

For the financial year  
ending 30 June 2020

# Annual Report 2020





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**Our vision is to see lives unlimited by cystic fibrosis, through support, information, advocacy & research**

**There are over 540 people with cystic fibrosis in New Zealand. Our mission is to optimise their quality of life, helping them to live a life unlimited.**

**We do this through local, family, and individual support by our team of fieldworkers, by covering the cost of medical equipment, providing financial assistance to transplant recipients, information packs, welfare assistance and many other means of support.**

**We also fund vital CF research, and lobby on behalf of the community for better access to services and care.**

# Board Report

Warwick Murray, CFNZ Board Chair



**We may still be in for some difficult times ahead, but there is no place I'd rather be than here in New Zealand, and for the first time for me, I feel there is a genuine opportunity for our people with cystic fibrosis (CF) to live their lives close to being unlimited by their condition.**

As I reflect on the past year and how I feel about our future, particularly that of the five-hundred odd people in New Zealand with cystic fibrosis (CF), I have mixed emotions. There is some anxiety given the uncertainty brought on by COVID and by the geo-political turmoil going on around the world, but mostly I feel a real sense of optimism. We may still be in for some difficult times ahead, but there is no place I'd rather be than here in New Zealand, and for the first time for me, I feel there is a genuine opportunity for our people with CF to live their lives close to being unlimited by their condition. There is still much work to be done before this becomes a reality for everyone, but I feel it is tantalisingly close.

So, looking back over the past 12 months for CFNZ, PHARMAC funding of Kalydeco must be the most positive development, not just for those for whom it's a lifesaver, but because it has opened the way for Trikafta. This was a credit to the team of people, Eddie and Emma Porter in particular, who campaigned hard to get this approval and it also showed the power of a well-planned, collaborative advocacy strategy. Advocacy has been the board's top priority for the past year, and it will continue to be for the coming year. There has been some shift of focus onto Trikafta, but we remain committed to advocating for better access to all the new modulator drugs and, more generally, to world-leading clinical care for everyone.

Providing support to those with CF and their families has continued to be a key element of our strategy through the year, where we have aimed to build a strong CF community that is best able to provide the support needed by people with CF. Ensuring we maintain equity in the support we provide continues to be a challenge and we would always like to do more. During the year we increased our field worker team to four and this has helped lift the level of support we can offer across the country.

People with CF and their families' need for information about CF – where to get help and support, what's happening with research, what's going on in the community – is as great as it has ever been, but in recent years, the way people access this information has changed radically. More people are relying on the internet and social media to help connect to the CF community and to seek out information, and there is less reliance on face-to-face social interaction. CFNZ has had to adapt its information strategy to meet this changing demand. We have significantly increased the level of information sharing via our website and we are more active than ever in engaging with the CF community on social media. This is likely to increase in the future. However, branches have continued to provide a source of social glue for many local communities and face-to-face support for those in need, and we hope that this too can continue.

The board is also continuing to focus on research to ensure our people with CF get access to the best possible medical treatment. We have developed a draft research strategy in which we have sought to leverage off the efforts of others by building partnerships with the likes of Cure Kids. In this way, we expect we will make the best of our limited resources and generate more direct benefits to New Zealanders with CF. To reduce audit and other compliance costs associated with running a separate entity, we have now dissolved the Shares in Life Foundation and brought the funds it held in under the CFNZ umbrella. However, these funds remain tagged for research and efforts will be made to continue to grow these.

An important under-pinning of our successes has been our strong organisation. CFNZ as an organisation has grown in strength in recent years. We are seen as a credible voice within the medical sector and within Government; we have grown our income in the face of a highly competitive market; we have expanded the range of services we deliver while keeping costs under control; and we have developed a range of systems to improve efficiency and to enable us to remain legally compliant with the rules governing charities. As of the end of June 2020, our balance sheet is relatively healthy despite COVID-19. We are also fortunate in having a very capable Chief Executive in Jane Bollard with a strong team to support her, and I have been privileged to work alongside a group of wise and capable board members.

There are, however, some significant challenges ahead of us. Many branches have struggled to recruit new volunteers onto their committees and some of the dedicated few remaining are tiring. Legal obligations on charities continue to grow and compliance costs have increased. Considerable uncertainty remains over the impact of COVID on our income, and we still need to do more to diversify our income base.

The organisational structure review project has therefore been very timely. The review team, under Michele Wilson's guidance, has made very good progress in carefully considering how we might best equip the organisation to face these challenges. The review group's proposals still need further discussion with the membership, so it seems unlikely we will be able to come to the 2020 AGM with firm proposals to vote on.

As chair of the board, I am proud of our achievements over what has been a challenging year. However, none of this could have happened without a lot of hard work by an army of volunteers out there delivering a wide range of services and support, and without the backing of many generous donors who have contributed financially to our cause. Without them, we simply would not exist, so I would very much like to acknowledge and thank them for their generosity and for the faith they have vested in us to make a difference in the lives of those with CF.

# Chief Executive Report

Jane Bollard, CFNZ Chief Executive



**Together we've navigated the uncertain waters of the pandemic and to date are weathering the storm well.**

It's my pleasure to present the Chief Executive's report to the membership.

In March we shouted from the rooftops that PHARMAC had reached agreement with Vertex for Kalydeco to be publicly funded. Working with Eddie and Emma Porter and CFNZ Advocate, Lisa Woods, and with Vertex and PHARMAC has been a highlight of my year and the opportunity to benefit Otis and his G551D buddies compelling. We're pleased to report Kalydeco has been rolled out across NZ and thank Kalydeco for Kiwis, the CF community, Vertex and PHARMAC for the huge effort and support in this campaign.

