

CF News

SPRING/SUMMER 2023

IN THIS ISSUE:

MARK ASHFORD SCHOLARSHIP

Meet Christopher Headey, our Scholarship recipient

FABULOUS FUNDRAISERS

From Chocky Fish to a Fun Run, read all about our community fundraisers

ADVOCACY UPDATE

What's the latest with CF medicines?



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

Writer of Christopher's article, Ingrid Grenar, member of our CF community.

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

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INSIDE



FEATURES

06 CF Achiever Awards
Meet the 7 individuals with CF who have been recognised as CF Achievers this year for their optimism, perseverance and success in their chosen category.

09 Thank you Dr Philip Pattermore
The community thanks Dr Pattermore, Associate Professor of Paediatrics, University of Otago, who is retiring after 31 years in paediatric CF care at Christchurch Hospital.

18 Mark Ashford Scholarship Recipient
Meet Christopher Headey, our 2023 scholarship winner as he talks about late diagnosis and striving to reach his goals.

25 A Meaningful Partnership
CFNZ is profoundly grateful for the unwavering support and dedicated pro bono assistance extended by Simpson Grierson over the past few years.

LIFESTYLE

10 CF Month Wrap Up
Read all about the craziness that was CF Month, including some wonderful Deliberate Acts of Kindness and many, many Chocky Fish.

14 Community Joy Board
Our community shares their special moments, celebrations and achievements

16 Fundraising Superstars
From fun runs to market stalls, catering jobs and Stars in Your Eyes, read about some wonderful people doing wonderful things to fundraise for our CF community.

ADVOCACY

20 Advocacy Update
Get the latest updates on CFTR Modulator and MRNA therapies.

22 Access to Medicines
NZ is at the very bottom of the OECD for public funding of medicines. What can we do about it?

23 My Life Matters Campaign
Read all about the new campaign from Patient Voice Aotearoa, supported by many other NZ organisations.



A NOTE FROM LISA

As I reflect on the achievements of the past year, I have been reminded of the incredible dedication and courage within New Zealand's CF community.



Throughout the previous year, your collective efforts have created change. You shared your personal stories, advocated passionately, raised funds, and devoted your time generously. This commitment has been instrumental in driving significant advancements for our community that has put us on an even playing field with the rest of the world.

While we contemplate the events of the previous year, our focus also turns towards the future. We acknowledge that there is an evolving nature to the models of care needed for CF. Some members of our community are benefiting from modulator therapies that hold the potential to reshape their futures. However, others may not have had a positive response, or these treatments have arrived too late, and some continue to struggle with access, meaning some of our community will unfortunately not experience the benefits of these therapies. We foresee an increasingly personalised model of care will be needed to support the unique experiences and challenges.

The quality of life and wellbeing of our community remain our priority. Adapting to the evolving realities of our community means we must be able to provide support to individuals through each stage of their lives.

CFNZ can provide our programmes because of the generosity and kindness of our supporters, donors, and volunteers. I continue to be humbled by the generosity of those who give their resources in time and money to support our community.

Sustaining our momentum in improving support for our CF community is of utmost importance, and that's exactly what we're committed to achieving. Positioned at the heart of our work programme is ensuring that we can address the insights that came out of our community survey earlier in the year. You have told us what you need, and we are working on how we can deliver this to you.

At CFNZ, we are not just an organisation; we are a family bound by a shared purpose. Our journey towards improving the lives of those affected by cystic fibrosis continues, and your support is what fuels our purpose. Together, we will strive to raise awareness, provide vital support, and work tirelessly towards a future where cystic fibrosis is cured.

My heartfelt thanks extend to our community, donors, volunteers, staff, sponsors, and partners throughout New Zealand. Your tireless dedication doesn't go unnoticed, please continue to support us so we can make a difference in the lives of those who need us.

Kia kaha / stay strong

Lisa

Lisa Burns
Chief Executive



LATEST NEWS



SWEATEMBER UPDATE

We've had an incredible amount of Sweaty Superstars running, rowing, and competing with each other to smash their goals and bring in the donations. We are so grateful to each and every one of them.

It's been an epic month raising funds to keep our support programmes going, but also for raising awareness of CF and how exercise of any kind can benefit us all. Most of all it's been so heartwarming to see so many of our community, their friends and family, medical professionals and CFNZ's corporate partners come together to get Sweaty for Purpose and try to make a difference. Thank you all from the bottom of our hearts!



Don't worry, there's still time to help reach our fundraising target and get our CE Lisa and Fundraising Manager Maree thrown out of a plane! Scan the QR code to find out more.



A VERY SWEET DONATION

The amazing team at PGG Wrightson/FruitedFed in Blenheim ran a retail promotion earlier this year whereby \$25 from the sale of every drum of Sweet was donated to the "sweethearts of local charities". How sweet is that?! Fruited Supplies is a leading supplier of products and services to the New Zealand horticultural sector. We are so grateful to the team for their kindness, and thankful to have been a recipient of the funds raised from this clever promotion. In this photo Nic Peters (left) and Nick Kole (right) from FruitFed present the cheque to James Rondel, CF community member, on behalf of CFNZ.

WELLINGTON AIRPORT CHRISTMAS TREE FESTIVAL



This annual event is a joyful display of creativity and beauty. It's become part of an iconic and unique experience only seen at Wellington Airport. These are no ordinary Christmas trees, they are TREES FOR PURPOSE, trees that make a difference to Kiwis living with cystic fibrosis. The 2022 Christmas Tree Festival was the biggest on record with 56 organisations who gave their time, kindness, and support to this event. In 2023 we're aiming for an even bigger festival. Do you have a business or organisation in mind who would like to take part? Visit our website Latest News page or email us fundraising@cfnz.org.nz to find out more.

