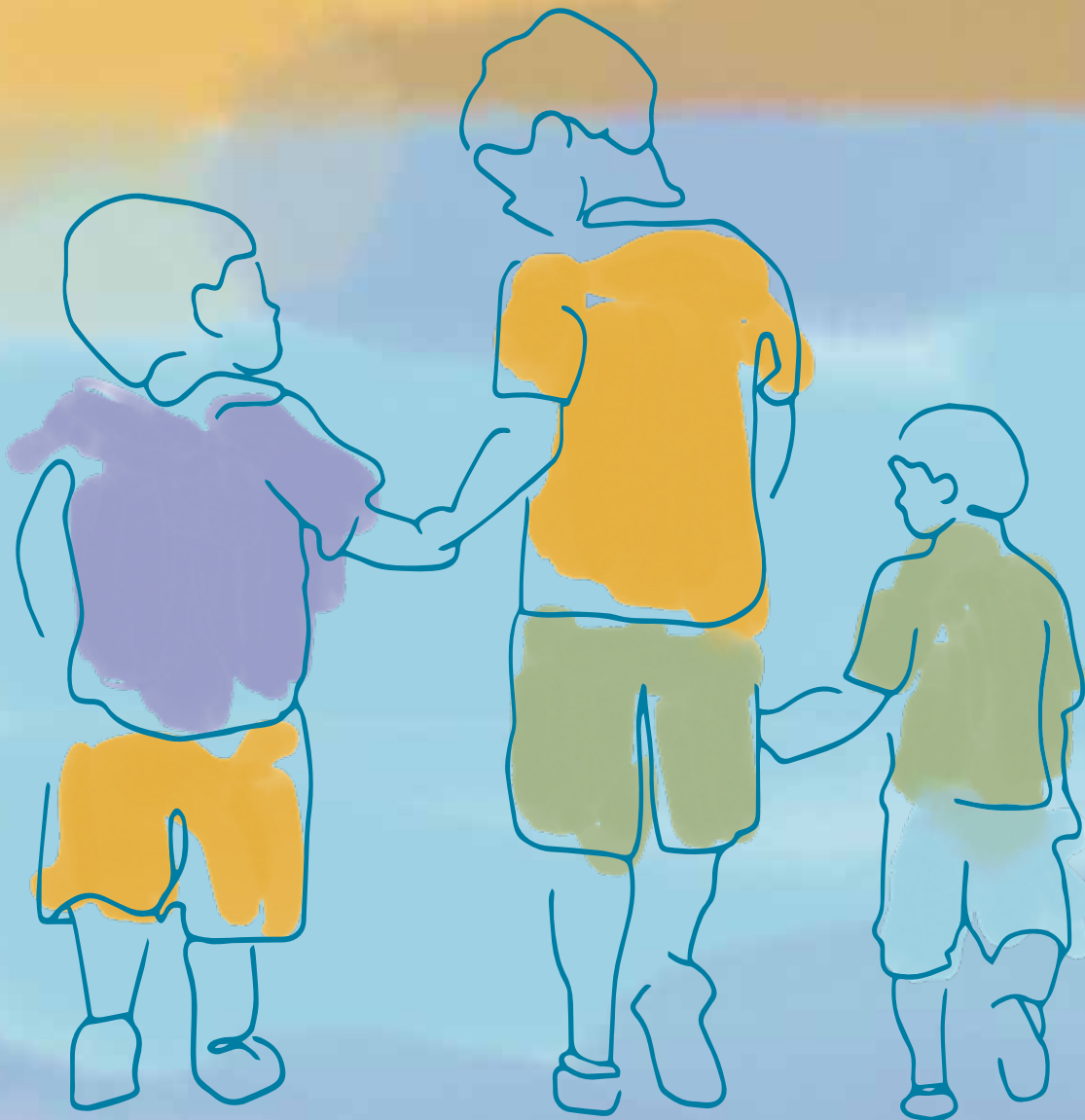




ANNUAL REPORT 2022



For the financial year ending 30 June 2022

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♡ Lizzie

All the illustrations through this report are created by one of our community members, and Communications Manager. Thanks Lizzie McKay.

OUR VISION

People with cystic fibrosis are thriving, living a life unlimited by their condition, and fully participating in life on their terms.

OUR MISSION

To empower people with CF, their families and whānau to have quality of life and wellbeing, through the delivery of high-quality and equitable support programmes.

OUR STRATEGIC GOALS

- A strong CFNZ
- We have strong communities
- Access to world class medicines and treatments
- High quality individualised care
- People with CF are connected to support, information and education

