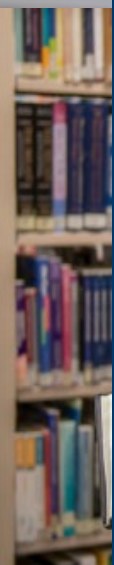
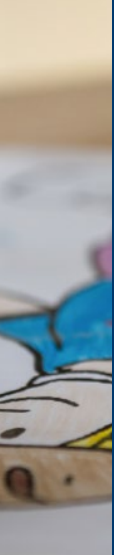


# Annual Report

2018



CYSTIC FIBROSIS NZ



# Farewells

Hollie Hale	21 September 2017	17 years
Bridget Hendry	29 October 2017	38 years
Kimberley Bryant	5 January 2018	26 years

## ***Life Well Lived***

*A life well lived is a precious gift  
Of hope and strength and grace,  
From someone who has made our world  
A brighter, better place  
It's filled with moments, sweet and sad  
With smiles and sometimes tears,  
With friendships formed and good times shared  
And laughter through the years.*

*A life well lived is a legacy  
Of joy and pride and pleasure,  
A living, lasting memory  
Our grateful hearts will treasure*

*- Author Unknown*



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# Board Report



This year has again been one of some change for CFNZ. Whilst many people may find the words strategic plan or strategic direction a little dull, this is where the CFNZ Board has put much of our energy in the last year. The process of gathering data,

questionnaires, workshoping and defining and refining where we see CFNZ going over the next three to five years. The sharing of this vision has happened throughout NZ and CFNZ management and staff are very aware of where focus, energies and resources will need to be targeted to ensure we meet our agreed goals.

Three of our key strategic goals: advocacy, a strong CF community and a strong CFNZ resonate deeply with the CFNZ Board, who whilst being relatively new to our Board, have shown a deep commitment for CFNZ and have considerable experience and skill that they bring to the role. Although we are a “young” board we have had some big projects, topics and issues that have needed tackling over the past year.

In the forefront of our CF community's collective minds is advocacy and the absolute requirement to get PHARMAC funding for new precision medicines. This will for the first time really address the fundamental issue of cystic fibrosis for some of our CF community. Now that CFNZ has a well-functioning Clinical Advisory Panel (CAP) and data from PORT CF (2015 and 2016) is ready for publishing we are in a stronger position than ever before to

campaign for Kalydeco and subsequently any other therapies that prove their efficacy.

The fact Australia is to now have access to Orkambi bodes well for NZ in that Vertex will now be entrenched in the South Pacific and will likely have time to invest in getting Kalydeco into NZ. Along with the Kalydeco for Kiwis cause CFNZ management is working on our campaign approach to ensure no stone goes unturned in getting the community, politicians and health professionals behind us in making our approach to PHARMAC successful.

Equity is one of the words I hear a lot within the healthcare arena. Or lack of equity. In NZ there is still too much variance of treatment, care and outcomes for PWCF. We have a country of haves and unfortunately... have nots. Addressing these issues through person to person advocacy is a crucial part of the work we do particularly the CFNZ fieldworkers. Our three fieldworkers do a sterling job and their client case load is high. CFNZ get limited support for this service through the Ministry of Health and there is a constant threat to this funding. With the complexities of our (thankfully) aging CF population the pull on resources and our assistance programmes grows each year. It's a delicate and difficult balancing act and the CE and staff do a mighty job managing the growing needs of our CF community.

I would like to sincerely thank and acknowledge our Chief Executive Jane Bollard for the guidance, skill and dedication she brings to her role. Under Jane's leadership CFNZ has grown in operational strength and sustainability even though it has been a period of much change within the not-for-profit sector.

I must also acknowledge our small army of



volunteers without whom CFNZ would not be able to operate. Special mention must be made of our Branch Chairpeople and their committees who are our grassroots backbone. Thank you for being willing to devote so much time, energy and love to CFNZ and for ensuring locally PWCF and families are well supported.

In this our 50th year of CFNZ we have much to commemorate and pay tribute to, both to those who have lost their battle with CF over those 50 years and to those who were fundamental in establishing CFNZ in 1968. This small but mighty group of parents who had a vision and the drive to want a better life for their children

with CF. We as a board salute you and thank you. We carry the torch that you so bravely lit all those years ago and hopefully those founders would be proud of where we are today and the difference we make in the lives of people with CF and their families.

**Jane Drumm**  
Board Chair

# Chief Executive Report



The focus for the year has been to understand the current needs of people with CF and how CFNZ can work to meet them.

