

# ANNUAL REPORT 2023

For the financial year ending 30 June 2023

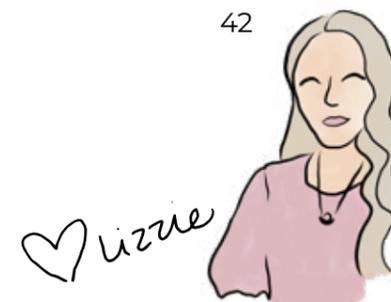




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**Artwork on inside front cover** is by Sarah Stanley, member of our CF community for our Art for Purpose project. Sarah says "This teddy painting represents hope for a better and brighter future for tomorrow". You can purchase this painting and our other Art for Purpose pieces here <https://shop.cfnz.org.nz>



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

# ABOUT CYSTIC FIBROSIS NZ

## 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

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 percent government funding and relies on the generosity of New Zealanders to meet the ongoing needs of our community.



# A WORD FROM OUR BOARD CHAIR



In my last Chairs Report, I expressed my personal disappointment and frustration that we did not have a decision from Pharmac on the funding of Trikafta. So, it feels so good to be able to express my delight that we now have it, not just for my own family, but for all those in our community for whom this medicine promises a new lease on life.

I wish to extend my heartfelt gratitude to the numerous individuals within our community who contributed their efforts to make this breakthrough possible. This achievement underscores the importance of collective action, highlighting that every contribution, no matter how small, matters significantly.

This achievement has also demonstrated the efficacy of a well-organised, coordinated, and focused campaign. CFNZ, as an organisation, has learned

invaluable lessons from this experience that will undoubtedly guide our future advocacy efforts on behalf of the CF community.

However, our endeavours extend beyond Trikafta. Over the past year, we have undertaken various initiatives to support our community. These include a nationwide awareness campaign, several fundraisers, updates to our community resources, such as the CF Journey, a significant increase in outreach by our Social Workers, totalling 4,742 contacts, and a substantial rise in opportunities to assist individuals with CF, reaching 723.

Looking ahead, our mission persists, even with the introduction of Trikafta. While it has been a monumental breakthrough for many, it is essential to acknowledge that it doesn't benefit everyone, nor does it represent a cure. There remains much work to ensure that individuals with CF in New Zealand thrive and lead healthy lives.

For CFNZ, our mission remains the same and we will be the continuous thread in the lives of people with CF and their family.

This will mean, we will continue to provide welfare support to those in need, to support those with CF to adapt to changes in their lives, and to make sure they have access to the information they need to make good life decisions. We will also advocate for access to new medicines, and treatments, and for a consistent high standard of care across New Zealand.

To fulfil these commitments, we require a well-governed, organised, and adequately funded organisation.

On the governance front, we have worked through a revised Constitution to our membership, laying the foundation for our future endeavours. We have bolstered our Board with exceptional individuals, including Kirsty Parsons (our adult with CF rep), Kristina Jeffery, Dame Pieter Stewart, and Evangelia Henderson, forming a robust team with diverse skills and experiences aligned with our goals.

Lisa has seamlessly transitioned into her role as Chief Executive, assembling a strong team to support our operational work. Their diligent efforts in establishing modern systems and processes, coupled with well-reviewed policies, position us well for future challenges.

Speaking of challenges, financial sustainability remains a significant concern. Reduced income, due to economic downturns and the misconception that CF is cured, has led to a deficit of \$168k for the 2022-2023 fiscal year.

While we've weathered this storm thanks to our reserves and solid balance sheet, it's not a sustainable solution. Tough decisions will be necessary in allocating our limited resources for the 2023-2024 fiscal year.

The sustainability of our branches and their memberships also presents an ongoing challenge. Nevertheless, we are pleased to witness the resurgence of the Central Districts branch. Changes to our Constitution aim to alleviate the burdens of branch management. However, areas with no branches and thinly populated existing branches require continued

attention. Alignment of national and branch objectives and priorities is also an area that demands further effort.

All of these challenges are within our capacity to address, and I have every confidence in our ability to do so while continuing to provide outstanding support to our CF community. Of course, none of this would be possible without the dedication of our volunteers and the generosity of our donors, to whom we extend our deepest appreciation.

A handwritten signature in black ink that reads "W. Murray". The signature is written in a cursive, flowing style.

WARWICK MURRAY  
CHAIR, CFNZ BOARD

# STATEMENT FROM OUR CHIEF EXECUTIVE



As I reflect upon the past financial year, I am thrilled to share the remarkable progress and achievements we have accomplished as a united CFNZ family. From the Branch Chairs Conference in November to our Board Strategy Meeting in February, we have made significant strides toward our strategic objectives, and it's with great pride that I present this annual update.

**Our accomplishments during FY23 are a testament to our dedication and hard work:**

**Trikafta Success:** Securing public funding for Trikafta, along with the resources and successful rollout from December through to April 2023, has been a monumental achievement.

**Centralisation of Branch Funds:** As of July 2023, we have successfully centralised our Branch funds, streamlining our financial operations for improved efficiency.

**Revamped Strategic Plan:** We have developed a refreshed strategic plan for 2023-2026, which will guide our future endeavours.

**Brand Refresh:** Our brand refresh initiative has given us a fresh identity that aligns with our evolving vision and mission.

**Governance Enhancements:** We have worked through a process of consultation to develop a revised Constitution and set of policy documents that set CFNZ up to be a modern charity that is fit for purpose.

**Community Insights:** The post-Trikafta announcement community insights survey has provided invaluable feedback for us to better serve our community.

**Digital Transformation:** The launch of our new donation portal and e-commerce platform, starting May 2023, enhances our online presence and donor engagement.

## OUR SUPPORT IN FY23

Our support programmes remain accessible to those who need them, with a total of 378 Breath 4 CF Grants, 258 Welfare Grants, and various other discretionary grant disbursements provided throughout the FY23 financial year. We are dedicated to delivering direct assistance whenever possible, along with a diverse array of supplementary information, advice, and support, as required.

Our team of dedicated Social Workers has seen an increase in support this last year with interactions up 36% to 4,742 from 3,465 last year.

CFNZ is committed to the holistic support of the CF community, covering our newly diagnosed families, to those facing their own unique ongoing challenges of living with CF. We recognise the importance of ensuring that every member of our community receives the essential support and resources they need.

## CHALLENGES & RESILIENCE

While celebrating our successes, it's important to acknowledge the challenges we've faced. The past six months have been demanding for our team and organisation, juggling heavy workloads and change management. Volatility in donations has impacted our revenue, as seen with the deficit result, and this remains a challenge we continue to address.

## A SHIFTING LANDSCAPE

CFNZ is operating within a shifting landscape, impacted by a cost of living crisis, unprecedented inflation, and fierce competition for charitable contributions. The forthcoming election and pressure on Kiwi families is creating uncertainty for many.

Although external factors remain beyond our control, we can shape our internal environment. We need to continue fostering a community that unites us, empowering us to navigate these challenges successfully. Our actions, words, and the way we treat our community, donors, and each other are within our control.

## LOOKING FORWARD TO FY24

It's worth emphasising that the present moment may be one of the most critical junctures in our organisation's history.

Looking ahead three years from now, we will likely find ourselves facing a markedly different prospect when responding to new models of CF care.

As we take on our next set of strategic priorities, we've set the stage for a successful future. Our focus now shifts to embedding these changes, building trust, and continuing to demonstrate why CFNZ is an exceptional organisation to be a part of and support.

At the heart of all our individual perspectives lies a common dedication to supporting our community through the profound transitions they are experiencing.

In essence, we stand at the threshold of a significant transformation, one that necessitates our unwavering commitment and strategic foresight.

In conclusion, FY23 was a year of notable achievements and challenges. FY24 beckons as a year of innovation, growth, and unity.

Together, we can steer our organisation through these changes, ensuring that we remain a steadfast pillar of support for our community, and be an organisation we can all be proud of.

I am grateful to all of our community, our supporters, partners, and volunteers for your support and dedication to our vision.

