

# Annual Report 2021





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**Cystic Fibrosis NZ is the only charity in New Zealand dedicated to supporting and improving the quality of life for people with CF and their families. Established in 1968 as a volunteer support group for parents with a newly diagnosed child, we dedicate ourselves to shaping a brighter future for everyone with cystic fibrosis.**

### **Our work**

We receive less than 4% government funding and rely on the generosity of everyday New Zealanders to meet the ongoing needs of our community.

Advocacy and awareness, support, information and research are the four pillars of service that provide the foundation for the work we do.

With your help, we advocate for new medicines and getting the best possible care wherever people live.

We provide personalised support, such as emotional guidance, practical advice and financial assistance, to people with cystic fibrosis and their families throughout the country.

Our team of four CF social workers visit and support families at home, in hospital and during outpatient appointments, facilitate parent to parent support, provide vouchers and allowances during hospitalisations, welfare assistance, offset the cost of mobile medical equipment and assistance towards organ transplant costs.

We also contribute to promising CF research projects and advocate on behalf of the community for better access to treatment and care.

Our vision is to see lives unlimited by cystic fibrosis.

# Board Report

Warwick Murray, CFNZ Board Chair



**As I write this, the entire country is in COVID lockdown and the number of COVID cases in the community continue to climb. We're uncertain about whether as a country, we will get on top of this outbreak and we're unclear about what a post-COVID world will look like and what it will mean for us individually. Thinking back to this time last year, there were similar uncertainties. But survive we did and in fact, we thrived.**

In the 2021 annual plan, the CFNZ Board sought to put a tight rein on spending given the uncertainties around our income, but to maintain the level of service we were providing to the CF community and its stakeholders. It did this knowing that the needs of those with CF had not changed and that there would never be a better time to push for access to the new modulator drugs. We had reserves available for a 'rainy day' and that perhaps this would be ours. So, the Board approved a \$45,000 deficit budget for national office. Our priorities for the year were to maintain our support programme for those in need, to push on with the Trikafta campaign, continue to keep people informed and to ensure the organisation remained viable and in fit shape to tackle future challenges.

As it transpired, we ended the year with a \$19,412 surplus in the National Office account (\$27,154 consolidated surplus), thanks in part to our generous donors who continued to contribute through a period

of financial uncertainty, but also thanks to the tireless efforts of our volunteers and staff. So, despite the uncertainties and challenges of maintaining delivery under COVID restrictions, we finished up the year in a stronger position than the previous year and having made significant progress toward our goals.

The Trikafta campaign continued to dominate much of the Board's attention through the year, so it was very pleasing to see the solid progress being made by Jane Bollard and Christine Perrins in building relationships with Vertex and Pharmac and in positioning CFNZ as a key partner in the process that we all hope will lead to our gaining access to the modulator drugs for all those in NZ with CF.

Another project that has been a focus of the Board over the past year has been the organisational review. This was undertaken to better position CFNZ to meet both new and existing challenges. It required a close look at some fundamental aspects of who we are and presented some challenges for many, so I would like to acknowledge the incredible work done by Michele Wilson and the review team in managing this process, and the wider group involved in the discussions, for their open and positive contributions.

Real progress was made with agreement on having a coordinated plan of action and messaging around this – speaking with one voice, having a centralised contacts database, a centralised management of legal contracts and a nationally coordinated volunteer programme. Recent agreement has also been reached on ensuring aggregation of financial data through all branches either using Xero, or having their funds managed by national office. All these changes will help us in being more efficient and effective and in meeting our legal obligations.

Looking ahead, COVID notwithstanding, the focus is clear. We must continue to do everything within our powers to advocate for access to the new modulator drugs, particularly Trikafta, for all those with CF in New Zealand. Evidence from their use to date suggests that this will be a major gamechanger in the lives of those with CF, so this must remain our primary focus. Good though it is, it will not be available tomorrow and even if it were, there will remain the need for support to those who need it. We must then, maintain our support programme.

We also face some challenges around supporting our branches, particularly those in regional New Zealand. Many branches are relying on a dedicated few to keep them afloat and most are struggling to attract new members. More discussion is needed then, on how we best support our branches, how we attract new members, and how we build our support base.

So, in what is my second Chairman's report, I can again say I am very proud of what we have achieved over what has been another challenging year. Again, I want to acknowledge the army of volunteers out there doing great work and those financial donors who have belief in our cause and trust that we will deliver. I also want to acknowledge and thank the CFNZ staff who, as a cohesive team, have knuckled down and got the job done, despite COVID and other challenges.

Finally, I would like to acknowledge and thank Jane Bollard for her outstanding leadership and commitment to the job and for the incredible contribution she has made CFNZ. We are a strong and healthy organisation, clearly focused on what is expected of us by our community and much of this is because of Jane's efforts as our Chief Executive. The Board is sad to see her go but we understand her need for a change and we wish her the very best for the future.

# Chief Executive Report

Jane Bollard, CFNZ Chief Executive



**In 2018, CFNZ conducted our first externally commissioned Insight Survey. From this we developed our four strategic pillars of advocacy and awareness, information, support, and research and remodelled our service delivery to ensure that advocacy was well resourced and central to our business. This year we re-surveyed our CF community and I'm pleased to share that our four key pillars are both valuable and important for people with CF, parents and whānau and advocacy is still the most critical focus of our work.**

Securing public funding of Trikafta as soon as possible is our highest advocacy priority and requires tireless commitment at all levels for its success. As his dying wish, our patron, Sir Bob Elliott, funded 3 months of Trikafta for Bella, a young woman with CF who was seriously ill, to have a better quality of life. Their story, together with the stories of Ed, Gracie and Izaeah who also have CF, were highlighted by New Zealand Journalist, Paddy Gower, who's actively using media to support Trikafta funding.