OUR VALUES

Engage with passion

Value equity

Work together

Behave innovatively

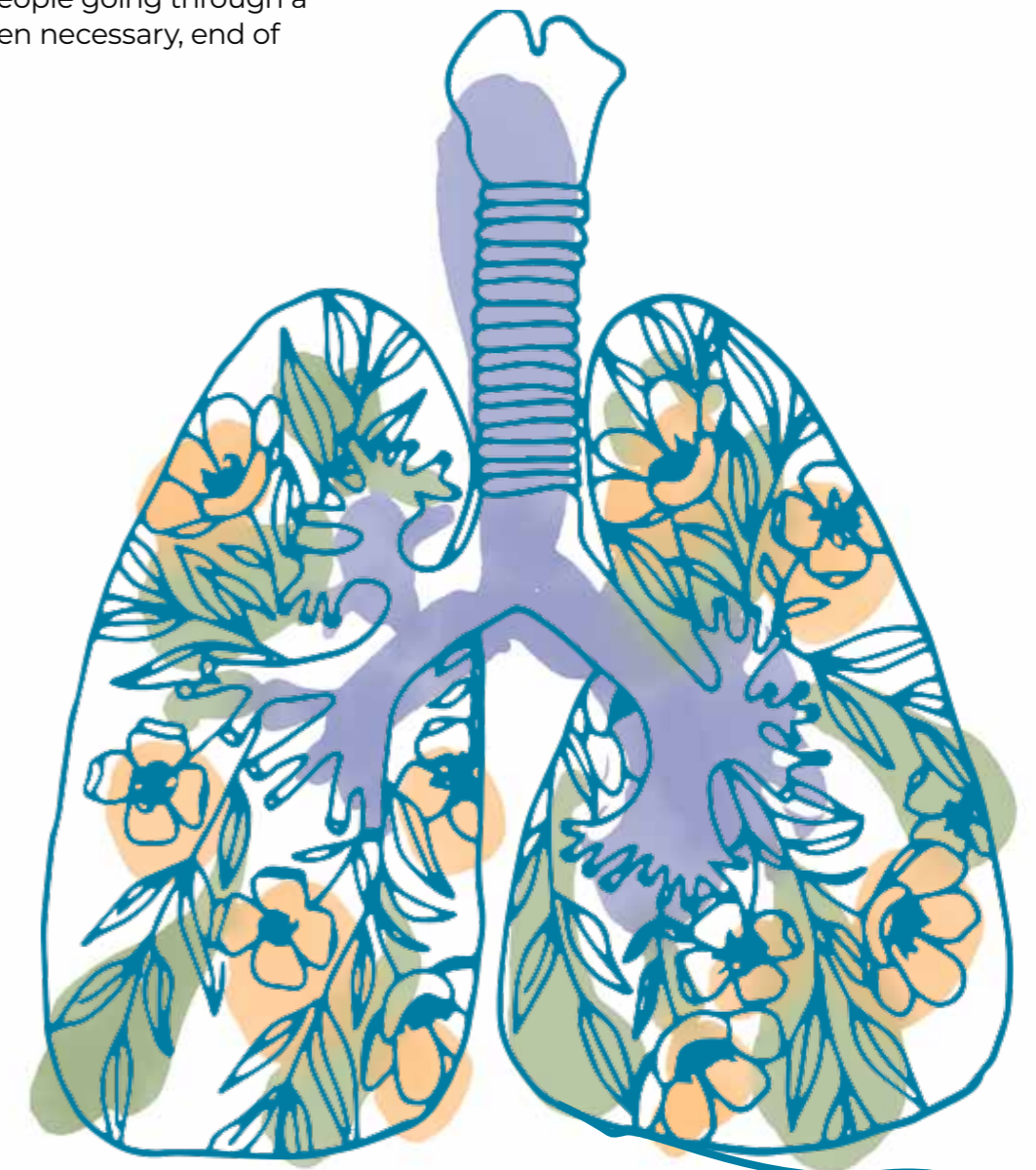
ABOUT CYSTIC FIBROSIS NZ

Cystic Fibrosis NZ is a charity dedicated to supporting the CF community by providing information, advice, and financial assistance to those with CF and their families throughout their journey with CF. We also advocate for access to world class medical care and modern medicines.

Our team of social workers visit and support families in their homes and medical settings. We provide parent-to-parent support, vouchers and allowances during hospitalisations, welfare assistance during hardship, medical equipment, assistance to our people going through a transplant and, when necessary, end of life support.

Cystic Fibrosis NZ also supports a comprehensive data registry containing clinical and other information about those with CF in New Zealand. The data registry provides an invaluable source of information to support assessment of health needs and applications for funding of medicines.

Cystic Fibrosis NZ receives less than 4 per cent government funding and relies on the generosity of New Zealanders to meet the ongoing needs of our community.



A WORD FROM OUR BOARD CHAIR



Following the 54th year of CFNZ, it's time to step back, reflect on our achievements and look to the challenges ahead.

We weathered the early COVID-19 period well, beginning the year in good financial shape. However, there was considerable uncertainty and disruption ahead. COVID was still very much with us, we needed to recruit and induct a new Chief Executive, and branches were continuing to struggle to find volunteers and raise funds.

Our highest priority was achieving public funding for Trikafta and other modulator drugs, while we remained committed to maintaining the same level of support for our CF community.

At the time of writing, Pharmac has yet to announce a decision to fund Trikafta. Although this is incredibly disappointing and frustrating, we've made significant gains toward achieving this goal. Thanks to the huge effort by our CFNZ team and the bravery of those from our CF community that shared their stories, we've significantly increased public awareness of the benefits of Trikafta. Although many deserve our heartfelt thanks, I would particularly like to acknowledge the contribution of Carmen Shanks in setting up and promoting her petition, which got the right people talking about Trikafta.

Our carefully crafted Trikafta campaign, created alongside the support from our Clinical Advisory Panel, helped us

maintain our credible voice and build relationships with key decision makers and politicians.

I feel for those who desperately need this drug for their survival but remain confident that success is not far away.

Over the past year, I'm pleased we largely maintained our level of service to support our CF community. The pandemic put real constraints on Fieldworkers, particularly for face-to-face support, and the need to replace two of our four Fieldworkers added an additional challenge.

Despite all this, we achieved 660 support initiatives compared to 690 last year. The Board is looking forward to seeing the results of the CF Journey project, which seeks to gather a deeper understanding of our community experience and what improvements can be made to the level of support we offer.

It continues to concern the Board that some branches are struggling to find volunteers at a local level to provide mentoring and support for CF families. Part of our future focus will be on providing better support to deliver this.

Financially, CFNZ is still in a reasonably sound position. With net assets of around \$1.8m (down from \$1.88 last year), we have an acceptable buffer to weather future storms or fund key projects. However, we ended the year with a total deficit of

around \$80,000. A surplus at the National Office has masked a collective branch deficit of around \$150,000. This reflects the challenges branches are having with fund-raising, and while many branches still have the assets to fund this deficit, it is not sustainable. It is important to discuss as a wider organisation our future priorities, what we spend funds on, and more specifically, how we fund B4CF and welfare around the country.

The Board was delighted to appoint Lisa Burns as our new Chief Executive in 2021. She's managed critical issues like COVID-19 mandates alongside getting to grips with a new organisation, exceedingly well and has already made some significant achievements. I'd like to thank Christine Perrins for the support she provided in maintaining the ship during that critical period after Jane left, and for her pro-bono contribution to managing our Trikafta campaign.

Focus for the year ahead:

Gaining public funding for Trikafta and other modulator drugs will remain our biggest challenge and a key focus for the board.

Our community regularly raises the inconsistency in the level of clinical care that people with CF receive around the country. As a well-known health charity, we must use our status to influence decisions made within health reforms to ensure consistent, quality clinical care, regardless of where they are in the country.

It's critical we address the role of branches and the struggles they have attracting volunteers and raising funds. This has implications for our constitution and how we operate and was not fixed with our previous organisational review process.

While we have challenges ahead, we also have some incredible opportunities. We are well-placed with a sound financial base, a strong team at the National Office, and a wide team of dedicated volunteers. I'd particularly like to acknowledge and thank our volunteers and donors who, year after year, come back and help because they know it makes a real difference in people's lives.

A handwritten signature in blue ink that reads "W. Murray".

