to welcome Catherine Rusby (Hawkes Bay) and Warwick Murray (BOP) to our fold, as new CFNZ Board members they bring many experiences and great skills to their new positions, and I know they are both very pleased to have been elected.

As a SILF (Shares in Life Foundation) Trustee something I am very excited about is that we now have an agreement with Cure Kids where applications for NZ-based CF research will be called for annually and we will be looking at joint funding for projects to the value of around \$100,000 per annum. Whilst we as trustees recognise that the big CF research happens overseas, smaller projects that can have a real impact on CF clinics and patients here and now in NZ can certainly happen in our own backyard. So watch this space!

Finally I would like to say something about our amazing CF Nurse Specialist at Starship Hospital; Jan Tate. As most of you know Jan came second in the Ansell Nurse Hero competition that was run for both NZ and Australia. It was my pleasure to be at a presentation that acknowledged Jan as a hero – she certainly is one to my family. Better yet was the fact that Jan selected CFNZ as her charity of choice and we received a \$3,000 donation from Ansell (Au). Jan had a whole country voting for her and on behalf of CFNZ I sincerely thank all of you who let your voting finger do the talking and supported Jan.

On behalf of the Board, I would like to extend best wishes to all of you, our CF whanau, for a healthy, happy and safe Christmas.

JANE DRUMM, CHAIRPERSON

AND WE SAY **THANK YOU** FOR THE CF NEWS

Cystic Fibrosis New Zealand and CF News are grateful for securing two grants to allow the publication and printing of this issue of CF News.

We have received \$2000 from the Pelorus Trust towards the printing and postage of CF News. We also received an additional \$2500 from the Blue Waters Community Trust and these two grants cover the cost of the magazine.

The CF community love reading the positive and inspiring stories about children and adults with CF. It's wonderful to receive support for our newsletter from these community funding groups.



UPDATE FROM THE CEO

A huge focus for the past months has been the development of policies and procedures particularly those health and safety policies which are designed to keep our workers safe. The value of this work was brought home to me on the morning of 14 November when I woke to hear of the earthquake that had rattled NZ particularly Kaikoura and Wellington. I was thankful that most people had not been at work at the time, and also that the new Health and Safety legislation sees workers' safety as paramount. Our thoughts go out to those impacted upon by this earthquake, particularly our CF families.

Our CFNZ Chairpersons Conference in October provided a platform for the organisation to discuss key priorities such as branch welfare, fundraising, health and safety, finance and our fieldworker service. This was also a wonderful opportunity for branch representatives to swap notes and to meet with the CFNZ staff. Many discussions arose on how we can work more collaboratively to reach our common goals, and we all came away buzzing with ideas and opportunities. We look forward to making a collective impact on key projects in 2017.

Due to the new financial reporting standards for not-for-profits we weren't able to have our financial report completed for the October AGM and this was presented in draft. We hope to have the final financial report incorporated into the CFNZ Annual Report and ready for publication shortly.

As a "not-for-profit" we operate on a "not-for-loss" basis and have the aim in the 2017 year of securing funding for key projects that optimise the quality of life for people with CF. We are seeking grant funding for 1) updating our key brochures and publications, and 2) a project focusing on understanding the experiences of families following a recent diagnosis of CF. I am pleased to report that the funding of this edition of CF News is via two grants, however future publications can only occur if funding is forthcoming.

This time of year promises good weather and Christmas festivities. We have a number of events coming up to celebrate the season. The Christmas Tree Festival held by CFNZ Wellington Branch will light up the Wellington Airport Terminal and the Charity Cricket event held by CFNZ in Christchurch is set to draw a huge crowd. Both events promise successful awareness raising and fundraising.

Season's Greetings and best wishes for 2017.

JANE BOLLARD, CHIEF EXECUTIVE

CHARITY CRICKET – starring Harry, Alana...and the Crusaders

Move over Crusaders...this year there are two new stars in the CFNZ annual Charity Cricket match and they are both from the CF community in Christchurch.

Seven-year-old Harry and Alana Taylor, who made headlines during her lung transplant last year, are the faces of the Cystic Fibrosis BNZ Crusaders Charity Cricket match on 11 December.

Harry is the first poster boy for the event and as you can see, absolutely loved the photo shoot with his heroes, the Crusaders, in the lead up to the event.

Alana also attended the photo shoot and will be speaking at the match about her own experience with Cystic Fibrosis – how her lung function was down to 19 percent and is now up to 95 percent thanks to her transplant. Her new lease of life means she's been well enough to go hiking and play touch rugby.

She's a huge supporter of the Cystic Fibrosis New Zealand (CFNZ) charity and says events like BNZ Crusaders Charity Cricket are a massive boost for the cause. She says that Cystic Fibrosis (CF) is an extremely expensive condition and not all equipment is funded by the government.

Harry and his younger brother and sister who live in Westmoreland are regular faces at Charity Cricket events. Last year Harry also received a personal introduction to the Crusaders at a training session. "He'd just got out of hospital and he had a bit of a bad patch. He got to talk to Israel Dagg, who is Harry's favourite player," adds Harry's mum, Charlotte Ensor.

Although Harry has also been diagnosed with Cystic Fibrosis Related Diabetes, he still manages to keep fit by playing cricket and soccer, which helps keep him as healthy as possible.

As the CF News went to print, the All Star team were preparing to face off against the Crusaders at the event at Christchurch Boy's High School. This year we have been fortunate to feature a number of Rio Olympians and Paralympians in the All Star team including bronze medalist Tom Walsh, Rugby 7's Sam Dickson, 4x Olympian javelin thrower Stu Farquhar, shot putter Dale Stevenson, hockey Olympian Bradley Shaw, and Paralympians Rory McSweeney, Byron Raubenheimer and William Stedman. New Crusaders coach Scott Robertson also joined the All Stars to bat against his own team.

This year a Cricket Academy held by former NZ cricketers Chris Harris and Geoff Allott was introduced to the day's events and received a number of early bookings.

It is CFNZ's 34th Charity Cricket match and CFNZ is grateful to all the local businesses which have shown amazing support for the 2016 event.



CHARLOTTE, HARRY AND GUY





SURPRISE! YOU'RE ON SEVEN SHARP

It was meant to be just a photo shoot for the CF News but Cystic Sisters Kristie Purton and Nikki Reynolds-Wilson got \$10,000 more than they bargained for when they were surprised by TV's Seven Sharp in Tauranga.

Seven Sharp had asked CFNZ to arrange an interview with the sisters so they could surprise them for their Good as Gold segment sponsored by ASB.

The girls were just posing for photos along with Nikki's daughter Skye (5) and Kristie's children Haylee (5) and Curtis (8) when Seven Sharp reporter Lucas De Jong and cameraman appeared by behind a bush, saying "this is actually a set up".

After the initial shock, the girls were more than happy to accept the \$5000 cash each that was to be their reward for their 65 days of Good Deeds.

Friends and family and CFNZ Tauranga had also been sworn to secrecy before the Sisters were led to a celebration for them both at a local café, which included an early birthday cake for Nikki who was turning 26 the next day.

The girls were also one of three nominations for the Spirit of Attitude Award in the Attitude Live Awards and the positive spin-offs from their good deeds have been too numerous to mention.

"We did the good deeds to make the world a better place not to

get anything for ourselves," says Kristie.

They first conceived the idea in 2015 on a trip home from a hospital appointment in Auckland when they decided they wanted to help raise awareness for CF Awareness Week that was coming up. Nikki says there are still a lot of people who don't know what cystic fibrosis is.

"You'd sit at tables collecting and people would walk straight past because they didn't know what CF is. And it's quite involved to explain," says Nikki.

There have now been 170 good deeds performed in two years – with the Sisters often leaving a note explaining they were courtesy of the Cystic Sisters.

