



# Annual Report **2017**

For the financial year ending 30 June 2017

**cf** CYSTIC  
FIBROSIS NZ

# Thank you

Finding out your child has a severe disorder like cystic fibrosis is a life-changing event, and one that comes with massive changes.

Parents adjusting to a new diagnosis are under a huge amount of stress in addition to the usual stress of being a parent, and many feel overwhelmed with how much there is to learn and the impact CF might have on their newborn baby's life.

Some people will be happy to discuss and share, while others will be too upset to talk about it. But all will need some support.

As the child grows into an adult, there are many life transitions, milestones and challenges to manage along the way.

Thanks to the many extraordinary people and precious donated dollars, Cystic Fibrosis New Zealand can be there to support these individuals and their families, advocate for them and help throughout their changing journey.



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**“Max’s test had come back positive for cystic fibrosis. My son was healthy, he was still growing and we thought everything was fine but it didn’t stop us feeling shocked and fearful.”**

“Like many parents the first time I found out that Max could have cystic fibrosis was when my midwife called me about the results of his newborn heel prick test.

Max’s test had come back positive for cystic fibrosis. My son was healthy, he was still growing and we thought everything was fine but it didn’t stop us feeling shocked and fearful. I looked at my cousin who had just been diagnosed with cystic fibrosis at the age of 8 and how her lungs were damaged, and instantly thought of the worst case scenario.

I wasn’t aware of the genetics behind cystic fibrosis at that time and how the cystic fibrosis gene can be in the families for generations without knowing.

My best coping strategy was listening to everything the doctor said. I made sure I did exactly what he said – all the time. We do physiotherapy all the time and if anything happens I am on the phone. I can call the outreach team at any time and they are very encouraging and supportive”.

*Tiffany*  
Mum to Max

# Chairperson's report

When thinking about the 2017 year I think about the following quote: "We don't grow when things are easy we grow when we face challenge".

However, along with the challenges, CFNZ has also been able to celebrate successes and at the pulse of everything that we do as governance, management and operational teams are our people with cystic fibrosis (PWCF) and their families.

We face many challenges: the chase for the charity dollar, the threat of limited or no access to game-changing medications and treatments for our NZ CF population, our (thankfully) ageing PWCF to whom cross infection has become an increased risk to manage – along with a multitude of treatments, and our dedicated but sometimes over-worked volunteer base which is ever diminishing in its current iteration.

This year the Board have had to make some brave strategic decisions that, whilst at first may not seem to make sense to our wider community, will we feel will ultimately position CFNZ for greater success as we move forward with our strategic targets.

Although we do face challenges I like to think that like most New Zealanders we tend to take the lemons that are our trials and make lemon meringue pie.

In 2017 it has been wonderful to welcome two new Board members to our small but mighty team Catherine Rusby from the Hawke's Bay and Warwick Murray from the Bay of Plenty. This year we have taken the opportunity to do some training in the strategic leadership space and are in the process of developing our Board Development Plan. At each Board meeting I feel we gain strength, knowledge and capacity, as a team.

The recent Australasian Conference has been very encouraging particularly with regard to our place in the global CF community. The conference theme of Optimism-Opportunities-Outcomes fits well with our CFNZ mission statement of "optimising quality of life for people with cystic fibrosis and their families – striving for normal life expectancy". Through our targeted services, branch outreach and our strategic direction I am confident that we move ever closer to achieving our mission.

I would like to take this opportunity to thank and acknowledge our hardworking and dedicated CE Jane Bollard and her amazing staff, many of whom are very new to our organisation, and already go the extra miles making such a difference in the lives of our PWCF and their families. I also thank and acknowledge Cheryl Moffat, who recently stepped down from the CFNZ Board, Cheryl has given her all to the role and her dedicated service is much appreciated. My sincere thanks to our entire volunteer base and in particular our incredibly hardworking branch committees. Branches are our grassroots, community hubs supporting and caring for their local communities, and they are vital to the success of CFNZ.

In 2018 we will be celebrating 50 years of CFNZ which is very exciting and a chance for us to really come together as a community and rejoice in our achievements and how far we have come. After all, as the saying goes...if nothing changes, nothing changes.

## Jane Drumm

CFNZ Board Chair

# Chief Executive's report

This year we welcomed Emma Nielsen (Administration Manager) and Chantell Taylor (Accountant) to the team, and confirmed Laura Huet (Project Coordinator) in the new role of Marketing and Fundraising Coordinator. We also welcomed Gretchen Kitching to the position of Northern Fieldworker, which had been vacant for many months, and she is working closely with Kath Sanderson, Auckland Branch Coordinator.

With so many new staff in a small team we have very much appreciated the knowledge and wisdom of Jane Drumm, CFNZ Chairperson; Denis Currie, CFNZ President and Board members together with long serving staff- Sue Lovelock, Southern Fieldworker/Team Leader who completed ten years of service to CFNZ and Vicky Tyler, Information Coordinator.

With three fieldworkers from March 2017 our ability to maximise the health and quality of life outcomes for people with cystic fibrosis (CF) is enhanced. Our recent survey results show

that of those initially surveyed 82% had an increased knowledge regarding the range of health, support and welfare services available. Those DHBs surveyed unanimously agreed that fieldworker services had enabled their DHB to deliver an improved quality of service to people with CF.

We have piloted in-depth interviews of families post diagnosis in Wellington and Christchurch and are seeking funding to continue this project in Auckland. Insights gained from this work will help inform how best to serve families during this time.

Ongoing lobbying of the Capital and

Coast DHB resulted in the appointment of a CF Specialist Nurse at the end of 2016, transforming the experience of families in Wellington.

We continue to provide input as part of the Paediatric Society NZ Child and Youth CF Clinical Network which works to provide



nationally coordinated care for children, youth and their families.

The CF Adult Advisory Group, led by Lisa Borkus, was set up this year and has been working with the Board and management to provide feedback on policy and issues facing adults with CF.