THANK YOU, FROM JAN TATE

"A huge thank you to all "my families and children" for your amazing words, best wishes, and lovely gifts when I retired from Starship in May. I feel very spoilt and touched by your generosity. I truly love my "Retirement Book" and the CFNZ magazine spread with your beautiful words and photos of the kids as babies, growing up, and as gorgeous young people. They have been read, reread and shown to family and friends - I will treasure these memories forever, thank you.

On my last day at Starship I had a lovely send off from the Starship team and my nursing colleagues, flowers, prezzies and a guard of honour from my office buddies, very emotional.

Retirement is going well, Aggie the cat, enjoys being my hot water bottle and consulting advisor when we are on Zoom meetings. Warren hasn't quite retired but we have done quite a bit of travel around NZ, Singapore and Melbourne (to see the grandchildren). There are lots of upcoming plans; travel, home projects, and I am busy working for CFNZ getting the Port CF data registry up to date. No time to go to work! I am missing you all and know you will always be part of my life."

INTRODUCING OUR NEW BOARD MEMBERS



PIETER STEWART

Tell us a bit about yourself

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

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

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

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

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

What's your biggest wish for the CF Community?

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



QUICKFIRE QUESTIONS:

Do you have any pets?

We have a new black Labrador puppy who's extremely naughty at the moment – we had forgotten how full on a new pup can be!!

Favourite song?

I play mainly jazz or classical most of the time. But to pick one – I have to say Leonard Cohen's – Anthem, and Luther Vandross – Last Dance with my Father.

What's your favourite food?

Fresh food - I love salads of all sorts.

Coolest place you have visited?

Tuscany is my favourite place in the world – but I'm planning a trip back to Amalfi then Sicily and Puglia where I've never been.

What gets you out of bed in the morning?

At the moment – the dog.

What's your favourite quote?

"A friend is one to whom one may pour out the contents of one's heart, chaff and grain together, knowing that gentle hands will take and sift it, keep what is worth keeping, and with a breath of kindness blow the rest away." George Eliot

What energises you?

Regular exercise and spending time with my grandchildren.

What's your coffee order?

It's tea for me.



KRISTINA JEFFREY

Tell us a bit about yourself

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

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

I feel privileged to be on the CFNZ Board and to be part of an incredible community who are extremely passionate and supportive. I enjoy helping others and being on the Board is a great opportunity to share my finance

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

What's your biggest wish for the CF Community?

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

QUICKFIRE QUESTIONS:

Do you make your bed every morning?

Yes! I have to make it before leaving the house.

What's your coffee order?

Oat milk flat white.

What's your hype song?

Levels by Avicii.

Favourite travel destination?

Italy.

Drink of choice?

A glass of red wine.

What's your favourite quote?

She believed she could, so she did.

Do you have any pets?

Bubbles, our 5 year old cavoodle who we flew back from the UK. He does not think he is a dog though!

What gets you out of bed in the morning?

I am quite an early bird so enjoy getting up to either walk Bubbles or go for a run.



EVANGELIA HENDERSON

Tell us a bit about yourself

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

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

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

What's your biggest wish for the CF Community?

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

QUICKFIRE QUESTIONS:

What's your coffee order?

Trim latte extra hot.

Who is your greatest inspiration

I don't have one single person, but look up to people who have overcome personal challenges and thrive to fulfil their aspirations.

Do you have any pets?

Not at the moment, but we had a dachshund called Brandi and a cat named Toulouse, they were best buddies.

You are happiest when?

When I have my family all together. Our daughter lives in London so it's very special when we can all be together.

What gets you out of bed in the morning?

Seize the day – live each happy day at a time!

What's your favourite quote?

The key to happiness is having something to do, something to love and something to hope for.

What's your favourite food?

Spanakopita (Spinach and feta pie).

Favourite holiday destination?

Greece.



CF ACHIEVER AWARD RECIPIENTS 2023



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



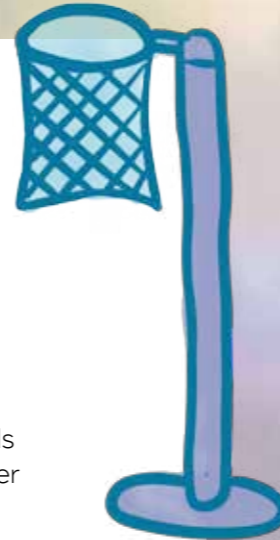
Thank you Viatris, for kindly sponsoring our 2023 CF Achiever Awards, and for joining us in celebrating our CF community.



KAIYA MILLER - SPORT

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

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



ANAHERA INNS - EDUCATION

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

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

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

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

STAN MILLWATER - LEADERSHIP

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

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

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



JESSIE MCKAY - LEADERSHIP

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

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

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





MAISY MILLWATER - EDUCATION

Maisy is an 18 year old nursing student living with CF as well as ADHD. "Despite the challenges that come with my condition, I have worked extremely hard to achieve the qualifications needed to be accepted into a nursing degree programme. However, I have recently experienced poor health and am currently undergoing an extended period of treatment in the hospital. Despite the difficulties I am facing, I remain determined to continue with my studies and submit my assignments on time, with the help and support of my friends and tutors." Maisy believes perseverance and resilience in the face of adversity are qualities that make her a strong candidate for this award, and we couldn't agree more!

BRAXTON PRENTICE - SPORT

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



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



RYLEE SINDEN - SPORT

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

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



THANK YOU DR PHILIP PATTEMORE

Philip Pattemore, Associate Professor of Paediatrics, at the University of Otago, Christchurch, is retiring after 31 years in paediatric CF care at Christchurch Hospital.