LISA BURNS  
CHIEF EXECUTIVE, CFNZ

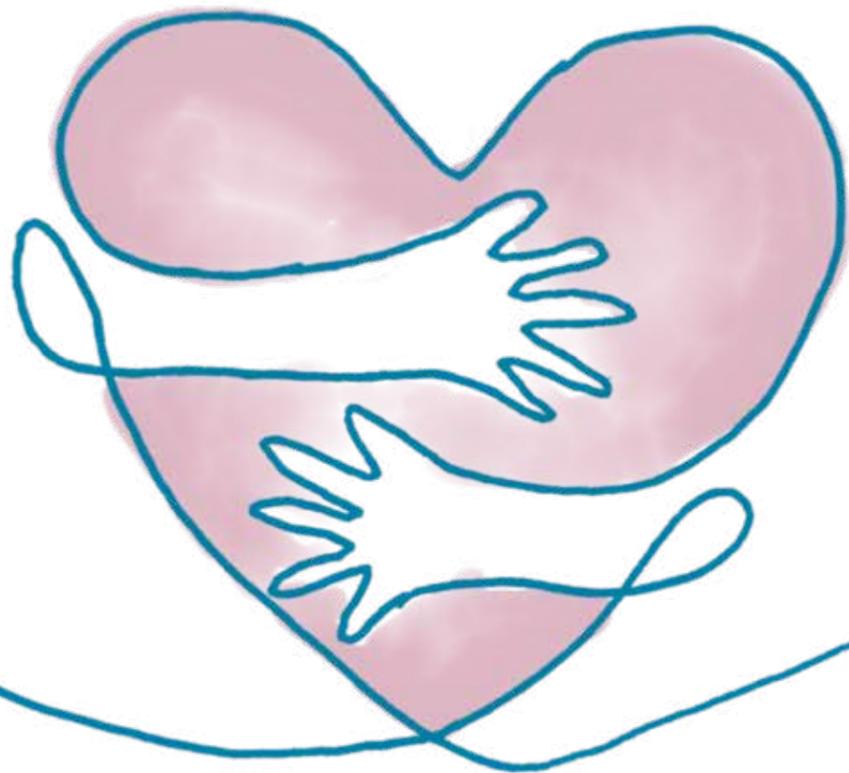
# FAREWELL

*We farewell one  
loved community  
member who passed  
on this year*

Samantha Phillips, Southland

Age: 25 years

2/9/22



# BY STARLIGHT

Sometimes the night  
Stretches into the day  
And the thoughts that I think  
Don't match the words that I say

Sailing by starlight  
I'm not afraid  
Just look at this beautiful  
Life that we've made

In the hours before dawn  
I hear the birds as they sing  
And find joy in their songs  
New morning melodies

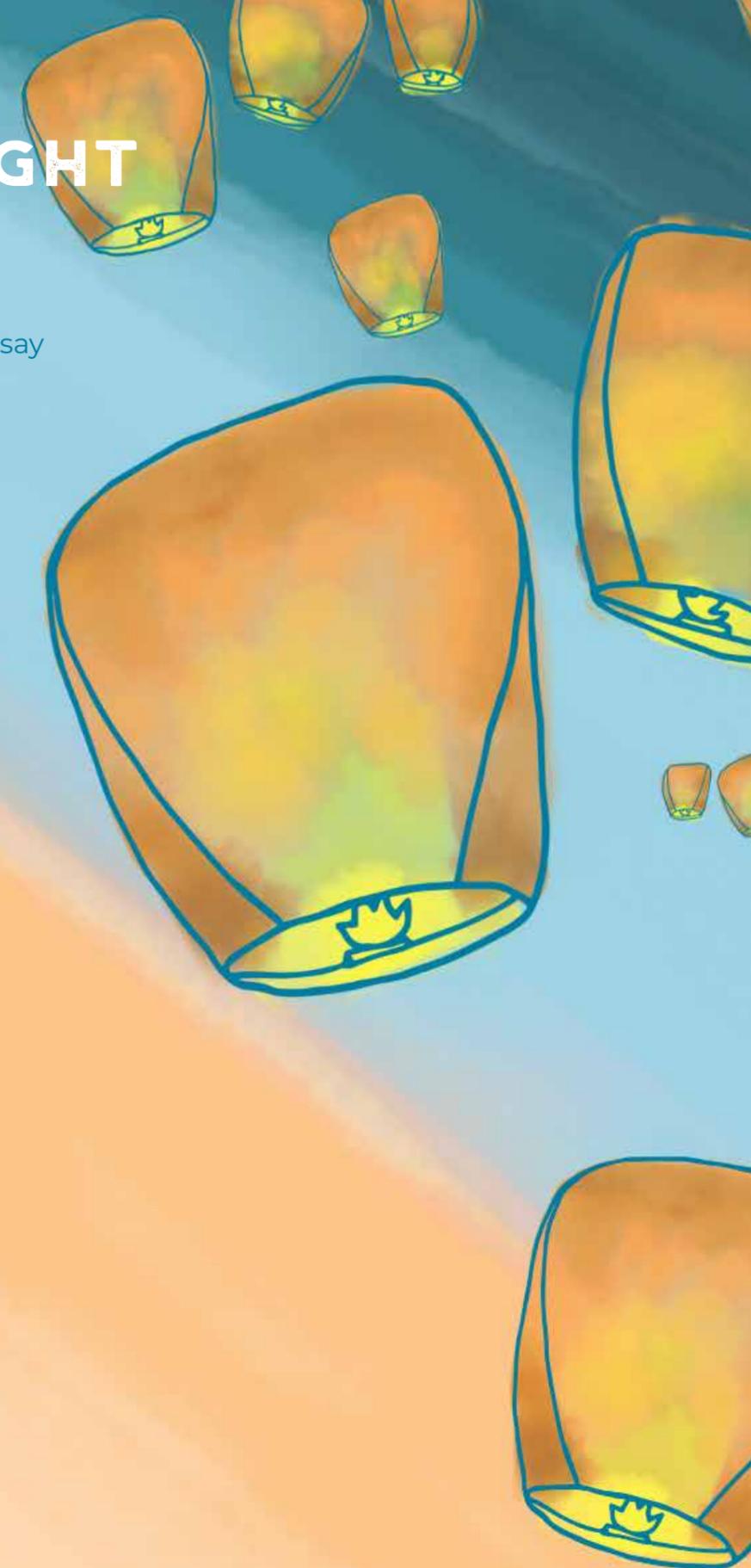
The world just outside  
The place where I live  
Feels kind and welcoming  
But also hurried and big  
I smile at strangers  
I meet on the street  
And wonder if they'll  
Ever really understand me

Life can be hard  
And dreams can get lost  
But together is better  
No matter the cost

So as I look up to the sky and  
Then look at the road ahead  
Where once there was fear  
I hold on to hope instead

Whatever comes next  
I know we'll be alright  
Take my hand in yours  
We won't give up this fight

**Cassie Roma**



# SUPPORT FOR PEOPLE WITH CYSTIC FIBROSIS AND THEIR FAMILIES



**12**  
people with CF supported with a Chris Howlett Endowment Fund grant on turning age 21

**1**  
family supported with a funeral grant

**157**  
inpatient visits by CFNZ Social Workers to support people with CF and their families

**129**  
contacts via mail

**94**  
individual healthcare plans developed by CFNZ Social Workers

**70**  
home visits to people with CF from CFNZ Social Workers

**20**  
newly diagnosed families supported

**378**  
physical activity grants (Breath4CF)

**12**  
transplant grants given to those going through the transplant process

**284**  
welfare support grants given to people with CF

**35**  
hospital allowances to support people with CF during admissions

**1143**  
contacts via phone call or text message

**4541**  
grants given to people with CF and their families

**497**  
interactions by CFNZ Social Workers to support people with CF and their families

**1979**  
discussions with support and welfare agencies on behalf of people with CF

**755**  
email contacts with people with CF and their families

**722**  
outpatient clinic appointments attended by CFNZ Social Workers to support people with CF

## CFNZ SOCIAL WORKERS

Our Social Workers play a crucial role in providing tools, information, advice, and guidance to help people with CF navigate the challenges associated with the condition. They offer emotional support, assist with accessing resources and services, provide information, and help individuals and families develop coping strategies.

The availability of our Social Workers can contribute significantly to the overall support and care provided to individuals with CF, helping them face the challenges of the condition with greater confidence and resilience.

*"Our CFNZ Social Worker has been an incredible support while my partner and I juggle getting married, moving, and undergoing fertility treatment. We couldn't be more grateful for everything she does for our little family."*

*"I moved away from home to study this year. I reached out to my CFNZ Social Worker to see if I could get any support with purchasing a heater which could also cool in summer. She was able to get a good price, and CFNZ was able to buy it for me. It has made such a difference – I really appreciate all the ways in which our Social Workers can support our community."*

*"Recently I had a CF clinic that wasn't going very well. Between tests, our CFNZ Social Worker came in to see me, made me laugh, and talked through what might happen for the rest of the clinic. It was a completely different appointment after her visit. She's a treasure."*

*"I've spent a lot of time in hospital recently, and my CFNZ Social Worker would check in each day, or visit with a coffee or some sushi – knowing I needed to put on weight! She encourages me rather than telling me what to do. My admissions wouldn't be the same without her kindness and grace!"*

*Below left to right:  
Gretchen Kitching, Sue Lovelock,  
Bev Darlow, Carolyn Downer*



# ADVOCACY

## #27MoreYears Campaign

After months of what appeared to be encouraging progress, we got news we didn't want to hear, that, following Pharmac's September medicines' ranking process, Trikafta had not moved up the Options for Investment (OFI) List. The outcome, Pharmac wasn't in a position to move forward with funding Trikafta. This defied all logic, given the encouraging recommendations from the Respiratory Advisory Committee (RAC), Pharmacology and Therapeutics Advisory Committee (PTAC) and the evidence outlined in the Technology Assessment Report (TAR).

Pharmac had acknowledged in August the major benefits that Trikafta offered, not just to the health system, but an extension of life expectancy and quality of life. Pharmac themselves estimated that Trikafta could provide benefits equivalent to 27 more years at full health when compared to current treatments.

Needless to say, as a community we were shocked and outraged – but we continued to hold on to hope, which we do so well!

