

Annual Report 2016



Designed and edited by Cystic Fibrosis New Zealand

Photography

Thank you to the communities we work with for the use of their photos and thank you to the photographers for capturing these moments.

Front cover

The front cover shot is of Tayler enjoying the waves at the Surf Experience Day for Kids with CF, run by the Maui Ola Foundation. The photo was taken by Scott Sinton, professional photographer and surfer, who was one of the photographers at the event.

Icons from The Noun Project

thenounproject.com

Farewell page drawings from FreePik

freepik.com

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1. People

Leadership point of view

Board Chair Message

At the end of each CFNZ Board meeting I reflect on one question....How have we added value to CFNZ today? Did we focus on our purpose? Do we have an effective governance culture that will stand us in good stead in hard times? Do we ask the hard questions and do we comply with all that is required of a Not-for-Profit organisation? Although this may sound like PC gobbledeygook to some, it is how we effect change and move ourselves along the path to our mission of: "Optimising quality of life for people with cystic fibrosis and their families – striving for normal life expectancy".

This year the CFNZ Board has added value by ensuring our strategic statement that we will work "Together as One – Creating Better Tomorrows" is our priority. This year has certainly been a year of rapid change for CFNZ yet I can say with confidence that we have had to work "Together as One" more than we have ever had to before.

Our Chief Executive of less than 18 months left at the end of January and once again we were in recruitment mode – just when we thought we would be in consolidation and possibly growth mode. We were fortunate to have extremely high calibre applicants for the CE position and welcomed Jane Bollard, our new CE, to CFNZ in March. This brought about another change in that our new CE would be working from our Auckland office. Two members of staff from our Christchurch office moved on to other positions leaving just the South Island Fieldworker in our Christchurch office. Rather than see this as a threat, the CE and Board saw this as an opportunity and the administration base for CFNZ was moved to Auckland. This has not been easy for staff, branches or our wider community. The Board has discussed the term of "National Office" as one that we prefer not to use as we now have staff and services

"As a result of this we identified three primary strategies to ensure sustainability for CFNZ going forward"

being delivered from three areas in NZ and we believe that the "National Office" term promotes a "them and us" mentality between the branches and national and we like a one-team approach.

Other ways that we have moved towards our one-team approach is our Think Tank and workshopping at our Chairpersons Conference in September 2015. As a result of this we identified three primary strategies to ensure sustainability for CFNZ going forward. Financially 2014/15 had been a difficult year and it was essential we look for long-term strategic solutions. As a result several different approaches have been put in place, although the changes in staffing and the unexpected move of our administration base has meant we have had to adapt our original thinking somewhat. Our successes include developing a shared funding model with several branches allowing us to implement a third fieldworker

service for the central area of NZ. This ensures there is better outreach and need assessment for PWCF and families, and therefore better support by CFNZ. Working together with our Wellington Branch has also ensured successful lobbying for a paediatric CF Nurse Specialist in that area, ensuring that there is finally equity of service with the rest of NZ.



Our CFNZ policy document is a foundation document that outlines all that we do and the essence of what CFNZ is all about. I am pleased to be able to say that we have overhauled our policy document and it is now more robust and comprehensive, and will ensure we are compliant with both government and Charity Commission requirements. I look forward to presenting the updated document to branch representatives at the 2016 Chairpersons' Conference.

Something that is very important to me is the culture and traditions of CFNZ. In May this year we celebrated 20 years of awarding the Mark Ashford Scholarship. This year the premier tertiary scholarship was awarded to Kirsty Parsons and as part of the celebration the audience watched a video presentation that spanned every recipient and outlined why the scholarship is so important, Mark's legacy and what that legacy has meant to so many PWCF. The video was a touching visual history and a memorial to more than just Mark as we remember our CF heroes.

I would like to take this opportunity to thank and acknowledge the staff who have left us this year; Belinda Burnett, Julie Clemett, Melinda Coombes and Hannah Wilson, we wish them all the best. Two of our long-standing Board members are retiring this year and I would like to thank John Parsons and Margaret Nicolls for being outstanding supporters of our CF cause, they will be big shoes to fill. I also want to acknowledge and thank our key sponsor, Choice Hotels, for their support and Kiwifirst for our fundraising and marketing campaign partnership. My sincere thanks to every person in NZ that has rattled a bucket, attended a branch meeting or conference, sold a chocolate fish or helped by adding value to CFNZ in some way this year, after all "Together as One – (we are) Creating Better Tomorrows".

Jane Drumm
Board Chair

**“Fundraising is the gentle art of teaching the joy of giving.”
– Henry Rosso**

Chief Executive Message

I was pleased to take on the role as Chief Executive in March. With a very clear direction for the organisation as set out in the CFNZ Strategic Plan 2015/18, and with the support of the Board, I present to you a year of strengthening the core structure of the organisation and achieving on objectives that move us forward.

The introduction of the Health and Safety at Work Act which seeks to improve the safety for all at their place of work, and the new financial reporting standards working to improve the transparency of ‘not-for-profits’ in the service they provide and the money they raise to do so provided us the opportunity to engage in new practices for the better. At the same time we reviewed all CFNZ policy and procedure, strengthened our IT platform (including updating our website) and extended CFNZ’s social media presence.

While it was difficult to immediately counteract the huge loss of organisation knowledge caused by the departure of a significant number of staff in early 2016, the new staff have settled in well and offer fresh ideas and a new perspective to CFNZ.

“Over the year we have seen over 1400 fieldworker interactions with our CF community and 136 care plans developed”

What has remained fundamental to the organisation this year has been the importance of meeting the needs of people with Cystic Fibrosis. In January, we implemented the new welfare policy striving for equity of access to support for all in our CF community. We will continue to work to improve our responsiveness in this regard.

CFNZ was delighted to welcome a third fieldworker to the team and to reach agreement with Capital and Coast DHB to fund a specialist paediatric nurse. Both initiatives strive to provide a higher level of care for the CF community.

We have been fortunate to renegotiate contracts with both the Ministry of Health and Canterbury DHB and to agree a Memorandum of Understanding with Central New Zealand branches – all of whom financially support our fieldworker services. Over the year we have seen over 1400 fieldworker interactions with our CF community and 136 care plans developed.

Lisa Borkus agreed to take on the role of chairperson of the CF Adult Advisory Group – a group being set up to inform and advise both governance and management on issues facing our growing adult population. I look forward to working with this group to shape our future.