After an extensive process of workshops, interviews and the CF Insight

Survey we have translated this knowledge into a new strategic plan which will guide us for the next three years to ensure we work on what is important to our community. A highlight of this process was attending branch meetings and talking with new, current and returning branch members.

It is clear from all feedback that advocacy is the most important service we can provide and as such we are aligning our resources to support this. The Clinical Advisory Panel is now actively providing much needed clinical leadership, advice and support. We have engaged Lisa Woods, based in Wellington, to develop an advocacy plan and to build on the work Vicky Tyler started as part of her comms role. Lisa is working with Kalydeco for Kiwis on the first of many campaigns to gain access to innovative medicines available in the OECD.

Our fieldworkers, Sue, Jude and Gretchen, continue to provide one-on-one advocacy support for people with CF across New Zealand as well as advocating for access to quality services at a local level.

This year our relationship with Cure Kids has moved to the next stage with the collective decision to work with researchers to identify,

with the view to funding, strategic research initiatives that would have the most impact. We look forward to meeting with CF researchers in November to begin this discussion.

In line with our research focus we funded Associate Professor Cass Byrnes to carry out work on the PORT CF database and we continue to fund the services of Jan Tate to work with DHBs to input data for development of meaningful and useful information.

The launch of the updated website with current useful information has resulted in increased usage both in terms of the number of people visiting the site and the length of time they stay. We are indebted to the support of the Awhero Nui Trust in this project. Also, our new information for parents, caregivers and whanau of newly diagnosed has been welcomed by those who are starting their journey with us.

As always, our sustainability is imperative and we have been fortunate to have the services of My Green Bookkeeper who has worked hard to meet the financial reporting standards and Charities Services requirements. Their engagement has provided an additional level of knowledge, internal control and risk management.

We have had a successful year of fundraising both at branch level and at the national level with the development of a fundraising plan being a lynchpin in our ongoing sustainability.

We acknowledge the effort and skill of the branch members, too many to name, together with Laura Huet, Jeanette Franklyn and Nicola Pearce as we all work to develop positive relationships with funders and supporters. We are grateful to all those who support us and the



difference they make.

We are also well supported by our fellow CF associations worldwide, by New Zealand Organisation for Rare Disorders and many other medical charities.

This year I joined the steering group of Patient Voice Aotearoa – a group of medical charities looking to have a collective voice on issues that impact on us all. It is with this collective support that much can be achieved.

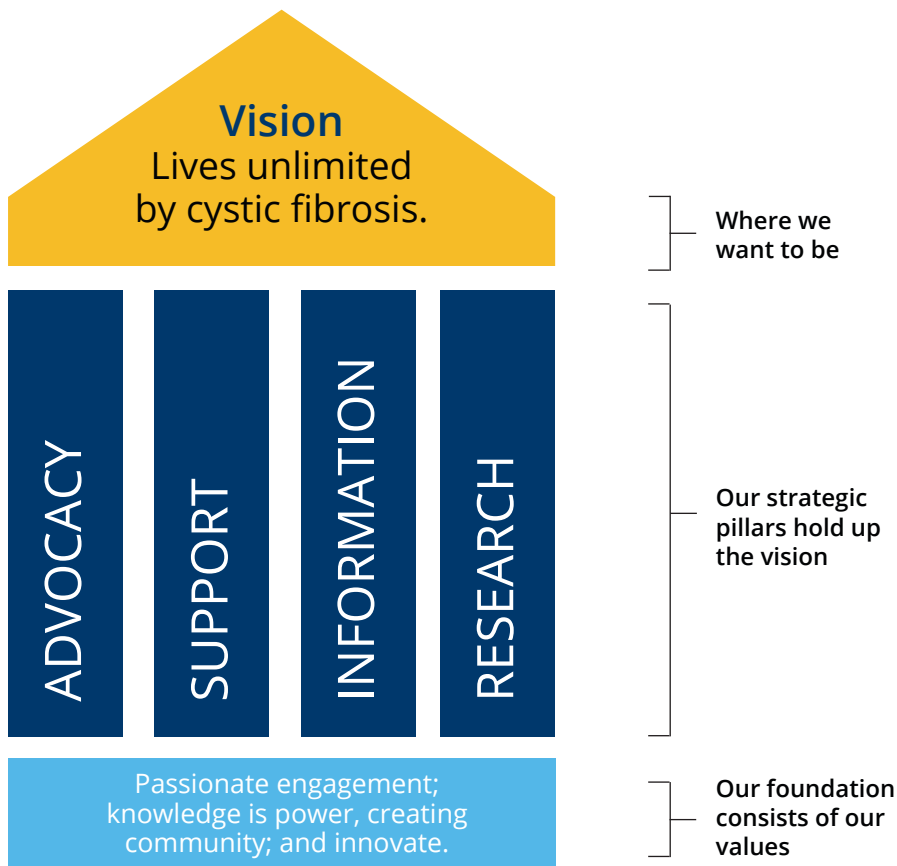
I look forward to the coming year as CFNZ's branches, national team and Board continue our collective focus on those important goals that will truly impact on the lives of people with CF.