We were also delighted PHARMAC funded Creon Micro, an application originally supported in 2015. Our Tobi Podhaler application remains under consideration by PHARMAC as to its cost effectiveness and budget impact.

Our desire to help address strategic issues in medicines funding saw us support Patient Voice Aotearoa and its associated 35 charities to promote the Double the PHARMAC Budget petition, Rare Disorders NZ with its Rare Disorders Framework and petition, and to feed into the review of the Medicines strategy by Medicines NZ. We commissioned Deloitte to undertake a report on the social and economic cost of cystic fibrosis (CF) report and thank Deloitte, Rare Disorders NZ, and the Awhero Nui Trust for their support in this endeavour. Anecdotally we've always known the high cost of CF to individuals, families/whanau, and communities and now we will know for sure of the cost of CF's impact.

Our campaign to have DHBs fund vital CF equipment occurred more quickly than imagined and this has decreased the financial and health and safety requirements significantly for CFNZ.

Advocacy occurs at all levels throughout the organisation and most importantly directly with individuals and our team of fieldworkers.

We welcomed our fourth fieldworker Chani to our team and shortly afterwards proceeded into lockdown with COVID-19. While we said this is 'most unusual' at the time we now think of it as 'more usual'. We're delighted to have this position funded by the Light House Foundation and to have Ministry of Health and CDHB contracts contribute to the fieldworker support we provide.

We continue to support people with CF where they're struggling to fund the most necessary requirements of their care. To their credit our fieldworkers Sue, Jude, Gretchen and Chani, moved effortlessly to non face-to-face contact and worked hard to manage pre lockdown concerns and requirements during this uncertain COVID environment.

Our Clinical Advisory Panel (CAP) met regularly and the 2017 Port CF data was made available during the year with more fulsome information than ever before. Associate Professor Cass Byrnes, Jan Tate and Emma Nielsen remain our Port champions. We're indebted to their work on Port CF and we look forward to the results of the global harmonisation project. CAP continues to provide invaluable clinical advice to CFNZ and the community – none more important than during the pandemic.

Sarah Cahill and Lizzie worked throughout the year, and specifically during COVID, to provide rolling updates on Facebook and the website in response to questions from the community.

With research very clearly one of CFNZ's key strategic pillars, the Shares in Life Trust (Foundation) was dissolved with funds transferred to CFNZ and ring fenced to be used for the original aims of the Trust. This will ensure that these funds are used for research and not eroded by compliance costs of running a separate charity. I would like to specifically acknowledge Denis Currie, CFNZ President, and Sir Bob Elliott, CFNZ Patron, for their work in setting up this fund, all those who contributed by purchasing a share in life and the trustees who governed the trust.

Our collaboration with Cure Kids continued with the co-funding of the CF Research Strategy which was drafted during the year. With CF community and clinical/research input we've developed a strategy that identifies key research components which will in time form the funding priorities for this collaboration. My appreciation goes to Cure Kids and to Dana Felbab, their research development manager, who worked part time with us to develop the strategy also working to encourage Pharma to seek NZ as a clinical trial site.

We also carried out a post-transplant care survey, and participated in external research on siblings and social isolation – all of which add to our understanding of our community and its needs.

I've been well supported by a highly skilled board. Together we've navigated the uncertain waters of the pandemic and to date are weathering the storm well.

The back-office functions of CFNZ have worked to ensure that we stay afloat and I want to acknowledge My Green Bookkeepers personnel Nicola, Colin and Emma, and our office manager Irene, all of whom are involved in the prudent management of our finances. A huge thank you to branch treasurers for their attention to the accounts and to everyone throughout the organisation in their role in fundraising. We're fortunate to have active branch members who give their all to raising funds and to have Laura, Lizzie and Jeanette focusing on developing new ways of bringing in funds. All credit to Laura for the amazing work she does and for her foresight to move to a digital platform for fundraising that has worked in our favour in recent times. I also note the successful Give an F awareness campaign and the new CFNZ signature fundraiser Sweat4CF, but more about that next year.

To all donors, supporters, active branch members, staff, clinicians, people with CF, family and whānau, I thank you and extend my warm wishes for the year ahead.

# Farewells

## Remember Me

To the living, I am gone.  
To the sorrowful, I will never return.  
To the angry, I was cheated.

But to the happy, I am at peace.  
And to the faithful, I have never left.  
I cannot be seen, but I can be heard.

So as you stand upon a shore,  
gazing at a beautiful sea – remember me.  
As you look in awe at a mighty forest  
and its grand majesty – remember me.

As you look upon a flower and admire  
its simplicity – remember me.  
Remember me in your heart, your thoughts,  
your memories of the times we loved.

The times we cried, the times we fought,  
the times we laughed.  
For if you always think of me,  
I will never be gone.

– Anonymous

### Hayden Hedley

17 June 2020  
34 years old

### Katherine Harris

28 December 2019  
37 years old

### Acacia Wanoa

18 January 2020  
27 years old

### Wanda Griffin

10 February 2020  
60 years old

### Juliet Hubbard

8 June 2020  
35 years old



# How we made a difference

Thanks to the generous support of our donors we've continued to support people with cystic fibrosis (CF) and their families through our fieldworker services, local branch networks, online communities, grants and financial assistance.

In January we welcomed our fourth fieldworker Chani to the team. Chani supports our Waikato and Bay of Plenty CF communities and is based in Hamilton. We secured funding in the last financial year so we're thrilled we can now offer increased fieldworker support.

Like many other charities, COVID-19 affected our fundraising, which we rely on to support our CF community. Thanks to an incredible response to our COVID-19 emergency appeal we raised almost \$16,000 within a few weeks. This meant we could continue to support people and their families in New Zealand.

