

CF News

AUTUMN 2024

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MEANINGFUL PARTNERSHIPS: LOCKTON CARES

We celebrate a beautiful partnership

ENDURING STRENGTH: A STORY OF RESILIENCE & HOPE

Read all about David Donohue and his incredible journey with cystic fibrosis

BOUNCING FROM OLYMPIC PODIUM TO CFNZ

Meet Dylan Schmidt, trailblazing gymnast and CFNZ's very first official ambassador





Cover 4 year old Lincoln Dunlop, on his bike. Read more about Lincoln and his family on page 7.

Writer of 'Bouncing from Olympic Podium to CFNZ' and 'Enduring Strength: A story of resilience and hope': Ingrid Grenar, a member of our CF Community.

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

Contact:

T: 09 308 9161

E: admin@cfnz.org.nz

Fundraising:

T: 09 308 9161


E: fundraising@cfnz.org.nz


Stories for CF News:

T: 09 308 9161

E: comms@cfnz.org.nz

 Facebook: [/CysticFibrosisNZ](https://www.facebook.com/CysticFibrosisNZ)

 Instagram: [@cysticfibrosisnz](https://www.instagram.com/cysticfibrosisnz)

 YouTube: [Cystic Fibrosis NZ](https://www.youtube.com/CysticFibrosisNZ)

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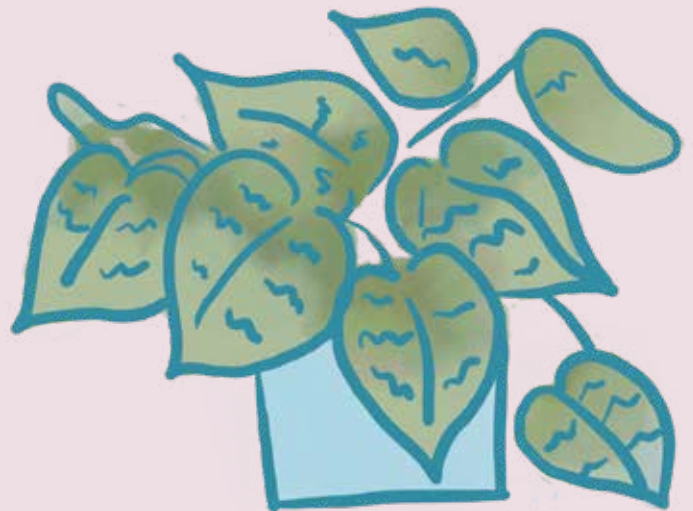
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A NOTE FROM LISA

One of the things I love most about our CF News magazine is the stories of joy and triumph, alongside genuine resilience which continues to inspire me and the entire CFNZ team every day.



After a rejuvenating break over the festive season, I took a moment to reflect on the monumental achievements of 2023. Yet, already into March 2024, it's clear we have a new set of challenges and opportunities to meet the evolving landscape of CF care in New Zealand.

The latest edition of CF News is packed full of incredible stories from people in our CF community, from navigating the unpredictable nature of CF to some passionate fundraising initiatives which have delivered remarkable contributions to help fund the services and programmes we deliver into our communities.

Nearly a year since the arrival of Trikafta, we find ourselves gaining deeper insights into the changing needs of our community. We must remain agile, continuously evolving to meet these needs while raising awareness that our journey towards a cure for CF is ongoing.

While once unattainable milestones are now a reality for some, we also recognise the stark reality that not everyone shares in these victories. We are striving towards ensuring there is equity and consistency around the support we deliver, regardless of personal circumstances or geographic location. It's our hope that every individual has the support they need so that no-one feels left behind.

On page 8 we share Jimmy Donohue's transplant story, which is one of courage and determination. It serves as a reminder that everyone's lived experience of CF is unique to them, and that CFNZ must continue to do all we can to provide support and enable quality of life in a way that is meaningful for them.

In the months ahead, we'll explore innovative avenues for support, starting with our first Think and Be Me Wellbeing Workshop on Saturday the 25th of May. Save the date! We'll also be looking at ways to address challenges such as educational gaps, career uncertainties, and financial struggles which requires a fresh approach, including psychological support to navigate emotional health.

I'm thrilled to announce that Olympic bronze medallist Dylan Schmidt has joined us as a CFNZ Ambassador, you can find out more about Dylan on page 16. Dylan is a valued member of the Gymnastics New Zealand Community, and we are delighted that CFNZ has become an official charity partner for this grassroots organisation to help us raise greater awareness.

I'd like to extend a heartfelt thank you to the CFNZ team and our Branches for their unwavering dedication to our mission. It's your hard work and commitment that allow us to make a tangible difference in communities across New Zealand.

We hope you find this edition of CF News as inspiring as we have in crafting it for you.

Warmest wishes

Lisa Burns

Chief Executive





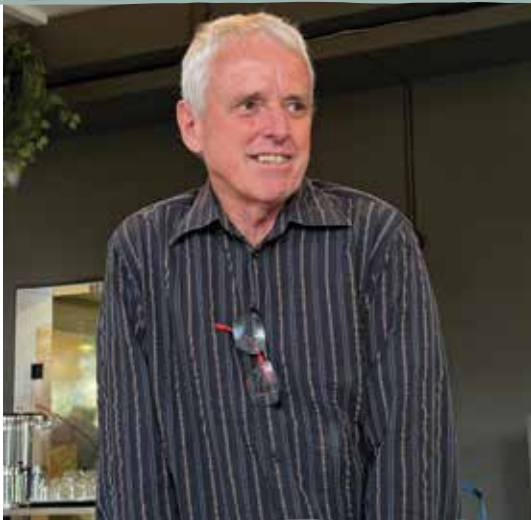
IN CASE YOU MISSED IT...

THE ULTIMATE FUNDRAISER

Following on from last year's success, Nexus Ultimate Frisbee ran another Ultimate Frisbee tournament in honour of their wonderful teammate and friend Kim Bryant. The tournament raised a total of \$2,134.24 for CFNZ. Wellington turned the weather on, and the day was full of competitive and well-spirited ultimate - something they know Kim would have been so proud of.

They would like to thank their generous sponsors for donating raffle prizes, the governing body New Zealand Ultimate for donating the tournament levy, and for the Wellington Ultimate Frisbee community for their support of this amazing event.

Thank you so much team Nexus, you guys are the ultimate!.



THANK YOU VERY, VERY, VERY MUCH

We want to express our gratitude and appreciation to Warwick Murray, a long serving member of the CFNZ Board who stepped down from his role as Board Chair in late 2023.

Warwick joined our Board in 2016, driven by his commitment to make a difference to the lives of the people in our CF community. Over the years, his efforts and contribution have propelled our organisation forward, guiding us through moments of challenge and celebrations. It is under his leadership as Board Chair that we achieved so much in 2023.

We are deeply grateful for his service and leadership during his time on the Board.

**SATURDAY
25 MAY
2024**

SAVE THE DATE

THINK AND BE ME WELLBEING SERIES



This session will be the first in our Think and Be Me Wellbeing series which will be accessible to everyone in our CF community from children to young adults, adults with CF, parents, family members, and even our clinical CF Teams. This will be a session focused on understanding mental health and wellbeing using engaging storytelling and visuals with memorable messages, and practical strategies. A mental wellbeing educator with 20+ years' experience delivering educational sessions on wellbeing in schools and workplaces, will lead this online webinar. More details to follow.