"We would like to acknowledge the retirement of Professor Philip Pattemore. Philip has not only taken the best care of our children for over 30 years. He has been a great support and level head for parents especially during diagnosis and fraught times of CF. Philip's demeanour and impromptu sense of humour have been greatly appreciated, along with his knowledge, research and CF conference sessions. We appreciate all that Philip has done for our community and wish him the best, well deserved retirement." *From Melissa Skene, Chairperson CFNZ Canterbury*

MESSAGES FROM OUR CF COMMUNITY

Thanks for all the care and support you have offered Tylah. Enjoy your retirement. You are so understated and humble. Parenting a new-born with CF is a fairly traumatic experience and we couldn't wish for a more exceptional physician than yourself. We have been eternally grateful for the professional experience and wisdom that you have brought to CF Canterbury clinic. However it is our son, Harry, whom you've had the greatest impact on. Please don't underestimate the importance of the role you have played. You have provided him with both the caution that he needs to understand about CF but also the belief to live his life to the full. Harry has a deep respect and admiration for you! Thank you Philip for your dedication, humility, honesty and professional wisdom. We will be eternally grateful, and we hope you can enjoy the retirement you deserve.



Dr Pattemore has seen many of our CF people through from diagnosis to transition to the adult clinic and we appreciated the consistency of his reassuring support.



Dr Philip is famous for his colourful assistant, a bright yellow duck attached to his stethoscope who can quack when required.



Dr Pattemore always explains things so we can understand and is always patient and kind. The only time he ever gets annoyed is with the computers, when his login doesn't work, or the printer won't do what it is told.

I am so very grateful you were Sam's CF Specialist. Your dedication and knowledge kept him well and set him up wonderfully to get through until a breakthrough came with the medication. Sam is now on Trikafta and his health has improved significantly. Something we are truly grateful for. We wish you a long and happy, well-deserved retirement.



To Dr Phil, thank you for taking care of me for so many years, will never forget the cool ties you used to wear. Love Alana and my family xo

Forever our favourite magician. Thank you for everything especially the best start to life, Logan and Paula.



To Dr Pattemore, Thank you so much for looking after me. All the best Jessica Rose.

CF IS A CRUEL CONDITION. IT'S FOR WHOLE OF LIFE.

Medicines help, but they're not a cure.
The need for support has never been greater.



CRUEL NEEDS KIND 2023

CF Awareness Month showed us once again how wonderful the CF community is in New Zealand.

It was a huge month with an unprecedented amount of Chocky Fish going out of our doors to fundraisers, only a small shoal of them made their way into the tummies of CFNZ staff but they helped fuel us to continue to pack and send out order after order of fish, t-shirts, books, artworks, and hoodies.

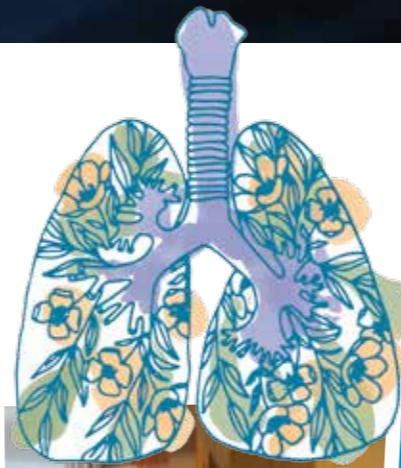
Schools, other community organisations and individuals all ran fundraisers, from selling Chocky Fish, to mufti days, catering and bake sales.

We also had many amazing organisations and business partners keen to support our CF community throughout the month, who came up with their own Deliberate Acts of Kindness, all making a tangible difference to the lives of Kiwis with CF. You can read more about them in the next few pages.

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

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

We still have some Chocky Fish at CFNZ HQ, and we welcome fundraisers of any shape and size any time of the year! We'll do whatever we can to support our fundraising efforts. Let's chat, email nikki@cfnz.org.nz



Thank you our incredible, generous sponsors and partners who all showed various Deliberate Acts of Kindness during CF Month:



CF MONTH 2023 DELIBERATE ACTS OF KINDNESS



EVENTFINDA PARTNERS WITH CFNZ

We can't thank the Eventfinda team enough for their involvement with our CF Awareness Month, Cruel Needs Kind. Their Deliberate Act of Kindness in offering Cystic Fibrosis NZ the opportunity to be their donation partner for May really made an impact for our campaign, and ultimately, for our CF community. There were an incredible 625 donations through Eventfinda; people topping up their checkout total to support people with CF! It's been a privilege working with Eventfinda, and we are very excited and fortunate to be working with the team again for our Sweatember campaign.

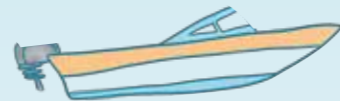


THE ADVENTURES OF DUSTY DUSTOFFERSON

Dusty Dustofferson is the creation of Wellington solicitor and author Vesna Wells. As an amazing Deliberate Act of Kindness for CF Awareness Month, Vesna wrote Dusty's story and had 500 copies of Whos' Who in the Zoo printed and 100% of the purchase price from each sale comes to CFNZ. Such a wonderful gesture of kindness. Everyone loves Dusty and you can still purchase Whos' Who in the Zoo on shop.cfnz.org.nz.

The book is dedicated to Fletch, Dusty's eternal companion as well as everyone touched by cystic fibrosis. Thank you so much Vesna!

THANK YOU, HUTCHWILCO NEW ZEALAND BOAT SHOW!



During CF Month this year, we were absolutely blown away to be gifted a (pretty big!) stand for the four days the show was running, as a Deliberate Act of Kindness. Within a week, we designed posters, had them printed (thanks, SCG!) and sorted out a very blue stand, ready to reel show-goers in for a chat about CF, hundreds of Chocky Fish sales, merch purchases, and kind donations. We had a brilliant time, and were blown away by the support of the general public. The success of the Boat Show was thanks to Veronica and Dave Gibbs (who ran the show and gave us the stand), Jamiee Lightfoot for all her assistance, our friends from Energi Advertising who volunteered, supporting us on the stand, and the CFNZ team and some of their families.