**Jane Bollard**  
Chief Executive

# Why we exist

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.





# How we made a difference

**2,285**

contacts fieldworkers had with people with cystic fibrosis

**10**

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

**607**

the number of clinic visits with fieldworkers

**\$77,250**

given to people with CF as part of the Breath4CF physical activity grant

**231**

inpatient visits by the fieldworkers

**13**

people supported by a transplant grant

**56**

careplans fieldworkers developed to support people with cystic fibrosis

**\$148,575**

spent on grants for our community, covering all aspects of life

**334**

people provided with a Breath4CF physical activity grant

## Empathetic interviews

As part of our commitment to provide up-to-date, New Zealand specific information to our CF community, we first needed to understand the experiences of parents of young children with CF.

Between June and December 2017, co-design company Connect+Co carried out in-depth interviews with 13 families in Wellington, Christchurch and Auckland, asking them to share their experience parenting a child with cystic fibrosis. Parents shared their stories about challenges and successes and the strategies they had developed to provide their child with the love and support they need to grow and develop. The interviews included parents in both urban and rural locations.

In December 2017 the CFNZ team met to review the findings and to begin to generate ideas and solutions to address the needs and challenges that parents face.

# Advocacy

This year we continued to advocate on behalf of the CF community on issues that matter – access to medicines and vital equipment, better welfare assistance and equal care for all.

How did we do this?

## Access to equipment

### July 2017

CFNZ attended a meeting with PHARMAC to express concern over inconsistency in the funding of vital CF equipment by DHBs.

### November 2017

PHARMAC responded to CFNZ's presentation on equipment recommending CFNZ's exit from equipment.

### June 2018

CFNZ advised DHBs of our intent to move out of the supply of vital CF equipment, with the view for all DHBs to provide these.

## Access to medicines

### 12 February 2018

CFNZ wrote to the Prime Minister, Minister of Health and all MPs regarding medications and PHARMAC funding.

### 18 April 2018

CFNZ wrote to the Minister of Health seeking innovative solutions to the funding of precision medicines in NZ.

### May 2018

CFNZ approached two clinicians regarding expression of interest for Rare Disorders Subcommittee.

### May and June 2018

CFNZ board members, staff and community attended PHARMAC's consumer voice workshops.





### **1 June 2018**

CFNZ engaged advocate Lisa Woods to develop an advocacy plan for CFNZ, focusing on access to better medication and care.

## **Other advocacy work**

### **September 2017**

CFNZ submitted recommendations on the development of the new Wellington Children's Hospital. CFNZ Wellington branch became active in community consultation around the new build.

### **May 2018**

CFNZ CE joined the steering group for Patient Voice Aotearoa, a group set up to express the wider voice of patients, families and whanau in decision making.

### **May 2018**

CFNZ undertook the CF Insight Survey whose findings indicate 92% of people with CF and their families see advocacy for new medicines and high-quality care as the most important function of CFNZ.