CHRISTMAS TREE FESTIVAL 2023 - A TREE-MENDOUS EVENT!

Our annual Christmas Tree Festival at Wellington International Airport is one of those events that is extremely special to all who take part and all who get to experience it while travelling through Wellington Airport around Christmas.

The trees were up and decorated on the 21st November and remained in place, spreading Christmas cheer until early January.

Last year we shared that 2022 was the biggest festival on record, and we are so happy to report that 2023 surpassed that with 58 fabulous organisations taking part, giving their resources, creativity, and support to the event.

Through tree sponsorship, the lucky dip tree at the Gala opening night, and donations from visitors walking through the Christmas Tree forest, raised an incredible

\$57k to support Kiwis living with CF. During the opening gala, Lisa interviewed the mother of a young teen living with cystic fibrosis, who has had a really rough time over the last 12 months. Their story was extremely inspiring, reminding the gala attendees why the festival is such a special and important event for our CF community.

We are so grateful to everyone involved in the 2023 festival, working to raise funds for CFNZ Wellington Branch, increasing awareness of CF in New Zealand, and overall contributing to a successful and magical festival once again.

Special mentions were given to new participants for their trees - Marvel, WT Partnership, The Children's Bookshop, Pots by Aimee, and Talbot Mills Research. Also deserving recognition were some of the trees from returning sponsors, Annie Newell – Lowe & Co, Colliers, Three Quarter Coffee, Christmas Creatives, New Zealand Rugby, and New Zealand Post.



We were star-struck by the Sam's Art House "It was on a Starry Night" themed tree – taking out the People's Choice Award for the second year running.



Winner of Best Tree was California Home and Garden Centre with their unbe-leaf-ably beautiful, NZ native and gardening themed tree.



We went absolutely nuts for the second place, woodland themed tree – from Squirrel – Mortgages, Saving and Investing.



And in third place the Scots College Junior School did a sweet job on their wonderful ice-cream themed tree which is too cool.

A heartfelt thank you from CFNZ to everyone involved in the 2023 Christmas





Judge and Artist, Lynne Sandri spoke at the festival opening night on the 30th November.

"So much hard work goes into creating these trees, the commitment from the businesses, staff, teams, and families that create these trees every year - thank you for doing that and being part of this.

Christmas trees signal the end of the year, beginning of summer, spending time with your families, and giving back really. It's been lovely watching the reactions to the trees, people playing around them, and some people smiling and laughing.

Every year I take a great delight in seeing the new trees, and of course the loyal sponsors returning each festive season."



Huge thanks to the brilliant Wellington International Airport team for once again making this magical festival a reality.



Tree Festival, we are so grateful for your generosity and support.



SHOOTING FOR THE STARS

As often happens around Christmas time, a very special person came to us with a very special idea. Jordi Boyd from The Hits Wellington became aware of the CF Christmas Tree Festival, and Shooting for the Stars was born! This project meant a lot to Jordi, who has a personal connection with CF.



The Hits sponsored a tree for the Wellington Christmas Tree Festival, decorated with 27 stars. These stars represented the 27 families in Wellington, with children aged 12 and under who are living with cystic fibrosis.

We asked each of the 27 families what wish The Hits could fulfill for their child for Christmas and they came back with some extra cute responses!

“ I would wish for a bendy-foot Barbie ” – Brooke

“ Tom would love some goal keeper gloves, he is football mad! ”
– Tom's mum

“ I wish for a pastel coloured rug for my bedroom ” – Madi

The children's wishes and some of their photos then featured in the stars hanging on The Hit's Christmas Tree in the Wellington International Airport terminal – the children were all so excited to have their wishes granted and delivered before Christmas by The Hits Wellington Christmas elves.

But it doesn't end there, the Hits delivered radio ads throughout the month of December calling for donations, and kicked it off with a generous \$1500 donation themselves for CFNZ Wellington Branch.

We are so grateful to Jordi and all of The Hits Wellington team for making this special event happen at short notice and with such success.

“The Hits Wellington were thrilled to partner with this year's CFNZ Christmas Tree Festival and help fundraise for such an amazing cause!

It was nothing short of an honour to help raise an additional \$1500 in donations for such an amazing foundation and celebrate such a special time of the year with the families affected by cystic fibrosis. We had an insanely fun time shopping for Christmas gifts for all of the children affected by CF in the Wellington region (we love the toy aisle!), and we can't wait to do it all again - bigger and better - in 2024. ”

Jordi Boyd, The Hits Wellington.



THE DRIVING FORCE BEHIND THE CFNZ CENTRAL DISTRICTS BRANCH

Lincoln (4) is the gorgeous little guy on the front cover of this edition of CF News.

You may also recognise him from our 2023 Christmas fundraising campaign.

Lincoln lives with his mum and dad, Kayne and Joelle, and sister Harriet (6) in Palmerston North, and they are the family behind the revitalised CFNZ Central Districts Branch.

The Dunlops were living in New Plymouth when Lincoln was born, and they received invaluable support from several local families when he was diagnosed with CF soon after birth. The family moved to Palmerston North to be closer to family and found it was difficult not having that same support network of families around them. The support that they received from CFNZ in the early days was the driving force behind their decision to head the local branch. They are passionate about being able to provide the same level of support, advice,

and experience to other families whose lives are affected by CF. "Being able to connect with six families in the region fairly quickly has been good for them and for us" says Kayne.

"CFNZ has been a great support for us from the start. We have derived great value from the families within CFNZ who have offered titbits of

advice, a sympathetic ear, and in some cases simply someone else who understands all the various aspects of having a child with CF. The resources that CFNZ provide to the families to help them along their journey, help to ease the pressure and provide support, often when things are the toughest, not least the support of the Social Workers and their help navigating the health system."

"For them to pass on a little bit of their experience and expertise was a game changer, it was a massive help"

says Kayne.

We are also hugely thankful that Kayne agreed to join the CFNZ Board late 2023. Kayne's history of working in pastoral care and people management brings a great skill to the Board, along with his experience as a parent with a child with CF, and running a Branch.

We are so excited and grateful to have this passionate family restart the Central

Districts Branch and bring their energy and enthusiasm to showing other families the support and kindness that can make such a difference.



Every year Bowls Palmerston North hosts a charity tournament and on April 28th the Central Districts CF Branch is fortunate to be the benefactor of the tournament. With Lincoln's Grandfather a member of the club we are very thrilled to be the recipient of their support this year.

Head to the **Bowls Palmerston North**

Facebook page if you would like to enter into this fantastic tournament.

ENDURING STRENGTH:



David 'Jimmy' Donohue has lived in Wainuiomata his whole life. He has four children including two-year-old twin boys, a 9-year-old daughter and a 13-year-old step-daughter with his partner Candace.

His life with CF has taken him on quite the journey. As a child and teen, Jimmy describes himself as, "A bit of a pain as I didn't want to take my pills or do physio."

He had good and bad years growing up and sports brought him lots of joy. Rugby is his obsession and he played until he was 23 but had to stop once his portacath was put in. This didn't stop him from being involved in the sport, "I went from playing to coaching and managing for both kids and adults. I just love it. My friends say the rugby club is my second home," said Jimmy.

He always wanted a big family and had spent many years working with kids and young people off the rugby field too, he said, "I was a teacher aid for special needs kids from kindergarten up to college."