While our ambassadors are rightly front and centre, CFNZ staff work in the background running a coordinated professional campaign to have Trikafta publicly funded in NZ. Over the last five years and more,

CFNZ Board and management have committed to strengthening the organisation to be best placed to support the Trikafta campaign by:

- **Strengthening** the robustness of the CF registry data
- **Engaging external consultants**, Deloitte, to develop a Social and Economic Cost of CF report
- **Building an engaged** and supportive Clinical Advisory Panel
- **Understanding people with CF**, how CF impacts them, their family, whānau, and society, and their needs/aspirations through surveys, interviews, and external research
- **Growing CF awareness** through active communications and marketing, storytelling, grant writing and petitions
- **Building relationships** within the sector to ensure our voice is heard.

After many months of meetings and relationship building, CFNZ facilitated a patient-led stakeholder meeting in March 2021 with Vertex, Medsafe and Pharmac. CF clinicians, an advocacy advisory and Trikafta for Kiwis representatives also attended, with the aim of working together to facilitate the funding of Trikafta. This meeting will stand as a milestone in the campaign and in patient advocacy.

Medsafe and Pharmac are now considering an application for Trikafta concurrently (an offer usually only offered to cancer medications) with Medsafe giving the application priority status. Vertex has also lodged applications for Orkambi and Symdeko which will mean more people with CF will benefit from modulator therapies.

As I write this report, it's joyous to hear that people in critical need who've been accepted into the Trikafta Managed Access Programme are having instant and wonderful improvements in their health and wellbeing. These success stories should be shared by all because we've all played a part in making this a reality.

I'm confident public funding of Trikafta will be achieved. This will herald a change in health care for people with CF and a changing role for CFNZ. The organisation is well placed to lead this change bringing us ever closer to lives unlimited for those with CF.

And finally, as I step away from my role as Chief Executive, I want to thank the CF community, donors and supporters, Board members and active branch members, staff and volunteers, and clinicians for allowing me to be part of your journey.

Warmest wishes to you all for the years ahead.

Jane Bollard

# Farewells

## Farewell to CFNZ patron, Sir Bob Elliott

In August, our CF community mourned the loss of Sir Bob Elliott.

Sir Bob Elliott made an extraordinary, lifelong contribution to cystic fibrosis, notably for his work on the newborn screening test, which he believed added 30 years of life for people with cystic fibrosis. His passion for research into childhood illnesses, along with co-founding the medical charity Cure Kids, were other highlights.

Sir Bob has left an extraordinary legacy, with people throughout New Zealand and the world who have lived lives that would simply not have been possible without his efforts.

There are many Kiwis with cystic fibrosis who grew up with Sir Bob Elliott, and will remember him not just as brilliant researcher and doctor but a true friend who cared.

Sir Bob Elliott's recent focus before he passed away was funding of Trikafta, which showed his deep humanity and care for people with CF right until the end.

His impact on the CF community worldwide is a legacy that will live on for many years to come.

**Last year we sadly  
farewelled four people  
from our CF community.**

### Croky Coulter

5 January 2021  
51 years old

### Sharon Mullacrane

14 January 2021  
64 years old

### Leigh Wishnowsky

6 June 2021  
22 years old

### Isaac Wells

16 June 2021  
28 years old

## If I Should Go

If I should go before the rest of you  
Break not a flower, nor inscribe a stone  
Nor when I'm gone speak in a Sunday voice  
But be the usual selves that I have known  
Weep if you must  
Parting is hell  
But life goes on  
So sing as well.

- Joyce Grenfell

# Support for people with cystic fibrosis and their families

**203**  
welfare support grants

**4,038**  
interventions by CF fieldworkers to support people with CF and their families

**870**  
outpatient clinic appointments attended by fieldworkers to support people with CF

**333**  
inpatient visits by fieldworkers to support people with CF and their families

**11**  
people with CF supported with a Chris Howlett Endowment Fund grant on turning age 21

**1,093**  
email contacts with people with CF and families

**1,182**  
contacts via phone call or text message

**127**  
home visits

**31**  
transplant grants

**126**  
contacts via mail

**584**  
discussions with support and welfare agencies on behalf of people with CF

**27**  
newly diagnosed families supported

**5**  
families supported with a funeral grant

**111**  
individual healthcare plans developed by fieldworkers

**664**  
grants given to people with CF and their families

**318**  
physical activity grants (Breath4CF)

**45**  
hospital allowances

## Fieldworkers



Sue



Chani



Jude



Gretchen

*“Our fieldworker is fabulous, not only with keeping in touch, with kind words and great encouragement, she certainly makes you feel important and not just another number.”*

*“I have known my fieldworker my whole life and she’s an absolute blessing to be able to come to with questions or problems I might have or not understand about CF.”*

*“My fieldworker is such a calm and gentle presence, while also being encouraging and engaging. She provides a space where you feel comfortable to say how you really feel. Having a fieldworker as part of the CF team in clinics (and in real life) is incredibly important to me.”*

*“Our fieldworker was priceless with her wealth of knowledge, and her support in introducing me to mums in our area has benefited us more than words can say.”*

# Local support initiatives



**Dargaville Bake Off**  
Dargaville

**Auckland Ladies Morning Tea**  
Auckland

**Charlie's Chocolate Fish Fundraiser, sold 1000's of chocolate fish**  
Tauranga

**Bidr Auction Waikato**  
Waikato

**Trikafta Tales booklet**  
Taranaki

**Duncan "IronDuncs"**  
Hawke's Bay

**Christmas Tree Festival**  
Wellington

**Canterbury Golf Tournament**  
Canterbury

**65 Hours of Bowls**  
Ashburton

**Nebulised antibiotics research project**  
Otago



# Advocacy and awareness

## Trikafta and other CF modulator therapies

The past year has seen significant progress in the campaign to get Trikafta, and other CF modulators, publicly funded in New Zealand. CFNZ has worked together with Trikafta for Kiwis to raise awareness of the urgent need for Trikafta to be publicly funded for Kiwis with CF.