May saw Professor Scott Bell from Brisbane receive rave reviews for his presentation at the annual CFNZ Conference. Over 100 attendees soaked up cutting-edge research developments alongside real life stories of challenge and achievement. This quest for knowledge, and advancement in care and treatment, is reflected not only in our CFNZ membership but also with the Shares in Life Foundation Trustees who

sought out a collaboration with Cure Kids to enhance the funding of both quality of life and pure CF research.

CFNZ continues to raise awareness of CF through our Awareness Week in August and via stories and information in social media, via our printed CF News and in presentations to service clubs and alike.

Fundraising also remains a core activity of everyone at CFNZ. At a national level, the Crusaders Charity Cricket continued its status as an iconic Christchurch event and CFNZ recognises the tireless effort of Todd Blackadder in his support of this event. We had our final year as ‘charity of choice’ for Challenge Wanaka, added the Charity Auction at the Quality Hotel Elms in Christchurch and the Maui Ola Foundation Surf Day to our events calendar. The CFNZ raffle continues to be a popular draw card for our supporters.

Choice Hotels continues its support both locally and as our key sponsors, and to fundraise on our behalf. They held the inaugural Choice Hotels Golf Day in 2105, provided both the first and second prizes for the CFNZ raffle and helped sponsor Bounce Day at Uptown Bounce in Auckland. Choice Hotels also provide a significant amount of free accommodation for our fieldworkers when they are visiting other centres. Kiwifirst has exceeded expectations with its fundraising on CFNZ’s behalf.

Our local community events are showcased in the Branch Reports section which you are about to read in the pages to come. They reflect the unwavering commitment of branch volunteers to continue to raise funds to support people with Cystic Fibrosis.



Jane Bollard
Chief Executive

The Board



Jane Drumm, Chairperson
 John Parsons
 Margaret Nicholls
 Cheryl Moffat

Kim McGuinness
 Denis Currie, President
 Lisa Borkus, CF Adult Advisory Group Chair

Investment Committee

John Parsons, Chairperson
 Steve Drumm
 James Lee
 Jane Bollard
 Administration Manager

Shares in Life Foundation

John Thorrat, Chairperson
 Margaret Nicholls
 Robyn Somerville
 John Parsons

Jane Drumm
 Jane Bollard

Patrons

Professor Bob Elliott
 Andrew Ellis (Sports Patron)

Staff



Belinda Burnett, Chief Executive (left Jan)
Jane Bollard, Chief Executive (from March)
Susan Lovelock, Southern Fieldworker
Jude Kelly, Central Fieldworker
Vicky Tyler, National Information Coordinator
Kath Sanderson, Auckland Branch Coordinator

Laura Huet, Project Coordinator
Jeanette Franklyn, Grants Coordinator
Melinda Coombes, Northern Fieldworker (left June)
Julie Clemett, Administration Manager (left April)
Hannah Wilson, Grants & Events Coordinator (left April)

Branch Office Holders

Northland

Mike Webb (Chair)
 Donelle Mason (Secretary)
 Janet Webb (Treasurer)

Bay of Plenty

Nicola Wakerley (Chair)
 Yvonne Murraray (Secretary)
 Anita Leitch (Treasurer)

Central Districts

Anna Scoullar-Jones (Chair/
 Secretary)
 Coralie Harvey (Treasurer)

Canterbury

Melissa Skene (Chair)
 Nicky Churton (Secretary)
 Viv Isles (Treasurer)

Auckland

Jill Thorrat (Chair)
 Allyson Harvey (Treasurer)

Taranaki

Nicola McCarthy (Chair)
 Shelley Gruchy (Secretary)
 Joan Tuffrey (Treasurer)

Wellington

Nicci Hughson & Paula Richards
 (Co-Chairs)
 Belinda Sheridan (Secretary)
 Beth Hughson (Treasurer)

Otago

Julian Cox (Chair)
 Jeremy Byfield (Secretary/
 Treasurer)

Waikato

Mike & Debbie Wood (Co-Chairs)
 Marieke Latminer (Secretary)
 Jenna van Rijen (Treasurer)

Hawke's Bay

Greg Stephenson (Chair)
 Claire Fisher (Secretary)
 John Parsons (Treasurer)

Nelson

Rebecca Colley (Chair/ Treasurer)
 Rachel Tobin (Secretary)

Southland

Jim Phair (Chair)
 Lynne Rangit (Treasurer /
 Secretary)

Farewells

**“Unable are the loved to die. For love is
immortality” – Emily Dickinson**

Julian Baker 28/3/75 – 27/10/15 - Canterbury

Sebastian Bell 28/5/81 – 30/11/15 - Auckland

Anabel Clouston 23/11/86 – 8/3/16 (Overseas)

Maddison Stuart (Maddy) 8/1/99 – 15/6/16 - Central Districts

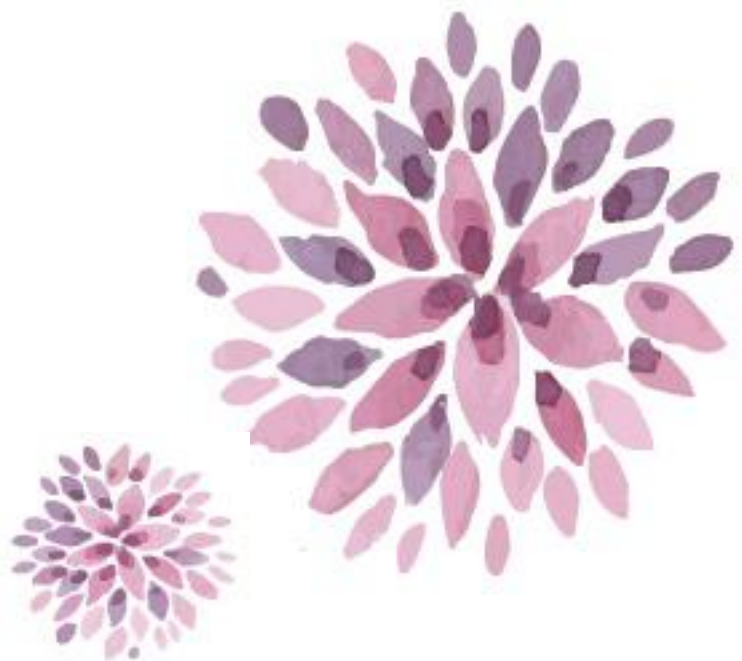
Katrina Turner (Kat) 21/2/85 – 17/6/16 - Taranaki



Endymion

A thing of beauty is a joy forever;
Its loveliness increases;
It will never pass into nothingness;
But still will keep
A bower quiet for us, and a sleep
Full of sweet dreams, and health,
And quiet breathing.