**676**

outpatient clinic appointments attended by fieldworkers to support people with CF

**202**

families supported with welfare provided by a branch

**239**

people supported with a physical activity grant

**10**

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

**3592**

contacts fieldworkers had with people with CF

**243**

inpatient visits by fieldworkers to support people with CF and their families

**\$40,411**

provided to people with CF through welfare support

**\$9,420**

provided in hospital allowances

**171**

care plans developed by fieldworkers

**\$57,787**

used to keep people with CF active through Breath4CF grants

**\$12,264**

provided through grants to help with pre and post transplant costs

**\$4,500**

provided to support with funeral costs

*During the financial year, CFNZ successfully transferred the funding of equipment such as basic nebulisers over to DHBs, which previously accounted for a large portion of the welfare spend.*

**"I had two chest infections during lockdown and was unable to go to the supermarket. I was grateful to have a friend do my shopping for me. Jude was in touch with me regularly and assisted me with a few food grants, which was very helpful. I am grateful to have Jude as my support fieldworker, she does an amazing job and goes out of her way to care for us all. Thank you CFNZ for the support."**

## **Advocacy & Awareness**

**This year we continued to advocate for people with cystic fibrosis (CF). Our four regional fieldworkers worked tirelessly as personal advocates, helping people with CF and their families from new diagnosis throughout adult life.**

### **The impact of our advocacy and awareness work for people with cystic fibrosis**

After a long campaign, PHARMAC in February announced its decision to fund Kalydeco for people with CF with the G551D mutation. Our community was thrilled with the decision which is a critical step forward for access to precision medication for other people with CF. People eligible began to have access in late March/early April.

All district health boards took over the funding of the PARI BOY SX nebuliser and consumables. In 2018 we decided to exit the funding of essential equipment and we spent 18 months working with DHBs to transfer funding. This move helps to improve equality of care throughout NZ.

From 1 June 2020 PHARMAC began funding Creon Micro. As we first submitted an application for its funding in late 2015 followed by a letter of support in April 2020 during PHARMAC's open consultation period, we were delighted when funding was approved.

We continued to engage with Lisa Woods to advocate both nationally and regionally on issues that matter to our community.

In February 2018, we submitted an application to PHARMAC for TOBI Podhaler to be listed on the Pharmaceutical Schedule. The application was reviewed at the Pharmacology and Therapeutics Advisory (PTAC) meeting in February 2020. The recommendations from the February PTAC meeting was that TOBI Podhaler be listed as cost neutral to the TOBI inhalation

solution, accounting for any offsets to the health sector. The application now moves into the "under-assessment" stage.

We supported the work and vision of Patient Voice Aotearoa (PVA) and facilitated a meeting with PVA and other support organisations to develop both a strategic and an action plan for access to medications.

We kept our community and supporters up-to-date on our advocacy timeline on our website.

We continued to engage with Vertex and PHARMAC for access to precision medications such as Trikafta.

Our strong partnership Rare Disorders NZ continued.



## Access to medicines

**2019**

**5 September**

CFNZ receives an email from PHARMAC regarding its new online system called PHARMConnect. PHARMConnect includes an online application form so anyone can submit funding applications for medicines online and an updated application tracker to view information on medications PHARMAC is considering funding.

**21 October**

The US Food and Drug Administration (FDA) approves the use of the triple combination CFTR modulator Trikafta (elixacافتor/tezacافتor/tezacافتor) for people with cystic fibrosis (CF) aged 12 and over who have at least one F508del mutation in the CFTR gene. CFNZ Chief Executive Jane Bollard writes to Vertex to congratulate them on their success and to urge them to engage with PHARMAC as New Zealanders with CF continue to be disadvantaged in accessing precision medicines.



**29 October**

CFNZ receives the Medicines NZ report, Funding Medicines in New Zealand: Revision of the Medicines Waiting List to 30 June 2019. Key findings include new listings on the waiting list and the average time a medicine sits on that list.

**2020**

**16 March**

CFNZ facilitates Patient Voice Aotearoa (PVA) meeting along with its support organisations in order to develop a strategy and action plan. CFNZ continues to work with PVA post-meeting to refine the strategy and plan.

**30 March**

CFNZ supports the PVA open letter to Prime Minister Jacinda Ardern, calling for increased funding of medications for people with rare disorders, chronic illness and cancer.

**20 April**

CFNZ CE Jane Bollard attends a virtual meeting with the new country manager of Vertex, Lauren Carey, who's based in Australia. Top discussion point is the need for funding of Trikafta in New Zealand. Jane and Lauren will meet again once Lauren has met with PHARMAC and has established the next steps for precision medicines in New Zealand with Vertex.

**20 April**

CFNZ CE Jane Bollard meets with Patient Voice Aotearoa (PVA) representatives to discuss progress following the open letter to the Prime Minister on 30 March. PVA reports good success with getting stories in the media. Advocate Lisa Woods continues to work with PVA to develop a communications plan, including charities talking with local media about the impact of COVID-19.

**April**

CFNZ submits a letter of support to PHARMAC for the funding of Creon Micro during its consultation period which ends 30 April 2020. CFNZ first submitted an application for Creon Micro in late 2015.



## Kalydeco campaign

**2019**

**21 November**

The 'Publicly fund Kalydeco Medication for New Zealanders with G551D Cystic Fibrosis' petition is presented to Parliament by Eddie and Emma Porter on behalf of Kalydeco for Kiwis. The petition had 11,000 signatures and was 1 of 8 medicine-related petitions presented.



**2020**

**24 January**

CFNZ is notified that PHARMAC has reached a provisional agreement with Vertex to fund Kalydeco for New Zealanders with cystic fibrosis. If feedback from a consultation process with health professionals is supportive and the proposal is approved, patients could get access from as early as 1 March.

**14 February**

CFNZ CE Jane Bollard writes to the Health Select Committee supporting Eddie Porter's petition for funding of Kalydeco for New Zealanders with G551D cystic fibrosis.