The CF community has been lucky to have significant support from media during the year, leading to increasing public awareness of CF and its challenges, and the urgent need for Trikafta. Special thanks go to Patrick Gower and Shannon Redstall of Newshub who have shared several stories on CF and Trikafta during the year and continue to provide support to the campaign to access this life-changing medicine.

But the biggest thanks must go to those people with CF who have been brave enough to share their stories publicly. Thank you to Bella Powell, Ed Lee and Izeaeh Twose in particular for fronting for CF during the last year. Thank you also to the many other people with CF around New Zealand who have provided CF with a human face and demonstrated the challenges faced by all of those with this condition.

CFNZ is also grateful for the commitment by Vertex to seek approval and funding for its CF modulator therapies in New Zealand. Vertex submitted applications to Medsafe for regulatory approval of the three CF modulator therapies which are yet to be made available in New Zealand - Orkambi, Symdeko and Trikafta. An application to Pharmac for funding of Trikafta was expected in July 2021.

Vertex also established a Managed Access Programme to provide Trikafta free of charge to Kiwis with CF who are in critical need. The programme provides a lifeline to those Kiwis while Trikafta goes through the regulatory and funding assessment process.

## Other Advocacy

This year has also provided the opportunity for CFNZ along with many other groups to seek change to the way medicines are funded in New Zealand, and to campaign for a significant increase in funding for Pharmac.

CFNZ supported Patient Voice Aotearoa's petition for the review of Pharmac and the doubling of its budget which was presented to Parliament in May 2021. CFNZ has also engaged with the Independent Panel undertaking a review of Pharmac. The Review Panel is expected to report back to Government with its findings by December 2021.

CFNZ made several submissions to Pharmac during the year. This included support for the transition of access to dornase alfa (Pulmozyme) to a Special Authority and the introduction of standard set of criteria for all people with CF.

CFNZ also provided input to Pharmac's consultation on its committee structures, strongly supporting the need for consumers – patients, their families, and representatives – to Pharmac's decisions over funding of medicines and devices.

CFNZ also supported the petition of Sue Haldane for Rare Disorders NZ: Develop a National Rare Disorders Framework.

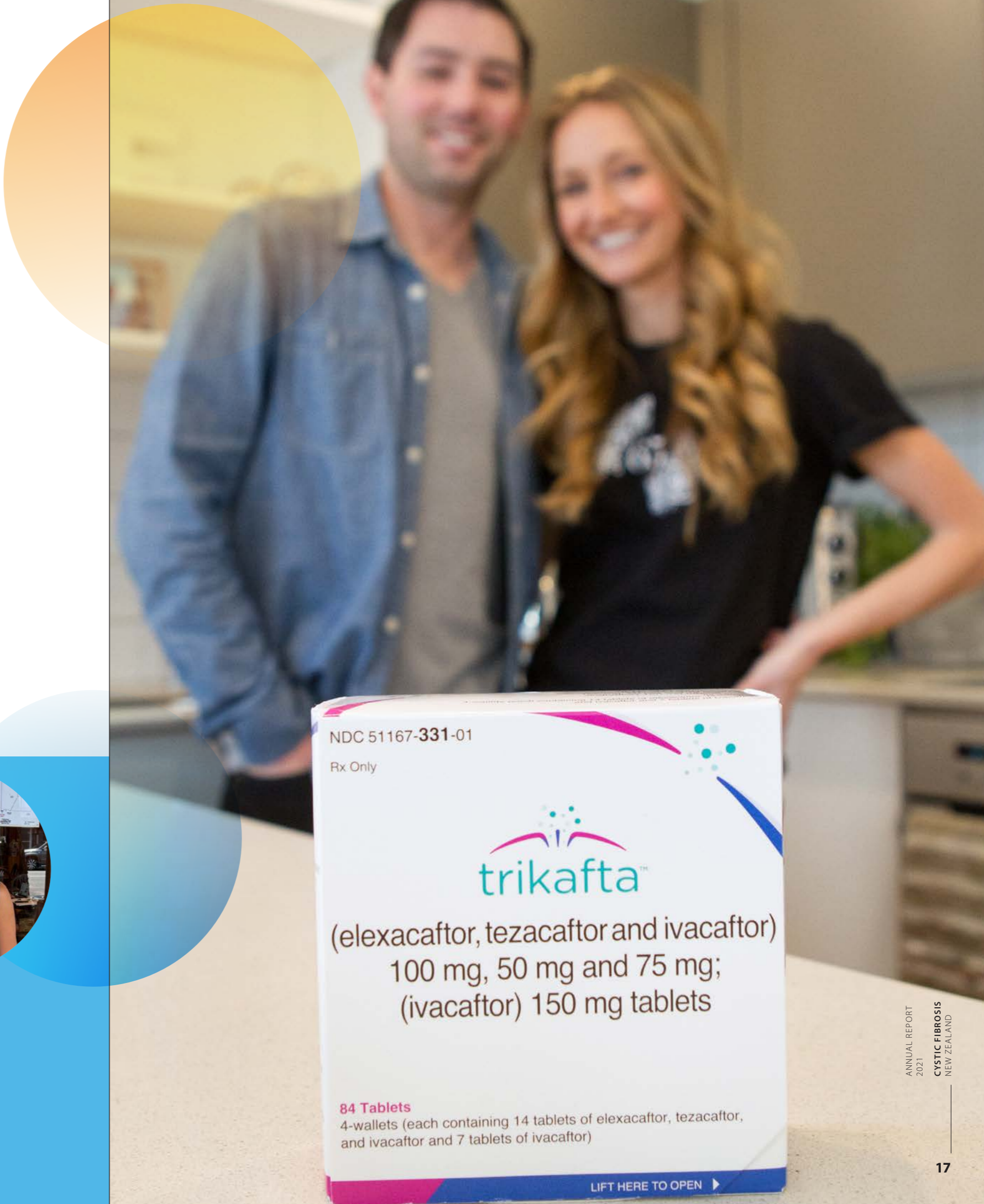
### Bruno

Bruno is one of 35 New Zealanders with cystic fibrosis who has the G551D mutation. He also has cystic fibrosis-related diabetes. For most of his life, he's had an average of three hospital admissions a year.