We were hooked from day one, and couldn't be more grateful to all involved. See you there in 2024?



THANK YOU WELLINGTON AIRPORT TEAM!

The wonderful Wellington Airport team went above and beyond on Deliberate Act of Kindness day on Friday 26 May. They purchased 1000 Chocky Fish to surprise and delight passengers, handing them out throughout the airport on the day along with a small card with information about CF Month and Cruel Needs Kind. What a way to honour the day and what it is all about.



LUMO LIGHTS THINGS UP

The Lumo team are always keen to support us with our campaigns whenever they can. Across the final two weeks of CF Month they came through with over 207 hours of digital billboard space for us! With a value of \$69k, they were able to reach over 1.3m people with our billboard messaging during that time. Thank you so much team Lumo.



BIRDBARN LENDS A HAND

When we were thinking about a creative way to package up Chocky Fish for part of our CF Month campaign we came up with the idea of small fishing nets and the gorgeous people at Birdbarn offered to provide them free of charge!

Furthermore they generously gifted us a full fish tank set up to use as a giveaway during CF Month. So we filled it with fishies of the chocolate variety and ran a competition at the boat show for visitors to guess how many fish were inside.

Here is the lucky winner Blake.



NZME HELP SPREAD THE WORD.

Ben Rose and the NZME team really pulled one out of the hat for us during CF Month with another Deliberate Act of Kindness.

They supported the Cruel Needs Kind campaign with 1248 adverts across New Zealand throughout the month of May, for a total dollar value of over \$45k. An incredible gesture, thank you NZME!



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



Amelia with the certificate and ribbon she recently received for her first on stage, solo dance.



Arielle is a Kaiwhakamana (Advocate) for VOYCE Whakarongo Mai - her dream job!



Billy and his friends who have a mate with CF, organised a multi day at school and raised \$541.90! Thanks team!



Braxton getting a bit of "air time"!



Oscar went to the snow for the first time!



Orson on holiday with his brother Harrison. They picked up an extra mate along the way!



Sophie, on the shores of Bellagio in Lake Como, Italy



Harry started school and met the infamous Harold the Giraffe!



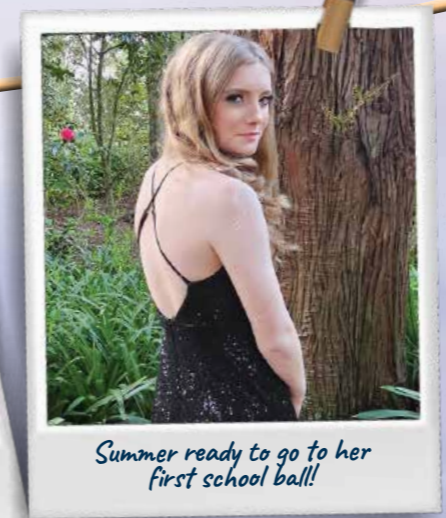
Liam and his big brother Coen at their last Rippa Rugby game for the season.



Lizzie alongside her parents at the Organ Donation Thanksgiving Service at the Parnell Cathedral.



Poppy loved her first visit to the snow!



Summer ready to go to her first school ball!



Tailen got a certificate at school 'Putting best foot forward in showing resilience at school and doing all his health procedures like a super champ!'



Precious cargo!

Putting the FUN (RUN) INTO FUN-DRAISING



As the sun rose on the morning of Sunday 2 April, at the Coastal Walk Way in New Plymouth, Taranaki, an incredible bunch of people were working hard to set up for the inaugural Cystic Fibrosis NZ Fun Run.

Bev Darlow, our CFNZ Central North Island Social Worker has a passion for competing in triathalons, ironman and other running events. So Bev decided to combine her passion for running with a fundraiser and so the CFNZ Fun Run was created! Bev's enthusiasm for the job is evident in the way she put so much effort and energy into pulling the run together and supporting the CF Community outside her working hours.

It was a huge undertaking for Bev as well as the wonderful team from the Cystic Fibrosis

NZ Taranaki Branch, particularly Shelley Gruchy and Trish Corkill. None of them had organised an event like this before, there were bumps along the road and many lessons learned but so many people rallied and over 50 volunteers helped on the day.

They brought together sponsors, CF community members and their families and just under 70 runners and walkers who took part in either a 20km, 5km or 2km around the stunning coastal pathway. From the more serious competitors to families just wanting to have

fun or walk the dog there was plenty to smile about on the day with the sun shining, prizes for best dressed and spot prizes, everyone had a great time.

Over \$2500 was raised for people with CF and their families, well done and thank you so much to everyone involved, especially Bev, Shelley and Trish for all the hard work that went into making the day such a success.

We hope to be able to bring you all an even bigger and better Fun Run in 2024.



Thank you so much to every one of the generous sponsors involved, you are amazing:

- FONTERRA • THINK WATER TARANAKI • BUNNINGS • PACK CENTRE • KAITAKE GOLF CLUB • HILLSBOROUGH MINI PUTT
- SHOE CLINIC • JACKIE B THERAPIES • NEXANS • CYCLE INN • MARIA BROCKHILL • CORSONS TYRES • HODGE MOTORS
- MERRILANDS • BELL BLOCK FLORIST • CHEMIST WAREHOUSE • DOBSONS MARQUEE & PARTY HIRE • TARANAKI
- HARDCORE • SMITHS SHOES • JADE RAIL PHOTOGRAPHY • TEGEL FOODS • OAKURA BEACH APARTMENTS • GRAPHIX
- PALMERS GARDEN CENTRE • CROWDED HOUSE • PAK N SAVE • THE COFFEE GUY MOBILE ESPRESSO • BOK SHOP
- FOOD ON WHEELS • ART HAUS • TRICK OR TREAT • TSH • EFTPOS TARANAKI • NEW PLYMOUTH PHOTOGRAPHY CLUB

FABULOUS FUNDRAISERS

FUNDRAISING FOR DAYS

It seems that there is no end to what Bex Blatherwick, her family and friends will do to help raise awareness and funds! From participating in Sweatember, to selling 19 boxes of chocky fish during CF month, organising raffles, to Bex and her amazing mum Jeannie donating the proceeds of a catering job.