**26 February**

PHARMAC announces its decision to fund Kalydeco for people with CF with the G551D mutation.

## Tobi Podhaler campaign

**2020**

**20 February**

Tobi Podhaler application assigned to the Pharmacology and Therapeutics Advisory Committee (PTAC) meeting. CFNZ to receive feedback once the minutes are released.

**28 April**

CFNZ receives the minutes of the Pharmacology and Therapeutics Advisory Committee (PTAC) meeting from 20 and 21 February where it reviewed the application for the TOBI Podhaler for the treatment of cystic fibrosis. PTAC has recommended that TOBI Podhaler (tobramycin dry powder for inhalation) for the treatment of Pseudomonas Aeruginosa infection in cystic fibrosis patients be listed on the Pharmaceutical Schedule with a cost-neutral priority. Further analysis may now be conducted by PHARMAC staff regarding the cost-effectiveness and budget impact of funding TOBI Podhaler.

## Access to equipment

**2019**

**11 July**

CFNZ is notified by PHARMAC that from 1 August 2019, the number of insulin syringes with needles that can be prescribed per prescription will increase from 100 to 200.

**2 October**

CFNZ receives a feedback summary from PHARMAC regarding the management of fairer access to hospital medical devices. CFNZ submitted feedback during the consultation period in early 2019.

**2020**

**February**

All district health boards have now taken over funding of the PARI BOY SX nebuliser and consumables.

## Other advocacy projects

**2019**

**3 September**

CFNZ receives an interim report from the Health and Disability Systems Review, which CFNZ submitted feedback for in May 2019. This is a progress report with specific recommendations expected by March 2020.

**6 November**

CFNZ launches a survey for the CF community to help identify the top 10 questions people would like researched in order to answer the biggest or most important challenges they face. The responses will be reviewed by the CFNZ Research Development Manager and used to create a second prioritisation survey.

**2020**

**28 February**

CFNZ CE Jane Bollard attends the Rare Disorders NZ launch of its Fair for Rare campaign at Parliament. The campaign calls for recognition and awareness of the challenges faced by people with a rare disease, and for the development of a national framework.



# Information

Providing up-to-date and relevant information for New Zealanders with cystic fibrosis (CF) is one of our strategic pillars

## How we supported our CF community

Our website and public Facebook page continues to be the go to place for information for our community.

We continued to contract medical writer Sarah Cahill to review and update our information and content and welcomed Lizzie McKay into the role of Communications Coordinator.

## Top 3 resources downloaded

1

2015 PORT CF REGISTRY REPORT

2

STARTING SCHOOL - A GUIDE FOR NZ PRIMARY SCHOOLS AND TEACHERS

3

A GUIDE TO CF FOR FAMILY WHANAU AND FRIENDS

## COVID-19 Website Information

2,857 VIEWS OF INITIAL COVID-19 UPDATE

1,065 VIEWS OF COVID-19 QUESTIONS AND ANSWERS

898 VIEWS CORONAVIRUS HELP AND ADVICE PAGE

6 DETAILED LATEST NEWS ARTICLES (VARIOUS VIEWS PER ARTICLE)

16 ROLLING UPDATES

## Website by the numbers

65

LATEST NEWS ARTICLES

33,171

USERS

32,997

NEW USERS

93,542

PAGE VIEWS

## Facebook

Our public Facebook page has 3,304 followers and continues to be an important tool to engage with our community.

Our closed Facebook group has 442 members.

## Our most visited pages

1 WHAT IS CYSTIC FIBROSIS?

6 LATEST NEWS

2 UPDATE ON COVID-19 FOR OUR CF COMMUNITY

7 HOW IS CF DIAGNOSED

3 FREQUENTLY ASKED QUESTIONS

8 CONTACT US

4 CORONAVIRUS HELP & ADVICE

9 RESOURCES

5 STORIES

10 GENETICS

11 CF CARE - TREATMENT AND MEDICATION

# Research

**We continue to fund and participate in New Zealand based research projects that make a difference to people with cystic fibrosis (CF) every day.**

## The impact of our research for people with cystic fibrosis

Work continued on the National Cystic Fibrosis Research Strategy led by our Research Development Manager (jointly appointed with Cure Kids). The strategy is a result of extensive collaboration with our CF community, clinicians and researchers and reflects the needs of both people with CF and health professionals and is due for publication later this year.

CFNZ commissioned Deloitte New Zealand to research and report on the social and economic cost of CF for individuals and families. The report looks at health sector and treatment costs as well as productivity losses and the cost of caring for people with CF, both formally and informally. It will also consider more qualitative data such as loss of wellbeing and the impact of premature mortality on families.

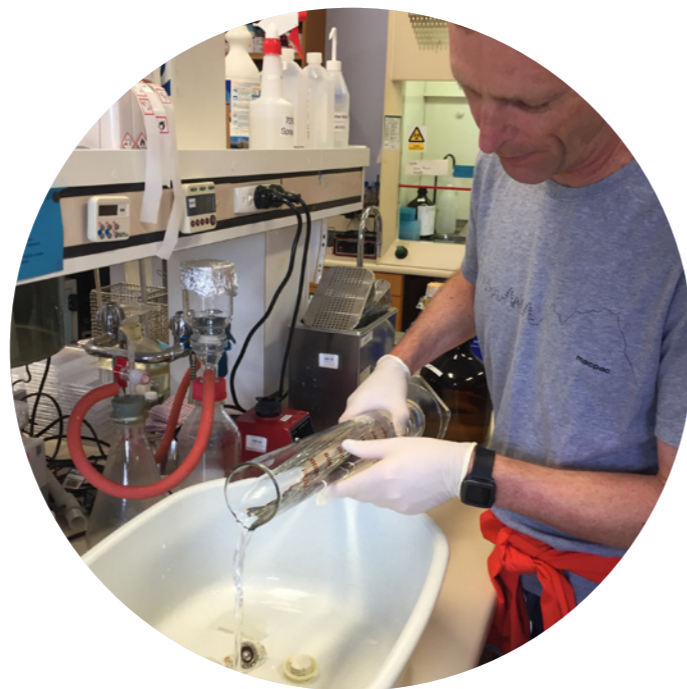
There is no data available on the cost of CF in New Zealand and study findings could have major implications for CF treatment and management.