WARWICK MURRAY
CHAIR, CFNZ BOARD

STATEMENT FROM CHIEF EXECUTIVE



I had the honour of joining CFNZ as the new Chief Executive in November 2021. It is a great privilege to be leading both this organisation and our CFNZ community into the future.

COVID-19 has been a real challenge for both our team and our community. Times are tough for most charities in NZ due to the pandemic, growing inflation, the cost-of-living crisis, and evermore competition for the charity dollar. A significant number of challenges in maintaining expenditure levels, and a reduction in fundraising revenue, led to a deficit in our forecasted results. We must continue to broaden our base of supporters, and look at ways to creatively grow our revenue through new channels.

Despite the disruption, our people proved to be resilient and adaptable. For part of the last year, our Fieldworkers were working remotely, unable to attend clinics or visit our community in hospital. I am so proud of how the team navigated this time and managed the risks during a prolonged period of both uncertainty and anxiety. However, there have been many achievements against our five strategic goals over the past 11 months, many of which I share below in my year-end report.

We need to create a strong, stable, sustainable, and predictable revenue strategy that allows us to be fit for purpose now and into the future. This includes a constitution that is well constructed to support our future ambitions, so this

will be a priority for the coming months. We are committed to delivering on the present and future needs of people with CF and their families.

Advocating for better access to world class medicines and treatments remains one of the top priorities for CFNZ, and we've taken huge strides forward over the past year. Fighting hard to keep Trikafta top of mind has been achieved through the incredible, dedicated support and commitment of the media and our community, many of who bravely shared their stories.

In the past 12 months, we have written letters, held meetings with MPs, Pharmac and Vertex, made submissions for the Pae Ora Health Legislation, and a further submission, both written and oral, to the Health Select Committee in support of Carmen Shanks' petition.

In August Pharmac acknowledged the major benefits of Trikafta. This included not only savings to the health system but also estimated improvements to quality of life, equivalent to 27 more years at full health when compared to currently funded treatments.

Advocacy and awareness aren't just about Trikafta. We want to drive systemic change via advocacy programmes, raising awareness while building relationships with stakeholders, and exceptional communication will allow us to deliver better outcomes.

While we will remain focused on getting public funding for Trikafta, we acknowledge that it is not a cure and won't be suitable for everyone with CF. This is why we are fully committed to a diverse and innovative programme of advocacy work and support programmes to ensure we can provide all people living with CF in New Zealand the support they need.

Our CF Awareness Month Campaign Cruel Needs Kind was also a big part of our advocacy strategy. Against significant competition, Cruel Needs Kind helped CFNZ raise both its profile and funds in the short term (+146% of our target). For the long term, it has helped establish an enduring identity in FRED Bear and strengthened our supporter base.

We want to foster an environment of trust and listening, one that means we can explore solutions together to better meet needs. We have an incredible community that supports each other so we will continue to find ways to improve our ability to connect and strengthen them.

Our support programmes continue to be accessed by all those who need them with 318 Breath 4 CF Grants, 203 Welfare Grants and several other discretionary grant payments made during the FY22 financial year. We are committed to offering direct help where possible, as well as a wide range of additional information, guidance and support where needed.

2022 also saw five winners of the CF Achievers Awards and a winner and two runners-up for the Mark Ashford Scholarship.

Kiwis living with CF in New Zealand have the right to access the highest standard of care regardless of where they live. While much of this is out of our control in the clinical setting, we are committed to working with our Clinical Advisory Panel to gain a deeper understanding of the variations in care.

We are working on a refreshed blueprint for the organisation looking out over the next five years, giving our community and the CFNZ team direction and inspiration to continue as a leading provider of support for the community of people living with cystic fibrosis in Aotearoa. Our 54-year history in New Zealand is an impressive legacy, and this plan will continue to build on the remarkable work we have already achieved.

Our organisation touches the lives of many, making a significant impact on the quality of life and wellbeing of our community.

It is my hope to accelerate outcomes for our cystic fibrosis community by being collaborative, results focussed, people-centric, and community-led. Recent changes in the wider health and disability sector, including the establishment of Health New Zealand and the Maori Health Authority, present CFNZ with the opportunity to reset, future-proof, and ensure we continue to align with the changing reality for those who require our support and care.

A handwritten signature in black ink that reads "Lisa Burns". The signature is fluid and cursive.

LISA BURNS
CHIEF EXECUTIVE, CFNZ

FAREWELLS

Those community members that have passed on this year.