And, more recently he had a busy career working as a courier driver for 50+ hours a week.

Throughout his adult life, his health has been up and down clocking up over 100 hospital stays.

"In 2019 the conversation about a lung transplant started, and in September, I was added to the waiting list in mid-November. I was pretty unwell, my lung capacity was 17% at the time - just walking from the lounge to my bedroom was a struggle."

Jimmy didn't need to wait long, "I got the call 17 days later, I had to scramble to get some blood results to the Auckland team for them to approve the transplant. They did, but there were no domestic flights available so I had to go VIP on a private plane to get to Auckland Hospital."

After nine and a half hours of surgery, Jimmy had his new lungs. His miracle had happened.

A STORY OF RESILIENCE AND HOPE



His timing was also not bad. As he returned home to spend pretty much a year isolating due to the rejection risk, the whole of New Zealand went into lockdown as the Covid-19 pandemic reached our shores.

In 2022, his twins arrived and Jimmy loved being their dad and living a normal life again. But in May 2023 things changed dramatically.

"One day at work I just couldn't do my deliveries properly and my lung function went from 80 to 45. Auckland Hospital asked me to come right away," he said.

"He had an infection and significantly lower lung capacity. The hospital started strong antibiotics and did a few procedures, and it still came back as an infection and no rejection. The doctors ended up concluding the infection had caused the rejection reaction that was reducing his lung capacity, so they started a plasma replacement on his blood right away and that went well," Candace said.

"You notice the breathing straight away. Before the transplant, you can't get a breath in but suddenly you can take a deep breath. It's amazing,"

recalled Jimmy

Candace was later on a video call with Jimmy while he had his mum by his side when he suddenly couldn't breathe.

"He called me back and said sorry if it scared me but then it happened again. His mum thought she'd ended the call but I was still there, so I heard all the doctors come in and whisk him down to ICU. I was glad to be able to be there in some way."

Five hours after Jimmy had a tube removed from his plasma treatment it was found he'd gone into sepsis which resulted in him being put onto a ventilator as his body went into septic shock.

At this point, the doctors prepared the family for the worst and Jimmy's friends and family all gathered to say their goodbyes. Candace recalls hearing the news but that they wanted him to continue to receive treatment,

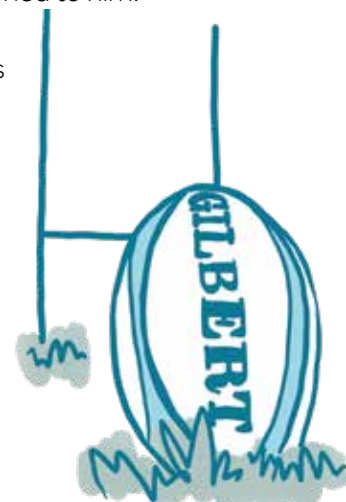
"It was very hard to see him that way. They chucked the book at him to help and even called a Toronto lung specialist to get advice on his condition. The doctors were amazing and they saved his life. I returned the next morning to find they were surprised his stats had improved overnight. We were told not to get our hopes up as there could be organ or brain damage so it was early days, but I just couldn't believe it. After a few days, he was moved to a ward."

Jimmy wasn't out of the woods yet but luckily Candace was with him on the ward,

"I am so glad I was there to press the call button. He had two seizures, so he was back in ICU but once he woke up, he was alert but obviously scared and confused about what had happened to him."

Jimmy's recovery was long, he spent 50 days in hospital and had to learn to eat, walk, and write again. He returned home in July 2023, in time to celebrate his birthday with family in August.

Continued on next page



In November last year, unfortunately Jimmy was added to the transplant waiting list again. Following a check-up they found his lung function was down again – having a second double lung transplant is not something many have experienced, Jimmy and his family are very glad this is an option for him.

He's still waiting and says this second time it's feeling excruciatingly slow but he wants to live as normally as possible, spend time with his kids, do treatment, and move when he can.

Candace says, "If you're awaiting a transplant you have a plan and a go bag. The kids know what's happening and everyone is ready to jump into action when we get that call."

Jimmy's advice for those who may one day need to go on to the transplant waiting list was,

"If you are going on the list, do your treatments before you get your new lungs and try to build muscle as you will lose a lot. You'll need those muscles to recover and building back up takes a long time and a lot of work. Eat and stay healthy, and stay away from anyone sick."



ACKNOWLEDGING YOUR MENTAL HEALTH

"Mental health is really important. It is a very scary time as you wait and you worry you are going to be too sick for a transplant."

"I am a positive person so I say keep active and normal and stick to your usual routine and treatments".

Jimmy now has a Givealittle page to help support this next journey. There are inevitably increased financial stresses for someone with CF and their family while they wait for, and go through a transplant, it is a time when extra financial support is necessary.

"As a family member, you are more than just support, you are a carer and are always there to update the medical staff regularly," said Candace.

Jimmy is thinking of the future and hopeful of receiving that call soon,

"I am slowing down but I want to do more and keep going. I am a positive person and keep life as normal as possible. We just plan on the day if we are going to do anything or go anywhere. It's really important to me to ensure people know they can be donors so we can save as many lives as possible for many different medical reasons."

Jimmy's Givealittle page: <https://givealittle.co.nz/cause/david-needs-new-lungs-round-two>

A MESSAGE ABOUT ORGAN DONATION

— HAVE THE CONVERSATION TODAY

A message from Candace

"I want people to sign up to be donors to help people like Jimmy if the worst were to happen."

Thinking now about whether you would want to be a donor, or not, and having a conversation with your family or whānau, will mean that if put in this uncommon situation, they will know what your wishes are.



THANK YOU FROM THE DONOHUES

"I would also like to thank CFNZ and their Social Workers, and all the doctors and nurses, for all their support during this time. We've had financial support through CFNZ's Transplant Grant which has helped a lot. To the Social Workers who helped navigate WINZ etc and to the doctors and nurses for keeping me alive and supporting my family during those hard times. You all are truly amazing."

CONQUERING LUGTONS ROUND THE BRIDGES



Last year the incredible team at SD European took on the challenge of the Lugtons Round the Bridges in Hamilton, doing an amazing job, raising awareness and funds for Cystic Fibrosis NZ. Sunday 12th November dawned bright and sunny and the SD European team of 28 powered through the 12km fun run.

It was so wonderful to see the team taking on the challenge to promote health and wellness, camaraderie as a team and doing a wonderful job of spreading the word about CF. In the lead up to the day the team collected donations via Givealittle, and then had a marquee set up that people could visit, find out more about SD European and donate on the day. In total they raised an amazing \$2840.