Cystic Fibrosis NZ - Otago Branch is working with the University of Otago to co-develop a practical nebuliser cleaning strategy to help reduce the risks of antibiotic resistance due to the variable disposal practices identified in Phase 1. From there the team will develop resources and share the results nationally to help build awareness of the importance of antibiotic resistance.

CFNZ has supported and encouraged people with CF to participate in two research studies whose findings will impact our CF community:

- Massey University study that aims to identify the unmet needs of siblings with CF, cancer and type 1 diabetes.
- Auckland University study investigating the impact a complex medical condition has on social relationships.

We published our 2017 Port CF report.



# Mark Ashford Scholarship

**The Mark Ashford Scholarship is awarded each year to a person with cystic fibrosis (CF) who's shown excellence in tertiary study and/or shown tenacity to overcome the challenges of CF while studying.**

## Georgie Northcoat

This year's Mark Ashford Scholarship winner is Georgie Northcoat from Christchurch.

Last year the 21-year-old graduated with a Bachelor of Applied Science from Otago University with a double major in Textile Science and Marketing. This year she's continuing with full-time study and is working towards a Graduate Diploma in Information and Communication Technology (ICT), majoring in Information Systems.

This year Georgie founded Lynk Solution, a company committed to minimising the amount of plastic pollutants entering our wastewater. Georgie developed the Lynk Microfibre Filter, a filter that's fitted to an existing washing machine and filters out 90% of microfibres during each wash.

Georgie plans to use the scholarship money to continue to invest in Lynk Solution. It also relieves a bit of financial pressure so she can focus on her studies and develop her business further.

**The Mark Ashford Scholarship 2020 was made possible through a generous, anonymous donation.**



# CF Achievers' Awards

The Cystic Fibrosis Achievers' Awards celebrate the amazing achievements of people with cystic fibrosis (CF). They are awarded to people who have achieved excellence in either leadership, the arts, sports or education.

This year, nine people with CF to people with CF have been recognised for their optimism, perseverance and achievement. We were delighted with the number and standard of the applicants this year.

The independent awards committee decided all applicants merited an award. A huge thank you to Mylan, makers of Creon, for sponsoring this award and supporting Kiwis with CF.



**Renee Hill, age 36**  
Education

Rotorua born Renee moved to Wellington 3 years ago to study a degree in alcohol and addiction counseling. She's now in her final year of study and is planning on graduating in February 2021. Due to the challenges of life with CF, Renee didn't get to finish high school; it's through much hard work and determination that Renee is achieving what she is today.

"Both my sister and fieldworker Jude Kelly encouraged me to apply for the CF Achievers' Award. I had my doubts, but when I found out I was a recipient, I was overwhelmed, happy and very appreciative because times are tough when you are a student earning little to no income."

The next step for Renee is to become an alcohol and addiction counselor, as well as immersing herself in further training, and picking up a te reo Maori paper. Renee would love to return to her hometown of Rotorua and work in the aid field.



**Jessica Scott, age 31**  
Leadership

Thirty-one-year-old Jess lives in Auckland with her partner and kitten, and has a job she loves in TradeMe's marketing team. Jess' friends encouraged her to apply for a CF Achievers' Award, after a tough year losing her much-loved cat, Missy, all while continuing to be a leader and mentor to those she worked with, and delivering on her goals.

Grateful to be one of the 2020 recipients of the Award, Jess said "I found out the first week of going into lockdown when there was a lot of uncertainty for me and my partner, so it was exciting to get a piece of good news."

Jess is a keen adventurer. She enjoys going on road-trips and finding different hiking trails. Jess has a dream of one day reaching Everest Base Camp.



**Jake Gawn, age 21**  
Sport

Jake has recently completed a Bachelor of Applied Science, majoring in sports technology at the University of Otago, and is planning on starting his honours study next year.

Jake has always shown a keen interest in sport, and competed in the Challenge Wanaka half ironman-length race earlier this year, after which his girlfriend suggested he apply for a CF Achievers' Award. Jake's goal was to complete Challenge Wanaka in 6 hours, he managed to do it in 5 hours and 44 minutes. While training, Jake also set up a page to raise awareness and funds for CFNZ. Out of the generosity of his friends and family, Jake raised \$7,200.

"The award helped with some equipment and a swim membership so I can keep training."



**Christopher Headey, age 21**  
Education

Christopher is in his third year studying law at the University of Waikato. He has a passion for public speaking, academia, motoring and music.

For Christopher, 2019 was particularly challenging year. Being an academically demanding year, while also facing new CF complications - ENT surgery and ongoing antibiotic therapies. Despite this, Christopher excelled in his studies. He's delighted and grateful to be a recipient of the CF Achievers' Award, and will use it to support his hobbies and study this year.

"I look forward to pushing myself further, with my sights set on finishing my degree by 2021. I strive for balance in my life, and I am certain there will be no end of fun and adventures in store for me along the path to my goal."



**Angus Drumm, age 20**  
Leadership

Angus is in his third year of his law and art degree at university. Angus has a strong passion for politics, leading the University of Auckland's Public Policy Club, while also being involved with the Labour Party. He was campaign manager for a local board election team last year, and this year is the assistant campaign manager for the Hon Phil Twyford.