"When something good happens to people they want to read and find out more about the Cystic Sisters," explains Kristie who says the acts of kindness have led to more people learning about CF.

After raising funds for the Tauranga Branch in 2015, this year they focused on awareness, and some local businesses also helped them by contributing rewards and services for them to use for the acts of kindness.

Despite the decline in Nikki's health prior to her lung transplant, there was never a time when she regretted going ahead with their 65 days of good deeds again. The sisters did ensure they had some easy good deeds up their sleeves that weren't energy taxing.

"We bought a whole lot of vouchers that we left on people's windscreens, or left petrol vouchers at the pumps," Kristie explains.

My favourite good deed was when Nikki was getting her lungs done and we organised a blood drive and tried to get 65 people to donate blood. We didn't quite get 65 because we were in Auckland," says Kristie, who also enjoyed handing out 65 cake lollipops in central Tauranga.

"One of my favourites was leaving bunches of flowers at people's doors. Kristie drove and I knocked and left the posy of flowers," Nikki says.

"We did more secret ones this time because last year if we approached people sometimes we found they got put off because they thought we were trying to sell something."

And the sisters can be proud of their achievements. Their regular newspaper and television appearances have helped raise awareness and they have more than 2000 "Likes" on their Facebook Page.

Just days before CF Awareness Week, Nikki received the call to go into hospital for her lung transplant and so far her recovery's been going well.

"Waking up in the morning I can just get straight up out of bed. I don't have to sit there for half an hour," says Nikki, who also enjoys hanging out the washing in five minutes instead of an hour.

"Walking around, not coughing, lying flat, having a shower and at the end of the day not feeling tired and exhausted," she says.

Kristie has also been assessed to go on the inactive lung transplant waiting list and naturally Nikki is wishing Kristie will get one as well because at the moment they are unable to socialise together – especially inside, because of the risk that Kristie could transfer infections onto Nikki who's taking medicine to suppress her immune system to help avoid her body rejecting her new lungs.

"I used to come to Kristie's every day and just sit here and we don't do that as much because it's not a good idea to hang out in the house," says Nikki.

They were always careful before Nikki's operation not to share drinks or cough near each other.

Now Nikki has to be more careful with what she eats and to avoid anyone with a virus.

"But its still way better than before," she says.

Her best advice to others facing transplant is stay as fit as possible and keep their leg muscles strong.

"One of the reasons I did so well is that I was quite fit going into the operation.

"Stay positive and think that it will happen," she adds. "Having children helped me. I had to get up every day for Skyla. Find something to make you keep going."

Kristie also stresses the importance of staying active.

"Push sport because it keeps you healthy and helps move the mucus. Don't treat people with CF any different," she says.

They have both made good use of the Breath4CF fund. Kristie to pay for sports and swimming, and Nikki has just bought running shoes because she's planning to start running.

Kristie and Nikki have always been close as sisters and believe they would have always been close even if they didn't both have CF.

Next year they are planning more good deeds but are considering a new format. In 2017 they are likely to encourage others to do a good deed and post it on their Facebook Page – possibly for them to match over the 65 days.

"We've had heaps of people ask if we're doing it again next year so it seems good to do it again," says Kristie.

As the interview concludes it's time for Kristie, Nikki and the kids to head to Yatton Park for photos and the Seven Sharp surprise.

"So did you come down from Auckland just for this interview?" Kristie asks. "It seems like a long way to come for an interview..."

"I was very privileged to take part in this photo shoot. It was very rewarding, a lot of fun. I'll never forget the look on their faces when the TV camera and presenter appeared!"

Photographer Yvonne Rooney of CFNZ Bay of Plenty

SPIN OFF FROM ROTARY CLUBS

SNIPPET

Cystic Fibrosis New Zealand has developed stronger ties to Rotary Clubs in NZ thanks to Fielding Rotarian Nigel Ramsden who has helped urge Clubs to each donate a nebuliser. CFNZ Chief Executive Jane Bollard and Jamie Archibald were also invited to speak at two meetings in Auckland to help Rotarians gain a better understanding of the condition and the work that CFNZ does.





On a road to **everywhere**

The Crow family may have had to sacrifice a trip to Italy because of their daughter's health but it hasn't stopped them hitting the road searching for the perfect place to live in New Zealand.

Kas Crow, her husband Nic, and two children Frankie (3) and Rio (17 months) packed their life in Tauranga into a caravan to travel the length of the country in May – hoping that Frankie's CF wouldn't be an obstacle, and Kas is happy to report that so far Frankie's health has been better than ever.



"She's actually been the best she's ever been since we have been in the caravan. I think it's mainly not having much contact with other people. If you're at home, there are people coming and going from your house. She's outdoors a lot and around the sea but I

think the main thing is living in a contained space," Kas explains.

Speaking from their recent base in Hokitika, Kas says when Frankie developed Pseudomonas, and was in an out of hospital after their second baby was born, they had to put their exciting travel plans to Italy on hold. The family had sold houses in Tauranga and Katikati and were keen to embark on a new adventure.

"Frankie having Pseudomonas was a full-on time for us. We wanted to go to Italy but with Frankie being unwell we didn't

quite know what that meant for us. We weren't ready to go to Italy and thought of this crazy idea instead.

"It was a bit risky at the time because the caravan's been a bit damp through winter, but it's not been a concern at all," says Kas who took a few months to adapt to family life in a caravan with young children.



"I did miss the comforts at home but now I'm just so in love with it – feeling how good summer will be."

The Crow's mainly stay at free camping sites and don't stay in one place for much more than a few days. So far, managing Frankie's CF treatment regime hasn't been difficult.

Frankie doesn't use a nebuliser. Her dad Nic is a physiotherapist and Frankie loves her daily physio sessions.

"It's the only time she ever watches her DVDs, so that helps and she pretty much asks for it. She's really easy going," Kas adds.

After Frankie was diagnosed with cystic fibrosis Kas and Nic considered using IVF and pre-gestational diagnosis (PGD) for their second child but were put off by the long waiting list.

"We thought 'let's just wing it', and we got lucky. Rio doesn't have CF and she's not even a carrier."

The children have adapted well to caravan life as they travel south before heading up north again. Frankie has now experienced a few different CF medical centres while her parents search for the perfect place to buy a house.

They loved travelling through Arthur's Pass but are unlikely to buy a house there. Kas believes the family will eventually decide to

live up north or back in the Bay of Plenty but in a smaller community rather than a main centre – somewhere near the sea. She says inland places like Murchison don't feel like home to her.

"I don't feel right if I'm not near a coast. Nic's the same, he likes to fish and be in the sea.

"We're also planning to go to Stewart Island but probably won't take the van, just book a bach to stay in. In January we'll be heading straight back up north," Kas says.



The Craw's haven't given up on their Italian dream though. Kas's sister lives in Italy and Kas herself holds a European passport which means if

she works there she and her children would qualify for free healthcare. If they don't find a house to buy before June next year, the family will head to Italy for a few months.

Kas wanted to share their new way of living with the CF community because she wants others to know that it is still possible to follow your dreams and have adventures.

"We were in quite a state of fear after last year and Frankie's time in hospital but I thought this might inspire people who could be blocked by fear and using CF as an excuse not to do things. It's been a realisation to me that you can do all the adventurous stuff that you want to do – you may just have to plan a bit more carefully.

With her philosophy to keep life simple and that we all only get one chance at life, Kas tries to stay focused on what's important.

"We are so conscious of how short it is – we want to make the most of every moment."

