



Annual Report 2019

For the financial year ending 30 June 2019

cf CYSTIC FIBROSIS NZ

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“When Amber was a baby 13 years ago, the CF nurse told me people with CF are special. She said she didn’t know if it was due to what they went through or whether it was nature’s way of balancing things out. These words have always stuck with me and I agree.”





The CFNZ Board stand zealously alongside our four strategic pillars – advocacy and awareness, research, support and information.

It's these pillars that will allow us to achieve our vision – lives unlimited by CF.

Board Report

Jane Drumm, CFNZ Board Chair



I know we listen to our community, we form strategic partnerships, we look to scan the horizon and we look for opportunities to grow and improve for the benefit of our very deserving CF community.

It's with a sense of pride I present this, my final Chairperson's report for CFNZ. CFNZ has evolved and grown significantly particularly over the last 10–15 years.

In December 2018 we gathered as a CF community and commemorated 50 years of CFNZ. Hosted by the Governor General of New Zealand, Dame Patsy Reddy, at Government House in Auckland, our 50th event was a wonderful occasion. The opportunity to bring together founding families, CF branch representatives, CF health professionals, sponsors and supporters, staff, the board and members of our various CFNZ governance committees was momentous.

Having an adult with CF who's a member of one of those founding families address the gathering was a moment I'll never forget. The happiness and optimism that resounded from those at the event for this split second in time reminded us of all the good that has happened over the last 50 years. The timeline of our past 50 years, that can be viewed on our website, details those significant moments.

Celebrating 50 years is of course bitter-sweet. There have been many advances in CF care and in the way we work in partnership to raise awareness, inspire, equip and support people with CF and their families and show leadership and innovation as a charity.

However, there is still no cure for CF. The new therapies that have now become commonly used throughout the developed world are not yet funded in NZ. Game changing, life altering medications are within reach and gaining access is a major focus for CFNZ along with keeping all our people throughout NZ as supported and healthy as possible.

With this in the forefront, the CFNZ Board stand zealously alongside our four strategic pillars – advocacy and awareness, research, support and information. It's these pillars that will allow us to achieve our vision – lives unlimited by CF.

This past year the Board and the Chief Executive have worked together with our branches to embed the four strategic pillars. Governance initiatives in the areas of communication, training, organisation and planning has strengthened our volunteer base and in turn that feeds our overall governance structure.

CF is a complex and multi-faceted condition. Thankfully more adults now have CF than children and this is a growing trend. These improved outcomes bring with them the increasing need to urgently fight the good fight on so many fronts. Our CFNZ strategic pillars help us see clearly where our energies need to be to have maximum benefit.

I sincerely acknowledge our hardworking branch volunteers and our amazing CFNZ staff members who have at their hearts the wellbeing of our CF community, both nationally and locally. I also warmly thank our founders, partners, supporters, sponsors and benefactors without whom we could not achieve all that we set out to do and more.

As I step away from the role as Chair of the CFNZ board I am confident the organisation is in a healthy, developmental stage and in good hands. I know we listen to our community, we form strategic partnerships, we look to scan the horizon and we look for opportunities to grow and improve for the benefit of our very deserving CF community. We should all be very proud of how far we have come and how much we can achieve together.

Chief Executive Report

Jane Bollard, CFNZ Chief Executive



The establishment of the 4 pillars of service and the targeted resourcing of these has meant that we have been able to respond to what is important to the CF community.

This has been a purposeful year with further developments in ensuring CFNZ's sustainability. The team of staff and contractors have worked extremely hard to achieve on the objectives in the annual plan being the first year of the newly developed strategic direction.

The establishment of the 4 pillars of service delivery (advocacy and awareness, research, support and information) and the targeted resourcing of these has meant that we have been able to respond to what is important to the CF community as identified in the 2018 CF Insight Survey. We are now able to be proactive in our planning given that we have a strong strategic direction with systems and personnel in place.

With the implementation of the co-design methodology into the organisation, initiated in 2017 with empathetic interviews of family on diagnosis and adults, followed by the development of the family and whanau, schools and employers guides, we have been able to respond to current issues faced by our community and provide information for the community by the community.

We are extremely grateful to everyone who has supported this work either financially or through giving their time so freely. I finish this report heartened that this support makes a huge difference.

"I am not affected by CF, but my 10-month-old daughter is failure to thrive, and I am currently grieving for her health and awaiting some breakthrough diagnosis which may or may not arrive. With it being CF Awareness Week I have visited your site and downloaded 'A Guide for Parents and Caregivers of Children Diagnosed with CF'. I am writing to commend you on such a helpful and insightful pamphlet. The insights in that document are immeasurably helpful for me and I presume would be equally useful to any other parents of unwell children, whether directly affected by CF or not. Thank you."

