CF News

SUMMER 2022

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CYSTIC FIBROSIS NZ

Cover Artwork by Helen Williamson, member of our CF community, for our Art for Purpose project. This painting is based on the analogy that CF (or caring for someone with CF) is like trying to swim in a stormy sea- constantly being hit with waves and taking on water. The clear sky represents hope for a calmer future, clear breaths, and an endless horizon.

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

Writer of Sophia, Lily, and Sam's articles, Ingrid Grenar, member of our CF community.

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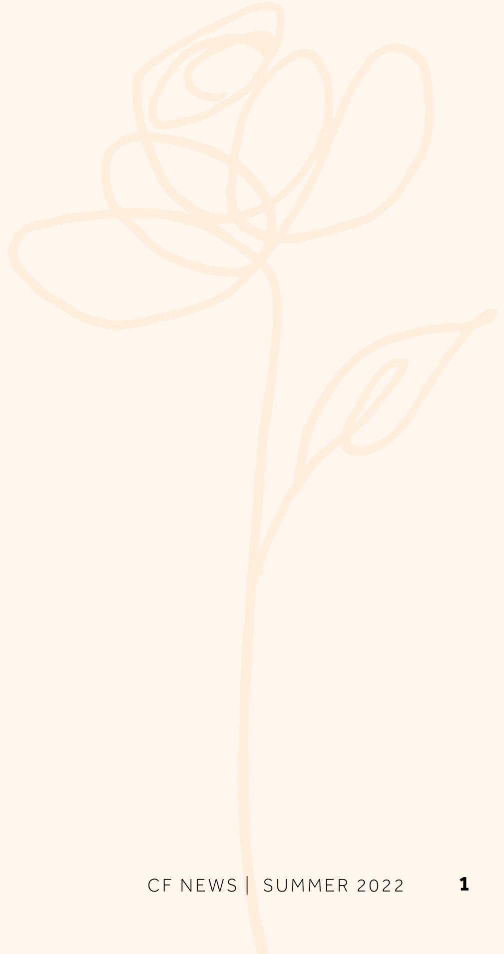


A NOTE FROM LISA

2022 has been another crazy year for everyone, a year of ups and downs with all that's been going on and I understand that the uncertainty will at times have made our community feel a little out of whack, particularly around our ongoing fight for Trikafta.

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

I don't have all the answers for what the future holds, but I want you to know that we're here and we're riding this right there with you. We will not give up! Pharmac gave us the gift of the 27 more years in August, and we will continue to use this powerful message in our advocacy work to fight for what is fair. I would encourage everyone to use our tools available to ensure our voice is loud and cannot be ignored.

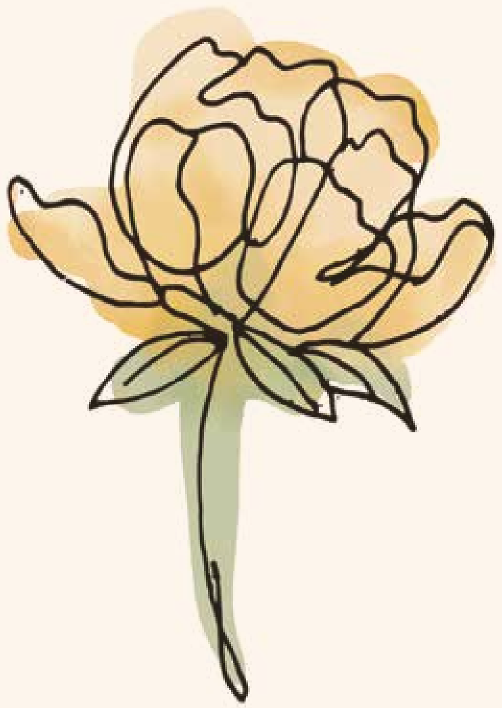
Behind the scenes, we've been head down, working hard to make sure we are listening to you and hearing your feedback and needs. As a team we have been reviewing the current experiences of our community, digging deep to understand the pain points and opportunities of how we can keep improving our support programmes for you. We're excited to be exploring a number of ideas that we hope to share with you in 2023.

Against some hefty competition, **Cruel Needs Kind** successfully helped CFNZ raise both its profile and funds, elevating our messages and awareness to a much broader audience. This campaign also delivered our new proxy for kindness, FRED Bear who has become an important identity for us and created a voice to share our messages. We are in awe of the talent in our community, who created inspired works of art through their interpretations of **Cruel Needs Kind**, and the picture on the front cover paints a thousand words. Thank you Helen for letting us share your work.

I am grateful for so many reasons as 2022 comes to an end. I've seen the kindness we're all showing to each other, and it warms my heart that I've experienced our community navigate a challenging path, but pull together to support each other through tough times and celebrate the good times. Our CF Achievers and Mark Ashford Scholarship recipients shared on pages 4-9 demonstrate resilience and determination, and we celebrate their achievements with them.

I want to say thank you to our community, our families, and whānau, all our supporters and partners. Collectively you've significantly impacted on the outcomes we have achieved this year, by sharing your stories and experiences, getting sweaty for CF during Sweatember, sharing our campaigns, buying our merch, and helping to lift the awareness of CF to new heights. I have been told many times this year that the awareness of CF and the understanding of the condition has increased considerably, and that wouldn't have been possible without your support and courage.

Cheers to you! Enjoy the holiday period, stay safe and if you need any support during this time know we'll be here when you need us.



Lisa Burns
Chief Executive

MEET OUR NEW TEAM MEMBERS

Bev Darlow – Community Support Lead, Central North Island

Who has been your greatest source of inspiration?
Family! My Dad has always showed me how to face my fears and challenge myself, my children have inspired me to be the best mom, and that they are also not afraid of challenge and change. And my husband who has been my strength when I have taken on some huge challenges and changes in life.

What songs would make the movie soundtrack to your life?
Happy by Pharell Williams, Chariots of Fire by Vangelis and Let it go, by Idina Menzel. Life is too short for unnecessary issues so let them go, and deal with things that we have control over.

What drew you to CFNZ?
The people and the cause. Understanding the challenges that families are facing and to know that I might have the skills to make someone's day a little brighter.

Carolyn Downer – Community Support Lead, Wellington and Hawkes Bay

If you could convince the world that you came up with one famous quote, which would you choose?
"He aha te mea nui te ao? He tangata he tangata he tangata! What is the most important thing in the world? It is people it is people it is people" a famous Maori proverb.

What energises you at work?
As a social worker I am privileged to work alongside families and share their journeys. This encourages me to do my best to support them to live their lives as best as they can.

You are happiest when...
I am walking along the beach. I love the sand under my feet, the rocks that have been shaped by the waves, the smell of seaweed, the driftwood, and the seashells.

Nikki Purvis Schischka – Marketing Manager

What has been your greatest source of inspiration?
My two children, they inspire me to be kinder, more patient and to find happiness and excitement in the little things.

You are happiest when?
Being at the beach, camping with my family – it always takes a bit of time to switch off but being that close to nature fills my cup.

What is the coolest place you have visited?
Cinque Terra, Italy – the seaside and Italian food, what more could you ask for?