Bex says "Every year since we found out our nearly 5 year old son Liam has CF, we decided to fundraise to help other kids and adults with the genetic condition. We have a very generous community who support us by donating items and buying raffle tickets, can't forget those boxes of chocolate fish too. It's the least we can do." **Thank you so much Bex, and all of your friends and family - we think you are amazing!**



STARS IN YOUR EYES

On Saturday 26 August Blair Halcrow took to the stage to perform in Stars in Your Eyes Blenheim. In front of a huge crowd Blair belted out The Gambler by Kenny Rogers and took 1st place! Blair won an amazing \$1000 for his chosen charity, CFNZ Nelson/Marlborough. Blair's first wife Janet passed away due to cystic fibrosis. He was supported on the night by their daughters Charlotte and Shannon and his second wife, Mel.

Thank you so much Blair, what a legend, you really are a star in our eyes!



FISHIES IN FOXTON

Peter Halcrow and his two daughters, one of who has cystic fibrosis, have been Chocky Fish selling superstars this year, they have attended many markets in and around Foxton where they live, setting up stalls, selling fish and taking donations for CFNZ. **Thank you so much Team Halcrow!**



MARK ASHFORD SCHOLARSHIP WINNER HEADS TO MONGOLIA



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

In his final year at university, Chris achieved A grades across all his results with an 87% average. Chris said, "At Waikato University I studied Law and completed my degree in December 2021. I started at Anderson Lloyd in Christchurch the following January working in commercial disputes."

SUCCESSING IN EDUCATION ALONGSIDE HEALTH CHALLENGES

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

This was my intro to the law. I always knew that I would work around people and have a literacy-based job. The

mooting gave me an experience that directed me towards law and by year 13, law aligned with what I was good at and my extracurricular activities."

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

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

A LATE WHIRLWIND DIAGNOSIS

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

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

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

"I remember my mum getting that phone call, the look on her face and the conversation we had later. It was May 2016 so I was almost 16 years



old. From there it was a whirlwind experience. I was very quickly taken up to Starship for treatment and given an intensive programme of education on CF - this is what it means, this is what to do. The IV antibiotics cleared up my infection. My family had basically never heard of CF before, so it was a tough time for all of us."

LIFE CHANGING TREATMENTS

Chris' induction into the world of CF was tough, learning and adjusting to treatments as a teen rather than from birth as is the case for most people with CF. His treatments were chest physio, IV antibiotics and creon, but a new treatment was just around the corner.

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

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

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

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

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

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

THE MARK ASHFORD SCHOLARSHIP 2023

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

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

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

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

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

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

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

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

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

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

Thank you Terra

for generously sponsoring the 2023 Mark Ashford Scholarship. We are extremely grateful for your support.

terra
consultants

ADVOCACY UPDATE

Trikafta

Kalydeco Update

mRNA Clinical Trial

Access to Medicines

MyLifeMatters Campaign

Pharmac Review

Rare Disorders Strategy

Therapeutics Products Act 2023

TRIKAFTA

The funding of Trikafta for those aged 6 years and over from 1 April 2023 has brought significant change for the CF community.

The benefits for many of those who have been able to access Trikafta are life-changing and bring opportunities that were previously out of reach for many.

Funding of Trikafta was a major milestone for the CF community in New Zealand but the work to ensure everyone with CF has access to the medicines and treatment they need is not over.

CFNZ is very much aware that not everyone has been able to benefit from Trikafta. Some have had to deal with significant side-effects, and the impacts that such a life-changing therapy can bring about, while others have been unable to tolerate it.

There are also those who are not yet eligible for Trikafta because they are too young, those who need access to other CFTR modulator therapies, and those for whom CFTR modulator therapies simply do not work. To address this, CFNZ will continue to highlight and advocate for medicines and treatments for everyone with CF.



KALYDECO

In its submission to Pharmac on the proposal to fund Trikafta, CFNZ requested that access to Kalydeco be widened as part of the same decision. CFNZ believed there was a strong case for this, given Kalydeco had been assessed and was already funded by Pharmac for some people with CF. It is also provided by the same supplier, Vertex Pharmaceuticals, and Pharmac's Respiratory Advisory Committee had recommended a high priority for funding. Unfortunately, however, CFNZ's request was not progressed.

While Pharmac acknowledged a strong desire for all those with CF who could benefit from a CFTR modulator therapy to have access to one, there is still no indication of when this will happen. CFNZ met with Pharmac staff in July to provide data on the numbers of people who would benefit. At that meeting, we again urged Pharmac to widen access as soon as possible and requested that Pharmac come back to us with advice on when a decision would be made. We have yet to receive that advice.

CFNZ has now written to Pharmac raising concerns over the continuing delay and requesting that everyone with CF be treated fairly and equitably, by adopting the same approach to widening access to Kalydeco as has been put in place for Trikafta. That is, by including rare mutations with evidence of benefit in the eligibility criteria for Kalydeco, and providing for those with other rare mutations known to benefit, to access Kalydeco through Pharmac's Named Patient Pharmaceutical Assessment (NPPA) process.

To make people who would benefit from the widening of access to Kalydeco wait while there is a further assessment and ranking is unfair and inequitable. There is no equity until everyone with CF who could benefit from a CFTR modulator therapy has access to one.