Keep up the Craw's adventures by visiting their website: nowweretouring.com

CFNZ RAFFLE ON A ROLL

SNIPPET

This year's CFNZ Raffle was a big success – not only did we raise \$15,000 we were able to enlist more sellers mostly through Facebook which was brilliant. Everyone did a great job selling the tickets so a huge thanks for that, and as you can see Marcus Hyde of Wellington was more than rapt with his All Black's shirt signed by the entire winning world cup team.



Beauty and the Beast!

A wonderful fundraising fantasy!

Belle, the "beauty" of Beauty and the Beast says: "Books take me to wonderful places – adventure, fun, romance..."

The 32-strong cast and support crew of "Musikmakers" Riverlea Theatre on Friday 5th August did just that, with their entrancing performance of their adaptation of the traditional French fairy tale. Superb acting, singing, live orchestra music, and spectacular choreography and costuming combined to make a magical night of fantasy based on the 18th century story. A vain prince spurns the pleas of a homeless old woman, an enchantress, who turns him into a beast. She gives him a rose and he must learn to love someone other than himself before it drops all its petals. The castle servants work together to coach the Beast in the art of love so the spell, which is turning their humanity into household items, can be broken.

What a mid-winter treat for all the audience, and Cystic Fibrosis Waikato are better off to the tune of nearly \$4000 dollars in ticket and raffle sales and supper koha as the privileged recipients of Musikmakers "Benefit Night" performance. This is something that Riverlea Theatre gives to different charities for many of their shows as a community service. Proceeds from the performance will go towards making life a little easier for CFers in hospital.

Good on you Riverlea and many, many thanks for a fantastic evening – it was a joy to be there!

By Robyn McBride

An inspiring step in the right direction

CHAIRS CONFERENCE 2016



“Stay inspired”, urged Chief Executive Jane Bollard, closing the 2016 Chairpersons' Conference.

These words perfectly summarised two days full of energetic discussions, progress reviews and skill-sharing sessions. The conference, held in Wellington, culminated in a range of inspiring conversations which had the attendees buzzing with new ideas and excitement for the future.

Jane Bollard kicked off the conference with an overview of the charity's strategic direction. A family-centric model is in the pipeline, with plans to work closely with families to understand their experiences and provide better, targeted support going forward. Some of the key projects for the next year include updating the range of informative brochures, further developing the CF Adult Advisory Group and establishing a strategic media and communication plan to enable CFNZ to better share its story.

Sustainability was also a key theme for this year's conference, with Board Chair Jane Drumm explaining possibilities for future focus. These include fostering regional relationships, having a clearly defined CF National Collection Day and a nationwide community fundraising event.

One of the stand out presentations from the conference was from Clive Pedley at Giving Architects. CFNZ has been working closely with Giving Architects to develop a sustainable fundraising plan and this riveting talk on fundraising provided real food for thought. During the presentation Clive outlined the many different types of fundraising needed to generate a sustainable income stream. Thinking long term, communicating the difference CFNZ is making and creating urgent and compelling appeals were amongst his key points.

Jeanette Franklyn, CFNZ Grants Coordinator, led a practical session on grant applications and accountability, stressing the important role grants can play in enabling CFNZ to deliver its mission and strategic goals. Within the session, Jeanette shared tips on filling out forms, ways of recognising the funders and communicating what was achieved with the grant money in order to increase the likelihood of funders helping CFNZ in the future.

An open forum discussion was held on both days of the conference, prompting enthusiastic debate on issues ranging from lobbying PHARMAC for medical equipment, meeting the needs of the newly diagnosed and position statements on topics such as genetic testing.

One of the major developments since the 2015 Chairpersons' Conference was the employment of the Central Fieldworker, Jude Kelly. Her role was established to provide essential support and regular contact for people with CF and their families in the central region and was well received in the community. Jude gave a fantastic insight to some of the work she's done over the past six months, noting that she has made it a priority to visit as many people in the CF community as possible, particularly in the isolated and more secluded regions.

This year's conference was highly practical, aiming to equip branch members with tools to support them going forward. The small group working sessions featured five different rotating sessions covering Communication, Finance 101, Grants, Welfare and Support, and Fundraising. These sessions were nothing short of lively – providing a space for knowledge and skills exchange, brainstorming for future activities and stimulating debate.

The conference was well attended with a total of 35 branch members, CFNZ staff and guests speakers in attendance. The atmosphere was positive and optimistic – “inspired” definitely being the choice word of the two days.

By Laura Huet



LEFT: FIGHTING THE GOOD FIGHT
Sophie managed to throw a few punches but it was CF that was the winner when she entered the boxing ring at the Canterbury Student Association Fight Night and raised over \$2300 for CFNZ.



RIGHT: SANTA IN TOWN
Klohe Bevan-Rolton (8) and her brother Xavier (5) from Darfield at the Special Children's Christmas Party in Christchurch.

GOLFERS ALL AROUND NZ TEE OFF FOR CF



First it was the corporate Choice Hotels Golf Day at North Shore Golf Club which was a lovely spring day, raising \$5000 for CFNZ.

The golfers were more than happy to donate to Choice Hotels' chosen charity and placed bids on many of the auction items. They also dug deep into their wallets to enter some of the friendly competitions on the day – such as nearest the pin, longest drive and straightest drive. Pictured top are some of the lucky winners.



This generous donation comes in addition to the \$15,000 raised during Awareness Week when \$2 from every night stayed at one of Choice Hotels NZ properties came to CF.

Keen golfer and CEO of Choice Hotels Asia-Pac Trent Fraser says that Choice is extremely proud to continue to support the efforts of CFNZ's hard-working team.

"We are dedicated to doing all we can to make a positive difference to the lives of those living with the disease."

CFNZ Chief Executive Jane Bollard has also praised Choice Hotels for raising a total of \$20,000 this year to support the CF community.

"This type of support means so much to our organisation and the lives of those living with cystic fibrosis across the country."

The second Golf Day was one week later when Canterbury held its annual tournament at the Templeton Golf Club to raise funds for the local Canterbury Branch – see Canterbury Branch News (page 21) for more details.

Then one week later New Zealand Certified Builders kindly named Cystic Fibrosis New Zealand as its official charity for their Taupo Builders Charity Golf Day thanks to one of their members Paul Riedel nominating CFNZ. The fact he has also been running for CF every day of 2016 gave NZ Certified Builders all the encouragement they needed to support CF.

The event was an extremely professionally-run Golf Day with impressive prizes such as sliding doors and power tools. There were also a few funny "dummy" prizes auctioned such as "Female Viagra" which fetched \$85 dollars.

Paul was also handed a big \$863 cheque for CFNZ from Taupo ITM to assist with his impressive efforts to raise funds.

CFNZ is very grateful to New Zealand Certified Builders and Paul Riedel. The Golf day is expected to raise up to \$5000 to support PWCF.



Tristram & Jade

BUILD AN AWESOME FUTURE TOGETHER

Tristram Buttner and his new bride have more than most to celebrate this year.



Their wedding at Ohariu Farm in Wellington in February was soon followed by another happy event, the birth of baby Sophira a few months ago.

"It's all happened in 2016 – marriage and a baby," says Tristram's wife, Jade.



Tristram (32) and Jade (23) had been engaged for two years before getting married with a Lego themed wedding – something that Tristram was keen on because of his Lego hobby.



There were Lego-themed wedding invitations, impressive displays of Tristram's Technic creations, Lego table numbers, Lego cake, and Tristram and his groomsman's Lego cufflinks.

And while Jade simply wore her wedding gown, she was carrying her own precious cargo – a much-longed for pregnancy.

The couple knew they were expecting a baby – which was very welcome news after a previous IVF cycle that produced four embryos had not resulted in a pregnancy.

"None of the embryos were successful in the first round and we were going to start the second round but realised Jade would be due when the wedding was, so we begged and pleaded with Fertility Associates to delay the start date. The second round worked on the first go," says Tristram, who has CF.