John Keats (1795 – 1821)



Branches

Support in the community



2. What we do

Mission

To optimise the quality of life for people with cystic fibrosis and their families - striving for normal life expectancy.

Vision

To see lives unlimited by cystic fibrosis.

Values

Passionate engagement
Knowledge is power
Creating community
Innovate



Grey Lynn Preschoolers having a ball at 'Bounce 4 CF' at Uptown Bounce, an event sponsored by Choice Hotels

**“Together as one;
Creating Better Tomorrows”**

Support



Marvellous Molly with her new bike gifted from CQ Hotels (Photo: Lynda Feringa / Wairarapa Times-Age)

Striving for lives unlimited through our support network

33 branch position holders

3 fieldworkers & 1 physiotherapist

6 support staff

Hundreds of volunteers

\$81,539 in welfare grants

\$6,740 in transplant grants

\$64,865 from the Breath4CF physical activity fund

"A big thank you to CFNZ - he had no idea he was getting a scooter so his face lit up when he saw it. The weather was lovely today so we let him use it at the skate park, it builds up a very good cardio/ lung workout. He wanted it to be by his bed last night so it was there in the morning!"

- Parent of a child with CF who received a Breath4CF grant

"I just wanted to let you know how fabulous it was to receive the CF gift bag on my recent hospital visit. I work really hard every day to stay well and when I get admitted to hospital it makes me feel despair that I am not coping and that my life is not in my control. The gift bag brightened my day and was the highlight of my stay. I cannot express how much it lifted my spirits - it made me feel cared for and spoilt. You cant beat the home baking and it was scrumptious. I used the eye mask that night as well as all the other goodies. This is an enormous thank you to the CF team for all that you do to support me and other PWCF. Your care, ongoing support and kindness make all the difference to my life. Thank you"

- Person with CF

"Without these people and everything they provide to the sufferers and their families, life would not be the same. It really does make a difference"

- Parent of children with CF



“From start to finish the day was superb and my child was on cloud nine. From Kala’s great welcome speech, to getting a one-on-one lesson with Mark Visser and learning the art of the wipeout(!), to Greg (CEO Surfing NZ) getting the kids out on the jet ski, the fun was never ending! The work you are doing is making a huge difference in our kids’ lives and for that we are truly grateful”



8,400
chocky fish sold



4,000
lapel stickers stuck

70
posters pinned

130
pens handed out

Cystic Fibrosis Awareness Week



An awesome
\$65,000
raised!



Mark Ashford Scholarship 2016



The Mark Ashford Scholarship is awarded to the person with CF who has attained the highest standard in his or her tertiary education for that year. It is sponsored by Pink Batts - part of the Fletcher Group in memory of Mark Ashford who worked for the group and made a huge contribution to their Healthy Homes book. This year CFNZ observed an important milestone for the Mark Ashford Scholarships as Kirsty Parsons was named the 20th Mark Ashford Scholarship recipient and was presented with her award at a special dinner at the CFNZ Annual Conference in May.

Winner 2016 - Kirsty Parsons



“There were definitely some tears in the room, but it was a great way to recognise Mark, the award, and all the past recipients in a very meaningful way. Their achievements are incredible.”

Mark Ashford's family are pictured here with Kirsty. Left: Megan, Kathryn, Kirsty and Scott.

The celebration of the 20th Mark Ashford Scholarship was marked with the screening of the Mark Ashford Scholarship video. This video looked back at the past recipients and told the story of Mark Ashford, who had CF, and passed away in 1996. Mark's employers Fletcher Challenge wanted to honour his legacy by introducing the Mark Ashford Scholarship.

Mark's widow Kathryn attended the special Mark Ashford Conference Dinner along with her two children and also Mark's parents, who all felt honoured and proud to watch the history of Mark's legacy. The video was produced courtesy of Kieran Wright with the help of a previous Mark Ashford Scholar – Alex McKay.

This year, Kirsty received the Award for excellence in her Bachelor of Science majoring in Biochemistry and Statistics. She attended the award presentation in Auckland just days before leaving for the UK to study for her Master's degree in Science at the University of Lancaster.

Kirsty was honoured to win the \$3000 Scholarship out of many strong applicants – and believes her success could be testament to her life skills.

“I think it shows me that I can balance university studies, socialising, sports and most importantly looking after my health so I'm still able to do all of these things.

“Being told the news gave me a great boost of confidence,” says Kirsty who was also inspired by the Mark Ashford Scholarship video. “There were definitely some tears in the room, but it was a great way to recognise Mark, the award, and all the past recipients in a very meaningful way. Their achievements are incredible.”

Kirsty plans to use her Scholarship to contribute to the cost of studying for her Masters in Science in the UK.

“Now I will be able to leave university with a lower student loan which in the long run is less restricting when it comes to taking advantage of any opportunities that may

come my way. Also the application process itself taught me a lot of skills I'll use later on in my career. I highly recommend anyone interested to apply. You never know what might happen!”



CF Achievers' Awards 2016



The CF Achievers' Awards 2016 saw five young people receive an award to mark their success in a wide range of endeavours. The awards, sponsored by Mylan, distributors of Creon products, aim to recognise the remarkable achievements that people with CF make despite adversity.

Christina (15)

Achievement in Sport

Christina won 1st place in all her running events at Fairfield College in Hamilton and came 2nd overall in athletics for the Year 11 students.



She entered the CF Achievers' Awards on the advice of her CF specialist in Waikato who was particularly impressed at how Christina overcame significant obstacles to reach her goals.

One of her goals was to have her feeding tube removed, allowing her to compete in even more team sports like rugby. "I'd always wanted to get it out because I want to play rugby and I couldn't play it while it was in," says Christina, who is urging other teens with CF to embrace sport as well. "Try your best when you do physical activity because that's what helped me," she advises.

Natalie (25)

Achievement in Leadership

Natalie's work, family and health balance is considered an inspiration to others, and led to her receiving a CF Achiever's Award.