“A heartfelt thank you to everyone who supported and contributed to our journey in preparing for the Lugtons Round the Bridges event. Your generosity and encouragement made a significant impact, as we were raising funds for Cystic Fibrosis NZ who provide crucial support to families in New Zealand affected by this condition and we are truly grateful for all your support”

Alexis Johnston, Marketing Coordinator

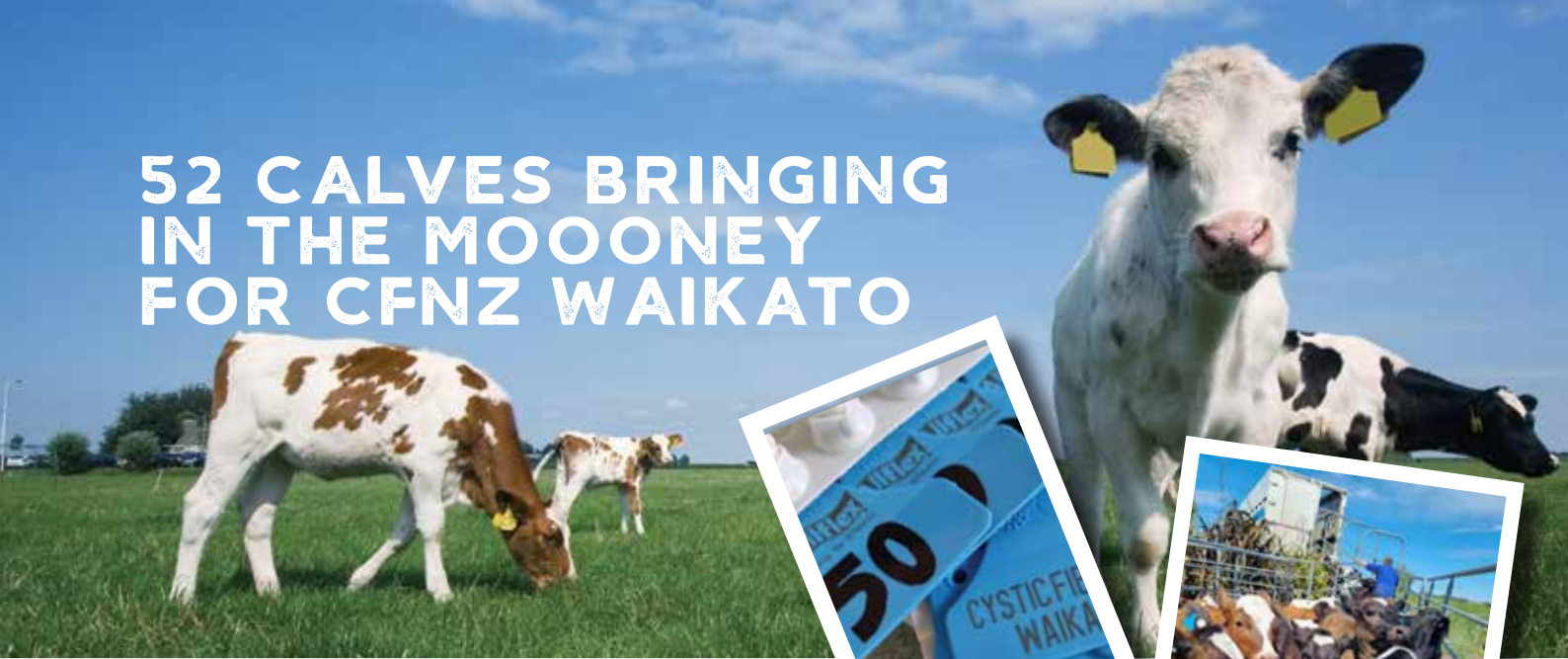
Raising funds for CFNZ is a cause that is close to the heart of the employees of SD European. Keaton Daly (6) was diagnosed with CF at just 4 weeks old. His grandfather Steve started the company in 1991, and now, Steve's three sons, including Keaton's dad, Garrett, are shareholders in the business.

Thank you so much to courageous Keaton, the rest of the Daly family, the team at SD European and everyone that donated to the Lugton's challenge!

“Together, we've found strength in the face of adversity, showcasing the incredible power of determination and resilience. Keaton's journey has been our journey, and we continue to learn, adapt, and grow.” Hayley, Keaton's mum.



52 CALVES BRINGING IN THE MOONEY FOR CFNZ WAIKATO



A calf auction may not be the first thing that comes to mind when thinking about fundraising for CFNZ, however for Josh and Kareena Sneddon it was a perfectly logical idea!

The Sneddon's are parents to 4 year old Natalie, who lives with CF. They wanted to run a fundraiser for the CFNZ Waikato Branch as a way to give thanks for all of the support they received during their first whirlwind year after Natalie was diagnosed.

"We received parking vouchers which helped during the first few months of weekly and fortnightly clinic visits. We have received food vouchers, during tough times at home and during admissions. We get support with medical supplies. But ultimately, we wanted to help out those around the Waikato that are traveling the same journey we are."



A total of 52 calves were donated, ranging in size and breed, from all around the Waikato and Bay of Plenty area. There were even 3 virtual calves donated!

The wonderful community rallied together to donate calves, deliver them, and then purchase them, with all proceeds, a phenomenal \$18,947.81 going to CFNZ Waikato Branch.

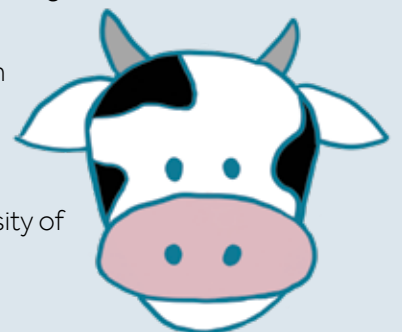
The highest price calf was a Murray Grey heifer who sold for \$575.

Special thanks for their kindness go to:

- Ryan Smit of Karapiro, from Mowai Transport Ltd, who transported all of the calves from the Sneddon's property to the saleyards, for FREE.
- Brogan Collins who drove 600km to collect calves from Te Awamutu, Huntly, Whangamata, Thames, Morrinsville, Matamata, and delivered them to the Sneddens in Tokoroa. He also donated a calf to the auction.
- Adam Stockholm who donated his time by gathering calves around the Otorohanga, Te Awamutu, and Arapuni area and bringing them to Tokoroa as well as donating a calf to the auction.
- Steve Emile was the stock agent, from NZ Farmers Livestock. He sorted the sale of the calves at Frankton Saleyards AND waived his commission fee.

Josh and Kareena's local community of Tokoroa reared and donated 50% of the total calves sold, a wonderful display of community spirit and how you can take just about anything and turn it into a fundraiser!

Thank you so much to Josh and Kareena and everyone involved in making the auction such a success, we are moved by the generosity of your community.



SUPPORT LOCAL



Fundraise to support your local CF Community

At CFNZ, we cherish our community fundraisers—they're vital for spreading awareness and gathering crucial funds. Your support through individual fundraising or with one of our Branches is beyond invaluable. We're always excited to welcome more fundraisers into our fold!

So if you've ever considered raising funds to support Kiwis living with CF in your local area but aren't sure where to start, we've given you a few ideas to get you going.



We are happy to help you wherever we can with fundraising resources, including coin boxes, lapel stickers, button badges, balloons, and posters, to power your chosen activity to raise awareness of CF and your Deliberate Act of Kindness.

Contact the team at fundraising@cfnz.org.nz OR your local Branch



CHOCKY FISH

Buy a box of our delicious **Chocky Fish** and watch them swim out the door at your school, workplace, club or just as an extra special treat for family and friends.



SAUSAGE SIZZLE

Who can say no to a cheeky **sausage**?

Approach your local Mitre 10 or Bunnings store and set up a sausage sizzle on a busy Saturday or Sunday morning.



BUZZWORD BAN

Have a buzzword jar in your workplace! Make a list of all the words you are tired of hearing around the office, and how much each word will cost you.



BAKE SALE

Indulge your sweet tooth while making a **difference!**

Get your school or organisation involved and host a community bake sale to raise money. Or simply bake your favourite cupcakes and sell them to your colleagues for a special morning tea.