The #27MoreYears campaign was launched! It was time to go into battle ahead of the December medicines' ranking process. CFNZ took a zero-tolerance approach to the way the process was being handled, asking the hard questions and not accepting this outcome. To amplify our voice and the campaign we needed the help of our whole CF community.

We ramped up the campaign to get

action, accountability, and decisions. We wanted our CF community to take a loud and active part in the campaign. The focus was to put pressure on Pharmac and the Government. Utilising an artwork created of Dame Jacinda Ardern from one of our talented members of the community we created advocacy cards containing key messages and providing space for people to add their own experiences, how Trikafta or expanded access to Kalydeco could change their lives.

The cards were sent to the Prime Minister, Minister of Health, Minister of Finance, Local MPs and the CEO of Pharmac. CFNZ provided an advocacy toolkit that contained information about the campaign, key messaging, letter templates, and examples of how the community could get involved and raise our voice – and that they did!

The CF community and the media got behind the #27MoreYears campaign more than ever sharing their stories, doing countless media interviews and purchasing CFNZ merch to reinforce the message. We sold 275 t-shirts and in from September to December we got 152 pieces of media coverage.



# TRIKAFTA FUNDING approved!

FROM 1 APRIL 2023

4 December 2022 is a day that we will remember forever. The day it was announced that Pharmac and Vertex had reached a provisional agreement to fund Trikafta for people with cystic fibrosis aged six years and over who would be eligible. We know there was a lot of celebrations around New Zealand, it took a while for this news to sink in.

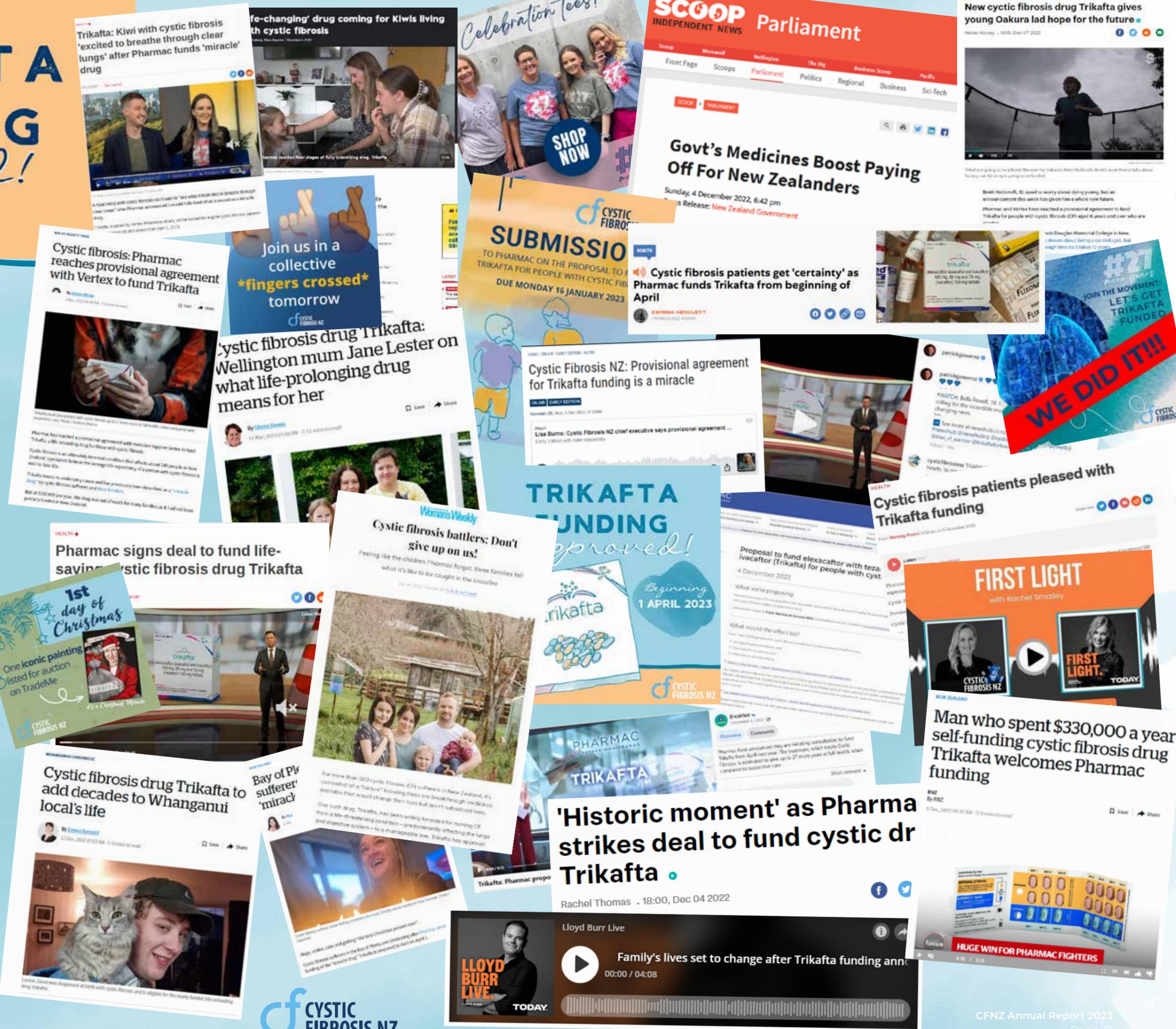
**Together, WE DID IT!**

## THANK YOU

The entire CFNZ Team thanks everyone who was part of the fight to get Trikafta funded. The collective voice of so many that made it happen.

*“There just aren't the words to convey what this means for our community.”*

Lisa Burns, Chief Executive CFNZ

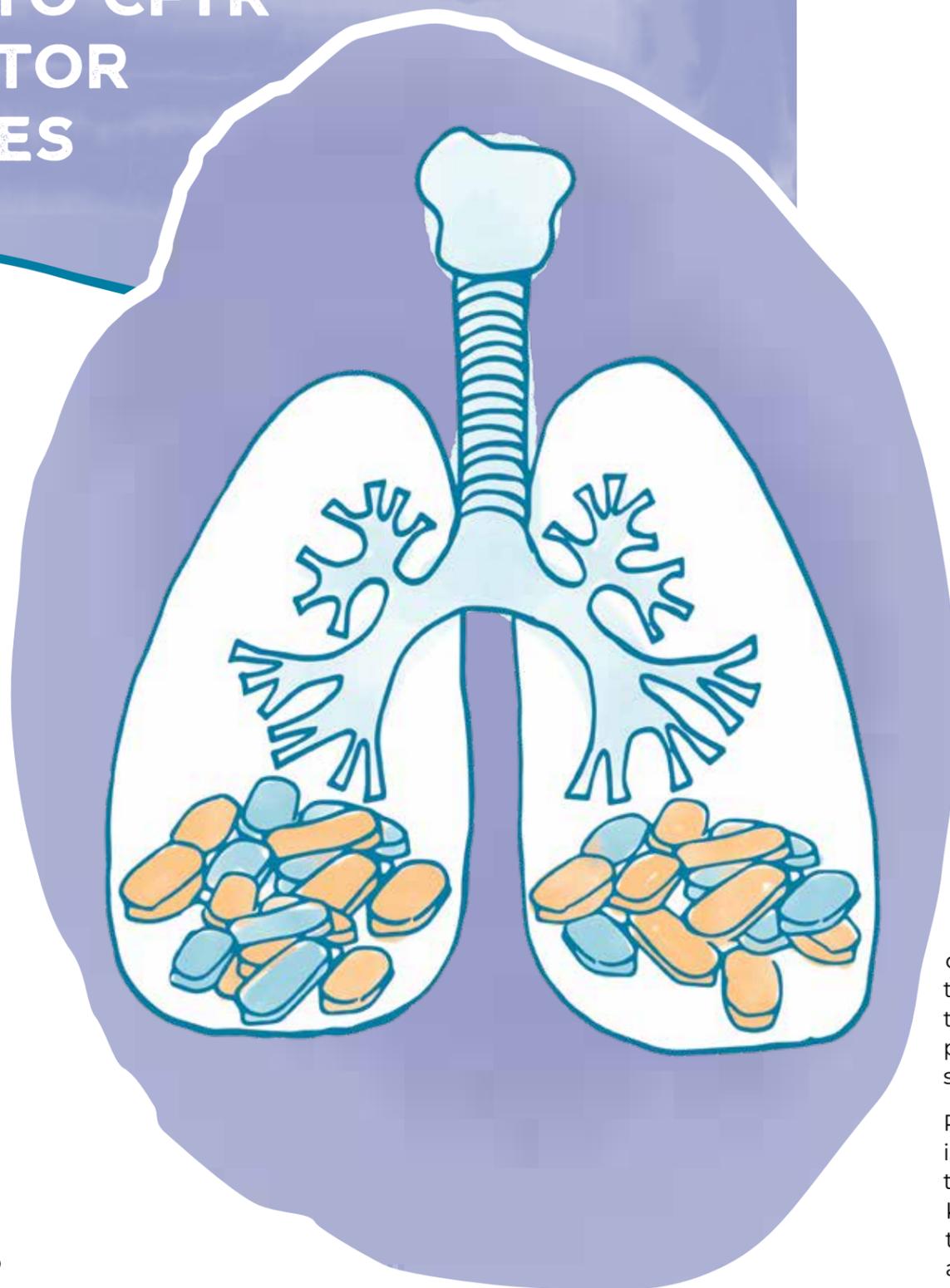


# ACCESS TO CFTR MODULATOR THERAPIES

## TRIKAFTA

Following the announcement on 4 December 2022 about the provisional agreement Pharmac advised that their proposal for funding Trikafta was out for consultation. The proposal provided for wide eligibility criteria for access for people with CF aged 6 years and over, for those who carry one or more copies of the F508del mutation, those with a G551D mutation, and those with mutations responsive in Trikafta in vitro.