Dean Toia-Levy
Waikato
Age 19
15/7/21

Ryan Marsden
Central Districts
Age 33
30/7/21

John Wallace
Canterbury
Age 71
12/1/22

Joe Muru-Haenga
Wellington
Age 21
21/1/22

Troy Stapleton
Wellington
Age 43
8/3/22

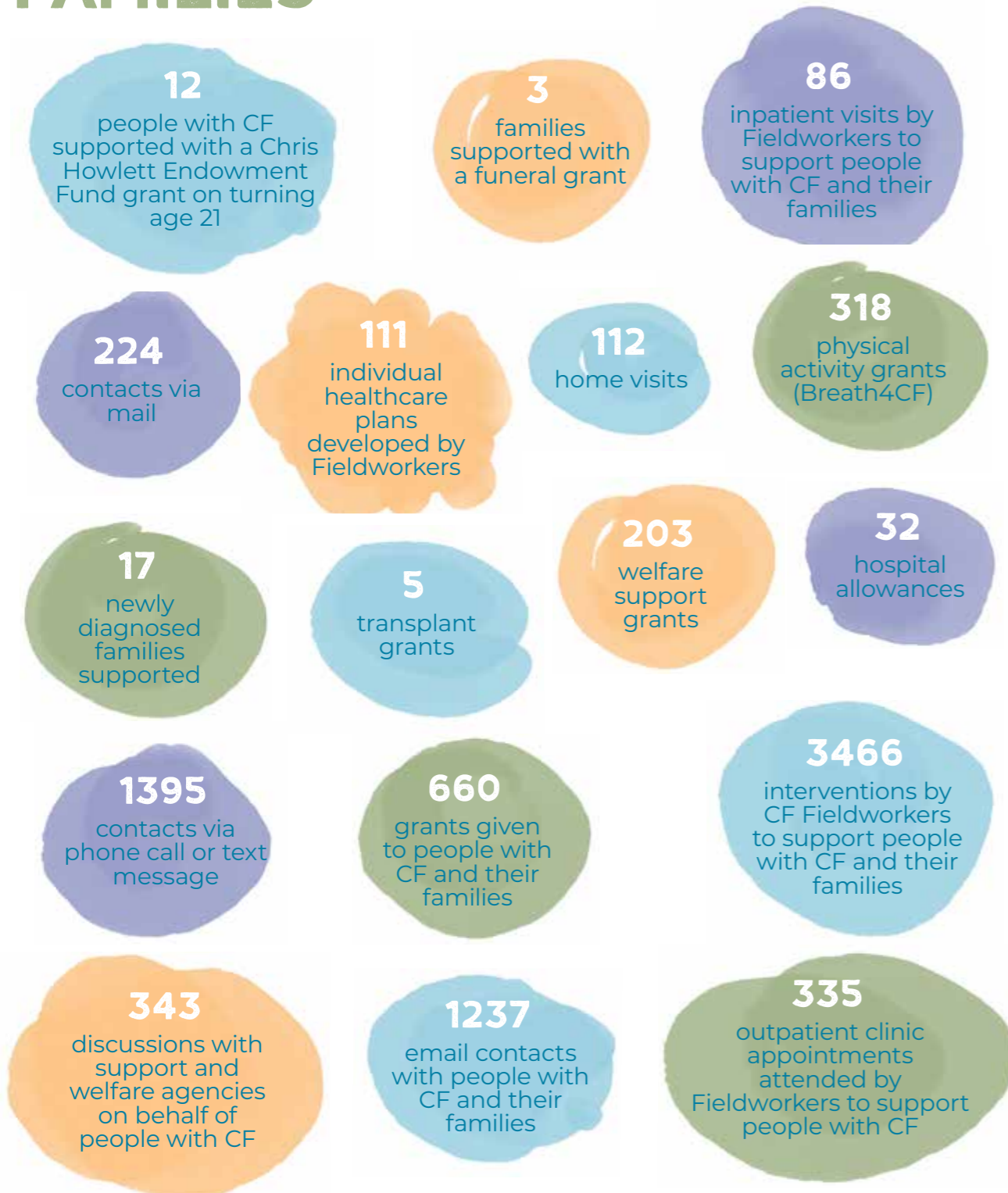


SOMETHING BEAUTIFUL REMAINS

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



SUPPORT FOR PEOPLE WITH CYSTIC FIBROSIS AND THEIR FAMILIES



Due to COVID face-to-face interactions were down, there was an increase in phone, email and mail contacts and the overall number of interventions remained stable.

FIELDWORKERS



Sue



Gretchen



Bev



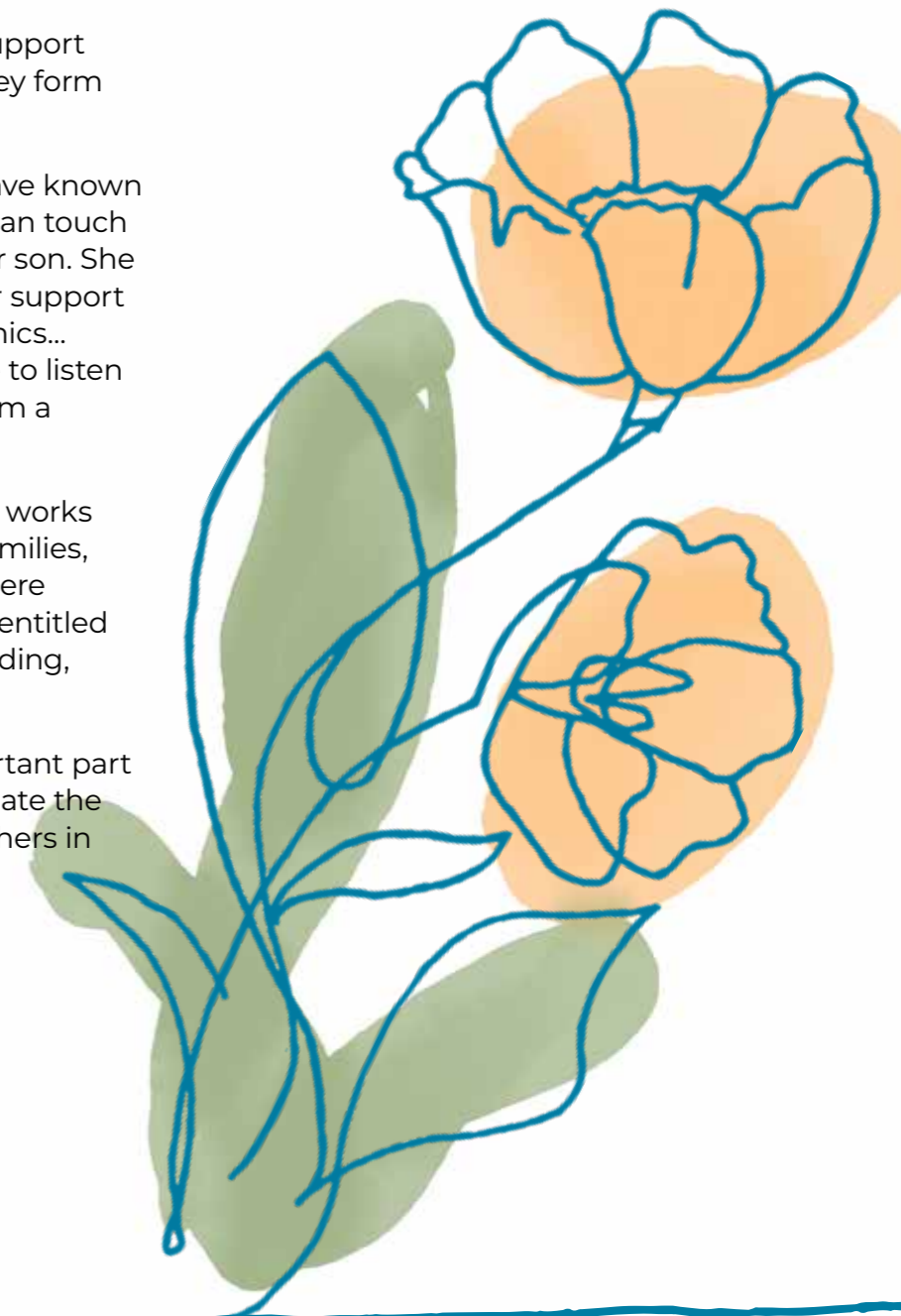
Carolyn

"Our Fieldworker was an amazing support when we were newly diagnosed. They form good relationships with families."