KINDNESS AUCTION

Sell your time for an act of kindness. Cut your neighbour's lawn, offer to pick up your grandparent's groceries, or wash your mate's car. Donate the proceeds to CFNZ or your local branch.



If all else fails just put the **FUN** in fundraising and ask yourself what would Bob do?



COMMUNITY JOY BOARD



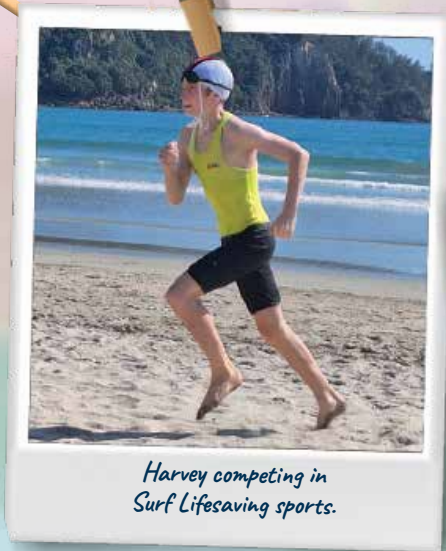
Koanga getting out there this summer, with her team getting 2nd place in their softball tournament.



Lachie has just started taking his first steps and walking, he has also ticked off a lot of firsts over the summer holidays.



Lucas enjoyed a summer of Surf Lifesaving.



Harvey competing in Surf Lifesaving sports.



Renee got married in February! A very happy day.



Maddox (5) and his Dad (Adam) at his Mum and Dad's wedding in January.

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



Luca has started crawling and loving solids. He's getting into everything.



Liam's mum and dad got married!



Ernest with his new bike that was purchased using the CF grant.



Leyla getting in her Summer swims on our road trip to see family for Christmas.



Adalyn started kindy in January and she loves it!



Orson and dad made some Hulk hands.

BOUNCING FROM OLYMPIC PODIUM TO CFNZ

CFNZ is jumping for joy to welcome our very first CFNZ Ambassador, Olympic medalist Dylan Schmidt.

Dylan Schmidt is New Zealand's trailblazing gymnast, who leapt to a historical victory by seizing the bronze medal in men's trampoline at the Tokyo Olympics. Not only was this an individual triumph, but it also marked a milestone as New Zealand's inaugural Olympic trampoline medal.

Dylan first competed at the Rio Olympics in 2016, setting the pace as the first Kiwi ever in the trampoline competition at the Olympic Games, securing a commendable 7th place. This year, his goal is to represent New Zealand again at the Paris 2024 Olympic Games.

In addition to his athletic accomplishments, Dylan also serves as a Special Olympics Ambassador. He travels across New Zealand, visiting schools to share his journey from the trampoline to the podium, inspiring the next generation to embrace healthier, more active lifestyles and now he's going to be helping inspire young people living with CF too.

"I might listen to a bit of country music in the hotel room but otherwise I don't keep earbuds in during the event as you can get a bit lost in them. I tell myself to have fun, be calm and just try and slow everything down."



"I started at five. We just wanted to do flips and have fun," said Dylan. "My parents kept thinking we'd get bored but we just kept going. When we moved to Waihi from Southland, they used to drive me to Auckland three times a week to train."

That family sacrifice paid off when Dylan hit his first big milestone, winning his first World Age Group Championships at age 12 in 2009.

"The world age champs was my first big comp seeing internationals like the Russians, but I beat them! My coach saw the potential and aimed for the Olympics and no one had ever gone from NZ before. The people around me didn't push me too hard. I was very much doing it because I wanted to do it. I still played rugby, tennis, soccer, hockey, and went shooting." He said.

Dylan attended Waihi College until year nine and then he was awarded a scholarship to King's School in Auckland,

"I took time out to train but did okay with my grades. I worked hard and had to catch up a lot on my own time due to training.

I always missed end-of-year exams but passed well with good grades. I did alright in the end, getting a degree in commerce from the University of Auckland, and a job at PWC following an internship."

Now preparing for Paris, Dylan's average training session lasts two hours.

"I do a lot of routine practice but it gets hard on your body, so I do lots of warm-ups and drills too. There's always technical stuff to work on. I've been doing this for 23 years so you wanna try and make it interesting and change it up."

The CF community knows how essential jumping on the tramp can be to keep those lungs healthy so we couldn't be happier to have Dylan Schmidt join the CFNZ family.

Trampolining was a family affair for Dylan too as he first started jumping with his siblings.





"I know how important physical activity is for all of us but especially to keep people with CF healthy so it'll be fun to see what we can come up with together," said Dylan.

Dylan doesn't have much of a pre-competition routine, You actually hate it at the time but as soon as you have finished you just want to do it again. There's just one chance, one moment to get it right. It's not something most people get to experience. It's super stressful in the moment. It's a feeling you can't really describe."

Outside of training and competing, Dylan says he can't sit still, "I am always looking for something to do. As athletes you can get all consumed in your sport but I'm just a Kiwi bloke who likes to do things the best I can. Trampolining is something I do and something I enjoy but when I come home from work the first thing I want to do is see my dog Taco and take him hunting. I'm big into my golf, hunting, fishing, shooting or just getting outside and camping."

Although he's in the spotlight as a successful athlete and reached crazy heights in the world of gymnastics, his feet are firmly on the ground.

"Sometimes people make assumptions that if you say 'I am going to the Olympics to win' they think you're arrogant. But I work hard to get there. You shouldn't be afraid to say things you want to achieve in life. People who don't know you can't judge. My friends don't care, we've known each other before the Olympics and they're just proud of me and enjoy my company either way. Nothing really changes." says Dylan

On working with CFNZ, he's looking forward to getting more involved.

"I just want to support the CF community. I was shocked to learn I couldn't just get lots of kids on a tramp together – CF kids need to do one-on-one and I had no idea about that before getting to know the people at CFNZ.



Here at CFNZ we are thrilled to announce that alongside our partnership with Dylan Schmidt we have also been named Gymnastics New Zealand's charity partner.

Gymnastics is the ultimate sport for full development underpinning a person's success in physical activity, and we know that for our CF community, trampolining is a great way to clear mucus from the lungs. Together with Gymnastics NZ we look forward to working towards bringing awareness to how the sport can positively impact our community.



MEANINGFUL PARTNERSHIPS:

THE MARTIN FAMILY

Niall Martin and his family first learned about CFNZ in 2008 when their son was diagnosed with cystic fibrosis. Niall tells the story about how CFNZ has impacted their family and why he has been so dedicated to give back.



As a family we have been connected with CFNZ since late 2008 when we got our son Sean's CF diagnosis at two weeks. On our very first visit to the team at Starship, we of course like many families, met Jan Tate and she handed us the little brown envelope with CFNZ Auckland Branch printed on it... A parking voucher.

We very quickly learned that CFNZ and the Auckland Branch were there to help, guide, and there to be called upon at any time. We moved to Ireland for a few years when Sean was really little, and when back in NZ, we came back under the care of the team at Starship. Each and every time, Sean was admitted to Starship we would get great support from the Auckland Branch and the work they do for the local community is simply amazing.

It was at that point that I started to get more involved with CFNZ and the Auckland Branch, first sizzling sausages each year with John Thorrat, Phil McKay, and Greg Collins, and spent a little bit of time as a committee member at the Auckland Branch.