Submissions on Pharmac's proposal closed on 16 January 2023. CFNZ's submission to Pharmac strongly supported the proposal and the proposed eligibility criteria. CFNZ also requested that Pharmac include widening of access to Kalydeco as part of the decision on Trikafta, and that it make Symdeko – also a Vertex CFTR modulator therapy – available to patients who may be unable to tolerate Trikafta.



# Finally the news we've all been waiting for – **TRIKAFTA IS FUNDED!**

On 7 March 2023, Pharmac announced that the decision to fund Trikafta had been confirmed, with no changes to the proposal and proposed eligibility criteria. Pharmac advised that it had received “lots of consultation feedback supporting the proposal” and thanked those who took the time to provide feedback, in particular those who had courageously shared their personal stories.

Pharmac also responded to the key issues raised in consultation, including the request for widening of access to Kalydeco and provision of Symdeko to be part of the decision. Pharmac advised that the application to widen access to Kalydeco is currently under assessment and will then be ranked on the Options for Investment list.

Pharmac also noted that it would welcome an application for Symdeko from Vertex. It acknowledged the strong desire for a funded CFTR treatment for everyone with CF, and its commitment to working with suppliers, advocacy groups, and the CF community on funding applications for CF medicines.

Confirmation that Trikafta would be funded from 1 April 2023 was a massive step forward for our CF community. It has already been life-changing for many kiwis with CF, families and whānau. New Zealand is one of the few countries in the world to provide such wide access to Trikafta. CFNZ thanks Pharmac, Vertex, and the Government for making this happen.

# ADVOCACY TIMELINE

## ACCESS TO CFTR MODULATOR THERAPIES

### MARCH 2022

Carmen Shanks presents her petition for public funding of Trikafta to Shanah Halbert, MP. The petition of 43,410 signatures is presented to the House of Representatives and referred to the Health Select Committee. 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.

### JUNE 2022

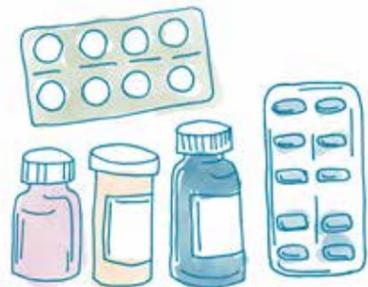
Carmen Shanks and CFNZ present to the Health Select Committee's hearing into Carmen's petition to have Trikafta publicly funded.

### AUGUST 2022

Pharmac releases an excerpt from the record of the Respiratory Advisory Committee's April meeting covering Trikafta. The Committee again recommends a high priority for funding Trikafta for those aged 6 years and over.

Pharmac releases its assessment of Trikafta, together with the record of PTAC's May meeting. PTAC recommends a medium priority for funding Trikafta for those aged 6 years and over.

Pharmac estimates that Trikafta would provide people with CF an extra 27 years of full health and reconfirms they want to fund it.



### SEPTEMBER 2022

The Health Select Committee presents its report on Carmen Shanks' petition to have Trikafta publicly funded to Parliament. The Committee notes that it is not Parliament's role to influence which medicines should be funded. It also notes the uplift in Pharmac's funding and its intention to monitor Pharmac's progress in implementing the recommendations of the Pharmac Review.

Pharmac releases the full record of the Respiratory Advisory Committee's April meeting, including the recommendation of a high priority for widening access to Kalydeco.

Pharmac advises CFNZ that, following its September re-ranking, Trikafta has not moved far enough up the Options for Investment list to progress to funding at this time. Pharmac advises CFNZ that "the door is not closed" and that "Trikafta is a medicine that we want to fund."

Pharmac also advises CFNZ that changes will be needed to enable Trikafta to move up the Options for Investment list but that, even if changes can be made, it will not happen before December 2022.

### OCTOBER 2022

CFNZ seeks advice from Pharmac as to the next steps for the application to widen access to Kalydeco. Pharmac advises CFNZ that Pharmac does not intend to take the full application to PTAC for review. The November PTAC meeting will review the record of the April Respiratory Advisory Committee meeting, which includes the recommendation to widen access to Kalydeco.

The next step for the application would be a full assessment against Pharmac's Factors for Consideration and ranking on the Options for Investment list. This ranking would determine its relative priority compared to other funding applications on the list. Pharmac would then be in a position to determine whether it is able to widen access to Kalydeco, based on its relative ranking and available budget.

Pharmac provides no indication of likely timing for the Kalydeco application to be ranked.

### DECEMBER 2022

Pharmac releases a proposal to fund Trikafta from 1 April 2023 for people with CF aged 6 years and over who meet specific eligibility criteria. The proposal is open for submissions until 16 January 2023.

### JANUARY 2023

Pharmac's consultation on its proposal to fund Trikafta closes. CFNZ makes a submission strongly supporting the proposal to fund Trikafta and the proposed eligibility criteria. CFNZ also requests Pharmac to include the widening of access to Kalydeco in its agreement with Vertex for Trikafta, and to fund Symdeko for those who may be unable to tolerate Trikafta.

### MARCH 2023

Pharmac confirms funding of Trikafta from 1 April 2023 for people with CF aged 6 years and over who meet specific eligibility criteria. No changes are made to the proposal for consultation.

Pharmac does not include the widening of access to Kalydeco or funding of Symdeko in its decision. Pharmac does acknowledge the strong desire for a funded CFTR treatment for everyone living with CF and states it is committed to working with suppliers, advocacy groups and the CF community on funding applications for CF medicines but gives no indication of timing.

## APRIL 2023

Trikafta is funded and available for all those eligible, over the age of six.

## OTHER ADVOCACY INITIATIVES

### 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 Panel's 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. The Act makes no changes to Pharmac's objectives and functions.

### SEPTEMBER 2022

Pharmac releases its interim response to the recommendations of the Pharmac Review Panel's Final Report. Pharmac's interim response provides little indication of action. A final response is expected from Pharmac by the end of October.

### APRIL 2023

Pharmac releases its final response to the Minister of Health in respect of the recommendations of the independent Pharmac Review. This follows Pharmac's Interim Response which was released in September 2022.

Pharmac's final response identifies five key themes in response to the Review's 33 recommendations. These are:

- Enhancing assessment and decision-making
- Striving for and achieving te Tiritiri o Waitangi excellence
- Doing more to achieve health equity
- Better involvement of and coordination with others
- Better integrating our responsibilities.

# FUNDRAISING AND AWARENESS

## THANK YOU WELLINGTON AIRPORT

for kindly sponsoring our 2022 Christmas Tree Festival and for joining us in celebrating our CF community.



### SWEAT FOR PURPOSE - SWEATEMBER 2022

Sweatember was so sweaty thanks to the 309 incredible sweating superstars, who ran, walked, roller bladed, swam, and skipped 1000s of kilometers, and together raised over \$100k towards support services and physical activity grants for our CF community.

Although we had set the bar a little higher, it was a bit tougher than we'd hoped to reach our goal. During the month, we also found out Pharmac's decision not to prioritise Trikafta. Our sweaty superstars used that to dig deep, and keep motivations high, and we finished Sweatember strong. We couldn't do what we do without the love from our sweaters, and supporters. We can assure you, your sweat has never meant so much!

Kindly sponsored by Viatris.



### WELLINGTON AIRPORT CHRISTMAS TREE FESTIVAL 2022

Our Christmas Tree Festival at Wellington Airport in 2022 was the biggest on record, we had a total of 56 organisations involved who gave their resources, creativity, and support to this event.

We are so grateful to all our incredible sponsors of our 2022 Christmas Tree Festival which raises awareness of cystic fibrosis in a wonderful and special way.

We want to share these words from the opening night of the festival from our Judge and Artist Lynne Sandri.

"Each year choosing three is so hard, as they just keep getting better and everyone steps up with their time, thought, and messages. They're 'Thought Trees' - so much more than 'Christmas' trees. Deeper messages, not just celebrating the joy of Christmas and the end of the year but also:

- sustainability
- our culture
- designs
- embracing local
- appreciating what's on your doorstep
- a time to remember and reflect.

So many traffic stopping trees".

Special mentions were given to Homeloan Shop and Dementia Wellington, Samuel Marsden School, Bay Plaza Hotel, Sam's Art House, Scot's College and Maude Wines.

The winners on the night, who took out the top 3 places were:

First place – Catalyst

Second place – Te Matatini Kapa Hake Aotearoa

Third place – Ben & Jerrys with Ghost Diving Aotearoa

Thank you also to Wellington Airport for their generosity of the digital advertising prizes for our winners and for their support every year in pulling the festival together, it is a wonderful event and we are so grateful to everyone involved.