Providing support at the local level has become increasingly challenging for some branches this year due to low volunteer numbers. One activity we would like to see removed from the responsibility of some branches and given to DHBs, is the provision of vital equipment. Armed with a detailed survey of who funds what, we approached Pharmac and are discussing how we might progress this.

Plans are underway to enhance our IT capability and we have worked with Auckland University's Synergy students to develop a brief for the refresh of our website, with Westpac (via Digital Wings) who provided 'nearly new' computers for staff and with a project team looking at the information we provide both in hard copy and on our site.

Innovative medicines for the treatment of CF have been front and centre of the Board's and CF community's consideration this year. CFNZ, with Associate Professor Cass Byrnes, undertook to ensure that our CF registry, PORT CF, is the best it can be as it is very clear from the Australasian and European conferences just how important CF data is for research, treatment and new developments. We employed Nidha Khan, summer intern and Jan Tate, PORT CF Coordinator, who has been very successful in working with DHBs to ensure data was inputted from as many of the CF community as possible. By June 2017 we were also well on the way to setting up a Clinical Advisory Panel to advise and support CFNZ to develop and implement an advocacy plan.

Our collaboration with Cure Kids has enabled us to fund two significant CF

research projects this year and we continue to look for opportunities to fund improvements in quality of life and quality improvement.

As we work through the opportunities that our fundraising strategy presented we are pleased to reconfirm the support of Choice Hotels, our major sponsor. Choice generously raises funds for us and provides accommodation for our staff especially our fieldworkers. We are grateful to all the companies, individuals and groups that generously donate to support people with CF.

Our thanks also goes to the late Janet Parsons who coordinated the national raffle, and to all the CFNZ branch volunteers who do so much fundraising, awareness raising and local support. CF Awareness Week only happens through the efforts of many and despite CF being the most common genetic condition in NZ, many people still know nothing about it.

### **Jane Bollard**

CFNZ Chief Executive



# Farewells

Cheryl Marshall, Wellington 2/8/88 - 7/7/2016

Steven Gordon, Wellington 6/8/85 - 2/9/2016


Glenn Moxon, Waikato 2/9/71 - 19/1/2017

Santana Daniels-Pakau, Bay of Plenty 31/3/95 - 4/2/2017

Vicki Kennedy, Canterbury/Otago 21/5/62 - 17/2/2017

Riki Towers, Auckland 17/5/85 - 24/2/2017

Nicolas (Nic) Ramsden, Australia 9/10/80 - 27/3/17



*The tide recedes, but leaves behind  
Bright sea shells on the sand  
The sun goes down, but gentle warmth  
Still lingers on the land  
The music stops, yet it echoes  
On in sweet, soulful refrains  
For every joy that passes  
Something beautiful remains.*

*Hardin Marshall*

# Making a difference in 2016-2017

Thanks to the many extraordinary people and precious donated dollars, we were able to support people with cystic fibrosis and their families, advocate for them and help throughout their changing journey.

- Our fieldworkers made 1,473 visits to people with CF
- 82% of people with CF and their families reported that they have increased knowledge regarding the range of health, support and services available
- We had 185 discussions with clinicians regarding patients' health and social needs
- Transplant grants were provided to 5 individuals (total of \$5,486) helping to assist with the costs involved with such a major operation.
- 2 issues of our magazine, CF News, were distributed across New Zealand to help connect the community.
- We gave face-to-face support to 313 people with cystic fibrosis outside of hospital
- We developed 55 individual care plans as part of our person-centred approach to support
- We funded 2 research projects that will help improve quality of life for people with CF
- 300 Breath4CF grants were provided (total of \$65,919) helping children and adults to better manage their condition by supporting physical activity.

• Every newly referred child and their family was offered support by one of our fieldworkers.

• 12 branches across New Zealand provided support to local families with cystic fibrosis.

• 11 electronic CF Panui's were sent out to the community, reporting regularly on news, updates and stories.

• We funded a research student to help grow support from DHBs to utilise Port CF, our CF data registry to help improve health outcomes.

“ My field worker Sue is a listening ear when I am worried about what the future might hold. She talks through my concerns about declining health and also my hopes and worries about a lung transplant. She's my advocate and support person. My life wouldn't be the same without her. ”

“ My health is much better since having someone outside of friends and family to discuss health issues with, and I feel very supported through the knowledge of cystic fibrosis from the field workers. ”

# How donated funds are used

Cystic Fibrosis New Zealand is the only charity dedicated to supporting and improving quality of life for people with CF and their families. We do this by providing information, support, advocacy, and through funding research.

Since being established in 1968 as a volunteer support group for parents with a newly diagnosed child, we have dedicated ourselves to shaping a brighter future for everyone with CF. This is just an example of some of the support we provided in the 2017 financial year.

## CF Fieldworkers

Provided one-to-one practical and emotional support to people with CF and their families.

## Medical Equipment

Essential medical equipment is not always funded by the government. We provided these so families didn't have to cover the costs.

## CF Research

We helped enable the nation's best scientists to research treatments that will improve quality of life.

## Welfare Assistance

We helped people with CF to stay healthy and achieve their very best through a range of grants, including our Breath4CF grant, which helps fund fitness equipment.

## Promoting Awareness

One in 25 of us carry the gene that causes CF. We raised awareness of CF and the challenges that those with CF and their families face each day.

## A Voice for CF

We lobbied on behalf of the CF community so that they receive the best care possible.

## Support in the Community

Our 12 regional branches, run by CF families for CF families, provided friendship and a support network, as well as organising medical equipment and fundraising activities.

## Household Support

Caring for a child with CF often means parents are unable to work full time, or have to regularly take time off during periods of illness. We helped with household expenses during difficult times.


## Travel Assistance

A large portion of people with CF travel out of town for hospital stays, clinic visits and treatment. We provided travel support to help minimise financial impact.

## Staying Informed

Conferences, CF News magazine, e-newsletters, information packs and publications helped keep families informed and up-to-date.



A hand is shown holding several capsules, with more scattered on a blue surface. The background is a blue patterned fabric. A yellow speech bubble contains text about Cystic Fibrosis New Zealand's advocacy work.