"I enjoy leading teams, coming up with a strategic direction for my team and then executing plans. I currently hold leadership positions in several organisations and I'm constantly trying to improve my skills and abilities in this area."

Angus has a young leaders conference coming up that he's attending as a member of the U.S Embassy Youth Councillor programme, where other young leaders come together for workshops on U.S. and New Zealand relations.



**Timothy Donkin, age 17**  
Leadership

Tim is an exceptional young man who has faced a huge year with such resilience and strength. Tim underwent a liver and pancreas transplant, the second of its kind in New Zealand, during COVID-19 Alert Level 4. While Tim was waiting for that miracle call for his transplant, he continued to be an excellent leader.

Tim has a passion for public speaking, has won his school speech award twice, and was chosen to represent his school in the O'Shea Shield Competition in Oratory and debating. Tim is also a Prefect at St Johns College this year. As well as his success at the microphone, Tim has also captained several cricket teams over the years.

With surgery, hospital stays, IVs and time off school is in the mix, these achievements are much harder to attain. "Because of Tim's perseverance and determination he's always more than caught up on anything he misses out on so he still achieved his goals," says his mum Louise.

Grateful for the CF Achievers Award, Tim will spend it preparing for university next year.

# CF Achievers' Awards



**Layla Collins, age 15**  
**Sport**

Layla lives in Pukekawa with her parents and younger sister who also lives with CF. Layla has been riding horses since she was young and has played Polocrosse during summer for the last 5 years.

Earlier this year, Layla was selected for the NZ Polocrosse junior under 16s team which travels to Australia to compete. They were lucky enough to be able to hold their inbound tour, of which the NSW under-16's competed in NZ, but unfortunately COVID-19 meant Layla's team couldn't get over to Australia for the competition this year.

"I was thrilled to be a recipient of the CF Achievers' Award for sport. I had intended on using the award money to assist with travel costs to Australia, hopefully that will happen next season."



**Tayler Payne, age 13**  
**Sport**

Tayler is in Year 9 at Botany College, and is a keen go-karter. He's been racing for about 3 years. Tayler travels all over the North Island to race in competitions, and he loves it. Tayler's dad is his mechanic and he's trained by Josh Bethune from Right Karts.

"Mum suggested I apply for the award so I could show others how CF doesn't stop me from doing what I really enjoy."

Tayler said this year has been a bit slow due to lockdown but he's looking forward to competing in North Islands and Nationals.



**Ashlee Sharp-Crowley, age 9**  
**Sport**

Ashlee is our youngest recipient this year. She lives in Lower Hutt with her mum, 2 year old brother Connor and two very loved pet rabbits. Ashlee loves gymnastics, horses and nature. She aspires to be a veterinarian and has a great desire to work in a field to help people or animals.

In 2019, Ashlee received Riding for Disabled 'Horse Rider of the year' out of 108 other riders.

"I had been working really hard over many years to achieve my long term goal of being selected to train with the Special Olympics Riding team to compete at the next summer Special Olympics, which finally came true at the end of 2019."

Ashlee said at times her goals were hard to see, and wondered if they were unrealistic, as the CF challenges are continuous, but receiving a CF Achievers' Award has reminded her that anything is possible if she wants it enough, CF or not.



# Partners and community supporters

Our biggest thanks to the organisations who continue to support the work we do and to help us achieve our vision of lives unlimited by cystic fibrosis.

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.



## Key Partners

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

# Major Funders



## Trusts and foundations

- AD Hally Trust
- Bendigo Valley Sports & Charity Foundation
- BlueSky Community Trust - Auckland
- Central Lakes Trust
- CERT
- Community Organisation Grants Scheme
- Community Trust of Mid & South Canterbury
- Community Trust South
- Constellation Communities Trust Ltd
- Dragon Community Trust Ltd
- Eastern & Central Community Trust
- First Light Community Foundation
- Foundation North
- Four Regions Trust
- Four Winds Foundation Ltd
- Grumitt Sisters Charitable Trust administered by Perpetual Guardian
- Hutt Mana Charitable Trust
- John Ilott Charitable Trust
- Johnsonville Charitable Trust
- Kathleen Dorothy Kirkby Charitable Trust administered by Perpetual Guardian
- Lottery Grants Board
- Mainland Foundation
- Milestone Foundation
- Ministry for Social Development
- The North & South Trust Ltd
- Otago Community Trust - Covid Response Fund
- Rano Community Trust Ltd
- Rata Foundation
- Redwood Trust Inc
- Robert & Barbara Stewart Charitable Trust
- Roy Owen Dixey Charitable Trust- Canterbury
- Sir John Logan Campbell Residuary Estate – Auckland
- Stewart Family Charitable Trust administered by Perpetual Guardian
- The Lion Foundation
- W. Duncan Bickley Trust Fund administered by Perpetual Guardian
- Wellington Children's Foundation
- Whanganui Community Foundation
- Winton & Margaret Bear Charitable Trust

## Thank you to the legacy gifts we received this year

- Estate of Nanette Geraldine Taylor
- Estate of Joan Alexander Robertson
- And the many 'in memoriam' donations we also received.

# Branch reports

## Auckland

Our branch has continued to benefit from a supportive and enthusiastic committee. Two of our members, Eddie and Emma were instrumental in the success of the Kalydeco for Kiwis campaign and we thank them for all their work.

Our fundraising efforts this year have enabled us to support our many families and individuals with hospital packs, food, parking and petrol vouchers, newborn packs for newly diagnosed families and Breath4CF grants.

We congratulate long-time Auckland branch member Jane Drumm on receiving life membership of CFNZ. Jane resigned as Board Chairperson after many years at the helm and her contribution to both the organisation and Auckland branch must be applauded.