Maree Cotter – Fundraising and Development Manager

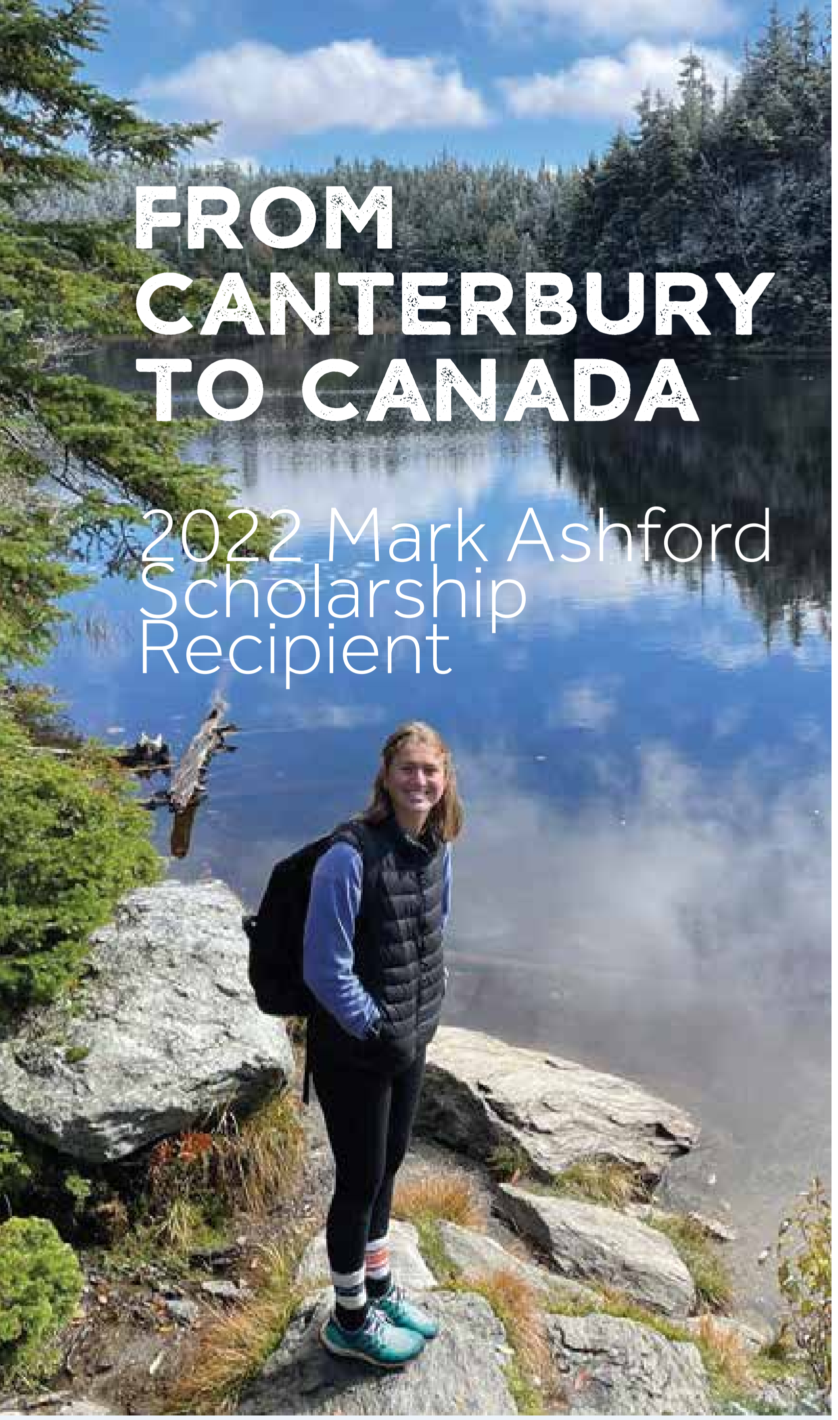
Who has been your greatest source of inspiration?
My father and his work ethic.

What energises you at work?
The culture of the people.

You are happiest when...
I'm in the garden.

FROM CANTERBURY TO CANADA

2022 Mark Ashford Scholarship Recipient



Law graduate Lily Tew is the deserving recipient of the CFNZ Mark Ashford Scholarship for 2022. The Christchurch-born Wellington-raised 23-year-old is currently living in a van while she travels the East Coast of the US during her OE to Canada, where she's been working as a ski instructor.

Lily found out she had won the scholarship in an email from CFNZ's Lisa Burns,

"I am so grateful and honoured to have won this scholarship. There were a bunch of amazing applicants so it's crazy to be chosen. I am so happy and thankful," she said.

DECIDING TO APPLY

Lily had initially been unsure whether she should apply or if she even deserved to be in the running. Lily recalled why she eventually did,

"I remember having a conversation with mum about it a few years ago. I brushed it off a bit. But then I saw an interview with the previous winner pop up on Facebook. I thought yes, I do have a degree and now my ski qualifications too so that's pretty cool I think when you have CF. We often just get on with things with CF but actually, it is a factor in my life and I've still achieved these things."

Upon hearing the good news, she couldn't have been happier but was sad not to be able to share it with her family in person.

"I couldn't believe it when I got the email! I had to wait to let my parents know due to the time difference. When my dad woke up he called and they were so excited for me. It was a shame I wasn't with them to celebrate," said Lily.

Lily spent five years at The University of Canterbury completing her double degree in Law and Arts. During that time, she interned at the prestigious law firm Bell Gully which later offered her a graduate job. She said,

"I was extremely proud of my degree and being offered the chance to work for Bell Gully. I enjoyed my time there and it made me keen to pursue law. It's very competitive so it was great to get that offer."

A CHANGE IN DIRECTION

Lily isn't one to stand still for long and her itch to travel needed to be scratched. The pandemic meant Lily was unable to do a university exchange abroad so even though the borders were still shut she didn't want to miss out. Lily said,

"I shyly asked if I could defer my job's start date. Then I applied for my visa to Canada and got my ski instructor level 1 certification. I got a job at Mt Norquay Banff National Park in Alberta and left two weeks after my final exam.

I was moving to the other side of the world with CF during a pandemic and to not use my law degree - but I felt I just had to go. I was pretty healthy so I thought if I don't do it now when would I do it?"

Once she arrived in Canada she knew it was the right choice. She said,

"It was amazing immediately and I met some great people. It's been such a brilliant experience. I wouldn't change a thing."

Lily wasn't letting CF hold her back so her achievements as a ski instructor were another aspect she highlighted in her scholarship application. Lily said,

"Ski instructing is very physical. It's hard work being out in the cold all day. For someone with CF who wasn't on Trikafta, it meant I had a constant cough and was still doing my meds every day. I was proud to be working in that job at 23 living with CF."

TRIKAFTA CHANGED EVERYTHING

Lily was proactive and booked a GP appointment within three weeks of arriving in Canada and applied for an Alberta Health Card so she could attend clinics and access medications. She had been completely ignorant to the fact that Canada had recently started funding Trikafta and now it looked like she would qualify to get it! She recalled,

"I went to a clinic appointment at the end of January where they said we'll get you on Trikafta. I simply had to sign up for a special type of health insurance that costs about $60 per month and they needed proof of my mutations. After I'd provided those, I received Trikafta on the 3rd of March."

This was a total surprise but a very welcome one,

> *"We often just get on with things with CF but actually, it is a factor in my life and I've still achieved these things."*

"I never came here for Trikafta so it was so good to have it. I felt better within 24 hours. My lung function improved by 20% in the first few weeks. I am off my meds now except for Trikafta and Creon and I've not had any antibiotics since I started taking it," she said.

Lily's life has completely changed and she's living with more freedom and without the need for multiple treatments a day.

"I feel so good - a million bucks better. I always thought I was healthy and active, but now on Trikafta, I can't believe how much better I am. I can ski the whole ski run without coughing and I wouldn't be able to do the van trip without it. My cough has gone completely and I've had covid a few times but I recovered like anyone else. I would have been way sicker with covid without Trikafta," said Lily.

Canada had only had Trikafta funded for five months when Lily got there but the benefits to the health system were easy to see.

"When I got to the clinic, they told me almost immediately they went from having 13 people in hospital every month to one every few months. It had such a big impact. It changes your life. I can look to the future. I am healthy and like everyone else. We need it in NZ as not everyone is healthy enough to make the move to another country to try and get it," she said.

CF SHOULDN'T STOP YOU TRAVELING

Her experience in Canada has been a game-changer for Lily and she thinks CF shouldn't stop you from experiencing new things,

"If you are well enough, don't be scared to travel. It's the best decision I've ever made for myself. Just don't go somewhere and forget you have CF. Get health insurance and sign up for local CF clinics if you can. Remember this is a factor in your life and you need to take responsibility for it."

Lily isn't sure what her plans are but more travel is on the cards. It's hard for her to return home for good without risking her health. She said,

"I am not sure what my future plans are but Trikafta is more important than anything to me right now so I may go to the UK and travel more. I am sending lots of love to NZ as I miss everyone. I would love to come back but the thought of coming off Trikafta is not something I could consider doing."

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

terra
consultants

MARK ASHFORD SCHOLARSHIP RUNNERS UP

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

JAKE GAWN

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

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

ANGUS DRUMM

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

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

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

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

FASHION FOR PURPOSE

Flaxbloom produce clothes from ethically sourced, natural fibres. With no prior knowledge of retail, running a small business, or clothing manufacturing,

Sue had to learn quickly! She found small workshops both here and in Indonesia, that she could be confident they treated their workers fairly and ethically.

Producing ethically was important as was being part of a community. We've given beautiful clothing to community organisations and support various community groups, both in New Zealand and in Bali, where much of the clothing is produced.