Kalydeco is a precision medication used for people with this CF mutation, but until 2020 it wasn't funded in New Zealand, and out of reach for people like Bruno. Every day this vital medication went unfunded, Bruno was enduring irreversible lung damage.

After years of campaigning, and thanks to everyone who supports CFNZ, Bruno finally got thrown a lifeline on 26 February, when Pharmac agreed to fund Kalydeco.

Since starting Kalydeco, Bruno hasn't had any hospital admissions. His lung capacity has improved by 91% and is diabetes is more stable than it's ever been.



# Advocacy timeline

## Access to CF Modulator Therapies

2020

August

A part of Newshub's Because It Matters series, Patrick Gower presents Bella Powell's story about access to Trikafta. Bella was gifted 3 months' supply of Trikafta by Sir Bob Elliott and it has been life-changing for her. Bella calls for Trikafta to be funded by Pharmac.

Vertex announces it will proactively engage with Pharmac for public funding of Trikafta.

Carmen Shanks of Trikafta for Kiwis launches a petition to the Health Select Committee urging the Government to publicly fund Trikafta for people with CF in New Zealand.

CFNZ signs a Memorandum of Understanding with Trikafta for Kiwis to help advocate for access to and funding of Trikafta for Kiwis with CF.



December

New Zealand Minister of Health, Andrew Little, attends the CFNZ Christmas Tree Festival at Wellington Airport. The festival raised awareness of CF and reinforced the urgent need for Trikafta funding for Kiwis with CF.

CFNZ CE Jane Bollard sends a letter to Minister of Health, Andrew Little, raising the urgent need for Trikafta funding and seeks support to ensure Pharmac can progress funding approval as soon as possible.



2021

January

CFNZ writes to all MPs seeking their support for public funding of Trikafta, a substantial increase in funding for medicines, and improvements to speed up access to life-saving medicines. CFNZ also asks for support of the Patient Voice Aotearoa petition to review Pharmac and double its budget.

February

Patrick Gower's Newshub documentary screens on TV Three, featuring Bella Powell, Ed Lee and Izaeah Twose, who are all taking Trikafta. The 3-night series highlights the benefits of Trikafta and the need for its public funding in New Zealand.

Vertex announces it will submit applications to Pharmac and Medsafe for three CF modulator therapies, including Trikafta, in the coming months. Vertex also states it is in discussion with Pharmac relating to a path forward for Trikafta.

March

Vertex announces that the Australian Therapeutic Goods Association (TGA) has approved Trikafta to treat people with CF in Australia with a least one F508del mutation. Regulatory approval in Australia can help to shorten Medsafe's process in New Zealand.

CFNZ convenes a meeting with Pharmac, Medsafe and Vertex to discuss how to progress the approval of Trikafta in New Zealand as quickly as possible. Pharmac and Medsafe agreed to consider Vertex's applications for Trikafta concurrently to shorten the application timeframe.

April

CFNZ supporters write to and visit their MPs to talk about the urgent need for Trikafta.

Vertex submits its application to Medsafe for regulatory approval of Symdeko in New Zealand. The application is for the first of the three CF modulators (Orkambi, Symdeko and Trikafta as registered in Australia) for which Vertex has advised it will seek approval and funding in New Zealand.

Fifteen-year-old twins, Manaia and Lili, who are both facing the prospect of double lung transplants, share their stories on TV3's Newshub.



May

Gracie McDonald, an 18-year-old with CF facing the prospect of a lung transplant, shares her story on TV3's The Project. Gracie and her family must decide whether to stay in New Zealand and wait for Trikafta or return to the UK where it's funded, but where she hasn't lived for 15 years.

CFNZ meets with Pharmac to discuss how it can provide information to support Vertex's applications for funding of CF modulators, including Trikafta.

Two people with CF, Kirsty and Angus, appear on TV1 News with Jane Bollard CE of CFNZ to raise concerns about the potential for funding of Trikafta, in the light of the Government's disappointing funding for Pharmac. Kirsty, who was able to access Trikafta on a UK drug trial, has to return to the UK every 3 months to secure the medicine, and will need to do so until Trikafta is funded in New Zealand.

Person with CF Kase Williams, his family and whanau appear on TV3's The Hui to show what life is like with CF and how access to Trikafta could change Kase's life and future. It shows Kase's daily routine, the family's journey to Parliament and their participation in Patient Voice Aotearoa's Lie Down for Life.

June

Vertex submits its applicant for regulatory approval of Trikafta to Medsafe. Medsafe accepts the application and grants it priority approval status enabling a shorter time for evaluation. Vertex also submits its application to Medsafe for approval of Orkambi.

Vertex establishes a Managed Access Programme in New Zealand to provide Trikafta free of charge to Kiwis with CF who are in critical need. The Programme is managed globally by Vertex and access is through CF clinicians.

CFNZ is delighted that Vertex has established a Managed Access Programme in New Zealand for the small group of Kiwis with CF in critical need, but notes that it is no substitute for public funding of Trikafta for all those who would benefit.