"It was painful. And it was hard to go through it twice," Jade admits. "The first time they said, 'congratulations you're pregnant', but a week later they said, 'sorry we got it wrong'."

They were delighted when Sophira was born in July, and the couple are hoping to eventually try for another baby using two other embryos that were produced via the fertility treatment.

Becoming a father was something Tristram was never sure would be possible as he was growing up, and he urges other couples struggling to have a baby to keep trying.

"Stick with it," he advises.

Hi-five from first cousin

All the way from the UK comes a heart-warming story about a little girl choosing to donate some of her hard-earned money to support her Kiwi cousin with cystic fibrosis.

Nine-year-old Mary lives in England with her younger brother, Marshall, and took part in a “Multiply-a-Fiver” Young Enterprise Challenge at school.

Mary decided to use her five pounds to buy lollies and drinks, and sell them after a friend’s dance class for a tidy profit. With that, she bought more sweets and made further sales at her school concert.

Mary’s school allowed the children to decide what to do with their profits and Mary generously offered to donate the \$NZ80 dollars to CFNZ Waikato which helps care for her cousin Amelia who’s the same age as her.

Although Mary has only met Amelia, who lives in Hamilton, once during a visit to New Zealand four years ago, it must have made quite an impression because she saw her for the first time in hospital.

Amelia’s mum Margaret Rickard recalls it was Easter time and there was an Easter egg hunt in the hospital ward.

“And Amelia was having I/v antibiotics as well so it’s a mixture of the excitement of the Easter egg hunt and seeing her cousin for the first time in hospital.”

Amelia was diagnosed with CF at four-weeks-old after the newborn heel prick test and by then Margaret had become concerned about her daughter’s health.

“She’d sleep through her bath, she’d take two hours to feed and lucky if she put on 20 grams in a week. It was a struggle,” says Margaret.

The day Margaret decided to stop breast feeding and use bottle feeding to help measure how much milk Amelia was getting, was the day the midwife told her that Amelia’s heel prick test had indicated CF.

There had been no family history, although Margaret’s mother’s older sister had not survived infancy because of an inability to gain weight.



“Back then they wouldn’t have known it was CF,” says Margaret.

Now nine-years-old, Amelia’s health is still a concern because of regular infections, and also because she’s coming to terms with a demanding treatment regime.

“She’d rather be playing than stuck doing her nebuliser and we do have our weeks of her not wanting to do it. Then we have good weeks when she just gets through it,” Margaret explains. “In the last year she’s asked lots of questions about things like transplants. She said to me that she wished she could get new lungs.”

While Amelia has only met her cousin once their small two week age gap means they still share a special bond.

“When they did meet they were just good friends and it’s really cool to see that bond. They don’t have a lot of other things in common and not much contact but I know Mary thinks of Amelia quite a lot and Amelia talks about Mary a lot.”

And they are both very thankful for Mary’s lovely gesture.

“I thought it was really cool that of all the type of different organisations that she could’ve given it to, she gave it to Cystic Fibrosis Waikato,” says Margaret who has own her advice for living life with a child with a serious illness.

“Don’t sweat the small stuff,” she says. “If you have a hobby you’ll get through – you have to have something to take your mind off it all so it doesn’t seem quite so big.”



And another **super special** fundraising effort...

Osher and Hattie are best friends. The nine-year-olds do everything together and when Hattie goes to hospital, more often than not Osher goes too.

So naturally raising funds for CFNZ in Christchurch became a team effort as well.

The girls decided to sell second-hand books outside the local Farmers' market and on the streets where they live for a gold coin donation – with a sign which read “all profits to Cystic Fibrosis”. It proved popular with residents who were happy to donate to the cause in return for a pre-loved book.

“People were really nice and added a bit extra. Some people donated just because the girls were showing initiative. They had a lovely day – it’s amazing how much fun they have doing things like that,” says Osher’s mother, Learne. “People thought they were getting really cheap books but at the same time they felt positive about giving to charity.”

The girls, who became friends as new entrants at Opawa Primary in Christchurch, collected all sorts of books from family and friends who were happy for them to raid their bookcases. Some of their friends also took turns at minding the stand and over 100 books were sold for a total of \$127 for CFNZ.

Hattie was only diagnosed with CF two years ago, which understandably came as a huge shock to Hattie and her family.

“Hattie had always had lung issues but they weren’t sure what it was – they thought it might be asthma but finally did some testing and discovered it was cystic fibrosis,” Learne recalls.

But the diagnosis has brought the two friends even closer together.

“Every time Hattie goes into hospital, Osher basically moves in. We go most days and sometimes end up having dinner there. It’s Osher’s job to make sure Hattie stays happy,” says Learne, who has also become friends with Hattie’s mum, Mel.

“It’s friendship that you need when you’re facing a bit of adversity,” she says.

WELCOME TO EMMA, CHANTELL, JEANETTE AND LAURA

A number of new staff members have joined CFNZ at the Auckland Office this year. Along with new Grants Coordinator Jeanette Franklyn and Projects Coordinator Laura Huet who have been with CFNZ for over six months, our most recent additions include Administration Manager Emma Nielsen and Accountant Chantell Taylor.



FROM LEFT: EMMA, CHANTELL, JEANETTE, LAURA

Emma’s work history includes fundraising, practice management and

general administration in the not-for-profit sector, with roles at the Anxiety New Zealand Trust, Arthritis New Zealand and most recently Family Works. Emma’s the one to contact about CFNZ grants and Breath4CF.

Email: admin@cfnz.org.nz

Chantell trained in accountancy in South Africa and worked as an accountant there for 10 years before coming to New Zealand to live with her family a year ago. She has worked as a teacher aide in Auckland and has now decided to return to finance at CFNZ, working in the Auckland office two days a week.

Email: accounts@cfnz.org.nz

Jeanette’s work history includes working as a pharmacist in both hospital and retail. She discovered a knack for applying for grants at the local kindergarten where her children went. Her past role as the grants coordinator for Plunket – Northern Region, has given her extensive knowledge of the grant sector. She is keen to work closely with branches to maximise the effectiveness of grant applications for our whole organisation.

Email: Jeanette’s_email_is_grants@cfnz.org.nz

After getting her communications degree in the UK, **Laura** started out in marketing, followed by public relations. She left the UK almost two years ago to go travelling and has found her way to Auckland and CFNZ. Laura’s been assisting with a wide range of projects including the Policies & Procedures, CFNZ Raffle, Charity Cricket, a plan to update CF pamphlets and brochures, marketing and design.

Email: office@cfnz.org.nz

Breath Test for Infection

A simple breath test to detect the presence of the bug *Pseudomonas* in lungs could be as little as five years away thanks to research being undertaken at Otago University in Christchurch.

Research Fellow Dr Amy Scott-Thomas has been researching the development of a breath test for *Pseudomonas aeruginosa* at the University's Infection Group for the past seven years, and the recent purchase of a new high-tech machine is likely to speed up the development of the test which promises to transform the lives of people with CF because they won't need the current invasive tests used to diagnose the infection.

So far Dr Scott-Thomas's studies, which have been funded by Cure Kids and the Lotteries Commission, have determined that people with *Pseudomonas* have what's called 2-aminoacetophenone (2-AA) in their breath.

"We've found that all *Pseudomonas* – it doesn't matter if it's grown in water or a burn on a victim, it always produces this compound. We were able to find it in the breath of cystic fibrosis patients that were colonised with *Pseudomonas*," Dr Scott-Thomas explains.

"The problem with this study is that we also found it in healthy individuals and patients without *Pseudomonas* colonisations. But it's significantly higher in those patients with *Pseudomonas*."