# FUNDRAISING AND AWARENESS

## CRUEL NEEDS KIND - CF MONTH 2023

CF Awareness Month showed us once again how wonderful the CF community is in New Zealand. It was a huge month with an unprecedented amount of Chocky Fish going out the door to fundraisers, only a small shoal of them made their way into the tummies of CFNZ staff, but they helped fuel us to continue to pack and send out order after order of fish, t-shirts, books, artworks, and hoodies.

Schools, community organisations and individuals all ran fundraisers, from selling Chocky Fish, to mufti days, catering, and bake sales.

We also had many amazing organisations and business partners keen to support our CF community throughout the month, who came up with their own Deliberate Acts of Kindness, all making a tangible difference to the lives of Kiwis with CF.

You all really helped us spread the word that cruel STILL needs kind. Medicines are a wonderful tool to living well with cystic fibrosis, but they are not a cure, and people with CF in New Zealand will always need the ongoing support that CFNZ provides.



The Hutchwilco New Zealand Boat Show kindly gifted us a stall for the show. We came away with \$7k in donations and Chocky Fish sales!



There were so many of you involved in the success of CF Awareness Month, please know we are grateful for every effort of spreading awareness, fundraising, donations, Deliberate Acts of Kindness. No matter how or what you contributed we are so thankful to each and every one of you.

Huge thanks to our incredibly generous sponsors and partners who all showed Deliberate Acts of Kindness during CF Awareness Month.

## CHRISTMAS APPEAL 2022 - ALL WE WANT FOR CHRISTMAS



Our Christmas Appeal featuring 3-year-old Poppy focused on how difficult the festive period can be for families that need to factor CF into their holiday plans. CF doesn't take a break for the holidays. It also highlighted the need for equitable access to Kalydeco which is currently not funded for Poppy's specific CF genes.

Comprising a direct mail piece and email to our donor database, as well as paid and organic social media content the campaign yielded donations of \$15,500, which was a good outcome given the DM landed in letterboxes the same week as the announcement that Trikafta was to be funded in April 2023.

Alongside this donation campaign, we also ran Gifts For Purpose, offering CFNZ merchandise including Chocky Fish, Fred Bear mugs and our existing apparel range as Christmas gifts solutions for our community and the general public. This provided a great lift in retail sales of over \$15k that we wouldn't usually see at this time of year, that is a lot of Chocky Fish!



# FUNDRAISING AND AWARENESS

# COMMUNITY FUNDRAISING

## WINTER APPEAL AND IMPACT REPORT - MARCH 2023

In March we contacted our donors with an email and mailout. This gave us the opportunity to connect with our key supporters for the first time since the Trikafta announcement.

Lisa's letter focused on the fact that although it was a huge milestone to have Trikafta funded, it was extremely important to remember that it is not a cure. There are people with CF who will not be eligible for Trikafta and that it won't work for everyone. It was a good time to remind our supporters of the ongoing need for CFNZ support and services.

We also provided our donors with their Impact Report, sharing the difference their kindness and generosity achieved for our community. The letter and ask for donations contributed to our Winter appeal, supporting the increased costs that the colder weather brings such as prescriptions, heating, and firewood costs. We raised over \$13,700.



Our passionate community once again showed us that actions speak loudly! Here is a snapshot of some of the wonderful supporters doing what they can in our communities around New Zealand, to raise awareness and raise funds.

## NEXUS - FRISBEE FOR CHERISHED FRIEND

Nexus Ultimate Frisbee in Wellington have a very special connection with cystic fibrosis, their friend and teammate Kimberley Bryant passed away in 2018. Kim lived with CF and her friends from Nexus find ways to honour her memory and help others with CF.

This year they held an Ultimate Frisbee tournament with over 50 participants who came together to compete, have fun and raise money with a raffle for CFNZ. Kim's friend Marah, who organised the event said "We loved being able to raise money and awareness for such a good cause. It's definitely something we will look to run again".

Thank you Marah and the Nexus Ultimate crew!



## A LONG-DISTANCE LEGACY FOR TERI-JANE

Local Wanganui resident Rae is wife to Wayne and step-mum to his four sons. Wayne lost his first wife Teri-Jane to CF, so it's always been a part of their family and it motivated Rae to set herself a big challenge to raise funds and awareness for CFNZ. Rae shares with us "Any loss of life is tragic, but to lose someone who was still so young, and to have been there supporting them through deteriorating health and in their last moments was life-changing for Wayne. Teri-Jane and Wayne have four amazing sons together".

Rae decided to enter the Wanganui 3 Bridges 21km Race, "I felt like everyone needed to be aware that not everyone can `just breathe". She completed her first one ever in 2 hours and 28 minutes. "I did it! And to find out later that we raised the amount that we did, made every step worth it".

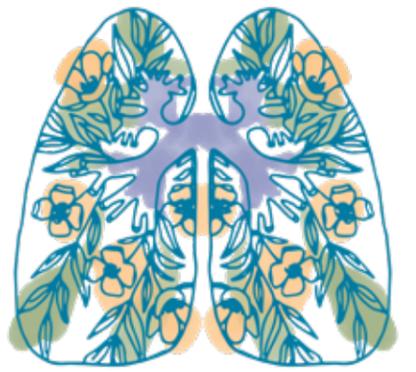
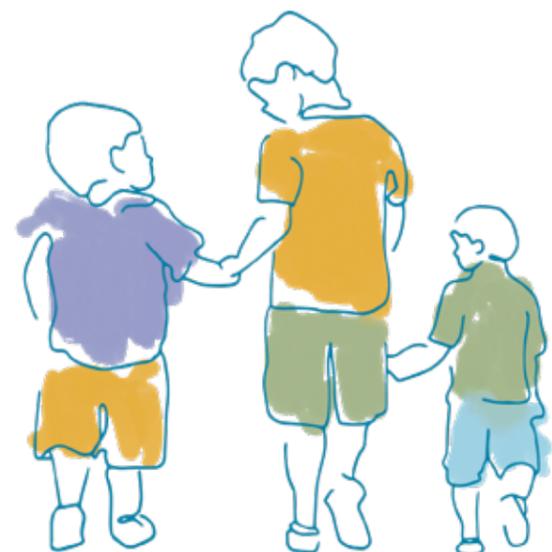
What an amazing challenge to achieve Rae, and we are so grateful to you and your family for sharing your story, raising vital awareness and funds to support families with CF.



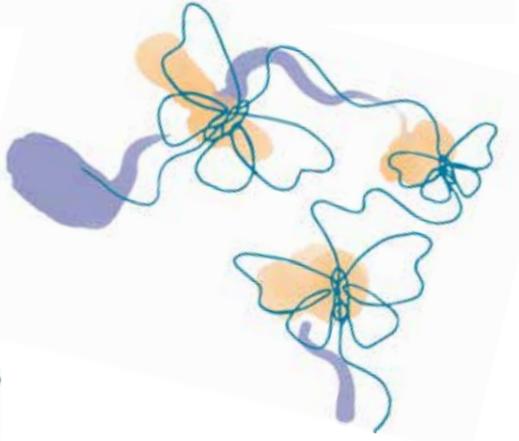
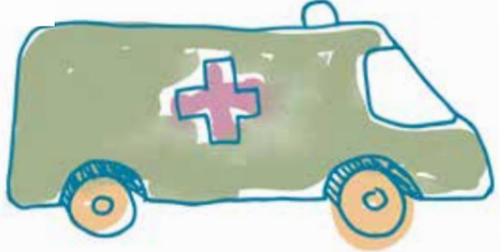
# OUR BRAND

## A NEW LOOK AND FEEL

Embracing a vibrant transformation, our brand has evolved from its traditional primary color palette to a contemporary, emotive identity that resonates with the dynamic spirit of our community. Through this rebranding journey, we've woven a visual narrative that captures the essence of our interconnected community, ushering in a fresh era of modernity and unity. We are incredibly privileged to have the opportunity to use Lizzie McKay's illustrations through our brand. The lines and line drawings represent the constant thread that CFNZ strives to be through everyone's unique CF journey in New Zealand.



CRUEL NEEDS KIND



# COMMUNICATION CHANNELS

Staying connected with our community and supporters is a big priority for us at CFNZ. Through our regular newsletters, donor impact reports, social media channels and website updates we've continued to communicate with our growing community. We've continued to build on our storytelling capability, sharing the stories of our people with CF and their families and capturing the impact our CFNZ Social Workers, branches, and our wider organisation deliver for our community.

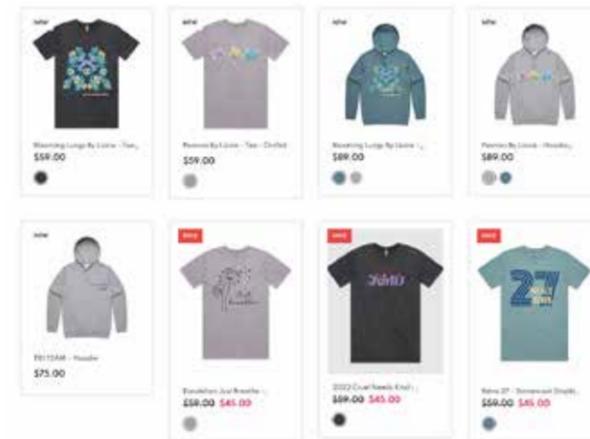
## SHOP FOR PURPOSE

Our merch range has steadily grown over the last 12 months with lots of new items being added from tees to hoodies, mugs, Fred Bears, paintings, and of course our ever popular Chocky Fish.