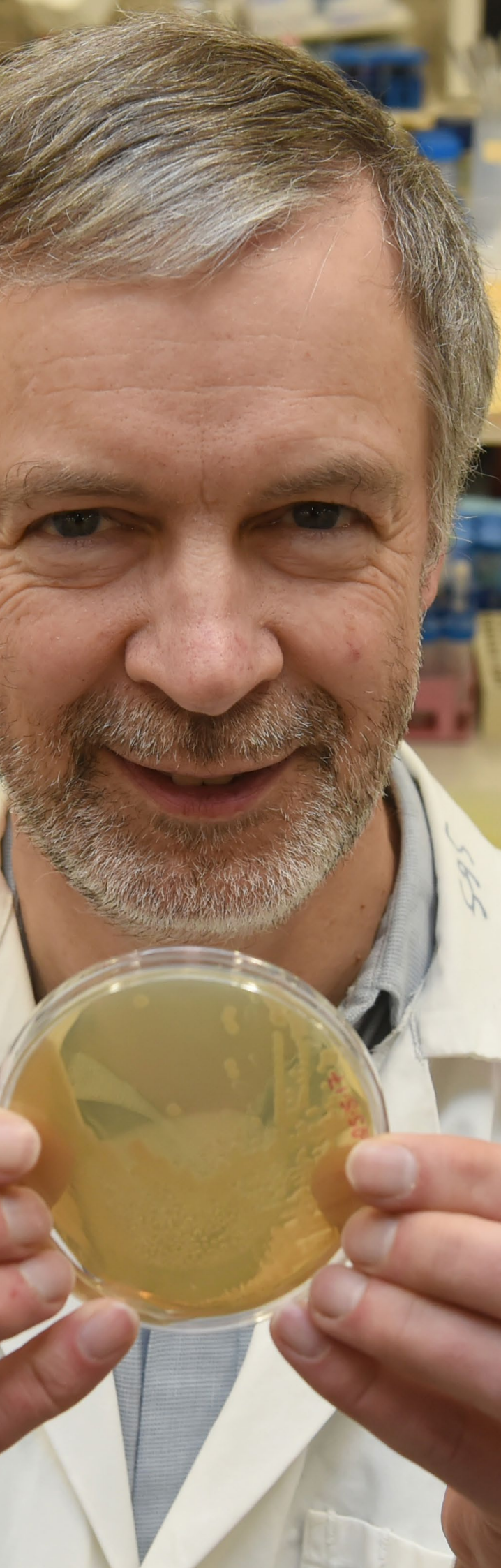
## **Tobi PODHALER campaign**

### **20 February 2018**

PHARMAC acknowledged CFNZ's application for Tobi Podhaler and requests a meeting with the respiratory therapeutic group staff.

### **6 April 2018**

CFNZ discussed its Tobi Podhaler application with PHARMAC staff.



# Research

Our mission is to work towards a better quality of life for all people with cystic fibrosis, through research into better treatment and management of CF.

## CFNZ and Cure Kids

This year CFNZ and Cure Kids continued to work together to identify, with the view to fund, areas of research that would benefit our CF community the most. We developed strategies to ensure we can continue to support and engage with researchers.

## PORT CF

PORT CF is a New Zealand data registry owned by CFNZ that uses anonymous patient data to analyse trends in CF care.

These reports can be compared to CF registries in the UK and Australia to help determine how NZ compares to other countries. They also provide information to help CFNZ lobby for new treatments.

This year we continued to work on maintaining the registry to ensure its robustness and sustainability. Keeping our PORT CF data registry updated continues to be a high priority so our PWCF in New Zealand can access innovative medications and treatments.

We funded Associate Professor Cass Byrnes and nurse specialist Jan Tate to work on the registry database.

*Left: Professor Iain Lamont and his Pseudomonas research*

# Information

## New resources developed

As part of our ongoing work to develop New Zealand specific resources for our CF community, we began work on a range of new guides and brochures.

The development of these guides included a comprehensive review of all our current information available, interviews with PWCF and their families and ongoing collaboration with our community to ensure the publications meet the needs of our community.

Thanks to many generous grants and collaboration with PWCF, the guides and brochures about to be published and available for download are:

### Guides

- A guide for parents and caregivers of children diagnosed with cystic fibrosis
- A guide to cystic fibrosis for family, whanau and friends

### Brochures

- Understanding cystic fibrosis
- Support available for people with cystic fibrosis and their families
- Where to from here?

## New website and branding

Our new website and refreshed branding was developed over the past year by CFNZ staff and design agency Transformer, and was one of the first significant enhancements to be delivered through our new strategic marketing plan.

Much of this work was made possible by a generous donation from the Awhero Nui Trust. The site was developed following extensive user research, with many key aspects of the user experience being improved. This includes streamlined navigation, intuitive functions and a cleaner layout, as well as updated information and resources.

Alongside the new website, we recently rolled out a refreshed CFNZ logo and branding to help build a strong visual identity.

The new website was scheduled to go live in July 2018.

*Below: Tailen, who features in the new guides*



# 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 scholarship is generously funded by Tasman Insulation, manufacturers of Pink Batts, 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 Health Homes book.

This year's Mark Ashford Scholarship was awarded to Damien Bell from Te Awamutu.

Damien is half-way through his three year degree, studying towards a Bachelor of Applied Information Technology at WINTEC in Hamilton.

"It was a real honour to be chosen for this scholarship and to be recognised for the hard work and commitment I've been putting in over the last year and a half with my studies.

"I plan to use the money towards covering some of my fees. This will

help ease the burden of my student loan allowing me to pursue some of my other life ambitions.

"A huge thanks to Tasman Insulation and CFNZ for providing this opportunity," Damien says.



Sponsored by



Sponsored by



**Mylan**

Better Health  
for a Better World

# CF Achievers' Awards

Four people received CF Achievers' Awards to mark their achievements in sport, leadership and education.