Game-changing, life-altering medications are within reach and gaining access is a major focus for CFNZ along with keeping all our people throughout NZ as supported and healthy as possible.



Farewells

The lily has so brief a time
To bloom in the warmth of
Sunlight's kiss upon its face.

Before it folds its fragrance in
And bids the world goodnight
To rest its beauty in a gentler place.

But we can know that nothing
That is loved is ever lost and
No-one who has ever touched
A heart can really pass away,
Because some beauty lingers on
In each memory of which they've
Been a part.

– Eileen Brennehan

Kay East

3 August 2018
63 years old

Jo Howlett

7 December 2018
33 years old

Kristie Purton

20 March 2019
35 years old

Emma Taylor

7 April 2019
20 years old

Joe Scott

9 May 2019
21 years old



How we made a difference

We support people with CF and their families through our fieldworker services, local branch networks, online communities, grants and financial support.

What does success look like for us?

- Our people with CF needs are met, both financially and emotionally.
- The achievements of people with CF are acknowledged and celebrated.

Celebrating our successes

- We continued to fund our three fieldworkers and secured funding for a fourth fieldworker.
- The Clinical Advisory Panel reviewed our Breath4CF policy to ensure its ongoing viability and ensuring it meets the needs of our community.
- Reviewed and implemented new criteria for branch discretionary funding to ensure equity throughout New Zealand.
- Improved access to grant applications through online applications.
- Purchased new laptops for the fieldworkers to allow greater connectivity to our database and website when in the field.
- Developed a new cross infection policy in line with international guidelines to ensure our community is kept safe.
- Our findings from our Insight Survey continue to be the driver behind our work.

237

inpatient visits by the fieldworkers to PWCF and their families

83

care plans developed by fieldworkers to support PWCF

\$76,536

used to keep PWCF active through the Breath4CF programme

2917

contacts fieldworkers had with PWCF

\$110,176

provided in welfare support, such as heating and nutrition

369

PWCF increased physical activity with Breath4CF support

757

outpatient clinics attended by fieldworkers to support PWCF

16

PWCF supported with a Chris Howlett Endowment Fund grant on turning age 21

32

transplant grants provided, for use towards expenses such as immediate family travel and accommodation

\$14,025

provided in post-transplant recovery support and care



Advocacy & Awareness

We advocate on behalf of our CF community on issues that matter. Results from our Insight Survey in 2018 told us what PWCF want life to be like in five years' time:

- Easier access to the best medicines and treatment for children and adults across the country (i.e. outside the main treatment centres).
- Day to day management of CF to be less demanding, expensive and time-consuming.
- Their day to day experience and functioning to be less impacted by the disease.

What does success look like for us?

- Government agencies provide a consistent approach to people with CF throughout New Zealand.
- The support we provide for people with CF and their families meets their needs and our work is seen to be of value by the Ministry of Health (MoH) and district health boards (DHBs).
- People with CF and CFNZ are included in all health-related decisions.
- Consistent quality of care and equity of access to care for people with CF wherever they are in New Zealand.
- DHBs fund vital equipment.

Celebrating our successes

- We continued to engage with our advocate Lisa Woods.
- We developed an advocacy policy and strategy to meet the needs of our community.
- We developed an advocacy kit for our community to download from our website to help with ongoing advocacy needs.
- We continued to be transparent with our advocacy work through our advocacy timeline on our website.

- A Kalydeco campaign was developed and executed in conjunction with Kalydeco 4 Kiwis; we were successful in getting Kalydeco recommended for funding by the Pharmacology and Therapeutics Advisory Committee (PTAC) of PHARMAC.
- We facilitated 200 letters written to PHARMAC urging the funding of Kalydeco.
- Local branches engaged with our advocate Lisa to develop local advocacy priorities.
- Our central fieldworker has begun working with the Wellington adult service.
- Our contract with the Ministry of Health was extended for another year.
- Our contract with the Canterbury DHB contract was extended for another two years.
- We met with the Minister of Social Development, Carmel Sepuloni, urging change for the need for PWCF to apply to WINZ every three months for support.
- We corresponded with the Minister of Education about the cross-infection risk in schools if more than one child with CF attends the same school.
- We began development of a workforce survey in partnership with the Clinical Review Group (CRG) and the Clinical Advisory Panel (CAP).
- We continued our strong relationship with Patient Voice Aotearoa and Rare Disorders NZ.

Access to medicines

2018

17 August

CFNZ CE attends video teleconference hosted by Rare Disorders New Zealand on rare disorder medicine funding in NZ. An interest group is set up to look at alternative funding arrangements for rare disorders.