Cystic Fibrosis New Zealand also has three fieldworkers to advocate on behalf of individuals to ensure they get the support they are entitled to. CFNZ will continue to advocate for improved treatment and access to care on behalf of the CF population

# Advocacy



### **Wellington CF Nurse**

For many years Wellington Branch lobbied for a CF Nurse Specialist for children in the Wellington region. All other regions with a significant population of people with CF had nurses, and it was becoming a matter of extreme concern. In February 2017, the appointment of Tricia Martin was very welcome news.

This appointment was a result of families willing to share their experiences and write to the DHB about disappointing standards of care. Both Board Chair Jane Drumm and Chief Executive Jane Bollard wrote many letters to argue the case for a dedicated CF Nurse. The CF Nurse's appointment had an instant and positive impact on the treatment of children with CF.

### **Rare Medicine Funding Pilot**

Pharmac sought feedback over its rare disorder medicine funding pilot which began in 2014 and saw \$5 million a year ring fenced to fund medicine for rare disorders. CFNZ worked with other rare disorder groups to seek their experiences about the pilot. Although CFNZ did not take part in the pilot scheme we did make a submission to Pharmac supporting a separate medicine fund for rare disorders. However, it's disappointing that only a small percent of a people with a rare genetic type of CF is covered by this fund, and it's an ongoing challenge to ensure fair consideration is given to funding new CF medications.

### **Letter to MPs Template**

In the lead up to election year 2017 we worked with a Wellington public relations agency to produce a template for families to use to contact their MPs with a single, strong message. The letter outlined issues with Pharmac's rare disorder

threshold – along with the fact that New Zealand is the only country with a high percentage of people with CF where Kalydeco is not funded.

The template was used by many families across New Zealand who shared their story and stated their concerns about the lack of funding for precision medicines such as Kalydeco and Orkambi in New Zealand.

### **European CF Conference**

The conference, held in Seville in June 2017, provided the opportunity for CFNZ Chief Executive Jane Bollard to meet with Chief Executives from the UK CF Trust, CF Ireland and CF Australia to gather information about their campaigns for high-precision medicines. Jane also met with the Vertex Pharmaceuticals Country Manager who agreed to provide Pharmac with additional data on Kalydeco.

### **PORT CF**

CFNZ made a concentrated effort on our CF data registry, PORT CF, to encourage DHBs to consistently input patient data and for people with CF to consent to their anonymous health information being recorded. As part of this we invested more funds by contracting CF Nurse Specialist Jan Tate for one day a week to help improve the quality of this information. The robust PORT CF data is key to lobbying for new medicines and for promoting pharmaceutical drug trials in NZ.

# Research

Cystic Fibrosis New Zealand and Cure Kids teamed up to help fund two important research studies which we hope will improve rates of physiotherapy for kids and also the effectiveness of antibiotics to treat Pseudomonas.

## BreatheHero video game study

A new video game called BreatheHero could hold the key to improving levels of compliance of chest physiotherapy for children with cystic fibrosis.

The tablet-based game, BreatheHero, rewards kids when they perform physiotherapy correctly, as well as collecting invaluable data on how often the exercises are performed. The study hopes to show that the game, connected to an acapella PEP device, will encourage children to do physio.

It is hoped that the more engaging form of therapy will see an uplift in compliance levels among children and adolescents, which currently sits at around 49%.

Dr Cass Byrnes, from Starship Children's Hospital, says the aim of the game is to make physiotherapy fun. "Physiotherapy is a major part of a cystic fibrosis patient's daily life – it can be necessary up to 3-times a day. It is critical to improving lung function and reducing infection," said Dr Byrnes.

## Pseudomonas research at Otago University

Pseudomonas aeruginosa are strains of bacteria that are widely found in the environment but its opportunistic nature means that it is a major cause of lung infections in people with cystic fibrosis.

Once Pseudomonas is established in the airways, it is very difficult to eliminate. Antibiotics kill Pseudomonas in the research lab, but are not effective in the lungs. It is thought that this is partly due to how the bacteria grows in the lab versus the reality of the environment in the lungs.

When present in the lungs, Pseudomonas is under an oxygen-starved environment. This is at odds with Pseudomonas grown in a lab, which is usually under conditions replete with oxygen. It is these oxygen-rich lab conditions where antibiotics are tested and hence may not reflect the reality of the lung environment. It is suspected that the bacteria respond to the deficiency in oxygen by triggering 'oxygen starvation' genes to fight the effects of the antibiotics.

Prof Iain Lamont, from the University of Otago, is investigating these genetic changes by exposing the bacteria to different levels of oxygen in the lab. The insight gained from this research could lead to more targeted antibiotic treatments for Pseudomonas aeruginosa.



# Fundraising and awareness

The 2017 financial year was busy with fundraising and awareness events across the country, helping us to raise the vital funds needed to continue our mission of optimising the quality of life for people with cystic fibrosis and their families.

Some of the highlights were:

## CF Awareness Week

This year's awareness week saw wide coverage across the media, and fun events such as Hawkes Bay's PJ party and a bubbles event hosted by the Otago Branch.

## Casino Night

In September the Hawkes Bay Branch held its annual Casino Party with a 'gangster' theme. The night was a huge success, raising \$12,000.

## Canterbury Golf Tournament

This Canterbury Branch fundraiser raised over \$5,800 and enabled them to continue supporting the local families with cystic fibrosis.

## Taupo Builders Charity Golf Day

CFNZ was grateful to be named as the official charity for this event thanks to Paul Riedel (who also ran for 365 days in aid of CF!), raising over \$5,000 for the charity.

## Thank you to our volunteers

A small army of people give up their personal time, their evenings and weekends, on top of their busy lives, to volunteer and help make the work we do possible – they are one of our most valuable resources.

Many of these volunteers contribute an enormous amount of time and energy as branch members. These individuals manage equipment, help other families on their CF journey, manage fundraising and lend their individual expertise experience to ensure the branch remains active and sustainable. Their passion for helping individuals and families with CF is what makes us who we are.

