

SUMMER 2015-2016

**cf** CYSTIC FIBROSIS NZ  
Creating Better Tomorrows

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# CF news

## MOLLY on the move



Meet our  
**CF ACHIEVERS**

Talking transplants with  
**JUSTIN FARROW**

MANY THANKS TO





# Update from the Chair

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**On behalf of the CFNZ Board I would like to take this opportunity to wish everyone a very Merry Christmas, and happy and safe holidays.**

Once again a year has sped past and it has been a full one for the CF Association of New Zealand. Our CFNZ Board remains stable with the current Board all returning for another term. At our AGM in September we reconfirmed our very popular Patrons; **Professor Bob Elliot** and **Andy Ellis** (Sports Patron), and our incredibly committed President **Denis Currie** for this coming year.

CFNZ has faced difficult times financially in the last year, however as an organisation we have significant strength in our people and our structure, and we seem to be weathering the storm.

At our Chairpersons' Conference in September the branch representatives, CE and the Board worked on strategies to ensure a "Sustainable CFNZ" moving forward into the future. We were expertly facilitated by **Andrew Cameron**, a dad of a young PWCF and I would like to take this opportunity to thank Andrew for the huge amount of planning and effort he put into the sessions. The Board, CE and branches are very pleased with what came out and we are now working on implementation. This kind of Think Tank doesn't happen as often as it could and I for one really appreciated the time and opportunity to really look at what we do, how we do it, and where to next, in line with our established strategic direction.

One thing that is very important for me as Chair is the opportunity to have feedback from our adults with CF. Currently we have no CF adult representative on our Board and the CE is working on establishing a reference group of PWCF who can provide input to the organisation and the Board. In the past we have had wonderful CF Adult Reps and have truly appreciated their input and perspective, and hopefully this will happen again soon. Please do contact Belinda or one of the CF Fieldworkers if you think you may be interested in being part of the reference group.

A group that has emerged from one of our Facebook groups is the NZ Campaign for Kalydeco Group. This group has just started its journey and is working with our CE to ensure our voice is heard loud and clear in the funding for new treatment "space". Thanks to those who have become part of this group. It is very important that our effort is thought out and well executed to ensure that we are as effective as possible with what may seem like a daunting challenge. I am certain that our CF community will rally to support this important cause. We will keep you updated about this Campaign via the CFNZ electronic newsletter, the Panui.

*I would like to thank people who work so hard during this year's Awareness Week... Bubbles were blown, buckets were shaken and I have never seen so many great articles about CF – both in print and electronic, in such a short period of time. It felt like CF overload and it was awesome!*

Thanks for those who shared their story; you telling your story makes our job as an organisation easier when we talk to DHBs, government agencies and even other not-for-profit groups.

We have a new information section on our CFNZ website that I would like to "advertise". Under the "ABOUT CF" header there is now a topic called "From the Clinical Team". There is a lot of great, current stuff in here that has been in the Auckland E News and has been written by various staff from Starship and Auckland Hospital CF Teams. This section will be added to regularly so watch this space.

Finally, I would like to let everyone know that Conference 2016 planning is in full swing and we are hoping to get a couple of great overseas speakers. I hope as many of you as possible can make this once-a-year chance to get together, learn and share together.

**JANE DRUMM, CHAIRPERSON**




## UPDATE from the CEO

*The end of 2015 has seen busy CFNZ offices with much achieved!*

The National Conference held in Wellington this past May had over 100 attendees – a great turn out. More importantly it was also podcast, so those with CF could attend virtually. The Chairs' Conference (reported on page 9) was well attended and proved to be a fun and informative two days.

I have met with many clinicians, pharmaceutical companies and sponsors and after 18 months in the role am feeling a real connection and understanding of what life with CF entails. I have had some success with both the DHBs, Ministry of Health and PHARMAC in getting their attention to the issues that PWCF and their families live with every day. I aim to report next year that some of these issues have been addressed.

Both the CFNZ offices and branches have worked together on successful fundraising and awareness campaigns – I am happy to say that I get a real sense of community among the members regardless of where in the country they reside – Together We Are One – is a theme that we are all working to achieve. This year has seen a record number of articles in both print and electronic media with regard to the CF community.

Once again I have endeavoured to meet as many of the branches on their home territory as possible. Some of the branches have had concerns with some elements of the policies of CFNZ so wherever possible we have worked together to come up with solutions that suit both parties.

The last financial year recorded a loss so it is with much pleasure I can report the finances for the first six months of this financial period are looking very healthy. This is due in no small part to the fabulous job Hannah and the team have done for CFNZ.

As always my contact details are on the back page, so please feel free to contact me at any time.

**BELINDA BURNETT, CEO**



## CHOICE HOTELS' \$15,000 week

**CFNZ is extremely grateful to Choice Hotels for hosting another campaign to raise money from every night's stay at one of their hotels across New Zealand.**

As part of their "Help those Living with Cystic Fibrosis Become Invincible" campaign, the hotel chain donated \$2 from every night's stay to CFNZ in the week leading up to Queen's Birthday Weekend. This year \$15,000 was raised - \$3000 more than last year.

Cystic Fibrosis NZ chief executive Belinda Burnett said the money raised will go directly towards assisting the CF Fieldworkers. "Our Fieldworkers travel the country to support and positively influence the lives of those living with cystic fibrosis."

"We are incredibly grateful to Choice Hotels for its support which has enabled us to significantly reduce our running costs, allowing us to make a stronger impact on the lives of those living with the disorder."

**To book a stay call 0800 803 524 or visit [www.choicehotels.co.nz](http://www.choicehotels.co.nz)**

## CF News grant



**Cystic Fibrosis New Zealand would like to thank the Infinity Foundation for providing a grant for this issue of CF News.**

The Infinity Foundation donated \$10,000 which covered the cost of the Winter edition of CF News in 2015, and also part of this summer edition.

CFNZ Chief Executive Belinda Burnett said this grant will ensure CFNZ can keep this avenue of communication open to members.

**"Communication is of vital importance in this day and age.**

**Given that people with cystic fibrosis shouldn't be in the same room together because of cross infection concerns, it's doubly important that our organisation has other ways to connect them together."**

The aim of the Infinity Foundation is to distribute the proceeds of gaming machines back into the community, including any charitable project that is beneficial to the community or a section of it.

CF News is published twice a year and unless indicated otherwise articles are written by National Information Coordinator Vicky Tyler. Please email Vicky at - [comms@cfnz.org.nz](mailto:comms@cfnz.org.nz) if you would like to publish a letter to the editor, or have any news tips or story ideas.

Vicky also writes the e-newsletter, CFNZ's Panui, which is emailed on the last Friday of every month.

**Please email: [comms@cfnz.org.nz](mailto:comms@cfnz.org.nz) to get on the mailing list.**



# MOLLY on the move

Marvellous Molly's been loving getting her Breath4CF thanks to her new free bike and the fresh Wairarapa air.

The four-year-old couldn't contain her excitement when she was gifted her new bike by CQ Hotels in Wellington earlier this year, and ever since then it's become a regular part of her exercise routine.

"I love my bike so much and love to ride it every day," says Molly who can be spotted riding around the garden and on the Greytown rail trail.

CQ Hotels gifted new bikes to Molly and two other children with CF in the Wellington region, with Molly's story reported in the Wairarapa-Times Age newspaper after her family were invited to a special ceremony to be presented with the new bikes.

Molly's brother Alex (8) and Meghan (10), have also got their own bikes and love being able to ride

along with their little sister now. And Molly loves taking along her doll Rosie as a pillion passenger in the back, making sure that Rosie is buckled up and that she's safe as well with her helmet on.

The family moved from Wellington where they'd lived for eight years to Greytown in the Wairarapa at the beginning of this year partly because Molly's Mum Libby Kelly, and Dad Lee Macri, believed that the country air and lifestyle would be helpful for managing Molly's cystic fibrosis – one of the advantages being a smaller school. "And we're still only one hour's drive away from Wellington Hospital," says Libby.