19 November

CFNZ CE submits feedback to PHARMAC on the proposal for cholecalciferol (vitamin D) oral liquid.



19 December

CFNZ receives a summary of feedback from PHARMAC about how it seeks and incorporates consumers voices into its work, including how it makes funding decisions for medicines and medical devices. CFNZ provided feedback for this report in July.

2019

18 April

Associate Professor Cass Byrnes completes submission on behalf of the CAP and CRG for the Therapeutics Products Bill.

Kalydeco campaign

2018

23 August

Kalydeco for Kiwis becomes a public Facebook page with Eddie Porter leading the charge.

25 August

Eddie Porter, Kalydeco for Kiwis campaigner, approaches CFNZ Board stressing urgency for an active campaign. Kalydeco for Kiwis and CFNZ agree to work together on a Kalydeco campaign.

26 August

CF community and CFNZ actively encourage Vertex to submit an application for Kalydeco.

3 September

PHARMAC's call for applications for medications for rare disorders close.

7 September

The CAP meets and discusses support for the Kalydeco campaign and other precision medicines.

11 September

Vertex advises CF community they have submitted an application for Kalydeco to PHARMAC.

25 September

Kalydeco campaign toolkit ready for use.

28 September

Kalydeco campaign launched.

28 September

PHARMAC advises receipt of 13 applications for medications for rare disorders, including Kalydeco.

2 October

Kalydeco campaign progress meeting held.



9 October

Medicines NZ releases report ranking NZ as lowest out of 20 OECD countries for its market access to modern medicines and offers its support to the Kalydeco campaign.

28 October

Lisa Woods speaks at our Chairperson's Conference. Eddie Porter and Lisa update the group on the Kalydeco campaign.

2019

12 February

The Rare Diseases Subcommittee recommends Kalydeco be funded (with a medium priority) for the treatment of cystic fibrosis in patients with a G551D mutation.

8 May

PTAC recommends Kalydeco be funded with a low priority for the treatment of cystic fibrosis with the G551D mutation

28 May

CFNZ CE Jane Bollard, Eddie Porter and Lisa Woods meet with a PHARMAC representative to discuss the PTAC decision re Kalydeco funding.

Tobi Podhaler campaign

2018

7 September

Novartis announces the sale of its cystic fibrosis products Tobi Podhaler and Tobi solution to Mylan.



2019

17 April

CFNZ received correspondence from PHARMAC regarding the Tobi Podhaler application. The application is awaiting review at the next respiratory subcommittee meeting which may not be scheduled until early 2020.

Access to equipment

2019

14 June

CFNZ sends a submission to PHARMAC to support the proposal to increase the number of needles from 100 to 200 per prescription for people with CF-related diabetes.

Other advocacy projects

2018

October

The CFNZ Board signs off advocacy strategy.

7 November

CFNZ CE receives consumer report from the Capital and Coast DHB on the design of the new children's hospital.

May

CFNZ receives an email response from the Medical Council relating to its feedback on the Medical Council of New Zealand's revised statement on information, choice of treatment and informed consent.



May

CFNZ sends a letter to the Minister for Social Development, Carmel Sepuloni, requesting a meeting regarding WINZ and the ongoing need for PWCF to reapply every three months.

31 May

CFNZ submits feedback for the Health and Disability Systems Review.



31 May

CFNZ supports Volunteering New Zealand's submission to the Department of Internal Affairs Medical Council review of the Charities Act 2005.

**“The whole family,
including extended
family, is impacted
when a loved one has
cystic fibrosis.”**



Information

We support PWCF and their families with relevant, New Zealand specific, up-to-date information, from newly diagnosed through to adulthood.

What does success look like for us?

- We provide resources, information and connections to meet the needs of our CF community via a multi-channel approach.
- Our team of health professionals agree on the information.
- Our website is the 'go to' website for information.

Celebrating our successes

We continued to engage medical writer Sarah Cahill to review and develop our information, both in print and online.

We developed and published three new guides:

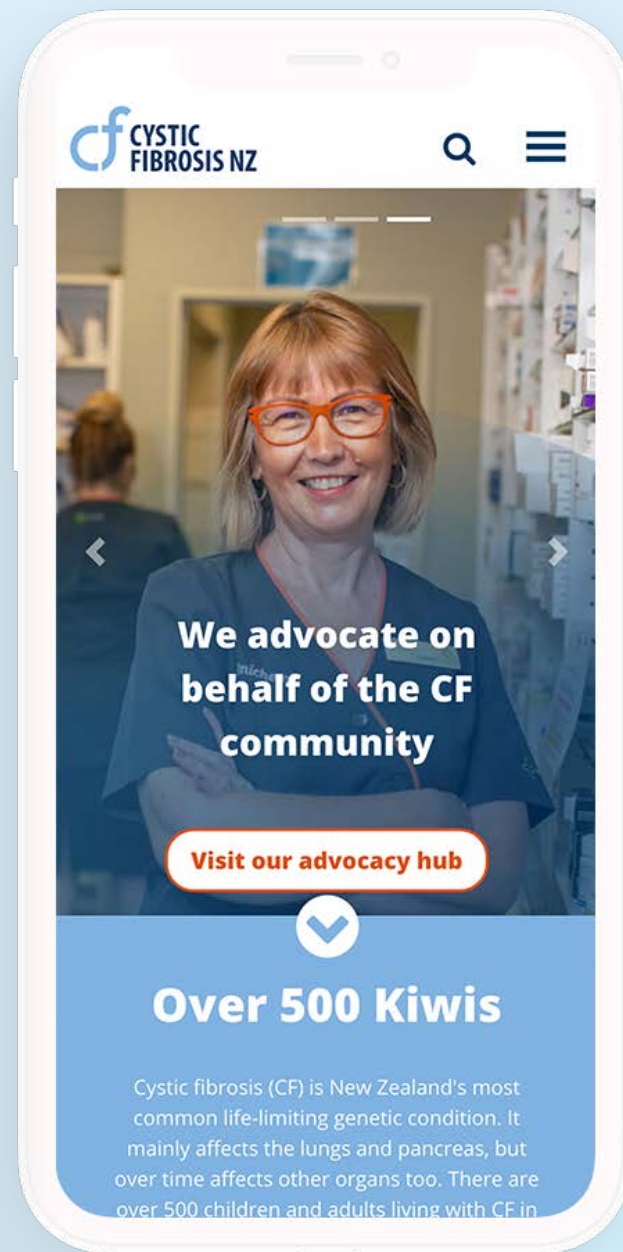
- Starting School – A guide for parents and caregivers of children with cystic fibrosis
- Starting School – A guide to cystic fibrosis for primary schools and teachers
- A guide to cystic fibrosis for employers

Each guide was developed using co-design to ensure the information was from the community, for the community. We also worked closely with the CRG and the CAP.

We were thrilled to develop and release a video for children with CF starting school, with the hope it will also be a resource for parents, schools and teachers to ease the transition into school life.

Launch of our new CFNZ website

Our new website was launched in July 2018, featuring our new logo and branding and up-to-date, New Zealand specific information.



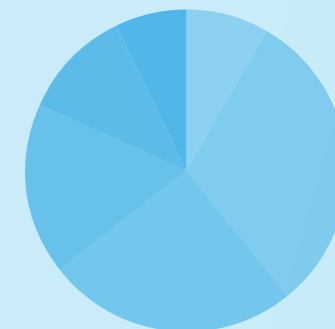
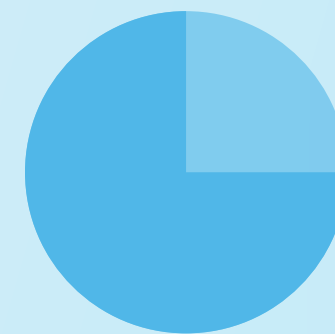
In its first year, our website has seen:

30,153
USERS

29,986
NEW USERS

93,043
PAGE VIEWS

10
MOST VISITED
PAGES



1
WHAT IS CYSTIC
FIBROSIS?

6
DONATE

2
FREQUENTLY ASKED
QUESTIONS

7
FIVE FEET APART
- WHAT YOU NEED
TO KNOW

3
LATEST NEWS

8
UPCOMING
EVENTS

4
CONTACT US

9
CAMPAIGN FOR
KALYDECO

5
HOW IS CF
DIAGNOSED?

10
GENETICS AND
CYSTIC FIBROSIS

WE KEPT OUR COMMUNITY UP-TO-DATE WITH 63 LATEST NEWS ARTICLES.

Research

Our mission is to work towards a better quality of life for all PWCF through research into better treatments and management of CF.

What does success look like for us?

- Our Port CF data registry provides meaningful and useful data.
- Our research supports strategic development, quality of life and quality improvement.
- Our work with Cure Kids and researchers continues to identify strategic research and funding opportunities.
- Our people with CF have access to clinical trials.
- We understand the needs of adults with CF and how they wish to engage with CFNZ.

Celebrating our successes

- Our 2015 Port CF report was signed off and our 2016 and 2017 report is near completion.
- Associate Professor Cass Byrnes uses our PORT CF data when presenting at forums.
- Our people with CF are encouraged to have current gene testing completed due to the increase in precision medicines.
- We hosted a strategic research day, with the results emphasising the need for clinical, research and funder collaboration.

