CF News

AUTUMN 2025

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All you need to know to attend the NZ CF Symposium this May

MEET OUR MARK ASHFORD SCHOLARSHIP RECIPIENT

Read Claire's story where resilience meets research

ADVOCACY

Keep up with the latest advocacy news

CYSTIC FIBROSIS NZ

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Cover Mark Ashford Scholarship recipient, Claire Scofield.

Line drawings throughout by CFNZ's very own Lizzie McKay.

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A NOTE FROM LISA

I truly hope 2025 has started well for you.

Firstly, I'd like to congratulate our Mark Ashford Scholarship recipient for 2024 – Claire Scofield. Her courage and passion for all she does is beyond words. Read more about Claire on page four. On page five we celebrate our amazing CF Achiever Award recipients; Charley, Ben, Sophie, Nichola, and Hamish, all exceptional individuals living with the challenges of CF, and excelling in their chosen category.

In May we'll host the first international CF Symposium: ***Shaping the Future of CF Care*** in Auckland, uniting healthcare professionals, researchers, and our CF community. It's been eight years since the CF community last came together in person. The landscape has evolved since then, bringing both remarkable progress and new challenges. Together we'll explore innovative approaches, address critical topics, and build a stronger, more connected CF network across New Zealand.

Global thought leaders and local experts will share insights on adapting to the post-modulator era, leveraging technology for better outcomes, and navigating the complexities of CF care. We'll also host interactive workshops on a wide range of topics that affect the diverse CF population.

This event is about more than just learning, it's about connection, sharing your experiences with others who understand. We know the power of coming together. Just look at what we've achieved with access to life-changing medicines like Trikafta- milestones that were reached through collaboration, advocacy, and unwavering community support.

Whether you are a healthcare professional, a caregiver, family member, spouse, or a supporter, your perspective is invaluable. I encourage you to register today at www.nzcfsconnect.nz and be part of this milestone event. Together, let's continue building a future of support, resilience, and possibility for our CF community in New Zealand.

It gives me great pleasure to introduce the very talented Simone Brown who joined CFNZ last year as our Community Engagement Manager. We are really excited to have her on board, you can find out more about her below.

I hope you enjoy our Autumn edition of CF News, it's always a pleasure to be able to share the stories, challenges and successes of our wonderful CF community.

Warmest wishes

Lisa

Lisa Burns
Chief Executive

MEET SIMONE

Tell us about your role at CFNZ

Currently I am leading core strategic projects such as the NZ CF Symposium and the launch of our Digital Village. Following this, we have loads of opportunity within community outreach - rebuilding connections, updating educational resources and activating the survey feedback received over the past couple of years. I am excited to partner with our Branches and community to develop programmes/tools where we collectively feel it is needed most. My inbox is always open, never hesitate to provide your feedback and insights - simone@cfnz.org.nz

What drew you to working with CFNZ?

Working on the other side (Pharma) I often felt the desire to be closer to the community, to the patient, and to the people we serve. As a former partner and collaborator of CFNZ I could see the great strides the team and community were making and jumped at the opportunity to be a part of it.

On the weekends we would find you...

Running around after two children, fitting in activities/errands/house chores, family visits and brunch. Always manage to fit in a good brunch!

BREATHE
The Ballet

Born from the incredible resilience of our CF community and a deep, heartfelt friendship, the ballet "Breathe" is a profoundly moving expression of the everyday challenges faced by those living with cystic fibrosis. Through the language of art, this poignant performance demonstrates the emotional landscape that so often remains unseen, offering a powerful reminder of the strength, and courage within our community.

Originally a gala performance in 2012, "Breathe" was choreographed by the gifted Medhi Angot, a former member of the Royal New Zealand Ballet, whose talent as both a dancer and storyteller brought this narrative to life in ways that transcend words. What started as a single moment of artistry has since left an enduring legacy that resonates to this day.

Medhi gathered a circle of friends, artists, and fellow dancers, all driven by a shared passion for capturing the raw and real experience of living with CF. What emerged from this collaboration is more than a ballet—it is a testament to friendship, and the unwavering determination to make a difference. With every movement, "Breathe" embodies the voices of those with CF, delivering a message of empathy, support, and the deep need for understanding. It's a symphony of emotion, purpose, and a story of hope with a lingering sense of connection.

> ***"CFNZ's passion for supporting and improving the quality of life for people with CF and their families makes us incredibly proud to support this initiative. Mehdi's ballet is a beautiful way of empowering the CF community around the world, raising visibility of this disease during CF awareness month."***
>
> *Barnaby Luff, Head of Marketing, Viatris NZ*

In 2023, with the generous support of our friends at Viatris, we had the privilege of bringing this extraordinary ballet to life once again. The performance was made even more powerful with the inclusion of Gin Wigmore's hauntingly beautiful piece, "Hallelujah," a gift from Universal Music New Zealand on behalf of Gin, completing the creative vision.

Launched during CF Awareness Month last year, this breathtaking performance left our audience spellbound. It brought tears to many eyes and deepened the sense of connection to our mission: to enable every person living with CF to thrive and live healthy lives.

"Breathe" is not just a performance. It speaks to the power of compassion, creativity, and the unshakable belief that, together, we can make an enduring difference in the lives of those who face extraordinary challenges.

> ***"In special memory of Flora and all our CF Warriors – past, present, and future."***
>
> *Medhi Angot*

VIATRIS

Thank you to the team at Viatris for your generous support.

RESILIENCE & RESEARCH

Meet Claire, our 2024 Mark Ashford Scholarship recipient

Claire Scofield is a remarkable 36-year-old horticultural scientist and this year's proud recipient of the **Mark Ashford Scholarship**. She lives in Otago with her firefighter husband, Dan and is currently pursuing a PhD with the Tasmanian Institute of Agriculture at the University of Tasmania. Claire's journey is a testament to resilience and determination and shows that you never know where life will take you. Born in 1988, Claire grew up in Glendowie, Auckland. CF testing was still new in New Zealand, and genetic testing was just emerging. Her newborn test results never reached her GP, so it wasn't until she was eight that she was diagnosed with cystic fibrosis.

"As a young kid, I kept getting sick and couldn't gain weight. I was pancreatic sufficient so that helped me fly under the radar but I had eight years of constantly getting sinus, ear and chest infections. So by the time I was diagnosed, I was already a step back with probably around 80% lung function," said Claire.

Her first admission came when she was 10, "After that, admissions were yearly. It was a massive change for everyone. I would say that I was a relatively non-compliant teenager due to starting CF treatments late. Starship was amazing though and I quite enjoyed the hospital as it was a good break from normal life."

AN UNEXPECTED PATH TO HORTICULTURE

School had never been her focus, as she preferred fine arts to academia, "I didn't love school. I probably didn't excel in my studies, which is funny considering what I do now, but I excelled in arts and fine arts."

In her late teens, she struggled with her health. She was in and out of hospital but still passed the university entrance to enable her to pursue her dream. Claire recalled, "I studied nursing and I absolutely loved it. It was all I ever wanted to do. In my second year, I found out I had Burkholderia, a potentially very dangerous bug. My doctor at the time said that I should no longer pursue nursing. At that point, I had a bit of a crisis and didn't know what to do."

Feeling uncertain about the future, Claire initially pursued a path in animal management. However, it didn't click for her but when she discovered a horticulture course in Palmerston North, everything began to fall into place.

"My grandma was a keen gardener and I had always loved spending time with her gardening during holidays. I also really wanted to get out of Auckland and make a massive change. I've not looked back.

Today, I'm a scientist for Plant & Food Research in Alexandra, Central Otago. I've worked here for 13 years. I started as an undergraduate and just loved it. It's never the same day-by-day and year-by-year."

STUDYING FOR A PHD WHILE EMBRACING THE GREAT OTAGO OUTDOORS

After completing her master's while working full-time, she started her PhD at the University of Tasmania last year. Her research centres on understanding the factors that influence calcium uptake in cherries, especially in protected cropping environments.

"The goal of the PhD for me is to produce an outcome that will be beneficial for growers. At the moment that might be as simple as nutrient updates for trees."

But is working in horticulture a risky field for people living with CF? Claire says yes and no,

"There probably are some CF risks to what I do. I am very careful if I work around potting mix – but we all should be. I have never felt that I have been putting myself at undue risk. It's probably 50% or more computer-based, 25% field and 25% lab so my exposure to the plants is pretty small."

Outside work, Claire lives an active lifestyle with her husband.

“When I moved to Otago I got into tramping, cycling and mountaineering – all the good things. I actually met Dan at primary school and we reconnected in our 20s when he came down here for a holiday. We met up to go rock climbing and mountain biking. That’s still what we enjoy doing but I now need to wear oxygen when I exercise.

We live on a lifestyle block and I’m hoping to grow flowers here to sell at local markets soon as a little side hustle.”

MANAGING THE CHALLENGES OF CF

With two rare gene mutations, Claire started Kalydeco around 3 years ago.

“It was my lifesaver. I weighed 53 kg and was getting sick a lot so we were talking about transplant at that time. After a few months, I had gained 10kgs. There was no big wow moment but more of a gradual improvement. I didn’t need to go down the road of transplant as I now have that future ahead of me.

With such a busy and active life it can be hard to balance treatments and self-care.

“Day-to-day, my CF isn’t always managed the best. I am not perfect. Prioritising rest has been my main way to keep going. The good thing about doing a PhD is that it’s flexible. I can wake up and set aside time for myself to walk the dog, do my deep breathing and do exercise and treatments.”

I think it could be easy for others to view me as having it quite easy due to the way that I portray myself online. But there are a lot of key things that I don’t show. It’s important to remember we don’t always know what others are dealing with,” said Claire.

THE MARK ASHFORD SCHOLARSHIP AND BEYOND

Claire had previously received an Achievers Award from CFNZ and had known about the scholarship for many years but felt she hadn’t achieved enough to apply until this year.

“I found out that I had the scholarship on the phone. I was so surprised. It was a really nice feeling and Lisa and Lizzie were so sweet about it.

There is the opportunity to attend the International Cherry Symposium in the US next year. I would probably be presenting two years’ worth of data from my PhD so I will use the money for that and do some travel in the US while I am there.”

Claire has some wonderful words of advice for other people living with CF on both applying for the scholarship and pursuing higher education, “My advice to others is to just do it. The worst that will happen is that you won’t get it and if so, try again next time. It’s been given to very accomplished people so I am very proud to be a recipient.

I am a strong believer in telling people that you never know where you will end up. I know a lot of people who were not able to prioritise education due to their health. I hope that future generations won’t have that worry. You can never lose from having further education. It opens so many new opportunities for a new career, and it’s never too late."

Thank you Terra
for generously sponsoring the
2024 Mark Ashford Scholarship,
helping us celebrate the
achievements of our
CF community.

terra
consultants

CF ACHIEVERS' AWARD RECIPIENTS 2024

The Cystic Fibrosis Achievers' Awards are awarded annually to people with CF who have achieved excellence in one of these four categories; leadership, the arts, sport or education. In 2024, five individuals with CF were recognised for their determination, resilience and achievement within their chosen category.

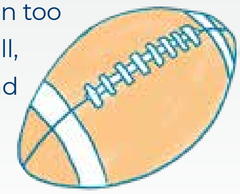
CHARLEY CAMERON - THE ARTS

Charley lives in Wellington and is part of hip hop crew NOVA, that last year won the Junior Mega Crew division at the New Zealand Hip Hop Championships. Going on to compete in the World Hip Hop Championships in Portugal, they triumphed and became the World Junior Mega crew champions.

"Living with CF has presented a lot of challenges, but it has never stopped me from pursuing my passions. Dancing has been a source of strength and resilience throughout my journey with CF, and keeps me fit."

Charley will use her grant money towards the coming years hip hop tuition and travel fees for competitions around New Zealand.

SOPHIE HUTCHESON - SPORT



Sophie, who hails from Otago has played and succeeded in too many sports to list on these pages, including touch, netball, running, volleyball, adventure races including kayaking and biking and rafting. She is also ticking off the great walks with her family. She is most proud of making it to the Rotorua Touch Nationals. Sophie will use the award money to pay for sports and event fees to keep her list of activities growing!

"There were many challenges in between training. The biggest one was probably trying to fit nebulising in-between trainings and school, remembering to take all my pills and fitting in hospital appointments."

VIATRIS

Thank You

Viatris for generously sponsoring the 2024 CF Achievers' Awards, helping us celebrate our CF community.

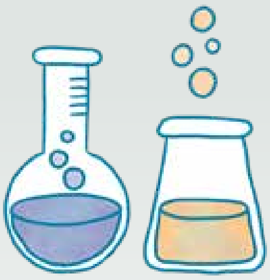
BEN PRINCE-SAXON - SPORT

Ben lives in Auckland and has completed two half (Mt Maunganui and Taupo), and one full marathon (Auckland) in the last year. He broke his toe two days after the Taupo half marathon which interfered with his training schedule for the Auckland marathon, but he still completed it with a finish time of 4 hours and 27 minutes. Ben is setting himself another challenge – to complete 12 marathons in 12 months.

"I completed Round the Bays in March 2024 with a time of 36:03, a 4 minute improvement on my time from 2023 before I started Trikafta."

Ben's grant money will be used to help him fulfil his '12 in 12' aspirations. Read more about Ben's mission on page 15.

HAMISH MOUNTFORD - EDUCATION



Christchurch based Hamish completed his Bachelor of Science in Physics in June 2022. Despite declining health towards the end of his degree he maintained a strong academic record, with an average grade of A.

An invitation to be part of a team researching neuromorphic computing was disrupted by Hamish having to leave New Zealand to access Trikafta in Australia to stop further decline in his health. Now that Trikafta has been funded here he has returned to complete his postgraduate studies.

"I have also rejoined the neuromorphic research team to pick up where I left off. Financial support for postgraduate students is limited and it will take a few years to complete a PhD."

Hamish's grant money will help pay for his living costs so that he can pursue this academic goal without further interruption.

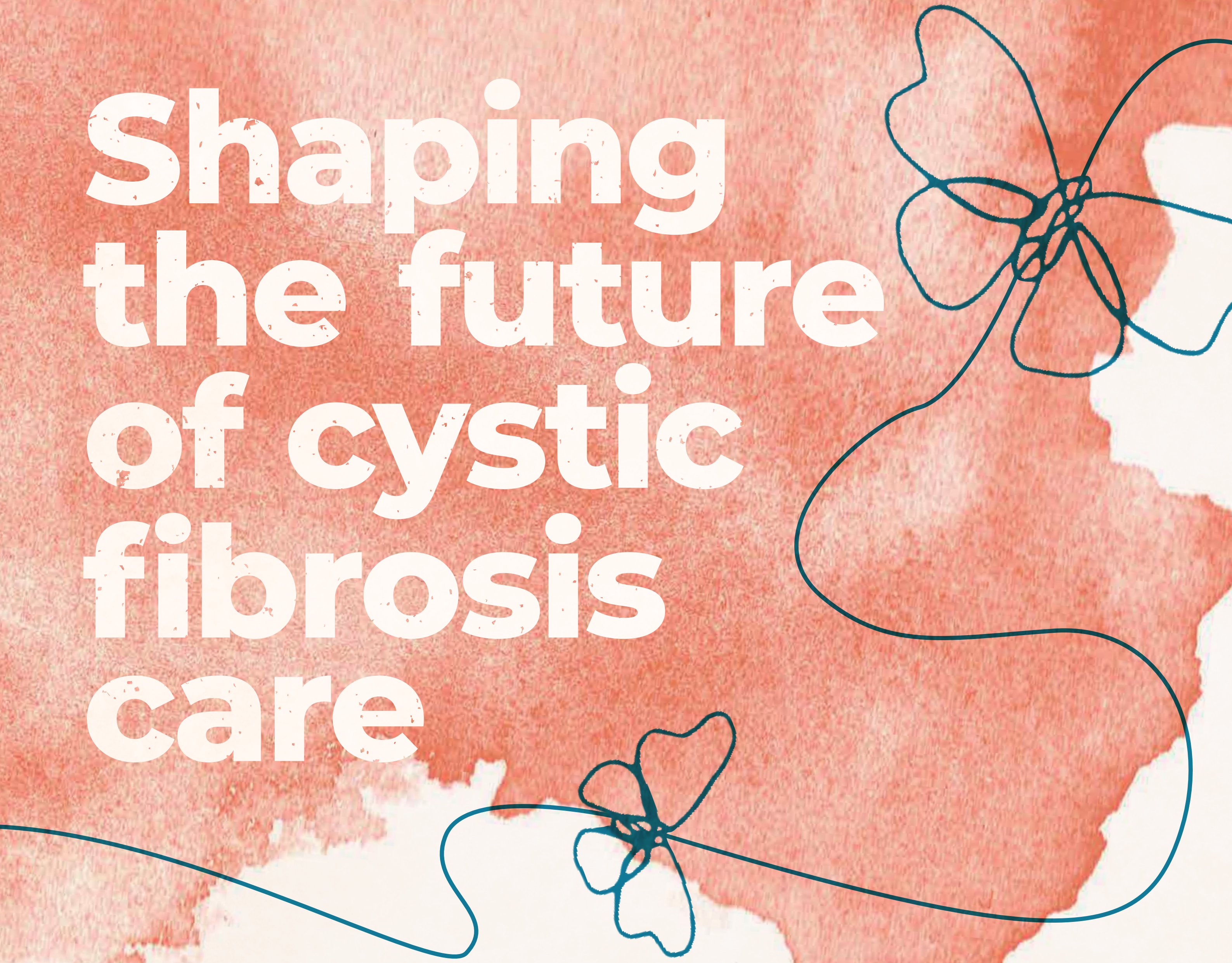
NICHOLA WILSON - EDUCATION

Nichola has seen significant advancements in CF treatment over the years. She was an early recipient of the groundbreaking Creon drug, participating in a Phase 3 trial somewhere in the mid-80s (yes, that's aging!).

After 'almost' undergoing a double lung transplant, access to Trikafta has been a complete game-changer for Nichola. With a renewed lease on life, she has embraced new opportunities—including the pursuit of higher education. Nichola is on track to finish her Master's in Sustainable Business (University of Otago) in the next few weeks. Her recently completed thesis, ***'Navigating the Green Shift – A Just Transition for NZ Small Businesses'***, explores the challenges and opportunities facing businesses in the transition to a low-carbon economy. The grant will help support her final course fees as she completes this academic milestone.

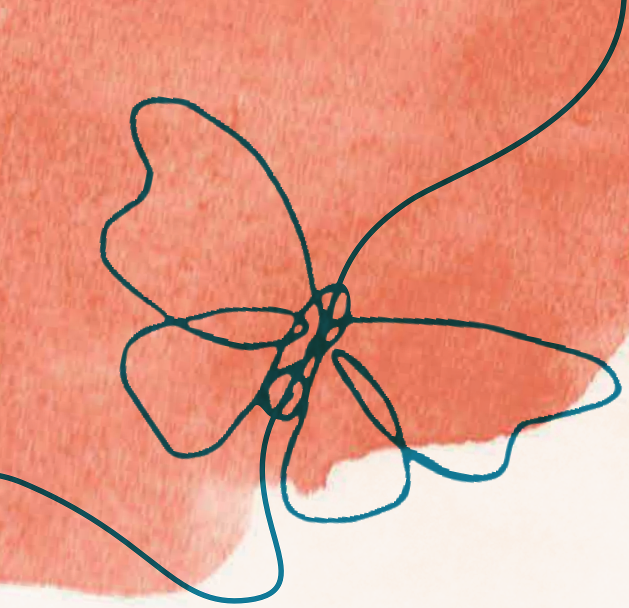
NZ CF
SYMPOSIUM
2025

Shaping the future of cystic fibrosis care



9 – 10 May 2025
Waipuna Hotel & Conference Centre, Auckland

This year's symposium is about two things. Firstly, it's about celebrating the power of community advocacy and looking back at the progress we've made. But it's also about charting the course ahead. Together with healthcare professionals and the wider CF community, we'll explore the evolving landscape of cystic fibrosis care and share stories, spark new ideas and shape a future that we can all look forward to.



Meet our speakers.

We're delighted to welcome a range of global thought leaders, from healthcare professionals to researchers to advocates and more. With fresh insights, information and innovation to share, they'll inspire us as we collaborate towards a brighter tomorrow for those living with CF.

Dr Elizabeth Tullis
MD, FRCPC
Director of the Toronto Adult Cystic Fibrosis (CF) Clinic at St. Michael's Hospital

Prof Scott Bell
MBBS MD FRACP FAHMS FThorSoc GAICD
Senior Thoracic Physician
The Prince Charles Hospital

Maggie Harrigan
Social Worker,
Research Fellow

Dr Yelizaveta Sher
MD, FACLP
Clinical Professor of Psychiatry and Deputy Chief of Division of Medical Psychiatry at Stanford

Associate Professor Tonia Douglas
MBChB, FRACP, MD
Co-Director Cystic Fibrosis Services, Senior Staff Specialist, Queensland Children's Hospital.
Clinical Associate Professor,
The University of Queensland

Dr Mark O'Carroll
MB ChB 1995 Auckland; FRACP 2003
Respiratory, Cystic Fibrosis, and Transplant Consultant, Auckland Hospital

Dr Cass Byrnes
MBChB, FRACP, MD
CFNZ Clinical Advisory Panel Chair, Associate Professor in the Paediatric Department of University of Auckland and a Paediatric Respiratory Specialist at Starship Children's Health & Kidz First Hospital

Dr Julianna Bailey
Senior Dietitian, PhD, Cystic Fibrosis and Respiratory Lead, Nutrition Department

Help shape the future of CF care.

Don't miss your chance to be part of this groundbreaking event.
Register today at nzcfsconnect.nz

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Want to take part?

We've got your back!

The NZ CF Symposium is an important event for our healthcare teams and for our CF community.

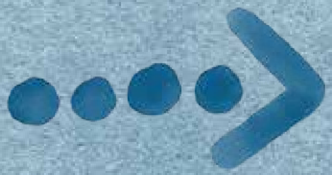
We recognise that there may be some financial barriers to attending and we want to ensure we can support you as much as possible.

If some financial assistance will help you get there, please scan the QR code below to find out more.

Applications must be received by Sunday 6 April.

> **"Conferences provide great opportunity to build a support network and this network became my CF family – it was huge for me. I know I can reach out, ask for help, and get tips to help make life easier."**
>
> **Shelley, CF mum
> and Taranaki Branch Chair**

SCAN HERE FOR MORE INFO



WELCOME TO HOLLAND

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... And they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... Because the loss of that dream is a very very significant loss.

But... If you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... About Holland.

By Emily Perl Kingsley

FANTASTIC FUNDRAISERS

BOWLS DAY
CENTRAL DISTRICTS BRANCH

Our Central Districts Branch was extremely grateful to be chosen as the benefactor of the Bowls Palmerston North annual charity tournament in April last year.

The 30 teams from the lower North Island and a wonderful bunch of volunteers along with some superb weather meant for an amazing day. Entry fees, raffles, an auction and proceeds from sales of knitted clothing from Made With Love meant that over $3000 was raised to support families with cystic fibrosis in the Central Districts area.

Kayne Dunlop, Chair of the Central Districts Branch, said "A special mention to Alex, who lost 2 nieces to CF, who donated his bright blue hair to a raffle with the winner having the pleasure of shaving his hair off on the day."

Thank you to everyone that supported the event, especially Bowls Palmerston North.

TEAM LOCKTON
AUCKLAND BRANCH

On Sunday 2 November a group of the amazing team at Lockton laced up and took to the streets to run the Auckland Marathon.

Head of People Solutions, Niall Martin has been fundraising for CFNZ for over a decade, more recently doing so through running the Auckland Marathon and encouraging the Lockton team to join him. The team raised $10,000 for Cystic Fibrosis NZ Auckland Branch to make a positive impact for those living with cystic fibrosis and their families.

Thank you so much to Niall and the Lockton team for your epic efforts to continue to support families affected by CF.

A BLOOMING GOOD FESTIVAL!
TARANAKI BRANCH

The Taranaki Fringe Garden Festival took place in Taranaki in November, and superstar gardeners Yvette and Keith Kelly generously donated the gate takings from their stunning Millfield Garden to Cystic Fibrosis NZ Taranaki Branch.

We are so grateful to Yvette and Keith for sharing their absolutely beautiful garden and choosing us to be the beneficiary of the funds collected from everyone who visited their garden during the festival. Just over $3000 was raised which will make a big difference providing support to families in the Taranaki area.

BLUE MUFTI DAYS!

We are so blessed to have the support of many schools around New Zealand, who hold mufti days, bake sales, ice cream sales and more to fundraise for Cystic Fibrosis NZ.
No schools are more supportive than the ones that have a connection and understanding of what it means to live with CF. Two of these wonderful schools came out in support of Kiwis with CF for CF Awareness Month in May last year, honouring their students Liam Juretich from Dargaville Primary School and Tailen O'Connor who attends Ngahinapouri School.

The involvement of schools in community fundraising is so important to us, not only from a fundraising perspective, but also to help spread awareness and understanding amongst a new generation of tamariki of conditions such as CF that exist among their peers. Thank you so much Ngahinapouri School and Dargaville Primary School.

NGAHINAPOURI SCHOOL

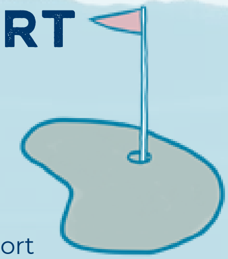
On Monday 27 May the amazing students and staff (and parents!) of Ngahinapouri School joined together for their Blue Day Fundraiser in support of CF Awareness Month. They raised an amazing $750 by selling some delicious blue themed cupcakes and Chocky Fish, as well as dressing in blue!

DARGAVILLE PRIMARY SCHOOL

On Friday 31 May, **Deliberate Kindness Day**, the wonderful teachers and students of Dargaville Primary School came together to honour CF Awareness Month with a Blue Mufti Day, raising an epic $570 for Cystic Fibrosis NZ.

HOLE-LOTTA SUPPORT ANNUAL GOLF DAY

CANTERBURY BRANCH



Friday 29 November saw the Cystic Fibrosis NZ Canterbury Branch host their annual Ambrose golf tournament, raising over $8000 to help support people with CF and their families in the Canterbury region.

A wonderful day was had by all! A huge amount of effort, planning and support goes into making this a successful fundraising event, thank you so much to everyone involved: Pak'n Save Moorhouse, ANZCO Foods Rakaia, Lynn River, New World Durham Street, Choice Hotels, Bush Bar, Life Pharmacy Riccarton, and Racecourse Hotel.

A MARATHON EFFORT FOR CFNZ

In August 2023, the Rooney family, Liam, Courtney and Beau (now 4) welcomed gorgeous Luca into the world. Three weeks after his arrival the family had to deal with the most difficult challenge of their lives to date – Luca was diagnosed with cystic fibrosis.

The news was crippling for the family and Liam and Courtney struggled to come to terms with Luca's diagnosis. His older brother Beau does not have CF and there is no family history on either side. However, it has also served as a reminder of what is most important in life, family and health. Liam says "I am very proud of how far we have come as a family, as it has only made us stronger and more united."

While they try to keep things as normal as possible, they have had to make adjustments for Luca's health. While Beau continues to go to daycare, Courtney and Liam make sure he changes his clothing and washes his hands and face when he gets home. The family sanitise hands, don't wear shoes inside and waterblast everything they can to help prevent the transmission of germs that could make Luca very unwell. They are now more mindful of where they travel and make sure they are near a hospital, just in case, and that the surroundings are safe and clean.

Amid all of this Luca is the definition of sunshine. "He is always smiling and brings so much joy to our family. He's been on the move since 5 months old and absolutely adores his big brother, Beau. Luca never fails to put a smile on your face although the older he gets the more we see his crazy, energetic side, which we love so much." says Liam.

To help raise awareness of CF and funds for Cystic Fibrosis NZ, Liam and Courtney set themselves a challenge for 2024. Liam ran five half marathons and Courtney ran her first full marathon. Their Givealittle page has received an enormous amount of support and they have raised an incredible $20,965.

They also had a group join together to fundraise and run the Auckland Marathon in November, raising $5076.

Liam explains "My thought process behind the marathons was that if I did one, I would just drop off after, but if I did five, I would form a habit and follow through to setting an example for Luca (and Beau), who is going to need to be active in his life. It provides great motivation."

They were blown away by how quickly they reached their goal of $20,000 – crediting their fantastic friends, family and clients for the support. "Anyone can see how special Luca is and what a good cause we are supporting".

The Rooney's say that their CFNZ Social Worker Gretchen has been an amazing support as well as Jan from CFNZ who was so helpful at a time they were really needing assistance. Courtney has found support via other mothers she has met online and the family have also received fantastic support from the Starship team of nurses, dieticians, doctors and physicians.

Of course, all Luca's parents want for him is to live a happy and healthy life doing whatever he wants to do. "In the short term, we pray that Trikafta funding is brought forward to 2 years old and his body reacts well to the drug. He and his brother are the lights of our lives." says Liam.

Going the extra mile

BEN'S INCREDIBLE 12'N'12 MARATHON CHALLENGE

At 24 years old, Ben Prince-Saxon is proving that limits are meant to be broken. Diagnosed with cystic fibrosis (CF) at the age of four, Ben was told his life would be filled with hospital visits and medical challenges. Ben's CF experience so far has certainly had its ups and downs, while his early years saw relatively few hospital admissions, this began to change in 2018. "I could slowly feel my health declining, with a cough hanging around almost every day and not having as much energy," Ben recalls. Then, in 2022, everything changed with the announcement that Trikafta would be funded in New Zealand.

For Ben, Trikafta has been nothing short of transformative. It has given him the ability to dream beyond what once seemed possible. "All of a sudden, I could plan 10 years ahead," he says. With newfound health and determination, Ben set his sights on running, completing his second Auckland Marathon in 2023 with a dramatic improvement in time—from 6 hours 12 minutes in 2020 to 4 hours 27 minutes.

That achievement sparked a deeper passion. In 2024, he pushed himself further, successfully completing three half-marathons and three full marathons, shaving an hour off his previous best with a personal record of 3 hours 27 minutes at the Taupō Marathon. But for Ben, this was just the beginning.

His 2025 mission—dubbed "12 in 12"—will see him running 12 marathons across New Zealand (and one in Melbourne) over the course of the year to raise $25,000 for Cystic Fibrosis NZ. More than just a personal challenge, it's a way to give back for the support that has helped Ben keep moving. **"The Breath4CF grant has been used every year to pay for football fees, new boots, and now running shoes to keep me injury-free,"** he shares.

> "TRIKAFTA HAS GIVEN ME A SECOND CHANCE AT LIFE, AND I'M MAKING THE MOST OF IT."

Ben's marathon journey will take him across the North Island, with races in Auckland, Pauanui, Hawke's Bay, Wellington, Taupō, Whangamatā, and across the Tasman to Melbourne. He hopes to inspire others with cystic fibrosis and raise awareness of the impact of Trikafta.

THE BEST WAYS TO SUPPORT BEN?

Cheer him on at a marathon near you, donate to his Givealittle page using the QR code, or follow his progress on Instagram @benprincesaxon. With every step he takes, Ben is not just running—he's proving that with the right support and determination, anything is possible.

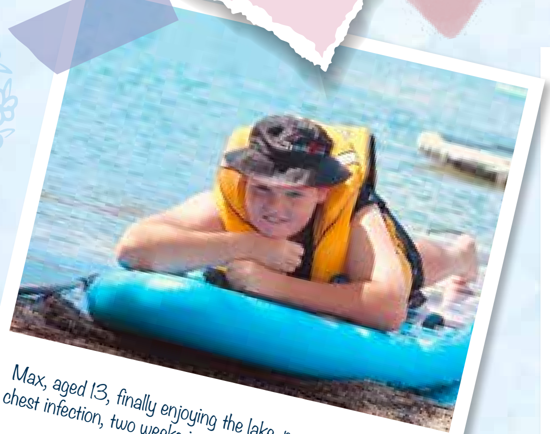
Community Joy Board

Grace bought her first laptop for tertiary schooling this year. A couple of years post liver and pancreas transplant, and starting Trikafta, living her best life!

Grace

Harvey as a Rookie lifeguard and competing in surf sports.

Harvey



Max, aged 13, finally enjoying the lake, post a month full of a chest infection, two weeks iv antibiotics and picc line removed.

Max

Lucas climbing the Pinnacles (with a broken wrist!)

Lucas

Poppy exploring the Abel Tasman.

Poppy

Madison – on her first trip to Queenstown.

Madison

Sophie had her first holiday without being unwell and loved every moment making special memories with her big sisters.

Sophie

Tailen first 5 aside games of soccer, received player of the day.

Tailen

Here is Emerson, aged 5 - first time camping this Summer! Huge milestone for our family!

Emerson

Roman is loving his bush walks.

Roman

Leyla on her first day of high school, happy and healthy.

Leyla

Amelia 6 mastered rolling skates in the holidays and loves riding the bmx track while on holiday.

Amelia

Summer gaining Trikafta after her rare mutation was added to the FDA approved list back in December. What a Valentines treat!

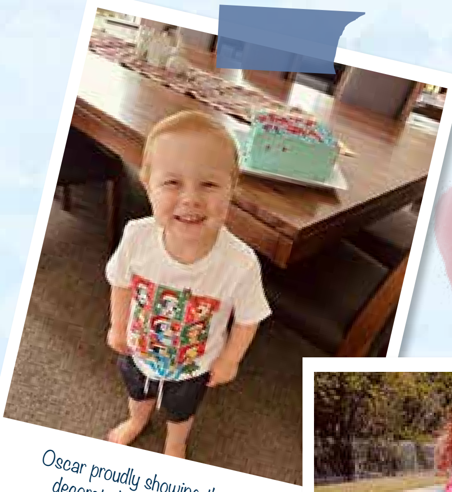
Summer

Natalie finally mastered the art of kayaking.

Natalie

Lincoln - Stopped for a Fanta on a family bike ride last week.

Lincoln



Oscar proudly showing the cake he decorated for his 3rd birthday.

Oscar

Summer fun for Quinn!

Quinn

Max - I am an independent cheerleader/gymnast, and gym advocate, and motorcycle rider!

Max

Holly and her parrot hat!

Holly

Thank you for sharing your moments of joy with us all! We know the whole community loves to see what others are achieving, it's pretty special.

Want to be featured in the next issue?

Email Lizzie – comms@cfnz.org.nz

CYSTIC FIBROSIS WELLINGTON CHRISTMAS TREE FESTIVAL 2024

A celebration of creativity and community

The festive spirit was in full bloom at Wellington Airport which was once again transformed by the magic of the annual Wellington Branch Christmas Tree Festival. Running from late November through to early January, this beloved tradition not only lights up the terminal, but brings together community, creativity, and compassion.

Building on the success of previous years, the 2024 festival spread Christmas cheer and also raised vital funds, over $65,000, for the Wellington Branch to support people living with CF. The heartfelt words of our winners remind us that the Wellington Branch Christmas Tree Festival is much more than a seasonal spectacle. It's a celebration of community spirit, artistic expression, and the power of coming together to make a difference.

> "We've hosted the Cystic Fibrosis Wellington Christmas Tree Festival at Wellington Airport for 10 years now, a milestone we're really proud of. We love working with the local Wellington Branch team, generous sponsors and our team of volunteers to raise vital funds and awareness in support of the CF community. The festival is very popular with travellers and the airport community and creates a fantastic Christmas vibe in the terminal. We're looking forward to making the 2025 event bigger and better than ever!"
>
> *Jo Maxwell, Manager Brand and Sponsorship at Wellington Airport*

Thank you so much to Christmas Creatives for doing an amazing job decorating our CFNZ Christmas Tree.

As always we had a huge range of organisations take part, providing a rich tapestry of themes for the trees, which completely refreshes the festival each and every year. We asked this years' winners to tell us about what the festival means to them.

FIRST PLACE WINNER

Scots College

At Scots College, the festival is far more than a seasonal display—it's an educational journey that fuses art, science, and community service. Alicia Lee, a dedicated Year 6 student led her school's project with a blend of passion and insight. "I researched cystic fibrosis, collaborated with teachers and experts, and even created a presentation for our Junior School," Alicia explained. "Seeing 140 young students understand how their creativity can support those affected by CF was truly inspiring."

The Scots College tree, adorned with lung-shaped lanterns, DNA molecule toppers, and carefully crafted ornaments, became a living canvas of empathy and learning. Art teacher Zoe Hainge says that in the 5 years she has taught at Scots College she has "cherished every moment of being part of the Christmas Tree Festival, an event that perfectly reflects our commitment to community service and creative expression. At Scots College, we embed the value of giving into our teaching, using the festival as a unique opportunity to raise awareness about cystic fibrosis while inspiring students to explore art and sustainable creativity."

SECOND PLACE WINNER

Sams Art House

Sams Art House is all about fun, colour, creativity, and community. Since debuting at the Christmas Tree Festival in 2021, founder Sam Walker has embraced the spirit of the season by letting her art classes run wild with every available medium.

"Kids adore Christmas, and as it happens, so do I," Sam said. "The first year I let the kids attending my classes have access to all my materials and let them go crazy. It was a splash of colour and chaos and now each year the kids look more and more forward to creating the decorations and seeing their art on the tree at the festival".

Participation in the festival brings a unique blend of creative expression and charitable spirit. "Christmas is such an awesome way of bringing community together and the Christmas Tree Festival not only brings joy and colour to the airport, it benefits such an good cause, CFNZ".

THIRD PLACE AND PEOPLE'S CHOICE WINNER

Catalyst

Having seen the joy the Christmas Tree Festival brings to Wellington Airport over the years, Catalyst Group took a closer look and learned about the incredible work CFNZ and the Wellington Branch do to support individuals and families living with CF. Beyond the festive spirit the event creates, the meaningful mahi and purpose behind it made supporting the festival an easy decision for Catalyst.

" We are proud to have been involved for the past three consecutive years - and counting!" The Catalyst tree always provides something a little different from the traditional Christmas tree, "For 2024, our tree was designed to spark playful cheer among travellers; we wanted to bring smiles to people's faces. Inspired by the classic Where's Wally? books, we came up with a 'Hidden Elves' concept, adding an interactive element to our tree. As a homegrown organisation with many parents on our team, we understand how demanding travelling can be. We hoped our 'Spot the Elves' game would provide a little respite, giving parents 10 minutes to enjoy a coffee break while their children were entertained". And it worked, with the team receiving fantastic feedback and people still taking photos and searching for elves as the tree was being dismantled! "The Christmas Tree Festival is an event our team loves being part of, and we're already looking forward to next year's tree. Watch this space!"

A HUGE THANKS TO OUR GOLD,

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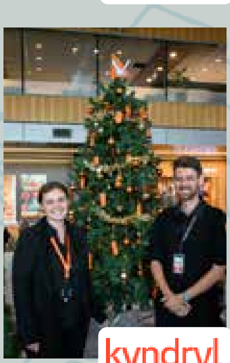
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URBAN LINK


SUBWAY


ADB SAFEGATE


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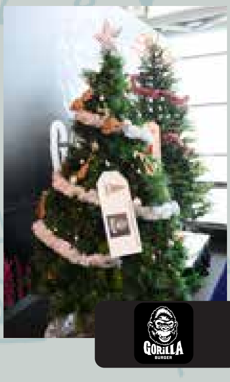
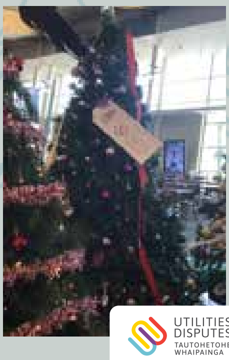

GORILLA BURGER


Park Road/ Wingnut Films


FIJI AIRWAYS


Lil'Rosie's


UTILITIES DISPUTES TAUTOHETOHE WHAIPAINGA

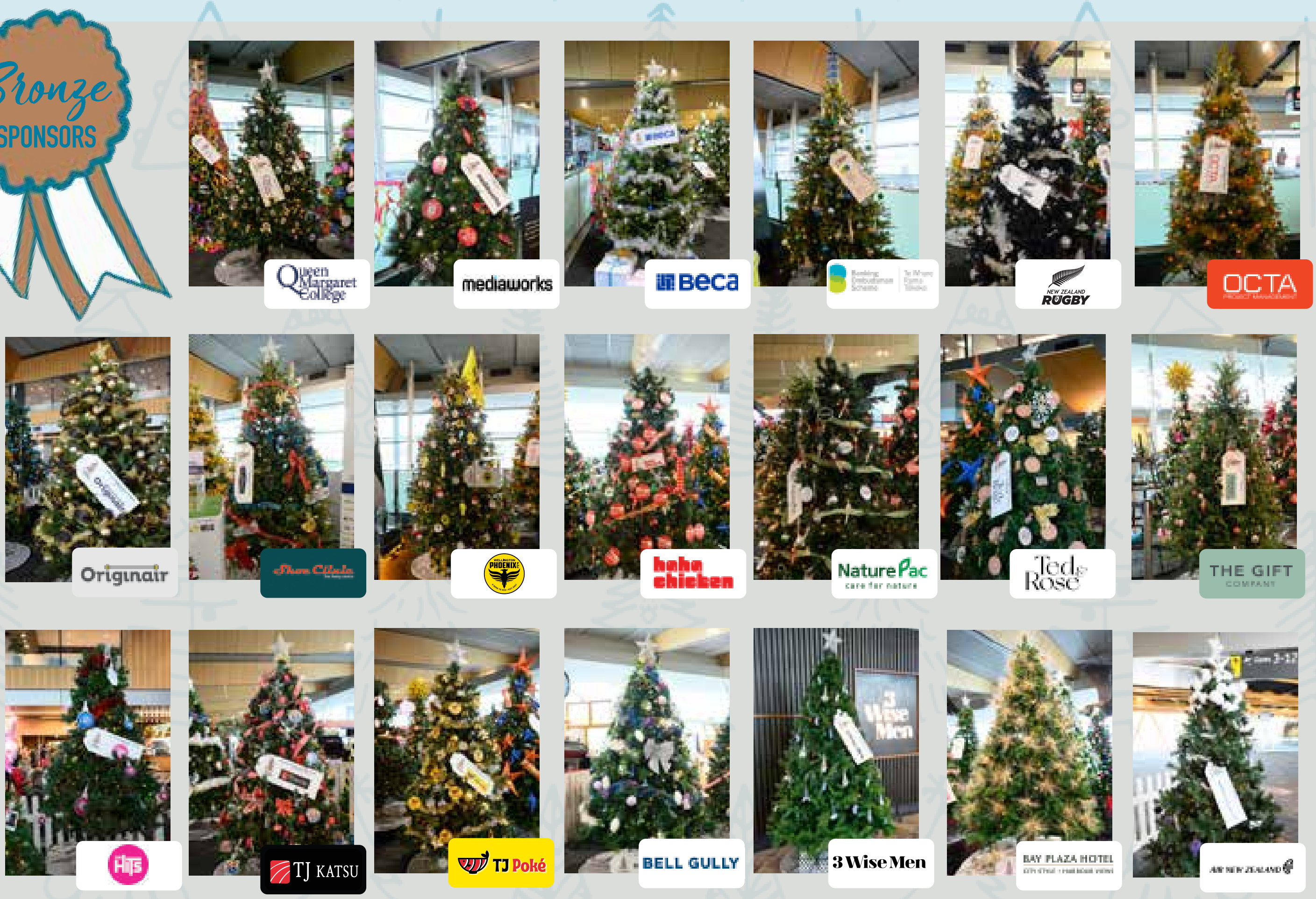
The Wellington Christmas Tree Festival has been held at Wellington Airport for the past 10 years. It is always amazing to see the airport transform and sparkle with festive cheer. Each year brings new designs and creativity from our tree sponsors. We have some amazing sponsors who return every year to decorate a tree, along with new sponsors who want to be part of the event. We are very grateful for the wonderful support from our supporters who help us raise around $65,000 to support people living with Cystic Fibrosis. Special thanks to Jo Maxwell from Wellington Airport, Mary Tapp our incredible event coordinator, and the rest of the Wellington CF team who work really hard to make this a special Festival every year.

Paula Richards,
CFNZ Wellington Branch Chair

SILVER AND BRONZE SPONSORS!

Silver SPONSORS

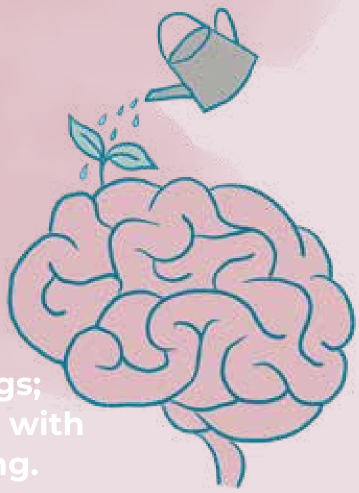
Bronze SPONSORS



Thank You

A heartfelt thanks from
CFNZ Wellington Branch and CFNZ to everyone
involved in the 2024 Christmas Tree Festival.
We are so grateful for your generosity and support.

MENTAL HEALTH: EDUCATION AND RESOURCES



From colouring in sheets to mood cubes, family games and songs; our mental health programme aims to equip the CF community with practical techniques and support for when times feel challenging.

Launching education and mental health resources was a key priority for the year. Feedback from our community survey highlighted two things:

- There is a need to improve access to mental health and wellbeing strategies, and
- Provide opportunities for mental health and counselling support.

With this, we developed and launched a mental health education programme in partnership with Cat Levine, a wellbeing educator. Following the programme, we released four webinars covering general mental health education, an introduction to cognitive behavioural therapy (CBT) techniques, and downloadable resources to assist our younger ones to understand and communicate their feelings.

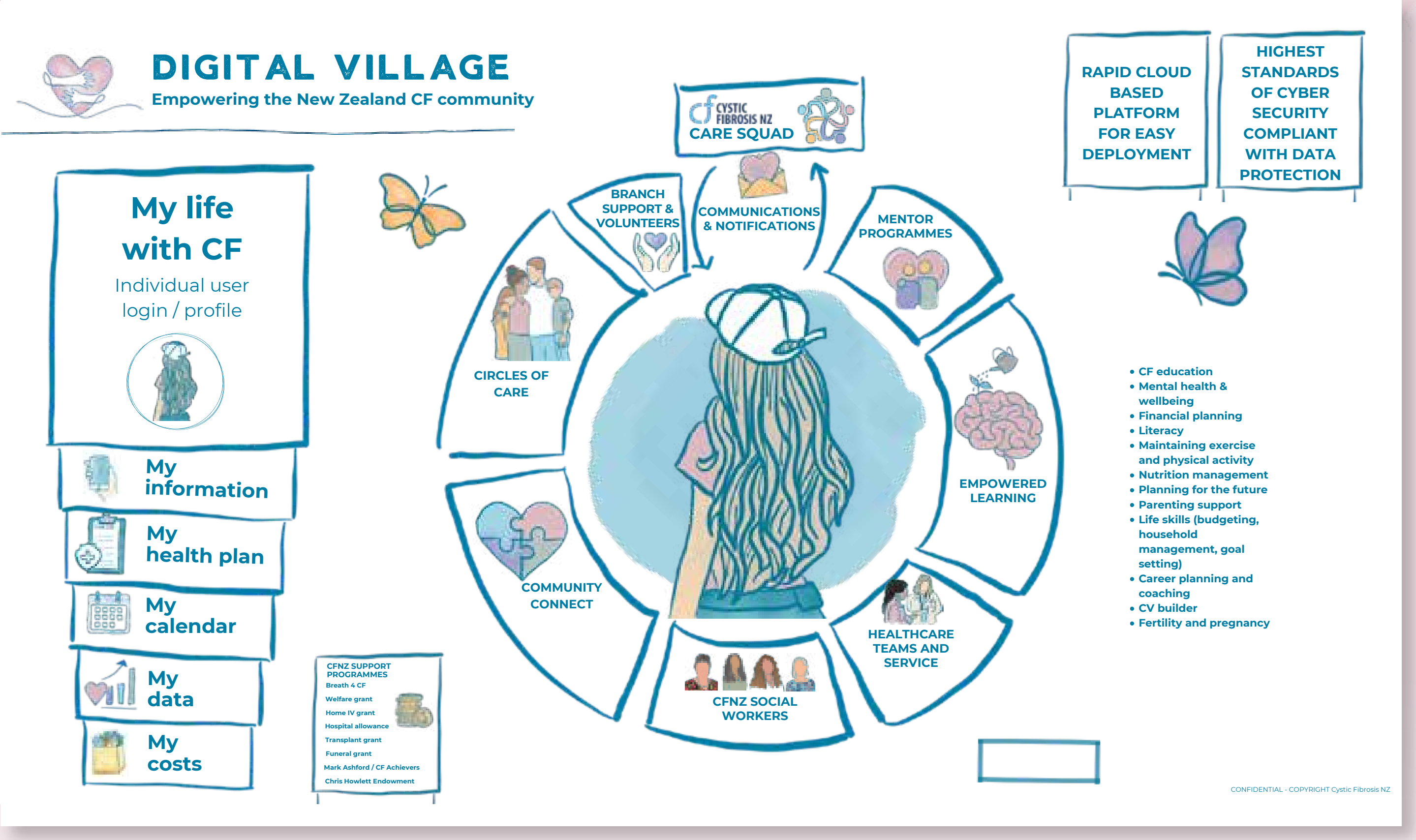
Our work to develop a programme suitable for adults living with CF is ongoing. In the meantime, we will continue to ensure our community has access to the mental health support they need.

Get in touch with your CFNZ Social Worker if you would like some cubes.

Scan the QR code to access all of the mental health and wellbeing resources, plus recordings of the webinars.

SHAPING THE FUTURE OF CF CARE

OUR PIONEERING DIGITAL VILLAGE



CFNZ SUPPORT PROGRAMMES
Breath 4 CF
Welfare grant
Home IV grant
Hospital allowance
Transplant grant
Funeral grant
Mark Ashford / CF Achievers
Chris Howlett Endowment

- CF education
- Mental health & wellbeing
- Financial planning
- Literacy
- Maintaining exercise and physical activity
- Nutrition management
- Planning for the future
- Parenting support
- Life skills (budgeting, household management, goal setting)
- Career planning and coaching
- CV builder
- Fertility and pregnancy

As the landscape of CF care evolves, we're taking bold steps to meet the changing needs of people with CF.

The Digital Village is our transformative digital response - designed to enhance, support, and empower individuals with CF, and their families to proactively manage their care for improved quality of life.

It is the product of years of local and global research, insights from our community, and conversations with our Clinical Advisory Panel. This is a significant step toward a more outpatient-focused model, ensuring that people with CF remain connected with their clinical teams while taking greater control of their health.

We are hopeful our design alleviates if not eliminates fragmentation seen within our healthcare delivery systems and strengthens our conversations with clinicians. It will provide an intuitive resource library which we will continue to fill with accurate and reliable information – supporting every stage of the CF journey.

We are building the Digital Village with our community sitting at the heart of the experience, working to bring all aspects of CF care together in one unified place, tailored to each individual journey and for you to use in a way that is most meaningful to you – whether on the go, at home, work, and accessible via desktop or mobile device.

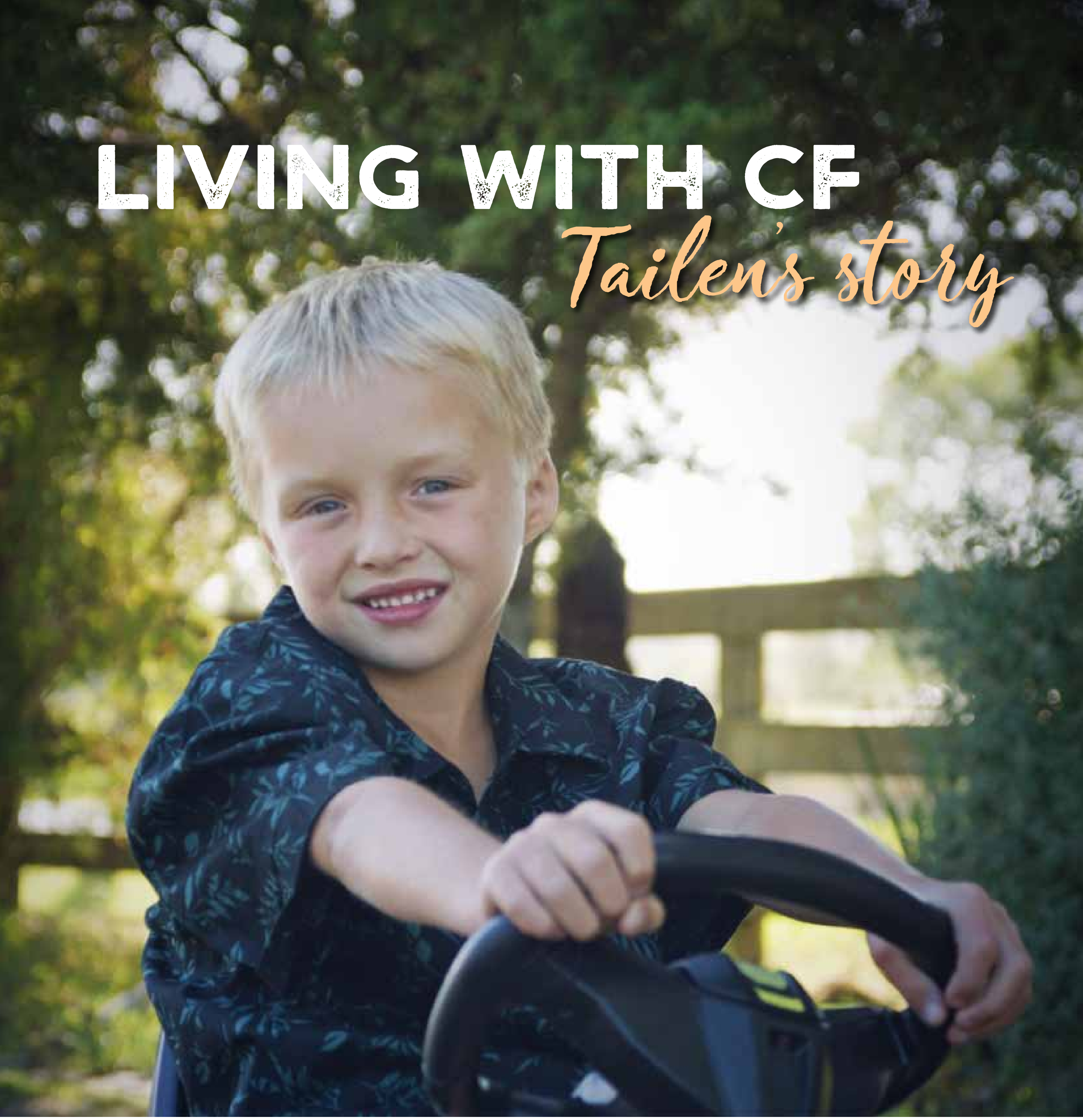
We have also made significant updates to the CFNZ Social Worker database. Changes which we know will streamline their work processes and provide seamless access to resources ensuring their time is spent where it matters most: supporting our community.

As we move towards user testing in April, we will be seeking expressions of interest to join the Digital Village advisory board. This input will be crucial in providing oversight and ensuring we deliver the best possible platform for our CF community.

Phase one of the Digital Village is expected to launch in May 2025.

LIVING WITH CF

Tailen's story



Every person with cystic fibrosis lives a unique experience of their condition, requiring different treatments, therapies, and varying support from CFNZ. This is Tailen's story.

Seven year-old Tailen lives with his family in Waikato. He had a rough start, living with the most severe symptoms caused by both cystic fibrosis and early infections that he had to battle through. MRSA lives in his lungs and he has smaller airways, about a third of the usual size. His amazing mum and dad Shanz and Jais said,

"His smaller airways were certainly a contributing factor to bouts of illness along with his CF. He has taught us so much and we have a strength we never knew we had but we've had to learn our resilience. With CF, it's such a complicated illness so no one can be treated the same. From a patient and parent perspective, you're not always listened to or understood and it can be frustrating when you just want to be heard. "

"CFNZ is our family channel of hope and strength. Support from our social worker for advocacy, to the financial support with hospital admissions and Breath4CF grant from CFNZ are simple acts of kindness

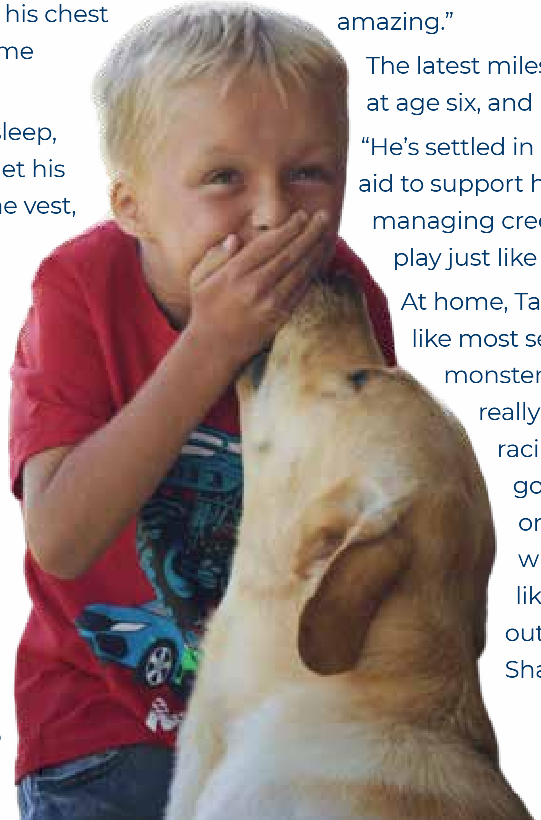
of combined support from many. Without CFNZ we would be so unbearably lost in cystic fibrosis insecurities. I am honoured to be a part of our CF community who have received the same support on the good days and the bad.

Tailen has had a hard ride on this life journey, and it is so uplifting to know CFNZ understand and are in our corner, helping us to become the best version of ourselves as sufferers, parents, and as a family." Says Shanz.

> **"He has taught us so much and we have a strength we never knew we had but we've had to learn resilience."**

The family fundraised for a high-frequency chest wall oscillation vest to help Tailen with his chest physio treatment, and it was a game changer.

"He loved his pink vest. He could sleep, eat and do everything as well as get his treatments done. Since getting the vest, his immunity to things started increasing. He went from 12 admissions a year to eight. He had crystal clear lungs on X-rays. I think his lung health definitely improved due to the vest," said Tailen's mum Shanz.



Another recent and exciting change to Tailen's treatment was access to Trikafta, but it wasn't a straightforward beginning. Jais said,

"We started Trikafta on 11 April 2023 but ended up having to stop and start as it just wasn't fitting for him. We switched the day and night pills around and that seemed to work. He's had no admissions and no IV lines but does still have a feeding tube with three to four feeds per day. We still struggle to keep weight on him."

Although he still has regular treatments, these are now around an hour a day and he can wear his vest at school which helps his everyday health.

Shanz added, "Every parent goes in with hope with Trikafta and I am a realist, but we've made it 22 months without an admission or an IV line which is amazing."

The latest milestone for Tailen was starting school at age six, and he loves it,

"He's settled in really well and he has a teacher's aid to support him with his feeding tube and managing creon. He loves to run around and play just like his peers," said Shanz.

At home, Tailen adores his dog buddy and, like most seven-year-olds, is obsessed with monster trucks and all things cars, "He really likes anything to do with cars, racing or his dog. He's just got a pedal go-kart and he just speeds around on that. He's an absolute character with such a funky personality just like his dad. In general, he is just so outgoing and he loves everyone," said Shanz.

ADVOCACY UPDATE

TRIKAFTA FOR 2-5 YEAR OLDS

Trikafta is manufactured by Vertex Pharmaceuticals (Vertex) and is currently funded by Pharmac for those people with CF aged six years and over with responsive mutations. In early 2024, Vertex applied to Medsafe and Pharmac for the approval and funding of Trikafta in New Zealand for those with CF aged two years and older who carry a genetic mutation responsive to the medicine.

Pharmac's Respiratory Advisory Committee has now recommended a **high priority** for funding of Trikafta for this age group.

The Committee considered that the CF disease trajectory is generally set before the age of six and there is no biologic or evidence based reason to commence treatment at six years. The Committee also considered that commencing Trikafta in children aged two to five years of age would be the best strategy to prevent deterioration, preserve normal lung function, and prevent any meaningful decline.

CFNZ is delighted that the Respiratory Advisory Committee has recognised that the best way to prevent deterioration and long term decline is to intervene early. Investing in Trikafta at this early age will give children with CF the greatest opportunity to stay well and live normal lives. It will also provide benefits across the health system through reduced treatments, hospital care, and surgery. There will also be wider societal benefits through reducing the burden of care on parents and caregivers, reducing lost school time, and providing the potential for parents and caregivers to work.

Pharmac advises that the next step for the application is assessment. CFNZ would like to see this step take as little time as possible. Trikafta has already been subject to a comprehensive assessment process prior to funding for those aged six years and over. The extension to those aged two to five years of age should therefore be a simple incremental process completed very quickly.

Investing in medicines such as Trikafta that help to prevent long term damage and reduce the burden of ill-health on individuals and society are a core part of this Government's reset for Pharmac.

Making Trikafta available to those aged two to five years therefore needs to happen as soon as practically possible to maximise these benefits.

Scan the QR code on page 28 to read the minutes of Pharmac's Respiratory Advisory Committee.

ADDITIONAL MUTATIONS APPROVED FOR TRIKAFTA

Vertex has announced that the US Food & Drug Administration (FDA) has approved expanded use of Trikafta for people with CF aged two years and over with at least one F508del or another responsive CFTR mutation. This approval adds an additional 94 non-F508del mutations to the approved list.

Pharmac's criteria for access to Trikafta in New Zealand is linked to the FDA approved mutation list, meaning expanded eligibility for Kiwis with CF aged six years and older.

Scan the QR code on page 28 to read the Vertex release, including the full list of additional mutations.

ONCE DAILY CFTR MODULATOR FOR CF - ALYFTREK

Vertex has announced that the US FDA has approved vanzacaftor/tezacaftor/deutivacaftor (ALYFTREK), a once daily CFTR modulator therapy for those people with CF aged six years and older who have at least one F508del mutation or other responsive mutation. The approval provides for an additional 31 mutations not responsive to other CFTR modulator therapies.

Scan the QR code on page 28 to read the Vertex release.

ALYFTREK IN NEW ZEALAND

Vertex has applied to Medsafe for consent for the use of ALYFTREK in New Zealand. The application is currently undergoing initial evaluation.

Consent for the use of ALYFTREK by Medsafe may provide an option for some Kiwis with rare CF mutations for whom no other CFTR modulator therapies are available. CFNZ has written to Medsafe seeking priority for consideration of the application to enable its use in New Zealand as soon as practically possible.

ACCESS TO KALYDECO

Kalydeco is currently funded by Pharmac for those people with CF who carry one or more of nine specific CF mutations. In addition to carrying two CF mutations, the criteria require that an individual must also have a sweat chloride level of at least 60mmol/L. However, this is not the case for access to Trikafta.

As part of its consideration of the extension of Trikafta to those aged two to five years, Pharmac's Respiratory Advisory Committee has recommended a change to the criteria for access to Kalydeco, to align with that for Trikafta. This would mean that there would no longer be a requirement to have two cystic fibrosis causing mutations and a sweat chloride level of at least 60mmol/L. Pharmac has yet to accept this recommendation.

An application was made in July 2021 to widen access to Kalydeco from the existing nine CF mutations. In April 2022, the application was given a high priority for funding by Pharmac's Respiratory Advisory Committee which recommended that access be widened to include those mutations approved as responsive by the US FDA, as is the case for Trikafta.

Pharmac has advised CFNZ that the application is still awaiting assessment.

Many of the people who would previously have benefited from a widening of access to Kalydeco are now able to access Trikafta. However, access to Kalydeco still needs to be widened to enable those who are unable to access or to tolerate Trikafta, to have a suitable CFTR modulator therapy.

In CFNZ's view, waiting three years for an assessment to widen access to a medicine that is already funded by Pharmac is unacceptable. As with the recommended expansion of access to Trikafta for those aged two to five years, it should be a simple and rapid incremental process.

ACCESS TO CFTR MODULATORS IN AUSTRALIA

Australia's Pharmaceutical Benefits Advisory Committee (PBAC) will be considering two applications at its March 2025 meeting to widen access to CFTR modulator therapies.

PBAC will consider the extension of Trikafta to those people with CF aged two years or older with responsive mutations, and the extension of Kalydeco for those aged one to four months.

OTHER DEVELOPMENTS

For those unable to benefit from CFTR modulator therapies, a Phase 1b trial is underway to assess the effectiveness of Recode Therapeutics' inhaled therapy for people with CF. The trial is being carried out in the United States and Europe.

The inhaled therapy, RCT 2100, is expected to provide lung cells with a healthy version of CFTR messenger RNA (mRNA) to allow the cells to produce a functional version of CFTR, regardless of the CF-causing mutation.

Vertex is also progressing the development of an inhaled mRNA therapy for those people who are unable to benefit from CFTR modulator therapies. The multiple ascending dose phase of the Phase 1 / 2 trial is underway with data expected during the first half of 2025. Scan the QR code below to read Vertex's original release about VX-522.

Scan this QR code for more information on all advocacy updates.

IMPROVING MEDICINES ACCESS

The Valuing Life - Medicines Access Summit, held on the 29th and 30th of April 2024, at Parliament in Wellington, was a pivotal moment for change.

The summit brought together a wide range of stakeholders including patient advocates, clinicians, representatives of the pharmaceutical industry, Government officials and academics. Presentations and discussions at the summit highlighted the complexities of medicines access in New Zealand, and acted as a precursor to four workshops held in the afternoon of the first day.

Although the workshops covered different aspects of medicines access, each identified a number of common themes and recommended actions.

TOP 3 RECOMMENDATIONS FROM THE SUMMIT:

1. Amend the Pae Ora (Healthy Futures) Act 2022 and its regulatory framework to revise Pharmac's statutory objective.
2. Review and reform Pharmac's Health Technology Assessment (HTA) and decision-making process.
3. Greater investment in medicines.

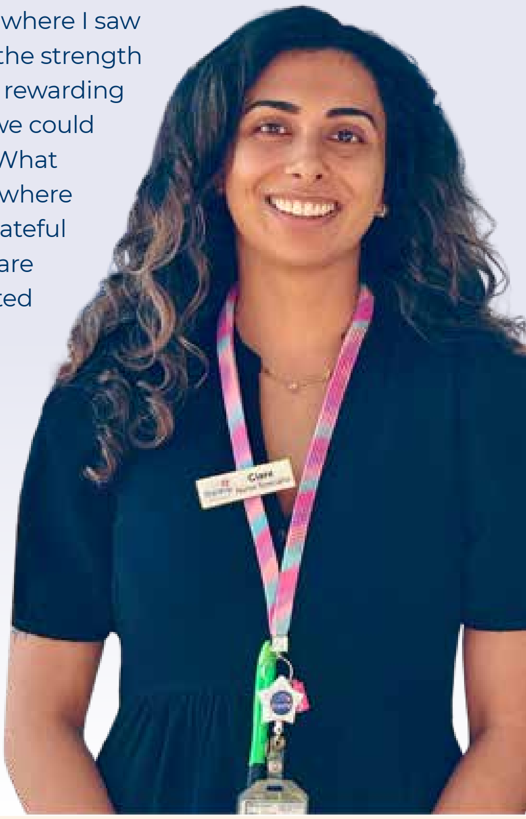
CFNZ welcomes the outcomes and recommendations published after the summit and will continue to lend its voice and advocacy to advance the improvement of medicines access for all Kiwis.

TO FIND OUT MORE
www.valuinglife.nz

> “Patient Voice Aotearoa is committed to ensuring that having a focus on being patient-centric when it comes to our drug procurement agency is not insincere but materialises in a way that positively supports patients and their families. Many of the recommendations have been formulated with that goal in mind.”
>
> **Dr Malcolm Mulholland, Chair**
> **Patient Voice Aotearoa**

WELCOME TO THE CF COMMUNITY

Starship Clinical Nurse Specialist Clare Calvert (pictured with her gorgeous pup Hank) joined the Respiratory Team in September last year, we asked her to tell us a bit about herself.



"My passion for working with young people with CF began when I worked on Ward 26B in Starship, where I saw firsthand their incredible resilience and the strength they showed in facing challenges. It was rewarding to be part of their journey and see how we could make a positive difference in their lives. What motivated me to return to the CF field was the opportunity to step into a role where I could provide care and support that is so important to our CF families. I'm grateful to build on the work Jan has done and am committed to providing the best care possible for our CF families. It's a responsibility I take seriously, and I'm dedicated to making a positive impact in this role."

FAVOURITE BOOK

"At the moment, I'm reading Atomic Habits by James Clear. It's been an interesting read for me, especially with its focus on how small changes can lead to big results. When it comes to my all-time favourite books, the Harry Potter series will always hold a special place in my heart. I grew up reading them, and each new book coming out around my birthday always felt like a little gift. I usually re-read one around Christmas as a tradition."

FAVOURITE QUOTE

"As for a favourite quote, I've always liked this one from Dr. Seuss: *'The more that you read, the more things you will know. The more that you learn, the more places you'll go.'* It's a great reminder of how much there is to discover and how reading can open up new possibilities."

CHOICE HOTELS, ARE, WELL... CHOICE!

Choice Hotels have been long time supporters of Cystic Fibrosis NZ and it is a relationship that we are enjoying growing and building into a mutual partnership, as we work with the lovely team based in Australia.

Choice have long supported CFNZ by providing a number of free nights accommodation for our Social Worker team, so that they can get to the members of the CF community that live outside of Auckland, Wellington, Canterbury and Taranaki. This generous arrangement means a great deal to us, helping to keep travel costs low.

The team at Choice have also included CFNZ as one of the charities that their customers can choose to donate their Choice Privileges loyalty points to.

In August Choice Hotels Asia-Pac ran their "Check in for Charity" campaign. For every hotel stay during the week 12-18 August Choice made a contribution to CFNZ, totalling $3,654 to support the CF community in New Zealand.

So, if you are planning a getaway, consider Choice Hotels, as they continue to choose us, it's a win-win!

CHOICE
HOTELS®

MAKE A SPLASH THIS CF MONTH WITH CHOCKY FISH!

There's plenty of fish in the sea and we aim to turn the tide by having our biggest ever year of Chocky Fish sales.

So dive on in! Hook up your friends and family and help us make this an epic CF Awareness Month.

BITE INTO KINDNESS AND SUPPORT PEOPLE LIVING WITH CYSTIC FIBROSIS!

Fundraise with Chocky Fish

Buy Chocky Fish