Committee members Waverly and Peter have been active supporters of Patient Voice Aotearoa and the double the PHARMAC petition. Thank you, and thanks to everyone who has supported the branch this year.

*Jill Thorrat*

## Waikato

The Waikato branch supported two community members to attend the Australasian CF conference in Perth in 2019. We've continued to foster our ongoing relationship with the Matamata Warehouse who run the Wrap for Good fundraiser at Christmas.

We've also continued our relationship with various Lions groups who donate to help our people with cystic fibrosis (CF).

Our ongoing fundraising means being able to support our CF nurses and fieldworkers and provide inpatient support through petrol, grocery and parking vouchers and Breath4CF.

We've also restarted community coffee meet ups for CF families.

*Alice Bell*

## Bay of Plenty

In the past year we provided funds to support our people with CF mainly in sport, physiotherapy and hospital stays. We continued to provide the Breath4CF funds to people who've requested help with the costs of activities to help their lung function.

We provided portable nebulisers for people travelling, and we continue to provide inpatient support with vouchers to help with the cost of an admission.

Last year we were fortunate to have a bequest from the Sewell family through the Geyser Community Trust which has enabled us to offer more support to our Rotorua-based families.

*Nicola Wakerley*

## Hawkes Bay

The year started with a full report from our paediatric nurse following the Australasian Conference held in Perth. We appreciated the value in her attending with our assistance.

We held another successful Casino Fundraiser in Havelock North, Masquerade theme, many thanks to those who attended. This may be our last Casino night for a while, so the efforts of Catherine's organisation and enthusiasm are very much appreciated. Unlike most CF fundraisers, Catherine doesn't have a family member with CF. So it seems even more extraordinary she's spent over six years supporting CF at both a branch and national level. Our committee would like to acknowledge how much we've appreciated Catherine's input on the CFNZ board, Hawkes Bay committee and as a significant fundraiser. If CFNZ had more volunteers like Catherine then there would not be such a burden on CF parents, to feel like they need to be advocates, fundraisers and committee members while caring for a person (or people with a chronic illness).

There was a small street collection held during CF awareness week but the Fashion Night was the main event. Thanks to all involved, especially the Richardson Family for sharing their CF journey, the Red Hatters group for organising the event and two CF grandmothers who worked very hard to support the Red Hatters. The event was a fundraiser, but just as importantly, it created great awareness of what life for people with CF is like.

Other fundraisers followed: CHB fishing competition in memory of Possum McCleary, this is increasing in popularity and a real tribute to a "good bloke". Good in the Hood (Z service stations) was also successful.

A music concert was dedicated to the memory of Byron Middleton and was a great night with tributes made by his brother. We really appreciate it when people outside of the committee offer to host much needed events for fundraising and CF awareness.

The committee has had semi regular meetings throughout the past 12 months and is pleased to continue to have adult representation.

COVID-19 certainly has had a major impact on being able to meet in 2020 and meant everyone had other priorities during recent months. We are looking forward to our first meeting shortly.

Our "Physio in Homes" continues to service young people with CF and is greatly appreciated by the families involved.

Hawkes Bay people with CF have been regularly contacted or visited by our CF fieldworker. This service is operating well and relieves the branch from direct contact with people with CF.

Kalydeco is now being prescribed in HB and is another CFNZ success.

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.

Nicci Hughson and Paula Richards continued the role of Co-Chair and Beth Hughson remained as Treasurer.

We had one new baby diagnosed with CF.

Wellington branch has two main fundraisers every year. Our Christmas Tree Festival held once again at Wellington Airport saw some fabulous trees decorated by returning businesses. It was fantastic to see new businesses getting behind our festival as well and we're extremely grateful to Wellington Airport for their continued support.

CF Awareness Week in August went well and having multiple schools involved enabled us to have a strong presence at our usual spots. Alongside our major fundraisers, we've also had chocolate fish sales, entertainment books, mufti days and individual donations, all contributing to our branch awareness and funds.

Fundraising has enabled us to support our people with CF by providing Breath4CF, hospital inpatient voucher packs and welfare assistance such as heating and counselling.

We also contributed \$15k 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 people with CF and their families in the region.

*Paula Richards*

## Nelson Marlborough

This year we've held several new fundraisers with the most popular being our pre-loved sale. This not only raised awareness of CF in our community but also supported our branch to provide welfare to people with CF via our CF fieldworker.

We've also held our branch meetings via Zoom, which we hope will increase the number of meetings we can hold each year and the number of people who can attend.

Our branch Facebook page has been up and running for a year now helping to give both people with CF and their families and the wider community information and resources.

*Rebecca Colley*

## Canterbury

Our branch had contact with CFNZ Advocate Lisa Wood to discuss our concerns regarding the nutritional supplements subsidy which was removed a few years ago. We wished to advocate for this so our people could afford these, especially the tetrapaks. We're still waiting to hear back about this.

This year we had an expensive repair on one of our oxygen concentrators which is now back available for our people.

We've provided 32 welfare grants and 70 Breath4CF requests via our CF fieldworker to our CF community.

The branch supported two allied health professionals to two different Australian conferences and one to the CF European Conference. The branch supports their attendance as they're in the front line of improving and maintaining the care of our people with CF.

We fundraised to support our people as inpatients with meal vouchers, taxi chits to get to and from school, petrol vouchers to help with travel associated with hospital stays and appointments, firewood and heating grants, home insulation assistance, payment for non-funded equipment and many other welfare associated costs.

We continue to employ a part-time community physiotherapist who supports our people with physio needs in their homes. This is a well utilised service. Canterbury DHB has embraced this position and our community physio attends CF hospital team meetings.

Our Facebook page and our Gmail account have been highly effective as ways of communicating with our CF community and supporters.