"Our Fieldworker is a treasure, we have known her for years and she adds that human touch to this CF journey we are on with our son. She can put you in touch with people for support also nice to have a smile when at clinics... Sometimes it's just having someone to listen to that isn't always talking to you from a medical point of view."

"Having a social worker that actually works with the people with CF and their families, and keeps in contact, offers help where needed, and explains what they are entitled to and when, e.g. criteria around funding, benefits etc helps in a huge way."

"The Fieldworkers are such an important part of our CF journey. They help to navigate the system, as well as helping us find others in the community."



ADVOCACY AND AWARENESS

The past year has been a remarkably busy one for advocacy, with increasing awareness of cystic fibrosis, major change in the health sector, and a damning report into the performance of Pharmac particularly in relation to those with rare disorders.

But the primary focus of the year for CFNZ has been the campaign to have Trikafta publicly funded, and to ensure that every Kiwi with CF has access to a CFTR modulator therapy that would benefit them.

The past year was a rollercoaster ride with hopes and expectations raised and then cruelly dashed. It was also a year of significant delay, reassessment, and of uncertainty. Sadly, as we move into late 2022 this has not changed.

The year began well with Vertex submitting its application to Pharmac to have Trikafta funded for those aged 6 years and over – a world first for the 6-11 age group. At the same time, Vertex established a Managed Access Programme to provide Trikafta free of charge to Kiwis with CF in critical need.

In addition to the Vertex application for Trikafta, a member of the CF community applied to Pharmac to widen access to Kalydeco by adding more CF mutations to the current eligibility criteria.

The good news continued in October 2021 when Pharmac announced that its respiratory experts had recommended a high priority for funding Trikafta for those aged 6 years and over, that Pharmac wanted to fund it, and that it had added Trikafta to its Options for Investment List.

Pharmac's announcement raised the expectations of the CF community who dared to hope that it wouldn't be too long

before Trikafta was funded in New Zealand. This view was reinforced in December 2021 with Medsafe granting consent for the use of Trikafta in New Zealand following a priority approval process.

But things went downhill very quickly in February 2022 with the announcement by Pharmac that its Pharmacology and Therapeutics Committee (PTAC) had recommended only a medium priority for funding Trikafta for those aged 12 years and older. PTAC also deferred a decision on those aged 6-11 years.

PTAC's assessment made clear that it did not properly understand Trikafta and the extent to which it would benefit those with CF. CFNZ and CF clinicians made their views on PTAC's assessment clearly known to Pharmac. This led to another round of committees, with Trikafta being considered for a second time by Pharmac's respiratory experts in April and by PTAC in May. Pharmac's respiratory experts also considered the application to widen access to Kalydeco.

The outcomes of these reassessments were released in August 2022 when Pharmac announced that its respiratory experts had again recommended a high priority for funding Trikafta for those aged 6 years and over, with PTAC recommending a medium priority for those aged 6+. Pharmac's respiratory experts also recommended high priority for widening access to Kalydeco.

At the same time, Pharmac released its Technology Assessment Report (TAR) containing its assessment of the cost effectiveness of Trikafta. Pharmac reconfirmed that it wanted to fund Trikafta, as well as advising that its assessment showed Trikafta would provide an extra 27

years at full health for a person with CF – almost doubling current life expectancy.

Hopes and expectations were again raised by these announcements and the CF community eagerly awaited the outcome of Pharmac's September 2022 ranking meeting. But those hopes were dashed yet again as Pharmac advised CFNZ that it would not be progressing funding of Trikafta at this time.

The raising and dashing of hopes over the past year and the uncertainty of if or when Trikafta will be funded and access to Kalydeco widened continue to cause significant distress to those with CF, their families, and whānau.

Many people are considering whether they should stay in New Zealand and wait for funding or make life-changing decisions to move overseas to access the medicines they so desperately need. But they can't wait forever. They need certainty and they need it now.

Those who do not have the option of moving overseas have to continue to live with the distress of knowing there is a medicine that could save their lives but that they cannot have access to it.

It is simply unacceptable in a first world country that a medicine that would provide an extra 27 years of full health and almost double life expectancy is not funded. It clearly demonstrates that the current system for funding modern medicines is broken and that there needs to be urgent change. Without that change, thousands of sick and vulnerable Kiwis will continue to experience needless suffering and early death.

We will continue to do all we can to make sure that does not happen.

Thank You

Our sincere thanks go to those people who have helped raise awareness of CF and the urgent need for CFTR modulator therapies and kept the issue in the public eye.

Thank you to the media for helping to tell what the heart-breaking stories that people have to tell.

Thank you to Vertex for establishing the Managed Access Programme for Trikafta, providing a safety net for those Kiwis with CF in greatest need. There is no doubt that this Programme has changed lives for the better and provided real benefit to the New Zealand health system. But the Programme is no substitute for public funding of Trikafta and Kalydeco for all those who would benefit.

The greatest thanks must go to all of those within the CF community who have courageously shared their stories and campaigned to raise awareness of the major challenges of living with CF and the urgent need for medicines like Trikafta and Kalydeco.

Particular thanks go to Carmen Shanks of Trikafta for Kiwis for leading the petition to have Trikafta publicly funded and for presenting her story in person to the Health Select Committee. To gain 43,410 signatures and wide media coverage was a major achievement. Thank you, Carmen.



ADVOCACY TIMELINE

ACCESS TO CFTR MODULATOR THERAPIES

2021

July 2021

Vertex submits its application for funding of Trikafta to Pharmac, a major step forward in securing access for Kiwis with CF.

CFNZ submits a comprehensive package of information about the challenges of CF and the current health needs of the CF community to Pharmac to support Vertex's application for Trikafta.

Vertex establishes a Managed Access Programme in New Zealand to provide Trikafta free of charge to Kiwis with CF who are in critical need.

August 2021

Pharmac's Respiratory Sub-Committee considers Vertex's application for funding of Trikafta.

A member of the CF community makes a consumer application to Pharmac to widen access to Kalydeco. The application seeks approval to have additional mutations added to Pharmac's existing access criteria for Kalydeco.

October 2021

The Respiratory Sub-committee's record is released, recommending a high priority for funding for people with CF aged 6 years and over.

The Sub-committee calls Trikafta a paradigm-shifting treatment. Pharmac confirms that it wants to fund Trikafta and adds it to its Options for Investment list.

November 2021

Pharmac's Pharmacology and Therapeutics Committee (PTAC) considers Vertex's application for Trikafta.