## Other Advocacy Projects

2020

July

CFNZ submits a paper in response to Medicine NZ's request for feedback on the development of a new generation medicines' policy. The submission includes the need for a national rare disorders framework to ensure people living with a rare disorder (300,000 New Zealanders) are not disadvantaged.

October

CFNZ submits to Pharmac in response to its proposal to transition funded access of dornase alfa (Pulmozyme) to a standard Special Authority. If successful, the effect for people with CF will be improved access Pulmozyme



November

Pharmac informs CFNZ of its decision to transition funded access of dornase alfa (Pulmozyme) to a standard Special Authority from 1 December 2020. This allows clinicians to use the Special Authority process instead of applying to the CF Panel, removes the requirement for spirometry, focuses the criteria on exacerbations rather than hospitalisations, and results in one set of criteria for all people with CF.

2021

March

The Government announces a review of Pharmac to be completed by December 2021. The review is to be undertaken by an Independent Panel led by consumer advocate Sue Chetwin. The review will investigate and make recommendations on how well Pharmac performs against its current objectives, how its performance could be improved, and whether its objectives should be changed.

CFNZ welcomes the independent review of Pharmac but urges a substantial increase in funding immediately to clear the backlog of medicines awaiting funding.

CFNZ makes a submission to Pharmac on its proposal to provide consumer input to its advisory committees. CFNZ strongly supports patients, their families and representatives having the opportunity to provide input to decisions on the funding of medicines and devices.

April

Pharmac reveals it needs an additional \$420 million to fund the 73 medicines currently on its list that it wishes to fund, an increase of 40% on its 2020/21 budget. This list has grown from 26 medicines in 2014 to the current 73, with some medicines waiting more than 6 years. Despite this, Pharmac had sought only very small budget increases in recent years.

May

Patient Voice Aotearoa's petition to double Pharmac's budget and review Pharmac is presented to Parliament, along with the Lie Down for Life. The petition has over 100,000 signatures and CFNZ and the community participate across the country.

Government announces \$200m for Pharmac over four years, with \$40m for 2021/22. Total funding over four years is only half what Pharmac has said it needs to fund the medicines currently on its recommended list. This does not include any new medicines coming through, such as Trikafta. CFNZ expresses its disappointment and concern over the lack of funding for Pharmac.

CFNZ meets with Sue Chetwin, Chair of the Independent Panel undertaking the Review of Pharmac. The meeting provides an initial opportunity to raise concerns over the funding of new medicines, including Trikafta.



June

CFNZ attends a workshop with the Pharmac Independent Review Panel, together with representatives of other medical charities. The workshop provides the opportunity to raise key concerns and hear how the Panel is approaching the Review.

# Fundraising and Awareness

## Sweat4CF campaign

In September 2020 we launched a new awareness and fundraising campaign – SWEATEMBER. We asked everyday New Zealanders to take on a physical challenge and break a sweat for CF, and we were overwhelmed with the support. The campaign raised over \$130,000 for vital support services, and saw 347 people get their sweat on, and over 2,500 people donating in support.



## Christmas Tree Festival

Thanks to the support of more than 30 businesses, community groups and organisation, our annual Christmas Tree Festival was another huge success. The joint event between Wellington Airport and Cystic Fibrosis celebrated its 12th year and continues to raise awareness of cystic fibrosis. The Minister of Health, Hon Andrew Little, formally opened the festival and New Zealand-owned natural lipstick company, Karen Murrell, received the first-place prize of a \$5,000 advertising package at Wellington Airport. Construction company Naylor Love took the People's Choice Award. Thank you to Wellington Airport, businesses, individuals, volunteers, and the New Zealand public who supported the event.



## Cystic Fibrosis Awareness Month

We re-launched our annual awareness campaign, Cystic Fibrosis Awareness Month, and moved it from August to May, to coincide with international awareness months also held in May. So many people in our CF community supported our giveafuture.org.nz campaign, which resulted in a lot of media coverage throughout the country, with people and families sharing their lives with CF through stories, videos and radio interviews.



# Information

Through our regular newsletters, donor impact reports, website and social media channels we continued to connect with our growing CF community and supporters.

We received funding from Te Hiringa Hauora/Health Promotion Agency to begin work on an Adult Wellbeing Guide, to provide adults with CF New Zealand specific information. We continue to work with our CF community and healthcare professionals on this working document.

We've continued to build on our story-telling capability, capturing the impact our fieldworkers, branches and our wider organisation has for our CF community.

## Top 3 resources downloaded

**1**  
2017 PORT CF  
REGISTRY REPORT

**2**  
STANDARDS OF CARE  
FOR CYSTIC FIBROSIS  
IN NEW ZEALAND

**3**  
A GUIDE TO CYSTIC  
FIBROSIS FOR FAMILY,  
WHĀNAU AND FRIENDS

## Website by the numbers

**46**  
LATEST NEWS ARTICLES

**33,457**  
USERS

**32,556**  
NEW USERS

**91,461**  
PAGE VIEWS

### Facebook

Our public Facebook page has 4,825 followers and continues to be an important tool to engage with our community.

Our closed Facebook group has 475 members.

## Our most visited pages

**1**  
WHAT IS CYSTIC  
FIBROSIS?

**6**  
DONATE

**2**  
HOW IS CYSTIC FIBROSIS  
DIAGNOSED?

**7**  
LATEST NEWS

**3**  
WHAT CAUSES CYSTIC  
FIBROSIS?

**8**  
TREATMENTS

**4**  
FREQUENTLY ASKED  
QUESTIONS

**9**  
CAMPAIGN FOR  
TRIKAFTA

**5**  
TREATMENTS  
AND CARE

**10**  
ABOUT US



**“Being full time working parents we have limited time and are incredibly grateful for all the hard work that is being done by CFNZ on [advocating for Trikafta] and other medications for people with CF.”**

**“Amazing team at CFNZ who have raised the profile of CF in NZ over and above that ever achieved before and have also had tangible results – like access to devices through DHBs – that have not been achieved in the past.”**

# Research

Thanks to the generous donations from individuals and organisations, we've continued to fund New Zealand-based research studies to improve the lives of people with CF.