The awards are generously sponsored by Mylan, distributors of Creon products, and help us to celebrate the remarkable achievements of those with CF, often in the face of adversity.

## **Vaughan Somerville**

*CF Achiever, Sport*

Auckland Vaughan Somerville (25) represented New Zealand in the World University Futsal Championships last year – just one of the reasons why he has received a CF Achievers' Award for Sport.

The 25-year-old was also named Tertiary Sportsman of the Year at the University of Auckland sports awards last year, after Auckland University won the NZ Tertiary

Futsal Championships and where Vaughan won the Golden Glove award for best goalkeeper in the tournament.

Vaughan plans to use the CF Achiever's Award for flights and accommodation for the World University Futsal Champs held in Kazakhstan in August.

## **George Blyth**

*CF Achiever, Leadership*

Canterbury teenager George Blyth (18) was awarded a CF Achievers' Award in recognition for leadership. George is described as an excellent role model who has provided leadership and support to younger students at Rangiora High School from his position as House Captain for the Lydiard school house and for being part of the leadership group for the school's 1st XV and 1st XI sports teams.

*Below: Vaughan Somerville*





George plans to spend his award grant on a new pair of tramping boots. He loves the great outdoors and all his sporting activities assist with airway clearance.

**Claire Scofield**  
*CF Achiever, Education*

Claire Scofield (29) has overcome many challenges to follow her dream in horticulture and win a CF Achiever's Award for Education.

Her training in horticulture has led to an impressive career in the scientific community, becoming an authority in fruit research in her job as a research associate at the New Zealand Institute for Plant and Food Research in Central Otago. Claire has been asked to present at a number of conferences around the world and is now embarking on a Master of Science.

**Caleb Skene**  
*CF Achiever, Education*

Talented Christchurch tertiary student Caleb Skene (21) has achieved excellence in his architecture studies with his impressive results and willingness to push architectural boundaries.

Receiving a CF Achievers' Award is a huge help with his future endeavours within the architecture industry. He plans to use the award to buy a high-tech computer which will help enhance his architectural designs.

*Left: Claire Scofield and partner Dan*



# How we raised funds





# 50 years of **CFNZ**

This year we began the celebration of CFNZ turning 50, and 2018 also marked the 50th anniversary of PARI BOY.

A unique fundraiser was kicked off at the start of the year. For every person who wore a PARI BOY/CFNZ t-shirt at a sports challenge, PARI donated 10 euros (approximately \$16 NZD) to us.

Throughout the first half of this year we've seen a huge number of people supporting us by wearing their t-shirts and posting them on the PARI BOY Facebook page.

# Partners & supporters

*We are incredibly grateful for the support of our partners who have joined us on our mission. Their generosity helps fund research, support the highest quality of care and provide emotional and practical support to people with CF and their families.*

## 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, 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.

## 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.

## Trusts and Foundations

Air Rescue Services Limited, Akarana Community Trust, BGP Products Limited, Blue Sky Community Trust, Blue Waters Community Trust, CERT, Community Organisation Grants Scheme (COGS), Community Trust of Mid & South Canterbury, Community Trust of Southland, Constellation Communities Trust Ltd, David Ellison Charitable Trust, Dragon Community Trust, Foundation North, Four Winds Foundation Ltd, Grumitt Sisters Charitable Trust administered by Perpetual Guardian, Hugo Charitable Trust, JH Thompson Charitable Trust – Auckland, John Ilott Charitable Trust, The Lion Foundation – Canterbury, The Lion Foundation – Waikato, Lottery Grants Board, Mainland Foundation – National, Mainland Foundation – Canterbury, Margaret & Huia Clarke Charitable Trust administered by Perpetual Guardian, Milestone Foundation, Ministry for Vulnerable Children, NZCT, One Foundation, Page Trust, Robert & Barbara Stewart Charitable Trust, The North & South Trust Ltd, The Southern Trust, Thomas George Macarthy Trust, Trust House Foundation, The Trusts Community Foundation, W. Duncan Bickley Trust administered by Perpetual Guardian, Waikato Community Funding – Waikato, WEL Energy Trust – Waikato.

## 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.



# Structure, governance & management

*As at 30 June 2018*

## Board

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.

**Jane Drumm**  
Chairperson

**Mark Passey**  
CF Adult Representative

**Denis Currie**  
President

**Warwick Murray**  
Board Member

**Catherine Rusby**  
Board Member

**Professor Bob Elliott**  
Patron

**Ed Campion**  
Board Member

**Michele Wilson**  
Board Member

## Staff

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.

