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cf CYSTIC FIBROSIS NZ

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# CF news



## RACHAEL'S MAKE-UP WISH COMES TRUE

LIPSTICK TO BE SOLD FOR CFNZ



Nigel Latta in Christchurch, DWTS Win for CF, NZ Joins Global Liver Study & Meet Our CF Achievers

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## UPDATE FROM THE CHAIR

In 1968 a small but mighty band of parents of children with cystic fibrosis decided that there

was strength and support in numbers, and Cystic Fibrosis New Zealand was born.

Last year my family had the great pleasure and privilege of meeting one of those founding families. To hear of their journey spoke to me. One family three children, two with cystic fibrosis – it hit pretty close to home.

I won't dwell of this family's story – it is not my story to tell. However, now, in our 50th year, I pay tribute to the people with CF, the parents, siblings and extended families who have so shaped CFNZ into the organisation it is today.

We have moved from being parent-to-parent support, to information, fundraising and support, to a framework that has professional fieldworkers, a fundraising programme to provide tangible support, advocacy for new treatments (such as pulmozyme, TOBI, Vit ABDECK to name a

few), and a strong branch structure that is grounded in the local region – knowing and meeting the needs of PWCF and families.

The CFNZ Board are well aware of the challenges of the next five years and beyond. There is serious hope and potential in the new triple therapy trials and battles ahead with getting that and other new treatments funded by Pharmac.

So in this, our 50th year as an established medical charity, I encourage all to think about the letters "CF". I like to think of these letters guiding us for the next period of time (that being a lot less than 50 years) and that being:

**C**ome **F**orward (with)

**C**ommunity **F**ervour (and a)

**C**an't **F**ail (attitude)

..resulting in a

**CURE FOUND!**

**JANE DRUMM, CHAIRPERSON**

Email: [chair@cfnz.org.nz](mailto:chair@cfnz.org.nz)

## CF News brought to you by...One Foundation

It's thanks again to **One Foundation** for its support for the CF News and helping to keep New Zealanders up-to-date with the latest news and views.

One Foundation has previously supported the publication of the CF News in its former life as the First Sovereign Trust. It has now had a rebranding and granted \$4847 towards the cost of printing and mailing the CF News, which we greatly appreciate.

We also had a number of people in the CF community send in donations to assist the publication of this issue, which is extremely heartening as well. Thanks also to all the people in this issue who have told their stories and offered practical advice to those in the CF community.

The CF News is a long-standing publication and one that aims to celebrate the achievements and milestones of people in the CF community. This issue also provides lots of news, research and device news, and updates from some of the branches around NZ. The CF News is published twice a year.

We also email out the CFNZ Panui once a month. Visit the CFNZ website or email: [comms@cfnz.org.nz](mailto:comms@cfnz.org.nz) to receive it. If you have already signed up but don't find it in your inbox on the last Thursday of every month, it might pay to check the junk email folder.



## UPDATE FROM THE CE

As I embark on a tour of branches to get feedback on the key success factors the Board has identified for the next 3-5 years, I want to thank the CF community for the involvement they have had in outlining what CFNZ's focus should be.

We had an amazing response to our CF Insight Survey and also have been privileged to understand the experiences of families of children with CF and of adults with CF during our empathetic interviews. CFNZ Board and management now have a very current picture of the issues people with cystic fibrosis face, where they want to be in the years to come, and what CFNZ can do to support them.

Our CF Insight Survey provided us with clear direction on what is helpful to people with CF and what was important to people going forward. Ninety two percent of respondents said that advocacy to government for medicines and high-quality care was extremely or very important, with 84% noting the importance of advocating on behalf of individuals with CF – this is an overwhelming clear directive from our community for more action.

In my recent catch up with the chief executives of the commonwealth CF associations, I found that access to care and treatment is a huge focus of their work. Globally the Chief Executives will continue to meet to discuss this issue, and I am heartened that the CE of CF Australia and the UK Trust, who are both running strong campaigns, and CF Ireland who has been successful, are very happy to share their successes and learning with us.



With the financial assistance of the Auckland Branch we have been able to engage a contractor with expertise in advocacy to work with us to develop a plan for the whole organisation. For advocacy to be effective it needs to occur at the local, regional and national (and global) level. Lisa Woods will be talking with interested parties as part of the plan's development which will identify key priorities and what resources are needed. We are also grateful to have the Clinical Advisory Panel up and running and able to help guide our priorities.

This August our CF Awareness Week will focus on advocacy and we have been fortunate to secure the pro-bono services of global marketing and communications agency, Y&R, who are developing a campaign with a compelling case for support. While the campaign may be challenging for our community, it will present a compelling message to the public to raise awareness and start conversations.

**JANE BOLLARD, CHIEF EXECUTIVE**

### Bowling 4 CF

The Birkenhead Bowling Club in association with Rotary Birkenhead presented CFNZ Chief Executive Jane Bollard with an impressive cheque for \$8000 following their bowling day to raise funds for CF. Jane is pictured with representatives from the Bowling Club and Rotary, and Curtis Ennor (left) who is the person with CF who was instrumental in naming CFNZ as the chosen charity and delivered a moving talk at the presentation. This was the highest total out of the Club's fundraising rallies and they are keen to support us again. There was a great silent auction and also lots of cool prizes such as the \$100 Jane Bollard won and then promptly donated back to CF! Curtis, his dad, and his brother were also pleased to win the prize for best wigs on the day.



### SNIPPETS

### SAVE THE DATE

### Charity Cricket 16 December

Tipped to be a good one to help celebrate CFNZ's 50th anniversary. We will be at Hagley Park in Christchurch this year. We will keep you up-to-date with developments as they come to hand.