TRIKAFTA FOR 2-5 YEAR-OLDS

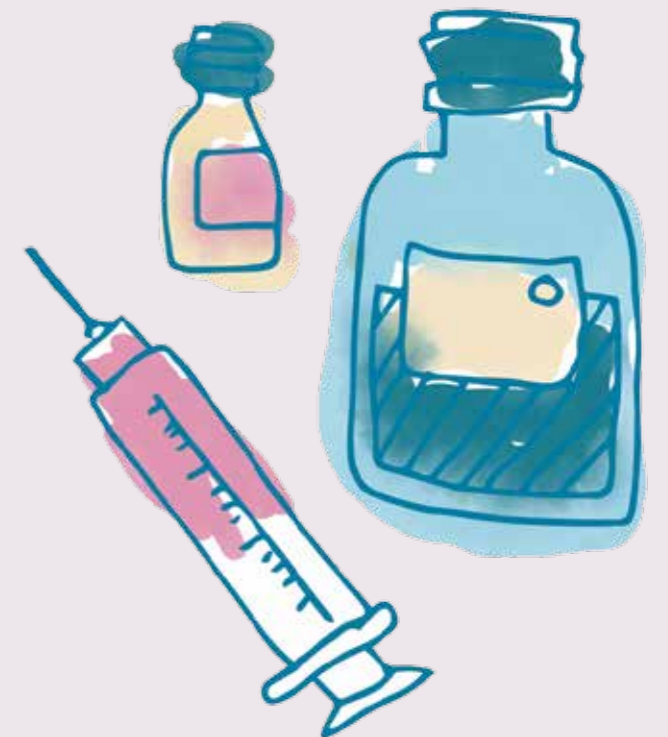
In April 2023, the US Food and Drug Administration (FDA) approved the use of Trikafta by children aged 2 years to 5 years old.¹ Vertex Pharmaceuticals has also made applications to the European Medicines Agency, and the UK's Medicines, and Healthcare products Regulatory Agency for the use of Trikafta by this age group. No application has yet been made to New Zealand's medicines' regulator Medsafe.

MRNA THERAPY CLINICAL TRIAL

In December 2022, Vertex Pharmaceuticals announced it had received FDA approval to trial VX-522, an mRNA therapy targeted at treating the underlying cause of CF lung disease in the approximately 5,000 people who cannot benefit from CFTR modulator therapies.²

A Phase 1 clinical trial has now been initiated to test the safety and tolerability of the therapy in people aged 18 years and older with CF, and a genotype not responsive to CFTR modulator therapy. The trial is expected to report by January 2024.

Phase 1 trials are the first step in what is usually a three-phase clinical trial process undertaken before a medicine is submitted to safety regulators for approval for use.



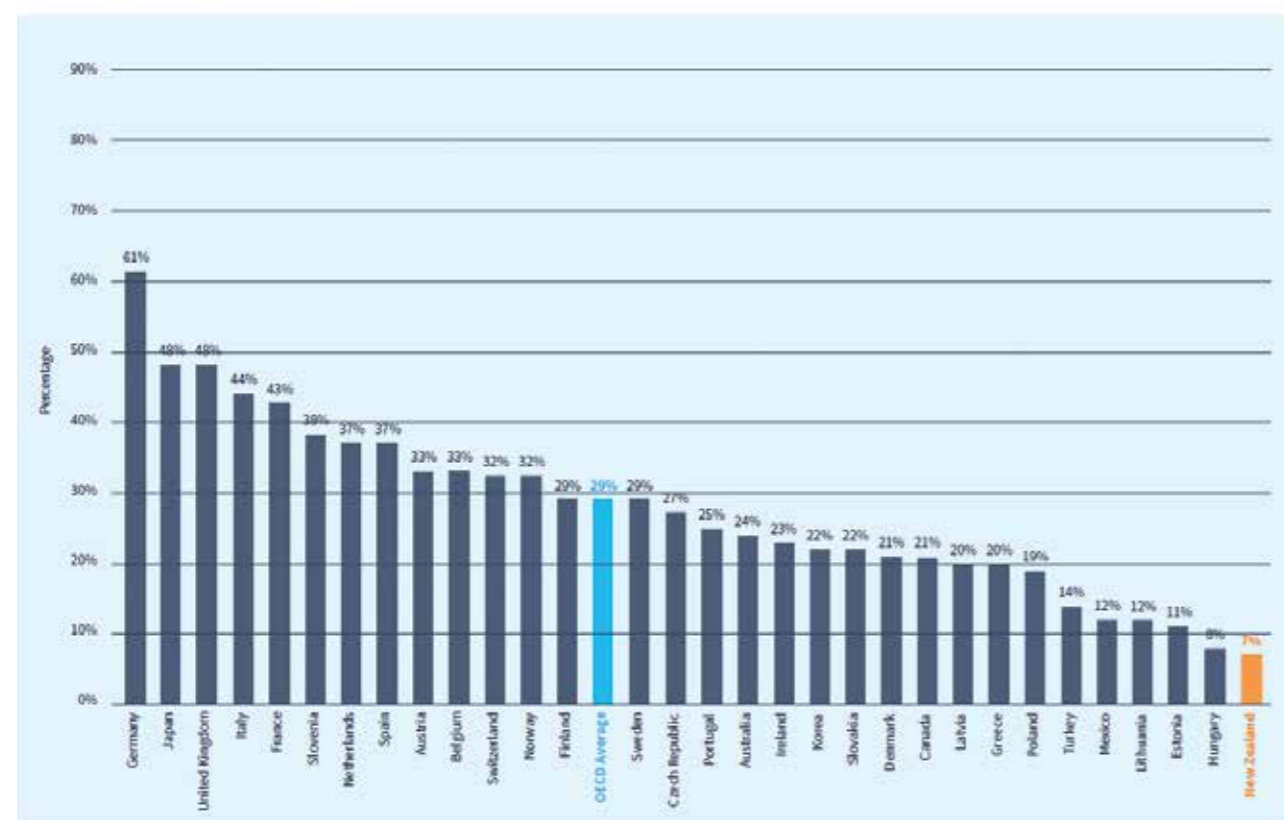
Access to Medicines in New Zealand

MEDICINES' FUNDING

Everyone in New Zealand should have access to affordable and essential medicines. Adequate investment is needed to maintain a robust health system and provide access to medicines that are part of standard international treatment regimes. Sadly, this is not the case in New Zealand.