Meet the owner

Sue has a background in nursing and nursing education, but due to her own health issues, she began to look down a totally different avenue for work. Sue was determined to create products she could be proud of, which was when Flaxbloom came to life.

Ponsonby Central Pop-up shop

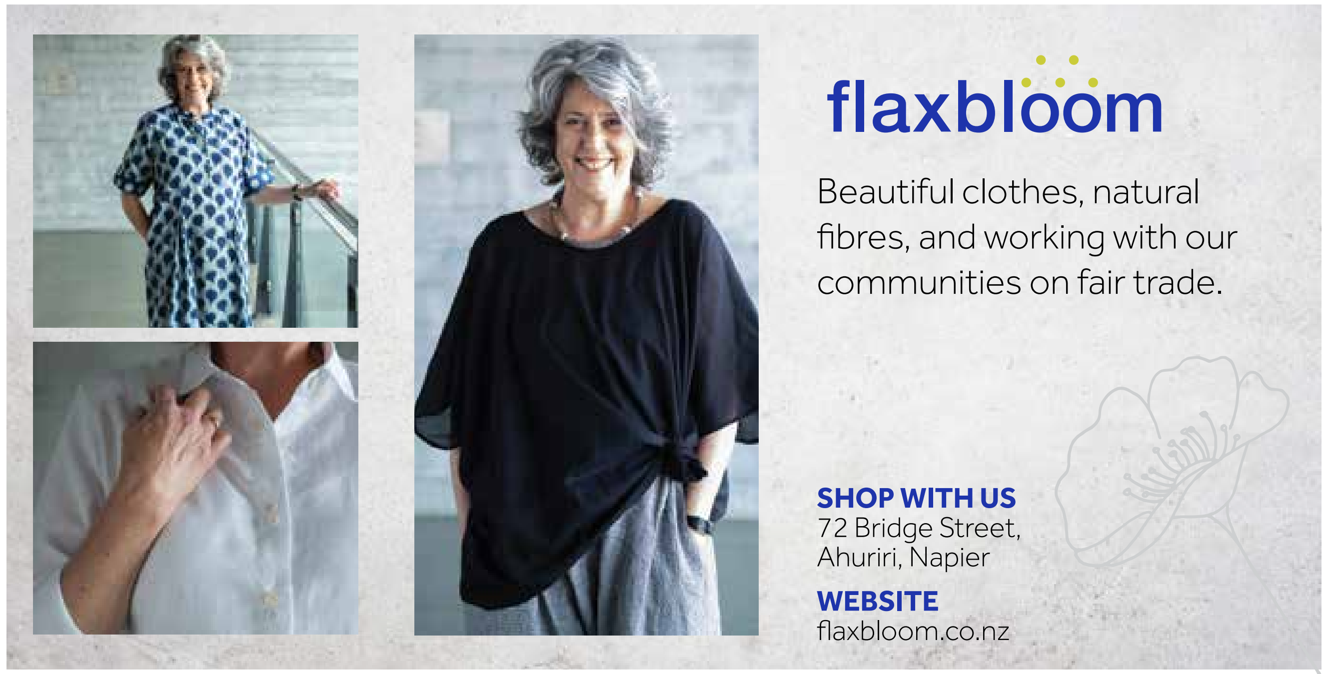
From the 20 June – 3 July, we took over one of the empty spaces at Ponsonby Central, and held a collaborative pop-up shop with the wonderful Flaxbloom.

For those two weeks, Sue, Flaxbloom owner, made a Deliberate Act of Kindness, donating 50% of all sales to CFNZ. Some of our team and volunteers from the community worked alongside her across the fortnight and truly loved, and believed in what Sue and Flaxbloom were doing to support our CF community.

Flaxbloom X Cystic Fibrosis NZ collab pop-up-shop!

"A friend put me in touch with Cystic Fibrosis NZ as a potential partner to fundraising for, and it's been one of the highlights of my journey with the business.

What a community! I met so many parents, friends and people who live with CF. It was humbling, exciting and so inspirational. Our pop-up store was so much fun and the support I got from the staff and friends of CFNZ was truly wonderful. I hope to repeat the event next year with more beautiful clothes."



flaxbloom

Beautiful clothes, natural fibres, and working with our communities on fair trade.

SHOP WITH US
72 Bridge Street,
Ahuriri, Napier

WEBSITE
flaxbloom.co.nz

CF ACHIEVERS' AWARD RECIPIENTS 2022

The Cystic Fibrosis Achievers' Awards are awarded annually to people with CF who have achieved excellence in any of four categories; leadership, the arts, sports or education. This year five individuals with CF have been recognised for their optimism, perseverance, and achievement in their chosen category.

JAMIE MCCARDLE - SPORT

Jamie is 18 years old and comes from Tauranga.

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

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

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

JOSHUA CHASE - EDUCATION

Joshua is 29 years old and comes from Auckland.

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

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

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

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

VIATRIS | Mylan+Upjohn

SOPHIE CARR - LEADERSHIP

Sophie is 27 years old and comes from Auckland.

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

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

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

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

LEAH-MAY ELLIOTT - SPORT

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

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

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

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

ZANYA COLLINS - SPORT

Zanya is 16 years old from Pukekawa, and has played representative netball in all age groups.

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

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

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

THE HAMILTON NINE-YEAR-OLD TAKING IT ALL IN HER STRIDE

Helen and Stuart Ulyatt and their two girls Amelia and Sophia live on the outskirts of Hamilton in a close-knit rural community.

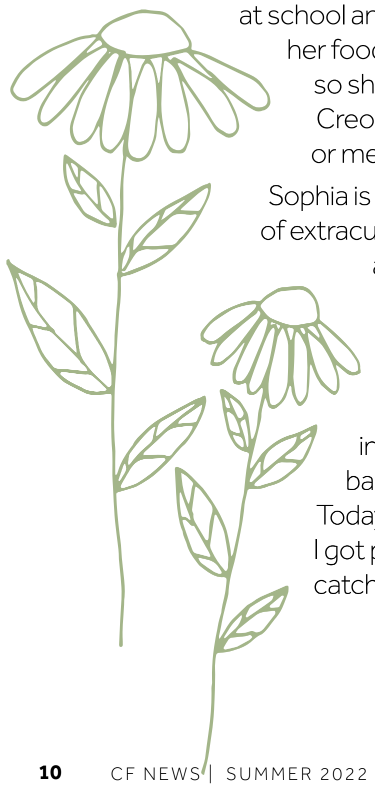
Nine-year-old Sophia has cystic fibrosis but she's not letting it hold her back from playing multiple sports, singing, dancing, or taking part in school camps.

If you think you recognise Sophia from somewhere you'd be right. She starred in the CFNZ video on starting school when she was five. Now, she's well and truly settled at school and has a lot to update us on.

SCHOOL LIFE WITH CF

Mum Helen, who also works as a teacher aide at the school, says Sophia is getting more independent by the day,

"When she first started she couldn't swallow her Creon so we had to open the capsule and sprinkle it into yoghurt. She's now managing it herself at school and as she's on a high-fat diet her food is all packaged up separately so she can calculate how much Creon she needs with each snack or meal."



Sophia is very active and does lots of extracurricular activities like netball and hockey in winter and now cricket and her new favourite, t-ball.

"I really like t-ball as everybody likes to take part in it and I like running around the bases and getting a home run. Today I got around the bases twice. I got people out as I managed to catch the throw," said Sophia.

A STARRING ROLE

But outside of sports she also does ballet and musicals. This year she was the sidekick in the school production of the comical musical The Amazing Adventures of Superstan by Craig Hawes. Helen recalls,

"They usually have year sixes as the main roles but she auditioned as a year five and got one of the major roles as Stans's best friend. She had to learn around 50 lines, sing two solos and dance. She was great and I was so impressed."

Sophie remembers the production fondly too, adding,

> "It was really fun as you get to know the others in the cast and I definitely made friends with some of them. I liked all the jokes in the production. It's funny being funny."

However, it took her lots of practice to get the confidence to proudly perform in front of a full audience.

"We knew she could sing but it took a while for her to get the confidence to sing in front of the whole school. After practicing and working hard, once she sang into the microphone she just went with it," said Helen.

Sophia used a few techniques to combat her nerves. She said,

"I got used to singing in front of everyone. I ended up holding a special key chain that I held in rehearsals that made me not as scared."