You are all amazing and we thank you sincerely for your support!







### **Wellington Christmas Tree Festival**

This annual event is the jewel in the crown for Wellington Branch's fundraising efforts – raising over \$30,000.

### **CF Charity Cricket Match**

The All Star team battled against the Crusaders at the 34th annual charity cricket match – helping us to raise \$20,000 – and featured seven-year-old Harry as the poster child.

### **Choice Hotels Golf Tournament**

Our principle partners Choice Hotels held a corporate golf event in Auckland in November, bringing its total donation to \$20,000 for the charity.

### **Pole-Tober Fest for CF**

Featuring performances from burlesque dances, comedians and pole performers, this quirky event raised over \$3,000 for the Canterbury Branch.

# Partners and community supporters

We are incredibly grateful for the support of our partners who have joined us on our mission of optimising the quality of life for people with CF, helping them to live a life unlimited. Their generosity is funding research, supporting the highest quality of care and providing emotional and practical support to people with CF and their families when they need it most.

## Principal Partner



Choice Hotels Asia-Pac provides substantial ongoing support through its fundraising and awareness efforts, guest contributions and by providing accommodation for our CF fieldworkers through its network of properties across New Zealand. We use many of the hotels to host coffee mornings for CF parents, for our conferences and Board meetings, as well as any talks and workshops for the CF community. We're grateful for the support from Choice Hotels, its staff and customers, who together have greatly impacted the cystic fibrosis community in New Zealand.

## Key Partners

Our Key Partners make regular contribution through fundraising initiatives and activities and by providing sponsorship and in-kind donations.



## Key Event and Support Partners

Thank you to our Key Event and Support Partners who facilitate and participate in key events to help us reduce costs and maximise our fundraising from these events.



## A special thank you to the following for their support at our 2016 CF Charity Cricket Match:

The Crusaders, BNZ, OneStaff, Christchurch Casino, The Rock 93.7FM, Mike Greer Homes, Mainland Foundation, Telogis, Gavin Lowe Energy, Craigs Investment Partners, BDO, Canterbury Vein Specialist, Aroma, Toshiba, BDL, Happy Hire, Tait Mobile Canterbury, Pitt Stop, Giesen, Bealey Dental, Coke, DB Breweries, Phoenix Printers, Richard Till, Annabel's Educare, Noordanus Architects, Duncan Cotterill, Tavendale and Partners, Hellers, Couplands, Misty Cove Wines, Barry's Bay, Cashmere Cuisine, New World, CERT, The Fitting Room, World Travellers, McKenzie Willis, Mike Pero, Gary Cockram, Scenic Hotels, Orana Wildlife Trust, Valley Storage, Eco Frame and Mirror Company, and Armourguard.

## Trusts and Foundations

Lottery Grants Board, Four Winds Foundation Ltd, Pelorus Trust, Grumitt Sisters Charitable Trust, Mainland Foundation, Blue Waters Community Trust, John Ilott Charitable Trust, BlueSky Community Trust, CERT, Constellation Communities Trust, Trillian Trust, Lion Foundation, Eastern and Central Community Trust, Southern Trust, Pub Charity Ltd, Rata Foundation, The Wilks Charitable Trust, First Sovereign Trust Ltd, Dragon Community Trust, Air Rescue and Community Services, Community Organisation Grants Scheme, Z Energy Good in the Hood, NZ Community Post.

## Donors and Community Supporters

Our most heartfelt thank you to our donors, fundraisers and other community supporters who help us to make our vision and mission come to life. We couldn't do this work without you, and for that, we are forever grateful.

## Mark Ashford Scholarship

Georgia Drumm has become the first person to receive the Mark Ashford Scholarship for achieving excellence in an education degree. An award ceremony for Georgia's scholarship was held in June where Georgia became the 21st recipient of the award for her impressive results during her early childhood education degree at Auckland University.

Now working at Peacocks Early Learning Centre in Auckland, which is based on the Reggio Emilia educational philosophy, Georgia wants to use her \$3000 scholarship to visit Italy and gain further knowledge of early childcare centres overseas. The Mark Ashford Scholarship was founded by the late Mark Ashford's employers Fletcher Challenge to honour his contribution to healthy homes with his Healthy House insulation book.

Previous to passing away from CF, Mark had hidden his condition from his employers.



Mark Ashford  
Scholarship Sponsor

## Cystic Fibrosis Achievers' Awards

The CF Achievers' Awards in 2017 saw three people receive CF Achievers' Awards to mark their remarkable achievements – often in the face of adversity.

### Rachael Cox (17) – Achievement in Art

Rachael of Otago received a CF Achiever's Award for her achievements in music and the dramatic arts. She is thrilled to be named a CF Achiever and plans to use her award for University fees at either Otago or Victoria University where she plans to major in music and drama.

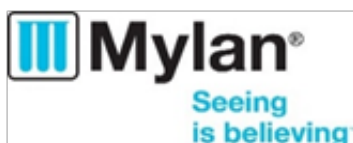
### Angus Drumm (18) – Achievement in Education

Auckland Liston College pupil Angus was able to gain Excellence endorsements for both Level 1 and Level 2 NCEA in spite of some of the challenges that CF cast his way. He plans to use his Award to help fund a six-month student university exchange – in the US or Europe.

### Joe Voyce (26) – Achievement in Sport

Joseph Voyce has received a CF Achiever's Award in sport after his mother nominated him for the hard work he's put into reaching his goals over the past few years. Joe continues to pursue his goals in health and sport and plans to use his Award for an overseas trip.

CF Achievers'  
Award Sponsor



# Structure, governance and management

Our Board oversees our strategic direction and monitors how we deliver our objectives. The diverse members combine their experiences and expertise to guide the Chief Executive, who works with the Cystic Fibrosis New Zealand staff to achieve the charity's vision.