New Zealand is ranked dead last. We are at the bottom of the OECD, 32nd out of 32 countries for the public funding of new medicines between 2012 and 2021. By comparison, Australia ranked 18th and the United Kingdom ranked third.

Percentage of New Medicines Reimbursed by Public Insurance Plans by OECD Country (of all 460 new medicines launched from 2012 to end of 2021)



New Zealand publicly funded only 8 percent of the modern medicines launched in the last decade, while Australia funds 105 modern medicines that New Zealand does not. New Zealand is also slow to publicly fund new medicines, being on average twice as slow as comparable countries.

Medicines that have been approved for funding and included in Pharmac's Options for Investment (OFI) list have been on the OFI list for over five years on average.³

In April 2023, there were 109 applications waiting for funding on Pharmac's OFI list.⁴

The key reason for this is the lack of investment in medicines, with the medicines' budget failing to keep up with population growth and inflation.

The additional funding provided to Pharmac by the Government to fund new medicines or widen access was only provided for in the 2022/23 and 2023/24 years.

To maintain access to the same list of funded medicines, an additional \$181 million is needed, and this **does not include funding for any new medicines. This could mean no new medicines will be funded until there is a commitment from Government to do so.** The Treasury has already warned the Government twice in the Budget Economic and Fiscal Update (BEFU) about the funding which is missing from the health budget from 2024 onwards.⁵

To meet the goal of providing access to medicines that are part of standard treatment regimens overseas will require significantly more investment from Government, potentially a doubling of Pharmac's Combined Pharmaceutical Budget (CPB).

Without such investment, Kiwis who need access to unfunded medicines will be forced to privately fund those medicines or leave New Zealand to access treatment. Those who are unable to do so will have to go without the treatment they so desperately need, with dire consequences for many.

A timely campaign has been launched by Patient Voice Aotearoa, **MyLifeMatters**. A collective of patient advocate organisations representing more than 1 million patients with cancers, rare disorders, diabetes, and other life limiting conditions, will be tackling the issue of investment and timely access to new and breakthrough medicines for the people of New Zealand, as we head towards the election. CFNZ will be one of the organisations supporting this campaign.



¹ <https://investors.vrtx.com/news-releases/news-release-details/vertex-announces-us-fda-approval-trikaftar-0>
² <https://news.vrtx.com/news-releases/news-release-details/vertex-announces-investigational-new-drug-ind-application-vx-522>
³ New Zealand's Medicines Landscape 2022/23 Medicines New Zealand
⁴ <https://pharmac.govt.nz/medicine-funding-and-supply/the-funding-process/priority-lists/>
⁵ <https://www.treasury.govt.nz/sites/default/files/2023-05/befu23.pdf> - page 90
<https://www.treasury.govt.nz/sites/default/files/2022-05/befu22.pdf> - page 80

PHARMAC REVIEW

The other key part of improving access to medicines in New Zealand is ensuring that the organisation that makes decisions about which medicines are funded, Pharmac, is operating effectively.

The Government established an independent panel to review Pharmac in March 2021. The purpose of the review was to ensure that Pharmac makes the best contribution it can to improving health outcomes for New Zealanders.

The final report of the Pharmac Review Panel was released in June 2022. The report made 33 recommendations for change, the bulk of which were accepted by the Minister of Health.

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

Reform of Pharmac is a key part of ensuring that New Zealanders have access to the medicines that many so desperately need.

With an election on 14 October, now is the time to urge those campaigning to be in Government to commit to making a significant increase in medicines' funding and fully implementing the recommendations of the Pharmac Review. The incoming Government also needs to hold Pharmac fully accountable for performance and delivery.

Other Advocacy initiatives

Rare Disorders Strategy

There are currently more than 300,000 people in New Zealand living with a rare disorder. The Ministry of Health is currently preparing a Rare Disorders Strategy to provide a clear direction of travel for the health sector as to how improvements for people with rare disorders will be progressed over the next decade.

CFNZ is supporting Rare Disorders New Zealand to provide input and feedback to the Ministry of Health on the Strategy and by participating in webinars held by the Ministry. CFNZ's view is that the Rare Disorders Strategy must lead to real action and measurable progress in health outcomes for people with rare disorders. There must be a clear plan of action with the roles and responsibilities of health agencies identified, together with a timetable for implementation, how progress will be measured, and how health agencies will be held accountable for delivery. Without these things, the Strategy will simply gather dust on a shelf.

Therapeutic Products Act 2023

The Therapeutics Products Bill 2023 passed into law in July 2023. The new Act replaces the Medicines Act 1981 and regulates medicines, medical devices, and natural health products.

A number of significant concerns were raised as the Bill went through Parliament. These included retaining the right for individuals to import unfunded medicines from overseas for personal use, the ability for organisations such as CFNZ to advocate for unfunded medicines, the ability to set up Givealittle pages to pay for medicines, and the continuation of compassionate access schemes where some

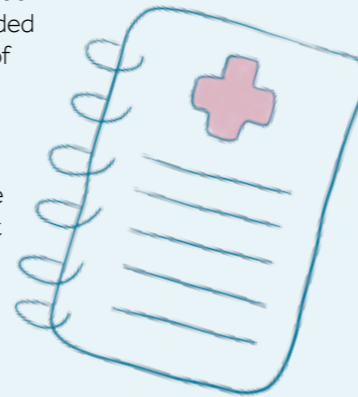
pharmaceutical companies provide access to unfunded medicines free of charge.