THE ANNUAL AUCKLAND MARATHON FUNDRAISER

Having run the New York Marathon in 2010 to raise money for CF Ireland, the most logical step for me was to use the Auckland Marathon as a way of raising funds for Auckland Branch.

It's been about 10 years now I suspect, since we first started the



Auckland Marathon fundraising for the Auckland Branch. I first did this with my former employer, WTW, with amazing support from friends and colleagues, some of whom now work with me at Lockton. And when we started Lockton in September 2021 here in NZ, we got straight into fundraising for CFNZ as a great charity to support.



WHAT IS YOUR 'WHY'?

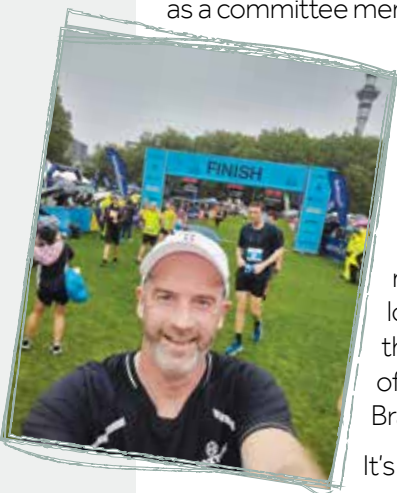
I like running, for sure, but really I love doing the fundraising as I know the value of what CFNZ and its Branches bring. And seeing the passion and commitment from Jill Thorrat, Lisa Burns, Lizzie McKay, and the whole team is just inspiring.

As a family we have been frequent flyers at Starship over the years and we know it's a very rough time for everyone. Fundraising some dollars can help make a real difference to real families – and that's why I do it.

INDUSTRY INVOLVEMENT

The majority of our fundraising is through our network of insurers and business partners each year. The response each and every year has simply been superb, with insurers only too willing to help, knowing that their donations make a real difference. We do a special 'Thank You' to them each year also, as without their support it just simply wouldn't all be possible.

Sean is now 15 and has just started Year 11 at school. He's a basketball and gaming fanatic and has made great progress on Trikafta. He's only so far been able to join me in one of the Auckland Marathon 11km runs, but I suspect this year in 2024 it will be a race to the finish and he is already getting his practice in!



LOCKTON CARES



MAKING THE WORLD A BETTER PLACE

Niall works at Lockton, an insurance company in New Zealand and around the world, where he is the Head of their People Solutions team for New Zealand. His team help employers put meaningful benefits in place for their employees. Through Niall's connections with both CFNZ and Lockton, it made sense to have Lockton as CFNZ's insurance broker, done on a pro-bono basis, of which we are very grateful!

THE LOCKTON CARES COMMUNITY IMPACT AWARD

Congratulations Niall, on being awarded the Lockton Cares Community Impact Award!

"The Lockton Cares Community Impact Award is an annual award and is given to a Lockton Associate in each region globally. The Lockton Cares Community Impact Award was created due to the Lockton family's generosity, and it recognises someone who has gone above and beyond to make their community a better place through volunteering, philanthropy or a combination of both. In total, 16 award winners were chosen globally and I was fortunate and so grateful and humbled that my colleagues across New Zealand and Australia went to the effort to nominate me.

As winner of the award, I got to choose a nonprofit organisation to receive a donation – which of course is Cystic Fibrosis New Zealand, for all the reasons above! "

"So, Lockton gets to donate \$40,000 to CFNZ."

Niall says, "We'll be back with a team running in the Auckland Marathon again later this year to keep chipping in a few dollars for this great little charity and community."

GRATITUDE FROM CFNZ AUCKLAND BRANCH

"Niall has been instrumental in organising and participating in the Auckland Marathon on an annual basis and raising funds for Auckland branch for about 10 years. It started out when Niall was with WTW and has continued with Lockton. A team would form with a great commitment to raising funds for our Branch. This also extended to corporate donations with companies that Niall approached for support. On the big day, Auckland Branch would provide a marquee, bacon and egg rolls, and physiotherapists who donated their time to give massages to the runners after the event.

The event has changed a little over the years but the commitment from Niall and his colleagues and corporate supporters has never wavered.

The funds raised annually have been used for supporting our local people with CF and their families in many ways. One year we purchased a Metaneb and donated it to the hospital, another time we purchased portable oxygen systems which enabled people with CF to socialise or travel.

We also use the funds for our continuing support for people with CF attending clinics and as inpatients, providing parking vouchers, food vouchers, activity packs, Subway and sushi vouchers. We are delighted to hear that Niall has been the recipient of the Lockton Cares Community Impact Award, much deserved. We appreciate the ongoing support from Niall and Lockton, and all that it enables our Branch to continue to do for our community."


-Jill Thorrat, Co-Chair, Auckland Branch.



"It is an absolute pleasure to have Lockton as part of our CFNZ family. Their fundraising efforts have contributed significantly to the support and programmes that are delivered into New Zealand communities.

I extend our grateful thanks to Niall Martin and whole team at Lockton for the ongoing commitment to support those who are navigating the challenges of cystic fibrosis"

Lisa Burns, CFNZ CE



ADVOCACY UPDATE



Access to Medicines in NZ

Widening Access to Kayldeco and NPPA

Trikafta Expansion

Trikafta 2-5 years in NZ



Next in class triple combination for CF

Continuous glucose monitoring devices

Rare Disorders Strategy

ACCESS TO MEDICINES IN NEW ZEALAND

Access to modern medicines continues to be a major problem, with New Zealand lagging well behind comparable OECD countries, ranking 32nd of 32 of OECD countries for public funding of medicines. In January 2024, Pharmac advised that there are 134 applications on its Options for Investment List awaiting funding.

There is a need for urgent change to ensure that all New Zealanders, including those with CF, receive timely access to up to date medication and treatment. Increased investment in medicines and faster and more appropriate decision-making are essential to improving the health of New Zealanders and helping to reduce the burden on the health system.

There are positive signs that the new Government recognises the seriousness of the current situation and has plans for improvement. The coalition agreements signed by the new Government contain a range of initiatives that indicate potential for positive change for access to medicines and the operation of Pharmac.

We are encouraged to learn there will be a Medicine Access Summit held at Parliament on the 29th and 30th of April which CFNZ will be attending.

CFNZ will be using its voice and experience to contribute to the collective work underway in New Zealand to advocate for the implementation of these changes as soon as practically possible.



THESE INITIATIVES INCLUDE:

- Update Pharmac's decision-making model to ensure it appropriately takes into account the patient voice.
- Reform the funding model to account for the positive fiscal impacts of funding more medicines.
- Require the Ministry of Health to publish a Medicines Strategy every three years.
- Require Medsafe to approve new pharmaceuticals within 30 days of them being approved by two overseas regulatory authorities recognised by New Zealand.
- Increase funding for Pharmac every year.

CFNZ will continue to work with Patient Voice Aotearoa (PVA) and the wider sector to advocate for improvements to the current system, including access to medicines for those with CF.

New Zealand must have a medicines' funding system that recognises the importance of investing in medicines to prevent chronic and irreversible damage and reduce the burden on the health system. Significant improvements to medicines' access, funding and decision-making in New Zealand are long overdue and we look forward to the Government moving ahead quickly with its initiatives for change.