The couple both work in the Wairarapa - Lee is a secondary school teacher and Libby works in local

government. And Lee says the move to Greytown is the best one they ever made, with the family all in better health over the winter months.

"The kids are healthy and happy and that's what matters," he says.

Libby wants to thank CQ Hotels for Molly's bike which is being used to help with exercise which is extra important for people with CF.

"It's better for her to be active," says Lee.

Molly was diagnosed with CF after her newborn screening blood test, and her family are doing what they can to help manage her condition. She has physio twice a day, with Lee and Libby taking turns at the "percussion taps" on her ribs.

Molly is just about to start school and Libby says the family are loving their new lifestyle.

"We are all loving being in the Wairarapa and looking forward to all the cycling we're going to do over the summer holidays!"

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Our cover photo is courtesy of the Wairarapa Times-Age newspaper which featured Molly's story in July this year after CQ Hotels in Wellington gifted her the new bike. The picture was taken by photographer Lynda Feringa who was able to capture Molly's excitement. Lynda recalls that Molly was the perfect subject. "Molly was a gorgeous, very obliging model, supported by an equally gorgeous and loving family," she says. **CFNZ wants to thank Lynda and the Wairarapa Times-Age for allowing us to feature this wonderful photo on the cover of CF News.**

# Meet our CF ACHIEVERS...

## Maddison (16) – Achievement in Education



Spending half the school year in hospital didn't stop Pahiataua student Maddison from passing her level one NCEA exam with merit.

Her top marks, despite ill health, earned Maddison a CF Achiever's Award in education.

The Tararua College student Maddison sat all her NCEA exams in Starship Hospital in Auckland

with a hospital teacher sitting in her room during the exam with no one else allowed to enter.

Being in hospital for six months during the last half of 2014 gave Maddison plenty of time to study.

Speaking from Starship Hospital in Auckland where she was spending another three weeks, Maddison told CFNZ that she was determined not to let her school work slide.

*"I allocated time each day to sit down and do something, and it also makes the time go a bit faster as well. I studied a lot and Mum helped me a lot. I sat down for at least two hours a day before all my exams and just read everything I'd done that year."*

This year Maddison is studying English, Drama, Classics, Photography and Print Making, and is hoping to become a beautician.

## Jemma (25) – Achievement in Sport



Jemma started playing netball when she was just seven and is still going strong at the same club 18 years later.

What started as a hobby at her local netball club, Waiau Pa, south of Auckland is now something that has earned Jemma a CF Achiever's Award, and also plays a vital role in helping to keep her well.

Playing at senior level can be quite challenging but also lots of fun, says Jemma.

*"I've stayed with my local club the whole time. I've moved upwards and there are completely different faces every year."*

Jemma also likes to get to the gym four days a week and enjoys participating in walk/run events.

*"As you get older you realise that exercise is such a huge part of it. You've really got to get out and use your lungs."*

The next step would be playing at a regional level, but Jemma says at 25 she's probably too old to be selected now.

*"These days the level of skill is getting so much higher that players are coming in so young – you've got to be in there at 18."*

Jemma believes that the nature of the stop/start game

of netball is good for people with CF and recommends it as a good activity for children with CF.

*"It's an enjoyable activity; there are good social aspects and we train inside."*

Jemma, who works two part-time jobs, is thankful for keeping in good health and emphasises the importance of PWCF keeping up a routine to manage CF.

*"You've got to keep to a routine of nebulising and physio. If I don't do them then I suffer the next day. If it's part of your routine you get it done."*

## Sam (17) – Achievement in the Arts

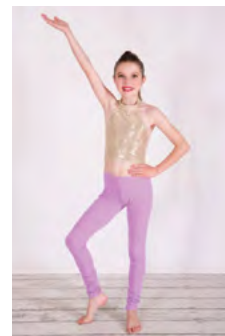


A natural performer, Sam has been entertaining his family and friends for years, and his recent success in the dramatic arts has led to him being granted a CF Achiever's Award in Art.

Sam has always been interested in performing, playing drums and acting since primary school, with a particular penchant for comedy.

Since taking up Drama in Year 12, Sam has shown a real talent and passion for acting. Over the last two years he has created and performed several short plays on stage, taken a leading role in the school musical and taken part in the Sheilah Winn Shakespeare Festival in Wellington. Sam is hoping to attend drama school next year.

## Kelea (10) – Achievement in the Arts



Dancing since the age of five, Kelea of Auckland, now attends four different dance classes, recently passing her grade 3 Royal Academy of Dance exam with distinction.

She is committed to attending her five hours of after-school classes each week, even when she could do with a rest. This is on top of her physio twice daily.

Kelea's first love is ballet but since starting to learn she has added three other genre's to her bow – jazz, tap and musical theatre.

Her parents believe that Kelea's dancing has been beneficial for her health but can see the 10-year-old's struggle to gain weight eventually impacting on her dancing because muscle strength is helpful for mastering some of the demanding dance moves.

Kelea wants to use her grant to either attend International Summer School of Dance in Sydney or to start learning how to play the piano.



# AWESOME Awareness Week



Photos by Hannah Wilson.



This year's Awareness Week – rolled out in August – was a better month for donations and volunteers, with two branches Auckland and Otago getting one of their best results.

The CFNZ Annual General Meeting held during the Chairperson's Conference issued a vote of thanks for the branches who helped make it a success. Auckland Branch raised \$30,000 and Otago's collection totalled more than \$20,000.

Two new National Office events were fun and entertaining. Bounce for CF, sponsored by Choice Hotels, was held at Uptown Bounce in Auckland where local pre-schoolers jump started Cystic Fibrosis Awareness Week, and the CF Charity Auction held at the Elms Hotel raised \$15,000 – much more than initially predicted.

There were two big news stories during the Week that helped enormously. The public's attention had been captured by Christchurch woman Alana Taylor who had just had a successful lung transplant, and also the Good Deed Sisters in Tauranga, Nikki Reynolds-Wilson and Kristie Purton who undertook 65 days of good deeds in the lead up to Awareness Week, including leaving coins at laundromats, providing home baking for emergency workers and giving kids free train rides.

A Bubbles Party to celebrate their achievement was a fitting conclusion to the week's activities.



A good time was had by all at the CF Charity Auction in Christchurch. Photos by Hannah Wilson.



## IZAEAH FINDS A NEW FRIEND

**Attending school more often has paid off for 15-year-old Izaeah of Picton who got the chance to take a free trip to Christchurch and meet an online friend for the first time.**

Izaeah is on oxygen 24/7 and has a feeding tube. His medical treatment means that he is unable to attend school very often, but his family were keen to see him going more – so CFNZ Fieldworker Sue Lovelock struck a deal with the teenager – if he made more effort with his school work she would arrange a free trip to Christchurch to meet his online friend, Bart.

Izaeah had only been attending school one hour a day once a week, but upped that to three hours a day twice a week so he could meet his end of the bargain.

In July, Izaeah and his dad made the trip to Christchurch where they were offered free accommodation at the Quality Hotel Elms in Christchurch including full complimentary breakfasts each morning and dinner at the hotel.

Izaeah was excited to finally meet his friend Bart, who did know about Izaeah's health condition.

*"I first met him playing on a server in Minecraft and Skyped him after that. He was talking to his buddy when I joined the call and they were talking about the Christchurch quakes. I asked them how they knew about it and Bart said he lived in New Zealand."*

Bart (14) is now part of Izaeah's League of Legends team – which is their group's favourite game.

Missing a lot of school has made forming friendships difficult for Izaeah.

*"I've never really had any friends to begin with. I'm not very good at socialising with kids my own age – they do sport and I don't, but with adults it's fine."*

Gaming has opened up a new world of friendships for Izaeah and he's pleased that the Cystic Fibrosis NZ Fieldworker helped his friendship with Bart by arranging the trip to Christchurch.

*"It was quite exciting," says Izaeah. "Bart is a lot bigger in person and he had two nice dogs."*

Quality Hotel Elms Events Coordinator Nadine Theron said the hotel was more than happy to help.