## Research highlights

### Port CF

Port CF is a New Zealand data registry owned by CFNZ. It uses anonymous patient data collected from children, young people and adults with CF in New Zealand to analyse trends in CF care.

New Zealand is part of a global project looking at harmonising CF data collected by countries holding CF registries. Associate Professor Cass Byrnes participates on behalf of NZ, to look at what data is collected and how it's collected to enable comparisons between countries.

NZ is also participating in a study run from Canada, comparing CF data between Canada, France, Australia and New Zealand. Initial results will be shared at the North American CF conference.

Port CF data has also been used to support the application to Pharmac for funding of Trikafta.

CFNZ showed great foresight in setting up a data registry years ago and this is now reaping rewards in being able to compare our CF population with other countries.

### Otago nebulised antibiotics research

With funding from Otago Museum Trust, the Otago nebulised antibiotics residue and resistance research entered Phase 2. This phase focuses on developing a practical nebuliser cleaning strategy (or strategies) to help reduce the risk of antibiotic resistance due to the variable disposal practices that were found during Phase 1.

Researchers will share their findings with the CF community and work to co-develop recommendations for the safe and practical disposal of antibiotic residue from nebulisers. It's hoped these findings can be shared more widely to help raise awareness of antibiotic resistance.

### Post lung transplant survey results

Last year we conducted a lung transplant recipient survey, to better understand the experiences of adults with CF who had received a lung transplant. Our aim was to find out their views on the health system, access to relevant support and information, ongoing care needs and any challenges post-lung transplant. We also asked for feedback on CFNZ services and support.

This year we collated the results, which highlighted three key findings.

### Overall, people's experiences were good

- People were positive, or at least pragmatic, about their lung-transplant experience.
- More than half reported no issues with care and support from the health sector or CFNZ.
- Financial support from CFNZ, such as transplant grants and Breath4CF, was appreciated.
- Some people reported they were treated differently post-transplant and lacked access to CF related support.
- More individualised care plans are needed to ensure concerns are acknowledged.

### Communication and information could be improved

- There was sometimes a disconnect and lack of communication between different health professionals and district health boards.
- Ongoing communication and information from CFNZ and other health professionals is needed long-term, not just in the early months post-transplant.
- More information before transplant was identified as an area for improvement.
- Recommendations about how and where to connect with other people post-transplant would be helpful.

### More specialist support needed

- All respondents had support from a transplant team and 10 people received ongoing support from their GP.
- Some respondents felt they were forgotten by their CF team post-transplant and would benefit from a combined CF and transplant clinic.
- Access to other specialists, including dermatologists and psychologists, and support with bowel, diabetes, fertility, liver and other health concerns was an issue for some people.

Recommendations from research for CFNZ and CF health professionals were received. We were delighted that the Auckland adult CF team has used the survey findings to set up a new annual review clinic for adults post-lung transplant. CFNZ and the Clinical Advisory Panel have used the findings to help improve post-transplant care.

# Mark Ashford Scholarship

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

### Emma Gawn

This year's winner is Emma Gawn, a 22-year-old marketing professional from Oamaru who now lives in Wellington.

Emma graduated this year from The University of Otago, Dunedin, with a double Communication Degree in Marketing and Economics and currently works for Mountain Buggy and Phil & Teds.

It was a big surprise when Emma found out that she'd been chosen as this year's recipient.

"When I got the phone call, I'd completely forgotten about it so I was pleasantly shocked. It was so exciting. It turned out to be perfect timing as my laptop had just broken so I was able to buy a new one and have some money left over to put into my savings," Emma says.

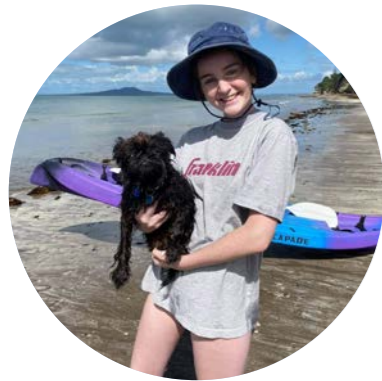
Emma advises anyone thinking of applying for the Mark Ashford Scholarship in the future is to go for it, and not underestimate what you've achieved.

"Even if you think what you've done isn't a huge achievement, you've done it while dealing with a lot of extra pressures and health worries. When I was working and studying at the same time people didn't know what was going on in the background. There were things like coughing all night but still making it to university each day, taking the time for treatments or having time out for hospitalisations. It means it's totally amazing you've achieved a degree when dealing with CF."



# CF Achievers' Awards

The Cystic Fibrosis Achievers' Awards are awarded annually to people with CF who have achieved excellence in any of four categories; leadership, the arts, sports or education. This year four individuals with CF have been recognised for their optimism, perseverance, and achievement in their chosen category.



## Gracie McDonald, Education

Eighteen-year-old Gracie is studying marketing and communications at The University of Auckland. Gracie and her family moved to Auckland from the UK when she was three. She was diagnosed with cystic fibrosis a year later but has never let it hold her back. Gracie achieved high academic results at college despite the fact she was often in and out of hospital and on IV antibiotics – a part of life with CF that many will understand.

"I was stoked when I found out that I was a CF Achievers' Award recipient; it made me feel like I had been heard – that my challenges were acknowledged by those who truly understand."

While Gracie was at school, she enjoyed history class. Achieving good marks was a big motivator for her, as she says, "it was one thing I had control over."

Gracie is pleased she can take a fraction of the financial burden of some of her medication off her family.