- We engaged Researcher Development Manager, Dana Felbab, to develop a research strategy (including clinical trials).
- We engaged Craig Fisher to review our Shares in Life Foundation structure.
- We supported two new research studies, one on siblings and one on social isolation.
- We developed a post-transplant care survey which is awaiting sign off by the CAP.
- Used the adult empathetic interview findings to focus on our adult care needs, including developing our guide for employers and discussion with WINZ.

Celebrating 50 years of CFNZ



PARI t-shirt fundraiser raises over \$8,000

In 2018, a special fundraiser was launched to mark the 50th anniversary of both CFNZ and PARI BOY. For every person who wore a PARI BOY/CFNZ T-shirt at a sports challenge or event, PARI donated 10 euros (approximately \$16) to CFNZ.

An incredible 289 New Zealanders participated, raising a fantastic 5,000 euros/\$8,000 NZD! We cannot thank PARI enough for its support and to the participants who whole-heartedly embraced the initiative.

Special celebration to mark 50 years of CFNZ

Volunteers, health professionals, staff and friends from all over New Zealand celebrated 50 years of CFNZ supporting people with CF and their families.

Governor General, the Rt Hon Dame Patsy Reddy, and Sir Peter Gascoigne welcomed over 100 guests to Government House in Auckland on 5 December. After a warm welcome from Dame Patsy, CFNZ President Denis Currie reflected on the past 50 years and how far the organisation has come. He also spoke about visions for the future for people with CF and the quest to find a cure.

Nichola, an adult with CF from Auckland, spoke on behalf of people with CF, touching on her life with CF and how the organisation has supported her and others in New Zealand with CF. It was inspiring to see Nichola's son Riley accompany her to the reception.

CFNZ Chairperson Jane Drumm read a poem and a memorial candle was lit alongside the commemorative book of the names of people in New Zealand who we've lost to CF.

"It was a very special evening and it was humbling to be part of such a fitting commemoration," Jane says.

Following the formalities, guests enjoyed talking with old friends and the opportunity to connect with new people from around the country who continue to support CFNZ and the CF community.

Sincere thanks to Dame Patsy Reddy and Sir Peter Gascoigne for hosting the celebration and to everyone who joined us to mark this special occasion. We look forward to a bright future and more lives unlimited by cystic fibrosis.



“My life hasn’t taken the usual path but I do live it to the full. I like to think anything is possible – you can achieve a goal if you set your mind on it. And don’t let anything get in the way.”

Mark Ashford Scholarship

The Mark Ashford Scholarship is awarded each year to a person with CF who has shown excellence in their tertiary study and/or has shown tenacity to overcome the trials of CF while studying. The award is generously sponsored by TelferYoung.

Caleb Skene

This year's winner was 22-year-old Caleb Skene from Christchurch, who was awarded the scholarship for excellence in his Bachelor of Architectural Studies degree which he completed last year at the Ara Institute of Canterbury.

Caleb was thrilled about winning the 2019 scholarship.

"I got the news when I'd just walked in the door after work one day. It's amazing and I'm over the moon about it. I feel proud knowing the meaning behind the award and grateful for the possibilities it will give me in developing my knowledge," Caleb says.

The scholarship is generously funded by TelferYoung in memory of Mark Ashford. Mark had CF and passed away in 1996 after making a huge contribution to home health with his work on the Fletcher Group's Healthy Homes book.



CF Achievers' Awards

The Cystic Fibrosis Achievers' Awards are awarded annually to people with CF who have achieved excellence in leadership, the arts, sports or education. The awards are open to all New Zealanders with CF who achieve their goals along with managing the high treatment burden of CF, and recognises their optimism, perseverance and achievement. The awards are generously sponsored by Mylan.



Jayde Knight CF Achiever – Education

Sixteen-year-old Jayde Knight is the youngest recipient of the CF Achievers' Award this year. Jayde is in Year 11 at Hamilton Girls' High School where she has an outstanding academic record. She's in extension classes for all her subjects and last year took Level 1 science subjects a year early, scoring merit and excellence.

Jayde plans to put the award money towards a school art history trip to Europe in September.

"It's amazing to win this award. The trip is expensive and the fact that others are supporting me to do this is, like – 'wow!'"



Briar Lomas CF Achiever – Arts

Briar is a top student in her Bachelor of Design course at Massey University in Wellington. Now in her fourth (honours) year, she achieved an A+ in all her courses last semester and was nominated as one of only two students to join the Design Institute of New Zealand's student council.

Briar says the 2019 award will be super-helpful in paying for fees and a new laptop, allowing her to focus wholeheartedly on her final major design project.