*Melissa Skene*

## Otago

Otago branch has had a few highlights this past year. We had a successful street appeal during CF awareness week and Hannah, Hutch and Aaron raised a significant amount for Breath4CF with their 31 times up Puketapu in 31 days campaign.

Julian and Camilla towed a coffin behind their tandem bike to Wellington to support the Double the PHARMAC budget. Although the Government response and signatures were disappointing we received some great press coverage of the cause.

We received a grant for the nebulised antibiotics residual and resistance research study which is being done through the University of Otago.

Our branch dinner in September was well attended.

*Julian Cox*

“We feel very grateful to live in NZ, and to have the backing of an organisation that supports us dealing with our child diagnosed with CF.”





# Financial summary 2020

## Statement of Financial Performance – as at 30 June 2020

	2020	2019
<b>REVENUE</b>		
Fundraising Revenue	731,258	902,512
Donations and Bequests	368,893	173,607
Grants	346,473	378,032
Sponsorships	70,105	94,132
Contract Revenue	75,000	75,000
Interest and Dividends	135,522	101,282
Revenue from providing goods or services	-	(2,146)
Subscription from Members	7,647	13,347
Write back Tertiary Assistance Accumulation	-	40,887
<b>TOTAL REVENUE</b>	<b>1,734,897</b>	<b>1,776,652</b>
<b>EXPENSES</b>		
Expenses related to public fundraising	388,592	490,356
Volunteer and employee related costs	549,149	513,209
Costs related to providing goods and services	349,090	297,866
Grants and donations made	312,747	462,513
Other Expenses	53,483	77,044
<b>TOTAL EXPENSES</b>	<b>1,653,060</b>	<b>1,840,988</b>
<b>SURPLUS/(DEFICIT) FOR THE YEAR</b>	<b>81,837</b>	<b>(64,336)</b>

## Statement of Financial Position – as at 30 June 2020

	2020	2019
<b>ASSETS</b>		
<b>Current Assets</b>		
Bank accounts and cash	1,052,538	1,008,444
Debtors and prepayments	89,021	106,985
Other Current Assets	24,586	35,849
<b>Total Current Assets</b>	<b>1,166,145</b>	<b>1,151,278</b>
Non-Current Assets	851,138	848,359
<b>TOTAL ASSETS</b>	<b>2,017,283</b>	<b>1,999,637</b>
<b>LIABILITIES</b>		
Current Liabilities	95,039	173,999
Unexpected Grants	63,609	49,030
<b>TOTAL LIABILITIES</b>	<b>158,648</b>	<b>223,029</b>
<b>TOTAL ASSETS LESS TOTAL LIABILITIES (NET ASSETS)</b>	<b>1,858,635</b>	<b>1,776,798</b>
<b>Accumulated Funds</b>		
Accumulated surpluses or (deficits)	1,858,635	1,561,469
Reserves	-	215,329
<b>TOTAL ACCUMULATED FUNDS</b>	<b>1,858,635</b>	<b>1,776,798</b>



# 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 2020

## Board

**Warwick Murray**  
Board Chair

**Jane Drumm**  
Board Member

**Michele Wilson**  
Board Member

**Rachel Harris**  
Independent Board Member

**Alex McKay**  
CF Adult Representative

**Andrew Cameron**  
Board Member

**Denis Currie**  
President

**Jaggar Bootten**  
Board Intern

**Patrons**  
Professor Bob Elliott  
Peter Miskimmin

## Sub-committees of the Board

### Finance, Audit and Risk Committee

Rachel Harris  
Warwick Murray  
Michele Wilson  
Jane Bollard  
Alex McKay

### Investment Committee

John Parsons  
Warwick Murray  
Steve Drumm  
Rachel Harris  
Jane Bollard

## 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

**Dr Mark O'Carroll**  
Adult Respiratory Specialist,  
Auckland City Hospital

**Cath Lamont**  
Adult CF Nurse Specialist,  
Auckland City Hospital

**Tory Crowder**  
Dietitian, Canterbury DBH

**Patricia Goulter**  
Adult Physiotherapist, Canterbury DHB

**Rebecca Scoones**  
Paediatric Physiotherapist,  
Starship Children's Hospital

**Jan Tate**  
Paediatric CF Clinical Nurse Specialist,  
Starship Children's Hospital

**Jane Drumm**  
CFNZ Board Member

**Jane Bollard**  
CFNZ Chief Executive

## 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

**Irene Vanderlaan**  
Office Manager/Accounts

**Susan Lovelock**  
Southern Fieldworker

**Gretchen Kitching**  
Northern Fieldworker

**Jude Kelly**  
Lower Central Fieldworker

**Chani Venter**  
Upper Central Fieldworker

**Laura Huet**  
Marketing and Fundraising Manager

**Lizzie McKay**  
Communications Coordinator

**Jeanette Franklyn**  
Grants Coordinator

**Sarah Connolly**  
Auckland Branch Coordinator

**Jan Tate**  
Port CF Project Coordinator

## Branch office holders

### Northland

Mike Webb (Chair)  
Janet Webb (Treasurer)

### Auckland

Jill Thorrat (Chair)  
Allyson Harvey (Treasurer)

### Waikato

Marieke Latimer (Chair)  
Alice Bell (Treasurer)  
Annelies Baker (Secretary)

### Bay Of Plenty

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

### Taranaki

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

### Hawke's Bay

John Parsons (Chair)  
Pip Harper (Treasurer)  
Claire Fisher (Secretary)

### Central Districts

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

### Wellington

Nicci Hughson (Co-Chair)  
Paula Richards (Co-Chair)  
Beth Hughson (Treasurer)

### Nelson

Rebecca Colley (Chair & Treasurer)  
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 Rangi (Secretary & Treasurer)