It's a lot for a nine-year-old but Helen knew she could do it. Sophia's tenacity hasn't wavered as she's proved this year, so it takes a lot of fuel to keep her going.

"We always make sure she has lots of water and Fortini Chocolate for morning and afternoon tea to give her a boost," said Helen.

So, although her parents were very vigilant in ensuring she looked after herself they weren't going to stop her from getting involved in the show. And a good thing too, as she received rave reviews from her CF nurse Dee, classmates, parents and teachers.

"A teacher walked past and just said, I love your singing," recalled Sophia.

AN ADVENTUROUS CAMP EXPERIENCE

As well as having a full school and sports schedule, Sophia also recently went to camp. She said,

"I liked everything about it. We did lots of different activities like frisbee, archery, paintball, axe throwing, BMX, kayaking, and low ropes. Kayaking was my favourite. I had never done it before but I was the only one who didn't fall in."

If you think that was enough adventuring for Sophia, she also had a run-in with a rogue raft,

"My group was purple so we were called the lavender grapes. We had to build a raft with only three tire tubes, string, rope and bamboo to take eight kids and one adult. I jumped off the raft into the water as it went in the wrong direction," said Sophia.

ORGANISATION IS KEY FOR PARENTS

While it's lots of fun for Sophia to go to camp, it's a lot of preparation and organisation for mum Helen.

"I take lots of extra food. It's hard as we have no idea what's in the food provided at camp to calculate Creon so it's easier for me to bring some. I also needed to get that extra food in her as she was running around all day. I was making sure windows were open to keep healthy ventilation in the dorm. I was sneakingly sanitising door handles. That was the first time she's been in a room overnight with other people so it was a bit nerve-wracking," she said.

Sophia mainly remembered it being hard to sleep due to," ... sleep talking and snoring."

But managing CF in a new environment brings new challenges. Helen learnt from a previous experience what to prioritise,

"Last year at camp it was stressful and exhausting for me to carry around her nebuliser stuff and sterilise everything. This year we decided we wouldn't do it so we had one day off and just put extra treatments in at different times. But, with all the exercise she was getting, that was probably a good substitute for the physio."

The family feel they've been quite lucky with Sophia's CF and they've not had an admission for a few years so felt comfortable she could go to camp without it affecting her health.

"If she'd been growing something or had a cough she wouldn't have gone," said Helen.

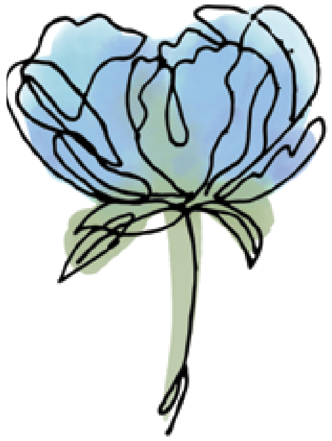
AN EXPERT JUGGLER

Helen juggles a lot between her kids, work and involvement in the PTA and school board,

"I am quite an organised person. People ask me how do you do all that. But you just do. I take the burden on my shoulders so she doesn't need to. It's about being organised and wanting her to be as normal as possible. She goes through all the same things as any kid does," she said.

Sophia was born in England which is where Helen grew up but they chose to move to New Zealand to give her the best life. They love their home in Hamilton but are sad that Trikafta is now available in the UK but still not funded here in NZ.

"I still think New Zealand is the best place for the girls to grow up. But if her lungs or liver gets damaged, then we'll have to go back to the UK as we won't have a choice. She's our priority. Life doesn't always go to plan but we just go with it and I wouldn't change it for the world," said Helen.



cruelneedskind

Me noho noho ao kia noho humarie

For CF Awareness Month in May, Cystic Fibrosis NZ launched a new campaign inspired by three simple yet powerful words, **Cruel Needs Kind**.

Momentum had steadily been building since February when the very disappointing November PTAC minutes about Trikafta were released. Following this announcement, many CF stories were shared across multiple media channels, which heightened the awareness of both the cruel reality of CF, and the desperate need for public funding of Trikafta in Aotearoa. We had a once in a lifetime opportunity to ensure our voice was heard, and that it had the greatest impact.

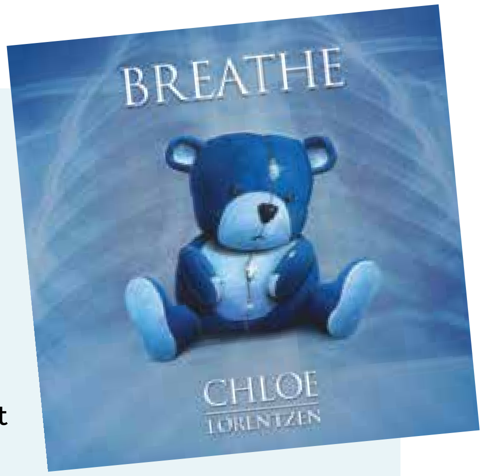
The unfairness from both the genetic 'cruel twist of fate' that brings CF to new-born life, and lack of funding of the "wonder drug" Trikafta in Aotearoa, inspired the campaign, created as a collaboration between Energi Advertising and Andy Lish (Lishy) for CFNZ.

The Deliberate Acts of Kindness movement

With the theme in mind, and knowing CFNZ didn't have the resources to deliver this size campaign, our friends at Energi sought 'Deliberate Acts of Kindness' from their industry partners to bring **Cruel Needs kind** to life. We were absolutely blown away: Simon Mark-Brown of Republic films directed and produced a TV commercial (TVC), written by Andy Lish, and between TVNZ, NZME, Mediaworks, and LUMO Outdoor, we had the TVC and radio ad played across the country, and billboards all over Auckland for the month of May. The media coverage **Cruel Needs Kind** received thanks to these generous partners couldn't have been more valuable! We asked the general public to make a Deliberate Act of Kindness to support our CF community, by making a donation, purchasing merch, selling Chocky Fish (832 boxes!), and we ended the month on a high with Deliberate Acts of Kindness Day, celebrated on the 27th of May.

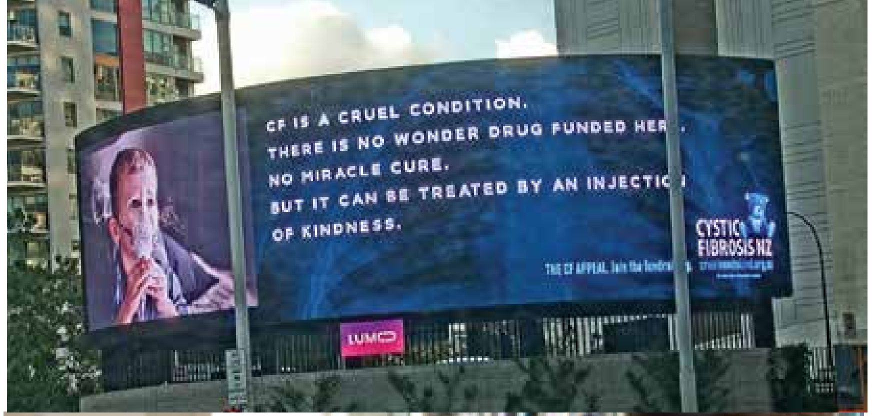
Introducing FRED Bear

Lishy became the father of FRED Bear – CFNZ's new proxy for kindness. FRED Bear began his humble beginnings as an idea in Lishy's head, to a painting on a canvas, to a real-life teddy, thanks to world renown teddy bear maker, Heather Lyell, from D'Lyell Bears. FRED was a hit - shared all over social media, got a spot on the couch on TVNZ's Breakfast, hit the radio waves with Flynny and Jayjay, and continues to join the homes of many families around New Zealand.



BREATHE

The story captured the attention of a young singer songwriter whose star is ascending. Based in the UK Chloe Lorentzen felt compelled to create a song to encompass the cruelty at an intimacy level of parent and child. Age 17, Chloe created BREATHE, an anthem that will endure fad and fashion, it is a love song. Written in her bedroom, then produced at the Abbey Rd studios in London within five days, BREATHE became the heart of the campaign, played in the background of the TVC. Chloe has gifted the lion's share of the global broadcast rights to CFNZ in perpetuity. Limited edition vinyls of BREATHE were pressed and can be purchased from cruelneedskind.org.nz



Thank you!

The gratitude we have for all who contributed to raising awareness, funds, and bringing Cruel Needs Kind to life knows no bounds!