**Jane Bollard**  
Chief Executive

**Jude Kelly**  
Central Fieldworker

**Jeanette Franklyn**  
Grants Coordinator

**Irene Vanderlaan**  
Office Manager

**Laura Huet**  
Marketing & Fundraising  
Coordinator

**Kath Sanderson**  
Auckland Branch Coordinator

**Susan Lovelock**  
Southern Fieldworker

**Vicky Tyler**  
Information Coordinator

**Jan Tate**  
PORT CF Project Coordinator

**Gretchen Kitching**  
Northern Fieldworker



## 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.

#### Associate Professor

##### Cass Byrnes

Paediatric Respiratory Specialist,  
Starship Children's Hospital

##### Dr Mark O'Carroll

Adult Respiratory Specialist,  
Auckland City Hospital

##### Cath Lamont

Adult CF Nurse Specialist,  
Auckland City Hospital

##### Tory Crowder

Dietitian, Canterbury

##### Patricia Goulter

Adult Physiotherapist,  
Canterbury)

##### Rebecca Scoones

Paediatric Physiotherapist,  
Starship Children's Hospital

##### Jan Tate

Paediatric CF Clinical Nurse  
Specialist, Starship Children's  
Hospital

##### Jane Drumm

CFNZ Chairperson

##### Jane Bollard

CFNZ Chief Executive

### Branch office holders

#### Northland

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

#### Auckland

Jill Thorrat (Chair)  
Allyson Harvey (Treasurer)

#### Waikato

Debbie Wood Co-chair  
Marieke Latimer (Co-chair)  
Alice Bell (Treasurer)  
Annelies Baker (Secretary)

#### Bay of Plenty

Yvonne Rooney (Chair)  
Nicola Wakerley (Treasurer &  
secretary)

#### Taranaki

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

#### Hawke's Bay

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

#### Central Districts

Coralie Harvey (Chair &  
Treasurer)  
Nigel Ramsden (Secretary)

#### Wellington

Nicci Hughson (Co-Chair)  
Paula Richards (Co-Chair)  
Helen Williamson (Secretary)  
Beth Hughson (Treasurer)

#### Nelson

Rebecca Colley (Chair)  
Rachel Tobin (Secretary)

#### Canterbury

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

#### Otago

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

#### Southland

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

# Branch reports

## NORTHLAND

This year we have two children and four adults with CF. Our member numbers are at the lowest they have been in the 12 years I have been involved.

Our local CF doctor has just resigned so there will be some changes at our quarterly clinics moving forward.

Unfortunately, this year our major fundraising golf tournament has not taken place due to a number of factors, hopefully we will get this back on track in 2019.

As a branch we are still in a more than stable financial position, however early in the new year I feel we will need to decide whether we keep going it alone or maybe look to fall under the Auckland umbrella.

**Mike Webb**  
Northland Chairperson

## AUCKLAND

This year has been a busy one for us with some real progress and achievements for our branch.

As we have established over the years that our fundraising needs to be best return for minimal effort, we continue with the events and opportunities that work well for us.

We were fortunate to receive a generous donation of two MetaNeb machines for Adult Services at Auckland City Hospital. These machines are designed to maximise treatment by combining three therapies in one and they were well received by the Adult CF team.

Our branch has made a financial contribution to the CFNZ advocacy plan and we have continued with successful fundraising to enable us to continue with our support and services for our CF community.

We have purchased a portable oxygen concentrator for our community and we have donated the two Metanebs for our adult PWCF. It's heartwarming to hear from a young man recently, heading into theatre to get a lung transplant, thank us on a video for making

available a portable oxygen system which made such a difference to his quality of life leading up to transplant.

**Jill Thorrat**  
Auckland Chairperson

## WAIKATO

I am pleased to report another positive, successful year for our branch. We were successful with three grants this year from Lions Foundation for nebulisers; WEL Trust for signage; Hamilton City Council for sterilisers.

One thing to be very proud of is we have paid funds to national to cover our Breath4CF costs which I believe is an awesome achievement.

We also had a contribution from our Deposit Box in Matamata. And several CF families donated goods or funds or services for us.

We have provided welfare through our nurses Jo and Dee and Gretchen the northern fieldworker and we have also supplied new fridges to be used on the wards.

**Deb Wood**  
Waikato Chairperson

## BAY OF PLENTY

The Bay of Plenty branch has welcomed many new families and adults to the region this year, including newborns and new diagnoses to adults moving here from overseas or from within NZ. We now have one of the largest paediatric populations of PWCF in NZ. A smaller number of adults and families have also moved on to new adventures in other regions and overseas.