WIDENING ACCESS TO KALYDECO AND NPPA

In late 2023, CFNZ met with Pharmac to discuss the application to widen access to Kalydeco. CFNZ has consistently urged Pharmac to progress the application as quickly as possible, and to treat those who would benefit, fairly and equitably.

The application received a high priority for funding from Pharmac's Respiratory Advisory Committee in April 2022 but has yet to be assessed and ranked. The application would increase the CF mutations eligible from the current nine to 97. A total of 92 of the 97 mutations proposed for inclusion are also responsive to Trikafta and are included in Pharmac's current eligibility criteria for access to Trikafta.

There may also be potential for some of those waiting for widened access to Kalydeco to access Trikafta via Pharmac's Named Patient Pharmaceutical Assessment (NPPA) process. Pharmac's current eligibility criteria include a provision where some people with rare mutations outside the current approved list may be able to access Trikafta where there is evidence of benefit.

Pharmac has advised CFNZ that it encourages clinicians to apply where they have a patient who meets the principles of the NPPA policy.

CFNZ encourages anyone in this situation to talk to their CF clinician about whether it is an option for them.

Pharmac has also acknowledged there remains a clinical need for Kalydeco for those who are unable to access Trikafta, and has advised CFNZ that it will provide an update when assessment and ranking take place.



¹ <https://investors.vrtx.com/news-releases/news-release-details/vertex-announces-european-medicines-agency-validation-marketing>

² <https://newshub.medianet.com.au/2024/02/vertex-announces-tga-approval-for-trikafta-elexacaftor-tezacaftor-ivacaftor-and-ivacaftor-to-treat-children-with-cystic-fibrosis-ages-2-5-years/36798/>

ADVOCACY UPDATES

TRIKAFTA EXPANSION

Extension of access to Trikafta for very young children has been gaining approval around the world over the last year. Approval was granted in the USA in April 2023 followed by the UK and Europe in late 2023. Vertex has also announced that it intends to seek approval for additional rare mutations responsive to Trikafta¹.

Australia's Therapeutic Goods Administration (TGA) has given approval for the expanded use of Trikafta for those aged 2 to 5 years old who have at least one F508del mutation². Australia's Pharmaceutical Benefits Advisory Committee (PBAC) will consider an application to fund Trikafta for this age group at its March 2024 meeting.

TRIKAFTA 2-5 YEARS IN NZ

In early 2024, Vertex applied to Medsafe and Pharmac for the approval and funding of Trikafta in New Zealand for those with CF aged 2 years and older who carry a genetic mutation responsive to the medicine. Trikafta is already approved and funded for those with CF eligible, aged 6 years and over.

CFNZ wrote to Medsafe to support Vertex's application for Trikafta for this age group to be given priority for assessment, and we understand that priority has been granted.

Pharmac has advised CFNZ that it will consider the application for Trikafta at the same time as Medsafe. CFNZ will be meeting Pharmac to discuss the application and how CFNZ can support and assist Pharmac's consideration.

¹Vertex Announces Positive Results From Pivotal Trials of Vanzacaftor/Tezacaftor/Deutivacaftor, Next-In-Class Triple Combination Treatment for Cystic Fibrosis | Vertex Pharmaceuticals Newsroom (vrtx.com)

²<https://pharmac.govt.nz/news-and-resources/news/cgms>



CONTINUED

We have made clear to Pharmac that we want to work constructively with them to ensure that the application is progressed as quickly as practically possible.

CFNZ welcomes these applications as a very positive step forward for the CF community. The earlier treatment begins for those with CF, the greater the prevention of chronic and irreversible damage.

Early treatment of young children will increase the likelihood of greater longevity and the potential for a normal childhood, teenage, and adult life. It will also reduce the burden of care on those with CF and

their families, and provide savings in costs to the health system from reduced medical treatment and hospitalisations.

CFNZ's goal is that funded access to CFTR modulators is available to everyone who would benefit. CFNZ will continue to work with Pharmac to advocate for and support the widening of access to Kalydeco, together with access to Trikafta for those aged 2 years and older.



OTHER ADVOCACY INITIATIVES

NEXT IN CLASS TRIPLE COMBINATION FOR CF

Vertex Pharmaceuticals (Vertex) has announced positive results from its once daily vanzacaftor/tezacaftor/deutivacaftor (vanza triple) trials. Vertex stated that the results demonstrated that the once daily vanza triple combination CFTR modulator regimen was “non-inferior to Trikafta in improving lung function and superior to Trikafta in lowering levels of sweat chloride in people living with CF.” Vertex noted that the results were more pronounced in the study of those aged 6-11 years, “demonstrating the potential that treatment early in life may prevent disease development”.

Vertex will now seek regulatory approval from global regulators for those aged 6 years and over³.

CONTINUOUS GLUCOSE MONITORING DEVICES

Pharmac is undertaking a procurement process for continuous glucose monitoring (CGM) devices, insulin pumps, and insulin pump consumables. Proposals have been received from suppliers and Pharmac has now advised that its evaluation committee met at the end of 2023 to evaluate bids⁴.

Consultation is currently scheduled for early 2024 but the dates for this have yet to be confirmed. Once Pharmac's proposals are available, CFNZ will prepare a submission following advice from the Clinical Advisory Panel.



IMPACT OF LIVIN

Rare Disorders Strategy

On the eve of Rare Disease Day, in the Grand Hall of Parliament, a significant gathering took place – a gathering fuelled by the urgency to address the often-overlooked challenges faced by those living with rare disorders in Aotearoa New Zealand. The occasion marked the launch of the latest Impact of Living with a Rare Disorder in Aotearoa New Zealand white paper, a culmination of insights gleaned from the monumental 2023 Voice of Rare Disorders Survey – the largest-ever survey of consumer-reported outcomes for individuals grappling with rare disorders across New Zealand.

The event had an encouraging turnout of over 130 people, ranging from representatives of patient support groups and research institutions to government Ministries, pharmaceutical industry leaders, advocacy organisations, and a cohort of MPs. Notably, the attendance of the Minister of Mental Health, the Minister of Pharmac, and the Minister of Health, this underscored the gravity and importance of rare disorders.



GG WITH A RARE DISORDER IN NZ



Authored by Health New Zealand and supported by Medicines NZ, the white paper serves as the third instalment, following previous reports in 2020 and 2022. Regrettably, the findings presented in this latest iteration echo a familiar set of themes, unmet needs and a persistent lack of progress in delivering to the health and wellbeing of New Zealanders living with a rare disorder.

Professor Gareth Baynam, a distinguished clinical geneticist, and the Medical Director of the Rare Care Centre in Perth, delivered a compelling address, urging policymakers and politicians to confront the stark realities unveiled in the white paper. "Rare and undiagnosed disorders represent the highest cost to the health system," remarked Professor Baynam, emphasising the imperative for transformative action.

The report's revelations paint a sombre portrait of the daily struggles endured by those affected by rare disorders. Financial burdens loom large, with many individuals shouldering the costs of healthcare out of their own pockets and the impact this has. Employment prospects are marred by the pervasive impact of rare disorders, necessitating adaptive work arrangements or, in some cases, forced exits from the workforce.

Yet, the repercussions extend beyond the individual, casting a shadow over the mental health and wellbeing of families and whānau. Profound

feelings of unhappiness and despondency permeate the lives of those touched by rare disorders, highlighting the urgent need for holistic support and intervention.

For the 300,000 New Zealanders living with rare disorders, the burden is palpable, with many feeling isolated and finding it tough to navigate the health system.