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

PARTNERS AND COMMUNITY SUPPORTERS

Our biggest thanks to the organisations who continue to support the work we do and to help us achieve our vision of lives unlimited by cystic fibrosis.

ANDY LISH
Lishy
energi
LUMO
flaxbloom
NZME. NEW ZEALAND MEDIA AND ENTERTAINMENT
MEDIAWORKS
SCG CREATIVE. CONTENT. PRINT.
KALEIDOSCOPE EST. 1992
REPUBLIC FILMS
tvnz Te Reo Tātaki
pead.
KALEPRINT

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

Lily turned one in September.

Natalie had her first week of kindy visits!

Tailen officially started school this term on half days. He has made heaps of friends!

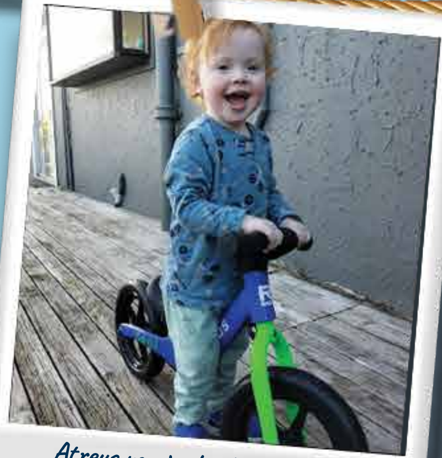
11 year old Max never fails to amaze! He decided to learn the bagpipes and can play Amazing Grace.

Oscar loving his first time at the beach.

Orson can't get enough of FRED Bear!

Honor turned four! With a cake fit for a princess after 3 nights in hospital.

Alex and Matt finally got engaged, in Monopoli, Italy, of all places!



Atreus received a bike from the good people at Fonterra! Grateful!

Georgia celebrated her 2nd birthday!

Adrian playing a gig with his band for the first time in 2 years.

Lizzie loves her niece Harriet as much as Harriet loves bread.

ART FOR PURPOSE

In May we put the call out to our wonderful community and all of our connections to participate in a Deliberate Act of Kindness.

We asked people to get creative to help us raise funds. The brief was to create an artwork that depicted their interpretation of **Cruel Needs Kind** on canvas. We sent out 25 canvasses donated by the wonderful Hadleigh from Blank Inspiration, an amazing deliberate act of kindness in itself!

In 2023 we will auction the completed artworks to raise funds to continue to do the work that we do. We have been absolutely blown away by the stunning artwork that has been returned to us, there are some amazingly talented and creative people in our community, thank you to every single one of you have has been involved in this campaign. We wanted to give you a small sneak peek of some of the incredible artworks that will be auctioned off. Please stay tuned for more details about when the auction will be held.

ALICE MUIR

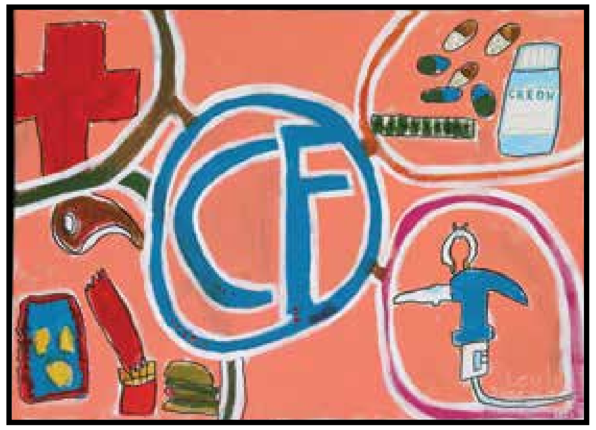
Aptly titled "It's a Christmas Miracle Drug!" Alice aimed to make light of a very serious situation, with the hope it would draw attention and change. With Alice's blessing, CFNZ turned this painting into an advocacy piece – a card to send to your local MP, the Ministers of Health, and Finance, the Prime Minister, and Pharmac.

JAMES HUNT

"This painting was a continuation of a series of works featuring an alien centaur except this time I was guided and inspired by the Cruel Needs Kind motto."

MORRISON

A friend of FRED Bear's Dad, Lishy, was inspired by the original painting of FRED Bear and his take on Cruel Needs Kind.



LEYLA

"My painting is to give an idea of what people with cystic fibrosis have to do every day. It's a lot."

Our heartfelt thanks to Hadleigh from Blank Inspiration for providing canvases and an opportunity for our CF community to get creative!

www.blankinspiration.com

ROBERT

A member of the CF community with a talent and passion for tattoo art created this beautiful piece.

JASMINE GIBBES

"The hearts represent people and how we are all so different and unique but we all deserve love."

SARAH STANLEY

"This teddy bear painting represents... Hope for a better and brighter future for tomorrow."

JAISON O'CONNOR

"Expression of a cystic fibrosis journey as a dad, creating a visible feeling of what it feels inside to the outside world.

Anxiety caused by no straight direction, sunshine and stormy experiences with learning to engage life by floating with the CF journey."

MANAGED ACCESS TO TRIKAFTA PUTS LIFE BACK ON TRACK

Sam Churton is a 28-year-old with CF who lives in Christchurch. His life has changed dramatically since he was put on Vertex's Managed Access Programme, giving him access to the miracle drug Trikafta a few months ago.

Sam has worked for the Salvation Army in Kaiapoi for almost four years. It's a job he loves but this year his health deteriorated meaning he had to take time away. He was regularly in hospital for three weeks at a time.

His lung function dropped to 20% and he was unable to exercise. He recalled that he would become short of breath just walking up his drive,

"I love to do stuff. I work as much as I possibly can and exercise as much as I possibly can. Sitting at home unable to do anything was incredibly difficult. I've had anxiety my whole life which can actually be positive for me as it pushes me to do things but when I couldn't push myself anymore, I felt very anxious," he said.

Sam's not a man who is used to being idle,

"I've never even played PlayStation and I don't really watch TV. I'm always on the go. When I was very sick I was limited in what I could do. Just sitting at home doing nothing is not me," he added.

THE NEW 'WONDER' DRUG

When Sam first heard about Trikafta a few years ago, he felt positive we'd see it funded here in New Zealand pretty quickly. At the time his health was ok and he felt sure it would be available to him before he really needed it. Unfortunately, his optimism didn't come to fruition.

"I had quite a rapid decline and I didn't want my health to drop to the point of needing a lung transplant. I did have the conversation with the transplant team, but I was told that I was unlikely to qualify as I have a kidney condition too which would mean a double transplant," said Sam.

> *"I'm always on the go. When I was very sick I was limited in what I could do. Just sitting at home doing nothing is not me."*

It was around this time that Vertex announced the Managed Access Programme for Trikafta here in Aotearoa. Sam said,

"Trikafta was my only way to survive. I met the criteria and my doctor applied right away. Sadly, I had one lung function result that didn't meet the criteria so I was declined."

This presented him with extra worry as he had to balance getting the results to get approved for the drug and staying well - as access to Trikafta wasn't guaranteed. It's a pretty tough balance to have to live with. Sam said,

"When your lung function is dropping it can be a quick decline. I was dropping 5% a month so during the 60-day period there was a real fear of getting to the realm of needing a transplant. Having to wait that time is very, very dangerous. I was extremely lucky. You're risking trying to meet the criteria or going well past it which could have catastrophic consequences."

THE BEST DAY OF MY LIFE!

The third time Sam went through the process he was granted access to Trikafta. He said,

"It was over a year later, I submitted a third application for compassionate grounds funding. It took just over a month and then I was accepted. It was the happiest day of my life! There were lots of tears and hugs and I took big cakes into work to celebrate. Everyone was so happy for me."

The impact of Trikafta was immediate,

"On the first day, I noticed a considerable difference. I coughed up all the gunk and mucus in my lungs for four to five hours. Once it cleared, I could feel my breathing improve quite significantly. By the end of the first week, I knew my lung function had gone up as I could walk up my drive again without shortness of breath," said Sam.

> *"It was the happiest day of my life. There were lots of tears and hugs and I took big cakes into work to celebrate."*

After only two weeks, his lung function went from 43% to 53%,

" This was the biggest gain in lung function in the last 10 years. It was amazing!"

LIFE IS BACK ON TRACK WITH BIG GOALS AHEAD

Sam has now been on Trikafta for a few months and he's back at work three days a week.