*"Quality Hotel Elms was pleased to be able to assist with Izaeah's trip to Christchurch by offering free accommodation to him and his dad. Izaeah is such a vibrant kid, everyone here was touched by his story and we are glad to hear that he had a good time."*

Thankfully, Izaeah's health has been looking up too.

*"I've been going up. My overall strength has been improving, and I've been gaining weight," he says.*

MARK  
ASHFORD  
SCHOLAR

# MEET VAUGHAN SOMERVILLE

Photo by: Megan Blackwell



It seems Vaughan Somerville was always destined to win the Mark Ashford Scholarship. Not only has he won CF Achiever's Awards on two occasions – his grandfather also predicted that Vaughan would one day be named the Mark Ashford Scholar – once telling Mark Ashford's wife, Kathryn, that his grandson would be getting the award in the future.

Vaughan Somerville is the 19th recipient of the Mark Ashford Scholarship after he graduated from Auckland University with a first-class honours degree in medical science.

The Mark Ashford Scholarship is awarded to the person with CF who has attained the highest standard in tertiary education for the year. It is sponsored by Pink Batts, which is part of the Fletcher Group where Mark Ashford, who had CF, worked before he passed away.

Vaughan was presented the 2015 Scholarship by Tasman Insulation Marketing Manager Alison Roberts at a function held at the Auckland Office. He completed his Bachelor of Medical Science last year. He's now studying law and working towards his PhD.

Vaughan plans to use his \$3000 Scholarship to help pay for his student fees and his PhD.

Originally Vaughan entered medical school wanting to become the first doctor in New Zealand with cystic fibrosis, but his health condition meant he had to change

his career path.

*"After discussions with the Faculty I realised that it wasn't going to be possible to balance the two so I had to look to change degrees,"* he explains.

At the Award's presentation, Mark's widow, Kathryn Ashford, spoke of how happy her late husband would be to see his legacy live on.

*"It blows my mind that it's been 19 years,"* she said at the function.

Just a few days before Mark passed away, Kathryn and Mark were told that the Fletcher Group had decided to provide a scholarship in his honour.

*"It shows the esteem that Mark was held in by his colleagues. And in those days no one knew about CF and the hurdles the kids had to go through."*

*"I'm happy that this year the award has gone to someone who is in the medical field, and the advances that have gone on in CF are just amazing,"* she said. *"Mark would be so happy to see that his name has lived on, for me and for Jill his mum."*

Vaughan, who won a CF Achiever's Award for leadership in



2005, and again for education in 2011, believes that having CF has pushed him to succeed in his studies.

*"Being in hospital made it harder to study so I guess it helped to push me a little a bit more. I think I developed quite a good work ethic with time management – being in and out of hospital."*

Vaughan really took to learning when he entered Auckland Grammar. He started in the educational stream of 3F – and was being placed in the A and B classes towards the end of his college years.

*"Grammar was where I started to realise I enjoyed learning,"* says Vaughan, whose family comes from a scientific background.

Vaughan is aiming to use some of his scholarship money for research into nutrition for high-performance athletes which he's doing for his PhD.

*"With the money I can do more measurements and get better quality results,"* says Vaughan who is specifically studying the effect of flavonoids on high-performance athletes including All Blacks.

*"Having CF means you can get thrown quite a few curve balls but you end up with good self-resilience and being able to adapt to change."*

Next year marks the 20th anniversary of the Mark Ashford Scholarship and a committee has been established to decide how to commemorate it.





# CONFERENCE REPORT

**The CFNZ Chairpersons' Conference has been hailed as a practical and positive event for the branch representatives who attended. All branches apart from Southland were represented at the conference held in Christchurch during September to address a large number of issues facing charities today including communication, branding and the financial sustainability of CFNZ moving into the future.**

CFNZ Grants and Events Coordinator Hannah Wilson provided an overview of some of the successful events that have raised money for CF including the CF Charity Auction held at Quality Hotel Elms which raised \$15,000. She urged all branches to consider approaching their local Choice Hotel with the possibility of helping with a fundraising event.

In particular, the balloons that were sold at this event were popular. They were sold for \$25, \$50 or \$100 dollars and were guaranteed to attract a prize worth more than the amount. The \$100 balloons sold in minutes, which was a nice surprise.

Administration Manager Julie Clemett outlined new reporting standards for charities being introduced on 30 June 2016 and how she will be working closely with branch treasurers to transition to the new system.

Belinda led a discussion about

branches complying with the law, with advice also being given by privacy expert Gareth Abdinor of Christchurch.

A closed session without CFNZ staff present saw branches discussing proposals for managing welfare payments, with North and South Island Fieldworkers being in charge of administering the system.

There were lots of great ideas put forward on Day 2 which primarily focussed on "Sustainable CFNZ" and how to grow the organisation. Conference delegates were asked to consider three ideas for improving funding and developing the growth of CFNZ – without making any decisions about how to proceed.

The three ideas presented by Andrew Cameron who is a dad of a PWCF and has a wealth of experience in the health industry, are for CFNZ to own a nationwide fundraising event, to build a "Friends with CF Community" to utilise business and personal connections, and establishing ways to achieve the goal of "One Voice-One CFNZ" with clearly established and agreed roles and responsibilities to achieve equity for all PWCF.

Conference feedback showed that the branch representatives were impressed with the positive vibe of the conference and that there is a more optimistic outlook towards the future.

## FROM COUNCIL TO CATWALK

Wanganui Mayor Annette Main proved to be a good sport when she took to the catwalk at the Ballentynes Fashion Show for the Central Districts Branch.

Annette joined other volunteer models who showcased new season trends at the fashion show in October to help raise funds for people with CF in the region.

It's the fifth year that Ballentynes has held the fashion show and Branch Chair Anna Scoullar-Jones praised the local Mayor for joining in the fun.

*"All six models did an amazing job and got a taste of the runway. Some of them were repeat offenders for the annual event, so clearly they enjoyed this chance to shine."*

This year's show was a sell out and raised \$850. All Ballentynes stores throughout NZ offer their stores free of charge for charities holding fashion shows.



Model Mayor



Central Districts Branch members Coraie, Anna and Andrea put on a good show.

CFNZ National Office currently have a total of seven staff who are responsible for helping to carry out CFNZ's mission statement to optimise the quality of life for people with CF and their families.

We introduce you to the team so you know who to contact if you have any questions.

# INTRODUCING... CFNZ STAFF



From left (back row) Fieldworkers Melinda Coombes (Northern) + Sue Lovelock (Southern), Admin Manager Julie Clemett, C.E. Belinda Burnett. Front row: AK Branch Coordinator Lorel Hallinan, Information Coordinator Vicky Tyler, Grants & Events Coordinator Hannah Wilson

## Fieldworkers Melinda Coombes & Sue Lovelock

The purpose of the two Fieldworkers is to provide relevant services for people living with CF, their families/whanau and caregivers within NZ. They offer professional support, practical assistance and information, and provide advocacy and empowerment for all our members as required. They spend a lot of time dealing with a number of other organisations and external agencies such as WINZ, Housing NZ, Salvation Army, and referrals for counselling. They have approximately 220 clients each (both paediatric and adult), and are always available to visit the parents of newly diagnosed children.

## Administration Manager Julie Clemett

The purpose of Julie's role is to manage the financial requirements of CFNZ – setting the budget and meeting legislation required for NZ charitable organisations. Employed part-time with Wednesdays off, Julie manages the welfare/grant schemes offered by CFNZ including Breath4CF, all financial functions, including banking, payments, invoicing, and record-keeping (MYOB). She is convener for the CFNZ Investment Committee (including approval, distribution and record keeping) and project manages other ventures as required. Julie is also Administrator for the Port CF Steering Committee, assists with health and safety, IT, and designs the advertising and billboards for the CFNZ website.