The branch supported three Tauranga Hospital-based BOPDHB staff members to attend the biannual Australasian CF Conference in Melbourne in August 2017. The branch supports their attendance as they are in the front-line of improving and maintaining the care of our PWCF. They brought back new ideas

and confirmation of the good work already underway in New Zealand and the regions, as well as renewed vigour and energy to do their best for our PWCF. Over the year we have seen the benefits through the clinics and approaches within our community.

After many years planning, seeking grants and two years implementation, the community physiotherapist trial has successfully come to an end with the Bay of Plenty DHB committing to continue and to fully fund the programme. This trial has been well documented and measured during the process with an aim of using the results to support the expansion of this initiative in other regions and countries.

Branch funds have again assisted with a variety of needs in our community:

- Purchasing equipment (Pari Boy Mobile nebulisers and sterilisers).
- Covering welfare costs – both assessed and discretionary (heating/power, grocery vouchers for hospital stays, additional nutritional costs).
- Allied health professionals' education costs (ie Australasian conference).
- Community physiotherapist programme trial.

**Yvonne Rooney**  
Bay of Plenty Chairperson

## TARANAKI

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.

Welfare costs are increasing overall and we are happy to pay them as it means our people are supported financially in their journey with CF.

We received an invitation to the TSB Community Trust 30 Year Community Celebration which members of our branch attended and enjoyed. And the young children in our branch were invited to the Special Kids Extravaganza sponsored by Sky TV and NZME held in New Plymouth.

The branch continued to support the funding for the services of the central fieldworker. Jude Kelly has worked alongside our people and attended clinics in Taranaki.

**Nicola McCarthy**  
Taranaki Chairperson

*Below: Waikato 'Wrap for Good' fundraiser*



## HAWKES BAY

Once again the Casino Fundraiser was a 60's themed success with everyone joining in the theme and activities.

We have had several meetings throughout the year and are pleased that we have adult representation. There were two social meetings at local venues for a more relaxed get together.

We part funded a study of empathetic interviews of adults with CF to access their needs and expectations. Petrol vouchers were also available for parents in the paediatric ward to assist in the many trips they do during an admission.

Hawkes Bay continued to fund a fieldwork to work in the central region of NZ. Our "Physio in Homes" also continues to service young people with CF.

At the May meeting we spent time discussing engagement with adults with CF and have resolved, through the fieldworker, to be more active in this area of need.

**John Parsons**  
Hawkes Bay Chairperson

## CENTRAL DISTRICTS

It was with great sadness that our branch farewelled Anna Scoullar-Jones this year and her passing has left a major hole in our group. We still regularly receive feedback and notices from those she was working with and this just proves how much work she did behind the scenes. Therefore, our branch is now in a position of restructuring the workload and ensuring that networking continues. We are still a small branch but have a few dedicated members who are working as much as they can to ensure efficient coverage.

Some of the highlights for us have been the local shops who have continued to support us. We value the support from head office which we receive and very much appreciate the input from Jude Kelly. We are looking forward to next year as we work to making a difference in those PWCF in our area.

**Coralie Harvey**  
Central Districts Chairperson

## WELLINGTON

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

We have provided PWCF in Wellington with Breath4CF top ups, hospital inpatient voucher packs, half price hospital parking, equipment and various other welfare assistance.

Our Christmas Tree Festival in 2017 was yet again highly successful. We had a fantastic turnout to the Gala event and the large banner at the Wellington Airport was unmissable. Planning is underway again for the 2018 festival with the ambitious target of "50 trees for 50 years" in acknowledgement of CFNZ turning 50. We are extremely grateful to the Wellington Airport for their continued support.

Our regular E-News and branch Facebook page has been highly effective as a way of communicating with not only our branch members but our supporters as well. Our Facebook following has increased to over 130 'likes'.

Our CF Paediatric Nurse Tricia Martin has greatly improved the services for children. Having Tricia as the first point of contact ensures parents can obtain test results, prescriptions and organise annual reviews easily and effectively.

We held and funded a workshop in November for parents of children with CF around building resilient children. This was presented by Skylight and was well received by the attendees. We also held social catch ups for parents of children with CF along with our annual Christmas Dinner.

The Wellington Branch continued to fund the central fieldworker and also contributed funds to national for the adults empathetic interviews.

Our plan over the next year is to focus on adult services, ensuring medical services are consistent with the rest of NZ. We will continue to develop relationships with the medical professionals and aim to increase engagement with the Wellington branch and wider community.

**Nicci Hughson and Paula Richards** Wellington Co-Chairs





*Above: Trees at the Wellington Christmas Tree Festival*

## NELSON/MARLBOROUGH

This year we have been fortunate in being selected for The Warehouse Bags for Good programme in the Richmond store and had an amazing partnership with Shampoo Plus top of the south. To foster this relationship, a basket of handmade yummys was delivered to the small team to enjoy for morning tea.