Now Dr Scott-Thomas is studying levels of 2-AA in the breath to determine if they can identify which people have less serious non-mucoid strains of the bug or the more worrying mucoid type which is harder to treat and remove from the lungs.

"I've just finished that research and we are getting the data extracted in the next couple of weeks and what we hope to show is that there will be a difference in the levels of 2-AA they produce."

Dr Scott-Thomas is also involved in *Aspergillus* and TB research but she says *Pseudomonas* is her first love.

"I get to go and see the patients here in the CF Canterbury community and they are just so wonderful, and they are all so willing to give up their time to help develop this test."

Up until the purchase of the new more sensitive machine, Dr Scott-Thomas says the introduction of a breath test could have been up to 20 years away, but now it's just between five and 10.

"This new machine means we can get samples through faster – we've got better sensitivity but we still have a lot of work to do but every experiment we do we get really promising results."

An interesting finding is that eating corn chips, corn products, some dairy products or honey can interfere with the breath test, so when it gets to the stage when patients can have the test, they may be asked to avoid eating these foods for 24 hours.

"The main aim is to produce a non-invasive breath test that can be used weekly or monthly so you can treat the non-mucoid infection before it turns to the mucoid and hopefully they won't need any further invasive procedures done like a cough swab or lavage," says Dr Scott-Thomas, who hopes the breath test will lead to an improvement in people's health.

"We are doing this so CF kids won't have to have invasive things done to them. We are passionate about this test. If we can detect *Pseudomonas* very early on and get the right treatment it can be eradicated far easier than if it's detected late."



DR AMY SCOTT-THOMAS IN THE LAB

FAREWELL CHERYL

We would like to pay our respects to Cheryl Marshall of our CF community who passed away on 7 August 2016. Cheryl is sadly missed – may she rest in peace and love.

Breathe Easy another step closer

NZ company Breathe Easy Therapeutics has issued a call for more people with CF to take part in a drug trial to test Citramel – its new medication under development.

Now that Citramel has been determined safe to use, the medicine has entered Phase IIa trials in CF subjects to test for safety and efficacy.

“Citramel is for daily use and we believe it will be most helpful in loosening the mucus associated with CF, which can create multiple issues as it builds up. Citramel can be used on

its own or we believe it can complement existing medications,” explains Breathe Easy Chief Executive Officer Andrea Miller.

There are people with CF taking part in the trials in Auckland, Hamilton, Christchurch and Dunedin but Breathe Easy is keen to enlist more subjects for testing and will compensate people for their time and travel involved.

“This is a wholly New Zealand story, so we are keen to involve candidates and clinicians across the country. We’ve got the main centres on board and are working on one other regional centre. We have been delighted with the tremendous support received from those with CF, their families and the physicians who treat them. We’re nearly there for this next phase of trials but need a few more people to make it as robust as possible so we can get optimum insight into how Citramel affects those with CF,” Andrea says.

Results of the Phase IIa study are expected in September next year but it could be five years before the medicine is available to patients.

“These things can take years, it’s just how they work, but as CF is classified as an “Orphan Disease” by the FDA, it’s eligible for fast-tracking in many areas if therapies prove successful in trial. We hope this will be the case with Citramel. There’s always a risk it might not work, but we have passed Phase I, and 50 percent of early stage trials don’t even get that far. Everyone is doing their absolute best – we just need more candidates,” she says.

Andrea is proud of the home-grown nature of the product. It’s been developed in New Zealand by people who have a key interest in cystic fibrosis here.



ANDREA MILLER WITH CFNZ'S JANE BOLLARD

Andrea herself has a 28-year-old daughter with CF, a Breathe Easy co-founder has a nephew with CF, and Citramel itself was invented by Professor Bob Elliott who is the patron of CFNZ and was a paediatrician for many years caring for children with CF.

“This is a positive story for CF,” Andrea says. “In the nearly 30 years I’ve been around CF, I’m the most excited that I’ve ever been about the work achieved in the past three years. To be part of the global push to develop CF-specific medications in order to add years to the lives of people with CF is an enormous privilege.”

So far Breathe Easy has raised \$2 million towards developing Citramel but another \$1 million is needed for ongoing costs around the trials.

“This is an expensive industry. We couldn’t have done it without the support of the New Zealand CF community and the medical specialists.”

If Citramel is successful it will be marketed worldwide with the aim of it becoming a routine treatment for CF care.

“We expect this to go out into the world as a CF medicine because the whole team is committed to combating cystic fibrosis,” Andrea says.

Note: CFNZ recommends seeking the advice of your CF medical team before enrolling in medicine trials.

For more information about Breathe Easy and Citramel visit: breatheeasytherapeutics.com

Clinical Trials are conducted in a series of steps called phases:

Phase I: Researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects.

Phase IIa: The drug or treatment is given to a larger group of people with CF to see if it is effective and to further evaluate its safety.

Phase III: The drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely.

Phase IV: Studies are done after the drug or treatment has been marketed to gather information on the drug's effect in various populations and any side effects associated with long-term use.

AWESOME AWARENESS WEEK!

We were blessed with fantastic weather and enthusiastic helpers for this year's Awareness Week in Auckland which all contributed to an impressive total!

It was humbling to be contacted by some inspirational young people who genuinely wanted to help our cause and rallied groups of friends and managed a number of sites over the two days.

We had plenty of positive feedback from people collecting, about how generous the public were and how many stopped to share a personal story of how they had been touched by CF. A lovely group of people assisted us from the International College of Auckland. Only recently having arrived in NZ, this was a new experience for them and they were so enthusiastic to help and learn more about CF.

We had fantastic support from a few local high schools, particular mention to Macleans College which sold thousands of chocolate fish, ran a bake sale and organised a roster of students for a couple of collection sites.

We had three fundraising sausage sizzles around Awareness Week, a big thank you to Tegel, Mitre 10 Warkworth and

Pak'nSave for their donations of food for the sausage sizzles.

The success of the Awareness Week would not have been possible without our many helpers and bucket shakers, but in particular those people from our hard working committee who pulled this Awareness Week together – our area co-ordinators Rachel Sinclair, Rebecca Hansen, Sally Sprosen and Malcolm Lambert – thank you! Awareness Week for Auckland Branch was not only a good fundraiser, but a great opportunity to raise awareness of CF to the wider Auckland community.

By Kath Sanderson



AUCKLAND'S MARATHON EFFORT

The CF Auckland marathon team members put on their trainers and headed out to take part in a variety of events as part of the Auckland Marathon on 30 October.

This was a culmination of months of fundraising and training to be ready for the big day. The event took place on a beautiful spring morning, starting at Devonport on the North Shore and progressed through the streets, over the iconic Auckland Harbour Bridge and finishing up at Victoria Park in the Central City. We had two committee members, Niall and Malcolm, and Branch Coordinator Kath taking part and a team of athletes from Willis

Towers Watson (organised by Niall). We were fortunate to have Helen and Larissa from Ultraphysio, who generously donated their time and skills to massage our weary athletes at the end and to do some fundraising massages in between. Our hard-working volunteers cranked up the BBQ and cooked up delicious bacon and egg butties for our weary athletes.

A big thank you to ...

Our fundraising runners from the Willis Towers Watson team – Abby Harris, Andrew Holland, Angelo dal Bello, Callum Hyde, Echo Cui, Jessica Schade, Melanie Harding, Niall Martin, Nigel Grantham, Peter Lowe, Richard Jackson, Sean Long.

Fundraising runners/walkers from the CF Auckland team – Anne O'Connell, Malcolm Lambert, Sara Warren, Caroline Redfearn, Alison Denne, Lynne Carter, Kath Sanderson.

To our support people – Phil McKay, Greg Collins, John and Jill Thorrat.