The Rotorua mum was able to complete her degree in Applied Social Science and still lead a fulfilling family life with a young child and partner – all while also coping with the challenge of two hospital admissions.

This year she has started working as a community social worker at Stand Children's Services and is loving her new role. She had planned to use her award to watch her cousin compete in the NZ Sevens women's event at the Rio Olympics but when her cousin wasn't selected for the team Natalie and her husband decided to invest the money towards a second property.

After receiving praise for her own perseverance and resilience, Natalie advises others with CF to not let the condition define you as a person.

"Cystic fibrosis can be a real struggle and it's challenging to get on with your life, but people with CF are resilient and if we stay positive we can achieve anything that we want to."

Jake (17)

Achievement in Education

Jake received his CF Achiever's Award after excelling at both NCEA Level 1 and Level 2 at Waitaki Boys' High School – something only six other students achieved in his year.



Although Jake has to work hard to catch up with any missed lessons due to CF, he never complains and instead will organise extra tutoring to meet exam requirements.

Along with representing his school in the 1st XV rugby, cricket, tennis and badminton, Jake was made Prefect and Head of Lee House this year, and represented the High School at the Russell McVeagh debating competition in Dunedin earlier this year. He has also earned his Bronze Duke of Edinburgh Award – all this on top of nebulising twice a day and taking all his medication and keeping up with his calorie intake.

Jake is using his Award to help pay for books and course fees when he attends University next year where he plans to study sport science.

Emma (17)

Achievement in Sport

Emma, who is Jake's twin sister, earned her CF Achiever's Award for representing Waitaki Girls' High School in hockey and squash and is captain of the hockey team.



Emmas has been praised for silently shouldering a debilitating disorder without complaint. There are times that CF can impact on her speed on the Hockey field but she has pushed herself physically and has learned to "think smarter" to achieve, according to one of her referees.

Aside from squash and hockey, Emma has played badminton and Touch for Waitaki Girls' and competed in the school's multi-sport team.

Emma also helped raise more than \$2500 for Cystic Fibrosis New Zealand when she competed in Challenge Wanaka in a trio with her friend Kate and brother Jake.

Emma planned to use her award to buy a Fitbit to monitor her fitness, and possibly a power board, which is a vibration platform which assists with muscle strength.

Kirsty (22)

Achievement in Education

Kirsty, who is also the 2016 Mark Ashford Scholar, was also named a CF Achiever in education because of her impressive academic achievements – completing her Bachelor of Science with an A to A- average, and being named in the 2014 and 2015 Massey University merit lists.



Living away from her family home in Hawke's Bay, Kirsty did not let her health suffer. She focused on living a balanced lifestyle while studying and competing her horse and managing CF. "My strong work ethic and determination has not let any of these take a back seat," says Kirsty who put her health first while studying.

"I had the mind-set that my CF came first, because if I was sick then trying to do school would have been a waste of time anyway."

Kirsty is using her CF Achiever's Award grant to contribute towards post-graduation course fees at Lancaster University in the UK.

Well done to all these inspirational young people whose strength and determination is typical of so many PWCF.

Event Highlights



Charity Auction at The Elms

A wonderful fundraiser as well as a great night out in Christchurch! The helium balloons were particularly successful – guests bought a balloon for \$25, \$50 or \$100 and were guaranteed a prize equal to or above that amount. They sold out in 12 minutes!



Charity Cricket

CFNZ's 33rd annual Charity Cricket match was celebrated as one of our most successful. The event saw the Crusaders Present team, led by Israel Dagg, taking on rugby stars from the Crusaders Past team, which was captained by Justin Marshall. The Crusaders Present team won the 20/20 match (again) this time by 20 runs.



Bounce 4 CF

An awareness raising exercise which saw local pre-schoolers in Grey Lynn Auckland, attend Uptown Bounce. The event was sponsored by Choice Hotels and all the children had a ball!



Mauli Ola Surf Day

This had to be the highlight for Auckland kids! The inaugural Maui Ola Foundation's Surf Experience Day in NZ was run in conjunction with the Ultimate Waterman competition. Participants were fortunate to get surfing lessons from athletes at the top of their game. We've heard of a number of kids who got the surfing bug and have now got surfboards thanks partly to the Breath4CF subsidy. We are thankful to Tauranga's Glenn Bradley for planting the seed for a Surf Day here.



Cystic Sisters

Not strictly an event but their 65 days of Good Deeds can't be ignored. The Cystic Sisters Kristie Pruton and Nikki Reynolds-Wilson have had a major impact on awareness and their kindness to strangers and wonderful ideas for rewarding some of NZ's unsung heroes have been an inspiration to all. The sisters and their families also starred in a very moving documentary about living with CF in April 2016.



Awareness Week

Awareness Week 2015 resulted in plenty of donations, and an increase in media interest. The 2015 Annual General Meeting issued a vote of thanks to all the branches for "the truly outstanding effort during Awareness Week. It was a tremendous effort."



Challenge Wanaka

CFNZ's final Challenge Wanaka event. A big thank you to the winner of the Women's Challenge, Yvonne van Vlerken, who kindly donated \$1,000 of her prize money to Breath4CF.

3. Branch Reports



A winning year for CFNZ Northland with it's ninth charity golf tournament held in April 2016 (Photo: The Northern Advocate)

Northland

The last 12 months have been relatively stable for our branch. We have had two new additions to Northland but one has since moved to Wellington. We now have four children and three adults. One child turns 18 this month and is moving to the Waikato to attend university.

Like the last few years, our main focus has been our charity golf tournament. This year it was held on 8 April and CFNZ Chief Executive Jane Bollard was able to attend, which was great. Due to our lack of numbers this has pretty much become our Awareness Week as well.

It was Northland's ninth golf tournament and it was another successful one. We were again well supported by LJ Hooker's Whangarei and many other businesses – OfficeMax and Balance to name a few. We netted \$10,000.00, which was a great result. And the demand for next year's tournament is out there already. Hopefully I can muster up enough energy and support to make our 10th a great success as well.

The local CLM swimming/gym complex has held their second multisport event in September to raise money and awareness for CFNZ. The proceeds from this go to head office.

“We netted \$10,000.00, which was a great result. And the demand for next year's tournament is out there already.”

To summarise, it has been a good year for CFNZ Northland and we are financially stable – hopefully 2017 will be the same.