December 2021

Medsafe, New Zealand's Medicines and Medical Devices Safety Authority, gives consent for the use of Trikafta in New Zealand following a priority approval process.

2022

January 2022

Medsafe grants consent for the use of Symdeko in New Zealand. Symdeko is one of the four CFTR modulator therapies manufactured by Vertex.

February 2022

Pharmac releases the record of PTAC's November 2021 meeting. PTAC recommends only a medium priority for funding Trikafta for those aged 12 years and over and defers a decision for those age 6 to 11 years.

March 2022

Carmen Shanks presents her petition for public funding of Trikafta to Shanan Halbert, MP.

The petition, which had 43,410 signatures, is presented to the House of Representatives and referred to the Health Select Committee for consideration. The Health Select Committee invites Carmen and CFNZ to make submissions.

Trikafta is listed on the Pharmaceutical Benefits Schedule in Australia for those aged 12 years and older.

April 2022

Pharmac's Respiratory Advisory Committee considers Trikafta for the second time. The Committee also considers the consumer application to widen access to Kalydeco.

Carmen Shanks and CFNZ provide written submissions to the Health Select Committee in support of Carmen's petition to have Trikafta publicly funded.

May 2022

Pharmac's PTAC considers Trikafta for the second time.

June 2022

Carmen Shanks and CFNZ present to the Health Select Committee hearing into Carmen's petition to have Trikafta publicly funded.

OTHER ADVOCACY INITIATIVES

2021

October 2021

The Minister of Health introduces the Pae Ora (Healthy Futures) Bill into Parliament. The Bill proposes the amalgamation of District Health Boards, the establishment of Health New Zealand and the Māori Health Authority, and sets out arrangements for Pharmac.

December 2021

CFNZ makes a submission on the Pae Ora (Healthy Futures) Bill seeking to ensure that people with CF have access to high quality care wherever

they live, access to up to date medicines. CFNZ also seeks change to the arrangements for Pharmac.

The Minister of Health releases the Interim Report of the Pharmac Review Panel. The Interim Report concludes that Pharmac is underperforming in addressing inequitable health outcomes and that its prioritisation approach disadvantages Māori, Pacific peoples, people with disabilities, and those with rare disorders.

January 2022

CFNZ presents its submission on the Pae Ora (Healthy Futures) Bill to the Pae Ora Legislation Committee.

May 2022

Government announces additional funding of \$171 million for Pharmac in its May Budget. The additional funding is spread over two years with \$71 million in 2022/23 and \$120 million in 2023/24. The funding is not enough to enable Pharmac to fund the more than 70 medicines on its Options for Investment list.

June 2022

The Minister of Health releases the Pharmac Review Panel's Final Report. The Final Report makes 33 recommendations for change and highlights significant problems with the way Pharmac works.

These problems include serious deficiencies in its decision-making process and the quality of its decisions, a failure to incorporate the lived experience of patients into decisions about medicines, and a lack of transparency and

timeliness. The Final Report also concludes that those with rare disorders are being disproportionately impacted by negative health outcomes and systemic failings.

The Minister of Health accepts the bulk of the Review Panels' recommendations and promises change, saying that getting the cheapest possible drugs isn't the only health strategy.

CFNZ writes to the Minister of Health urging him to advise Pharmac that he

expects them to give priority to funding medicines for rare disorders in addition to cancer medicines. Other rare disorder organisations write to the Minister supporting this request.

The Pae Ora (Healthy Futures) Act 2022 is given Royal Assent and comes into effect on 1 July 2022. The Act makes no changes to Pharmac's objectives and functions.

FUNDRAISING AND AWARENESS

SWEATEMBER CAMPAIGN

In September 2021 our annual awareness and fundraising campaign SWEATEMBER launched. We again 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 \$164,000 for vital support services, and saw 324 people get their sweat on, and over 2702 people donating in support.

This is Reese one of our Sweatember champions.



WELLINGTON CHRISTMAS TREE FESTIVAL

It is heart-warming to see such amazing support again with 47 Christmas trees making the Wellington terminal shine, after 24 long months full of unknowns. An amazing 15 new businesses got involved in the fun, joining 32 who had already been supporting CFNZ in previous Christmas Tree Festivals. These businesses and organisations truly came together to make the airport come alive with the “magic of Christmas”.

Every year, the team works tirelessly to prepare for the event. The trees are placed into groups the night before set-up, they are fluffed up by a group of people generously volunteering their time, and lights are installed in the morning before the sponsors and fairies come in to decorate. The sponsors arrive throughout the afternoon to create their master pieces - they also get a chance to have a look at what others are creating. After everyone has left, the trees are plugged in and festival is staged - ready for the Gala Opening Evening.

The festival is a success due to the support of Wellington Airport, and all the sponsors who put in an enormous amount of effort to create unforgettable trees. CFNZ is immensely grateful for all the support and love shown through the Christmas Tree Festival.

CF MONTH - CRUEL NEEDS KIND

Every day we hold our CF community in our hearts and minds to make sure our community has access to the emotional, physical, and financial support when they need it. Every day we fight for access to Trikafta, the wonder drug not yet funded in New Zealand. The inspiration behind our CF Month Campaign - Cruel Needs Kind.

Cystic fibrosis is relentless, it's cruel and it's the story we've told across the month of May. CF is a condition for whole of life and for most of our community that means hours of treatment, hospitalisations, medications, missed days from school and work, and lost opportunities to be a part of social activities because of the risks it carries.

CF Month exceeded all our expectations, with so many kind and thoughtful Deliberate Acts of Kindness we can continue injecting kindness into the lives of our people with cystic fibrosis often when they need it most.

We couldn't have done any of this without our incredibly generous donors, fundraisers and supporters who have been so passionate in their support for CF and CFNZ.

This billboard was a Deliberate Act of Kindness from Lumo Digital Outdoor



INFORMATION CHANNELS

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

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. CF News Spring 2021

FACEBOOK

Our public Facebook page has **5,613** followers and continues to be an important tool to engage with our community.

Our closed Facebook group has **514** members.

WEBSITE BY NUMBERS

Latest News articles: **47**

Users: **36,332**

New users: **36,137**

Page views: **94,164**

OUR MOST VISITED PAGES

1. [About/what-is-cf/](#)
2. [/advocacy/trikafta](#)
3. [/life-with-cf/cross-infection/](#)
4. [News-and-events/latest-news/](#)
5. [/about/how-is-cf-diagnosed/](#)
6. [/life-with-cf/cystic-fibrosis-care/](#)
7. [/about/stories](#)
8. [/about/faq](#)
9. [/life-with-cf/cystic-fibrosis-care/treatment-and-medication](#)
10. [/donate/](#)



SCHOLARSHIP AWARDS 2022



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.