The Bill also provided for regulations to be made to prevent "astro-turfing" - defined as a situation where a professionally orchestrated public relations or marketing campaign is disguised as having arisen from grassroots support or unsolicited public comments. The regulations would require a person or organisation to disclose any funding or in-kind support from the sponsor, manufacturer, or supplier of any therapeutic product that was being communicated or advertised.

As part of the finalisation of the Bill, the right to import medicines for personal use was retained and the Minister of Health clarified in Parliament that patient fundraising, advocacy and media activities were not intended to be covered. The Minister has also since indicated that there was no intention to reduce compassionate access schemes.

The Act is now in place but regulations have yet to be put in place. CFNZ will be keeping a watchful eye on the new regulatory framework to ensure that the Act works as intended and to ensure compliance with any requirements relating to advocacy for unfunded medicines, and any other relevant activities.

Being free to advocate for new medicines and treatments is essential, given the current poor state of access to medicines in New Zealand. Without such advocacy, there is little doubt that Kiwis with CF would have had to wait much longer for Trikafta to be funded.



A MEANINGFUL PARTNERSHIP

CFNZ is profoundly grateful for the unwavering support and dedicated pro bono assistance extended by Simpson Grierson over the past few years.



Zac Fargher
Senior Associate,
Simpson Grierson

Pro bono relationships are of immeasurable value to organisations like CFNZ, serving as a cornerstone of support that extends far beyond financial contributions. These partnerships offer access to specialised expertise and resources that we would otherwise not be able to afford, empowering the opportunity to amplify our impact.

Since 2020, Simpson Grierson has wholeheartedly undertaken giving us legal support on a pro bono basis, and we are indebted to the numerous individuals within the firm who have contributed their time, expertise, and passion to our cause.

CFNZ is profoundly grateful for the unwavering support and dedicated pro bono assistance extended by Simpson Grierson over the past few years. As the sole charitable organisation in New Zealand wholly devoted to enhancing the lives of individuals with cystic fibrosis (CF) and their families, CFNZ acknowledges the pivotal role that Simpson Grierson has played in furthering our mission.

We are especially appreciative of Senior Associate Zac Fargher, who, as a member of the CFNZ Board, has seamlessly bridged the gap between the Board's vision and the legal work conducted in partnership with Nick Bland during the constitution review. After two years serving on the CFNZ Board, Zac now leaves New Zealand to pursue a new adventure in Sydney. Zac has used the gift of his legal craft to support CFNZ with one of our largest organisational projects and we are truly grateful to him in ensuring we meet the needs of a modern charity in New Zealand.

Simpson Grierson's pro bono work for CFNZ has covered a wide range of initiatives, including advice on our



Vaughan, Shan, Lisa, Ange. Photo credit: Werk Agency

Cruel Needs Kind campaign and our new mascot, Fred Bear and for this, we extend our gratitude to Raymond Scott and Vaughan Somerville, whose dedicated legal counsel on intellectual property matters has been hugely valuable.

"Together, we are making a real difference, one pro bono effort at a time."

One of Simpson Grierson's team, Vaughan Somerville, has CF so he knows all too well the challenges that CFNZ faces. "While there are a number of us in New Zealand with CF, it doesn't quite get the recognition that other genetic conditions do. Funding can be hard to come by for CFNZ, especially in comparison to other charities, so it's great to see a firm like ours getting involved in work that actually matters to people and has real-world significance every day for people with CF."

"On a personal level, Trikafta is life-changing for me. My parents were told that if I made it to 21, that's great.

So, for me to be where I am today, working in a firm that is committed to supporting people living with CF, like myself, that, to me, is awesome."

"We have so much gratitude for the team at Simpson Grierson. Their support of CFNZ by way of pro bono legal advice and support has been hugely beneficial for us, as well as being a great help. We love working with Simpson Grierson, and their commitment to partnering with us, so we

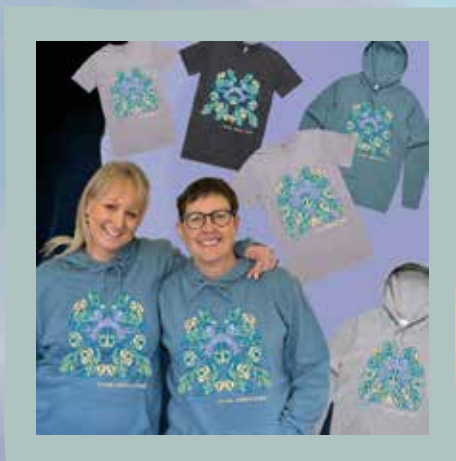
can channel our full focus into our CF community, means more than we can say." Lisa Burns, Chief Executive.

When we passed on our thanks to Simpson Grierson's Pro bono Partner, Shan Wilson, she said that it "meant a lot to Simpson Grierson to be able to work in partnership with CFNZ so that we can save CFNZ spending much needed funds on legal fees, as opposed to CF support. We also feel pleased to lend our expertise to keep CFNZ safe from legal concerns, as we know this all helps CFNZ focus on what the charity does best, helping those in the community."

The partnership between Simpson Grierson and CFNZ provides inspiration about the power of giving, demonstrating how making a Deliberate Act of Kindness and providing pro bono support can profoundly make a difference in the lives of people with CF. CFNZ extends our heartfelt appreciation to Simpson Grierson for their unwavering dedication to our cause and their significant contributions towards enhancing the quality of life for individuals with CF and their families in New Zealand.

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