Mike Webb, Northland Chairperson

Auckland

Once again the last 12 months for CF Auckland Branch has been a year of change and challenges. We had a period without a branch coordinator and typically the committee stepped up to fill the gaps. We now have Kath Sanderson working as Auckland Branch Coordinator. With the Chief

“I'm forever in awe of our hard-working committee, who continually find the energy and enthusiasm to keep achieving”

Executive and Admin Manager now based in Auckland, our Grafton office has filled up, it is great to see how well this works with good communication and sharing of skills between staff.

Due to the diligence and hard work of our committee and keen members, we have had a successful year raising funds and maintaining our core business and support.

We had another successful Awareness Week, raising around \$28,000 for the branch. Other fundraisers have included Sail4CF – run by Malcolm, a committee member. This event, held at the Manly Sailing Club, gave the kids a great opportunity to have a go at sailing and raised funds for Breath4CF. Auckland Marathon unfortunately clashed with the World Cup Rugby final, and although numbers were down, this was still a good fundraiser for Auckland Branch. We had an enjoyable fundraising movie night in May and have also had the Sileni wine fundraiser. We were fortunate to be selected for five different Z Energy stations as part of

the “Good in the Hood” campaign. Our hardworking committee members spent many hours at these stations promoting CF, this raised over \$5,000 for CF Auckland.

We have had some success with grant applications, which has enabled us to re stock our equipment supply.

CF Auckland continue to deliver hospital packs (and vouchers) to PWCF in hospital every Thursday. These now include delicious home baking donated by GBB bakers as well as donated magazines, games, toiletries and other goodies.

Our committee continues to organise mums’ nights, dads’ nights and

morning teas to provide an opportunity for parents to meet up socially.

We have welcomed three new members onto our committee – Niall Martin, Malcolm Lambert and Jan Tate (our Paediatric CF Nurse Specialist). I am forever in awe of our hard-working committee, who continually find the energy and enthusiasm to keep achieving – our community really do benefit from their efforts.

Jill Thorrat, Auckland Chairperson

Waikato

It is with pleasure that we submit our annual chairperson report for 2016. What a fantastic year for CF Waikato – with a strong and dedicated committee we have accomplished a great deal.

The stand out event for the year was Beauty and the Beast benefit night, inspired by Robyn, unfortunately we could not be there, but we wish we could have, it is reported to have been truly amazing and we were especially taken with the personal connection with the cast to CF.

We wish to thank Jenna for her treasurer’s role. It was especially trying this year as she was a guinea pig for trailing the new finance templates

“We have spoken at a few of these Lions Clubs and are well received – it is always good to improve CF Awareness through speaking to groups”

through CFNZ. She has done an awesome job and manages our CF finances perfectly.

Marieke in her inaugural year as secretary has done a great job. With the huge effort she put in to contacting Lions and Rotary Clubs paying off for CFNZ Waikato, with donations totalling over \$3000. This is a huge

benefit to us, as these funds can be used for things that are difficult to get grants for and to help with National funding of our branch through hospital vouchers and transplant costs. We have spoken at a few of these Lions Clubs and are well received – it is always good to improve CF Awareness through speaking to groups. Marieke will be attending Chairpersons’ Conference with Debbie which will be of great benefit to her.

And a huge thank you must go to Robyn for firstly doing our flash newsletter and secondly organising the benefit night. The newsletter is an important connection with our CF families.

A special thank you goes out to Dee and Jo, our invaluable CF Nurse Specialists as not only do they help us by selling incredible amounts of chocolate fish and Entertainment Books, but they are also our link to what is needed in our Waikato CF community.

It is with regret that Mike Wood is stepping down from the Co-Chairperson’s role. Mike has been a great asset to the branch and people always identify with him as a Dad of a PWCF. He has been a valuable member of our committee and we thank him.

We received a grant for more sterilisers from the Lions Foundation. And we have also received some private donations from our greater CF community.

Participants of the Sail4CF event held at Manly Yacht Club on the North Shore, Auckland in October 2015



We helped send nine people to National Conference this year, thanks to Central Districts who were able to help with this cost for us as well. Conference was informative and as usual a great opportunity for us as Chairpersons to network with other branches.

This year Debbie has phoned in on most monthly Chairperson Teleconferences, they are an excellent way to keep up with what is happening nationally and what other branches are up to.

We sold Entertainment Books again this year and sales were up on last year which is very pleasing. It is an established fundraiser and nearly runs itself now.

At present we are in the middle of the Rear-a-Calf fundraiser with hopefully 14 calves pledged. These will be sold in November through RD1 so will see how much we raise.

Bay of Plenty

The establishment of a community physiotherapy service has been one of the highlights of this financial year. This has been a long-held goal for our branch and we are confident this service will help improve the health of our community.

Using funds raised from the Police CIB charity auction in the 2014/15 year, the branch was able to work with the Bay of Plenty DHB to employ a physiotherapist with expertise in caring for people with CF. Shontelle

“Their random acts of kindness raised a priceless amount of publicity and awareness for cystic fibrosis”

Pengelly has worked with our CF families in the past. She’s extremely passionate about improving their lives and is perfect for the job.

The 2015/16 year also saw the start of the “Cystic Sisters” 65 days of good deeds in the lead up to Awareness Week. Their random acts of

kindness raised a priceless amount of publicity and awareness for cystic fibrosis and culminated in a Bubbles Party at the end of Awareness Week 2015. We are extremely grateful to Kristie Purton and Nikki Reynolds-Wilson for their contribution to the CF cause. We were also humbled to hear the sisters decided to do their 65 days of good deeds again in 2016.

Once again Kelly donated a photo shoot auctioned off through Facebook – thank you for this Kelly.

Thank you also to Janelle for her many years of organising the hospital packs for our paediatric ward. Unfortunately, Janelle and her family have left the Waikato – we will be keeping the packs going though.

So thank you to our great little committee and here’s to another great year next year!

Mike and Debbie Wood, Waikato Co-Chairs

The Tauranga Arts Festival provided a \$3500 boost for the Breath4CF fund when Rotarian Peter Tinholt organised a breakfast meeting with guest speaker, author Nicky Hagar. I attended the meeting along with one of our mother’s, Veronica Furze. We appreciate all the fundraising that Peter has done for the organisation.