*As at 30 June 2017*

## Board

**Jane Drumm**  
Chairperson

**Kim McGuinness**  
Board Member

**John Parsons**  
Seconded Board Member

**Warwick Murray**  
Board Member

**Catherine Rusby**  
Board Member

**Denis Currie**  
President

**CF Adult Advisor Group Chair**  
Lisa Borkus

**Investment committee**  
John Parsons (Chairperson)  
Steve Drumm  
James Lee  
Jane Drumm

**Patron**  
Professor Bob Elliott



The members of the Cystic Fibrosis New Zealand team combine their expertise to support the CF community and carry out the strategic plan, goals and vision set out by the Board.

*As at 30 June 2017*

## Staff

### Jane Bollard

Chief Executive

### Jude Kelly

Central Fieldworker

### Jeanette Franklyn

Grants Coordinator

### Emma Nielsen

Administration Manager

### Vicky Tyler

Information Coordinator

### Kath Sanderson

Auckland Branch Coordinator

### Susan Lovelock

Southern Fieldworker

### Laura Huet

Marketing and Fundraising  
Coordinator

### Chantell Taylor

Accountant

### Gretchen Kitching

Northern Fieldworker

## Branch office holders

### Northland

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

### Hawke's Bay

John Parsons (Chair)  
Claire Fisher (Secretary)  
John Kavanagh (Treasurer)

### Otago

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

### Auckland

Jill Thorrat (Chair)  
Allyson Harvey (Treasurer)

### Central Districts

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

### Southland

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

### Waikato

Debbie Wood (Chair)  
Marieke Latimer (Secretary)  
Jenn van Rijen (Treasurer)

### Wellington

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

### Bay of Plenty

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

### Nelson

Rebecca Colley (Chair)  
Rachel Tobin (Secretary)

### Taranaki

Nicola McCarthy  
Joan Tuffrey (Secretary)  
Shelley Grunchy (Treasurer)

### Canterbury

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

# Branch reports

## NORTHLAND

Northland Branch held its 10th annual golf tournament in April this year switching to the Northland Golf Club for this event. This is the Branch's major fundraising event of the year with funds going to supporting the seven people who live with CF in the region.

This year's profit from the golf tournament was a little down on previous years - \$9000 compared to \$10,000 in 2016. We had a couple of late team withdrawals and expenses were also up because we bought a few prizes for the tournament this year. As a small Branch the tournament is becoming harder to organise each year and I'm not sure if we will have our 11th in 2018 which would be a pity because it's definitely an event that's enjoyed by many. Jacinta from LJ Hookers who helps organise it still remains keen though so I guess we will wait and see.

The CLM Swimming Centre continues to support CFNZ with fundraising events, thanks to Jamie Archibald, Manager of Massey Park Pool in Auckland, who lives with CF himself. The Whangarei CLM held another multi-sport Ahipupu Challenge to support the CF community in September 2016.

I'd like to extend a sincere thank you to all the businesses in Northland that support our Branch. Fortunately, we remain in a good financial position to continue to provide the same level of assistance to our people with CF.

## AUCKLAND

Auckland Branch has had a good year, with our main fundraisers CF Awareness Week and the Auckland Marathon – while continuing with our core business of supporting our CF community. We welcomed Gretchen, our Northern Fieldworker this year, after a long break with this role vacant. It was a relief for the Branch to have this filled to ensure that the welfare needs of our community are being met.

We had another successful CF Awareness Week, raising around \$29,000 for the Branch. We are fortunate to have committee member, Rachel Elliott, who with her family, works tirelessly on making this huge event a big success every year.

CF Auckland had a team in the Auckland Marathon. As well as people from our community and friends running, we also had a group from Willis Towers Watson who fundraised and ran for the organisation, raising over \$13,000. The weather was perfect and the Branch was able to treat the CF team runners to bacon butties and a massage at the finish.

Auckland Branch was selected at two Z stations to be part of Z Energy's Good in the Hood programme – a tougher year this year due to the number of charities involved but still a very positive experience for the Branch. The Warehouse supported CF Auckland through its Bags for Good programme by choosing us at two Auckland stores.

We continue to apply for grant funding. This year we have had success with JM Thompson Charitable Trust with a \$25,000 grant for medical equipment. Also \$10,000 was received from Louisa and Patrick Emmet Murphy Foundation for the purchase of parking vouchers to be used for our PWCF attending medical appointments.

CF Auckland continue to deliver hospital packs and vouchers to PWCF in hospital every Thursday, this is



also supplemented by the donated baking from the GBB (Good Bitches Baking) bakers and this is very gratefully received.

The Branch tries to organise some social get-togethers including a Christmas gathering, morning teas and Mums' drinks. We have had mixed success with attendance at these events.

We as a committee are continually looking at ways to ensure that we are meeting the needs of our community and are always open to new ideas about how we can improve on this. I continue to be in awe of the energy and enthusiasm of our hard-working committee, who have committed year after year to help run a successful CF branch.

## WAIKATO

What an amazing positive year we have had at CF Waikato. I truly believe the awesome team we have has helped. The Bull Calf, and the Beauty and The Beast Show fundraisers ended our year off on a positive note, with the funds from the Bull Calves going to pay for CF Waikato's Breath4CF. Our applications to Z stations were finally successful, with Te Awamutu taking us on and the Bell family did a great job of promoting us with them. The Warehouse Bags for Good was phenomenal. We were selected at nine stores and at least two have carried us on for a bit longer.

Entertainment Books have been another huge success, with someone (don't know who) selling 20 Books for us! We are still receiving orders, and thanks to Jo Ridder for the great amount of books she has sold. We have received a few donations from In Memory, which have been gladly received.

Thanks to the Baker family for their generous donation from their wood sales. And to Kelly Oliver for her donation of funds from auctioning off a photo shoot. We sadly say goodbye to Jenna, our Treasurer, who has done an epic job over the last few years with all the changes from CFNZ and my ignorance of anything financial. Thank you Jenna, your service has been greatly appreciated.

We sent only two people to the CF Conference this year in Christchurch – Damien and Alice. Hopefully CFNZ will still be doing conference and we can interest a few more people next year. Marieke and I attended the Chairpersons' Conference which we both found very motivating.