## Chief Executive Belinda Burnett

The purpose of Belinda's role is provide leadership, strategy, representation, and financial management (planning, budgeting and reporting to the Board and members), operational management (overseeing all the staff performance) while ensuring CFNZ continues to meet the needs of the CF community. She provides CFNZ representation at government level including advocating with Pharmac for new medicines and equipment, advocating with the Ministry of Health to get sustained funding for the Fieldworker service (and hopefully a third fieldworker), and liaising with the DHBs to help ensure they meet the standards of care. She also represents CFNZ with external organisations such as Cure Kids, Disability Sector CEO Forum, the Clinical Advisory Panel (CAP), Cystic Fibrosis Australia and other international CF organisations. She regularly provides advice to the Board and branches about a wide range of issues.

## Auckland Branch Coordinator Lorel Hallinan

Lorel is responsible for the Auckland Branch committee meetings (including minutes and agendas), all correspondence, liaising with the Auckland Branch Treasurer, maintaining the Auckland Branch website and membership records. This role is also responsible for administering the CFNZ voucher system (both National and Auckland) based on requirements determined by the

CF Fieldworkers, organising the CF Auckland Branch hospital gift packs, purchasing and delivery of equipment, maintaining equipment records, reporting to the Chair and CF Auckland Branch Committee, and maintaining any records and reports pertaining to the Auckland Office health and safety responsibilities. Lorel works part-time Monday to Thursday, and also assists with organising Auckland Branch fundraising and awareness activities such as Sail4CF and Awareness Week.

### Information Coordinator Vicky Tyler

Vicky's role is to research, publish and organise information services for CFNZ. She is responsible for developing educational tools and CFNZ pamphlets, maintaining the CFNZ website, CFNZ Facebook Page and producing this national newsletter CF News. Vicky is employed part-time, and also writes the monthly electronic newsletter the CFNZ Panui, and produces press releases, the CFNZ Annual Report, responds to media queries, and takes minutes at CFNZ Board meetings, staff meetings and other special interest meetings.

### Grants and Events Coordinator Hannah Wilson

The purpose of Hannah's role is to manage Grants and Event requirements nationally and locally where requested. This means managing and fostering existing fundraising projects and corporate relationships such as Kiwifirst & Choice Hotels alongside identifying new grants and income streams for CFNZ. Hannah is at the forefront of organising national events such as the National raffle, and CF Charity Cricket which require negotiating with businesses for prizes and sponsorship. She also assists with some regional events such as the Wellington Christmas Tree Festival.



## Jerry Collins remembered

The CF Community in Auckland has paid tribute to the late rugby star Jerry Collins who went out of his way to meet a young fan back in 2008.

Ben was in hospital for the first time after being diagnosed with CF at the age of four. His mum, Raewyn Saxon tells CF News that she had bought tickets for her and Ben, who is a huge rugby fan, to attend the Blues vs Hurricanes match unaware that Ben would need to be hospitalised for intravenous antibiotics. But his doctor allowed Ben to be discharged for the game – which the eight-year-old attended with a drip still attached to his arm.

*"Before the game we caught up with my brother Grant who is the Auckland Rugby Union liaison for the Hurricanes and he asked Ben who his favourite player was. Ben said, 'Jerry'.*

*Grant organised for us to meet Jerry after the game so we waited patiently outside the dressing room for Jerry to come out. Then Jerry asks us to come in.*

*Jerry was very accommodating, friendly and made us feel welcome and at ease. This is where we got our photo.*

*Ben and I were so happy – we didn't want to leave but he had to get back to the hospital and it was already after 10pm.*

*We downloaded the photo and one of the nurses kindly printed it out for us. We taped it to the door and it became a topic of conversation for everyone to talk to Ben about. It is a moment he will never forget nor I. It was a wonderful way to take our mind off the reality of the hospital admission.*

*When the news came out that Jerry had died in a car accident. I text Ben to see if he had heard. He replied, 'Yes'. I know that Jerry's passing was felt deeply by Ben, not in a sad way but in a very respectful way.*

*Jerry was a great man whom Ben held in high regard and he managed to leave behind a memory that Ben will never forget. Thank you Jerry."*

**RAEWYN SAXON**

## CHARITY CRICKET Crusaders battle it out



As CF News was going to print the Crusaders Super Rugby team were about to take on some rugby legends in CFNZ's 33rd Charity Cricket match.

Held on Sunday 6 December this time the current Crusaders team were taking on former Crusaders' stars in a 20/20 match at Christchurch Boys High School between 11am – 3pm. It was shaping up to be a fun match, with balloon raffles and a live auction with sports memorabilia up for grabs.

# JULI TAKES THE CHALLENGE



National Office is now gearing up for Challenge Wanaka in more ways than one – not only are we the official charity for the event, our Administration Manager Julie Clemett, is taking the challenge - AND fundraising on behalf of CFNZ.

Working at Challenge Wanaka for the past two years has tempted Julie, a keen cyclist, to take on the Challenge in February by competing in the Lake Wanaka Half Iron event, along with her son Nic who is willing to do the half marathon run and swimming leg of the race.

*"I've always wanted to do a bit of a challenge and a few years ago my eldest son Nic did Coast to Coast in a team. I was going to do it with him the next year but a hamstring injury has stopped me doing any major running event so I've taken up cycling,"* Julie says.

*"Road cycling in groups scares the bejesus out of me so I wanted an event where I could ride by myself. There's no way I could run but I would love to cycle."*

The cycle circuit for the Lake Wanaka Half is 90km long – 20km more than Julie has ever cycled before, but after working at CFNZ for almost six years, Julie is no stranger to taking on new challenges.

She loves working at CFNZ

because of the variety that's involved in her work day.

*"It's not just accounts, it's the website, design, going out and shaking a bucket, and attending some of these events. All the variation is what I like,"* Julie explains.

She cycles to and from work at the Christchurch office and has been using these rides to help train for Challenge Wanaka.

*"Twice a week I also go on a long ride which involves hills,"* she adds.

After working at the Ironman events as well when CFNZ was the official charity - Julie thinks Challenge Wanaka is going to suit her better.

*"Challenge Wanaka is a real laid-back, relaxed atmosphere. It's a lovely place – you don't have the same competitiveness as Ironman which is quite elitist. Whilst the top athletes at Challenge Wanaka are at the top of their field, they're really approachable. Challenge also promotes the fact that it's a family event."*



*"It's a really good weekend."*

Julie's only concern is that she lacks the contacts via Facebook or a large group of friends to help her fundraise online.

*"That's why I've never fundraised before,"* she explains. *"I don't have a huge circle of contacts that I can hit up. But I'm quite happy to raise money,"* says Julie, which is why CFNZ is keen to promote her efforts as much as possible. At least 10 other athletes are also fundraising for CFNZ as they prepare to take on Challenge Wanaka on Saturday, 20 February 2016.

This is the third year that Cystic Fibrosis NZ Breath4CF has been the official charity for the event, which is also celebrating its 10th anniversary.

To sponsor Julie's CFNZ fundraising efforts please visit her fundraising webpage: <https://give.everydayhero.com/nz/julie-cfnz>

## THE ART OF FUNDRAISING

The Tauranga Arts Festival has set the scene for another positive fundraising venture for Breath4CF when a breakfast meeting with guest speaker Author Nicky Hagar drew \$3500 for the charity.

The breakfast meeting at the Readers and Writers Festival was organised by long-term Rotarian

Sally Morrison and Rotarian Peter Tinholt who began fundraising for CFNZ almost 10 years ago. Tickets cost \$46 and 220 people attended including Bay of Plenty Branch Chair Nicola Wakerley and Veronica Furze.

Peter says many people were intrigued to hear about Nicky Hagar's latest book Dirty Politics.

*"I think it opened people's eyes to the dirtier side of politics on both sides of the fence,"* says Peter.

The Rotary Club also regularly

host a Quiz Night around March/April, and this year's event resulted in a \$3600 donation to CFNZ.

Peter has no personal link to CF but has a personal goal to raise \$100,000 for CFNZ. So far he's raised \$89,000 – the majority from the big sums he raised while competing in Ironman for six years.