"My job is physical, I do lifting, carrying and moving furniture. I also do a 5k walk each day. Before Trikafta, I tried to do that walk and I ended up in hospital for three weeks," he said.

But Sam's determination and drive has never faltered,

"I feel I'm pushing myself more. Trikafta will give me the best opportunity to improve my lungs while I am still young. My goal is to get it to 82%."

His ambitious goal isn't without precedent for him,

"At 16 I was a competitive mountain bike racer and got my lung function from 64% to 110%. It stayed that high for a year and I was out of hospital the whole time."

For the time being, he's taking it easy and sticking to walking to gently increase his fitness levels. Sam said,

"I feel very good. I know I'm going somewhere in life. I can set goals, save for a house, and move out of my family home. Life is much easier being on Trikafta."

THANKFUL FOR THE LOVE AND SUPPORT

When reflecting on what has got him here, Sam was thankful for the support he received both at work and home. He said,

"Along with my own determination I've had a lot of fortunate circumstances as to why I am still here at 28. It's a miracle in itself.

My work was so good to me and I have a very supportive family too. Whatever it takes to keep me alive, they'll do it. They've always put me first."

The Covid-19 pandemic added a layer of stress to those with CF and Sam now feels that Trikafta is giving him some more freedom. He no longer has the same level of fear around catching Covid saying,

"With Trikafta, it greatly improves your chances of coping with covid, so now I feel so much safer. I'm still careful but Trikafta has given me a much more normal life now."

Sam sees reminders of how far he's come all around him,

"My bedroom used to have four boxes of feeds by the bed, a feed machine, nebulisers and antibiotics, all different pill bottles, all organised, but lots of them. My room was like walking into a hospital. Now, anyone walking into my room wouldn't know I have CF. There's no feed, no nebs, no equipment. It's like a normal person's room. I'm no longer drowning in medical supplies."

Sam is looking forward to going back to full-time paid work soon and continues to work towards his new fitness goals.

SWEAT FOR PURPOSE

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

Although we had set the bar a little higher, it was a bit tougher than we'd hoped to reach our goal. During the month, we also found out Pharmac's decision not to prioritise Trikafta. Our sweaty superstars used that to dig deep, and keep motivations high, and we finished Sweatember strong. We couldn't do what we do without the love from of our sweaters, and supporters.

We can assure you, your sweat has never meant so much!

NIKKI RALSTON

Nikki was a Sweaty champion, posting almost every day throughout September getting her audience to join in with Sweatember or sponsor her. She also went the extra mile, hosting a FREE (donations encouraged) online yoga class on the last day of the month with all proceeds coming to CFNZ.

You can follow Nikki on Instagram @theralstonmethod

"It was my pleasure to join SWEATEMBER and help out in any way I could. Growing up I watched my uncle struggle with CF and how that put so much stress on my family. I ran an online yoga class so that people could join in from across the country and support Sweatember. Yoga is about linking breath to movement, through this challenge I realised that it's easy to take something that most people do over 20,000 times a day with ease, for granted.

Thank you CFNZ for helping me and others learn and understand more about CF. I hope our efforts offer more kindness to the families you are supporting."

Kindly Sponsored by Viatris

TEAM LUNN

The team target was to row 340km, the length of the Lunn's awa (river) with a daily goal of 10 - 15km. Their challenge was to do this every morning, while still getting ready for work and school.

Their motivation was knowing that every person with CF has to fight for their breath & fight for their health every morning, before they start their day. ...And then keep fighting for it all day!

They chose a tough challenge to represent a tough condition and the tough but tired people with it. They were rowing to help fund the fight to gain access to a drug available in over 30 countries that would, without doubt, eliminate the need for a person with CF to simply 'fight to breath'. To give them a chance to live relatively normally, to experience normal people lives, normal people breaths & normal people's health.

PHOEBE O'CONNOR

My Sweatember challenge wasn't so much sweaty but was definitely a challenge - a swim in the freezing Wellington ocean bright and early every morning in September! My inspo was my incredible cousins Lizzie and Alex who live with CF, plus all the people with CF in Aotearoa. They all have an unfathomable amount of strength and it's absolutely heartbreaking that Trikafta isn't funded in NZ yet, so this was a very important cause to support.

TOM CONNOR

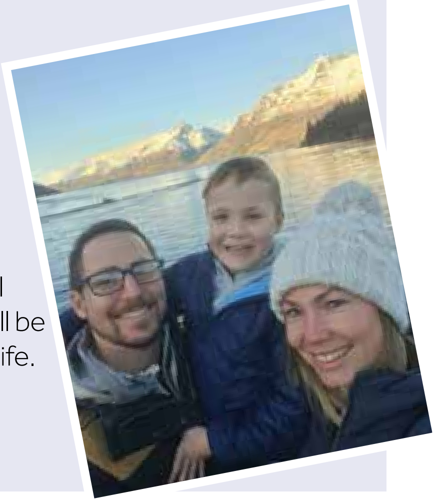
My inspiration for Sweatember was my son Emerson (Emy), 6yrs old. Emy has CF and we witness his struggles daily and what's required for him to lead a somewhat normal life.

My wife and I would do anything for him and so sweating for a month is nothing compared to Emy's Daily CF routine and the impact it has on him every day.

For Sweatember, I either swam for 30 minutes or attended a CrossFit session each day.

I like to demonstrate to Emerson the importance of being active in my own daily life through my own activities. I like hearing from Emerson things like "I can't wait till I'm older and I can do CrossFit with Dad". It means Emerson will be active and have this installed in him to assist with his CF struggles through life.

I love this photo of our Family (My inspiration) with huge joy on Emy's face.



ADVOCACY

Access to CFTR Modulator Therapies

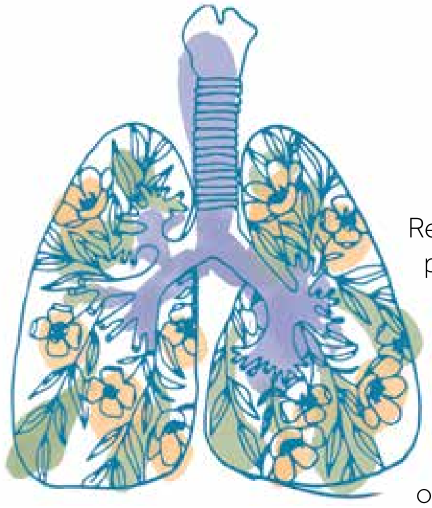
The last six months have been challenging for the campaign to have Trikafta publicly funded and to ensure that as many Kiwis with CF as possible have access to a CFTR modulator therapy that would benefit them.

It has been a time of increased awareness of CF, the urgent need for Trikafta to be funded, and for access to Kalydeco to be widened. There have been positive moves forward but unfortunately there have also been steps back.

On the positive side, Pharmac's experts on the Respiratory Advisory Committee yet again recommended a high priority for funding Trikafta for those aged 6 years and over, as well as recommending a high priority for widening access to Kalydeco.

Even Pharmac's Pharmacology and Therapeutics Committee managed a more positive view when it considered Trikafta for the second time, recommending a medium priority for funding for those aged 6 years and over. PTAC had previously deferred a decision on funding for those aged 6-11 years.

The release of Pharmac's Technology Assessment Report (TAR) setting out its view of the cost effectiveness of Trikafta was also a significant step forward. Pharmac estimates that Trikafta would provide a person with CF an extra 27 years of full health, almost doubling current life expectancy.



Carmen Shanks' petition to have Trikafta publicly funded was also a highlight. Presentation of the petition to Shanan Halbert MP gained significant media coverage and attention. Review by the Health Select Committee provided the opportunity for Carmen to talk to the Committee in person about the challenges of CF, her experience of Trikafta, and the urgent need for it to be funded.

The Committee's hearing also provided the opportunity for CFNZ to speak in support of Carmen's petition and raise the need for urgent change to the medicines' funding system to enable modern medicines like Trikafta to be funded.

Unfortunately, more recent news is not so positive. Pharmac has advised CFNZ that, following its September ranking meeting, Trikafta had not moved far enough up its Options for Investment list to progress to funding at this time. Pharmac indicated that it still wants to fund Trikafta but could not do so without change, and even if that were to happen, there would be no progress before December 2022.

As to widening access to Kalydeco, Pharmac has confirmed that PTAC will consider the recommendations of the Respiratory Advisory Committee at its November meeting. This would be followed by assessment against Pharmac's Factors for Consideration and ranking against other medicines. However, there has been no indication from Pharmac as to when this will take place.