Again, it’s wonderful to see Adults with CF in the Bay of Plenty living life to the full – they are inspirational role models for our children.

Nicola Wakerley, Bay of Plenty Chairperson

Cystic Sisters Kristie Purton and Nikki Reynolds-Wilson handing out gifts as part of their 65 Days of Good Deeds





Woodford House School performed 'John Lennon and Me', a production centred around a young woman who has cystic fibrosis

Taranaki

The Taranaki Branch is proud to report that we still have a very strong and committed committee made up of a great representation of the CF community that they support.

Our community grew in numbers this year with the short visit from David and his new family moving back to Taranaki for a year before they moved back down to Wellington. We have also had a new young family relocate from Wanganui to Stratford and a new diagnosis of a teenager in New Plymouth to add to our members list. We also welcomed the Paterson family back into the area. I guess the pull of that mountain and green grass got too much.

It is also with great sadness that we reflect on the passing of the beautiful, kind and lovely girl who was a part of our committee and a huge part of our Taranaki CF community along with her family for many years. Katrina (Kat) Turner was well known fondly by many, if not all, people around this table and she will be sadly missed by everyone.

The Taranaki Branch is still a very financial branch and in the last financial year we successfully fundraised with the standard chocolate fish and a sweetcorn campaign. We also raised \$4,585 shaking buckets on the street during the annual CF Awareness Week and a further \$1,176 was pledged through donations throughout the year. Urenui School also held a Wacky Hair day and raised \$88, which was thoughtful and much appreciated.

"It was decided at committee level that the real potential and assistance that our members could receive from this service, meant it was worth accepting the offer"

We used the money that was raised to extend an offer to all Taranaki members to attend the annual CF conference which was held in Auckland this year. Shelley, Janelle, the Taranaki physio and myself attended and as always it is such a well-run event, abundant with excellent presenters and information so important to the CF community. We encourage anyone out there who has ever thought about attending to put your hand up and take advantage of the offer. You won't regret it.

Shelley, Errol and myself also attended the annual Chairpersons Conference in 2015 where the new welfare policy and the stance of the Taranaki Branch was made very clear and was debated at length!

We continue to support our people when they are unwell with Boredom Buster packs for entertainment and high-calorie snacks while in hospital, petrol to help with travel associated with hospital stays, top-ups of Breath4CF requests, payment for non-funded equipment and many other

welfare associated costs.

This year at a National level, change has been their middle name. The new CEO Belinda resigned not long after her venture to Taranaki to discuss the future. Her resignation meant Jane Bollard came on board. This resignation was followed quickly by Melinda, who some of you may or may not have met as your Fieldworker support person, Hannah who ran Grants and Events work and Julie in the accounts area. I guess the good news is that Jane was able to recruit high-calibre replacements very quickly. There was also a change in head office location from Christchurch to Auckland, as the majority of the National team are based in and around Auckland.

This last year we also farewelled Sharani from the TDHB and her familiar face will be missed at clinics.

Around the same time as Melinda announced her resignation, the Wellington Branch, after years of lobbying, managed to secure the services of a much-needed designated Fieldworker in their area, with their own fundraised money. The offer was made to the Taranaki Branch that if we agreed to cover the costs out of our own budget, we could also have this Fieldworker dedicated to our branch with a detailed service level type agreement in place. It was decided at committee level that the real potential and assistance that our members could receive from this service, meant it was worth accepting the offer.

The new Fieldworker is Jude Kelly and Shelley and I have both had the privilege of meeting her at conference and more recently in New Plymouth. We both believe that she will be an excellent source of knowledge, resource and assistance for our members and we look forward to building a long and lasting relationship with her.

I would like to take a moment now to thank the wonderful committee that I work alongside. Your passion, care, knowledge, support and the commitment to people with CF in our region is really appreciated and second-to-none. You selflessly give your spare time to a cause close to all of our hearts and I really believe what we do makes a real difference and helps our people.

I would also like to thank and acknowledge all of the volunteers that have helped shake a bucket, pick corn, run quiz nights, raise awareness and support our people over the past year. I look forward to doing it all again with you this year.

Nicola McCarthy, Taranaki Chairperson



Claire Fisher helped raise a fantastic \$10,000 for CFNZ Hawke's Bay with the Staples Rodway Cape Kidnappers Challenge

Hawke's Bay

The Hawke's Bay Branch of CFNZ raced through a year of change and growth. After a number of years of faithful service, Glenda Sinden decided to take a break as Chairperson. While she is sorely missed, Greg Stephenson attempted to stand in the gap.

The Staples Rodway Cape Kidnappers Challenge provided an awesome boost in our fundraising and awareness campaigns. This was followed by our branch being named the official charity for the Napier City Pakn'Save Half Marathon. Along with a few other events, our campaigns rolled along into winter.

A local boys high is the school for one of our PWCF. This school decided to name CFNZ Hawke's Bay as the charity for their campaign and it went off brilliantly. We have just headed into the 2016/17 financial year with our annual casino night. This excellent event provides a great platform for our funding and awareness campaigns.

Of course, all the efforts at raising awareness and money is for the purpose of making every day better for those PWCF in our community. Of our welfare and assistance programmes, in-home physio support continues to be a huge blessing. Our hospitalisation rates are very low and this is in-part due to the physio support.

Central Districts

We've had a mixed bag this past year in Central Districts. Our numbers are sitting on 14 children and nine adults.

We were extremely sad to lose one teen to CF. There has been a new (late) diagnosis in the region and we have gained a few new branch members through a family moving into our region. On a positive note, we also received the good news of one of our young CF Adults having their second baby.

"We look forward to a great year ahead, with our new fledgling relationship with Rotary NZ"

We were happy to be successful with two grants for the CF Conference this year and were able to fully fund five of our members to attend in Auckland, and also help out four other branches with contributions

Nora Dunphy, our new paediatric CF Nurse has been a great addition to the DHB and along with our paediatrician, Sarah Currie, providing a great level of care. This year we have also gained a new Adult physician, Dr Dan Garner, who comes with a wealth of experience and expertise to add to CF care. Adult PWCF have been a particular focus for us and we are pleased to see the progress through such a capable physician.

"Of our welfare and assistance programmes, in-home physio support continues to be a huge blessing. Our hospitalisation rates are very low and this is in-part due to the physio support"

Looking ahead, we anticipate another year of raising awareness and funds, as well as the regular change that affects us all.