Although we have not had an organised CF Awareness Week programme for several years, we are hoping with new energy we can get this up and running again to help raise a greater profile of CF in the community. We will be focusing on developing a robust 2019 fundraising calendar and look at dedicated fundraising meetings to bring in the skill of other potential volunteers in the community.

**Rebecca Colley**  
Nelson Chairperson

## CANTERBURY

It is with much sadness we acknowledge the loss of Holly Hale last September. Holly was a vibrant young lady and our thoughts go out to Debbie, Steve and family.

Our family numbers stand at 103 with 39 children up to the age of 15, 45 people aged between 16 – 44 years and 19 people aged 45 and over which is absolutely amazing showing longevity.

The coffee and dessert evenings held at various

restaurants for our young parents' group are still going well and we meet every three months, this works well and is a lovely little supportive group.

We still employ our community physiotherapist. Hiliare O'Dea is a great asset to have and works in well with the hospital teams and our families. This position is still unfunded by the CDHB. I was hoping to announce this year that things had changed with this position but sadly not. Things are still moving slowly in this area and it is just really a waiting game.

Sue Lovelock our fieldworker visits our families and attends clinics finding any welfare issues as they arise and tends to these on our behalf. Sue's move to the Can Breathe Office in Shirley last year has helped our branch greatly with us being able to use the board room for our monthly meetings and with the great car parking Sue is more assessable for our community.

We are still providing our families with birthday vouchers, meal vouchers when in hospital, trampolines, up-to-date medical equipment such as nebulisers, oxygen concentrators and welfare when required. In this last financial year, we made 32 welfare payments to our community in need.

Our branch has always support allied health professionals to upskill gaining new knowledge at conferences, and this past year has been no different.

We provided financial assistance for attendance at The Cystic Fibrosis Nurses Conference, supporting two nurses, one from ward 21 and

one from adults. As a branch we see this as being very important for the care of our CF community.

Our main focus this coming year is to continue finding the funding for our community physiotherapist, to take care of our CF community as best as we can and to find some new members for our committee.

**Melissa Skene**  
Canterbury Chairperson

## OTAGO

It has been another quiet year for CF Otago with everything focussed around two events – CF Awareness Week and a dinner with Sue. We organised a dinner at the Speights Ale House to coincide with one of Sue’s visits, which was attended by approximately 10 members and associates. It was a good chance to catch up and learn what was happening with those present in general.

At the majority of our committee meetings it has just been Jeremy and myself present. This is partly due to the spread-out nature of our region which would require some members to drive for more than an hour each way to attend, however, it is something we need to address if we want to keep CF Otago going as a viable branch.

**Julian Cox**  
Otago Chairperson

# Financial summary

## Summarised statement of financial performance

REVENUE	2018	2017
Fundraising Revenue	880,486	795,506
Donations and Bequests	135,769	133,441
Grants and Sponsorships	374,677	227,632
Contract Revenue	75,000	75,000
Interest and Dividends	119,136	106,816
Fees, subscriptions & other revenue from members	2,490	-
Revenue from providing goods or services	2,356	-
<b>TOTAL REVENUE</b>	<b>1,589,914</b>	<b>1,339,434</b>
<b>EXPENSES</b>	<b>2018</b>	<b>2017</b>
Expenses Related to Public Fundraising	453,663	406,675
Volunteer and Employee Related Costs	510,746	464,438
Costs Related to Providing Goods and Services	218,646	213,205
Grants and Donations Made	396,657	369,521
Other Expenses	50,563	23,908
<b>TOTAL EXPENSES</b>	<b>1,630,274</b>	<b>1,477,747</b>
<b>NET SURPLUS/(DEFICIT)</b>	<b>(40,360)</b>	<b>(138,313)</b>

## Summarised statement of financial position

ASSETS	2018	2017
Cash Held	1,093,687	1,134,458
Fixed Assets	8,805	10,915
Investment Portfolio	832,945	853,735
Other Assets	164,330	131,139
<b>TOTAL ASSETS</b>	<b>2,099,767</b>	<b>2,130,248</b>
<b>LIABILITIES</b>		
Grants	63,353	52,212
Other Liabilities	195,282	196,545
<b>TOTAL LIABILITIES</b>	<b>258,634</b>	<b>248,757</b>
<b>TOTAL EQUITY INCLUDING CAPITAL FUNDS</b>	<b>1,841,132</b>	<b>1,881,491</b>

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



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