## Maisy Millwater, Education

Maisy, who lives in Hawea Flat, Otago, is age 16 and our youngest recipient this year.

She's an animal lover with four dogs, lots of chickens, and most recently, has acquired a wild kitten. Maisy has just started a distance Southern Institute of Technology course in pre-health science, with the dream of one day becoming a nurse – something she already knows a lot about.

"Sometimes you have to really push to get to do what you want to do," Maisy says.

The course Maisy is doing usually only accepts applicants aged over 17, but Maisy found out that SIT do consider people on a case-by-case basis.

"With a great supporting letter from a teacher, and the backing of my specialist, I was accepted," she says.

Despite quite a bit of time off school last year, Maisy managed to do very well in art.

It was her art teacher who decided to push her to apply for a CF Achievers' Award, with one of her referees saying, "Maisy is a person of enormous character and strength. She is consistently moral, practical, wickedly fun and fundamentally kind."

Maisy is grateful for the incredible teachers she has had, particularly those who introduced her to the different options and ways to study.



A huge thank you to Viatris, makers of Creon, for sponsoring this award.



## Simon Cowley, Leadership

Last November, 19-year-old Simon achieved his Queen Scouts Award. Presented by the Governor General, this award is the highest achievable youth award within Scouting New Zealand, achieved by only 50 people last year.

To qualify, Simon had to complete a range of activities in a set period, including community service, multi-day expeditions in a bush environment and personal and leadership development.

Simon took this adventure in his stride, and at the same time gained skills in organising his medication on the trips away with limited resources and learned how to manage his health in less-than-optimal weather conditions.

Simon has also gained knowledge in managing people and groups of all ages.

"These skills have given me the resources to go into a career in outdoor education and leadership."

Receiving the CF Achievers' Award for leadership has enabled Simon to invest in items he needs for his future career too.

In-line with his Scouting, Simon loves mountain biking, rock climbing, hiking, kayaking and all outdoor pursuits, and looks for any excuse to go camping with his friends. He's working towards his diploma in outdoor and adventure education, which will allow him to go into teaching, guiding and leading groups in the outdoor industry.



## Reese Robertson, Sport

Reese is from the Wairarapa and is studying a bachelor's degree in health psychology at Victoria University.

Reese has been awarded her CF Achievers' Award for her incredible involvement, leadership and achievements in sport, namely hockey.

"I play for the Dalefield Premier Women's 1 hockey team, which competes in the top Wellington hockey league. I will also be a part of the Wairarapa Women's team later this year in the National competition where there is a tournament in Tauranga."

Throwing-back to school, Reese was in the Wairarapa College 1st XI hockey team for five years, played over 120 games, and was captain for the final two years. She also captained the Wairarapa Representative teams in U13s, U15s and U18s.

"In years 12 & 13 it was an honour to be presented with the Kim Condon Cup for Best All Rounder Girls' 1st XI hockey."

Reese is keen to continue doing her degree, while also playing for the Dalefield Premier Women's 1 team for the next three years, out of passion, but also, she finds playing is a good way to keep fit.

"Sport is something that I've been passionate about my whole life, and I'm very grateful to have been recognised as someone living with CF doing well in sports."

Reese would like to thank her coaches and family for giving her the push she needed to apply for the award.

# 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.

## Superhero partners



## Champion partners



## Hero partners



## Major Funders



# Trusts and foundations

## Trusts and foundations

AD Hally Trust – proudly administered by Perpetual Guardian  
 Air Rescue Services Ltd  
 Akarana Community Trust Ltd  
 Bendigo Valley Sports & Charity Foundation  
 Blue Sky Community Trust Ltd  
 Blue Waters Community Trust  
 Canterbury District Health Board  
 Central Lakes Trust  
 COGS - Auckland City  
 COGS - Central Otago  
 COGS - Coastal Otago/Waitaki  
 COGS - Hutt Valley  
 COGS - Kahungunu Ki Heretaunga  
 COGS - Kirikiriroa/Hamilton City  
 COGS - Manawatu/Horowhenua  
 COGS - Manukau  
 COGS - Marlborough  
 COGS - Mataatua  
 COGS - North Taranaki  
 COGS - Papakura/Franklin  
 COGS - Rodney/North Shore  
 COGS - Rotorua  
 COGS - South Taranaki  
 COGS - Southland  
 COGS - Tauranga/Moana  
 COGS - Tongariro  
 COGS - Waikato South  
 COGS - Wairarapa  
 COGS - Waitakere City  
 COGS - Wellington  
 COGS - Whanganui/Waimarino/Rangitikei  
 COGS - Whangarei/Kaipara  
 COGS - Whitiareia  
 Community Trust of Mid & South Canterbury  
 Community Trust South  
 David Ellison Charitable Trust  
 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 – proudly managed by Perpetual

Guardian  
 Hawke's Bay Community Foundation  
 Hugo Charitable Trust  
 Hutt Mana Charitable Trust  
 Infinity Foundation  
 JBS Dudding Charitable Trust  
 John Ilott Charitable Trust  
 Kingston Sedgfield Charitable Trust  
 Lottery Grants Board  
 Louisa & Patrick Emmett Murphy Foundation  
 LW Nelson Charitable Trust  
 Mainland Foundation  
 Margaret & Huia Clarke Trust – proudly managed by Perpetual Guardian  
 Milestone Foundation  
 Norah Howell Charitable Trust  
 New Zealand Community Trust  
 Oxford Sports Trust  
 Pelorus Trust  
 Rano Community Trust  
 Rata Foundation  
 Redwood Trust  
 Robert & Barbara Stewart Charitable Trust  
 Roy Owen Dixey Charitable Trust  
 Stewart Family Charitable Trust - proudly managed by Perpetual Guardian  
 Te Hiringa Hauora/Health Promotion Agency  
 The Kingdom Foundation – proudly managed by Perpetual Guardian  
 The Lighthouse Foundation  
 The Lion Foundation  
 The Southern Trust  
 Trillian Trust  
 Trust Aoraki  
 Trust Waikato  
 The Trusts Community Foundation  
 Vernon Hall Trust – proudly managed by Perpetual Guardian  
 W. Duncan Bickley Trust Fund – proudly managed by Perpetual Guardian  
 Wellington Children's Foundation  
 Whanganui Community Foundation  
 Youthtown Inc

Thank you also to the bequests and 'in memoriam' donations we also received this year.