2022 RECIPIENT – LILY TEW

This year's very deserving winner is Lily Tew. Lily is a 23-year-old Wellingtonian, who studied a Bachelor of Laws and a Bachelor of Arts at the University of Canterbury. While she was at university, she was selected to do an internship with Bell Gully.

"I am extremely proud of how I managed to uphold very strong academic grades enabling me to be earn a role with leading New Zealand law firm. I am excited to return to NZ in 2023 to earn my admittance to the bar and begin my legal career with Bell Gully."

After Lily completed her degrees, she set to pursue another passion of hers, and went on to gain her level one ski instructor qualification through New Zealand Ski Instructors Alliance. Lily then made the decision to head over to Canada, where she gained her level 2 instructors' certification through the Canadian Ski Instructors Alliance.

Lily has always had a keen interest in sports, playing volleyball, netball, football water polo, and basketball while she was at school. Lily and her flatmates also participated fully in the 2020 and 2021 Sweatember Campaigns, running 100kms both years.

CF has presented many challenges in Lily's life, but she truly believes it has also instilled her with a firm determination to

never let it limit or stop her from achieving her goals. Lily has learned to be extremely disciplined with her treatments, and works hard to maintain her health and not let it get in the way of the life she wants to live. CF has also taught her the importance of remaining positive and optimistic, despite the obstacles.

It's an honour to present Lily with the Mark Ashford Scholarship this year, she's an inspiration to our community, with a huge amount of resilience facing challenges, while achieving excellence in all areas.

A huge thank you to Terra for generously sponsoring the 2022 Mark Ashford Scholarship.



MARK ASHFORD – RUNNERS UP

This year we had a record number of high-quality applicants for the Mark Ashford Scholarship this year. We made the decision for the first time, to create a runner up prize funded by Cystic Fibrosis NZ, for two applicants to acknowledge the incredible results they have achieved.

JAKE GAWN

Jake recently completed a Bachelor of Applied Science in Sport Technology at the University of Otago. He then went on to do some postgrad study, being awarded a Bachelor of Science with First Class Honours in Sport, Exercise and Health. Jake has always been very active, played a lot of sport, so he wanted to combine that with his academic studies. Jake is now working at the New Zealand Institute of Sport in Wellington, as their lead tutor of the Diploma in Human Performance, as well as tutoring classes for their Personal Training Qualification.

Jake and his girlfriend are planning a move to the UK in 2023 so he can access Trikafta, so he's saving this award to put towards the cost of moving abroad.



ANGUS DRUMM

Angus is currently finishing off his Law and Arts degree, with majors in politics and history. Once he completes this, he will go straight into professional legal training over summer. For the foreseeable future he'll be working as a Political Communications Advisor for an Auckland based Member of Parliament.

"Whether you're making decisions about your career, education, family or life in general, make sure that it is consistent with your values. The path I have landed on is not what I expected at all, but I've loved every moment because I've always made sure to have my values front of mind before taking action."

.I think the runner up position was an exceptionally generous decision and I was delighted to have received that. It's also a reflection of how people with Cystic Fibrosis are still really thriving and accomplishing their goals.



Both Jake and Angus have said how grateful they are to have been considered for the Mark Ashford Scholarship, and appreciate CFNZ deciding to present them with a runner-up award.

CF ACHIEVERS AWARD RECIPIENTS 2022



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 five individuals with CF have been recognised for their optimism, perseverance, and achievement in their chosen category.

JAMIE MCCARDLE - SPORT

Jamie is 18 years old and comes from Tauranga.

Jamie is currently in his first year at Waikato University studying a Bachelor of Computing and Mathematical Sciences. Throughout his school career, Jamie was always in the top basketball team (Junior A and Senior A) and in his final year, he was also captain. Jamie was also selected for the Eastern/Western Bay of Plenty rep team. As part of Jamie's CF journey, he was diagnosed with chronic pancreatitis and atrial fibrillation which caused ongoing pain, and the need for bed rest.

"Despite my health challenges I continued to turn up to practices, games, coach teams, and assist my coach to lead our team."

Jamie will use his grant money to pay his university and basketball costs.



JOSHUA CHASE - EDUCATION

Joshua is 28 years old and comes from Auckland.

Joshua has gained his Level 4 & 5 qualifications in personal training, and a diploma in weight management. He achieved all of this, while also having frequent hospital stays for IV antibiotics.

"I got into this area of education because I have always been into fitness and exercise. I wanted to better myself with health and wellbeing so I can help others with CF."

Joshua will use some of the money to pay off the personal loans he got to do these certificates, and put the rest towards buying a car.



SOPHIE CARR - LEADERSHIP

Sophie is 27 years old and comes from Auckland.

Sophie started teaching in 2017 and since then, has grown and developed in her leadership. She has encouraged hundreds of children to become the best versions of themselves, and learn the vital skills that are required to succeed in the future. For the past three years, Sophie has mentored Provisionally Certificated Teachers (PCTs), through the process to their Full Registration.

Sophie's health rapidly declined in 2018 with a lung function of 28%. She was accepted into Vertex's Managed Access Program for Trikafta and it has changed her life.

"Despite my failing health, I continued to work full time as a Year 8 teacher, while trying to get my health back on track."

Sophie will put the money towards following her dreams of travelling the world.



LEAH-MAY ELLIOTT - SPORT

Leah-May is 12 years old and comes from Rotorua.

Leah-May has trained in Brazilian Jiu Jitsu for 4 years. She competed at the New Zealand Nationals and received the national gold title for her division. At one point, Leah-May competed just a week after a two-week hospital admission.

"Leah-May is always reaching to set greater accomplishments for herself."

Leah-May will use this money to help towards her competing fund in order to get her to Australia to attend the Pan-Pacific competition.



ZANYA COLLINS - SPORT

Zanya is 16 years old and comes from Tuakau.

Last season as an under 16 rep player, she won the Defender of the Year award - the recipient of this award is selected from of all rep players. Zanya is involved in cross country and has won every year. She has also had a lot of success with high jump, and represented her school at regional levels.

"I don't let too many people know about my CF as I like to do my best and be judged on my performance the same as others."