Shifting to a new retail platform was a crucial step for us, aligning with our commitment to continuously enhance the overall customer experience. The move was driven by a strategic vision to streamline and modernise our operations, ensuring that that not only improved our efficiency but also provided a better opportunity to connect with our community.

The user-friendly interface allows us to add new products and showcase others at different times of the year during campaigns. This transition is part of our dedication to innovation.

If you haven't yet checked out our Shop for Purpose, take a look you can access it at [www.shop.cfnz.org.nz](http://www.shop.cfnz.org.nz). Every purchase goes directly towards the support and programmes provided by CFNZ.



## IMPROVING THE DONOR EXPERIENCE

We are thrilled to share that we've given our donation experience a significant facelift! Recognising the importance of a seamless and user-friendly process, we have revamped our donation platform to make it easier than ever for our supporters to contribute to our mission. This enhancement reflects our ongoing commitment to improving accessibility and engagement. We believe that by providing a more intuitive and efficient donation experience, we can empower our community to contribute to the vital work we do in supporting people with cystic fibrosis and their families. The generosity of all our supporters fuels our efforts, and this upgraded donation experience is just one way we strive to make a positive impact together.

Our commitment to ensuring the best possible experience for our donors and supporters means that we can more easily see the various channels of engagement and support we get in one place.

## FACEBOOK AND INSTAGRAM

Our public Facebook page has **5,822** followers and continues to be an important tool to engage with our community.

Our closed Facebook group has **569** members.

This year we also started a Facebook Group – Trikafta Team – NZ, it has **201** members and this is a place to share all things related to Trikafta.

Our Instagram account has **1,511** followers.

## WEBSITE STATS

Users: **38,260**

New users: **38,061**

Page views: **102,595**



# MARK ASHFORD SCHOLARSHIP WINNER HEADS TO MONGOLIA



Christopher Headey, a 24-year-old lawyer, is this year's deserving recipient of the CFNZ Mark Ashford Scholarship. Born in the UK, Christopher's family arrived in NZ in 2006, settling in New Plymouth. He attended Waikato University, and now lives and works in Christchurch.

In his final year at university, Chris achieved A grades across all his results with an 87% average. Chris said,

*"At Waikato University I studied Law and completed my degree in December 2021. I started at Anderson Lloyd in Christchurch the following January working in commercial disputes."*

## SUCCESSING IN EDUCATION ALONGSIDE HEALTH CHALLENGES

*"At high school, I was never that amazing at maths or science, but I was always literature focused and took part in lots of speech competitions. I got the opportunity to take part in mootings which is a mock court hearing competing at a national level. We did really well, and I enjoyed being involved."*

*This was my intro to the law. I always knew that I would work around people and have a literacy-based job. The mootings gave me an experience that directed me towards law and by year 13, law aligned with what I was good at and my extracurricular activities."*

Unfortunately Chris' health was starting to decline but he was not yet diagnosed with cystic fibrosis. He recalled,

*"My health meant that I wasn't able to be as involved as much as I'd have liked. In hindsight, I can see that it was around that time in my teens that my main symptoms started but previously there had been nothing seemingly out of the ordinary health-wise when I was growing up."*

## A LATE WHIRLWIND DIAGNOSIS

Chris was not diagnosed via a heel prick test like most people with CF. He said,

*"In the UK they did not have standardised testing for CF when I was born so I flew under the radar. I can look back now and think certain things make sense. When I was younger I would complain of chest pain, was very thin and would cough up sputum. Then in 2015, I got glandular fever and from there everything started to fall apart."*

Chris' family assumed the glandular fever caused the sudden decline, and he then suffered from eight months of chest infections. Finally after a referral to a specialist he ended up doing a sweat test which showed cystic fibrosis was likely. Following a blood test, the results were confirmed. Chris said,

*"I remember my mum getting that phone call, the look on her face and the conversation we had later. It was May 2016 so I was almost 16 years old. From there it was a whirlwind experience. I was very quickly taken up to Starship for treatment and given an intensive programme of education on CF - this is what it means, this is what to do. The IV antibiotics cleared up my infection. My family had basically never heard of CF before, so it was a tough time for all of us."*

## LIFE CHANGING TREATMENTS

Chris' induction into the world of CF was tough, learning and adjusting to treatments as a teen rather than from birth as is the case for most people with CF. His treatments were chest

## THANK YOU TERRA

for generously sponsoring the 2023 Mark Ashford Scholarship.

We are extremely grateful for your support.



physio, IV antibiotics and creon, but a new treatment was just around the corner.

*"I had a few hospital admissions during high school but once I was at uni my health got worse and I got sicker. I ended up having 22 months of intensive antibiotics and that is the reason I now wear glasses as the drugs damaged my eyesight and my liver. So I was treading water and on a downward trajectory. Definitely, during the first two years of starting uni, it felt like there was no good news."*

*In 2020, Kalydeco became available to people like me with a Class III gene mutation, so I was able to start on the drug just as we went into Covid-19 lockdown," he said.*

Like many on CFTR modulator treatments, Chris found the improvements life-changing,

*"It's very hard to put into words. I am now at 101% lung function, I have very little wrong with me. My management of CF now has gone from a dominating part of my life to a small factor of each day. The mental and physical difference is enormous. Naturally, being healthier and having that weight off my shoulders put me in a better position to achieve."*

A few years later, now with Trikafta available to those who are eligible in NZ, he's pleased that now more Kiwis with CF can have the benefits of modulator treatments. Chris said,

*"There will be so many kids and adults who will now relate to the experience I've described rather than the 30-odd of us who were able to take Kalydeco. It's enormous. It's such a complicated, wonderful and confusing but fantastic thing. I will probably move to Trikafta at some time this year. It will be interesting to see if I feel any difference or feel even better."*

## THE MARK ASHFORD SCHOLARSHIP 2023

Chris thought that because he'd finished university he wouldn't qualify for the Mark Ashford Scholarship this year.

*"Lizzie at CFNZ confirmed that I could apply and encouraged me to do so as I had just completed my 18-week Professional Legal Studies Course, which I did alongside my full-time work," said Chris.*

He was at work the day he got the news that he'd won the scholarship. He recalled,

*"It's always lovely to receive good news like that. You never go in expecting things. I walked home from work and phoned my mum as she talked about her day and at the end of the conversation I told her. She was delighted as any mum would be."*

*It's always nice to have recognition of an achievement, especially for an achievement that I've worked hard for from my own merits. I find it hard to allow myself the time or mental real estate to say well done you. You did alright."*

Chris has some exciting but unusual plans for the award money,

*"My uni mates and I have been talking about doing the Mongol Rally, a race from London to Mongolia in sub-1000cc cars for years. We're now planning on doing it in 2025 so I've put the money away to help me fly over to the UK and buy a crappy car for the race."*

When asked if he would encourage others to apply he said,

*"My advice would be to absolutely do it. Even if you aren't successful, I think it's a really good way to put down your achievement on paper. No matter the outcome it's an excellent opportunity to reflect on the positive things you have done and the achievements you may not otherwise celebrate. You don't need to be defined by your illness but there is a lot to be said for achieving in the face of adversity."*

*When I take a step back and look where I am, it's nice to be able to look back and reflect and say that now this is where I am and where I want to be."*

# CF ACHIEVER AWARD RECIPIENTS 2023

The Cystic Fibrosis Achiever 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 seven individuals with CF have been recognised for their optimism, perseverance, and achievement in their chosen category.

## KAIYA MILLER - SPORT

Kaiya is in year 11, and attends Raglan Area School. Kaiya is currently striving to achieve Excellence endorsed Level 1, NCEA this year. Kaiya is an avid fan of fitness and Formula 1. Despite the challenges CF brings, Kaiya works hard at what she does, saying "It was a real pleasure to hear my achievements were notable enough for a CF Achievers' Award."

Kaiya loves lacrosse and netball and hopes to make the Central North Island team for netball again next year. She finds that sports put her on an even playing field with others, where her opposition has no idea what challenges she faces with her health.



## MAISY MILLWATER - EDUCATION

Maisy is an 18 year old nursing student living with CF as well as ADHD.

"Despite the challenges that come with my condition, I have worked extremely hard to achieve the qualifications needed to be accepted into a nursing degree programme. However, I have recently experienced poor health and am currently undergoing an extended period of treatment in the hospital. Despite the difficulties I am facing, I remain determined to continue with my studies and submit my assignments on time, with the help and support of my friends and tutors." Maisy believes perseverance and resilience in the face of adversity are qualities that make her a strong candidate for this award, and we couldn't agree more!



## STAN MILLWATER - LEADERSHIP

Stan is 20 years old and lives in the lovely Wānaka. Stan has recently completed his general engineer apprenticeship at Central Lakes.

Stan never lets his CF get in the way of being able to live everyday life, he doesn't let it stop him achieving his goals. He is going to spend the money awarded on tools for work.