While work has been done to formulate New Zealand's first Rare Disorders Strategy, tangible action is crucial to translate this into meaningful change.




As we reflect on the findings unveiled in the white paper, we are confronted with an unchanged reality, the absence of a national strategy and the need for a cohesive and coordinated approach is urgent to address rare disorders in New Zealand.

It is incumbent upon us to continue support for the Rare Disorders Strategy ensuring that this transforms intent into concrete action. It's only through our collective efforts and unwavering commitment where people with rare disorders in New Zealand can not only be seen but feel they are getting the inclusivity, equity, and compassion they deserve. The time for change is now.

DON'T GHOST YOUR CF TEAM

Keep the communication alive



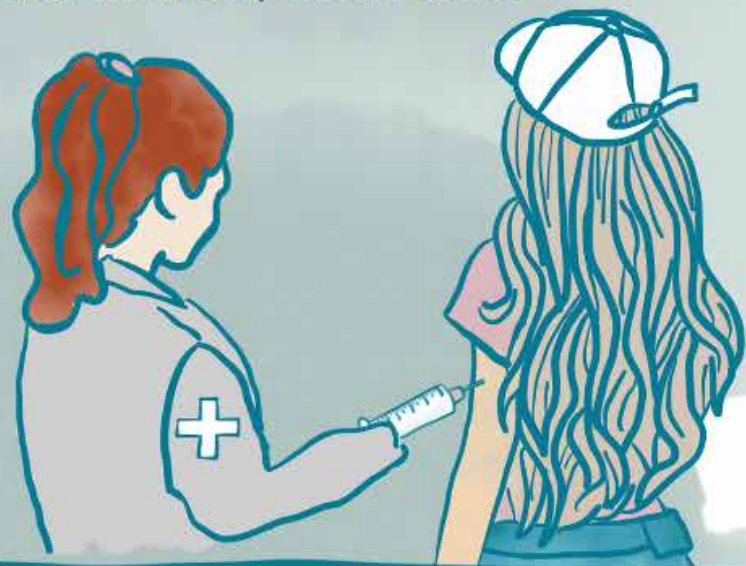
-  It's important to keep up the maintenance of your health, even when you're feeling great.
-  Negotiate a shared care plan.
-  Actively manage and monitor it with your CF Team.



REMINDER: INFLUENZA VACCINES FROM APRIL

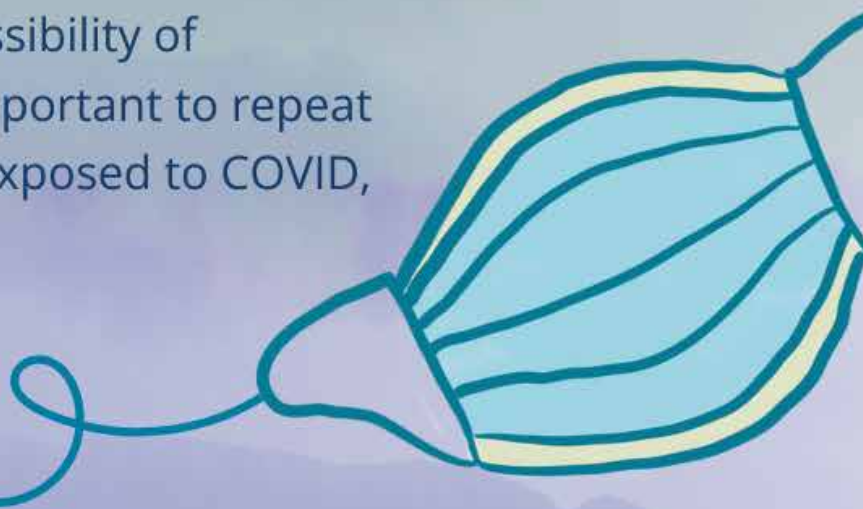
It's imperative that our people living with CF and their families receive the influenza vaccine as soon as its available, to ensure you are well protected for the cooler months, when colds and flus generally run rampant.

Contact your GP clinic



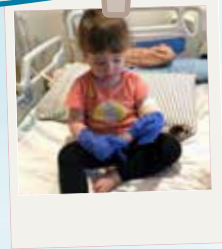
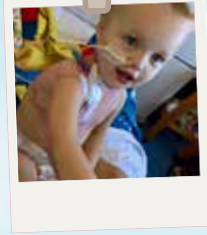
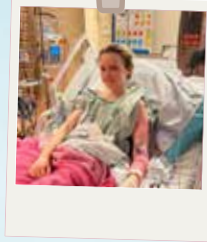
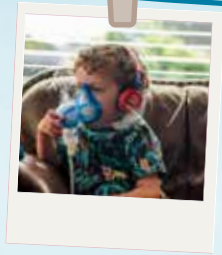
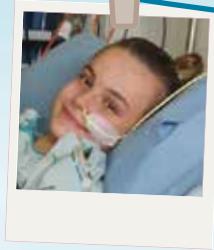
COVID IS STILL HERE

Stay vigilant around the possibility of COVID-19 infections. It is important to repeat RAT testing if you've been exposed to COVID, or you're feeling unwell.



FREE RAT TESTS ARE STILL AVAILABLE UNTIL JUNE 2024

CF NEVER TAKES A BREAK MAY IS CF AWARENESS MONTH



CF Awareness Month is an important opportunity to let all our supporters know that the journey with CF is long, and a person with cystic fibrosis still needs support for the whole of their life.

The message is simple.....

CRUEL STILL NEEDS KIND

One way we'll be sharing this message is through the diverse experiences of our community living with the challenges of CF.

From parents navigating a diagnosis with their newborn, to children and young adults as they manage kindy or school, those on Trikafta, and or have had a transplant.

Each story and each experience is unique, and all still require ongoing support from from the programmes and services delivered by CFNZ.

ARE YOU READY TO HELP SMASH OUR RECORD AND MAKE A REAL DIFFERENCE?



OUR GOAL FOR 2024:

Let's smash the 2023 record
and together push it up to
50,000 Chocky Fish sold.

Be a Chocky Fish Champ and sign up today to order
your boxes for your CF Month fundraising.



www.cfnz.org.nz/fish

WILL YOU HELP?

This CF Month, let's ignite a wave of kindness across New Zealand!
It's time to rally together and **Click To Be Kind**



CLICK TO BE KIND

Join us this May, get involved to spread awareness and raise funds in whatever way resonates with you to make a difference.

Explore our kindness menu and discover the perfect opportunity that matches with how you want to get involved this CF Awareness Month.

THE kindness MENU

-  Purchase chocky fish
-  Buy some some of our rad new merch
-  Make a donation
-  Fundraise with chocky fish
-  Create your own fundraiser
-  Make a Deliberate Act of Kindness

www.cruelneedskind.org.nz



DELIBERATE ACTS OF KINDNESS DAY

We have some great partnerships in the pipeline with organisations and sponsors who will be supporting CF Awareness Month with Deliberate Acts of Kindness.

What will you do on Deliberate Acts of Kindness Day – Friday 31 May 2024?

Let's all choose kindness for the month of May and let everyone know they can **CLICK TO BE KIND.**



AUTUMN
2024



All proceeds from
merch orders go
directly into our
CFNZ support
programmes.

SHOP

shop.cfnz.org.nz

Merchandise

LIMITED EDITION

