

CF News

AUTUMN 2026

CELEBRATING

- Wins in advocacy
- Our CF achievers
- Fantastic fundraisers



Thank you, Lisa

After four incredible years, in October we farewelled our Chief Executive, Lisa Burns.

Lisa has contributed a huge amount of energy to CFNZ and the CF community during her time as Chief Executive, she has taken the organisation to new places and has seen through major projects in that time.

Lisa's courage, bravery, and relentless drive will leave a lasting legacy. She has championed the voices of people with CF, stood firm through challenges, and celebrated every win with joy and humility. We are deeply grateful for her vision, her heart, and her belief in what's possible.

From all of us - thank you, Lisa. We have loved working with you, and have been inspired by your passion and commitment to our people. We wish you well for what is ahead.



Cover: Natalie Sneddon and Snowflake, her Calf Club calf.

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

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Thank you

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A NOTE FROM SIMONE



Watching Ben Prince-Saxon cross the finish line in his 12th marathon was one of my personal highlights for 2025. The atmosphere and genuine warmth felt across the running community was incredible – not quite enough to get me up at 6am for a daily run. But in spirit, I am always with you, Ben!

The resilience, tenacity, and determination on display was an inspiration that I know carried across our community. And now, we have the privilege of following Kirsty Parsons as she takes on the Taupō Ironman. The limits pushed and goals set by this community – and especially our adults – continue to inspire me, and I know many of our younger generation and their families as well. There is never a limit to what is possible, and I think that is what makes this community so special.

Support and community fundraising across our Branches is critical to our organisation – not only for raising funds and providing local support, but for continuing to strengthen awareness within the wider community. This past year saw two Branches merge to become the Auckland/Northland Branch. This change in our Branch infrastructure ensures continuity of support across the region.

We hosted our first Symposium - bringing global insights and international expertise to our local shores, we shared in celebrating the achievements of six CF Achiever Award recipients, welcomed two Life Membership awards, and introduced three new Board members.

Recently, we said goodbye and good luck to Cath Lamont, Adult CF Nurse and member of our Clinical Advisory Panel, as she sets off into a happy and adventure filled retirement. We are truly grateful to Cath for her service spanning nearly 20 years. We also farewelled Helen Gibbs, Transplant Coordinator with over three decades of service. Helen was a steady hand and a compassionate guide for so many families during the transplant journey, offering reassurance in moments of uncertainty and genuine care when it mattered most.

A huge thank you to all the families who sent a letter as part of our Trikafta 2-5 year old campaign last year. Your letters were heartbreaking, tear inducing, and reaffirming of why we stand tall as patient advocates. It has been over 10 years advocating for access to medicines – 10 years of hard work, resilience, and pure grit. But every single minute, every bit of effort, will always be worth it.

With Pharmac due to widen access to Kalydeco, Trikafta and the funding of the new therapy Alyftrek, the blood, sweat and tears have paid off, and the future looks brighter. However, it will always remain in our hearts to acknowledge those for whom these medicines have come too late, or where there is not yet a therapy for their gene type. For this reason, while the brake may ease on our advocacy for a moment, our focus will always stay on the horizon: monitoring emerging therapies in clinical trials and continuing to work toward consistent care across Aotearoa.

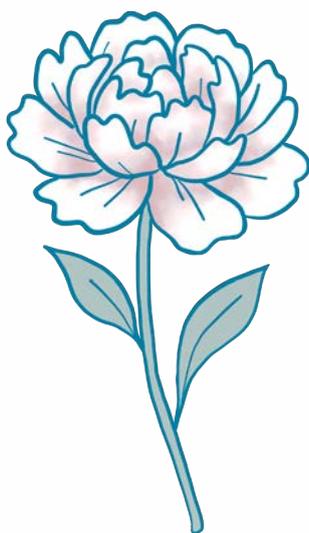
A huge thank you to our Board, Branches, volunteers, fundraisers, supporters, donors, and CF clinicians.

As we all know, “the greater the obstacle, the more glory in overcoming it.” – Molière.

There is still much work to be done, and the remainder of this year brings an exciting opportunity to reset and refocus on what our community truly wants and needs. But for now, join me in celebrating the great accomplishments of our community.

Standing with you always.

Simone Brown
Executive Lead



Holding Space FOR EVERY STORY

A win for the cystic fibrosis community is a win for us all - but it's important to recognise that these medicines aren't available or suitable for everyone, and for some, this news has simply come too late.

Some Kiwis with CF will not be eligible for Trikafta, Alyftrek, or Kalydeco because of their gene type. Others, including those who have had transplants, liver disease, or additional health challenges, may not be able to take these treatments or may not see the same benefits. We hold space for them, and for the whānau whose reality does not change with this news. Watching a large part of our community celebrate a brighter future can be bittersweet.

THE FIGHT CONTINUES, AND NO ONE WILL BE LEFT BEHIND

CFNZ exists to walk alongside every person with CF - Trikafta or no Trikafta. We will continue to support wellbeing and quality of life, and as our community's needs evolve, so will we. Our strength lies in each other, and we remain grounded in hope for what comes next.

THEIR LEGACY LIVES ON

We also honour those we have lost over the past year.

Their courage, humour, generosity, and light touched so many. Their absence is felt deeply across whānau, friends, care teams, and the wider CF community. Their stories and their strength continue to shape us, living on in our memories and in the way we care for one another.

They will always be part of us - held in our thoughts, in our hearts, and woven into the fabric of the CF community.

Today, and always, we honour them.



What a way to kick off 2026!

We were delighted to be able to share in January that Pharmac had announced a Provisional Agreement to widen access of Trikafta to include 2-5 year olds, expanded access of Kalydeco and access of Alyftrek for Kiwis living with cystic fibrosis.

This is a culmination of two years of joint effort. We want to give our heartfelt thanks to all of the families and people connected to the CF community that shared their stories, wrote letters and submissions, shared and commented on social media, asked questions, appeared in media and spoke up when it mattered. All of which leads us to this point, where more of our community, including our younger members, will have access to life-changing medicines from 1 April 2026.

We are in awe of the support, dedication, love and compassion shown and it proves that together we can make waves in this space!

Another huge thank you to Vertex for creating these groundbreaking medicines, and Pharmac for listening and recognising the need in our community - we are so grateful.



CF CYSTIC FIBROSIS NZ

IMPORTANT MEDICINES UPDATE!

Pharmac announces Provisional Agreement to widen access to life-changing CF medicines for children as young as two.

- + TRIKAFTA 2-5
- + ALYFTREK
- + EXPANDED ACCESS TO KALYDECO

The Post

Brighter prospects for children with cystic fibrosis

January 28, 2026

Two-year-old Ollie Carrott has cystic fibrosis, but with the help of the drug Trikafta is likely to stay well into middle age and beyond.

ADILE RYCKROFT / MANAWATU STANDARD

CF CYSTIC FIBROSIS NZ

Your gift this Christmas helps families like Billy's find hope and support through every challenge.

THIS IS THE DIFFERENCE YOU CAN MAKE

- \$25 provides one day of parking, keeping families together during unplanned admissions these holidays
- \$50 helps our fight for life-changing medicines access so that families like Billy's can worry less, and participate more
- \$150 provides a Breath 4 CF Grant for a child, to promote exercise and lung health as part of daily treatment, as well as providing joy and fun moments

Give a gift of your choice to help support and provide hope to families like Billy's

Pharmac proposes to extend funding for 'miracle' cystic fibrosis drug, Trikafta

27 JAN 2026 9:00 AM

A Lower Hutt family relocates to access Trikafta for their 4-year-old daughter, aiming to prevent further irreversible cystic fibrosis. Video | Herald NOW

'It's a good day': Pharmac moves to fund CF drug for toddlers

By Aziz Al Saifi, News Reporter | Fri, Jan 23

Potential life-changing breakthrough in cystic fibrosis

Pharmac announces a provisional deal to fund a drug for children as young as two. (Source: News)

THE PRESS

Pharmac has provisionally agreed to fund for children as young as 2 from April 1.

Edward Harrington-Ashton and his wife Emily seriously considered moving to Australia if Pharmac didn't fund Trikafta

EDWARD ASHTON

"I was almost in tears when I got the news," Harrington-Ashton said.

"It's a massive relief that we can stay where our comforts are and give Noah the best chance possible for a long and happy life."

Pharmac opens consultation over funding of cystic fibrosis drugs Trikafta and Alyftrek

4:11 pm on 22 January 2026

Photo: Cystic Fibrosis NZ

Cystic fibrosis drugs Trikafta and Alyftrek could become available for all children, regardless of age, with drug-buying agency Pharmac opening consultation on funding the two drugs.

Currently only funded for children aged six and over, Pharmac is consulting on making Trikafta available for all children with an eligible diagnosis, and fund a new treatment, Alyftrek.

Open letter on expanding access to cystic fibrosis treatments

23 JANUARY 2026

(elexacaftor, tezacaftor and ivacaftor) 100 mg, 50 mg and 75 mg, (ivacaftor) 150 mg tablets

Cure Kids commends the Government on its announcement that Pharmac will widen access to groundbreaking cystic fibrosis (CF) treatments including Trikafta and Alyftrek for children of all ages.

Parents hope two-year-old will be able to get life-extending cystic fibrosis treatment

20-month-old child's father said he was "nearly at the point" that Pharmac had made a decision considering leaving New Zealand to access life-changing medicine for their toddler can now come after Pharmac proposed funding the "miracle drug" for younger children.

Sweatember challenges New Zealand to get moving for cystic fibrosis

EDITOR / SEPTEMBER 1, 2025 / NEWS / MAKE A COMMENT

AUCKLAND, Today: Kiwis are being urged to get moving this September and join Sweatember, the annual fundraiser helping people across Aotearoa living with cystic fibrosis (CF).

Now in its sixth year, Sweatember challenges participants to choose a sweaty activity, with donations flowing from friends, whānau and colleagues backing their efforts.

Christchurch dad, Edward Ashton is swimming 3000 laps to raise funds. His 16-month-old son Noah has CF, and the preschool teacher says it's a challenge he's determined to tackle.



“ Trikafta represents real, tangible hope for a healthier, more stable future for our son. ”
Liam Rooney,
 Luca's Dad



“ I was almost in tears when I got the news. It was a relief more than anything, to be honest. We had considered moving to Australia and leaving behind our families and support networks to get access to Trikafta for Noah. It's a massive relief that we can stay where our comforts are and give Noah the best chance possible for a long and happy life. ”
Eddie Ashton,
 Dad of 20 month old Noah



“ We're hopeful, we want Billy to have the chance to live a full life – to go to school, make friends and just be a kid”. ”
April Petersen,
 Billy's mum



Four-year-old Lily Olliver is likely to be one of the first children under 6 to benefit from Pharmac's proposal to extend access to Trikafta.

“ Our hope is not just fewer hospitalisations or treatments, but a future where CF has a much smaller impact on her daily life, her independence and her life expectancy. ”
Niketia and Wade,
 Parents of 4 year old Lily Olliver



“ There were many “very excited” families looking forward to their children gaining access to Trikafta. The drug is not a cure, but it would boost lung function and help prevent infections and the scarring they could cause from an early age. ”
Kayne Dunlop
 Central Districts Chairperson



“ For many, it's the beginning of a new chapter – one where children with cystic fibrosis can grow up healthier, with more opportunities, and with the promise of a longer, fuller life. ”
Simone Brown,
 CFNZ Executive Lead



Natalie, Kyle & Olivia Sneddon

Dear Government,

If you allow kids to have Trikafta between the ages of 2 and 5 years old my sister could have had it when she was two and she would not have had to have Whale (IV Antibiotics). She had to have surgery because she had an infection. Me and my twin brother had to go to Grandma and Grandad's house.

I feel very sad and angry because she has to struggle with this Cystic Fibrosis. It is when she is doing her medication (nebuliser) and when she could be learning she has to do something called Physio which is Nebs (Nebuliser) and PEP (Positive expiratory pressure) mixed together.

So pretty please give these kids what they deserve and make them happy.

From Olivia Sneddon
 Older sister to a 5 Year Old Cystic Fibrosis Warrior

“ Trikafta funding for 2-5 year olds would make an incredible difference. In those early developmental stages of life its crucial for all the organs to be working as they should and not giving CF the chance to win. We need to give every human the best chance they can possibly have. ”
Ben Prince-Saxon
 12 in 12 marathon runner



“ These treatments are lifechanging for Kiwis living with cystic fibrosis and their families. If approved, this proposal would give children access to these life-changing treatments as soon as clinically appropriate. Cystic fibrosis can cause harm very early in life, so waiting to meet age-based eligibility criteria is not an option. ”
Hon. David Seymour
 Deputy Prime Minister



CF ACHIEVER AWARD RECIPIENTS

The Cystic Fibrosis Achiever Awards are presented annually to people with CF who have achieved excellence in one of these four categories; leadership, the arts, sport, or education. This year, six individuals with CF have been recognised for their determination, resilience, and achievement within their chosen category.



SUMMER - Education

Summer excelled in Childcare Studies, earning the Ruth Moss Trophy and a distinction despite frequent absences due to CF. Now in Year 13, she's pursuing nursing through a Gateway placement and plans to study paediatric nursing at university. Her achievements reflect her commitment to shaping a future where her experience with CF becomes a strength in helping others.



SUZANNE - Education

Suzanne's journey includes a lung transplant, stroke, and re-learning to speak. She supported postgraduate students at Victoria University, earning an Honorable Mention for her contributions. Now working part-time at TalkLink, she continues to improve her communication skills through therapy and community groups. Her story highlights the impact of lived experience and the value of persistence in education and advocacy.



HARVEY - Sport

Harvey is a talented athlete across running, swimming, surf lifesaving, and football. He's represented his school and club at regional and national levels, including the AIMS Games and Oceans event. His achievements include top placements in cross country and surf sports, and he's progressing toward becoming a qualified lifeguard. Harvey's passion and versatility make him a standout in youth sport.





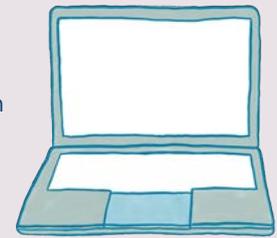
AMELIA - Education

Amelia overcame gaps in her education caused by hospital stays to complete a Certificate in Animal Care. Inspired by her hospital play therapist, she's now studying early childhood education to pursue a career in play therapy. Her journey reflects personal growth, self-awareness, and a desire to support children facing medical challenges, turning difficult experiences into meaningful goals.



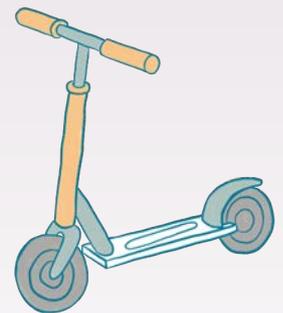
MAX - Education

After spending most of the year in hospital, Max completed multiple qualifications and gained early entry into a business course. He identified a marketing flaw at BurgerFuel, leading to a role on their regional team. Now in his final year of study, Max runs a digital marketing agency. His story showcases initiative, creativity, and a drive to turn ideas into action.



DANIEL - Sport

Daniel is Head Judge for FRS, New Zealand's scootering body under World Skate. He's judged national competitions, X-air events, and the Oceania Continental Champs, and developed judging criteria used across action sports. With over 15 years of riding experience, Daniel is working toward judging a world final. His leadership and expertise have helped shape the sport's future in Aotearoa.



Thank You

Viatris for generously sponsoring our CF Achiever Awards, helping us celebrate the achievements of our CF community.

Welcome **LENA, MIKE AND CHLOE**

Prior to the last AGM, three positions became available on the Board, one through normal rotation, and two for personal reasons.

The Board was very mindful of making sure we have the balance of skills around the table for a small Board, and to this end are delighted to welcome Lena Su who has extensive financial experience and is now chairing the Finance, Audit and Risk Committee, and Mike Picot who has worked with Vertex and wishes to extend his governance and health experience to work with a charity with strong purpose.

Very importantly, while it is great to have the energy of people offering their services, it is extremely important to maintain a strong balance of Board members closely involved with CF, so we were delighted when Auckland Branch nominated Chloe Hunt, who comes to us with the added bonus of being Branch Chair.

We feel we have a strong Board to move forward with all the developments and changes ahead of us.

Dame Pieter Stewart
CFNZ Board Chair



LENA SU

What experience or skills do you bring that you hope will support the organisation's mission?

I have had 10+ years in compliance and commercial finance experience and hoping to use these skills to assist the organisation in achieving its mission as efficiently as possible. Being a team player is critical, especially for this organisation that achieves so much.

We are lucky to have so many Board members with differing skillsets and connections. Sometimes alone we can do so little little but together we can do so much.



MIKE PICOT

What inspired you to join the Cystic Fibrosis New Zealand Board?

I've worked previously on CF treatments and wanted to use my experience and skills in a way that makes a difference. CFNZ's strong mix of purpose, advocacy and community support really resonates with me.

I have experience in health, strategy, economics and governance from senior roles in large organisations and consulting. I enjoy helping organisations focus on where they can achieve the best outcomes.



CHLOE HUNT

What inspired you to join the Cystic Fibrosis New Zealand Board?

Having a child with CF and the knowledge and understanding of CFNZ from a committee perspective, I am particularly driven and passionate about supporting others, especially parents of younger children with CF, to navigate the challenges of care and draw on my own experiences of parenthood.

I bring a blend of professional expertise and lived experience to the CFNZ Board. My background in healthcare, combined with my experience as a parent of a child with CF and my involvement at a Branch level, gives me a unique perspective that balances both governance and community needs.

CALVES FOR A CAUSE

For the fourth year running, the Sneddon family has proven that when it comes to supporting the cystic fibrosis community, they can mooove mountains! Their annual calf auction, a unique event, has now become a heart warming staple in the Waikato farming calendar.

Josh and Kareena Sneddon began the fundraiser as a way to give back after their daughter Natalie, now eight, was diagnosed with CF. What started as a simple gesture of gratitude has grown into a full blown community tradition, rallying farmers, transporters, stock agents, and supporters from across the region.

The Sneddon's now Chair CFNZ Waikato Branch. Armed with experience, dedication, and passion, they're creating a community of support across the region. They will champion fundraising efforts in the Waikato, and work with CFNZ as the voice for their local community.

This year was their biggest yet, raising an incredible \$29,000 to support CF families in the Waikato, with services such as Breath4CF grants, peer support, financial assistance and equipment support. A record total of 20 farmers donated animals, some even contributing more than one. And for those without calves to spare, the "virtual calf" option once again proved popular: supporters simply donated the average sale price of a real calf, meaning everyone could join the herd.

None of this would be possible without the generosity of key supporters. Kerley Brothers Transport donated their time and trucks to ensure the animals made it safely to auction. Luke Gilbert of Carrfields Livestock not only oversaw the sale but kindly waived his commission, ensuring every last dollar reached the CF community.



Josh also invested a huge amount of his time, driving many kilometres to pick up calves for the auction from around the region.

Each year, this very special fundraiser continues to grow, proof that a small but novel idea, backed by a big-hearted community, can raise life changing funds. We're *udderly* grateful to Josh, Kareena, and their incredible rural crew for making this event such a resounding success.



WANT TO FUNDRAISE? ANYTHING GOES!

Whether it's a bake sale, a bike ride, or a herd sized calf auction, your creativity powers our support for people with CF.

Big or small, we're here to help you every step of the way.

Thinking of hosting your own fundraiser? Contact us—we'd love to support you!

Email: community@cfnz.org.nz



FANTASTIC FUNDRAISERS

FROM 12 IN 12 TO EUROPE FOR BEN PRINCE-SAXON

After starting Trikafta in 2023 Ben set himself the challenge of running 12 marathons in 12 months in 2025, to raise funds for CFNZ and increase awareness of CF. Ben raised an incredible \$26,250 and was also an ASB Good as Gold recipient, receiving \$10,000 which Ben is planning to put towards his next marathon challenges this April, in Paris and London!

Keeping momentum for a challenge for a whole year is no mean feat. Ben took up many opportunities to speak on radio, TV and feature in magazines, always managing to spread awareness. Towards the end of 2025, Ben also used his platform to express our community's call to fund Trikafta for our 2-5 year olds.

We are so proud of what Ben has achieved, we can't wait to see what he does next!

Follow Ben's journey to the Paris and London marathons on Instagram:



FULL CIRCLE MOMENT FOR KIRSTY PARSONS

As a teenager in 2008, Kirsty (Adult Representative, CFNZ Board) was first introduced to Ironman in Taupo during a 10 year partnership between Ironman and CFNZ. At the time, Kirsty was paired with athlete Patrick Bristowe as an "Ironman buddy" and got to run down the finish chute alongside him, a moment that sparked her long-standing connection to the event. "Watching Ironman as a kid completely blew my mind," says Kirsty. "Getting to run down the finish chute was so special, and to now be preparing to stand on the start line myself feels surreal."

On 7th March Kirsty will take part in the iconic Taupo Ironman alongside her brother Duncan, and all going well, will be the first person in New Zealand with cystic fibrosis to complete an Ironman! We will be cheering her on all the way, you can support and follow her journey here:



CHOICE HOTELS

We're incredibly grateful to our friends at Choice Hotels for their amazing support through their Check-in for Charity campaign. From 11-17 August, Choice Hotels donated \$2 from every stay to CFNZ, raising an amazing \$4,674.

Choice Hotels also generously supports CFNZ by providing accommodation for our Social Workers, so that they can offer in person support throughout New Zealand.

Whether you're travelling for work or a weekend getaway, choosing Choice Hotels means you're also choosing to make a difference.

SERS - Thank you

CONQUERING THE AUCKLAND MARATHON, SIX YEARS RUNNING

HUGE SHOUTOUT TO TEAM LOCKTON!

For the 6th year running Lockton have fielded a team to run the Auckland marathon in support of CFNZ Auckland/Northland Branch. Last November the largest team yet got together and raised funds and completed the marathon.

Together they raised an incredible \$12,500. This amazing organisation shows up year after year with dedication, energy and heart, we truly value our relationship with the Lockton team, and appreciate their ongoing support for the CF community in New Zealand.



KOKPIT MEDIA

Thank you so much to Craig Booker of Kokpit Racing And Media and everyone involved in the Rees Racing Tour around the South Island last year.

Due to some connections to cystic fibrosis in the racing community, CFNZ was chosen as the beneficiary of their fundraising efforts and an incredible \$21,191 was raised to help support Kiwis living with cystic fibrosis and their families.

The tour travelled from Blenheim to Woodford Glen over 16 nights and 11 stops in between, spreading awareness of cystic fibrosis and raising money through donations and auctions.

What an exciting and incredible event! Thank you Craig and team, for putting pedal to the metal and going full throttle. It really does make a huge difference to the CF community.

NEXUS IS NEXT LEVEL

The Nexus Ultimate Frisbee tournament took place in March 2025, with the team running an epic event including support from participants and sponsors who contributed with donations and raffles to raise funds for CFNZ.

It was the fourth year in a row that the Nexus team showed their commitment to supporting CFNZ, honouring and celebrating the memory of their teammate Kim Bryant.

Not only was that tournament a huge success, but the Nexus Ultimate team also ran a Christmas Charity fundraiser, raising a further \$1,304 which is the equivalent of 8 Breath4CF grants for children living with CF, to help remove financial barriers to exercise.

Thank you so much to all involved in both tournaments, what a fantastic bunch you are to honour Kim this way year after year!





SWEAT FOR CYSTIC FIBROSIS *Sweatember*

WE SAID TURN UP THE HEAT AND GET SWEATING, AND YOU DID!

Sweatember 2025 reminded us of something the CF community knows well: movement isn't just about fitness, it's a vital part of living well with cystic fibrosis. This year's campaign kicked off with an 80s vibe, retro tunes, fluoro sweatbands and neon shell suits! Thanks to our incredible community, supporters and partners, it delivered both energy and impact.

We had a clear goal of raising \$50,000, so we are very excited to share that thanks to our sweaters, their supporters, and our corporate partners we raised over \$75,000. Every dollar raised helps support people living with CF, especially with funding of Breath 4 CF grants to remove financial barriers to participate in exercise of any kind.

Individuals, schools, workplaces and families embraced the fun, taking opportunities to participate in media stories, sharing workout photos, progress updates and fundraising milestones which plays a huge role in spreading the Sweatember message.

We were thrilled to welcome back Olympic trampolinists Maddie Davidson and Dylan Schmidt as ambassadors, who despite competing overseas, shared and collaborated during the month - we are so grateful for their time and support. Ambassador Ben Prince-Saxon, the legend behind 12 marathons in 12 months, also championed Sweatember through media interviews and his highly engaged social channels.

SWEATY DOGS - The dogs took out the top team spot. Let's face it, they were onto a winning thing - who doesn't love cute dog pics out enjoying extra walks and adventures.

"I'm sweating on behalf of my Mum who lives with CF. I'm planning on sweating my way through 50km in September, mostly with my Poppa."

Cory McKay



JOSIE SPILLANE

- Josie was our actual real life Sweatember unicorn! Josie raised an incredible \$8,438 during Sweatember with her cheeky challenge to her people: "Maxx and I will do the sluicings every day in Cromwell for the month of Sweatember and I'd appreciate a few of your pennies (-actually folding, don't be a tight a***) as we join Lizzie's team to raise money for CFNZ."



REESE ROBERTSON - Reese is a true good sort, and raises funds year after year for Sweatember. "I'm excited to be taking part in Sweatember again this year to help raise vital funds for our Cystic Fibrosis community in Aotearoa. Sweatember is a fantastic campaign that not only raises awareness of this genetic condition, but also provides crucial support for those living with CF. What I love most about this kaupapa is its focus on physical activity, something especially important for people with CF, as it boosts our quality of life and overall taha tinana!"



KELSIE WARREN – Kelsie made an epic effort during the month with her 300km goal. “My cousin Quinton lost his fight with CF in his 20s. To honour him and support the 600+ Kiwis living with CF today, I’m taking on the challenge of completing 300km in 30 days this September for Sweatember.”

TEAM MAYA – An epic bunch of friends and family ran and ran to raise funds for CFNZ on behalf of Maya, alongside her parents McKenzie and Maddie. “We’re sweating for Maya and everyone living with CF in NZ. We’re using our lungs to promote active lifestyles, to raise funds for support and to advocate, to give them the quality of life they deserve. Each time we feel the burn, we’re reminded how important this cause is!”
Esther, Sweatember participant 2025



ALAN STEEL - Alan set himself a mountainous challenge! “I rode the height of Mt Everest—8,849m—in one day. For Sweatember. For Felix.

After our newborn son Felix was diagnosed with cystic fibrosis, we were overwhelmed by the support from Cystic Fibrosis NZ. Our family felt compelled to give something back. For me, exercise has always

been a way to process emotions—so it felt right to turn this challenge into something meaningful.”

EDDIE ASHTON - Eddie took on a massive swimming challenge for his son Noah, swimming 75km, that’s 100 laps per day, 3000 laps in total. He smashed his goal of \$1 per lap by over \$2000.

“If I can help raise a bit of money and awareness at the same time, then it’ll be worth it.”

“He looks so normal that people often forget,” Edward says. “But there’s still a chance he could die a lot sooner than other children.”



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By Sam Henderson

The Star

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3k 2k

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Before and after of the 5k Mudder

Sweatember.org.nz

Children sweat it out to support cystic fibrosis fundraiser

Supporter

Supporter

Supporter

Supporter

Supporter

Supporter

Supporter

Supporter

With thanks...

None of this would have been possible without our partners. Heartfelt thanks go to Viatrix for their ongoing sponsorship, and to Vertex for their generous contribution towards campaign costs. We’re also extremely grateful to Bounce Trampoline Parks for encouraging donations on their own booking site throughout September and October, to Coffee Club for providing us with giveaways, and to Shnack for contributing products for prizes.

Sweatember 2025 showed what’s possible when movement, community and 80s vibes come together, and we can’t wait to build on this momentum for 2026.



Community Joy Board



Nyah



Micah



Lewis



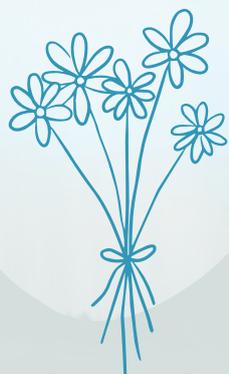
Liam

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



Alex



Lincoln



Lizzie



Matthew

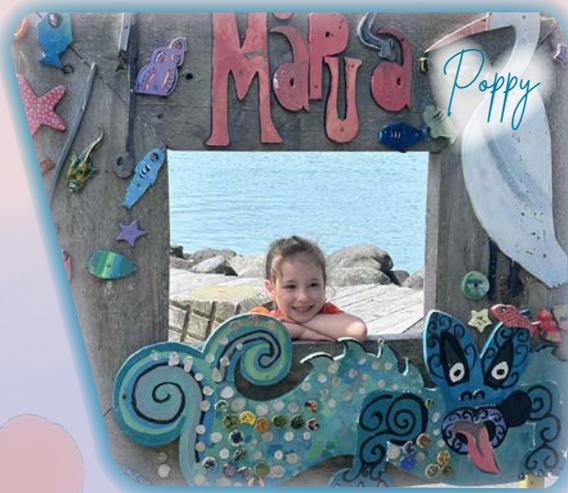


Thomas



Madison

- Nyah breathing in plenty of the salty air this summer in Gisborne.
- Micah and Tyler got married last year!
- Thomas had a great holiday in Thailand.
- Madison celebrated her 14th Birthday with a surprise trip to the Gold Coast!



Poppy

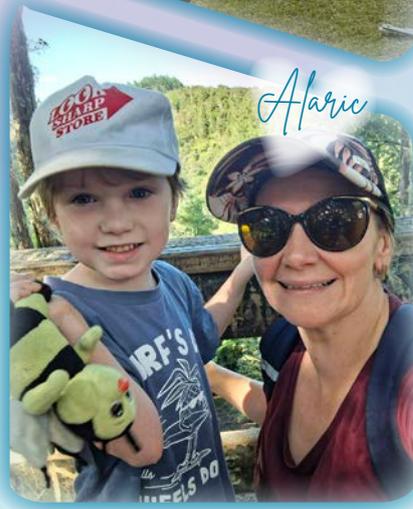


Harry

- Lewis and Payge got married!
- Liam with his big brother Coen, Mum and Dad at the top of Maunganui Bluff in Northland.
- Poppy is all settled in after a big move to the South Island
- Harry completed the Weetbix TRYathlon, what a champ!



Gracie



Alaric

- Meet Alex and Matt's puppy, Brenda.
- Lincoln, very happy to give his Christmas fishing rod a whirl on the lake.
- Gracie is getting stuck into gardening!
- Alaric enjoying some hiking to the waterfalls with mum!



Nikki



Orson

- Lizzie's nieces Harriet and Isabelle visited from Perth.
- Matthew enjoying his new pool at home.
- Nikki and Skylar out on a mother / daughter dinner date.
- A happy Orson loving his swimming lessons.



A FESTIVAL OF TREES, ... a Season of Aroha



A heartfelt thank you from CFNZ Wellington Branch to all the sponsors involved with the 2025 Festival - we are so grateful for your support!

The festive spirit was once again in full bloom at Wellington Airport, as the terminal transformed into a vibrant showcase of creativity for the annual Cystic Fibrosis Wellington Christmas Tree Festival. Thanks to the incredible support of 65 generous businesses, organisations, and community groups, this year's festival raised over \$69,000 to help support families living with cystic fibrosis across the region, the most successful festival to date!

If you travelled through the terminal this holiday season, you couldn't miss the stunning rainbow flower tree created by Mary Potter Hospice - a joyful burst of colour that radiated warmth and aroha, earning both our People's Choice Award and first place at the opening gala night.

This much-loved tree was joyfully decorated with handmade flowers and bead bunting, lovingly crafted by hospice patients and volunteers from the Mary Potter Hospice Porirua Day Programme. Their creation brought Christmas cheer to travellers and stood as a beautiful expression of giving back to the community.

“The Cystic Fibrosis Wellington Christmas Tree Festival once again lit up Wellington Airport for the 11th year. We were blown away by the 65 beautifully sponsored trees, all lovingly decorated with their own story to tell. We are very grateful to our wonderful supporters who helped us raise \$69,000 for 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, Chair,
CFNZ Wellington Branch**



PEOPLE'S CHOICE AND FIRST PLACE WINNER

Mary Potter Hospice

We had the best time being part of this event!

Our Porirua Day Programme offers hospice patients living in the community an opportunity to safely socialise, and engage in meaningful, fun activities. Our excellent volunteer, Murray (Mana Lions member) arranged for the Lions to sponsor a tree and we planned and designed, sorted beads, threaded bunting, cut, pasted, hot glued and glittered rainbow-coloured flowers. Our plan was to appeal to children with bright colours, lots of things to look at and joyful colours were also an inclusive nod to the Pride flag.

The project provided a sense of purpose and satisfaction, the appreciation of the collective effort was palpable, the joy of winning the icing on the cake! We have since lost some of the people who helped make those flowers, so in a small way it is a legacy they have left in the last months and weeks of their lives.

Thank you to CFNZ Wellington Branch and Wellington Airport for giving us this opportunity and creating an event that benefits different groups in so many different ways.

Susi Maxwell on behalf of the Porirua Day Programme, Mary Potter Hospice



SECOND PLACE WINNER

Catalyst

This year's design drew its inspiration straight from Wellington's wild winds. The concept of a kinetic tree, one that actually spins, felt like the perfect way to capture the joy, chaos, and energy of our city.

From there, we paired the movement of the wind with something far more meaningful: a message of breath, hope, and support for those living with cystic fibrosis. Our rainbow windmill tree moves with the wind - and with your breath. Each spin is a gentle reminder of the beauty and effort in every breath, and a tribute to the strength and resilience of those for whom breathing is never taken for granted.

We were thrilled to be awarded second place this year and are proud to support such a fantastic cause, one our team looks forward to being part of every year.

It's always a highlight on our calendar, bringing together our creative thinking, hands-on making, and great team building, all in support of something truly meaningful.

Sae Saint-Pere, Catalyst



THIRD PLACE WINNER

Good Bitches Baking

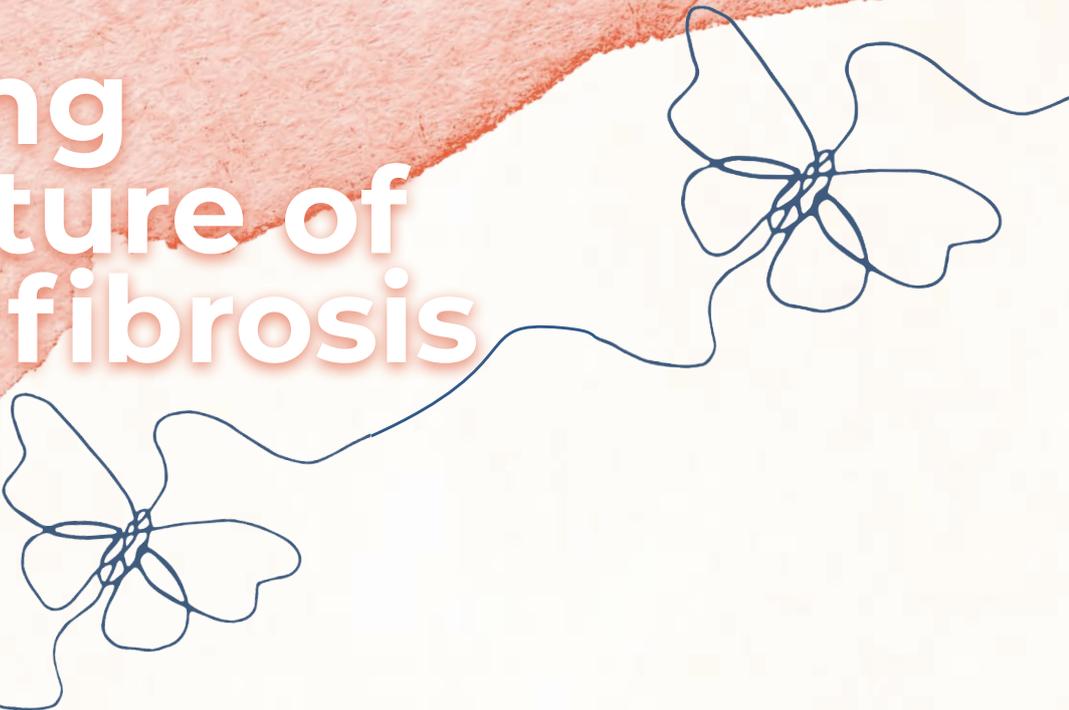
Good Bitches Baking was proud to take part in the Christmas Tree Festival, an idea sparked while I was walking through the airport during the festival in 2024. Earlier that day, one of our Good Bitches had shared with me that volunteering and delivering baking to recipients had given her a reason to get out of bed during a particularly tough time. It got me thinking about the power of our GBB community and how meaningful connection and giving back can be, and so project GB Tree was born!

Entering the festival felt like a natural fit, a way to bring our volunteers together, do what we know best, and help raise awareness of cystic fibrosis. Over several weekends through the year, we ran workshops and also had volunteers decorating from home. Using our cake boxes instead of a traditional tree gave us a point of difference, but more importantly reflected how we deliver kindness across Wellington, around 550 boxes of baking every month from a community of over 530 Good Bitches. We were especially proud of our star "cake" topper too. To place third was incredibly special, and seeing Mary Potter Hospice — an original GBB recipient for the past 11 years, take out first place truly was the icing on the cake.

We're immensely proud of our generous, kind community, and this experience will forever be one of our highlights.

Belinda Barber, Head Bitch, GBB Wellington Chapter

Shaping the future of cystic fibrosis care



The NZ CF Symposium 2025 marked a significant milestone for cystic fibrosis care in Aotearoa, bringing together health professionals, researchers, advocates, sponsors, and community members for the first national CF gathering in over eight years.

NZCF Symposium explored how emerging treatments, shifting patient needs, and new models of care are redefining the landscape for people living with CF in New Zealand.

Held over two days at the Waipuna Hotel & Conference Centre, the event welcomed over 140+ delegates each day and featured international speakers, interactive workshops, panels, and an engaging exhibitor space.

Minister of Health, Hon. Simeon Brown officially opened the Symposium, highlighting the growing recognition of CF and rare disorders at a national level.



”

Hearing from the CF community and international speakers reinforces that we still have so much to do, and reminds me why I do what I do. It was important to hear about the NZ health system and the unique challenges patients and carers face, especially in the context of mental health care.

Anonymous Medical Professional

Community Feedback

89% found the content directly relevant to their clinical role / lived experience.

92% expressed interest in ongoing learning or future events.

94% said the symposium met or exceeded expectations.

Hon. Simeon Brown (Minister of Health),
Lisa Burns (Former CE CFNZ), Professor Cass Byrnes

Symposium snapshot

- Attendees travelled from the top of the North Island to the very bottom of the South Island
- 77 clinical attendees
- 103 community and industry attendees
- 20+ speakers and facilitators from NZ, Australia, Canada, and the US
- 30 workshops, panels, and plenary sessions
- 11 groups of exhibitors and sponsors in attendance



CFNZ Board



CFNZ team



Bev Darlow, CFNZ Social Worker

A message from Bev

Presenting on the mental health challenges since Trikafta felt deeply important to me. As a social worker, I've witnessed its life-changing physical benefits, but also the emotional complexities it brings - feelings of anxiety, uncertainty, and identity loss after years of survival. These stories are often unseen, and I felt compelled to share them with honesty and compassion. It was humbling to carry our community's voices to the conference stage, reminding us to look beyond treatment outcomes and keep people's resilience, fears, and hopes at the heart of the conversation.

Bev Darlow, CFNZ Social Worker



Associate Professor Tonia Douglas

Symposium videos



A huge thank you to all our supporters

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Sensory sam



International speakers

INTRODUCING Brittany



We are very excited to be able to tell you a bit more about the new Adult CF Clinical Nurse Specialist in Auckland, Brittany Wade.

TELL US A BIT ABOUT YOURSELF

I'd say I pride myself on being 4 main things - a wife, a Mum, a Nurse, and a kind person. Those things really sum up who I am to my core.

Q WHAT DREW YOU TO THE ROLE?

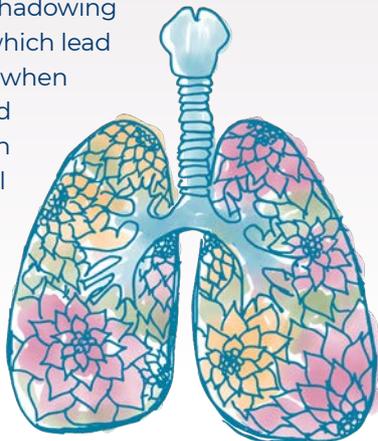
I feel like I have a lot to offer this role, I'm committed, clinically sound in my practice, compassionate and adaptive, and I'm someone who really enjoys championing people on their health journey. I was also drawn to the role since the addition of bronchiectasis patients, which has made the role unique and something I can really make my own.

Q WHAT ARE YOU LOOKING FORWARD TO?

It's such a changing time in CF care with the introduction of modulators, and I'm really looking forward to the challenge of adapting the role and services to the new and changing needs of people living with CF.

Q HOW LONG HAVE YOU BEEN INVOLVED IN THE CF COMMUNITY?

I've been working on the respiratory ward for 11 years in Auckland, so I met and looked after people living with CF all the time! And what a resilient bunch. I was lucky enough to start shadowing Cath three years ago, which led to covering the CF role when Cath went on leave, and eventually to working in the role every Friday. All that experience gave me a pretty good grip on what's what but I'm really open to how the role can change and grow in this new era.



THE QUICK TAKE ON BRITTANY:

Favourite Snack:

Chocolate covered pretzels

Do you make your bed in the morning?

Someone always makes the bed (whoever gets out last is our rule)

Favourite quote:

"One must champion oneself and say, I'm ready for this" - *Moira Rose (Schitts Creek)*

Coffee Order:

Double shot flat white with a caramel shot

What song puts you in a good mood?

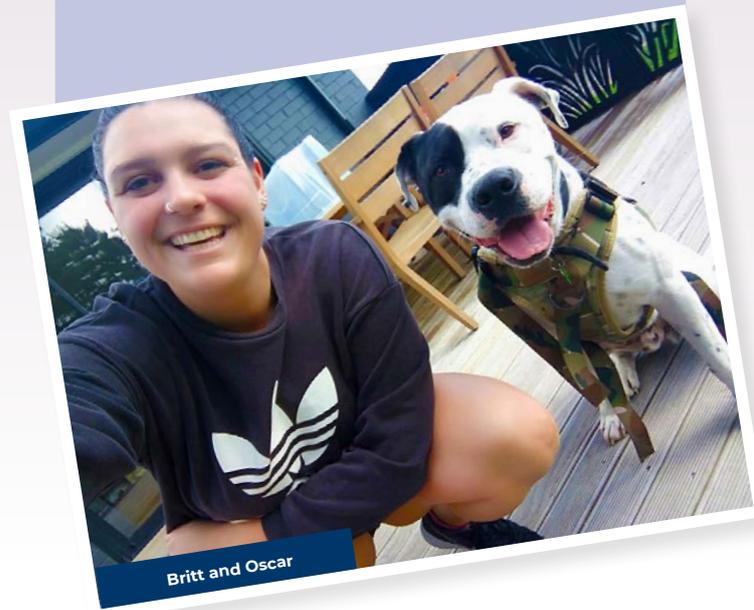
When it Rains it pours - *Luke Combs*

Most used emoji:

The laughing crying face or the face melting emoji

Do you have any pets?

One big rescue doofus of a doggy



Britt and Oscar

CARRYING HER LIGHT *Forward*

How Charlotte turned her family's connection to CF into a lifelong commitment to helping others - and why her next chapter may change lives.

GROWING UP WITH CF IN THE FAMILY

Cystic fibrosis has always been part of my life. I grew up in Blenheim with mum, Janet, who had a rare form of cystic fibrosis. Some of my earliest memories are the drives to Christchurch Hospital with my sister, Dad and Nan Nan to see her, then the long waits at home until she was back. That rhythm became normal for us. When I think about it now, I don't go straight to the hard parts - I think about her strength. She carried so much with humour and love, and that's what shaped me. Growing up like that makes you aware of how much families carry together. You see how important clear communication and genuine care are. The way people speak to you, the way they include you - those things stay with you.



FINDING A PATH THROUGH SCIENCE AND UNDERSTANDING

At university I studied Biomedical Science, majoring in Genetics at the University of Auckland. Choosing genetics felt obvious. I wanted to properly understand the science that had quietly shaped so much of my own story. But over time I realised I was more drawn to the people side of it - how to explain complex information in a way that feels manageable, how to support someone when decisions feel heavy.



CONNECTING WITH CFNZ AND GIVING BACK

I got in touch with CFNZ in Auckland not really knowing what to expect, and I was lucky to be welcomed like family. I helped with the CF Awareness campaign Air for All, and volunteered at the NZ CF Symposium. I was lucky enough to be asked to speak at the community day of the symposium, sharing my family's story, and how even though my Mum isn't here anymore, she still pushes me to do my best. I also talked about studying genetics and my goal of becoming a genetic counsellor, and how this next step feels like something I'm doing for her as much as for myself. It never felt like "just volunteering." It felt like staying connected and giving back to a community that had shaped my life.

A FUTURE GROUNDED IN EMPATHY AND LIVED EXPERIENCE

Somewhere along the way it became clear that genetic counselling brought everything together for me - science, empathy, and real impact. I have just moved to Melbourne to begin my Masters of Genetic Counselling at the University of Melbourne. It's exciting and a bit daunting, but it feels purposeful. I want to work with families facing inherited conditions and help make complex information clearer and less overwhelming. Growing up in a rural town has also made me aware of how access can differ, and that's something I care deeply about. I don't see this next chapter as leaving CF behind. I see it as building something from it. Everything I learned from Mum - resilience, perspective, compassion - comes with me. Her strength shaped my life. Now I want to use that to help shape someone else's future.

GIVE A

FIVER

**FOR CYSTIC
FIBROSIS**

CF is NZ's most common life-threatening genetic condition. Treatments have improved, but CF is **NOT** cured.

YOUR DONATION CAN HELP!

**FULL LIFE
FUTURE
FRIENDSHIP
FOCUS**

cf CYSTIC
FIBROSIS NZ

www.cfnz.org.nz

GIVE A F*** FOR CF THIS CYSTIC FIBROSIS AWARENESS MONTH

We are so fortunate to be able to celebrate wins with modern therapies as they develop. Lives have been transformed, lives will be extended, and hope, especially for our younger community members, has soared. But here's the truth our community knows better than anyone:

CF IS STILL NEW ZEALAND'S MOST COMMON LIFE THREATENING GENETIC CONDITION

Treatments have improved, but CF is NOT cured. That's why during Cystic Fibrosis Awareness month this May, we are bringing back a cheeky, disruptive and impossible-to-ignore message:

GIVE A F* FOR CF.**
Give a fiver. Give a future. Give a focus.

A MONTH OF GIVING A F***

Each week during May we will highlight a real aspect of cystic fibrosis, educating the public more about life with CF. A strong PR campaign, featuring families whose stories relate to each theme will help to improve CF awareness, centred around the voices of the CF community, and give people a clear, personal reason to **Give a F***** and take action!

WEEK 1	Babies continue to be born with CF → Give a Full Life for CF
WEEK 2	We are still losing people to CF → Give a Future for CF
WEEK 3	Cross Infection & Isolation → Give Friendship for CF
WEEK 4	CF as a Whole Body Condition → Give a F*** for CF

Please note: Our upcoming CF Awareness Month campaign will feature real, honest stories and imagery about the challenges our community continues to face. Some content may be confronting for some people. We will share further information via our pānui, social media channels and our website before the campaign begins to ensure everyone is aware and can choose how and when they engage with the content.

SO, WHAT CAN YOU DO?

Everyone can "Give a F***" in their own way!

Chocky Fish fundraising will play a big part in CF Month, as it has now for many years. These will be available through CFNZ and most of our branches. It's a fun and easy way to raise money and have conversations about CF to spread awareness.

Below are some ideas that we know have been very successful during previous CF Awareness Months:

SCHOOLS

Contact your local schools where you have a connection, they may want to try:

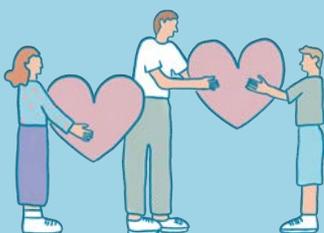
- ▶ MUFTI DAY: Wear blue for CF
- ▶ "Blue Day" awareness event
- ▶ Cupcake bake sale
- ▶ Sell Chocky Fish (always a hit!)

CF FAMILIES & SUPPORTERS

- ▶ Share your story of living with CF
- ▶ Share our stories, if that feels easier
- ▶ Convince all your friends, family and colleagues that they need to stock up on chocky fish!

EVERYONE

- ▶ Donate and share that you have given a fiver, a few bucks, a future for CF
- ▶ Help by boosting awareness on social media, share stories and share our posts from our social channels
- ▶ Talk about CF - help people understand
- ▶ Arrange a Blue Day or morning tea to raise funds at your workplace



If you would like support with your fundraising efforts or if you are willing to share your journey with CF with the media, please contact community@cfnz.org.nz and we will get back to you. Whether you're selling cupcakes, wearing blue, sharing your story, or simply donating, let's all give a F*** for CF together in 2026.

Thank you CATH

In November 2025, Cath Lamont, Adult CF Nurse Specialist in Auckland retired after over 17 years of absolute dedication to our adult CF community. So many people living with CF and their families experienced the all-encompassing support from Cath – at clinic, on the wards, and always just a text or phone call away. Cath has always been there, proudly marking milestones alongside our community.

Over the last 8 years, Cath also played an integral part on our CFNZ Clinical Advisory Panel. We want to thank Cath for sharing her insights, knowledge, and wisdom throughout her time on CAP.



Our CF community wish to share memories and messages of thanks...



Cath has been an integral part of our journey for so many years, and her impact on us has been immeasurable. She will be deeply missed, and her absence will leave a void that's hard to fill.



Cath has been a consistent part of our adult CF community that it will take us a while to adjust. Always only a text or email away she's at the frontline of our care and always ready to be a cheerleader with a good lung function result, weight gain and for personal achievements too.

Such an amazing woman and did so much for the CF community. She will be missed immensely.



When the modulators were funded Cath was thrilled to see such improvements in health and I think especially those who had struggled for so long with endless hospital admissions and declining lung function.

I transitioned to adults from paedics a year after Cath joined the team – so she is all I've ever known for my entire adult life, Cath has always been there. Always visiting on ward 72 or 7a, opening the curtains to start the day – one of us enjoyed this more than the other! Supporting me through some really rough patches which led to a lung transplant many years ago. After my transplant, my main care went to the transplant team, so her visits turned into social ones which was very special, lots of laughs were had. I remember one day Cath came in and proudly said she now had more patients than the paedics team, and we talked about what an amazing problem it was to have an aging CF population!



I remember I had a hospital admission not long after Cath had started as CF Nurse Specialist, and when she saw me on the ward she gave me some advice. She said "you are your own best advocate" and this is something that I've taken with me over the years and when working through a few health challenges. I've passed this sentiment onto others also navigating the healthcare system.

Celebrating LIFE MEMBERSHIPS

At the Cystic Fibrosis NZ AGM, held in September 2025 the board acknowledged two outstanding members whose contribution to CFNZ at both Branch and national Board level have been exceptional. Jill Thorrat and Melissa Skene were both unanimously appointed Life Members.

Our President Denis Currie QSO, and the Board extend their warmest congratulations and thanks to Jill and Melissa.

Jill Thorrat



Jill has been actively involved with CF for over 35 years, and her dedication and commitment have been truly invaluable to our community.

Throughout her long association with CFNZ and the Auckland Branch, Jill has contributed in many significant ways, including serving as a Board Member, Committee Co-Chair, and as a highly engaged and supportive member of our current committee.

Her unwavering support, leadership, and consistent efforts have had a lasting impact on the CF community, both regionally and nationally. Jill continues to support the Auckland/Northland Branch and community, and we believe she is most deserving of recognition as a Life Member of CFNZ. Congratulations Jill on your Life Membership and thank you so much for all that you have done and continue to do! 

Chloe Hunt, Auckland/Northland Branch Chair



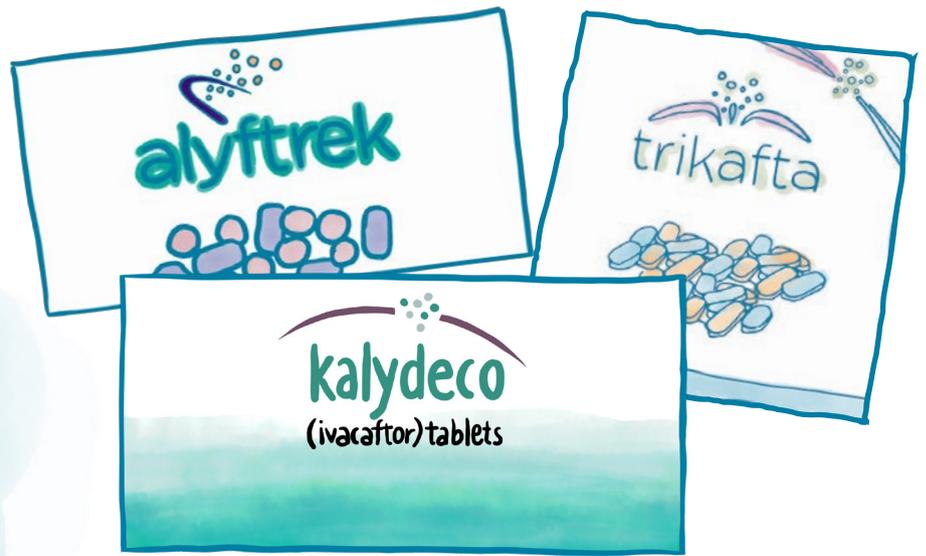
Melissa Skene

Melissa has been a member of the Canterbury Branch committee since 1997, the Branch Chair for over 20 years and has also served on the CFNZ Board. Melissa has worked tirelessly for the Canterbury community and has been the linchpin in keeping the local committee functional and motivated. Melissa meets every newly diagnosed family and keeps in contact with them.

Melissa has been at the helm of running our annual fundraisers, including the Golf Day, Annual play and chocolate fish fundraising. She is a huge asset to the CF community in New Zealand having given significant, sustained and high quality involvement, she is well worthy of this recognition.



ADVOCACY UPDATE



PHARMAC PROPOSAL TO FUND KALYDECO, TRIKAFTA AND ALYFTREK

Finally, the news the CF community has been waiting for has arrived.

On 22 January 2026 Pharmac announced its proposal to widen access to existing treatments and fund a new treatment for people with cystic fibrosis (CF) through a provisional agreement with Vertex Pharmaceuticals (Australia) Pty Ltd (Vertex).

The proposal includes:

- **Trikafta** – widening access for all people with eligible mutations
- **Kalydeco** – widening of access for all people with eligible mutations; and
- **Alyftrek** – funding of a new treatment for people with CF with eligible mutations.

The proposal was announced by Hon. David Seymour, Associate Health Minister. You can read the Minister's statement here:



Pharmac opened consultation on the proposal seeking feedback from all parties, including people with CF and their families, clinicians, advocacy and support groups, pharmacies, and Health New Zealand.

Consultation closed on 11 February 2026. Pending consultation, access to all three medicines will commence on 1 April 2026. You can read the detail of Pharmac's proposal here:



HOW WE GOT HERE

This proposal has come after years of advocacy from the CF community who have been waiting for funding applications to work their way through Pharmac's system. It has been twelve years since the first application for a modulator therapy was submitted to Pharmac for funding.

Kalydeco

The original application for funding of Kalydeco was made by Vertex in 2014. It was finally funded in March 2020 following an extensive advocacy campaign, with access for people with one of nine CF causing mutations.

The application to widen access to Kalydeco for those with other rare mutations was submitted to Pharmac in July 2021 by a consumer - a member of the CF community. It was given a high priority for funding by Pharmac's Respiratory Advisory Committee (RAC) in April 2022. Pharmac's current proposal to widen access to Kalydeco will extend eligible mutations from the current nine to almost 100.

Trikafta

The application to fund Trikafta for those aged 6 years and over was submitted to Pharmac by Vertex in July 2021 and was given a high priority for funding by RAC in August 2021. However, in November 2021, Pharmac's Pharmacology and Therapeutics Advisory Committee (PTAC) downgraded the priority for funding Trikafta for those aged 12 years and over and deferred a decision on funding for those aged 6 – 11 years.

The application was then reconsidered by RAC in April 2022 which reconfirmed its original high priority for those aged 6 years and over. Trikafta for this age group was finally funded in April 2023 after an extensive and, at times, bruising, advocacy campaign.

Vertex submitted its application to widen access to Trikafta for those 2-5 years old in February 2024 and was given a high priority for funding by RAC in August 2024. Again, the CF community rallied to raise awareness of the urgent need for Trikafta for this young age group. A highlight was the submitting to Pharmac of more than 70 heartfelt letters from parents, caregivers, relatives, friends and clinicians demonstrating the social, financial and emotional impacts of living with CF.

Alyftrek

Alyftrek is not currently funded in New Zealand. It is a once a day CF modulator therapy and Pharmac's proposals will provide access for people with CF aged 6 years and over with one of more than 300 CF causing mutations. Vertex's application to fund Alyftrek for those aged 6 years and over was submitted to Pharmac in November 2024, considered by PTAC in May 2025 and given a high priority for funding.

ACCESS TO MODULATOR THERAPIES IN NEW ZEALAND

Pending successful consultation, Kalydeco, Trikafta and Alyftrek will be available to all people with CF with eligible mutations, regardless of age, from 1 April 2026. This will place New Zealand alongside 30 other countries who already offer Trikafta from the age of 2 years and among the first to have access to Alyftrek for those aged 6 years and over.

Extending access to all people with eligible mutations regardless of age will give the youngest and most vulnerable the chance for a long and healthy life. It will reset the trajectory of our young ones' lives and help to spare children from serious illness and prevent lifelong and irreparable damage. It will also ease the emotional burden on families and give them a future to look forward to. Pharmac's proposal will also enable those with young children to remain in New Zealand and provide the opportunity for those who have already left to reunite their families.

The proposal to widen access to all of those with eligible mutations regardless of age is very significant, particularly for Trikafta and Alyftrek. Trikafta is currently approved for use in New Zealand for those aged 2 years and older while Alyftrek has been approved for those aged 6 years and older.





◀ **Billy Peterson**

the consequent delay in access. If this approach had been put in place as part of its original application, Trikafta could have been available to those aged 2 – 5 years in March 2025.

Allowing doctors to use their clinical judgement to prescribe Alyftrek or Trikafta to any patient who would benefit is also a very significant and positive step. This will enable clinicians to prescribe outside the current Medsafe approval, for example to provide Trikafta to a child under 2 years of age where the benefits of treatment are assessed to outweigh the risks.

CFNZ SUBMISSION TO PHARMAC

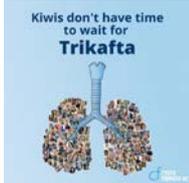
CFNZ has made a submission strongly supporting Pharmac’s proposal to widen access to Kalydeco and Trikafta, and to fund Alyftrek from 1 April 2026. In its submission, CFNZ has sought some minor amendments to eligibility criteria to provide greater clarity and consistency, and to ensure that access is as wide as possible.

A final decision is expected in March 2026. CFNZ is positive and hopeful that Pharmac will confirm the proposal.

Once Medsafe approval is achieved for even younger age groups, these medicines will automatically become available without the need for further applications to be made to Pharmac for funding and



ADVOCACY- *that moves us forward*

2019	2020	2021	2022	2023
<ul style="list-style-type: none"> The United States Federal Drug Administration (FDA) grants approval for the use of Trikafta for those aged 12 years and over - calling it a “landmark approval”. 	<ul style="list-style-type: none"> Interview with Sir Bob Elliott - CF expert clinician, researcher, CFNZ Patron, and lifelong supporter of the CF community sparking the Trikafta campaign for access in New Zealand. Trikafta for Kiwis, launches a petition. 	<ul style="list-style-type: none"> Medsafe grants the Trikafta application priority status. Trikafta application submitted to Pharmac. Vertex establishes the Managed Access Programme in New Zealand. CFNZ submits a comprehensive pack of information to Pharmac. Respiratory Advisory Committee gives Trikafta a high priority. PTAC considers Trikafta. Medsafe gives consent for the use of Trikafta in New Zealand. 	<ul style="list-style-type: none"> PTAC recommends a medium priority. Trikafta petition signed by 43,410 presented. Respiratory Advisory Committee re-consider the application. PTAC re-consider the application. Health Select Committee hearing. Pharmac releases the record of the Respiratory Advisory Committee and PTAC. Pharmac releases the TAR and confirms Trikafta would provide an extra 27 years. Preliminary agreement reached to fund Trikafta for 6 years and over with eligibility criteria. 	 <p>TRIKAFTA OFFICIALLY APPROVED!!!</p> <ul style="list-style-type: none"> Trikafta will be publicly funded for people with CF aged 6 years and over who meet eligibility criteria from 1 April.  <ul style="list-style-type: none"> MyLifeMatters joint pre-election advocacy campaign. CFNZ makes submission in response to Pharmac’s consultation on Rule 8.1.b for paediatric cancer medicines. CFNZ writes to Pharmac and meets to discuss the issue of fairness and equity from the delay to expand access to Kalydeco. CFNZ provides feedback on the drafting of the Rare Disorders Strategy. Launch of Rare Disorders White Paper at Parliament. CFNZ lends its voice to the concerns over the Therapeutics Products Act 2023.



ALYFTREK IN AUSTRALIA

Alyftrek was approved by Australia's Therapeutic Goods Administration (TGA) – the medicines' safety regulator - in December 2025. It has now been listed on Australia's Pharmaceutical Benefits Scheme (PBAC) effective from 1 February 2026 for those with eligible mutations aged 6 years and over.

TREATMENT FOR THOSE UNABLE TO BENEFIT FROM MODULATOR THERAPIES

CFNZ's goal is that everyone with CF has access to a medicine that treats the cause of their CF. Pharmac's proposal to widen access to Kalydeco, Trikafta and Alyftrek is a major step towards achieving that goal.

However, there remain 5-10 per cent of people with CF who cannot benefit from such therapies because the mutations that they carry do not result in any CFTR protein being made. There are a number of clinical trials currently underway to assess the effectiveness of inhaled therapies for this group of people.

Vertex is progressing the development of a CFTR mRNA therapeutic in collaboration with Moderna and is expected to share data from its Phase 1/2 trial in the second half of 2026.

You can read Vertex's update here:



In November 2025, Recode Therapeutics announced that it has initiated the third part of its Phase II trial of its inhaled therapy RCT 2100 combined with ivacaftor (Kalydeco).

The trial will focus on the tolerability and safety of RCT 2100 co-administered with ivacaftor over 6 weeks in up to 12 patients. The goal is to restore function of the CFTR protein absent in some CF patients.

You can read Recode Therapeutic's update here:



Our commitment

Advocacy remains a cornerstone of CFNZ's work, we will continue to champion access, equity, and lived experience to ensure every person with cystic fibrosis receives the care and support they deserve.

2024

- Valuing Life: Medicines Access Summit, 29-30 April.
- Launch of the Rare Disorders Strategy.
- CFNZ meets with Pharmac to discuss the lack of progress with Kalydeco.
- Trikafta application for 2 to 5 year olds considered at the Respiratory Advisory Committee meeting.
- FDA accepts the application for Alyftrek, a next-in-class triple combination treatment.
- Pharmac funds CGM devices, insulin pumps, and consumables that include eligibility for CF-related diabetes.
- Valuing Life Summit White Paper published.
- Buller Health Declaration on the state of the New Zealand health system launched.
- CFNZ participation in Pharmac Consumer Engagement workshops.
- CFNZ submits a formal letter to Medsafe, urging priority approval of Alyftrek.



2025

- Medsafe approval of Trikafta for 2 to 5 year olds.
- NZ Cystic Fibrosis Symposium, our first in-person event in eight years, opened by Minister of Health Hon. Simeon Brown.
- CFNZ meets with Pharmac and Vertex to discuss the application progress for Trikafta for 2 to 5 year olds and ongoing delays to expanded access for Kalydeco.
- Alyftrek receives provisional high priority recommendation from PTAC.
- Pharmac's Pharmacology and Therapeutics Committee implement the publishing of provisional recommendations 30 days after PTAC meetings.
- 67 letters of support delivered to Pharmac to support the assessment and prioritisation of Trikafta for 2 to 5 year olds.
- Trikafta for 2 to 5 year olds prioritised and ranked on the Options for Investment List.
- Written and oral submission on Healthy Futures (Pae Ora) changes to legislation.
- Submission on the proposed Online Casino Gambling Bill.
- Submission on Pharmac's proposed changes to rare disorders definition and the way Pharmac assesses medicines.
- Alyftrek prioritised on the cost neutral list in August.
- Valuing Life Medicines Access Summit 2025.
- Medsafe approved Alyftrek.



2026 and beyond

- Expected funding for expanded access to Kalydeco.
- Expected funding of Trikafta for 2 to 5 year olds.



- Expected funding of Alyftrek for those eligible six and over.
- Ongoing horizon scanning of new therapies.

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WE HAVE MOVED!

We are still around, still providing the same level of service and support, just from a little further up Grafton Road!

Our new street address is:

Suite 3, Level 2
89 Grafton Road
Grafton
Auckland

Otherwise it's business as usual.