To Helen and Larissa from Ultra Physio for the amazing sports massages. Check out their website at: www.ultraphysio.co.nz

Pak'nSave Glen Innes – for their generous donation of food for the post event tent.



Ansell Nurse HERO Award presentation to Jan Tate

The Ansell Australia staff headed to NZ recently to present CF Nurse Specialist Jan Tate with the Ansell Nurse HERO Award following a voting campaign earlier in the year that saw Jan get thousands of votes from our CF community and contacts. It certainly showed how many lives Jan had touched and was a great opportunity to show Jan how much her dedication and hard work is appreciated.

As well as giving Jan her award, Ansell Healthcare also presented her with a \$3000 cheque to donate to charity. (A big thanks to Jan for choosing CFNZ as her nominated charity). One of Jan's patients, Kelea, spoke about how Jan has always been there for her – from helping with advice at her school to staying by her side during those dreaded blood tests. Congratulations Jan from everyone at CFNZ Auckland Branch!

KELEA'S SPEECH ABOUT JAN TATE'S SPECIAL NURSING CARE

"I was four and a half when I first met Jan, though I don't really remember a time when I didn't know her. She's always been there when it comes to my CF. She came and met with me and my teachers on my first day of school. She had to bravely fight the traffic and make it through police road blocks to get there. She always greets me with a cheery "Hello Kelea" at clinics before doing my weight and height measurements. It's great because clinics always make me nervous. She's guided me through the dreaded blood tests which still to this day freak me out. When I was a few years younger she even excused herself from an important meeting to come and be with me for a series of tests on the ward - there was no way the doctor was going to do them without Jan there. Sorry mum, you didn't count on that day! I gave her a bit of a heart attack when I did something, that I'm not supposed to talk about but has something to do with swimming when I shouldn't have in case something got wet... Its ok Jan I haven't done that since. Jan's ears took quite a hammering (so did those in the children's playground below) from my screams as my first PICC line was removed. Sorry Jan. I think we've sort of nailed it now. Thank you so much for being there for me through the good times and the not so good, just like I know you've been there for all of those with CF who are lucky to have had you on their team. You SO deserve this special award. Congratulations."

Kelea x

FROM LEFT JAN, KELEA, PHILIPPA FROM EBOS AND JENNA FROM ANSELL





RUN WALK HB 5 GENERATIONS!

From left to right: Cefiro-Jai Kemp and Teizahr&Tré Puna (4th Gen), Great Grandmother Mahue Crete Pinkham (1st Gen), Akinehi Kemp (behind, 4th Gen), Grandmother Moe Va'aulu (2nd Gen) holding Jeremiah-Taylor Kemp (5th Gen), Leahna Tumarae (4th Gen), Lea Moa (3rd Gen), and on knees Piripi Kemp (4th Gen).

Supporters **Gang Up** for CF

The Hawke's Bay Branch has been busy this winter and spring.

For the first time in a few years we were able to have a few collection points out during **Awareness Week** thanks to the organisation skills of **Joan Fisher**, a grandmother of a CFer. Also in Awareness Week, Pakowhai Primary school – that has a student with Cystic Fibrosis – held a Pyjama Day and sausage sizzle in support of Cystic Fibrosis and their student, Amber (who was the inspiration behind the fundraiser).

In September, the Hawke's Bay (HB) Branch hosted the annual **Casino Party**, with **Catherine Rusby** once more doing a fantastic job of organising the evening. This year's theme was "Gangster" and people came looking fabulous and ready for a good time. They were not let down! A fantastic night was had by all who attended and we even had some VIP guests – Auckland CF Branch members – whom we are very grateful to for attending. All in all the night was a huge success with more than \$12,000 being raised.

For the second year in a row **Run Walk HB** has donated to the HB Branch as a result of proceeds from the Napier City Pak'nSave Half Marathon. This year the Branch gratefully received more than \$2000. Not only is this great for financial reasons, it was also a chance for increasing awareness and gives friends and family an opportunity to do something proactive for Cystic Fibrosis. At least three CF families participated on the day and also various friends and family members. Lily Hasselman (PWCF) aged 11 completed the 10km with her cousin, and one newly diagnosed family had five generations also complete the 10km event (see photo).



Recently **Claire Fisher** hosted a **movie fundraiser** with proceeds going to the HB Branch. The movie was 'Be Here Now – The Andy Whitfield Story' and was very thought provoking. No doubt guests went away with a new appreciation of their own lives.

The Keirunga Park Railway Club in Havelock North hold a fundraising event every year where proceeds from the day go to a charity. They have asked to support Cystic Fibrosis at next year's event. Although details are yet to be finalised, it is pencilled in for Sunday 5 February. This is an exciting opportunity and could be a great fundraiser. For more information refer to the club's website. www.keirungaparkrailway.org.nz



TIM'S STANDING OVATION

The Branch has issued a huge thanks to Tim for helping raise an impressive \$4500 from a school fundraising initiative. Tim has reported on how this was achieved:

"My name is Tim, I'm 13 years old and live in Hawke's Bay. This year I started secondary school at St John's College in Hastings. I'm enjoying being at high school but I'm sure that like everyone starting in Year 9 it can be both exciting and stressful. With Cystic Fibrosis that feeling can be amplified as although you don't really want to be different from any of your mates, I think it is a time when you have to be brave enough to ask for help if it's needed and brave enough to let everyone know what life with Cystic Fibrosis is like so they understand, as without that awareness they cannot offer help if it is ever needed.

I am very lucky to be at a school where everyone has supported me. Every year the St John's College Year 11 students with the help of the PE (head of dept) Mr Jason Pearson select a cause for the school's 'Commit to a Cause' and if possible they try and relate it to a charity that is linked to a student at the school. This year they chose Cystic Fibrosis Hawkes Bay and on a hot day in May all the Year 11 boys ran or walked from St Patrick's Church in Napier to our school chapel in Hastings, a distance of approximately 20 km.

For this event all the students taking part gathered sponsorship and a massive total of \$4,500 was raised to help Hawke's Bay CF families in all sorts of ways including extra funding for physio sessions, support with hospitalisations, essential medical equipment and more.

Our principal Mr Paul Melloy drove me to meet and encourage some of the students at about half way through their run which made me realise how much effort goes into this annual fundraiser. At our school assembly on Fridays we have what is known as "The Last Word" where a student gets up in front of the whole school to talk about something significant connected to the school or their life or both. As a Year 9 I was quite nervous but I wanted to give the school an awareness of CF as well as thanking them for such an amazing effort. I prepared and delivered my speech and was surprised to receive a standing ovation from the whole school! A feeling I will always remember!



Because of this event CF Hawke's Bay also asked me to be a guest speaker at their annual Casino fundraiser event which was a fun night where they also included me to help the auctioneer with some of the fundraising."

RYLEE'S A WINNER

First place overall in athletics is definitely something to celebrate. This 10 year old is living life to the max, despite having to cope with some of the curve balls thrown by CF. She has recently returned from a five week trip around the USA which she handled really well. Her mum says Rylee loves athletics and high jump is her fave. Good going Rylee!

SNIPPET



Spotlight on Central

Chairperson Anna Scoullar-Jones reports on a positive upswing at Central Districts thanks to more fundraisers and extra assistance from Rotary.

"We are thrilled to have made over \$1000 in chocolate fish sales in past three months. I have spoken at a South Wanganui Rotary Club meeting, Nigel Ramsden has run four movie night fundraisers in Feilding, Levin and Masterton – showing "Chasing Great" to keen crowds in boutique cinemas and spreading CF awareness at the same time. We are gearing up now for the next Ballentyne's Fashion Show in Palmerston North on 4 April 2017, with CF Conference a few days later."

Anna's Labour of Love

Anna was also featured on Wanganui Online with the following report when the local news website requested information about CF:

Central Districts Branch Chair Anna Scoullar-Jones has two good reasons why she's the driving force behind the Ballentyne's Fashion Show to raise funds for local families.

Show to raise funds for local families.

Anna had a great friend growing up, Erin Bartrum, who had Cystic Fibrosis (CF) but sadly passed away four years ago. And then 16 years ago, Anna gave birth to her wonderful son, Lockie, who was also diagnosed with CF.

Having such personal connections to the genetic condition led Anna to take a leading role in the CFNZ Central Districts Branch – taking on the position of Co-Chair alongside her childhood friend Erin before she passed away at the age of 42 from liver cancer following a lung transplant.

"I knew that Erin needed help – her health wasn't so good," Anna explains.

It was Anna and Erin who worked to make the annual Ballentyne's Fashion fundraiser for Cystic Fibrosis a reality six years ago, with the latest Show at Ballentyne's Wanganui on 21 September (see top picture).

"Ballentyne's do several fashion shows a year for various charities," says Anna. "We make sure we book well ahead and



STEPHANIE, LYNN, JOAN, DEBBIE, CARLA AND KATIE

we make sure to advertise. It's something that's fairly easy to organise because Ballentyne's are so helpful – they run the whole thing for you – you just have to provide the models, the supper and sell tickets."

Since then the shows have grown in popularity. The Branch likes to include a special guest model and Mayor Annette Main hitting the red carpet for the event last year was a high point for the Branch.

Now working as sole Chair, Anna says she never has trouble finding potential models to walk the catwalk at the event.

"It's really fun getting the models and they have a great time. We only need six and there're always people who say, 'I'd love to model'," Anna says.

There's always a full house for the fashion show, which can raise to \$1000 for the Central Districts Branch from ticket sales, raffles and extra donations on the night.

This year's September show raised \$550 and Anna personally knew all the women who modelled – two were clients from work, one the wife of a colleague and three ex workmates.

The success of the Wanganui event has led to more Fashion Shows for CF around the region. There was one at Ballentyne's in Feilding on 26 October thanks to Rotary's Nigel Ramsden who offered to assist with organising the event at his local Ballentyne's store. Central Districts are also planning an extra pre-winter Fashion Show on 4 April 2017 at the Palmerston North store.

Funds raised go towards supporting adults and children with CF in the Central Districts region. The Branch provides a wide range of grants for people with CF including travel vouchers, welfare assistance and medical equipment such as nebulisers.



ANNA



LOCKIE



WELLINGTON PRESENTS 8th XTF

Wellington's Xmas Tree Festival (XTF) is the jewel in the crown for Wellington Branch's fundraising efforts and this year is no exception. It's attracted new sponsored trees – there's one from the All Blacks and also Hell Pizza. CFNZ have sponsored a tree this year but sadly can't compete with the interest shown in the All Blacks tree! The Branch wants to extend a huge thanks to all the previous sponsors who have signed up again for the Festival at Wellington International Airport again – such as Wellington Phoenix, Whittaker's Chocolate and Eftpos, and also all the CF families and friends who have helped put up trees, helped with bucket collections at the Airport and spread the word. This year's Festival runs until 7 January 2017.

Awareness Week was another high point for the Branch – a kids disco at Step Out Dance raised over \$1000 and a total of \$8000 was raised during the Week with help from the street collectors and chocolate fish sales. A special thank you to Streetwise Coffee who sold chocolate fish, and ANZ staff, CQ Hotel and ACC who all helped with the collection.

The best news of the year is the imminent arrival of a part-time CF Nurse Specialist for children in Wellington. We are pleased to announce that Tricia Marton has accepted the role and will take up her position in the New Year. Tricia is currently Clinical Nurse Specialist on Ward 1 Children's Ward and comes with lots of experience. Tricia will make a fabulous addition to the Wellington team, which also includes the CFNZ Central Fieldworker Jude Kelly who has been helping adults and families.

Wellington Branch is currently in the process of updating the database so please notify the Branch if you have had a change of address, email or phone numbers.

Wellington Branch now sends out the CF Wellington E-News. Contact Paula to be added to the list.
Email: paulafisher5@hotmail.com



CHOCO-NANA SMOOTHIE RECIPE

Courtesy of Chelsea Winter (First published in the Wellington Branch E-News.)

This smoothie is filling and full of good energy. A quick and easy afternoon pick me up and it's so yum! If you remember, try soaking the almonds and dates in a covered bowl of water in the fridge overnight or for a few hours before making. They will blend up more easily.

- 10 Raw Almonds
- 2 Medjool dates, pitted
- 1 1/2 cups chilled milk (or coconut, rice or almond milk)
- 1 large ripe banana
- 1/2 small or 1/4 avocado
- 1T coconut oil
- 2 t raw cacao powder or cocoa
- 5/6 ice cubes

Drain the almonds and dates (if soaked), then add them along with all the other ingredients to a blender and process until very smooth. Enjoy!



Pole-Tober-Fest for CF

Juliet Hubbard has turned her exercise of choice, pole classes, into a surprisingly successful fundraiser for the Canterbury Branch.

This year's Pole-Tober-Fest has been the most impressive so far generating over \$3000 and featuring performances from burlesque dancers, comedians, and pole performances.

Since enrolling at the Liberate studio, Juliet has been able to keep fit with the added bonus of becoming close friends with her teacher Liv.

"When I met Liv she didn't know what CF was till she met me – now she's keen for everyone to know what CF is and get it out there," Juliet says.

"I remember when Juliet first got hold of me to join my pole lessons and I thought it would be such a great charity to start doing annual fundraisers for," says Liv, who also helped Juliet and her brother collect during CF Awareness Week.

She believes Pole-Tober-Fest has grown because they have succeeded in creating more awareness and people have recommended the show to their friends.

"This year Halo Bar here in Christchurch kindly donated their venue to us which meant we could have a lot more people come along which

made the event the biggest yet! Previous years it has been held at the Liberate pole dance studio." Juliet adds.

"Also this year Liv decided to open the show out to other performers so that it was pole acts plus a big variety of all sorts of performers, such as acro (circus), singing, a comedian, aerial hoop and burlesque dancers. The first year we raised \$400, the second year \$800 and this year \$3000! Also when we went collecting during CF week at Barrington Mall we had flyers to hand out about the upcoming Liberate show. It was so nice to see people at the show who took flyers from us that day."

The funds were raised through a combination of ticket sales, raffle, bucket collectors in the crowd and also selling pop-for-a-prize balloons which had prizes written inside that people could find for a gold coin donation. Some of the companies that donated items included Making Faces, One Shape Cleaner, Ray White Rangiora, Speights Ale House Ferrymead, Perzonal Glass NZ, Pure Romance by Sara Whyte, Forever Framed, Roadrubber



tyres, Divine Digits, Red Laser and Beauty, Wicketts Dog Grooming, Isupps Papauni and Lo TV Rentals.

Juliet also recommends pole dancing to others. For her it's a form of exercise which also holds her interest.

"It's not as boring as some other forms of exercise that's also another reason I do it. I have my own pole up at home as well so I can practise. You need a lot of strength. I do recommend pole but it's a lot harder than it looks."

Another Pole-Tober-Fest is planned for next year – this time with a goal of raising extra funds.

"At half time and the end of the show I had a number of people come up to me who said I did a really good speech that touched their hearts," Juliet says.



JULIET (LEFT)

JULIET TALKS TO THE CROWD

In her speech, Juliet told the audience to take a deep breath and imagine living life without being able to do that. Here is an excerpt:

"So name is Julz and I was born with cystic fibrosis on the 26th of January 1985. As a kid I lived a pretty normal-ish life and didn't have too many hospital admissions.