And a big thank you to Robyn for firstly organising the Beauty and the Beast fundraiser, and for doing our newsletters and hosting our meetings. Thank you. And finally to Marieke, who has been my sounding board and rock this year. Thank goodness she is computer savvy and so good as our Secretary. A huge thank you to you Marieke.

## BAY OF PLENTY

The Bay of Plenty Branch had a very positive start to the period with its branch-funded community physiotherapist settling into her role covering half the region and some very positive publicity through the 'Cystic Sisters' and their 65 Days of Good Deeds.

The Branch has worked for a number of years to fund and establish a community physiotherapist position. Grants were gained and then an agreement reached with the Bay of Plenty District Health Board, resulting in a part-time physiotherapist now working in the community with our PWCF and their families. The DHB employs the physio and invoices the Branch for agreed services, meaning the Branch is not the employer and saving us multiple headaches.

The Health Board has committed to continue to fully fund the community physiotherapist position from the 2018-19 financial year. Our physiotherapist Shontelle Pengally is also employed part-time by the Health Board as the CF physiotherapist, so her roles combine to offer the best in-patient and community/home-based care. Her priority has been our PWCF who have had recent hospital admissions, patients on home IV treatments and those who needed extra input, support or supervision to undertake their physiotherapy regimes. One of the benefits is that Shontelle can visit our PWCF at a location of their choice – such as their home or gym – to help them improve their physiotherapy compliance and techniques.

A key philosophy has been to gather data and information to measure and report on the effectiveness of the position. Having reliable and consistent data is important for both the Branch (and CFNZ) and the DHB, to ensure the aims are being met, and to inform future decisions on CF physiotherapy services and funding.

The Cystic Sisters Kristie Purton and Nikki Reynolds-Wilson again undertook their 65 Days of Good Deeds in the run up to CF Awareness Week and they continued to generate an amazing amount of good will and publicity.

They didn't quite reach their target as Nikki was whisked off to Auckland for her lung transplant just days before Bubbles Day ended CF Awareness Week for the area. Their energy and attitude was reflected in them being presented with various awards and nominations for recognition. Most notably TV's Seven Sharp worked with CFNZ to surprise them with an ASB-sponsored Good as Gold award and \$5000 each. They were also finalists in the Spirit of Attitude Award in the Attitude Live Awards.

This year we farewelled Tauranga Hospital's CF Nurse Specialist Stephanie Parker when she retired away from the area. Stephanie was a constant in many of our PWCF childhoods and her cheerful and tenacious advocacy will be missed. We're lucky her replacement Vonne Wong was able to start work before Steph left and there appears to have been a good transition and we're looking forward to continued excellent and ever-improving Health Board service.

We continue to support our people on admission with grocery vouchers, non-funded equipment (i.e. nebulisers, sterilisers etc.) and many other welfare-associated costs. A new lockable fridge cabinet was delivered to Rotorua Hospital.

I wish to take this opportunity to thank Nicola Wakerley for her many years as Chairperson of the BOP Branch. Nicola, and her husband Todd before her, have been the heart of the Bay of Plenty Branch since before my now 9-year old PWCF was born. In that time they've been key to the Branch presenting a positive attitude, public face and financial status.

Nicola has relentlessly pursued countless funding and grant applications and proposals, built ongoing and positive relationships with supportive service clubs and organisations and has willingly shared her knowledge about the Branch and CF in general. Having a medical background has been invaluable and I look forward to continuing to work with Nicola in future years.





# TARANAKI

The Taranaki Branch still has a very strong and dedicated committee made up of a great representation of the CF community that they support. This year we welcomed a new member onto the committee who is full of knowledge and passion for all things CF and whose input has proved already to be very valuable.

In the last financial year we successfully fundraised with the following activities:

- Oakura School 'Blue Day' fundraiser for CF Awareness Week
- Chocolate fish – an oldie but a goodie
- Street Appeal this year raised \$4,528
- A sweetcorn street stall raised \$685
- The Warehouse New Plymouth supported us in their Bags for Good programme
- Francis Douglas Memorial College quiz night raised an almighty \$3,260
- The Liam Neil Rear a Calf fundraiser raised over \$5,000
- Womad tickets were donated by Taranaki Arts Festival Trust for auction as a fundraiser
- Hawera Bridge Club charity and catering job raised over \$1,000.

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, firewood grants, home insulation assistance, payment for non-funded equipment and many other welfare associated costs. We extended an offer to all Taranaki members to attend the annual CF conference which was held in Christchurch this year. Natalie and her mother attended on behalf of our Branch and reported that the content and information shared was well worth while attending to hear. Our annual Branch Dinner and AGM was well attended at the Plymouth Choice Hotel. And the young children in our Branch were invited to the Special Kids Extravaganza sponsored by Sky TV and NZME held in New Plymouth.

Last year the Branch agreed to sign the new MOU to help contribute towards paying for the

services of the Central Fieldworker. Jude Kelly has worked alongside our people and attended clinics in Taranaki.

Our Branch is working hard to put together what we consider core information to make our community's lives easier. We started with developing a fact sheet of what nebulisers are ideal for which situation with the approval of Starship paediatric physiotherapist Rebecca Scoones and CFNZ Fieldworker Jude Kelly, and the committee intends to vote and agree on funding amounts for each nebuliser for our people on a case-by-case basis.

We are pleased to announce that two of our members that we know of, have been granted pulmozyme for life after clinical trials through our DHB. We will be encouraging as many of our members as possible to see if they too are eligible for consideration and trials.

We had amazing coverage in the Taranaki Daily News this year with Raupunawaiariki giving a very honest and open account of living with CF. She really did all PWCF and herself proud with a great story that would have raised awareness to all that read it.

I would like to take a moment now to thank the wonderful committee that I work alongside. You really do give 100% to the cause even though you are all busy people. Your support to Taranaki people with CF is appreciated and gratefully received. You are a great bunch of passionate, humourous and committed people. And you are all seriously good bakers so we will keep you on.