Zanya will use the award money to buy netball shoes and some specialised high jumping shoes. She will also look at getting some specialised high jump coaching.



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.



TRUSTS AND FOUNDATIONS

- AD Hally Trust - proudly administered by Perpetual Guardian
- Akarana Community Trust
- Bendigo Valley Sports & Charitable Foundation
- Blue Waters Community Trust
- Charities Aid Foundation America
- Canterbury CF Trust
- Central Lakes Trust
- COGS - Auckland City
- COGS - Canterbury Rural
- 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 - Tairāwhiti
- COGS - Tauranga
- COGS - Tongariro
- COGS - Waikato South
- COGS - Waikato West
- COGS - Wairarapa
- COGS - Waitakere
- COGS - Wellington
- COGS - Whanganui/Waimarino/Rangitikei
- COGS - Whangarei/Kaipara
- COGS - Whitiāreia
- 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
- Geyser Community Foundation
- Grumitt Sisters Charitable Trust - proudly managed by Perpetual Guardian
- Hawkes Bay Foundation
- Hutt Mana Charitable trust
- John Ilott Charitable Trust
- Kathleen Dorothy Kirkby Charitable Trust - proudly managed by Perpetual Guardian
- Kingston Sedgfield Charitable Trust
- Kiwi Gaming Foundation Ltd
- Lindsay Foundation
- Lion Foundation
- Lottery Grant Board
- LW Nelson Charitable Trust
- Mainland Foundation
- Milestone Foundation
- Norah Howell Charitable Trust
- North and South Trust Ltd
- Oxford Sports Trust Ltd
- Pelorus Trust
- Rata Foundation
- Redwood Trust
- South Canterbury Trusts - proudly managed by Perpetual Guardian
- Stewart Family Charitable Trust - proudly managed by Perpetual Guardian
- Taranaki Foundation
- TG Macarthy Trust
- Trust House Foundation
- Trust Waikato
- Vernon Hall Trust Fund - proudly managed by Perpetual Guardian
- W.Duncan Bickley Trust Fund - proudly managed by Perpetual Guardian
- WEL Energy Trust
- Wellington Children's Foundation
- West Coast Community Trust
- Whanganui Community Foundation
- Youthtown Inc

Statement of Financial Performance

Cystic Fibrosis Association of New Zealand
For the year ended 30 June 2022

Account	Notes	2022	2021
Revenue			
Fundraising Revenue	1	916,744	610,105
Donations and Bequests	1	230,975	439,572
Grants	1	390,572	366,508
Sponsorships	1	110,059	69,950
Contract Revenue	1	90,216	84,000
Interest, dividends and other investment revenue	1	42,884	64,223
Subscription from Members		2,595	1,497
Total Revenue		1,784,045	1,635,855
Expenses			
Expenses related to public fundraising	2	400,267	366,457
Volunteer and employee related costs	2	771,214	656,471
Costs related to providing goods or service	2	328,396	250,177
Grants and donations made	2	293,723	276,898
Other expenses	2	70,304	58,698
Total Expenses		1,863,904	1,608,701
Surplus/(Deficit) for the Year		(79,859)	27,154

This statement should be read in conjunction with the Notes and the Independent Auditor's Report.

Account	Notes	30 Jun 2022	30 Jun 2021
Assets			
Current Assets			
Bank accounts and cash	3	1,033,512	1,221,152
Debtors and prepayments	3	83,827	81,347
Other Current Assets	3	59,286	26,127
Total Current Assets		1,176,625	1,328,626
Non-Current Assets			
Investments	3	827,335	793,705
Property, Plant and Equipment	3	17,787	20,093
Total Non-Current Assets		845,122	813,799
Total Assets		2,021,746	2,142,424
Liabilities			
Current Liabilities	4	182,363	145,155
Unexpended Grants	4	33,453	111,481
Total Liabilities		215,816	256,636
Total Assets less Total Liabilities (Net Assets)		1,805,930	1,885,789
Accumulated Funds			
Accumulated Surpluses or (Deficits)			
Retained Earnings/Accumulated Funds			
Branch Equity		807,108	807,108
Retained Earnings		392,705	365,551
Retained Earnings - B4CF		97,914	97,914
Retained Earnings CHEF		588,061	588,061
Total Retained Earnings/Accumulated Funds		1,885,789	1,858,635
Current year earnings		(79,859)	27,154
Total Accumulated Surpluses or (Deficits)		1,805,930	1,885,789
Total Accumulated Funds		1,805,930	1,885,789

This statement should be read in conjunction with the Notes and the Independent Auditor's Report.



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 2022

BOARD

Warwick Murray
Board Chair

Denis Currie
President

Alex McKay
CF Adult Representative

Zac Fargher
Board Member

Rebecca Colley
Board Member

Chris Shanks
Board Member

PATRONS

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

Lisa Burns
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 (until Sept 2021)
Chief Executive

Christine Perrins (Sept - Nov 2021)
Interim Chief Executive

Lisa Burns (started Nov 2021)
Chief Executive

Angela Crates
Administration Manager

Susan Lovelock
Southern Fieldworker

Gretchen Kitching
Northern Fieldworker

Jude Kelly (until Mar 2022)
Lower Central Fieldworker

Chani Venter (until Apr 2022)
Upper Central Fieldworker

Laura Huet
Fundraising and Marketing Manager

Lizzie McKay
Communications Coordinator

Christine Perrins
Advocacy Adviser (volunteer)

Jeanette Franklyn
Grants Coordinator

Raki Debebe (until Oct 2021)
Fundraising Coordinator

Nashwa Soliman
Database and Fundraising Administrator

Jan Tate
Port CF Project Coordinator

BRANCH OFFICE HOLDERS

Auckland

Jill Thorrat (Co-chair)
Jane Drumm (Co-chair)
Allyson Harvey (Treasurer)
Joanne Hurford (until Aug 2022)

Waikato

Annelies Baker (Chair)
Alice Bell (Treasurer)

Taranaki

Shelley Gruchy (Chair)
Kayne & Joelle Dunlop (Secretaries)

Joanne Hurford (Auckland Branch
Coordinator/volunteer Coordinator)
June 2022

Hawke's Bay

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

Wellington

Paula Richards (Chair)

Nelson

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

Canterbury

Melissa Skene (Chair)
Viv Isles (Treasurer)



Please call 09 308 9161 or
freephone 0800 651 122.

You can also contact us by
emailing info@cfnz.org.nz

For the financial year ending 30 June 2022