In the near future, Stan plans to move over the ditch to Perth, where he would work as a general engineer in the mines.



## THANK YOU VIATRIS

for kindly sponsoring our 2023 CF Achiever Awards, and for joining us in celebrating our CF community.



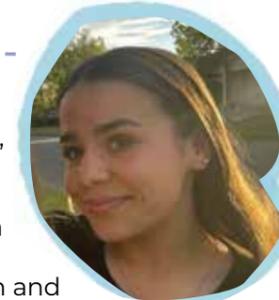
## ANAHERA INNS - EDUCATION

Anahera is 16 years of age, lives in Christchurch and attends Burnside High School, where she holds a leadership role. At school Anahera enjoys art design and playing netball. Anahera's CFNZ Social Worker knew how well she was doing, and suggested she apply for an Achievers' Award.

"At the 2022 Maori Prize giving Poroporoaki awards I was awarded academic achievement, consistent effort, and leadership awards.

I was previously part of He Puna Putaiao, a 6 week Science programme run with University of Canterbury and was also apart of the Junior Rangatahi Tu Rangatira Leadership Programme."

In the future, Anahera hopes to attend university and pursue her interest in design.



## JESSIE MCKAY - LEADERSHIP

Jessie currently lives in Auckland, having moved there about 5 months ago from Tauranga for her new job! Jessie is working as a Flight Attendant and is absolutely loving it!

"I applied for the Achievers' Award as I had finally got the job I had worked quite hard for, after being denied the same job previously due to my cystic fibrosis. Thanks to Trikafta I reapplied and got it as my condition was so stable!"

Jessie was grateful to be a recipient, as it's been able to help set up her flat in Auckland. Looking forward, Jessie will plan to gain further opportunities in her new career.



## BRAXTON PRENTICE - SPORT

Braxton is nine years of age, our youngest recipient this year. Braxton is very active and participates in lots of sports, and has a love for motocross. He is also competing in a few mx winter series, where he hopes to podium at the end of the series (Manawatu series, Taupo series, Martinborough champs, C4 series, Wanganui series). But his sight is firmly set on the NZ nationals in a few months.

Braxton started Trikafta in April and has noticed how beneficial it has been for all his physical activities. Braxton has never felt so fit before, and this years' achievements are going to be even greater than the last.



## RYLEE SINDEN - SPORT

Rylee has loved sports from a young age and would give anything a go. For the past three years, Rylee has been in the top school netball team, she can outrun most of her team-mates, and is an unstoppable force against her opponents. Watching her play, you wouldn't know she had a lung condition! Last year while competing in a week-long secondary school tournament, she needed IV antibiotics, but that didn't stop her. Rylee had daily IV lines placed despite her massive fear of needles, just so she wouldn't miss out or let her team down.

Rylee is now in year 13 and her positive attitude and dedication to sport has earned her the position of Sports Leader (prefect) this year, a great achievement in itself. She has been having a bit of a rough time, but she is determined to get her fitness back, so has been doing self-directed gym sessions instead, and has definitely been seeing a difference.



# 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

- Aotearoa Gaming Trust
- Blue Sky Community Trust
- CAF America (4)- Bright Funds Foundation
- Central Lakes Trust
- Community Organisation Grants Scheme
- Community Trust of Mid & South Canterbury
- Eastern & Central Community Trust
- Estate of EH Davis and Ted & Mollie Carr and Endowment Fund
- Estate of Gordon Lindsay Isaacs
- Estate of Sybil Ada Hensley
- First Light Community Foundation
- Foundation North
- Four Regions Trust
- Freemasons District Grand Lodge of North Island New Zealand
- Grummit Sisters Charitable Trust
- Hutt Mana Charitable Trust
- JM Thompson Trust
- John Ilott Charitable Trust
- Kathleen Dorothy Kirkby Charitable Trust C/- Perpetual Guardian
- Legacy Trust
- Lottery Grants Board
- Louisa & Patrick Emmett Murphy Foundation
- Kingston Sedgfield Charitable Trust
- Kiwi Gaming Foundation
- Mainland Foundation
- NZ Charitable Foundation
- Oxford Sports Trust
- Pelorus Trust
- Rano Community Trust
- Redwood Trust
- Southland Care and Welfare Trust (McMillan Trust)
- Taranaki Foundation
- TG Macarthy Trust
- The Kingdom Foundation
- The Lighthouse Foundation
- The Trusts Community Foundation (TTCF)
- Toi Foundation
- Trust House Foundation
- Trust Waikato
- West Coast Community Trust
- William Toomey Charitable Trust
- Youthtown Inc



## Statement of Financial Performance

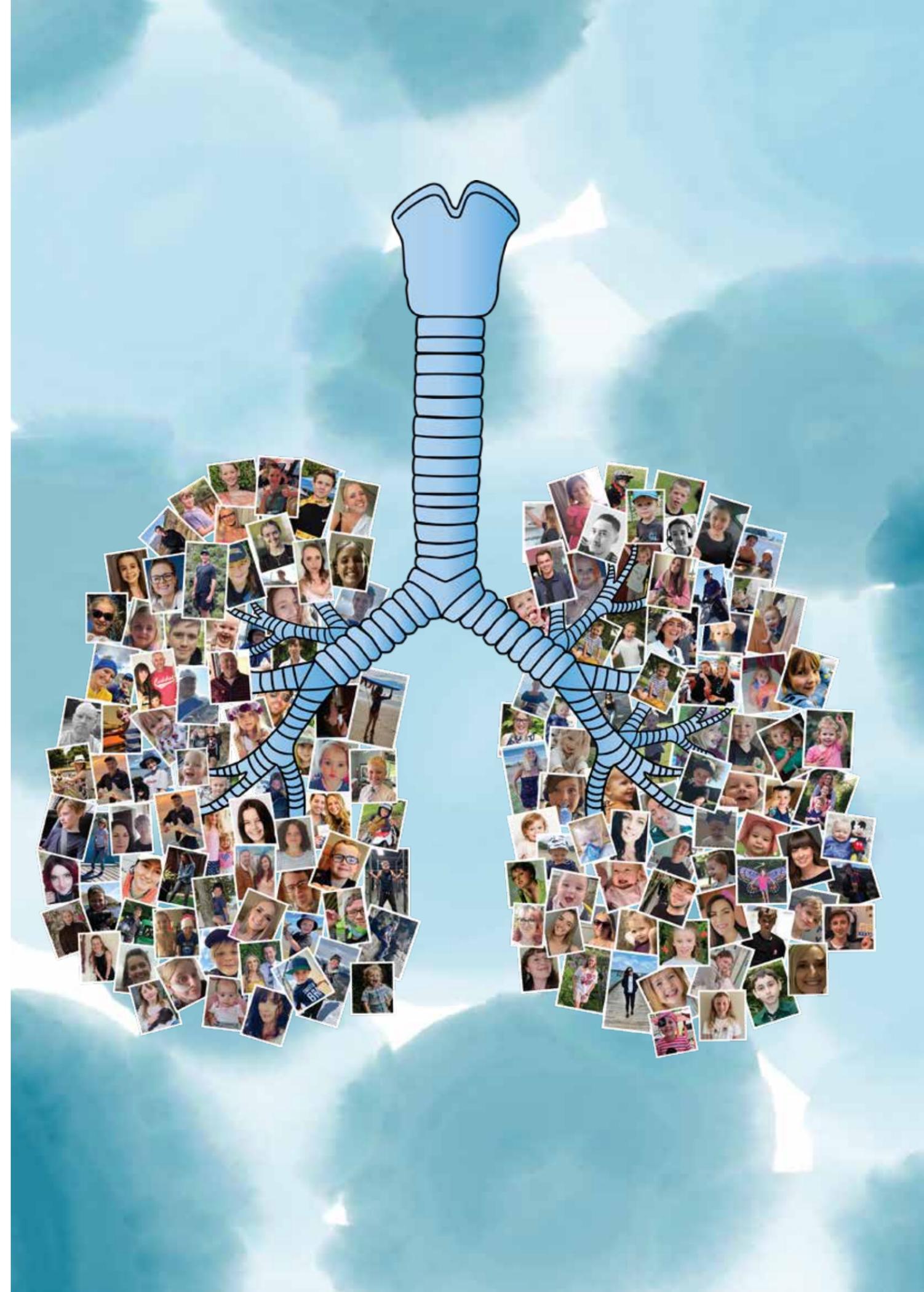
### Cystic Fibrosis Association of New Zealand For the year ended 30 June 2023

	NOTES	2023	2022
<b>Revenue</b>			
Fundraising Revenue	1	904,389	916,744
Donations and Bequests	1	238,071	230,975
Grants	1	273,497	390,572
Sponsorships	1	84,056	110,059
Contract Revenue	1	78,421	90,216
Interest, dividends and other investment revenue	1	88,040	42,884
Subscription from Members		2,170	2,595
Other revenue	1	-	-
<b>Total Revenue</b>		<b>1,668,645</b>	<b>1,784,045</b>
<b>Expenses</b>			
Expenses related to public fundraising	2	374,215	400,267
Volunteer and employee related costs	2	855,941	771,214
Costs related to providing goods or service	2	307,243	328,396
Grants and donations made	2	250,356	293,723
Other expenses	2	44,721	70,304
<b>Total Expenses</b>		<b>1,832,476</b>	<b>1,863,904</b>
<b>Surplus/(Deficit) for the Year</b>		<b>(163,831)</b>	<b>(79,859)</b>