*"I first watched Ironman in 2006 and met people raising money for CF and that's how I got involved. My Rotary Club really gets behind the cause too,"* he says.



## SHOP4CF A WINNER

### HealthPost

Being named charity of the month by one of New Zealand's biggest online shopping websites, HealthPost, was a big boost for CFNZ. Those who shopped for health supplements and skin care products helped to raise almost \$16,000 because up to \$2 from every order could be donated to CFNZ. This amount was well over expectations and one of the largest amounts raised for a charity of the month, so that's pretty good going.



CFNZ has also entered into an agreement with OurEcoHome, which sells environmentally friendly cleaning products online at [www.ourecohome.co.nz](http://www.ourecohome.co.nz). Use the code "CFNZ2015" at checkout and 15% of the sale comes straight to CFNZ at no extra cost.



We would also like to extend our warm gratitude to Noel Leeming for the discount weeks it has had for CFNZ this year. We have just finished a two-week run where 2.5% of their sales to those who presented a CF Noel Leeming flyer were donated to CFNZ.



# BACKSTREET'S BACK with Nick

Meeting the Backstreet Boys during their recent tour was more than just a trip down memory lane for Hawke's Bay's Nick Laing.

It's the second time that Nick has met the band – this time he got to go backstage when he attended their sole concert in Auckland in May.

As a member of the fan club Nick was fortunate to get a VIP pass when he bought his tickets. And not only did he get his photo with the band, he even got the chance to talk to Backstreet Boy, Brian Littrell.

It helped that Nick also knew the band's photographer through a mutual friend in the UK, and he recognised Nick straight away when he saw him backstage. The pair had first met after meeting at the Backstreet Boy's tour of NZ in 2010.

Backstreet Boys Nick Carter and Brian Littrell also remembered Nick from the time he met them backstage when they toured here in 2010. This time Nick didn't want to miss his chance to have a conversation with Brian because he wanted to discuss a mutual friend who had cystic fibrosis in America.

"He knew my friend Kristina who had CF and she passed away just after the first time I met them. He remembered Kristina and her mother, Debbie – she went to most

tour concerts in her area of Kentucky.

"I told him that Kristina and I have the same condition and Brian asked how I was going. I spent five to ten minutes talking to him."

Nick Laing has been a fan of the Backstreet Boys since the 1990s when they released their hit single "Everybody". And it's also how he connected with his friend Kristina, who was also in the Backstreet Boy's fan club.

"They also have a new song, "Breathe"; says Nicky. "And that reminds me of CF."

Going to Auckland for the concert turned out to be a particularly entertaining trip for Nick (30) because he also got to attend one of the televised X-Factor shows during his stay.

Nick was pleased he was allowed to get film footage of the Backstreet Boys performing during the sound check, as well as a signed photograph of the band.

"It was good. I was on cloud nine for quite a while."

Nick's own health has been up and down. His lung function is currently at 34% but that's an improvement compared to when it was down to 18%.

"I've discovered that going hard-core with gym and weights has been helping."

Nick didn't only meet the Backstreet Boys, he also formed a new friendship with photographer Natalia Holden who was inspired to launch a photographic portfolio, called the **Cystic Fibrosis Courage Collection**, which will feature people with CF and their families. Anyone who is interested in being part of the Courage Collection can **contact Natalia on 021 1220015 or Email: [Njoyphotography@outlook.com](mailto:Njoyphotography@outlook.com)**.



# Battling the bugs

Professor Tony Kettle with PhD student Kate Vick: “What we are trying to do is a novel approach, but hopefully one that will be successful.”

As bacteria have become increasingly resistant to currently available drugs, a team of Otago scientists, led by Professor Tony Kettle, is working to develop new and more effective antibiotics.

It began with a tub of margarine in the mid-1980s. Then recent University of Otago chemistry graduate Tony Kettle was working as a research chemist at an Auckland food manufacturer, figuring out how to stop the butter substitute from going rancid.

*“I’d finished my chemistry degree and got a job at a margarine factory. While it might not seem that exciting, that job taught me some very useful things about myself and science. It demonstrated the role of free radicals in food; my boss taught me the value of hard work and perseverance; but, most of all, that job taught me that doing science can actually be a lot of fun.”*

*“I’d been a distracted undergraduate student, but after being in the workforce I decided I wanted to fulfil my academic potential and headed off to do my master’s in Vancouver.”*

More than three decades on, that young research chemist is an internationally respected professor and Director of the University of Otago, Christchurch’s Centre for Free

Radical Research. He and his team were recently awarded a \$4.8 million Health Research Council (HRC) programme grant to find new ways to diagnose and treat bacterial infections.

This grant recognises the significant threat posed by growing rates of global infections and the declining ability of antibiotics to kill bacteria that cause fatal infections. Professor Kettle also won an HRC project grant of \$800,000 to understand how white blood cells damage the lungs of young children with cystic fibrosis.

Kettle says antimicrobial resistance is recognised by governments and international medical bodies as a serious threat to health and lives. Dire scenarios predict that, within the next decade, people will die from infections we now treat simply with antibiotics.

*“The overuse of antibiotics, particularly general ones that target many types of bacteria, has allowed a wide range of bugs*

*to develop resistance and render many common antibiotics useless,”* he says.

*“One of the ways our body fights infection is through the action of neutrophils, a type of white blood cell. Neutrophils hunt out and kill pathogenic bacteria. However, in some not-yet-well-understood cases, fatal infections occur when neutrophils are overwhelmed or bacteria evade them. In these situations, more neutrophils rush to the site of infection and damage healthy tissue rather than killing the bacteria.”*

Kettle says unlocking the secrets of how bacteria escape from neutrophils could be critical to combating antibiotic resistance and is central to his \$4.8 million HRC programme grant.

*“New antibiotics, or antimicrobials, could be designed to negate bacterial defences so that neutrophils kill bacteria normally and stop the bacteria from causing major life-threatening infections. What we are trying to do is a novel approach, but hopefully one that will be successful.”*

With the HRC’s financial assistance, over the next five years Kettle and his team will develop better ways to determine exactly which bacteria are responsible for an

infection so the right antibiotics can be used. They also aim to determine how some bacteria evade neutrophils and promote serious infections, thus helping identify new strategies for the development of new types of antibiotics.

*“While these free radicals are central to fighting infections, they can also cause tissue damage during inflammation. This type of damage – known as oxidative stress – is involved in diseases such as heart disease, Alzheimer’s disease, cystic fibrosis and cancer, to name a few.”*

Kettle says his \$800,000 HRC project grant, focused on cystic fibrosis, is a chance to explore the most extreme and negative aspect of free radicals.

*“Our goal in this project is to find biomarkers present in urine or plasma that will signal infections in the lungs of young children with cystic fibrosis. The hope is that by detecting infections early, the children can be treated with antibiotics that will suppress inflammation and limit damage to their lungs. We will also use an animal model of cystic fibrosis to test a drug that dampens oxidative stress to determine whether it preserves lung function.”*

Both the neutrophil and the cystic fibrosis studies will involve international collaborative teams of scientists including Kettle’s Centre for Free Radical Research colleagues, clinicians specialising in areas from rheumatology to infectious diseases, and members of other research groups within the University of Otago.

*“A team approach has been the key to our success in getting these grants. Lots of people with different areas of expertise and at different levels are pitching in to solve the questions we propose to tackle.”*

Kettle has been working with many of his collaborators for decades. He joined the Centre for Free Radical Research (formerly known as the Free Radical Research Group) as a PhD student in the late 1980s.