CFNZ is very much aware that the repeated raising of expectations and dashing of hopes by Pharmac and the continued uncertainty as to if or when Trikafta will be funded and access to Kalydeco widened is causing major distress for the CF community.

Certainty is needed now to enable people with CF and their families to make decisions about their futures, including whether they stay in New Zealand and wait, move overseas to access desperately needed medicines, or seek to access unregulated and unfunded alternatives.

It is shocking that a medicine that provides an extra 27 years of full health to those who live on average to 31 years of age has not already been funded. The failure to do so clearly demonstrates that the current medicines' funding system does not work for those Kiwis who need modern medicines like Trikafta.

Other Advocacy Initiatives

There have been significant events in the health sector over the last six months, with the passing of legislation to reform the health system and the release of the Final Report of the Pharmac Review Panel.

HEALTH SECTOR REFORM

The Pae Ora (Healthy Futures) Act 2022 came into effect on 1 July 2022. The Act disestablishes District Health Boards (DHBs) and establishes three new entities:

- Health New Zealand (Te Whatu Ora) as the national organisation to lead and coordinate the delivery of health services across New Zealand.
- Māori Health Authority as an independent statutory authority to drive improvement in hauora Māori.
- Public Health Agency within the Ministry of Health to lead and strengthen public health.

Pharmac continues as the Government's medicines' buying agency, with no changes made to its objectives and functions.

PHARMAC REVIEW

In June, the Minister of Health released the independent Pharmac Review Panel's Final Report, together with the Government's response to the Report.

The Review Panel had made 33 recommendations, the bulk of which were accepted by the Government. In releasing the Final Report, the Minister stated that getting the cheapest drugs is not the only health strategy and that other factors needed to be taken into consideration.

The Review Panel's Final Report raised serious concerns over the operation of Pharmac, including amongst many others:

- Serious deficiencies in Pharmac's decision-making processes and the quality of the decisions that come out of it, resulting in inequitable outcomes for Māori, Pasifika, disabled people, and other priority populations.

- Those with rare disorders being disproportionately impacted by negative health outcomes and systemic failings.
- A lack of transparency as to how decisions are made, and a lack of timeliness resulting in major uncertainty for patients.
- Failure to incorporate the lived experience of patients into decisions about medicines.

The Review Panel's findings in respect of Pharmac's performance for those with rare disorders was particularly damning. The findings included:

- The lack of an agreed definition of rare disorders, with Pharmac adopting a much narrower and more restrictive definition than most of the rest of the world. That Pharmac's definition excludes conditions such as cystic fibrosis is particularly concerning.
- Only 0.8 percent of Pharmac's medicines budget in 2019/20 was spent on medicines for rare disorders.
- Only 426 patients received medicines for rare disorders in 2019/20. Rare Disorders NZ estimates that there are 300,000 people in New Zealand with a rare disorder.
- Pharmac's Rare Disorders Committee has met only four times since its establishment in 2018.

Pharmac provided its interim response to the Review's recommendations in early September but that response provided no sign that that real action is underway to address the recommendations.

Pharmac's full response to the Review is expected to be provided to the Minister of Health by the end of October. We can only hope that it demonstrates a sincere acknowledgement of the need for change and a clear plan of how and when the Review's recommendations will be implemented.

FUNDING FOR RARE DISORDERS MEDICINES

The Pharmac Review Panel's Final Report laid bare the dire situation facing people living with rare disorders who are waiting for medicines. Pharmac spends only a very tiny percentage of its budget on medicines for rare disorders -0.8 per cent in 2019/20.

Following the release of the Review Panel's Final Report , CFNZ wrote to the Minister of Health acknowledging the work and recommendations of the Panel but noting that it would take some time for those recommendations to translate into action. CFNZ therefore asked that the Minister advise Pharmac that he expects them to give priority to funding medicines for rare disorders in addition to cancer medicines. Other organisations representing those living with rare disorders in New Zealand also requested the Minister to advise Pharmac to take this action.

It is now more than four months since that request was made and there has still been no response from the Minister.

WHERE TO NEXT?

The coming months are crucial in the campaign to have Trikafta funded and access to Kalydeco widened. We need to make all the noise we can to maintain public awareness of CF and urge Pharmac to rank Trikafta and Kalydeco high enough up the Options for Investment list to progress funding this year.

But we also need to put pressure on politicians to finally wake up and do something about New Zealand's disastrous medicines' funding system. They must address the increasingly desperate situation facing people living with rare disorders like cystic fibrosis who need to access life-saving modern medicines.

Whatever politicians may say about how the need for them to stay out of decisions on medicines, they are the people in charge, they set the budgets, and they have the power to change things for the better.

We must do all we can to make sure they deliver on their responsibilities.

BUILDING TRIKAFTA AWARENESS AND MOMENTUM

– the Trikafta Petition

An update from Carmen Shanks

The Trikafta petition was started amongst a flurry of media attention on the issue of the lack of funding of Trikafta - thanks to late Sir Bob Elliott and Bella Powell. It was very clear that the wider NZ community were shocked that such an effective medicine was not being funded or at that point, even considered, and many wanted to know how they could help push the issue along and have it brought to the attention of decision makers. And so, the petition for Trikafta was started.

It was very exciting to see the signature amount grow from the thousands to the tens of thousands. Every milestone was celebrated by Trikafta for Kiwis and the CF community and for a while checking the number of new signatures became addictive. We received over 43,000 signatures which was phenomenal, and was testament to the determination and passion of our community. To everyone who helped push the petition along, I can't thank you enough.

As the petition had such a large amount of public support and was such a hot topic, myself, CFNZ and Pharmac were invited to present to the Health Select Committee. I also used the opportunity to draw attention to how far behind NZ is in terms of medicines spending and providing access to Trikafta – a fact many of our community are acutely aware of, it was important to highlight in a forum such as the one I was in.

I believe the presentation to the HSC was a valuable opportunity that was well utilised - important issues were highlighted to the committee and personal stories were able to be told, which are extremely powerful in the context of medicines funding.

Trikafta Petition Presentation

On 28 March 2022, the Trikafta Petition was presented to Labour MP Shanan Halbert, on behalf of the Chair of the Health Select Committee, Dr Liz Craig. The morning was spent setting up the Kauri Steps in Cornwall Park, placing 1000 red roses to represent all members of our CF community – it was a perfect setting for a very important milestone in our fight for Trikafta.

Lisa was our MC for the morning, along with sharing a message about the work done to date on the Trikafta Campaign. We had a special welcome from Fred on the guitar, and a beautiful karakia from Lili, who then spoke with her twin Manaia about their gruelling journey to get Trikafta, "A miracle happened, and we got Trikafta,and it's been a life-changer. We're planning goals, and a future. Why do CF patients have to be on the verge of dying for their lives to be saved?"

Carmen shared her moving CF story, about being a Mum who never wanted her children to lose their Mum, and the full life that she wants to be able to live, and the same for our CF community.

Carmen presented the Petition to Shanan Halbert MP, who then addressed the crowd, followed by speeches from: Brooke van Velden (Act Party co-leader) and Golriz Ghahraman (Green Party MP).

There was a huge amount of media interest and coverage on the day and days following, namely a feature on Newshub that evening, articles on Stuff and Scoop, and interviews on a few TodayFM shows.

The entire morning was live streamed onto the Cystic Fibrosis NZ page, you can still watch it here:

Thank you from CFNZ

We would like to extend our heartfelt thanks to Carmen for starting the Petition calling for public funding of Trikafta for all those eligible in New Zealand, and to Carmen, Trikafta for Kiwis, and other key members of our CF community, for the collective mahi put in to getting 43k signatures – that's approximately 78 signatures per person living with CF in New Zealand.

ADVOCACY TIMELINE

Access to CFTR Modulator Therapies

March 2022

Carmen Shanks presents her petition for public funding of Trikafta to Shanan 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 22

CFNZ seeks advice from Pharmac as to the next steps for the application to widen access to Kalydeco. Pharmac advises CFNZ that 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.

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.

Advocacy Toolkit

Help us in the #27MoreYears movement, we are stepping up our fight to get Trikafta publicly funded in New Zealand.

Download our Advocacy Toolkit to find out how you can get involved.

THE POWER OF HOPE

Hope – noun - a feeling of expectation and desire for a particular thing to happen.