## Statement of Financial Position

### Cystic Fibrosis Association of New Zealand As at 30 June 2023

	NOTES	30 JUN 2023	30 JUN 2022
<b>Assets</b>			
<b>Current Assets</b>			
Bank accounts and cash	3	790,290	1,033,512
Debtors and prepayments	3	85,334	83,827
Other Current Assets	3	83,990	59,286
<b>Total Current Assets</b>		<b>959,614</b>	<b>1,176,625</b>
<b>Non-Current Assets</b>			
Investments	3	837,437	827,335
Property, Plant and Equipment	3	12,275	17,787
<b>Total Non-Current Assets</b>		<b>849,711</b>	<b>845,122</b>
<b>Total Assets</b>		<b>1,809,326</b>	<b>2,021,746</b>
<b>Liabilities</b>			
Current Liabilities	4	146,890	182,363
Unexpended Grants	4	20,337	33,453
<b>Total Liabilities</b>		<b>167,227</b>	<b>215,816</b>
<b>Total Assets less Total Liabilities (Net Assets)</b>		<b>1,642,099</b>	<b>1,805,930</b>
<b>Accumulated Funds</b>			
<b>Accumulated Surpluses or (Deficits)</b>			
<b>Retained Earnings/Accumulated Funds</b>			
Accumulated Funds		1,805,930	1,885,789
<b>Total Retained Earnings/Accumulated Funds</b>		<b>1,805,930</b>	<b>1,885,789</b>
Current year earnings		(163,831)	(79,859)
<b>Total Accumulated Surpluses or (Deficits)</b>		<b>1,642,099</b>	<b>1,805,930</b>
<b>Total Accumulated Funds</b>		<b>1,642,099</b>	<b>1,805,930</b>



# STRUCTURE, GOVERNANCE AND MANAGEMENT

Our Board is a diverse set of members who bring a combination of experience and expertise to the organisation. They set the strategic direction and oversees governance. The organisation is led by the Chief Executive who works with the CFNZ team to achieve our mission and objectives.

As at 30 June 2023

## BOARD

Warwick Murray - Board Chair  
Denis Currie - President  
Kirsty Parsons - CF Adult Representative  
Zac Fargher - Board Member  
Andrew Cameron - Board Member  
Dame Pieter Stewart - Board Member  
Kristina Jeffery - Board Member  
Evangelia Henderson - Board Member

## PATRON

Peter Miskimmin

## 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

Jan Tate – CFNZ Port CF Administrator

Cath Lamont – Adult CF Nurse Specialist, Auckland City Hospital

Rebecca Scoones – Paediatric Physiotherapist, Starship Children's Hospital

Andrew Cameron – CFNZ Board Member

Warwick Murray – CFNZ Board Chair

Lisa Burns – CFNZ Chief Executive

## BRANCH OFFICE HOLDERS

### Auckland

Jill Thorrat - Co-chair  
Jane Drumm - Co-chair  
Allyson Harvey - Treasurer

### Waikato

Annelies Baker - Chair  
Alice Bell - Treasurer

### Taranaki

Shelley Gruchy - Chair  
Allyson Harvey - Treasurer  
Ashlee Butler - Secretary

### Hawkes Bay

John Parsons - Chair  
Pip Charlson - Treasurer  
Claire Fisher - Secretary

### Central Districts

Kayne Dunlop - Chair  
Joelle Dunlop - Treasurer

### Wellington

Paula Richards - Chair & Treasurer

### Nelson/Marlborough

Rebecca Colley - Chair & Treasurer  
Rachel Tobin - Secretary

### Canterbury

Melissa Skene - Chair  
Viv Isles - Treasurer

## STAFF

### Lisa Burns

Chief Executive

### Angela Crates

GM Finance & Operations

### Maree Cotter

Fundraising & Development Manager

### Nikki Purvis Schischka

Marketing Manager

### Lizzie McKay

Communications & Public Awareness Manager

### Nashwa Soliman

Database Coordinator

### Sue Radcliffe

Philanthropy Manager

### Susan Lovelock

Team Leader Community Support, Registered Social Worker – South Island

### Gretchen Kitching

Community Support Lead – Auckland, Northland

### Carolyn Downer

Community Support Lead, Registered Social Worker – Hawkes Bay, Wellington

### Bev Darlow

Community Support Lead, Registered Social Worker – Waikato, Bay of Plenty, Taranaki, Central Districts

### Christine Perrins

Advocacy Adviser – Volunteer

### Jan Tate

Port CF Project Coordinator

# INTRODUCING OUR NEW BOARD MEMBERS

This year we had the pleasure of inducting three new members to the CFNZ Board. Our Board is made up of eight individuals who combine their experience and expertise to improve the lives of people with CF in New Zealand.

## DAME PIETER STEWART

### Tell us a bit about yourself

My home is in Mid Canterbury where I brought up my (now adult) children on a large deer farm. In recent years the farm has been sold and we continue to live in a large old homestead on a 20 acre block.

For the last 30 years or so I have owned and run a business in Auckland – something I could not have considered when the children were young. Prior to starting my Auckland based business, I had my own PR and Events company and worked with Child Cancer and other charities. I spent ten years as Chair of an Independent School in Christchurch and served as Deputy Chair for almost the same amount of time on the Independent Schools Board in Wellington.

Consequently, since selling my business, I am taking on Board roles where I hope I can be of use, mainly in the not for profit arena in health and education.

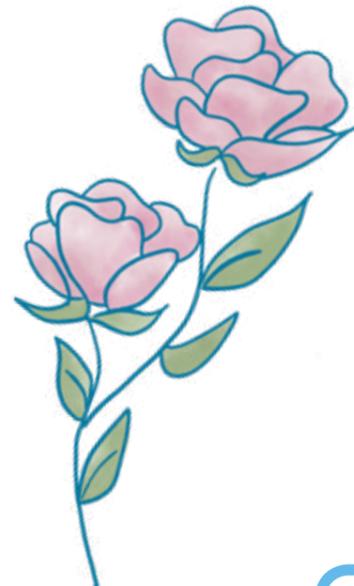


### What does being on the CFNZ Board mean to you and what do you have to do?

When approached to consider being on the CFNZ Board, I researched the condition and organisation as much as possible. This was prior to Trikafta, and I decided I wanted to help in any way I could. There's a lot to learn, but meantime working closely with Lisa on additional ways of sustainable funding for the organisation is my priority.

### What's your biggest wish for the CF community?

That those with CF get to live normal lives, and look forward to a long future. That the future holds even better drugs able to be tolerated by everyone with CF and an eventual cure.



## KRISTINA JEFFREY

### Tell us a bit about yourself

I recently turned 33 and moved back to Auckland at the beginning of last year, after living in London for almost five years. As well as moving back to Auckland (and spending 10 days in MIQ) I also got married to my English fiancé late last year who I met in a pub in London! I currently work at Auckland Airport in the strategy, planning and performance team, having recently joined after working at TVNZ for just over a year.

### What does being on the CFNZ Board mean to you and what do you have to do?

I feel privileged to be on the CFNZ Board and to be part of an incredible community who are extremely passionate and supportive. I enjoy helping others and being on the Board is a great opportunity to share my finance background and experience as well as learn about cystic fibrosis, which I did not know much about prior to joining the Board. In addition to being a Board member, I am also the Chair of the Finance, Audit and Risk Committee, so am responsible for preparing agendas for committee meetings, drafting minutes, and reporting back to the rest of the Board. In preparation for committee and Board meetings there are documents to read through and the odd thing pops up in-between meetings that we usually cover off over email or put on the agenda for the next meeting. I usually have a committee or Board meeting once a month that is for around two hours on a weeknight.

### What's your biggest wish for the CF community?

For people with cystic fibrosis and their families to live their lives not being defined by having cystic fibrosis - no limitations on aspirations and anything being achievable.



## EVANGELIA HENDERSON

### Tell us a bit about yourself

I retired two years ago after 10 and a half years as CEO of Breast Cancer Foundation, and prior to that, occupied corporate roles in NZ and overseas. I am married to Peter, have two adult children - a daughter in London and a son in Auckland. I love to do all things I didn't have time to do whilst working - international and national travel, cooking as a hobby, taking long walks, and lots of reading everyday.

### What does being on the CFNZ Board mean to you and what do you have to do?

I like to utilise my corporate experience in management and my past experience as CEO of a successful NGO to help guide funding decisions and strategy and to ensure CFNZ continues to grow, and prosper, for the wellbeing of the CF community. The responsibility of the Board is to ensure the ongoing health, sustainability, and reputation of CFNZ and that it stays true to its declared mission.

### What's your biggest wish for the CF community?

That research continues to evolve, developing smart new drugs that ensure people with CF live normal healthy lives and CF is no longer a life limiting condition.





Please call 09 308 9161 or  
freephone 0800 651 122.

You can also contact us by  
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**For the financial year ending 30 June 2023**