"It's such a lovely validation, very affirming. I've put lots of work into my studies and it's a wonderful incentive to keep achieving the best," she says.



Georgie Northcoat CF Achiever – Leadership

Georgie is only 20 years old but has already demonstrated her flair for leadership and innovation. Now in her third and final year studying clothing, textile sciences and marketing at Otago University, Georgie's aim in life is to solve universal problems, challenge herself and create.

With a Bachelor of Applied Sciences under her belt when she graduates in December, Georgie has several career options open to her. Right now, the idea of starting her own business is the most exciting.

"I would like to upskill and fill the gaps in my personal knowledge. This grant is the first opportunity I will have to invest in myself and pursue entrepreneurship at these early stages of development," Georgie says.

Partners and community supporters

Every year we are supported by organisations who help us to continue our work, working for lives unlimited by cystic fibrosis. Through their generosity they help to fund our four pillars of service – support, advocacy and awareness, information and research.

We thank you.

Principal Partner



Choice Hotels Asia-Pac provides substantial ongoing support through its fundraising and awareness efforts, guest contributions and 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, our conferences and Board meetings and talks and workshops for our 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.

For more information on Choice Hotels, visit the Choice Hotels website – choicehotels.co.nz



Key Partners

Our key partners make regular contributions through fundraising initiatives and activities and providing sponsorship and in-kind donations.

Trusts and foundations

- AD Hally Trust
- Air Rescue & Community Services Ltd
- Anstiss-Garland Charitable Trust administered by Perpetual Guardian
- ANZ Staff Foundation
- Bendigo Valley Sports & Charity Foundation
- Blue Waters Community Trust
- BlueSky Community Trust
- Central Lakes Trust
- CERT
- Community Organisation Grants Scheme
- Community Trust of Mid & South Canterbury
- Community Trust of Southland
- David Ellison Charitable Trust – Canterbury
- Dragon Community Trust
- Estate of Gordon Lindsey Isaacs administered by Perpetual Guardian
- First Light Community Foundation
- Foundation North
- Four Winds Foundation Ltd
- Grumitt Sisters Charitable Trust
- Hazlett Trust administered by Perpetual Guardian
- Hugo Charitable Trust
- John Ilott Charitable Trust
- Kindercare Group
- Lottery Grants Board – Auckland
- Louisa Patrick Emmett Murphy Foundation
- Mainland Foundation
- Milestone Foundation
- Ministry for Vulnerable Children
- The North & South Trust Ltd
- NZCT
- ONE Foundation Ltd
- Otago Community Trust
- Page Trust
- Pelorus Trust
- Procure Charitable Foundation
- Pub Charity Ltd
- Rata Foundation – Canterbury
- Redwood Trust Inc
- Roy Owen Dixey Charitable Trust
- South Canterbury Trusts administered by Perpetual Guardian
- Stewart Family Charitable Trust administered by Perpetual Guardian
- The Lion Foundation
- The Lion Foundation – Auckland
- The Southern Trust
- The Trusts Community Foundation
- Thomas George McCarthy Trust
- Trillian Trust
- Trust House Foundation
- W. Duncan Bickley Trust Fund
- Whanganui Community Foundation
- Winton & Margaret Bear Charitable Trust
- Youthtown Inc

Branch reports

Auckland

This year the Auckland branch has continued to support our people in hospital with hospital packs, food vouchers, petrol vouchers to help with the cost of travelling to and from hospital and parking vouchers to subsidise the high cost of parking when attending clinic appointments.

We've also contributed some of our fundraised money to help with the purchase of non-funded equipment and other welfare associated costs. We were also able to purchase equipment for the Auckland Hospital level 7 gym that AWCF will benefit from when they're an inpatient.

Our branch is fortunate to have Emma and Eddie dedicating much of their time and effort into the Kalydeco for Kiwis campaign. They've kept up the momentum and continue to make effective progress.

Having identified to the Clinical Advisory Panel that post-transplant care in Auckland differs from other areas, we've agreed to fund a survey and interviews to explore this issue further.

We've hosted several successful evening meetups this year, including a parents' night and a dads' get-together. These have been a great way to help connect our community and we've received positive feedback from families who have attended. We're also delighted to have some of our AWCF regularly connecting with us via Zoom for our monthly committee meetings.

Our monthly E-newsletter and branch Facebook page continue to be an effective way to communicate with our community supporters.

Jill Thorrat

Waikato

The Waikato branch has had another successful year supporting our CF community, through fundraising and other avenues of raising money and awareness.

Our committee is still going strong, with nine members who actively contribute to meetings and fundraisers. Our adult representative continues to be a great advocate for our adults with CF during committee meetings.