*“I came to Christchurch to undertake my PhD with Professor Christine Winterbourn who, even then, was regarded as one of the world’s leaders in free radical science. Professor Margreet Vissers was working here too and Professor Mark Hampton was the first PhD student I supervised.*

*“The four of us have been together for a long time and now we lead a team of hard-working and talented scientists. It is through their efforts at the laboratory bench that we continue to be at the forefront of free radical science.”*

*This article by Kim Thomas appears courtesy of the University of Otago Magazine.*

# New diagnosis

**A diagnosis of CF for parents is often the start of a long-term relationship with their medical specialist, leading to a new study highlighting the importance of the method of breaking bad news to parents.**

A study published in the July Journal of Cystic Fibrosis interviewed 38 parents of children in a Belgium Clinic diagnosed in the past five years and recommended doctors “doing things well from the start” helps families to learn to live with CF and treatment.

An earlier study had reported that parents who were told about the CF diagnosis were often receiving a kind of lecture. This lecture contained more information than parents could take in at once. This study recommended regular consultations with the provision of reading material and audio visual demonstrations.

Newborn screening for CF is yet to be introduced in Belgium. The majority of parents were told of the CF diagnosis in a one-to-one talk; 10 parents received the term “CF” by telephone. Most diagnoses were made during hospitalisation.

Nineteen appreciated the doctor showing some emotion during the talks. Only one couple criticised the doctor for not showing emotion. All parents were introduced to members of the CF team (nurse, physiotherapist, dietician, social worker and psychologist), which was considered valuable. The vast majority of parents were generally content with their own experience. Most parents preferred a professional attitude with a personal touch.

Twenty parents reported they had never heard of CF prior to the diagnosis, four knew someone with CF and 14 parents had heard of the disorder.

Mothers and fathers coping styles were similar although mothers used social support more often. All but one couple discussed the diagnosis with family and friends.

The research linked the three different coping styles of stress to a diagnosis of cystic fibrosis:

- **ACTING COPING** – where a person tries to change the stress (finding out information, learning new skills)
- **ACCOMMODATIVE COPING** – where a person tries to adapt by changing their emotions, distraction, meditation, relaxation.
- **PASSIVE COPING** – where a person avoids the stress (relying on others, helplessness)

The first two coping styles are considered healthier than passive coping which is linked to depression.

The majority of CF parents in this study used active and accommodative coping styles.

Parents recalled varying emotions and thoughts. Most common were “anxiety” and “how will the future be”. Few parents recalled thinking “God will help us”.

The study concluded that there is no “best way” to break bad news and that the quality of these discussions depend on the doctor’s ability to estimate the preferences of the parents.



## ANCHORS AWAY in Auckland

Auckland Branch has been celebrating a few good wins recently. We had a very successful Awareness Week in August, and launched a new fundraising and awareness event – Sail4CF in October.

Our dads have been enjoying a few get-togethers at a local pub, along with a new venture launched this year called **Sail4CF** – which is a great initiative for the City of Sails.

The **Auckland Marathon** was a success thanks to the athletes who supported CF on Rugby World Cup day.

Two **Sileni wine** fundraisers raised \$2000, and we were delighted to get \$3000 from three **Z Energy Service Stations for Good in the Hood**.

Although we farewelled Anthea Wendelborn as Co-Chair – she remains on the Committee, and we are extremely pleased to welcome four new Committee members.

Our fundraising success this year would not have been possible without such a hardworking Committee and team in Auckland. It's been wonderful to see so much commitment to our CF community this year.

**JILL THORRAT, CHAIRPERSON**



## Sail4CF

Auckland Dad, Malcolm Lambert, thought of a great way to raise awareness and funds for Breath4CF using his love of sailing. He planned a new event that he named Sail4CF, held at the Manly Yacht Club on the North Shore one breezy Sunday morning in October. Despite coinciding with an All Blacks World Cup match, keen sailors lined up to participate in five races. In the afternoon it was "Have A Go Day" where for a gold coin donation people were taken out for a sail.

Auckland Branch helped out with a raffle and Malcolm's extended family and friends ran an all-day BBQ. All of the goods and services were donated including the race official's time. Our thanks to Malcolm for fulfilling this fun event, which we can hopefully expand to other yacht clubs around the Auckland region.

**LOREL HALLINAN, AUCKLAND BRANCH COORDINATOR**

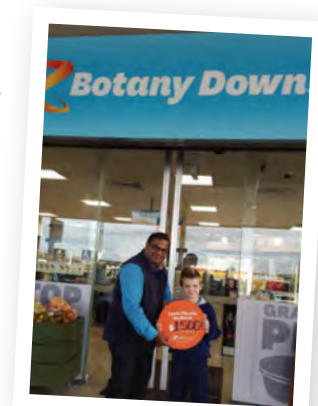
## Tayler's good in the hood

Auckland Branch was thrilled to collect the most tokens at the **Botany Downs Z** service station during the Good in the Hood programme, receiving a total of \$3000 from four stations that had CF token boxes.

Z Winter Developments Operations Manager Shiv Gupta presented Tayler (8) with a big token worth \$1500 once all the tokens from the Good in the Hood programme had been counted.

Tayler's mum Stephanie said it cost her a fortune in coffees – she was at the local Z Botany Downs every day to vote. In the end it was a close race with Age Concern coming 2nd with \$1200, Arthritis NZ 3rd with \$700 and the Life Education Trust received \$600. Auckland Branch members rallied support through Facebook – regularly posting pics of the tokens filling up.

"Rachel and I came down once a week for a couple of hours handing out lollies and flyers, and trying to get support that way," Stephanie explains.



## AUCKLAND BRANCH E-NEWS

The decision for Auckland Branch to produce an online e-newsletter in the place of publishing a 'mini-mag' of our own twice a year has been greatly welcomed. Not only has this proven to be a more cost effective way to communicate with our members but it has meant we can keep in touch more regularly. For the past year our E-News has been emailed out on a monthly basis communicating our branch happenings and articles of importance from our CF Medical Teams from Starship and Auckland Hospitals.

Our E-News is distributed to our existing Auckland database (parents/families/adults) and anyone else who has 'opted-in', indicating they would like to receive our monthly communications. If you are not receiving our E-News and would like to keep up-to-date on our "branch happenings" please contact our Auckland Branch Co-ordinator on [auckadmin@cfnz.org.nz](mailto:auckadmin@cfnz.org.nz) or **021 820 566** with your details.

**ANTHEA WENDELBORN**



# Awareness Week **TOTAL \$30K!**

CF Awareness Week 2015 was an amazing success and the Auckland Branch Committee is so very grateful to all who made it such a special and successful campaign.

Raising awareness about CF throughout the wider community and much needed funds for our Branch is what it was all about but we'd like to think that fun and friendships also resulted.

Awareness Week raised around \$30,000 through very successful street, mall and supermarket collections, school fundraising events and selling those ever popular chocky fish.

As a Branch we provide support and services to around 120 PWCF and their

families and CF Awareness Week fundraising helps us purchase vital nebulisers, compressors, physio equipment, food vouchers when in hospital, hospital packs and parking vouchers when attending clinic.

The Auckland Branch would like to take this opportunity to thank **APC Innovate** who kindly sponsored our Awareness Week sandwich boards. The Branch also thanks **Finely Finished Ltd** who very generously sponsored the CF balloons (which were used in Auckland and were also sent to various CFNZ branches throughout NZ for use during Awareness Week). Huge thanks also to our Awareness Week coordinators;



Rachel, Sally, Rebecca and Steph, our Branch Committee and the many other helpers who went the extra mile each and every day.

**JANE DRUMM**



## Emily uses her Breath 4 CF!

**Auckland teen Emily is a good sport in lots of ways...**

"This is my first year at Rangitoto College. I will be turning 14 in a couple of weeks. I am really looking forward to flying down to Wellington to compete in the Secondary School National Volleyball Championship.

I will be away for six days, this will be my first school trip away without my mum attending! I feel ready to do all my treatments on my own and I am really excited about going.

We have single rooms while we are away. I can do all my treatments in privacy without any of my team mates needing to know about me having CF. Only my closest friends know that I have CF.

I have a portable nebuliser that is perfect for taking away. It is compact and heaps quieter than my home one.



I currently do around 12 hours of Volleyball and Club Beach Volleyball a week. I have also recently finished a season of Soccer for Waitakere City Under 14 Conference team. I was the only girl and could out-run a lot of the boys!

I received the Sports Person of the Year award, and have been asked to play again next season.

I really enjoy sport and I make it my goal to keep physically fit to stay on top of my CF.

I find it really helps. I feel healthier with less infections and I recover a lot quicker than I used to.

I would encourage you to go out and join a team or do a sport that you love. Be active and have fun!"

**EMILY**



# Talking with the CF Team

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

*As mentioned in previous CF News articles, representatives from the Auckland Branch Committee and the CF Adult Services Team at Auckland Hospital meet a couple of times a year to chat over topics of relevance and any issues that we have identified (anonymously) that PWCF who attend the clinic here in Auckland either as residents of our fair city or as visitors – for whatever reason.*

Last time we met was in July 2015 and relevant notes from the meeting have gone up on the CFNZ website under the title “About CF” and then: From the Clinical Team. Below are some of the questions and answers from our last meeting.

## Clarity around access to physio equipment

Auckland Branch provides all physio and nebulisers for adult PWCF in Auckland and this equipment is distributed by members of the CF team. PWCF should talk with the CF Nurse Specialist and/or the physio, or the CFNZ Fieldworker if they have an equipment query.

## Hospital admissions

The following are some queries by AWCF:

### **When having an admission in hospital if the PWCF has issues with their room who should they be complaining to?**

*The charge nurse on the ward would be the one to speak with.*

### **What is the protocol around washing physio equipment in the hand basins – where everyone is washing their hands and some people may be doing their sinus rinses?**

*The best practice would be to bring click-clack containers (or similar) into the hospital to wash in the containers (so the equipment is not touching the basin) and dry on the ledge (hopefully in the sun!)*

### **Are there guidelines (especially useful if it is a first admission post-transition) about the ward and how things are done?**

*Currently – no but this is a good idea. The CF Nurse Specialist will work on a ‘one-pager’ resource for AWCF coming to hospital covering:*

*What to bring? What to do on arrival? What to expect? Who to contact?*

*Explain about replacement of tubing, pack (brown paper bag of goodies), fridges, exercycle use etc.*

*This information would be invaluable for our AWCF and we will post as soon as available.*

### **How to deal with inappropriate manner/procedures in hospital? For example, failing to wash hands**

*The charge nurse on the ward is the one to speak with.*

*If an AWCF feels uncomfortable about raising an issue of concern/complaint with the charge nurse themselves then they are welcome to speak with their doctor and have confidence that their doctor would raise the issue on their behalf.*

### **Medical Certificates - what is the process for PWCF to follow re obtaining a medical certificate for an admission or for missing work due to being unwell? Can they be sought from their GP?**

*The team explained that the CF Nurse Specialist is the person to contact for a medical certificate. A medical certificate from the CF Team would be for CF-related illness/admissions.*

*Usually a certificate would be given if there was intervention for the period of illness e.g. admission, antibiotics. The team believes a GP would not be willing to write a medical certificate for work/study absence for CF-related issues.*

### **System for admission - what is the assessment procedure if a PWCF is feeling very unwell?**

*The team shared that if AWCF feel that an admission is needed they can either contact the CF Nurse Specialist or go to ER directly. An over the phone assessment is not always easy.*

*The CF Nurse Specialist relies on AWCF providing thorough details of their symptoms. If an admission is not felt necessary at first contact it does not mean that the PWCF cannot call back again to the CF Nurse Specialist and express “no improvement” or “I’m getting worse and need to come in.” they can even text – if the CF Nurse Specialist is not able to answer the phone at the time the PWCF calls, she will always follow up a text message.*

*It was felt that this is an area where some AWCF need to be encouraged to speak up if they feel their health is declining in some way.*



## A GOOD RUN FOR HAWKE'S BAY

It's been a big year for the Hawke's Bay Branch, with three key sporting events where CF was named as the official charity.

The **Hastings Half Marathon** chose CFNZ as its charity – it was the first time in its 35 years that it parented with a charity for the event.

Then the **Napier division of RunWalk HB** dedicated \$2000 in proceeds to the local Hawke's Bay Branch from the Napier city Pak'nSave Half Marathon.

The Fisher family including Amber (9) who has CF, appeared in the local newspaper to promote the event and awareness of CF.

This was followed by the **Staples Rodway Challenge** in November. The event is now regarded as one of the most popular sporting events in the region. It takes in some of the Bay's most stunning landscapes on a course that is mainly on private land and includes windswept beaches, native forest, waterfalls, river gorges

and stunning coastal farmland. The area includes Cape Kidnappers Wildlife Reserve and passes through the largest gannet colony in the world.

Staples Rodway choose a different charity each year and this year CF Hawke's Bay was chosen thanks to the help of Claire Fisher who completed the 32km course in 2014 in the hope that CF Hawke's Bay would be named as the charity, so her efforts didn't go unrewarded. This year \$10,000 was raised, which was an amazing result.



Casino photos courtesy of Hawke's Bay Today

## JOHN LENNON AND ME WOODFORD HOUSE SCHOOL PRODUCTION

Woodford House Senior School entertained the community with the comedy **John Lennon and Me** by Cherie Bennett.

The play is set in a medical facility for teenagers with long-term medical conditions. It centres around the young woman "Star" who has cystic fibrosis. The play is considered an insightful look at the reality for young people with the illness and is told to a background of early Beatles and John Lennon tunes. A committed cast and crew, including three students from Lindisfarne College, had a lot of fun performing it and some gained NCEA credits for their work.

Refreshments were sold which raised \$250 for Cystic Fibrosis HB. The Food Technology students made star-shaped shortbread to sell as part of this effort.

## Viva Las Hawke's Bay!

CF Hawke's Bay was the big winner at the Branch's second casino night – walking away with \$10,000 from the evening. Held during Awareness Week, the casino night is providing a popular fundraising event for the Branch. This year the Havelock North Community Centre was transformed into a Las Vegas gambling den where those who bought tickets could recklessly gamble their tokens away. Tickets cost \$100 each and guests also got to bid on gifts and prizes donated by the local community. There was even a special guest appearance by Elvis.

The Art Deco Bus was hired for the event so those living in the Napier/Taradale area could be picked up and dropped off. A great time was had by all so you can bet on another casino night in 2016!



## CHRISTMAS TREE FESTIVAL LIGHTS UP WELLINGTON

The Christmas Tree Festival now on display at Wellington Airport is the highlight of CF Wellington's year.

It's the seventh year that Wellington branch has held the festival. Last year we raised \$15,000 from our XTF and this year we're hoping that having it at Wellington Airport will bring in extra donations.

The gala night to launch the Xmas Tree Festival (XTF) in December will be

an opportunity to thank the sponsors for some of the amazing trees which have been created. The best tree on display will also be announced at the gala.

Wellington Phoenix and the NZ Rugby Union have sponsored and decorated xmas trees, along with Lewis Road Creamery, Eftpos and NZ Post. We're expecting the Weta Workshop Tree to attract plenty of interest.

The Festival is running until 7 January 2016 so hopefully lots of travellers to Wellington will get to enjoy the displays featured in clusters around the Airport.

The CFNZ text-to-donate number for Vodafone customers will also be earmarked for CF Wellington during this time. Text "CFNZ" to 7003 to donate \$3.

We also need volunteers to help with the collection at the Airport. Email [nicolahughson@clear.net.nz](mailto:nicolahughson@clear.net.nz) if you are able to help.



## JAFFA SMOOTHIE

Our paediatric dietitian Linda Williams published a yummy smoothie in Wellington's June newsletter:

- 1 orange (peeled)
- 1 cup of milk (full fat cow's milk or you could try almond milk)
- 1 tablespoon of cacao powder or drinking chocolate powder
- 3 ice cubes
- 30ml cream or one scoop vanilla ice cream

Mix it all up in blender and serve immediately.

## Farewell and THANK YOU!

This year our Co-Chairs **Kim McGuinness** and **Nicole Doriguzzi** both stepped down to pursue other interests.