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 also thank every person who ever donated even just 10 cents. Every bit makes a difference towards a brighter future for people with CF.

## HAWKES BAY

The year started with a successful Casino Night, themed around 'Bugsy' and there were plenty of winners. An active auction raised over \$12,000. Many thanks to all involved. Other fundraisers followed: movie night, HB run/walk, Keirunga Park Model Railway and school fundraisers. A special mention to St Johns School which focused on CF as told by one of their pupils, raising \$4,700.

Greg Stephenson, who has been Chair of Hawke's Bay Branch for two years, transferred to Warkworth in the New Year. We thank Greg for his management skills, keeping meetings on track and on time. Engaging speakers and social events were characteristic and much appreciated.

A meeting with DHB staff enhanced our relationship, explaining what we can do to assist them and PWCF. Hawke's Bay has joined two other branches along with CFNZ to fund a fieldworker to work in the central region of NZ. This has been a welcome addition to servicing PWCF and the Branch look forward to more engagement from PWCF. Our 'Physio in Homes' continues to service young PWCF. Ideally, the caregiver attends five times a week for 20-minute sessions – this is to ensure good habits are formed with age-related therapy.

## CENTRAL DISTRICTS

Central Districts Branch membership totals 22, with nine of these being adults. We have had only a few meetings this year but with improved attendance as our committee changes shape somewhat.

In the past financial year, I have spoken at a Rotary meeting in Wanganui, and have trialed using the PowerPoint presentation, alongside an oral presentation, with great feedback. Rotary donated \$900. We have held two Ballentynes Fashion Shows, in Wanganui and Palmerston

North. Wanganui Hell's Angels have done another Poker Run event that we will benefit from. Four movie nights at boutique theatre in Feilding, Levin and Masterton were all organised by Nigel Ramsden. (The Masterton takings were given to Wellington Branch).

A local trust gave us \$2500 for nebulisers – a grant we wouldn't have thought to apply for, but for a tip-off from a Rotary President, so we have Rotary to thank again!

I have started a Central Districts Facebook page to advertise our Branch's happenings and to pass on information mostly shared from other CF pages. Four of our CF kids were able to attend the Special Children's Christmas Party in Porirua, which was much enjoyed. And three of us attended the CF Conference in Christchurch this year – fully funded thanks to a grant from Lion Foundation.

This year we applied to eight Z stations for Good in The Hood. Unfortunately, we were unsuccessful for all. But our success turned with the Bags for Good programme at The Warehouse. We have had a token box for CF in the Wanganui and Palmerston North stores from February to the end of July. Our token boxes were consistently the most popular for both stores!

I am still selling chocolate fish year-round in Wanganui at two local businesses and we managed to sell several cartons over the region around Awareness Week. This year we ran street collections in Feilding and Palmerston North – our first collections in six years.

Big changes are afoot within our Branch, as I step down from my role as Chairperson and Secretary after several years in these roles. I would like to extend my gratitude to Coralie who remains Treasurer. We hope to continue the hard work of the Central Districts Branch so watch this space!

## 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. Nicci Hughson and Paula Richards continued the role of Co-Chair for the second year. Helen Williamson took on the Secretary role and Beth Hughson continued as Treasurer.

We have provided PWCF in Wellington with Breath4CF top-ups, hospital inpatient voucher packs, half-price hospital parking, equipment and various other welfare assistance. We fully funded one person from the Branch to attend the National Conference in Christchurch this year. We also paid for flights for our Paediatric Physiotherapist and Dietician to spend a training day at Starship Hospital.

Our Christmas Tree Festival in 2016 was yet again highly successful, raising over \$30,000. The 2017 Festival will also be our main fundraiser for the year. We applied for The Warehouse Bags for Good programme. We were accepted at four stores in Wellington.

Our new CF Paediatric Nurse Tricia Martin commenced her role at the beginning of the year and has provided much needed support to Dr Robert Winkler and families.

A small number of successful networking events ran through the year for families. In March, we held a special event where we were presented with a donation of 13 Nebulisers from the Freemasons. We also said farewell to Robyn Lange, retiring Paediatric Physiotherapist. We also organised a talk for parents of children with CF, which was presented by Skylight. This was well received and we had a good turnout on the night.

CF Awareness Week 2016 went well with the Branch targeting successful spots from the previous year. We also had one kindergarten 'Bubbles' fundraiser and a disco.

Our 'paid' membership numbers for the year were the highest they have been in many years. This was due to mailing out membership forms as well as sending by email. We also had one new baby diagnosed with CF this year.

Our plan over the next year is to work closely with our Fieldworker and identifying 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 and wider community.



## NELSON

This year Nelson Branch was fortunate to be selected for The Warehouse Bags for Good programme with voting boxes in boxes in both Nelson and Motueka stores. There was amazing support for cystic fibrosis with the CF box filled to the brim with tokens.

The Branch held what's become an annual stall on Anzac Day to raise funds for the Branch. We sell hot soup and cheese rolls which are very popular and something my niece and I have now done for three years.

In general, it's been a quiet year for the Branch but there is still a strong level of support for people with CF in the Nelson/Marlborough region. We are grateful that we can still help families and adults to get the treatment they need – contributing to petrol costs for travel to CF clinics and providing nebulisers for people with CF to take their medication.

## CANTERBURY

It is with much sadness that I report the loss of two of our members this past year – Vicki Kennedy, a wonderful and vibrant adult from Oamaru, and Luke Donnithorne, father of two CF children.

We have a great committee of six hardworking people from our community and great support from our wider community this year. We meet monthly and are lucky to be able to use the Can Breathe building that our Fieldworker Sue Lovelock has an office in.

Our Gmail address is working well for communication with our families and community. Information is given on up and coming fundraisers, conferences and events. This year the uptake of chocolate fish sellers from our community was amazing with our complete supplies distributed in a week.