# Financial summary 2021

## Statement of Financial Performance – For the year ended 30 June 2021

	30 June 2021	30 June 2020
<b>REVENUE</b>		
Fundraising Revenue	610,105	731,258
Donations and Bequests	439,572	368,893
Grants	365,508	346,473
Sponsorships	69,950	70,105
Contract Revenue	84,000	75,000
Interest and Dividends	64,223	135,522
Subscription from Members	1,497	7,647
<b>TOTAL REVENUE</b>	<b>1,635,855</b>	<b>1,734,897</b>
<b>EXPENSES</b>		
Expenses related to public fundraising	366,457	388,592
Volunteer and employee related costs	654,699	549,149
Costs related to providing goods and services	251,949	349,090
Grants and donations made	276,898	312,747
Other Expenses	58,698	53,483
<b>TOTAL EXPENSES</b>	<b>1,608,701</b>	<b>1,653,060</b>
<b>SURPLUS/(DEFICIT) FOR THE YEAR</b>	<b>27,154</b>	<b>81,837</b>

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

	30 June 2021	30 June 2020
<b>ASSETS</b>		
<b>Current Assets</b>		
Bank accounts and cash	1,221,152	1,052,538
Debtors and prepayments	81,347	89,021
Other Current Assets	26,127	24,586
<b>Total Current Assets</b>	<b>1,328,626</b>	<b>1,166,145</b>
<b>Non-Current Assets</b>		
Investments	793,705	834,654
Property, Plant and Equipment	20,093	16,484
<b>Total Non-Current Assets</b>	<b>813,799</b>	<b>851,138</b>
<b>TOTAL ASSETS</b>	<b>2,142,424</b>	<b>2,017,283</b>
<b>LIABILITIES</b>		
Current Liabilities	145,155	95,039
Unexpected Grants	111,481	63,609
<b>TOTAL LIABILITIES</b>	<b>256,636</b>	<b>158,648</b>
<b>TOTAL ASSETS LESS TOTAL LIABILITIES (NET ASSETS)</b>	<b>1,885,789</b>	<b>1,858,635</b>
<b>Accumulated Funds</b>		
Accumulated surpluses or (deficits)	1,858,789	1,858,635
<b>TOTAL ACCUMULATED FUNDS</b>	<b>1,858,789</b>	<b>1,858,635</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 2021

## Board

**Warwick Murray**  
Board Chair

**Denis Currie**  
President

**Michele Wilson**  
Board Member

**Rebecca Colley**  
Board Member

**Chris Shanks**  
Board Member

**Alex McKay**  
CF Adult Representative

**Jaggar Bootten**  
Board Intern

**Patrons**  
Professor Bob Elliott  
Peter Miskimmin

## Sub-committees of the Board

### The Clinical Advisory Panel

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

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

## Members of the CAP

**Associate Professor Cass Byrnes**  
Paediatric Respiratory Specialist,  
Starship Children's Hospital

**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

**Andrew Cameron**  
CFNZ Board member

**Jane Bollard**  
CFNZ Chief Executive

**Warwick Murray**  
CFNZ Board Chair

## 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

**Angela Crates**  
Administration Manager  
(From February 2021)

**Irene Vanderlaan**  
Office Manager/Accounts  
(until Dec 2020)

**Susan Lovelock**  
Southern Fieldworker

**Gretchen Kitching**  
Northern Fieldworker

**Jude Kelly**  
Lower Central Fieldworker

**Chani Venter**  
Upper Central Fieldworker

**Laura Huet**  
Fundraising and Marketing Manager

**Lizzie McKay**  
Communications Coordinator

**Jeanette Franklyn**  
Grants Coordinator

**Nashwa Soliman**  
Database and Fundraising Administrator

**Sarah Connolly**  
Auckland Branch Coordinator  
(until May 2021)

**Jan Tate**  
Port CF Project Coordinator

## Branch office holders

**Northland**  
Mike Webb (Chair)  
Janet Webb (Treasurer)

**Auckland**  
Jill Thorrat (Co-chair)  
Jane Drumm (Co-chair)  
Allyson Harvey (Treasurer)

**Waikato**  
Annelies Baker (Chair)  
Alice Bell (Treasurer)

**Taranaki**  
Shelley Gruchy (Chair)  
Joan Tuffery (Secretary)

**Hawke's Bay**  
John Parsons (Chair)  
Pip Harper (Treasurer)  
Claire Fisher (Secretary)

**Central Districts**  
Coralie Harvey (Chair & Treasurer)  
Nigel Ramsden (Secretary)

**Wellington**  
Paula Richards (Chair)  
Beth Hughson (Treasurer)

**Nelson**  
Rebecca Colley (Chair & Treasurer)  
Rachel Tobin (Secretary)

**Canterbury**  
Melissa Skene (Chair)  
Viv Isles (Treasurer)

**Otago**  
Jeremy Byfield (Secretary & Treasurer)

**“CFNZ works tirelessly to support and foster the wellbeing of the community. Their support extends through advocacy, medical research, “holding the hands” of individuals, support in the community, fundraising and a host of other mechanisms to ensure the objectives of CFNZ are met.”**