Greg Stephenson, Hawke's Bay Chairperson

towards their own members attending. This was a switch around from last year where we were the ones needing financial help. Great teamwork when we can help each other in this way.

Our annual fundraising event, the Ballentynes Summer Fashion Show was held in October 2015 and we raised more than usual – possibly due to the appearance of the Wanganui Mayor, Annette Main, on the catwalk. Great publicity and a popular raffle on the night boosted profits also. This always goes off without a hitch and is eagerly awaited each year by the ladies of Wanganui!

Other funds were gratefully received after a fundraiser by a Wanganui group who ran the "2016 Whanganui Poker Run" and a multi-day at a Palmerston North intermediate school – these were both surprises to us. Tararua College in Pahiatua performed a school production about Cystic Fibrosis in honour of their very recently lost schoolmate with CF, Maddy

Stuart, and all funds raised came to the Central Districts Branch. We continue to sell chocolate fish all year round at two dedicated places of business in Wanganui.

We were also successful with Z's promotion "Good in The Hood" in Wanganui and received \$500 of BP Vouchers upon asking BP for help. We are one of the few branches who need to travel long distances for our committee to meet. These vouchers will help alleviate the costs

incurred.

We are a smaller committee than most but we look forward to a great year ahead, with our new fledgling relationship with Rotary NZ showing great promise under the guidance of Nigel Ramsden of Feilding.

Anna Scoullar-Jones, Central Districts Chairperson

Wellington

Wellington Branch has enjoyed a busy and highly successful year supporting its members and raising awareness of CF. We have a small and dedicated committee who all work incredibly hard despite their many other commitments.

Kim McGuinness stood down as Chairperson in August 2015 and remains on the Wellington Committee and CFNZ Board. Nicole Doriguzzi also stood down as Chairperson. Paula Richards and Nicci Hughson took over the role of Co-Chairpersons.

We have been successful in securing funds through a grant for equipment and have provided PWCF in Wellington with Breathe4CF top-ups, hospital in-patient voucher packs, half-price hospital parking, equipment and various other welfare assistance. We also part-funded 16 people from the Branch to attend Conference in Auckland this year plus two nurses from the Adult Ward.

Our Christmas Tree Festival in 2015 was our most successful yet and raised over \$30,000. Planning is underway again for the 2016 Festival which will be our main fundraiser for the year.

"Our Christmas Tree Festival in 2015 was our most successful yet and raised over \$30,000."

Our "new look" electronic newsletter was successfully rolled out and quarterly newsletters and email updates are sent to the Branch to keep everyone up-to-date with what is happening with CFNZ Wellington.

A small number of successful networking events ran through the year

for families, including parent catch-ups, drinks evenings to coincide with CFNZ Fieldworker visits, the Christmas Tree Festival (XTF) gala opening and our end-of-year function.

Awareness Week 2015 went well with extra collection points generating more revenue than previous years. This year we will have a few different locations as well as the usual lucrative spots around Wellington City and Lower Hutt.

A third Fieldworker, Jude Kelly, was employed in May. The Wellington Branch Committee played an important role in the establishment of this new role. Jude is based in Wellington and despite only being in the role a few months, has managed to meet many Wellington-based PWCF and their families.

The Wellington Committee was also delighted to receive the news in July that the Wellington DHB will be employing a paediatric CF Nurse. Wellington Branch has been lobbying for many years to have a CF Nurse in Wellington and this is a huge achievement.

Our plan over the next year is to work closely with our new Fieldworker and identify areas where we can further assist our PWCF. We will continue to develop relationships with the medical professionals and aim to increase engagement with the Wellington Branch, with increased focus on Adults with CF.

Paula Richards, Wellington Co-Chairperson

New Zealand Rugby Union CEO Steve Tew speaking at the Wellington Christmas Tree Festival in Wellington Airport



Nelson

Nelson Branch was delighted to be named one of the beneficiaries of Z Energy's Good in the Hood programme. We greatly appreciated the \$620 donation made to the branch after all the orange tokens were counted.

This has helped us to maintain a workable bank balance, and allowed us to continue to assist families and Adults with petrol vouchers, welfare grants and equipment.

“My niece and I particularly enjoyed holding an Anzac Day stall to help raise money. We sold hot soup and cheese rolls which proved popular and generated \$280 for the branch.”

I would like to acknowledge the special donations that were made following two funerals in our region. Michael Neate's wish was for donations to be made to Cystic Fibrosis and Dorothy Norgrove's funeral also resulted in

donations to assist people with CF.

We would also like to thank the Richmond Lions Club who have once again been extremely generous with a \$1000 donation to contribute to the assistance we provide the Nelson/Marlborough community. The Lions raised this sum with firewood projects and other fundraising activities.

My niece and I particularly enjoyed holding an Anzac Day stall to help raise money. We sold hot soup and cheese rolls which proved popular and generated \$280 for the branch.

Our committee is small and we have only met once this year. However, I'm always encouraged by how much support there is for people with CF in the Nelson/Marlborough region.

Rebecca Colley, Nelson Chairperson

Canterbury

We have a solid committee of eight hardworking people for our community and received great support from our wider community this year. We meet monthly and are lucky to be able to use the CFNZ Christchurch office, and when our Fieldworker moves to her new office in November, we are also able to use the new premises for meetings.

We set up a Gmail address this year and send out regular communications with our families about different fundraising activities, support required and any events happening. This has replaced our newsletter. This communication is working very well and we have received great feedback from it.

Our fundraising for the year has consisted pretty much what we know works, our annual Golf Tournament at Templeton Golf Club, 2x Bunnings

“We are still able to subsidise our families by offering accommodation at \$30 per night. Many of our families utilise this, which is great to see”

stock takes, selling of the Entertainment Book, school multi-days, chocolate fish selling and another theatre production night, which was enjoyable and profitable.

Canterbury resident Caleb living his life unlimited by cystic fibrosis





Alana made the headlines in July 2015 when she had her double lung transplant

Our biggest windfall this year was being a chosen charity for The Central South Island Bike Ride. One of our fantastic mums, Paula Thompson, in Timaru rides in this event each year, supporting different charities even if we are not a chosen one. It is an amazing event and very professionally run. This year we received \$11,100.00 from this. Paula also organised her annual Swimathon and a street appeal for appeal week. We thank her immensely.