Kim remains on the Board of CFNZ and Nicole has been making renewed efforts to improve animal welfare in Chile. We offer our sincere gratitude to the time they spent as Chairpersons and offer a warm welcome to our new Co-Chairs **Nicci Hughson** and **Paula Richards** who have taken on these demanding and voluntary roles.

## Awareness Week

We were fortunate that we were able to have collectors at Wellington Airport this year during our Awareness Week. We also had collectors at New World supermarkets in Lower Hutt, Thorndon and the Metro. We raised \$8000, which is \$2000 more than last year! A big thank you to CQ Hotel for the fantastic job collecting on Cuba Street for us.



Our branch also appreciated being named a finalist in the Wellington Airport Community Awards, but "Project Fields" took the top spot.



## A YEAR TO REMEMBER



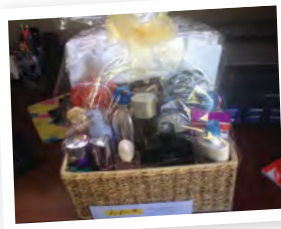
This year in the Canterbury Branch we have had some great events, including a theatre night with **Brick Road Productions**, which was a very enjoyable evening, seeing many new faces. The play was "Shirley Valentine", which was very well received. The tickets were very easy to sell with the help of the theatre company themselves. We are very fortunate to be chosen again for another charity evening in May 2016.

Our annual golf tournament at Templeton Golf Club was a very successful day with many helpers from our community assisting on the day and gathering prizes. This day is a fun day with golf, raffles and an auction – we raised \$5000.

We have had other smaller fundraisers that have been held within

our family connections such as a spin bike event and an enduro motorbike race.

Bunnings stocktake 2x a year are fun nights and very profitable, and sadly at the last count I had to turn volunteers away as we had reached our numbers capacity very early.



**Riccarton Life Pharmacy** have always been great supporters of cystic fibrosis. This year they kindly donated a

gift basket valued at \$1600 which we have decided to raffle at \$10 per ticket with a limit of 200 tickets. This is to be drawn on December 23rd.

To buy a ticket please email Melissa Skene at: [paul.mel@xtra.co.nz](mailto:paul.mel@xtra.co.nz)

**MELISSA SKENE, CHAIRPERSON**

We are starting 2016 with our first event in February – we have been very lucky to be a charity selected for "The South Island Charity Bike Ride".

This is a gruelling 3-day event of road riding through beautiful scenery. We have a dedicated mother, Paula, of a CF boy who has been part of this event twice before. Paula is very passionate about this event and has organised a group of family and friends to ride with her and be her support team. Also we are very excited to say that one of our CF adults is also racing in this event! We wish them all good luck.



Jessica - Mt Koya Japan



Mitchell and mate at the races

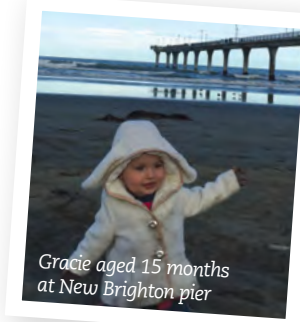


Our wishing well bride Nicky Hatton (see story in CF News May 2015) with new family member Mercedes.



## ALANA'S NEW LEASE OF LIFE!

Alana Taylor won the hearts of New Zealanders when she made headlines in July with her double lung transplant. Alana is an inspiring and positive young woman, and it's great to see her giving her new lungs a work out – climbing the gruelling Rapaki Track.



Gracie aged 15 months at New Brighton pier



Harry's letter to the tooth fairy



Anahera - school athletics



Caleb skydiving in Ashburton 12000ft



Madison who loves tea parties at the coffee shop



## TALKING TRANSPLANTS



Baby Manaia Francis Farrow, born 9 November.

Aucklander Justin Farrow was faced with not one but two huge life-changing events in the space of one week when he found out he was becoming a dad and getting new lungs.

Getting the phone call to come straight to Auckland Hospital for a lung transplant couldn't come at a better time for Justin and his partner Donna Lote who found out she was pregnant just a week before.

The couple were worried about how they were going to cope with a new baby because Justin's lung function was down to just 19% and had been forced to stop work because of his health. He had been on the inactive waiting list for a lung transplant since 2013, and the active list for three months when he got the call in March 2015.

Since then, Justin has amazed clinicians and his family with his swift recovery. And they're both able to enjoy becoming parents.

"People usually spend three months in rehab at Hearty Towers," says Justin, who was discharged after just two weeks.

Four months later he was able to return to part-time work, and has more than enough energy to cope with a new baby.

"It's just awesome to see that he can breathe again," Donna says. "I used to have to wait for him to catch up now I have to catch up with him."

Justin was finding it so hard to breathe before the operation that he was forced to leave his job working on the Auckland Harbour Bridge in October 2014 even though he was on light duties.

"Just unloading the shopping coming up the stairs was becoming a bit of a mission. I was starting to get breathless having showers and getting dressed," Justin recalls.

"I could see it was frustrating for Justin that he couldn't do the things he wanted to and we pretty much became hermits because of that," recalls Donna. "But with these new lungs he is able to do things and the smile on his face says it all."

"It's amazing how different you feel afterwards," adds Justin,



who is being careful to take his medication to help avoid the possibility of organ rejection.

The couple have been together for seven years after meeting at work. At first Justin kept his condition from her, and she only discovered after he was admitted to hospital.

*"With anyone I don't like letting on unless they ask me. I just didn't want people to feel sorry for me and think 'he can't do that', or baby me. I just wanted to carry on with normal life,"*

Then one of their workmates mentioned to Donna that Justin had CF.

"It didn't faze me," says Donna. "Quite a few people thought I might have considered ending the relationship but it was the last thing on my mind."



## Good advice

Justin and Donna's best advice to others with CF is to keep fit and active to help prolong the need for a transplant, but if the time comes try to have some money put aside.

"The worry about money was the hardest part with Justin having to give up work," Donna says. The couple were only entitled to an accommodation supplement when they asked WINZ for help.

They are grateful to have received a lot of support from the Lung Transplant Foundation and Cystic Fibrosis New Zealand, which assisted with food and petrol vouchers.

"We could put money onto our bills without having to worry about groceries," says Donna. "But we would advise anyone who is looking to get on the inactive or active list to start saving as soon as you can.

"It's best to be prepared as much as you can be," Justin says.

For more information on support available for organ transplant check website: [www.cfnz.org.nz](http://www.cfnz.org.nz)

## RECIPE ROUND-UP



Here's a family favourite recipe courtesy of Michele Wilson (who has a daughter with CF). She is co-owner of the personal catering business, **Wilson Jones** in Wellington.

## Stuffed red peppers

1. You need half a red pepper for each person you are serving.
2. Slice red peppers in half - length ways (try slicing the stalk in half and leaving it attached for effect). Place cut side up in a large roasting pan.
3. Scrape out all the seeds and white membrane
4. Chop ripe tomatoes into chunks 1 cm bits and stuff into the peppers until quite full.
5. Finely slice several peeled garlic cloves, and again stuff into peppers with the tomatoes, about 3 fine slithers of garlic in each half pepper.
6. Crumble or break up one pack of feta cheese and stuff about 3 or 4 pieces of cheese into each pepper.
7. Sprinkle with fresh basil leaves before serving.



## A sincere thank you

to the following service clubs and community groups which have supported Cystic Fibrosis NZ over the past six months – their contribution helps us continue our mission to improve the lives of people in the CF community.

[Christchurch North Lions Club Inc](#)

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[Rotary Club of Tauranga Sunrise](#)

## FAREWELL JASPER

*We would like to pay our respects to Jasper Thomas of our CF community who passed away on 6 June 2015. Jasper is sadly missed - may he rest in peace and love.*

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**Post to: Cystic Fibrosis Association, PO Box 8241, Christchurch**

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Name: \_\_\_\_\_ Ph: \_\_\_\_\_

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