Tess Gatchalian reflects on her insights about hope through social work.

> *.... each person is unique and the way they perceive hope is always different from the others. A person's life experiences, values, and beliefs entrenched from their social and cultural upbringing all affect our perception of hope.*

How do social workers end up in their profession?

Social Workers have varied reasons for choosing this profession. Most Social Workers would say they want to make a difference in the world; for others it can be a "choice and a calling" (Gatchalian 2012). Regardless of the reasons we had for being in this profession, I guess we are all hoping for the best, both for ourselves and for the clients we serve. Hope is a very significant word for us, social workers and the social work profession in general. After all, social work is the profession of hope (Clark2020). It is the profession that deals with the most vulnerable people in our society, people who are on the verge of losing their hope in their struggles to survive. Most of our clients are vulnerable older people, women victims of family violence, vulnerable young children, people with mental health issues, people with physical disabilities, among others.

How do we define hope?

People may come up with different definitions and opinions of what hope is. According to Merriam Webster, hope means to cherish a desire with anticipation or to want something to happen or be true. As defined by Clark & Hoffer 2015, hope is an essential experience of the human condition. It is a psychological asset, a guide against despair, a way of coping and a quality-of-life enhancer.

Based on these definitions, I would say hope is a part of our human existence, of how we live. It is a part of our everyday lives, that is, to hope that each day will be a good one. Depending on what part of the globe we live in and based on our values, cultural and religious backgrounds, hoping for the best in our everyday life is always a must for us. However, each person is unique and the way they perceive hope is always different from the others. A person's life experiences, values, and beliefs entrenched from their social and cultural upbringing all affect our perception of hope.

Hope and beliefs

Many people associate hope with a sense of religious belief. As a practicing Roman Catholic myself, I would say, hope is a major part of who we are. During our most desperate moments, we even hope for miracles. I guess for most of us, this kind of hope encourages us to keep going and keep our sanity intact.

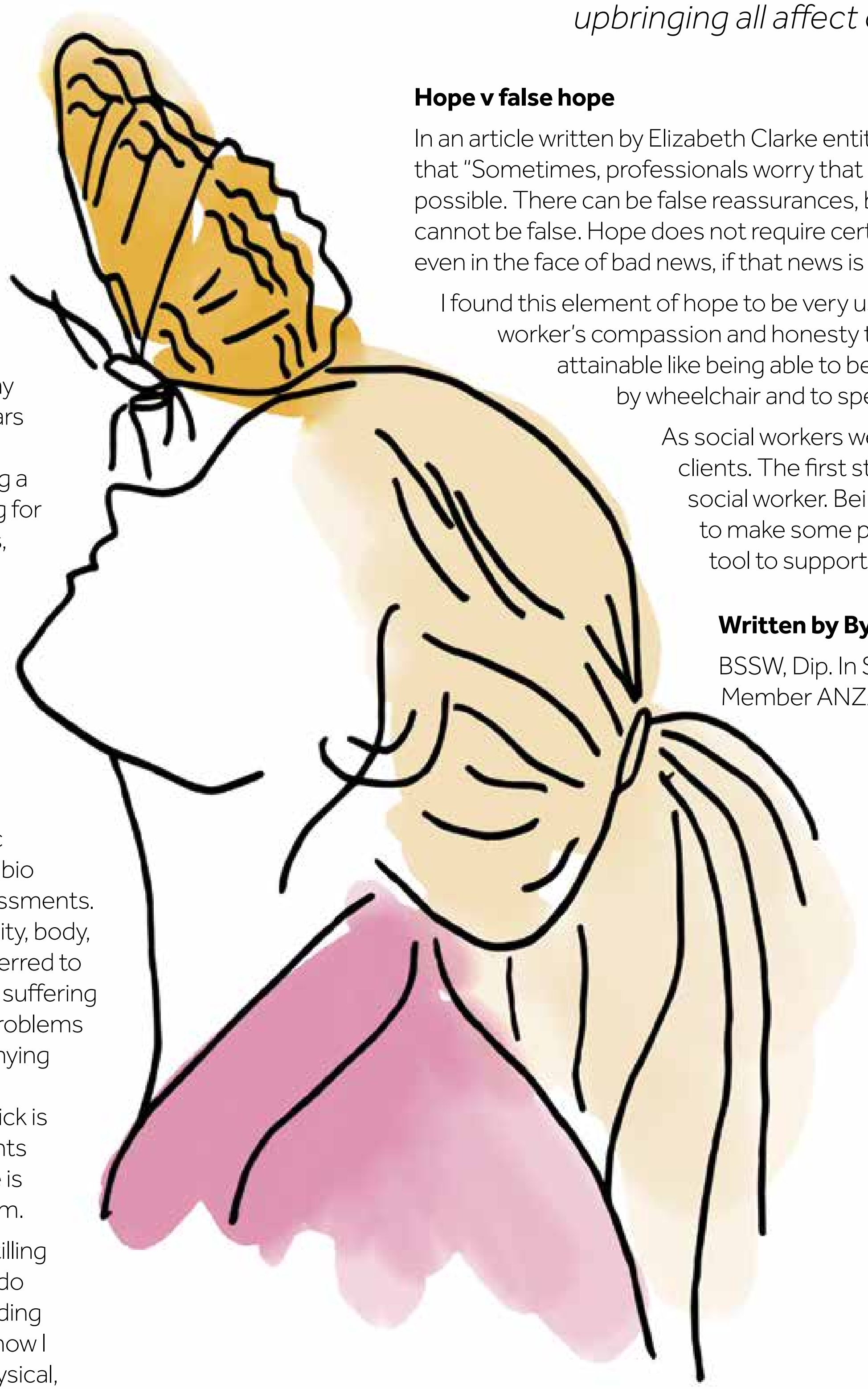
Using hope as a resource

Since social work is a profession of hope and we cater to the most vulnerable people in our society, I reckon it is worth examining how we can use hope as a good resource in our everyday practice. I would focus on social work in the hospital setting as my social work experience of 40 years is centred in the hospital. They always say health is wealth. Being a patient is not a very good feeling for most people. For some patients, being sick could mean the loss of independence, change in lifestyle that they have been accustomed to, loss of ability to make decisions, inability to work and provide for their families.

Holistic approach

Social work is based on a holistic approach, and we often use the bio psychosocial theory in our assessments. We look at the person in its totality, body, mind, and spirit. Most clients referred to our attention are those who are suffering not only from serious medical problems but also experiencing accompanying social, emotional, spiritual and psychological concerns. Being sick is already a burden for most patients and it can even be worse if there is no family around to support them.

As a social worker, I find that instilling hope is a major part of what we do every day for our patients. Providing hope has always been a part of how I supported my clients in their physical, emotional, and psychological journey. Encouraging our clients to hope and look forward to a positive future is a form of empowering and supporting them achieve their goals.



Hope v false hope

In an article written by Elizabeth Clarke entitled 10 Essentials Social Workers Must Know about Hope, she states that "Sometimes, professionals worry that they may, inadvertently, give a client "false hope", but that is not possible. There can be false reassurances, but not false hope. Just as truth cannot be false, hope by definition cannot be false. Hope does not require certainty or assurance of success. It can be maintained and refocused, even in the face of bad news, if that news is accompanied with honesty, compassion, and support."

I found this element of hope to be very useful in my work. Sometimes what the patient needs are the social worker's compassion and honesty to help them refocus their hopes into something that is more attainable like being able to be well enough to attend a daughter's wedding, being able to mobilise by wheelchair and to spend happy moments in the park with their grandchildren.

As social workers we need to be hopeful ourselves in order to provide hope to our clients. The first step is to keep reminding ourselves the reason why we chose to be a social worker. Being a social worker is like believing that every person has the capacity to make some positive changes in his life and that hope is always there as a powerful tool to support us in reaching our goals.

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All we want for Christmas...

is to be able to provide joy and support to families like Poppy's who don't get a break from CF for the holidays.

"For the first time Poppy is aware of Christmas and Santa and her excitement levels are rising daily! She has also just discovered Bluey and she has asked for a Bluey toothbrush from Santa."

Poppy's mum and dad Sophie and Chris have a bigger Christmas wish for Poppy – they alongside other families are waiting for equitable access to Kalydeco which is currently not funded for Poppy's specific CF genes.

The reality for our families is that CF won't take a break this holiday season.

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