### Thank you MAGS!

Huge thanks to the Mount Albert Grammar School students who raised \$607.50 and awareness by taking CFNZ buckets around classrooms and talking to students about the health issues linked to cystic fibrosis.

### Livewire for 12 and overs

Livewire is a website for Aussie and NZ teens who are living with a chronic illness. The website welcomes over 12-year-olds to share stories, have a rant, and to make friends. Plus there's a pop quiz on the first Tuesday of every month. The website, <http://livewire.org.au/>, already has a number of people with CF who are excited to chat to others with CF. There is also a private group dedicated for members with CF.



## Stars Shine for CF

An incredible \$9250 was raised on All Star Family Feud when Dancing with the Stars contestants selected Cystic Fibrosis New Zealand as the charity to play for on the game show.

Suzy Cato, Shavaugh Ruakere, Jess Quinn and Zac Franich played for CFNZ against Robert Rakete, Gilda Kirkpatrick, David Seymour and Naz Khanjani, who were playing for Starship Children's Hospital. It was super exciting to watch the nail-biting finish which saw Suzy's team take out the win.

Some CFNZ staff and Auckland Branch committee members got the chance to attend the recording, with Anthea, Kelly and Niall pictured with our favourites from Dancing with the Stars.

All Star Family Feud pledging \$10 for every point scored helped push Suzy Cato's team over the \$9000 mark.

Suzy says every team member had a chance to choose a charity and it turned out many of them knew of someone who has been affected by CF.

Her own association comes from her support for Cure Kids at Christmas in the Park, 2000, when she met one of their ambassadors from Wanaka who had CF and learned about the treatment burden involved with living with cystic fibrosis.

At the age of 15, Rebecca Dixon, who has since had a lung transplant and is now living in Australia, delivered a speech to the crowd with Suzy and four All Blacks by her side.

"It was scary walking out there, but I was standing next to four All Blacks and Suzy Cato," Rebecca said at the time.

Suzy and Rebecca have kept in touch on Facebook and Suzy says her DWTS team was more than happy to help raise funds for cystic fibrosis on Family Feud.

"We were delighted to put such a good team together for you. Raising awareness is very important. An illness like cystic fibrosis, which isn't an obvious one, is so unknown. It's wonderful to help raise the profile and to raise the funds to support families in need."

## CF SPEEDWAY DRIVER'S DREAM COMES TRUE

Oliver Klotz has had a taste for motor racing ever since the Make-A-Wish Foundation granted his wish for a new mountain bike.

Oliver will always remember being presented with the bike by former motocross Grand Prix Kiwi star Josh Coppins.

"My mum put in the application. I was so happy to get a mountain bike," he says.

Now Oliver's friends are involved in car racing so it wasn't long before Oliver decided to build a TQ (three quarter) midget car to race at Speedway in Westport.

Wanting to give back to the Make-A-Wish Foundation for his mountain bike, Oliver has dedicated his midget car to them and will also be fundraising so other children with chronic conditions can enjoy some moments of joy.

"It's an awesome Foundation. Sometimes with sick kids money isn't all that great so it's really cool if they can get a mountain bike or go overseas," he says.

Oliver's first race was at Westport but unfortunately a frightening crash into a wall in the last race put his midget car out of action and left Oliver with some serious bruising. But it hasn't put Oliver off the sport at all. He's planning to have it fixed in time for the Speedway season which kicks off in September.

Oliver, who is now 24 and lives in Nelson, is in the process of re-building the broken car.

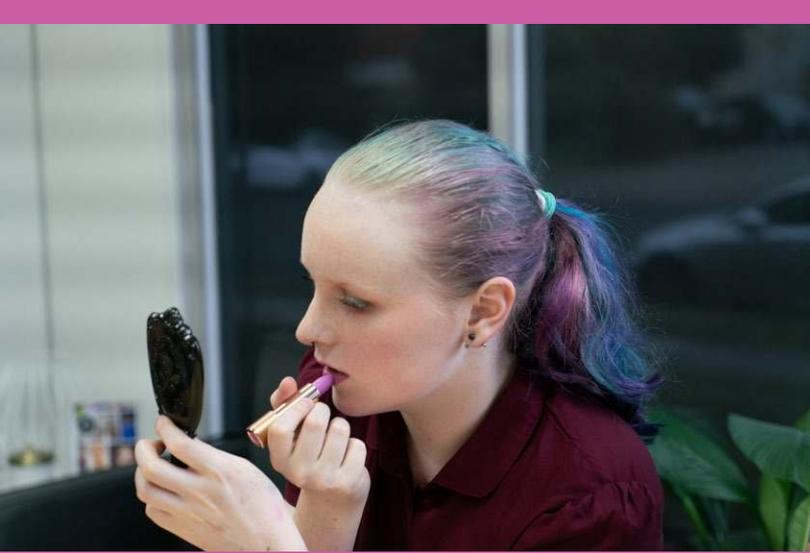
"I will have to spend quite a bit of money on that to get it fixed, but that's okay because I'm in quite a good position," says Oliver, who works long hours at his timber-treating job at Carter Holt Harvey in Nelson.

"My good friends Chris and Cam are helping me fix it and I can't thank them both enough for their long hours."

Car racing doesn't seem to have had any effect on Oliver's CF, although he can start coughing towards the end of a race – an obstacle that won't defeat Oliver.

"We're going to try to put a Camelbak (hydration pack) in the car so I can sip on water to suppress the cough," he explains.





# Rachael Gets Lippy for CFNZ

It took her many years to apply and by the time she did Rachael Cox of Dunedin was granted one of the most original Make-A-Wish wishes yet – getting her own lipstick produced to help raise funds for CFNZ and Make-A-Wish New Zealand.

With the help of environmentally-friendly lipstick manufacturer, