

# CF News

AUTUMN 2023

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We celebrate the news of Trikafta being funded

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**Cover Artwork** is a celebration of all the faces of our CF community

**Writer** of CF in the Workplace and contributor to Trikafta and Your Wellbeing: Ingrid Grenar, member of our CF Community.

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

**Tribute poem** written by Cassie Roma [www.cassieromaco.com](http://www.cassieromaco.com)



## A NOTE FROM LISA



By the time this edition of CF News reaches your letterbox or inbox, Trikafta will be available in New Zealand, and those who are eligible will be embarking on a new path.

The last two years have been significant in so many ways for our community. While many have celebrated the announcement of Trikafta, it's been hard for others for whom the arrival of Trikafta has come too late for their loved one.

I was recently reminded that sometimes we need a safe place to land, to know that there's someone to catch you, or reach out a hand when it's needed. We will be that for you, for our families. We are dedicated to walking beside you, providing relief and support where we can.

As we move forward through a period of adjustment for all our families, I want to reassure you, that we do so together. We will not be leaving anyone behind, and we remain committed to working towards a future where every person with CF has the opportunity to live a full and healthy life. There is still a lot of work to do.

Over the last 12 months we have been working on our support programmes, this has been informed by the information that you have shared with us. Over the coming 12 months, we will be developing and rolling out programmes to better meet the needs of our community for education, connection, mental health, and wellbeing, and supporting our people to transition to more independent lives.

As I write this message, we're two days away from attending the Annual Scientific Meeting for Leaders in Lung Health & Respiratory Science in Christchurch. The conference programme will deliver a range of clinical and research sessions with a key theme being disparities in respiratory health.

After this landmark achievement of getting Trikafta funded, we must also look ahead to see what's around the next corner. This conference gives us the opportunity to gain an understanding about future treatments and care, alongside important sessions that will discuss mental health and wellbeing for people with CF.

CF Appeal month in May remains an important opportunity for us to raise awareness and generate vital funds for our community. Despite incredible advancements with access to Trikafta, CF is a condition for life. We need to ensure we can keep delivering the vital support and services to our families who need them. We encourage you to be involved in the awareness efforts across May, whether it be selling Chocky Fish, or holding your own fundraiser – every bit counts!

I hope you enjoy this edition of CF news as much as the team has enjoyed putting it together.

Kia kaha / stay strong

Lisa Burns  
Chief Executive

## MEET OUR NEW BOARD MEMBER



Meet Kirsty, our CF Representative on the CFNZ Board

### TELL US A BIT ABOUT YOURSELF

I'm 29 (need to start planning a big 30th party, who thought!). I work in software as a Data Scientist. In my spare time, I'm a keen hiker, biker, and gardener. I was fortunate enough to join the early-stage Trikafta trials back in 2018, when I was living overseas. I can't emphasise enough, the change it's made to my life and to the important people around me. The trial was a great experience (maybe not the 7 stints I spent in MIQ during Covid!) and a real insight into the way new medicines are trialled.

### Q Why did you decide to apply for the Adult Rep on the Board role?

**A** My dad (John Parsons) has always been very involved in CFNZ, so he suggested I give it a go. From a personal point of view, I'm career driven and thought it would be a great experience to learn a new set of skills. Especially moving back to NZ after living overseas, I was looking for a new challenge. To be involved in a non for profit (even better, an organisation that has done so much for me) is very important.

### Q What does the role mean for you, and what do you have to do?

**A** CFNZ has always been such a supportive organisation to our family. It has provided so many opportunities to people with CF through grants, support, and a great community. I am passionate about helping others, and this was a slightly different kind of opportunity but one I was very interested in. Having my life being changed so dramatically, there's a lot of learnings I'd love to bring to the CF community in preparing for the future. Of course, it's important to ensure the level of support by CFNZ always remains strong to every person with CF. We all have individual journeys and it's important to recognise this.

I was always interested although found it a daunting idea - but I can honestly say it's not, the Board are a lovely group of very inspiring and approachable people. We have board meetings (via Zoom) on a Tuesday evening once every 3 months, and the occasional conference or strategy weekend. There are also special interest sub-committees to join, if you are passionate about a strategic area. As board members we bring our individual experience to help make decisions in the best interest of CFNZ and its people.

### Q What's your biggest wish for our CF community?

**A** Every person with CF is incredible. I wish that everyone can live a life less restricted by CF and fulfil their dreams (however big or small). CF has been such a big part of all our lives, for most of us it's all we've known. It's also something we've battled with as individuals, and hopefully one day we can find a way to come together and share our journeys.

## QUICKFIRE ROUND

**Do you make your bed every morning?** *I try.*

**What's your coffee order?** *Oat milk Flat White.*

**Do you have any pets?** *Yes, a dog Lenny (my best friend).*

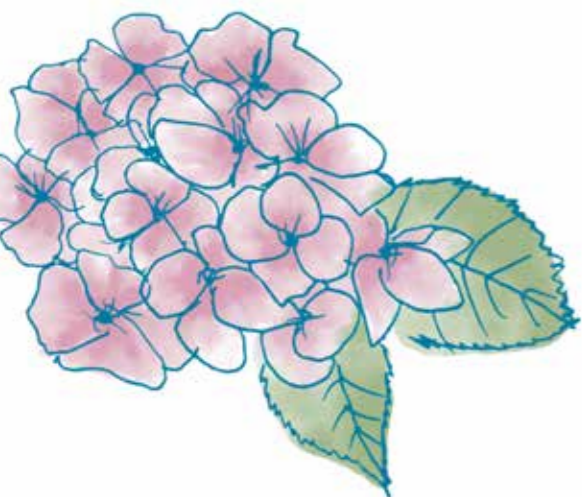
**What's your hype song?** *Anything by Macklemore.*

**Favourite place to travel?** *Tricky!! I think NZ is pretty amazing, you can't beat a good beach!*

**Drink of choice?** *A cocktail... espresso martini.*

**What gets you out of bed in the morning?** *Walking my very energetic dog*

**What's your favourite quote?** *"You can do this" - not really a quote, but I say this to myself a lot and its works magic.*



# 2022 CHRISTMAS TREE FESTIVAL

Our annual Christmas Tree Festival at Wellington International Airport took place from 22 November 2022 until 9 January 2023.

We are absolutely jolly to share that this was the biggest festival on record, with a total of 56 organisations taking part, giving their resources, creativity, and support to the event. An incredible \$54k was raised supporting Kiwis living with CF; through tree sponsorship, the lucky dip tree at the Gala opening, and donations from people walking past the forests of Christmas trees.

Judge and artist, Lynne Sandri couldn't be at the Gala Opening, but judged the trees beforehand, and left a message for Lisa Burns to read on her behalf, "Each year choosing three is so hard, as they just keep getting better and everyone steps up with their time, thought and messages. They're 'thought trees' – so much more than 'Christmas' trees."

"Deeper messages, not just celebrating the joy of Christmas and the end of the year, but also sustainability, our culture, design, embracing local, appreciating what's on your doorstep and a time to remember and reflect. So many traffic stopping trees"

The festival was opened by Newshub journalist and staunch Trikafta campaigner, Paddy Gower, and the amazing Jake Gawn told his lived experience of CF, and how Trikafta could change his entire world.

We are so grateful to everyone who made this event such an incredible success, raising funds and increasing awareness of cystic fibrosis in such a wonderful, festive and special way.



Thank you so much to Lizz Santos from The Christmas Decorators for doing such a beautiful job decorating our very own CFNZ tree.



Special mentions were given to Homeloan Shop and Dementia Wellington, Samuel Marsden School, Bay Plaza Hotel, Sam's Art House, Scott's College and Maude Wines, but the winners who took out the top places were:



Catalyst Group



Te Matatini – Kapa Haka Aotearoa



Ghost Diving NZ and Ben & Jerry's Ice-cream



Sam's Art House



Thank you to the team at Wellington International Airport for once again running such a brilliant festival for CFNZ!



If you are interested or know of an organisation that may be interested in participating in the 2023 Christmas Tree Festival by sponsoring a tree, please email [maree@cfnz.org.nz](mailto:maree@cfnz.org.nz)

A heartfelt thank you from CFNZ to everyone involved 2022 Festival, we are so grateful for your generosity and support.





# A LONG-DISTANCE LEGACY

for Teri Jane

"When Teri-Jane passed away, Carlos, Keelan, Kane, and Kyba were all between the ages of 7 and 14. She loved them dearly and was a truly dedicated mother. Those four boys were with her 24/7, stuck to her hip. My husband recalls her never complaining of her condition. She was a true CF warrior."

"In memory of this most beautiful person, of which 2022 marked their 10-year memorial, I decided that I would enter the Wanganui 3 Bridges Race, which takes place annually around 3 of our 4 bridges here in Wanganui."

## RAE AND WAYNE'S SPECIAL CF CONNECTION

"My amazing husband Wayne, is my connection to cystic fibrosis. He lost someone very close to him 10 years ago due to complications surrounding cystic fibrosis. Any loss of life is tragic, but to lose someone who was still so young, and to have been there supporting them through their deteriorating health, and last moments, was life changing for him. Teri-Jane and Wayne had four amazing sons together."

Rae entered the half marathon category; to give herself a good challenge, really improve awareness of CF and also raise some funds to donate to CFNZ.

## RUNNING AND ADVOCATING

"Breathing is so important in every aspect of life, even if you're not running! And I felt that people needed to be aware that not everyone can 'just breathe'. The more that I spoke to Lizzie from CFNZ and understood the importance of the Trikafta advocacy, the more passionate we got about spreading the awareness. Days before the Trikafta provisional agreement for funding was announced in December, Wayne and I were on the front page of the local newspaper. We took that opportunity to really focus on the cold hard facts of CF, and what Trikafta could do for those who desperately needed it. We were so happy when days later, the announcement was made! I was no longer preparing to run a half marathon for the awareness, I was running in CELEBRATION."

## RACE DAY

It was just Rae's luck that it had been raining solidly for 48 hours before the run. Race day came and it was a scorcher, 26 degrees by 10am, meaning they were running in 90% humidity – not the conditions Rae had been training in!

"It was so very hard to breathe in that thick, warm, heavy air. The entire way around the set course, I kept thinking of all those living with CF who can't breathe easily 24/7, those who need regular hospital admissions, and those who don't have the privilege of running around outside. Those thoughts kept me going – thinking how dare I give up or feel sorry for myself!"

Rae completed her first ever 21km race event in 2 hours and 28 minutes.

"I did it! And to find out later that we raised the amount that we did, made every step worth it. I'd do it all over again in a heartbeat... So, I am! I intend on doing another half marathon in May in Palmerston North."



## MAYHEM SUPPLEMENTS AND MAYHEM CUTS

Rae and her husband own Mayhem Supplements, and Mayhem Cuts, both located in Wanganui, and have an online store for Mayhem Supplements too.

[www.mayhemsupplements.co.nz](http://www.mayhemsupplements.co.nz)

"Once upon a time I was very unfit and overweight, and would never have dreamed of being someone who enjoyed running! However, since meeting my husband almost seven years ago, I have changed my life around drastically with the help of his guidance and knowledge in the fitness and health industry."

Mayhem Supplements was founded in 2020, during the first COVID-19 lockdown. They had 13 people in their bubble, all training in their home gym and buying supplements online so they decided to open their own store in Wanganui.

Mayhem Supplements went from a thought between husband and wife over the dinner table, to a flourishing business, that is passionate about doing community-based projects, and they sponsor several young, local athletes.



# TELLING CYSTIC FIBROSIS STORIES

from Aotearoa and beyond

What The CF! A Cystic Fibrosis Podcast launched in early 2021 and is the only dedicated CF podcast dealing with the impacts and challenges of parenting a child with CF. It was created to help process our son's diagnosis of CF at six months old, one week before the first 2020 lockdown.

We feature conversations with people working with or who have specialist knowledge of CF, as well as personal interviews with parents of CFers and adults living with CF. Covering everything from diagnosis, starting school, careers and treatments like Trikafta, lung transplants and more, we're proud to have the support of CFNZ as we navigate this journey.

What the CF! talks openly and honestly about cystic fibrosis. We want to support individuals and families by providing the answers to their questions in a clear, correct but (hopefully) entertaining way while increasing both the value to our community and the awareness of CF within Aotearoa New Zealand and beyond. Last year we were honoured to be nominated for a NZ Podcast Award and are forever grateful to all our supporters who donate to us online and to our podcast sponsor Zoono.



Our podcast shares stories that really resonate with our community and has helped overwhelmed parents feel less alone and isolated during diagnosis and CF parenting. There are more than 540 Kiwis with CF (70k globally) so our audience is a niche, small, but warm community of dedicated, engaged listeners around the globe. We regularly received thank you messages from listeners, particularly from parents, that make all the work worthwhile:

- "I felt like nobody in the world would be going through what we were at the time but turns out there was! NZ listener
- "I just had to share how comforting it has been to listen to your podcast as we go through testing and concerns... it's been a bit of a security blanket... USA listener
- "I love what you are doing. I am learning so much! UK listener
- "...thank you for this wonderful podcast...it's been amazing to feel others are in the same boat as me. It's been a lonely journey... NZ listener
- ".. great episode guys - we have a little 7 weeker so are in the throes of cf diagnosis and education. AU listener
- "Thanks for putting this info out into the world! I'll definitely be sharing when people have questions. USA listener

You can listen to What The CF! A Cystic Fibrosis Podcast wherever you get your podcasts and support the podcast via a donation on our **Buy Me a Coffee** profile.

- Listen on Apple Podcasts**
- Listen on Google Podcasts**
- Listen on Spotify**
- whatthecf.com**

# CYSTIC FIBROSIS NZ

cruelneedskind.org.nz



## CF Awareness Month

May is CF Awareness Month in Aotearoa, and across the globe. We will be running our Cruel Needs Kind campaign again throughout the month, culminating in Deliberate Acts of Kindness Day on Friday 26 May.

We are asking New Zealanders to bring hope to the CF community and be the relief for the cruelty of CF.

Since the preliminary announcement about Trikafta in December, we've been asked many times whether this means CFNZ now shuts up shop because our job is done. We can tell you hand on heart, absolutely not! There is still work to do.

While it's wonderful news for those eligible to receive Trikafta, the needs of our community are diverse. As we are shifting gears to work on what is needed to support those who now face a future they hadn't prepared for, we still have those whose reality hasn't changed.

CFNZ needs to continue providing support for quality of life to our people with CF who will not be eligible for Trikafta, or are unable to take it. It is also important that we continue ensuring our community who have had a transplant or those in palliative care receive our support.

This means we still need the support of Kiwis to raise awareness and funds so we can continue to walk beside every family living with CF, so that they're supported for life.



## CRUEL Still NEEDS KIND BE THE RELIEF

We are turning Random Acts of Kindness upside down for May, Friday 26th is *Deliberate Acts of Kindness Day!*

There are so many ways a **Deliberate Act of Kindness** can contribute to the success of our **Cruel Needs Kind** campaign.

**So how can you get involved this May?**

-  Make a donation
-  Buy some chocky fish from [www.cruelneedskind.org.nz](http://www.cruelneedskind.org.nz)
-  Purchase some of our amazing merch from [www.cruelneedskind.org.nz](http://www.cruelneedskind.org.nz)
-  Tell everyone! Talk about Cruel Needs Kind, wear your CFNZ tees proudly and post on social media
-  Comment, like and share our social media posts throughout the month of May
-  Run your own fundraiser and let us know how we can help
-  Do you know an organisation that can help CFNZ with a Deliberate Act of Kindness? Let's chat!
-  Buy your very own Fred Bear at [www.cruelneedskind.org.nz](http://www.cruelneedskind.org.nz)



## CRUEL NEEDS KIND

*Me noho noho ao kia noho humarie*

### Purchase a box of Chocky Fish

You can make a Deliberate Act of Kindness by buying some Chocky Fish from [www.cruelneedskind.org.nz](http://www.cruelneedskind.org.nz). Great for parties, class treats for birthdays or rewards for your workmates- Chocky Fish level up any occasion!

**OR**

### Order a box to use as a fundraiser

You can fundraise and sell Chocky Fish on behalf of CFNZ – sell them at an event or at the office, or just among your friends and family – find out more and register for your boxes of fish online using this QR code or by email – [fundraising@cfnz.org.nz](mailto:fundraising@cfnz.org.nz)



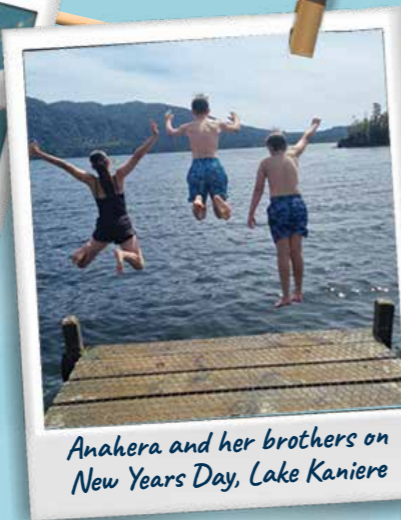
# COMMUNITY JOY BOARD

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](mailto:comms@cfnz.org.nz)



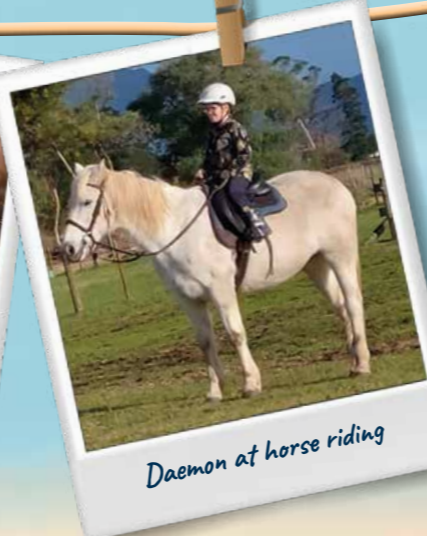
Alana snorkelling in Bali over the holidays



Anahera and her brothers on New Years Day, Lake Kaniere



A day Bekah never allowed herself to dream about, it was perfect



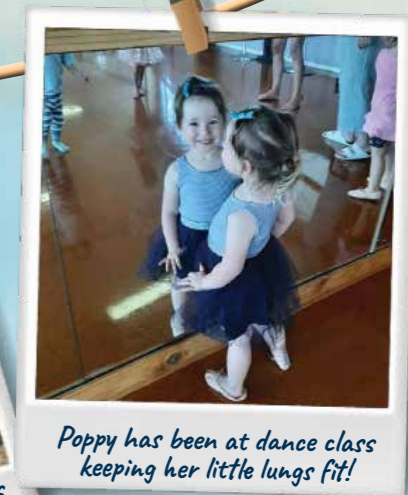
Daemon at horse riding



Ferghus smashing out the Milford Track



Harry stoked with catching his first kahawai in the Clutha river



Poppy has been at dance class keeping her little lungs fit!



Kase at the mini stocks in Palmy!



Max with the whole world in his hands



Pippa age 6 enjoying a real fruit ice-cream



Liam and his bestie Riley at Kindy. Hanging out, sharing stories about SpiderMan.



Oscar having a ball celebrating his 1st birthday, icing everywhere



Hannah and her Dad doing the Queenstown 10km



Sarah and her new Queenstown ride!



Nexus Ultimate is a frisbee club in Wellington who have a very special connection with cystic fibrosis.

Their friend and frisbee teammate Kimberley Bryant passed away in January 2018. Kim lived with CF, and her friends from Nexus Ultimate try to find ways to honour her memory and help those who still live with CF today.

They have had a group participate in Sweatember for the last few years, and this January decided to hold a one-day, ultimate frisbee tournament to commemorate 5 years since Kim's passing.

Marah Neal, friend and teammate of Kim, who helped organise the event says "She really left a big impact on our club. We actually give the Kimberley Bryant award out each year to the player who gives their all throughout the season, through a combination of their game performances, spirit on and off the field, and their commitment to the squad and to becoming a better player."

## FRISBEE FOR A CHERISHED FRIEND



On the day of the tournament there were 50 participants, largely from Wellington, who came together to compete and have a lot of fun together. During the lunch break there was a pyjama competition, Marah says "One year Kim had a teammate who

/// *She really left a big impact on our club. We actually give the Kimberley Bryant award out each year to the player who gives their all throughout the season, through a combination of their game performances, spirit on and off the field, and their commitment to the squad and to becoming a better player.* ///

welcome. We think that perfectly sums up the kind of person she was, and we now wear pjs each year at our nationals in her memory."

Kim's mum, brother, and sister were invited to the event and there was a special moment



when they met one of the players who has a sister living with CF, something that the organisers of the event weren't aware of until that point.

They also held a raffle with lots of great prizes donated by local Wellington businesses. Marah was blown away by the support they received and says "The day was a great success. We got really lucky with the weather so the frisbee was great and everyone had a great time. We loved being able to raise money and awareness for such a good cause. It's definitely something we will look to run again."

Thank you and congratulations to Marah, the Nexus Ultimate crew and everyone involved in this amazing event, honouring Kim and doing so much for the CF community.



## CHRIS HOWLETT FUND

### About Chris Howlett and the Endowment Fund

The endowment fund is made possible thanks to the Chris Howlett Trust, which was established in 1991 to fund the medical and quality of life needs of Chris Howlett, a young New Zealander with CF. Sadly, Chris passed away in 1996. The money is now used to benefit future young adults with CF.

The proceeds are now used to pay each New Zealand resident with symptomatic cystic fibrosis a sum of \$1,700 upon reaching the age of 21 – every 21 year old who has received the Chris Howlett Fund understands how meaningful this fund is, and are grateful the fund still exists today.

### IT'S A CHRISTMAS MIRACLE PAINTING

In December we listed this now iconic piece of art for auction on TradeMe.

We didn't quite reach the framed-Hansard-quote level of bidding – a well-deserved donation to the Prostate Cancer Foundation!

Instead, a donation has been made from the Chris Howlett Endowment Fund of \$10,000 in recognition of the advocacy work done on Trikafta. A medication like Trikafta came too late for Chris, and we would like to honour Chris Howlett, and the ongoing legacy work that is being done in his name.

The painting will be gifted back to CFNZ, and a special plaque will acknowledge both Chris Howlett, and the advocacy work that has been done over the past two years.



### A message from the artist, Alice:

■ *A friend of mine has a little boy with CF. I've seen her deep passion for him and the whole CF community. I know as a mother, covid was a very scary time for her.*

*I was honoured when she asked me to create an art piece for the 'Cruel Needs Kind' campaign in May 2022.*

*The first thing that came to mind, were the families who wish for a miracle, and their plead for help from Pharmac and the Government.*

*I didn't know if I could paint a vision that people would see as I imagined, and I'm very new to portraits. It was great people understood my message of hope, but more importantly, I was over the moon to hear the CF community's Christmas Miracle came true, the dream became a reality, with the news that Trikafta would be funded in New Zealand from 1 April 2023.* ■





# HONOURING *Jan Tate*

The wonderful Jan Tate is retiring from a job she dedicated her life to for decades. Jan is our CF Nurse Specialist, and Starship hero. A huge number of our CF community has experienced the all encompassing support from Jan. Having a child diagnosed with CF is of course a huge and heavy adjustment. We hear countless stories from families about how much they appreciated the guidance and unwavering support from Jan especially in the early days, and with every different curveball CF throws, Jan has been right there.

## OUR CF COMMUNITY, PRESENT AND PAST PATIENTS WANTED TO SHARE A FEW MESSAGES OF GRATITUDE...

Jan, thank you! We love how you made Gracie feel at ease and the kindness you placed into her hands. Your care, dedication, and outstanding ability to smooth the difficult CF journey will never be forgotten. We are so happy as a family that we experienced your guiding light, thoughtfulness, and care. You alone made Gracie feel so special, loved and cared for from diagnosis until transfer to adult care. We adore you. Jan, you are one in a million, a truly special person. The very fact that you continued in your role longer than anticipated speaks volumes to the wonderful person you are. We hope your retirement is fulfilling and filled with love from your family (and your extended CF family, you will always be a part of us). With love, The McDonald family.

*One of the most genuine, caring people.  
Thank you for being our light Jan.*

Jan, you have been with us since day one of our quite long journey. Now as we're about to enter the new age of Trikafta, CF will look a lot different from how it looked 27 years ago. Thanks for working with us in your beautiful and supportive way to ensure Angus and Georgie have had the support and care needed to become adults with CF, in reasonable health ready (like you) to enter this new stage of life. We so appreciate your friendship. Drumm family

Thank you Jan, for all the incredible care and time you gave me when I was up at Starship. You always made the big scary hospital trips less scary, and you were always someone I trusted so much. You've been an incredible person for so many CF children and teenagers, plus all their families. I don't think anyone could ever replace you. Enjoy the next chapter, you deserve a lovely break! Kirsty Parsons

Jan, you were amazing helping us transition from Melbourne to Starship, and again in supporting us to move from Starship to Whangarei. The continuity of excellent care and compassion you gave were well above your duties. It was always so reassuring amidst all other changes in life. Kelcie and Donelle.

Congratulations Jan on your retirement. Just like to say thank you for being so loving and caring whenever our son Joe Muru-Haenga came in for his out patients even when he went up to the ward to stay, you would always come and visit. Thank you very much. Maha and Manawa Haenga.

*After being diagnosed late with CF, she welcomed me into the community with open arms.*

Congratulations on your retirement Jan. Time now for a well-deserved break. Thank you for absolutely everything... Much love... Kelea and fam xxx

Thank you Jan, for being the perfect person to welcome us into the scary and overwhelming world of CF. You were the right level of kind and practical and always there to answer any questions that popped into our heads. Orson has really enjoyed his clinic time with you, and we very much appreciated your warmth and kindness whenever we've see you. Your skills are priceless, so we're sad that Orson won't grow up around your experience but are very thankful that we all had the pleasure to get to know you over the last few years. Thank you for your decades of care and service to the CF community. Lots of love from Ingrid, Ian, Orson and Harrison.

Jan, in the worst and most stressful moments on our CF journey you were our rock in stormy seas. Your beautiful empathy towards Matt and the efforts you made to reduce his stress and anxiety is so missed. You deserve this retirement, rest well knowing you truly made a huge difference to so many! Rebekah Jessen x

Jan was such an amazing part of my young CF era, she was always so happy and cheerful and made admissions and appointments so much more bearable! I appreciate all that you did for us Jan. Josh Chase



*Will miss Jan so much.  
She made Starship infinitely better.*

All the very best Jan! Thank you for being so helpful when we had to fly up to Starship when our Adalyn was only 3 months for her bronchoscopy. You will be missed by so many. Kayla

I remember Jan for her patience, empathy, and knowledge, which always put me (and fortunately my parents) at ease. She always took the time to communicate everything to us, and helped us through some hugely challenging times throughout my childhood. I spoke to Jan for the first time in years a few months ago at a social event, and she was still on to me about doing my physio. I guess old habits die hard! I wish her the best for her retirement, because God knows she has earned it! – Will Thorrat

I'm lost for words when it comes to my darling Jan, affectionately nick-named JC when I was about 14. It was about the same time that I realised that all the care, love, kindness, and empathy she showed our family... Was the exact care, love, kindness, and empathy she showed every family that was lucky enough to cross paths with her. I'll be forever grateful for Jan's guidance, going above and beyond, her support, and the 236 ways she came up with to help improve my weight. When you're a kid / teen in hospital, you need someone who's got your back. Jan always had my back. Thank you for sticking round til we moved to adults, and thanks for sticking round as a friend and my hero ever since. Love you JC x Lizzie Lou

*We will never forget meeting Jan.  
She was a ray of sunshine on our darkest days.*

Jan, you have been an incredible support to our little family since Alaric was born. We are so thankful to have had you support and guide us even in just a short period of time. We will thoroughly miss seeing you at clinic and being on the end of a phone call or txt. Thank you so much for everything and thanks for being you.

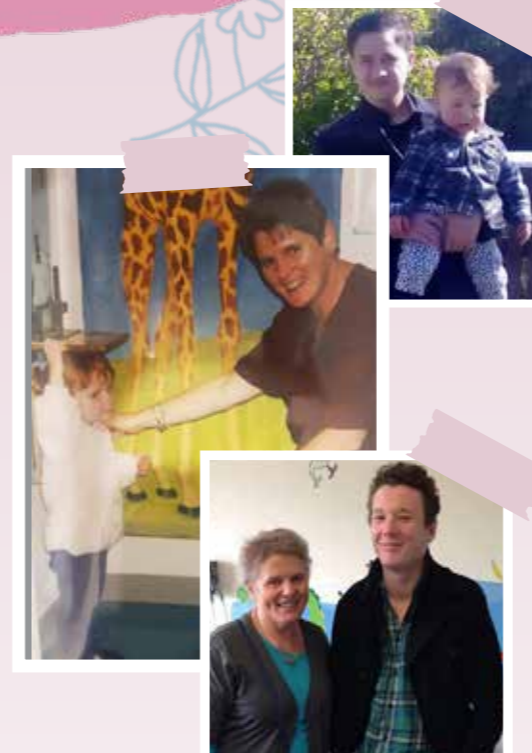
*Jan is a total legend.*

Jan has always been there for me in any time of need. It didn't matter how often or how big the obstacle, when I needed her, she was always there to help. It was magic. Max and the Fawcetts

Jan, from a late diagnosis to leaving Starship you've been there for Sam and our family. You were the calm in the CF storm! You will be missed. Sally Sprosen

Jan was such a friendly face at clinic, she made everything a little less scary for a newly diagnosed seven year old. I'll never forget the extra help she gave with transitioning over to adult clinic, as I was very scared to be losing my CF security blanket, which was Jan. - Jess Scott

Our family is forever in awe of Jan's ability to provide help, advice, calm, and support when, and often before, we needed it. Her CF knowledge and hospital know-how were only surpassed by her humanity. Jan, you are a true friend who happened to be on the DHB payroll. Elliot and I still often ask each other, what would Jan do? Elliot is thriving, and just pipped you to leave after 18 years at Starship, but you were there longer. The things you've seen, culminating in this new era of miracle medication, must be mind boggling. Thank you for being you. We wish you the absolute best retirement. You deserve it. Much love, Elliot and the Blakey family.



## CF IN THE WORKPLACE

Cilla Van Heervan works at Terra Consultants, a land development business that sponsors the CFNZ Mark Ashford Scholarship and a company that once shared a building with CFNZ. She's been there for 16 years and is currently the Administration and Finance Manager. She describes herself as, "A bit of a mother in the company."

Since 2014, she's worked closely with an adult with CF. She knew little about cystic fibrosis when he joined the company so promptly Googled it to find out more.

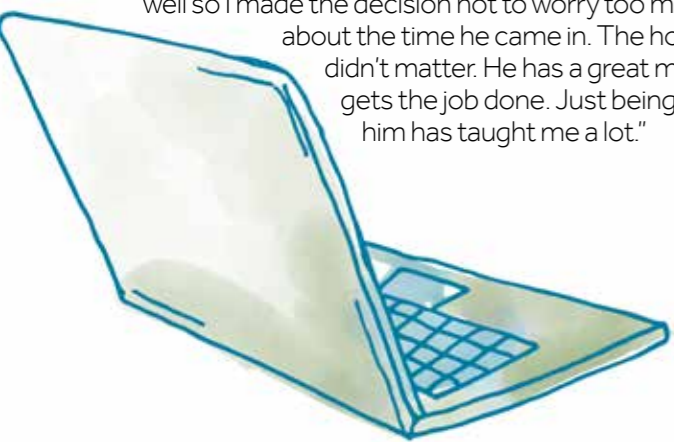
"I really didn't know anything about it. CF didn't even register with me as I didn't know what it meant for his health. Once I knew more it never phased me as an employer as I was interested in his skills but I knew that I would be more attentive to him," she said.

The two have built up a very close relationship over the years that's enabled trust and communication,

"He would always just let me know if he had an appointment and so on and we would adjust work around it. It wasn't a big deal at all."

She saw him as no different from any other staff member but did ensure she offered him flexibility. Cilla said,

"I got to understand CF as I watched him from the sidelines. I knew with his cough he didn't always sleep well so I made the decision not to worry too much about the time he came in. The hours didn't matter. He has a great mind and gets the job done. Just being around him has taught me a lot."



### TRUST, LOYALTY AND RESPECT

By working closely together, the two built a reciprocal loyalty and respect that has made him irreplaceable for Cilla. She said,

"He's an excellent employee. I can't function without him. He's a genius and his mind is brilliant. He's my go-to person, even now we've grown the company. He's still my person that I can not do without."

Their mutual respect means they both have their boundaries,

"I don't pamper him but I don't ignore that he has CF. I am pretty intuitive with people so I just check-in. For me, it's not about the doing, it's the person behind the doing. I watch out for him and he knows he can come to me with any worries. I trust him to do his job."

Over the years she's understood what works best for her team and the business. She said,

"People with CF have enough stress in their lives. They shouldn't always have to tell you if they are late or tired. It's hard enough. I think we should have the freedom to show up as who we are. You can't micromanage that. Kindness and understanding have motivated him more than any other measures could."

### DEALING WITH ABSENCES

Overall, Cilla has found that the person with CF has worked as hard as anyone else in the company. Their strong bond has meant that when he was admitted to hospital for a few months after about two years of working at Terra, Cilla wasn't phased,

"He got ill one winter and was in hospital for a few months. He kept me up to date and we just supported him through his illness that winter. I made sure he was ok and very lenient with his sick leave as it's not his fault that he was absent. He needed to earn something while in the hospital. As an employer, we had the discretion to do that. It was also a fact that in my experience of working with

him, no matter what else he had going on with his health I could always rely on him to be there."

He's actually never had an absence like that since. I think in general he doesn't take all his sick leave compared to some other employees. So, these things balance out."

### SUPPORTING A CF EMPLOYEE

Cilla feels lucky to have got to know an adult with CF. She said,

"I think employers should value the person for who they are and not stress about their underlying condition. They know their bodies and what's best for them. Just keep communication open."

She has always made an effort to be interested in his life and health and ensures she checks in on him regularly.

"I always ask him how he is feeling and if he's looking after himself. In winter I ask what he needs and generally take an interest in him without a hidden agenda with work. I am balanced with our priorities and I don't pamper him — it's tough love sometimes but I am very aware of what he's going through," said Cilla.

### THE POSITIVE IMPACT OF WORKING WITH A PERSON WITH CF

Cilla reflected on the impact of working with a person with CF,

"Even though they have health issues they are the same as any other employee and they need to be valued in the same way. They can fit right in and be as efficient if not more efficient than someone who doesn't have a chronic illness. His skills are what he relies on, not sympathy or special arrangements."

If she was to offer any advice about hiring a person with CF, Cilla thinks you shouldn't worry about it. She said,

"There is a possibility of times that they won't be at their desk so you have to be flexible. But, the value he's added over the years, totally outweighs any absences. He's given me the best service out of all my staff and I think he really values his work and always performs to the best of his ability."

Don't discount people with CF. It's had a profound effect on me personally and professionally. You could be missing out on a brilliant young person that could have a massive impact on your company. My life has been so enriched by having an employee with CF in my life. I will always treasure that," concluded Cilla.

## ON SPONSORING THE MARK ASHFORD SCHOLARSHIP

Terra Consultants have always had a passion to support young people to advance in their studies, so when CFNZ approached Cilla about sponsoring the Mark Ashford scholarship, she was keen straight away.

"I was approached by CFNZ to be a sponsor. It was a no-brainer to say yes. Getting to know a person with CF at work definitely motivated the decision and any chance we can give to help improve the lives of young people with CF then we'll take it. Sometimes companies choose good causes strategically but this was personal for us," she said.

Last Years Recipient was Lily Tew, you can read more about her here



**Thank you Terra**  
for generously sponsoring the 2022 CF Achievers' Awards, helping us celebrate the achievements of our CF community.

**terra**  
consultants

# TRIKAFTA FUNDING approved!

FROM 1 APRIL 2023

4 December 2022, a day we will never forget! Pharmac announced it had reached a provisional agreement to fund Trikafta for people with CF aged six years and over, who are eligible. The joy and relief across the country was immense - the celebrations began!

**Together, WE DID IT!**

## THANK YOU!

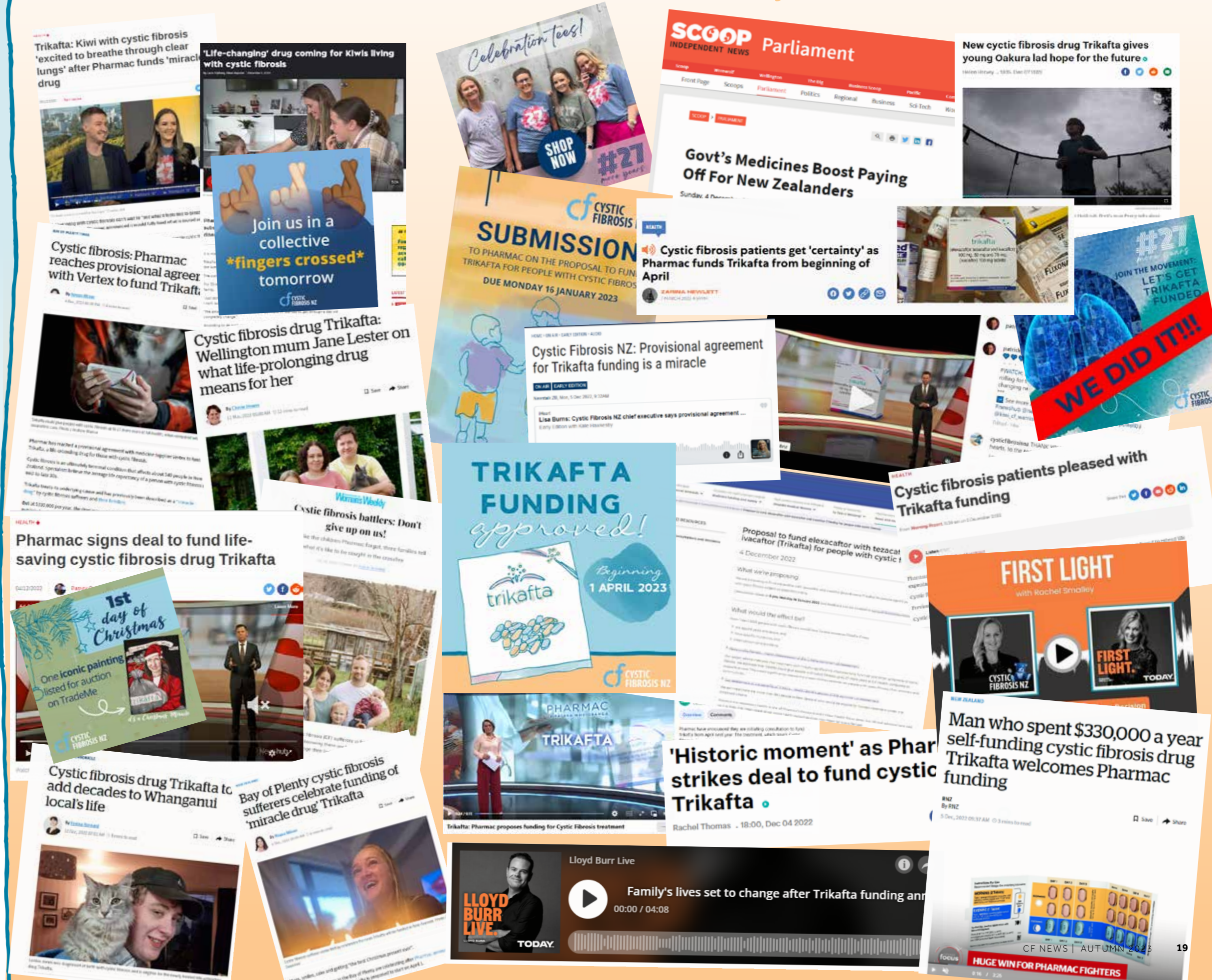
CFNZ extends our heartfelt thanks to the all those who played a role in the lengthy fight to get Trikafta funded; our amazing community of CF families, and extended community of journalists and advocates.

The collective voice of so many people made Trikafta a reality.

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

Lisa Burns, Chief Executive CFNZ

# TRIKAFTA - TOGETHER, WE DID IT!



## *By Starlight*

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

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

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

*The world just outside  
The place where I live  
Feels kind and welcoming  
But also hurried and big*

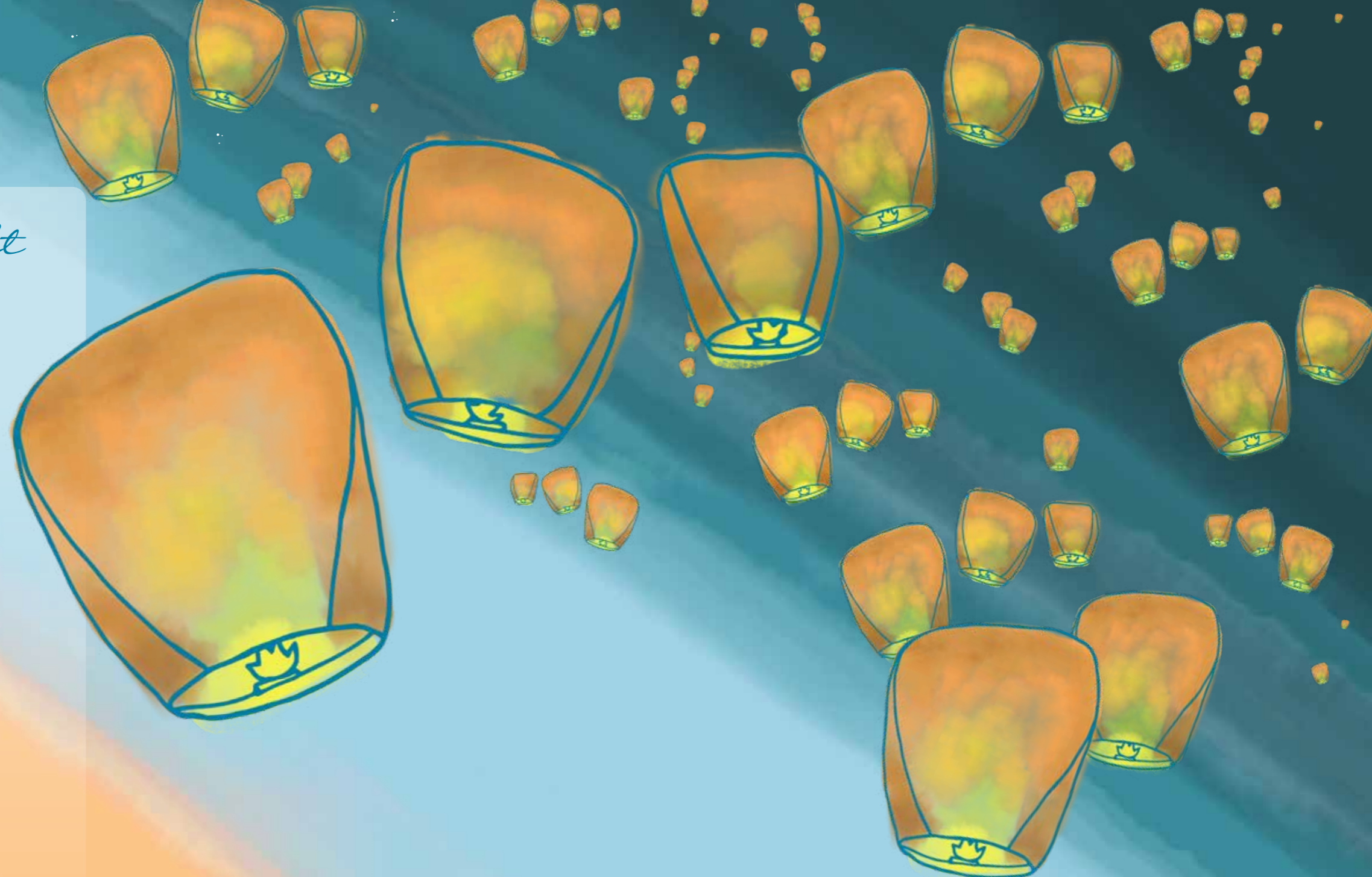
*I smile at strangers  
I meet on the street  
And wonder if they'll  
Ever really understand me*

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

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

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

**Cassie Roma**



## HOLDING ON TO HOPE

A win in the New Zealand cystic fibrosis world is a win for all of us; but as you'll know, Trikafta isn't for everyone, and for some, has come too late.

There are Kiwis with CF who, due to their gene mutation, will not be eligible for Trikafta, those who have had transplants, have liver disease, and other issues who may not be able to take it or see an effect. We want to take this

time to acknowledge them and send aroha to our families whose reality does not change with this announcement. Watching on as a large part of our community celebrates a brighter future, will be bittersweet.

The fight will not stop, and no one will be left behind. CFNZ exists to walk beside our community for life, Trikafta or no Trikafta – we will continue to provide support for quality of life and wellbeing, and as the needs of our community evolve, so do we.

Our community has strength in abundance, and we know that whatever comes next, we have each other, and we hold on to hope always.

To honour this special corner of the community, we asked Cassie Roma, to write a tribute poem. Beautiful words put together, and we know they will resonate with many.



# ADVOCACY

## Access to CFTR Modulator Therapies

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

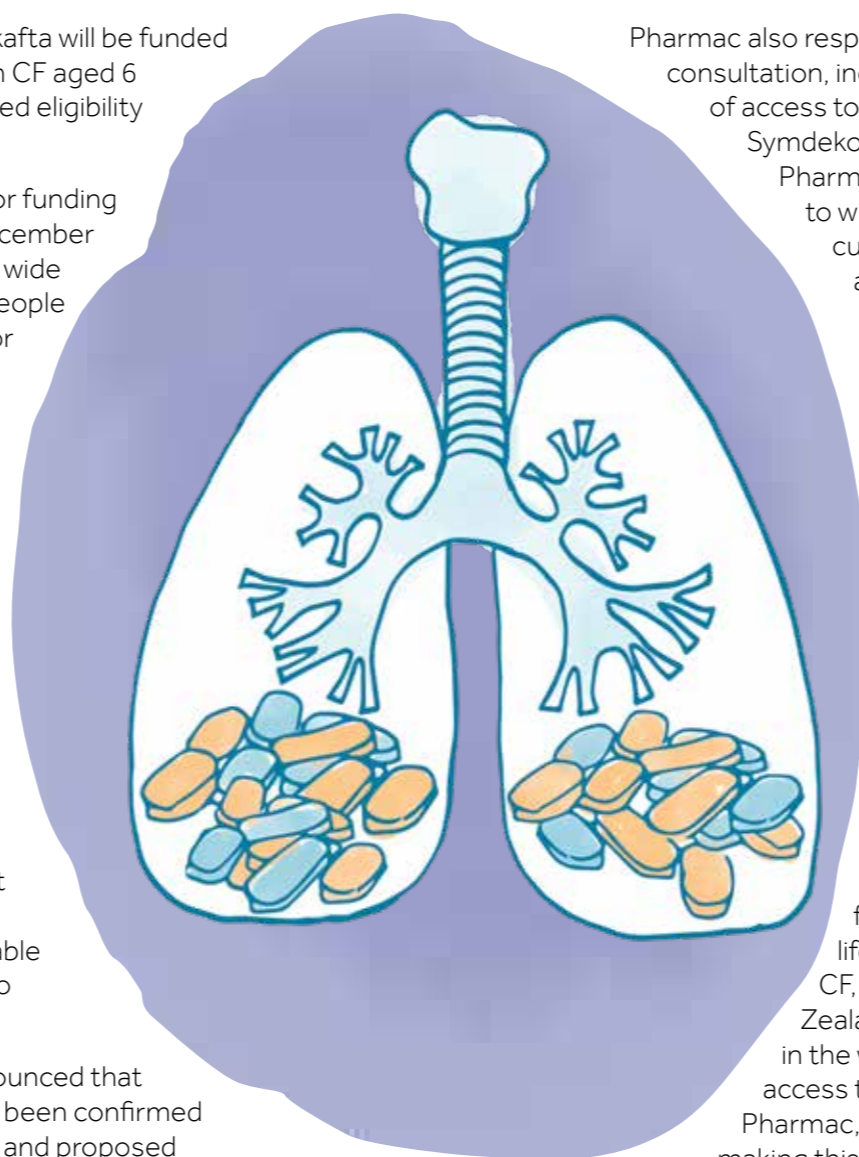
### TRIKAFTA

Pharmac has confirmed that Trikafta will be funded from 1 April 2023 for people with CF aged 6 years and over who meet specified eligibility criteria.

Pharmac released its proposal for funding of Trikafta for consultation in December 2022. The proposal provided for wide eligibility criteria for access for people with CF aged 6 years and over, for those who carry one or more copies of the F508del mutation, those with a G551D mutation, and those with mutations responsive in Trikafta in vitro. Submissions on Pharmac's proposal closed on 16 January 2023.

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

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



Pharmac also responded to the key issues raised in consultation, including the request for widening of access to Kalydeco and provision of Symdeko to be part of the decision.

Pharmac advised that the application to widen access to Kalydeco is currently under assessment and will then be ranked on the Options for Investment list.

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

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



## KALYDECO AND SYMDEKO

CFNZ is however disappointed that the widening of Kalydeco was not part of the Trikafta decision. There was a strong case for this, given Kalydeco is supplied by Vertex, it is already funded for some people with CF, and Pharmac's respiratory experts have recommended a high priority for funding.

While CFNZ is encouraged by Pharmac's acknowledgement that there is a strong desire for all people with CF to have a funded CFTR therapy, there is no indication of when this will happen. We have urged Pharmac to widen access to Kalydeco and provide access to other CFTR therapies to everyone who would benefit as quickly as possible. There is no equity until everyone who could benefit from a CFTR therapy has access to one.

## NEED FOR CHANGE

The funding of Trikafta was achieved due to the tireless advocacy, campaigning, and awareness raising of many people in the CF community, and the courage of those who shared their very personal stories. CFNZ would like to thank everyone who helped to get this momentous decision across the line.

But, in a civilised and humane society, it shouldn't be necessary for the sick and infirm to have to share their suffering publicly to gain access to the medicines they need and deserve. A medicine as effective as Trikafta should have been funded without the need for such extensive public exposure and campaigning.

New Zealand must have a medicines' funding system that is adequately funded, where medicines are treated as an investment not a cost, and where the public parade of suffering plays no part. CFNZ is committed to doing all it can to advocate for change to the current system to make sure this happens.



## Next Steps

We have been working behind the scenes compiling practical information for our CF community about what happens next in the Trikafta rollout.

You can download the Trikafta Next Steps document which includes the following:

- How getting access to Trikafta will work
- Collecting your Trikafta
- Continuing with existing medicines and treatments
- Eligibility criteria
- Rare mutations
- Update about widening of access to Kalydeco, and funding of Symdeko.

Pharmac is pleased to be funding a treatment with the potential to greatly improve the health outcomes of people living with CF, and quality of life for families, and whānau. The feedback they received from the consultation reflected what they had heard from the CF community and clinical advisors when assessing the application for Trikafta. Pharmac acknowledged that they are grateful to those who took the time to provide feedback to the proposal, in particular those who courageously shared their personal stories.

Use the camera on your phone to open the Next Steps document below.



## Other Advocacy Initiatives

### Pharmac Review

Pharmac has released its Final Response to the recommendations of the Pharmac Review.

The Final Report of the independent Pharmac Review Panel was released by the Minister of Health in June 2022. The Panel made 33 recommendations, the bulk of which were accepted by the Government. The Review Panel's Final Report raised serious concerns over the operation of Pharmac and its findings in respect of Pharmac's performance for those with rare disorders was particularly damning. Pharmac released its Interim Response to the Review Panel's findings in September 2022 but that response provided little indication that real action was underway to address the recommendations for change.

Pharmac released its Final Response to the Review in March 2023. CFNZ had hoped that this would provide a clear plan of how and when the Review Panel's recommendations will be implemented. Unfortunately, it does not do so. The Final Response from Pharmac is vague and lacks detail of what will be implemented and when.

In its submission to the Health Select Committee hearing the petition from Carmen Shanks for funding of Trikafta, CFNZ asked that the Committee monitor Pharmac's progress in implementing the recommendations of the Pharmac Review.

The Committee noted in its report on the Trikafta petition that a full implementation plan for the recommendations was expected from Pharmac by October 2022 and that the Committee "looked forward to monitoring its progress."

CFNZ looks forward to the Health Select Committee monitoring Pharmac's progress and holding it accountable for delivery.

### Medicines for paediatric cancer submission

CFNZ wrote a submission in response to Pharmac's consultation on Rule 8.1.b of the Pharmaceutical Schedule. This rule means that any medicine currently used to treat cancer in a paediatric setting is automatically funded without a Pharmac assessment. CFNZ understands that Pharmac is revisiting the rule because concerns have been raised around its fairness when compared to other populations and conditions, and the growth in the costs of new cancer medicines.

With respect to fairness, it is CFNZ's strong view that the only equitable approach is to expand the current arrangements to include other life-threatening and life-limiting conditions, including rare disorders such as cystic fibrosis.

CFNZ strongly objects to amendments to Rule 8.1.b of the Pharmaceutical Schedule that would limit or remove access to paediatric cancer medicines, and strongly supports the expansion of Rule 8.1.b to include other life-threatening and life-limiting conditions, including rare disorders such as cystic fibrosis.



## RARE DISORDERS NZ

The CFNZ team proudly donned our #RareDisordersNZ tattoos, and our CFNZ Lizzie tees to 'glow up and show up' for Rare Disorders Month this March.

It's not rare to have a rare disorder. In Aotearoa, more than 300,000 people live with one of 6,000 rare disorders - that's similar to the population of Wellington.

As it stands in New Zealand, people with rare disorders often feel invisible in our healthcare system. Unlike most OECD countries, we don't have a rare disorder strategy. The CFNZ team stand by Rare Disorders NZ using our collective voices to raise meaningful awareness for rare disorders.

# ADVOCACY TIMELINE

## Access to CFTR Modulator Therapies

### March 2022

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

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

### April 2022

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

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

### June 2022

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

### August 2022

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

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

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

### September 2022

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

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

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

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

### October 2022

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

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

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

### December 2022

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

### January 2023

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

### March 2023

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

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

## Other Advocacy Initiatives

### May 2022

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

### June 2022

The Minister of Health releases the Pharmac Review Panel's Final Report. The Final Report makes 33 recommendations for change and highlights significant problems with the way Pharmac works. These problems include serious deficiencies in its decision-making process and the quality of its decisions, a failure to incorporate the lived experience of patients into decisions about medicines, and a lack of transparency and timeliness. The Final Report also concludes that those with rare disorders are being disproportionately impacted by negative health outcomes and systemic failings.

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

CFNZ writes to the Minister of Health urging him to advise Pharmac that he expects them to give priority to funding medicines for rare disorders in addition to cancer medicines. Other rare disorder organisations write to the Minister supporting this request.

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

### September 2022

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

### March 2023

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

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

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



The arrival of CFTR modulator treatments like Kalydeco and Trikafta have revolutionised CF care around the world.

As some eligible New Zealanders with CF prepare to take their first steps with such treatments, there's a whole new life to now consider. Pharmac's director of operations Lisa Williams estimated that,

*"Trikafta could give people with cystic fibrosis up to 27 more years at full health, when compared with supportive care. This would significantly reduce the impact of the condition on people with cystic fibrosis, their whānau and communities."*

These amazing predictions of 27 more years of health for our community are obviously seen as a blessing but also create new problems. With a longer healthier life comes new opportunities and responsibilities like education, careers, raising a family, buying property, and saving for retirement.

With all this change we want to offer support to our community and encourage them to proactively manage mental health and well-being during these periods of adjustment.

So how do you know if you're just feeling a bit sad or if you are depressed? What level of sadness is 'normal'? How do you work out what's going on when you feel down? What kinds of treatment are available? How do you help a family member or friend who is depressed?

We spoke to clinical psychologist Gwendoline Smith, and our wonderful CFNZ Social Workers to get their advice, expertise, experience, and some practical tips on some fictional CF community scenarios that could affect some of our readers.

## TRIKAFTA AND YOUR WELLBEING

### SCENARIO ONE

Joe is a 25-year-old living with CF, due to his ill health throughout his teens and shortened life expectancy, he hadn't given much thought to long-term career plans. With the prospect of Trikafta, Joe will have many more years of good health and will now need to plan for a healthy, lengthy future he couldn't have anticipated before. Do you have any tips on how to prepare for and care for your well-being during such a huge adjustment?

Joe needs to give himself time to adjust, to accept and sit with the emotions that are present, they are all valid feelings and natural responses. Talking and sharing is great, taking little steps such as thinking "what can I focus on today that makes me feel good, that I struggled with before?"

Anxiety can be a positive motivator! Think about – what is out there for me? What are my interests and what makes me happy? What did I enjoy doing at school?

It's important to remember that many people make career changes later in life and through different life stages.

*"Psychologically faced with such an enormous consideration, would, not surprisingly result in a degree of 'worrying overthinking'. This situation, although life changing in a positive way, will bring with it uncertainty and self-doubt,"* says Gwendoline.

#### Practical tips

- See a life coach, career counsellor or vocational counsellor for practical advice and support
- Consider volunteer work while you are planning and deciding what you might do
- Look at upskilling courses or short courses
- There are bridging courses available for those that did not complete high school
- Consider part time work or work experience to try out different industries

### SCENARIO TWO

In the New York Times article, **What it's like to learn you're going to live longer than expected**, Dr. Cernadas noted,

*"It's a tremendous blessing for many patients, but it can also be a source of anxiety...You had this thought of how your life would play out. It's what you prepared for. But now you're going to live a lot longer. It can be a lot to go through, a lot to process. What are you going to do with that time?"*

Having a chronic condition can start to define someone and result in them spending their life anticipating worsening health and coping with negative change. With the advancement in medicines, which are seen as a symptomatic relief for eligible people with CF, does it become an issue of identity when you are no longer so defined by your illness? Even though it is a positive change, individuals need to find out who they are, if they are no longer a person whose life is ruled by CF. How can someone embrace this sudden change in identity?

It will take time for everyone to navigate their new normal and everyone's experience will be different. Go at your own pace and don't compare yourself to anyone else.

Take time to remind yourself of everything that you are – a brother/sister, a friend, a son/daughter, a basketball player, a swimmer, an animal lover – not just someone with CF.

Plan to make small advances – more physical activity, family outings or push yourself to socialise in a larger group or at places you may not have considered previously.

#### Practical tips

- Planning and journaling can help with anxiety and perspective
- Counselling
- Plan a celebration with friends and family
- Try yoga, meditation or find out more about practicing mindfulness

### SCENARIO THREE

Sarah and James have a 17-year-old daughter with CF called Tess. Due to caring for her daughter, Sarah hasn't been able to hold down employment as Tess is constantly in and out of hospital and has a huge amount of treatment she needs to do each day.

Tess has needed much more support than the average teen, but now that Trikafta is on the horizon, she may not need to depend on Sarah as much, she will hopefully have more energy and fewer hospital admissions.

What advice would you give to parents/caregivers who will now need to take more of a back seat, and allow their children more independence than was previously possible? Is there anything they can do to help them adjust to a new normal, watching their child take on the future?

An unexpected flow on effect for one family was that when their child had been on Trikafta for a while they found it difficult to sleep – they were used to waking to their child's coughing and now it was too quiet!

*"A vigilance and fear-based hypersensitivity will have developed over the years leaving them feeling constantly on the edge, listening and observing, waiting for change for the worst. Sleep is understandably often disturbed and poor sleep patterns become the norm,"* says Gwendoline.

For parents of children with CF it may help to think about how growing up was for you NOT living with a chronic condition and the anxiety and fear, check ups and treatments that go with it. This is what you want for your children - to live a normal life participating in activities with their peers, developing independence and exploring the world and their options. It hasn't been their normal before, but it can be now and that is a wonderful thing for them, and for you.

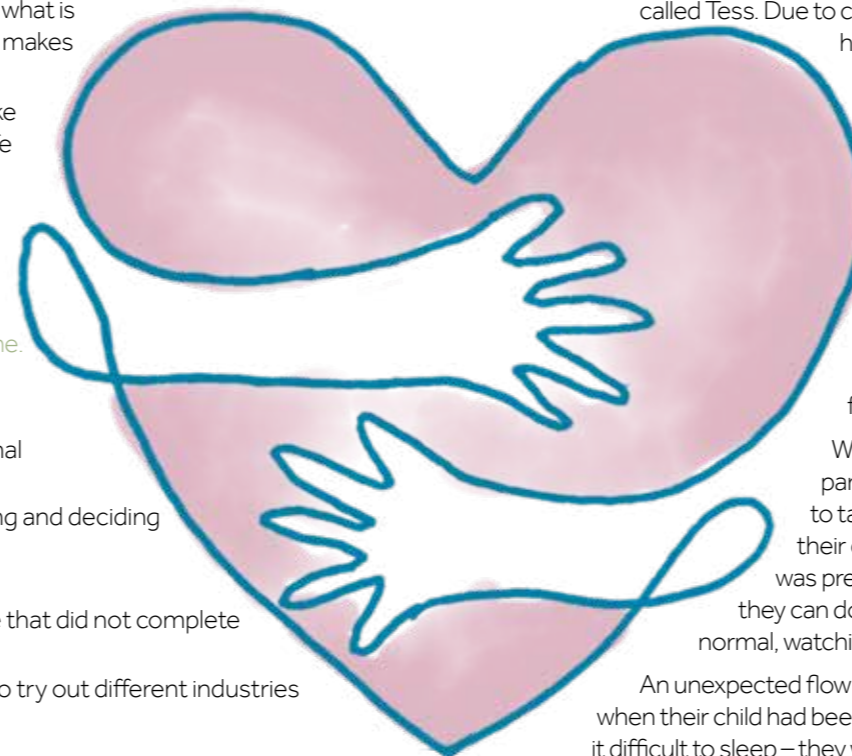
However it does mean your parenting skills and boundaries for your child will need to change. Parenting courses may be helpful here, and you can also talk with your child, depending on their age, about what you can do as a parent and where they want or need parental input compared with how you used to do things.

It is a big change going to a caregiving parent to just being a normal mum or dad! Take time to remind yourself what life would have been like without CF. Are there things that you would have done with your career or spare time if you could have? Can you do them now? Remember that it is okay to take the time to focus a bit more on yourself and your needs and wellbeing now.

#### Practical Tips

- Utilise school and career counsellors
- Parenting courses
- Support groups
- Talk to your child about how your parenting could change with this adjustment
- Gratitude journals
- Re-explore the things that you used to love doing but haven't had time for in recent years

Remember that our social workers are always available to provide support and advice throughout this period of adjustment, they are just a phone call away.



Gwendoline Smith uses her broad scientific knowledge and experience to explain in clear and simple language what's going on when you are feeling overwhelmed, anxious and confused. Originally aimed at young people, these books work for anyone because it helps you work out what is going on in your mind and how you can take control of your feelings. It's relevant whether you have a diagnosed condition or whether you are just experiencing life as too difficult right now.





# MAKE A BIGGER IMPACT THIS WINTER

Winter can be an even more challenging time for people with CF, your support can make a world of difference.



**\$25**

will cover the cost of the increased prescriptions that winter can bring.



**\$50**

will help pay for parking during an extended hospital stay.



**\$100**

towards groceries can make a huge difference to a family during winter.



**\$300**

will provide a load of firewood to keep a CF family warm this winter.

Your kindness means CFNZ can walk beside every family with CF, so that they can be supported for life.

## 4 EASY WAYS TO HELP US MAKE A DIFFERENCE

**DONATE NOW**



### PHONE

0800 651 122 to make a secure credit card donation



### ONLINE

at [www.cfnz.org.nz](http://www.cfnz.org.nz)



### INTERNET BANKING

Account: 12-3147-0230576-00



### SCAN OUR QR CODE

with your phone camera