We've continued to support our people through our contribution to the Breath4CF fund and we worked with National and the fieldworkers to increase our welfare payments; we know the need is there, but we weren't being asked. This seems to be improving which is very positive.

We assisted two people to apply for funding to attend the Australasian conference in Perth, we organised a zoo day out in Hamilton through Dinsdale Lions who invited local charities and we're planning a parents' coffee group to be held soon.

We've provided support to our CF nurses with their requests for help for both paediatric and adult in-patients and for nurses to attend the National Cystic Fibrosis Multidisciplinary Forum in Christchurch.

Debbie Wood & Marieke Latimer

Taranaki

This year our fundraising efforts have allowed us to continue to support our people with boredom buster packs for entertainment and high calorie snacks while in hospital, petrol to help with travel associated with hospital stays, firewood grants, home insulation assistance, payment for non-funded equipment and many other welfare associated costs.

The money we've raised through fundraising has also allowed us to continue to support the fieldworker service for the people of Taranaki and the continuation of the Breath4CF grants for our community.

Two of our Taranaki committee members attended the national CF Chairperson's Conference to represent the views of the Taranaki CF community.

This year we also had a pot-luck lunch to welcome our new families and reacquaint with our 'older' CF families.

We are thankful for the support of the New Plymouth Warehouse Customer Choice programme, Karl Ripen Trust, Hawera Masonic Trust, Mellowpuff Charitable Trust, Hawera Bridge Club, Hawera Pak'nSave and all those families who donate calves for our Rear a Calf Campaign.

Nicola McCarthy

Hawke's Bay

Our branch has had another good year supporting our CF community. Through many fundraising activities over the year we've continued to fund local Breath4CF grants.

We've had regular meetings through the year and we're pleased again that we have adult representation and two new volunteers. We've also hosted social meetings at local venues for a more relaxed get-together.

Our physio in homes continues to support young PWCF. This programme was reviewed, and it was recommended that by Year 10,

PWCF should be independent with the skills to maintain their own lung condition themselves.

We had five people represent the Hawke's Bay branch at the national celebrations at Government House for 50 years of CFNZ and this was a time of both reflection and prowess for our organisation.

Thank you to all who are involved in our branch for your contributions.

John Parsons

Wellington

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

We continue to support our PWCF by providing Breath4CF grants, hospital inpatient voucher packs, half price hospital parking, essential equipment and welfare assistance such as heating and counselling. We also supported seven DHB staff members to attend the CF medical forum in Christchurch.

Over the year we've held social catch ups for parents of children with CF along with our annual Christmas dinner. Our regular E-News and branch Facebook page have been highly effective as a way of communicating with our branch members and supporters.

Our branch chairs met with CFNZ Advocate Lisa Woods and developed an advocacy plan, which includes work previously done by the branch around adult services and maintaining standards of care in both inpatient and outpatient settings. We've also pledged \$15,000 towards the Deloitte paper on the social and economic cost of having CF.

A big thanks to the Wellington Branch committee who work so hard throughout the year to assist PWCF and their families in the region.

Nicci Hughson & Paula Richards

Canterbury

This year we've purchased equipment for the hospital including PARI nebulisers and a MetaNeb for our physio department. Having a MetaNeb ensures some equity for our South Island CF people. We also purchased two portable oxygen concentrators to make life a bit easier for people who needed them.

We've provided welfare through our fieldworker, nurses and B4CF and exercise grants to help our people to remain well, keep moving and make sure they have no barriers with the cost of exercise.

We worked with the CFNZ Advocate Lisa Woods and discussed the unfunded pre-made supplement drinks. Lisa is writing a letter to PHARMAC on our behalf.

The branch supported our clinical nurse to attend the CF European Conference, two DHB staff members to attend the CF Australasian Conference in Perth and our part-time community physio to attend a breathing conference in Australia. WE feel this is very important to keep our hospital team upskilled and updated as the frontline carers of our PWCF.

We fundraised to support our people in hospital with meal vouchers, parking assistance, petrol vouchers, grocery vouchers, winter heating, payment for unfunded equipment and many other welfare costs. In the last financial year, we made 21 welfare payments to our community in need.

Our community physiotherapist is a valuable asset and adds an extra part of care in the home to our community, working in with the hospital teams.

Melissa Skene

Otago

We continue to support of our members by providing nebuliser parts, New World and McDonalds vouchers, heating and welfare support, fuel subsidies and Breath4CF. We've also set aside a contribution to the CF care report which we feel is very important.

Through direct advocacy with the Southern DHB we were successful in restoring access to a pharmacist and dietitian at CF clinics. We also received a grant from the public science participation fund to start investigating how best to dispose of antibiotic nebuliser residue given the potential risk of antibiotic resistance. This research will begin next year.