My first admission for a lung infection was at about age nine and after that it was about every year or so I was admitted for I/v antibiotics. Gradually as I got older the hospital admissions became a bit more frequent.

Nowadays, I'm what they call a frequent flyer – I'm in and out of the hospital a lot – if I last two months out, that's what I call having a good run for me. When I'm admitted I'm admitted for I/v antibiotics, lots of physiotherapy and rest. It has sadly become a more regular thing for me these past few years and life in general and every day activities have become tougher especially in winter time.

My lungs function on only 36 percent capacity. I have to keep active to help my lungs to function as much as possible which as you can imagine is hard to juggle especially when each day you wake up low on energy and feeling poorly from infection. People with CF use a lot of their energy trying to breathe so you can imagine there's not a lot left for much else.

If it weren't for CF I wouldn't be who I am today – it really makes you appreciate all the little things in life!

Each day is a gift to me and many others living with CF and you definitely know not to take anything for granted."



Charity Golf Tournament – Templeton Golf Club

This year Canterbury Branch's annual Golf Tournament turned out to be a wonderful day in terms of the weather and funds raised.

We raised approximately \$5,500 which we are absolutely delighted with.

We had a good turnout of players and they all dug deep to help our cause by buying raffles and auction items. Once again our auction was conducted by Roger Dawson – a welcome sight back on the golf course again.

Together with some new teams, this year we had our regular supporters, including Seamus Logan who has been playing in all 29 of these tournaments.

The Canterbury Branch would like to thank Templeton Golf Club and all our sponsors, players and helpers for making this such a successful day.

It will be our 30th year for this tournament in 2017, and we would like to make this a special day – so watch this space!

By Nicky Churton

JOE SHAPES UP FOR TYLAH

When CF News last caught up with Joe Voyce he had placed second in the South Island body building champs. Two years later he's winning gold with his wife-to-be.

Joe recently won first place in the NABA South Island Championships physique section, while his fiancée Tylah Flett also came first in the shape category – adding to the happiness that they've found together.

Joe (25) met Tylah when she was working at the supplement shop that he managed and found they had plenty in common – body building for one.

“He was my boss!” Tylah laughs.

They began training together and hanging out together.

“And one thing led to another,” says Joe.

“She was quite similar to me – quite committed to training. I'd never met anyone like that,” says Joe who now has a new job running Snap Fitness gym.

“He was funny. I could talk to him about anything. We built more of a friendship first,” explains Tylah who has a daughter, Mila (5).

A few months into the relationship Joe told Tylah about his health condition.

“I knew he had CF but I didn't understand really what it was,” Tylah says. “I cried because I wasn't really aware of the severity and Joe doesn't seem sick as such.”

Tylah (26) recently switched from body building in the strict “figure” category to the “shape” category to give her body a rest as she prepares for the couple's IVF treatment.

“I toned it down a bit because I wanted my body to be the healthiest it could be. It's quite dramatic what you've got to put your body through to get to that lean point.”



Joe believes he won in September because his body's larger – something he attributes to an increased diet, improved training and being more careful with his Creons.

The wedding proposal was the most romantic that Joe's ever been in his life – presenting Tylah with a diamond ring on Christmas Day at Brighton Beach in Dunedin.

“I had no idea,” Tylah says. “I was so excited. It was awesome.”

Joe believes he has the relationship stability he's found with Tylah to thank for an improvement in his health.

“I've had to drop the excuses for not keeping up with some of my treatment. Apart from colds, I have not had one hospital visit for I/V treatment since May 2014. My health has improved massively.”

Note: It's recommended that people with CF check with their medical team about any sporting activity or the use of supplements.

ADULT ADVISORY GROUP

To help the CFNZ Board identify the needs of adults living with CF, a CF Adult Advisory Group has been set up to provide feedback and input to the Board.



This group consists of CF Adults all across the country, with experiences in a number of areas such as travel, lung transplants, pancreatic issues, having children etc, and includes a variety of ages. The Chairperson of the Group, Lisa Borkus (left), will act as a conduit between the Board and the Advisory Group. The aim is to provide a balanced overview of how CFNZ can

meet the needs of adults living with CF, taking into account the diversity within the CF community.

Also, results of our recent survey sent out to all CF Adults in NZ, indicated that some of you would like to see more connection opportunities with other people with CF. For those of you who are not aware, we have a Facebook group set up with the sole purpose of allowing CF adults to chat, get to know others on the same journey and share information. This page is called "CFANZ Adults Network" and you can request to join by going directly to the page or make a request via Lisa Borkus. (lborkus@gmail.com) or phone **0272062855**.

And a big thanks to **Alex McKay**...

Congratulations and thank you to Alex McKay who won the top prize in his employers, PriceWaterhouseCoopers' Volunteer Awards. The PwC Foundation rewards good deeds with winners judged on making an outstanding level of commitment to a particular organisation, an enduring commitment over several years and a significant contribution to multiple organisations. A number of employees are awarded \$1000 for their charity but Alex, who was named the overall winner, received \$2500 to donate to the charity of his choice which was Cystic Fibrosis New Zealand.

Over the years, Alex and his twin sister Lizzie pictured here, have been strong supporters of the work of CFNZ, Cure Kids and the CF community. This year Alex was instrumental in voluntarily organising the Mark Ashford Scholarship video with producer Kieran Wright which was screened at the CFNZ National Conference and can be viewed via the CFNZ website:

cfnz.org.nz/our-services/library/clips.

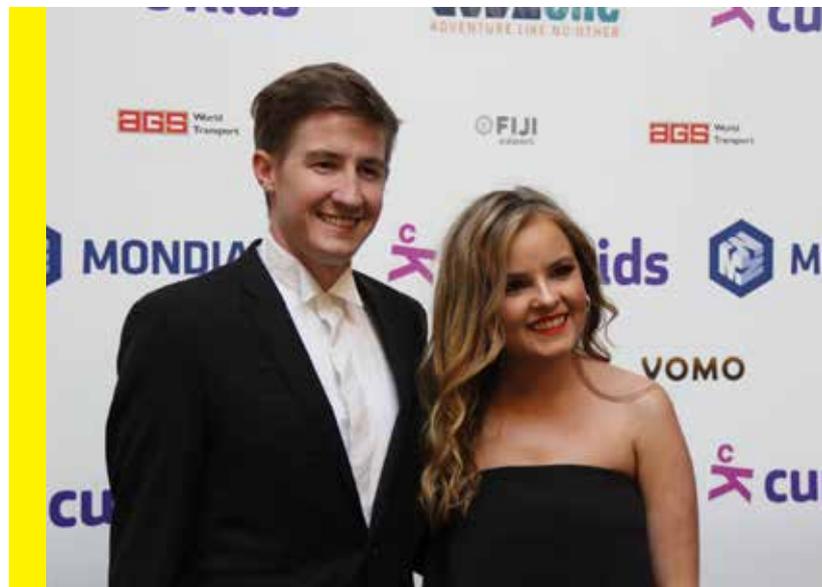


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CFNZ PANUI

Sign up to CFNZ's electronic newsletter, the Panui, to get the latest in news and views once a month.

Email: comms@cfnz.org.nz to get on the list. CFNZ also provides immediate updates on our Facebook Page: [@CysticFibrosisNZ](https://www.facebook.com/CysticFibrosisNZ). Please "Like" us on Facebook if you haven't already.



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The information contained in CF News is not intended to take the place of medical advice from your general practitioner or Respiratory Specialist. Opinions expressed are not necessarily those of CFNZ. The purpose of this newsletter is to provide a wide range of accurate and timely information on all aspects of CF. Cystic fibrosis is a dynamic specialty and therefore opinion may change or vary from time to time.

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