Our fundraising for the year has consisted pretty much what we know works; our annual Golf Tournament at Templeton Golf Club, 2x Bunnings stocktakes, selling of the Entertainment Book, school mufti days and bake sales, chocolate fish selling and another Theatre Production night which

was enjoyable and profitable. Sadly our Bunnings stocktake has come to an end with new technology now being used. There is no need for community groups to count anymore.

Through contacts of one of our CF adults we have had a small fundraiser over the last three years ticking along. Liv from Liberate Pole organises a variety show made up of dancers from her pole exercise classes, burlesque dancers, comedians and a magician. This event has grown considerably and last year we received \$3000. The show was a sell-out. These ladies also man a table at a local mall in Awareness Week for us and advertise their event at the same time.

Timaru Freemasons gave us a very generous donation of \$3000 and we received a \$200 donation from Lions Club of Temuka Pakete, which was very kind.

We were lucky to be chosen by Z Belfast as a charity for Good in the Hood and received funds of \$800 which was greatly appreciated.

We have also had other smaller fundraisers run by our supportive members throughout the year, all which really help our cause. We have had bake sales from large businesses, biggest loser competitions, and a production of the play Annie where we received the opening night ticket sales.

We have been successful with grants this year from Four Winds Foundation (\$3000), Mainland Foundation (\$9,365.60) and Rata Foundation (\$10,000) – this money going to wages for our part-time Community Physiotherapist and medical equipment. Grants are more difficult to come by and we would like to thank the CFNZ Grants Coordinator for her help and support.

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

## OTAGO

It's been a pretty quiet year for CF Otago. With the committee down to two members, Jeremy Byfield as Treasurer/Secretary and myself, there have been minimal ideas and initiatives, as well as a reduced need for committee meetings. We did have a mostly successful Branch dinner at Etrusco in March organised by Arthur and Sue (thank you). There were a couple of new faces and quite a few old ones as well!

We were selected by three Warehouse stores (two in Dunedin and one in Alexandra) for their Bags for Good programme. When I last checked the Dunedin ones, both CF boxes were well ahead of the competition.

CF Otago was selected as a recipient charity for the Kia Dunedin Golf Classic (thanks to Melissa at Canterbury Branch for the referral). Although we still don't have a final total raised at this stage, the excitement on the day was that, for the first time ever, a player won a car by scoring a hole in one at the designated hole. The insurance for this unlikely event happening was set up so that there is also a \$1,000 extra pay out to the recipient charities. The final total should be around \$2,000.

We had another surprisingly successful street appeal (given the last minute organisation). Thanks again to Kate Croy and Camilla, and Rupert who stepped up as main organiser this year. With collections in

Oamaru, Alexandra, Waikouaiti and Dunedin we raised just over \$14,200. I expect that will pretty much meet our budget for the next financial year.

I'd like to personally thank our fundraising committee: Rupert, Kate, Camilla - and all the collectors for their help with street appeal. Also Kevin for hosting the counting, Arthur and Sue for their help organising the dinner, and especially Jeremy for all his work managing the accounts and attending committee meetings. It's been a surprisingly successful year given the dwindling committee and participation.



# Financial summary 2017

## SUMMARISED STATEMENT OF FINANCIAL PERFORMANCE

	CONSOLIDATED	
	2017	2016
REVENUE		
Fundraising Revenue	795,506	723,612
Donations and Bequests	137,480	111,986
Grants and Sponsorships	224,632	233,555
Contract Revenue	75,000	75,000
Interest and Dividends	86,055	90,659
Realised Gains on Investments	20761	
TOTAL REVENUE	1,339,434	1,234,812
EXPENSES		
Expenses Related to Public Fundraising	406,675	317,380
Volunteer and Employee Related Costs	464,675	444,715
Costs Related to Providing Goods and Services	213,204	201,862
Grants and Donations Made	295,058	269,934
Other Expenses	23,909	19,040
TOTAL EXPENSES	1,403,283	1,252,931
NET SURPLUS/(DEFICIT)	(63,849)	(18,119)

## SUMMARISED STATEMENT OF FINANCIAL POSITION

	CONSOLIDATED	
	2017	2016
ASSETS		
Cash Held	1,134,459	1,129,345
Fixed Assets	10,915	12,135
Investment Portfolio	853,735	932,308
Other Assets	131,139	50,914
TOTAL ASSETS	2,130,248	2,124,702
LIABILITIES		
Grants	196,545	152,832
Other Liabilities	248,757	179,362
TOTAL LIABILITIES		
TOTAL EQUITY INCLUDING CAPITAL FUNDS	1,881,491	1,945,340

Full audited accounts are available on [www.charities.govt.nz](http://www.charities.govt.nz)



## **“We think it’s important to live your life as normally as possible and don’t let CF hold you back.”**

“Max is six years old now and although he’s been in hospital a few times, he’s been fine for the last two and a half years – in fact more than fine. He’s a healthy weight and doing so well at sport.

He’s a fast little runner and received the most valuable player of the year award for his first year at Rippa Rugby. Kids are meant to do Rippa for two years but because he did so well, and because of his size, they have moved him up a level.

When we decided to have a second child we took the option of having IVF and pre-gestational diagnosis screening for cystic fibrosis. Out of four embryos, one had cystic fibrosis and the other three had the cystic fibrosis gene. Isabelle was born in 2015. She’s a carrier for CF but does not have the condition, and she’s just as outgoing as her brother.

We’ve never held Max back from anything. We offer him any opportunity we can. Living where we are in Southland he can do anything – he can go biking, boating, motorbiking, hunting and fishing.

I still can’t help worrying about what the future might hold for Max. My biggest concern are the teenage years – that’s when kids with CF can stop doing their physio and their daily treatment.

We want Max to be able to take advantage of any opportunity he wants. We think he’ll go down the sporting route but he also did a great job in his school production ‘Little Stars’ – performing right in the front row.

We think it’s important to live your life as normally as possible and don’t let CF hold you back.”

If you would like to help support people like Max living with cystic fibrosis, please visit our website [www.cfnz.org.nz](http://www.cfnz.org.nz).



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