We have also had other smaller fundraisers run by our supportive members throughout the year – all which really helps our cause. One of our CF mums is competing in marathons and raising money for Breath4CF Canterbury, which we are very thankful for.

We have been successful with grants this year from The Southern Trust (\$6000) and The Mainland Foundation (\$2500) and these funds are used for wages for our part-time Community Physiotherapist. Grants are

more difficult to come by and we would like to thank the National Grants Coordinator for her help and support this year.

We are still able to provide medical equipment, hospital café vouchers, birthday vouchers, parking, taxi chits, trampolines and welfare where required for our families.

The Hanmer Holiday Home still ticks along and is well used in school holidays and summer weekends. We are still able to subsidise our families by offering accommodation at \$30 per night. Many of our families utilise this, which is great to see.

Melissa Skene, Canterbury Chairperson

Otago

CFNZ Otago has once again had a strong year financially. Building on the first foundation Kevin Helm established, Camilla Cox and Kate Croy once again led a successful street appeal raising \$20,574.90 in total.

This funding will allow us to continue to provide nebulisers, sterilisers and other equipment, Breath4CF top-ups, heating grants and hospital vouchers to members.

“Camilla Cox and Kate Croy once again led a successful street appeal raising \$20,574.90 in total”

The surplus of around \$3,000 from last financial year was donated back to CFNZ head office to cover Otago’s Breath4CF grants.

There has been little branch activity outside of support for members via

CFNZ Fieldworker Sue Lovelock and the annual street appeal.

The general interest and participation by members in committee meetings has, once again, been disappointing. With Kevin stepping down last year, the committee is now down to two members and we really need some more active participation to inject some fresh thinking.

I would like to extend a big thank you to Jeremy for all his work in his dual role of Secretary/Treasurer. I appreciate it is not a small task and his work not only takes a load of my shoulders but is vital to the smooth running of the branch.

Julian Cox, Otago Chairperson

4. Supporters

Principal and Corporate Supporters

We would like to thank our principal supporters Choice Hotels and Kiwifirst for partnering with us to make a real difference in the lives of people with cystic fibrosis and their families across New Zealand. Both companies have helped us enormously and continually display a real and genuine empathy with the CF community.



Choice Hotels

“Choice Hotels Asia-Pac and its 30 franchisees have loved being involved in the fundraising efforts for Cystic Fibrosis New Zealand over the past four years. They are passionate about making a positive difference to the lives of Cystic Fibrosis sufferers and their families, no matter how big or small. This partnership is all about improving the quality of life for those living with CF and making them invincible.”



Kiwifirst

“Themselves sufferers of a chronic lifelong condition, the directors of Kiwifirst are passionate about making a difference in the lives of people with Cystic Fibrosis. That passion and energy resonates throughout the whole Kiwifirst organisation and we are extremely proud supporters of Cystic Fibrosis New Zealand.”

Business Supporters & Funders

CFNZ has been fortunate to receive the support of several businesses and organisations, many of which are listed below. Their financial support is vital to our existence and CFNZ gratefully acknowledge their contribution to the wellbeing of people with CF.

Avon	KiwiKarma	Rebel Sport
Bernina NZ	Liberty Brewing Co	Robert and Barbara Stewart Charitable Trust
Canterbury District Health Board	Lions Clubs of NZ	Rotary Clubs of NZ
Challenge Wanaka	Lions Foundation	Schwarzkopf
Christchurch Casino	Mauli Ola Foundation	Shares in Life Foundation
Christchurch Polytechnic Institute of Technology	Mighty River Power	Smith City
Community Organisation Grants Scheme	Ministry of Health	Soroptimist North Canterbury
Crusaders Super Rugby	Mylan	Tasman Insulation (Pink Batts)
Foundation North	Noel Leeming	Top Notch Book Keeping Solutions
Four Winds Foundation	NZ Lotteries Community Grant	Ultimate Waterman
Grumitt Sisters Charitable Trust	Our EcoHome	Uptown Bounce
HealthPost NZ	Priority Partnerships	Whangarei Aquatic Centre
Infinity Foundation	Pub Charity	Zoom Group
Kindercare Learning Centres	Purell	
	Quality Hotel Elms Christchurch	



The BNZ Crusaders Super Rugby Team played ball for Cystic Fibrosis at Charity Cricket in December 2015

Charity Cricket Sponsors & Supporters

Alexanders Marketing	Hellers	Outpost 42
Armourguard	Hell's Pizza Riccarton	Papanui Youth Development
Bealey Dental	Hilo Decorating	Parry Field Lawyers
BNZ	Hire King	PitStop
Bodyworks Massage Therapy	Inflatable World	Quality Hotel Elms
Bounce NZ	Kiwianis (NorthWest)	Raeward Fresh- Harewood
BurgerFuel Bush Inn & Spitfire	Kookaburra	Rangoon Ruby
Canterbury Weather Updates	Labour MP's	Sergios Menswear
Coca-Cola Amatil NZ	Loisn Ltd	Sharp Corporation NZ Ltd
Christchurch City Council	Lonestar Papanui	Sport Canterbury
Christchurch Boys High	Mainland Foundation	St John
Christchurch Casino	Manup Merivale	Streets Ice Cream
Commodore Airport Hotel	McDonalds Christchurch	The Antarctic Centre
CTV	McDuffs Mini Golf	The Crusaders
Denise Jones—Segway	Mike Greer Homes	The Fitting Room
EFTPOS NZ Ltd	Mike Pero Northwood	The Rock
Espresso Carwash	Monteith's	The Star Canterbury
Gary Cockram Hyundai	Muffin Break Riccarton	The Warehouse South City
Goom Landscapes	Ned Allison Auctioneer	Umpire—Brent Watson
Hang Up Entertainment	Noordanus Architects Ltd	Umpire—Mark Wood
Happy Hire	NZ Cricket Players Assn	YMCA Christchurch
Heathcote Cricket Club	Orana Wildlife Park	

Community Supporters

A huge thank you to all the groups and individuals who have raised money for CFNZ this financial year. We've seen an amazing spirit and determination from our supporters - all in the aid of helping to improve the lives of people with CF. A special thank you also to all our regular donors - your generosity has made a huge difference. Donations go directly to supporting the CF community.

Supporters cycling to raise funds for CFNZ Canterbury at the Central South Island Charity Bike Ride