Julian Cox

Financial summary 2019

	2019	2018
REVENUE		
Fundraising Revenue	902,512	880,486
Donations and Bequests	173,607	135,769
Grants and Sponsorships	472,164	374,677
Contract Revenue	75,000	75,000
Interest and Dividends	101,282	119,136
Fees, subscriptions & other revenue from members	13,347	2,490
Revenue from providing goods or services	(2,146)	2,356
TOTAL REVENUE	1,776,652	1,589,914
EXPENSES		
Expenses Related to Public Fundraising	490,356	453,663
Volunteer and Employee Related Costs	513,209	510,746
Costs Related to Providing Goods and Services	297,866	218,646
Grants and Donations Made	462,513	396,657
Other Expenses	77,044	50,563
TOTAL EXPENSES	1,840,988	1,630,274
NET SURPLUS/(DEFICIT)	(64,336)	(40,360)
SUMMARISED STATEMENT OF FINANCIAL POSITION		
ASSETS		
Cash Held	1,008,444	1,093,687
Fixed Assets	12,537	8,805
Investment Portfolio	820,893	832,945
Other Assets	157,635	164,330
TOTAL ASSETS	1,999,509	2,099,767
LIABILITIES		
Grants	49,030	63,353
Other Liabilities	173,999	195,282
TOTAL LIABILITIES	223,029	258,634
TOTAL EQUITY INCLUDING CAPITAL FUNDS	1,777,080	1,841,132

Full audited accounts are available on www.charities.govt.nz



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 CFNZ staff to achieve our charity's vision.

As at 30 June 2019

Board

Jane Drumm Chairperson	Melissa Skene Board member	Denis Currie President
Warwick Murray Board member	Mark Passey CF adult representative	Patron Professor Bob Elliott
Ed Campion Board member	Michele Wilson Board member	

Staff

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

Jane Bollard Chief Executive	Jude Kelly Central Fieldworker	Sarah Connolly Auckland Branch Coordinator
Irene Vanderlaan Office Manager/Accounts	Laura Huet Marketing and Fundraising Manager	Jan Tate Port CF project coordinator
Susan Lovelock Southern Fieldworker	Lizzie McKay Communications Coordinator	
Gretchen Kitching Northern Fieldworker	Jeanette Franklyn Grants Coordinator	

Sub-committee of the Board

The Clinical Advisory Panel

The CFNZ Clinical Advisory Panel (CAP) was formed in May 2018 to provide CFNZ with timely, honest and impartial advice on clinical aspects of the activities of CFNZ.

Members of the CAP represent the multi-disciplinary clinical team model of care and are representative of clinical services for cystic fibrosis in New Zealand.

Members of the CAP

Associate Professor Cass Byrnes Paediatric Respiratory Specialist, Starship Children's Hospital	Tory Crowder Dietitian, Canterbury	Jan Tate Paediatric CF Clinical Nurse Specialist, Starship Children's Hospital
Dr Mark O'Carroll Adult Respiratory Specialist, Auckland City Hospital	Patricia Goulter Adult Physiotherapist, Canterbury	Jane Drumm CFNZ Chairperson
Cath Lamont Adult CF Nurse Specialist, Auckland City Hospital	Rebecca Scoones Paediatric Physiotherapist, Starship Children's Hospital	Jane Bollard CFNZ Chief Executive

Branch office holders

Northland Mike Webb (Chair) Janet Webb (Treasurer)	Taranaki Nicola McCarthy (Chair) Joan Tuffrey (Treasurer) Shelley Grunchy (Secretary)	Nelson Rebecca Colley (Chair & Treasurer) Rachel Tobin (Secretary)
Auckland Jill Thorrat (Chair) Allyson Harvey (Treasurer)	Hawke's Bay John Parsons (Chair) Claire Fisher (Secretary)	Canterbury Melissa Skene (Chair) Nicky Churton (Secretary) Viv Isles (Treasurer)
Waikato Debbie Wood (Co-chair) Marieke Latimer (Co-chair) Alice Bell (Treasurer) Annelies Baker (Secretary)	Central Districts Coralie Harvey (Chair & Treasurer) Nigel Ramsden (Secretary)	Otago Julian Cox (Chair) Jeremy Byfield (Secretary & Treasurer)
Bay of Plenty Yvonne Rooney (Chair) Nicola Wakerley (Treasurer & Secretary)	Wellington Nicci Hughson (Co-Chair) Paula Richards (Co-Chair) Beth Hughson (Treasurer)	Southland Jim Phair (Chair) Lynne Rangī (Secretary & Treasurer)

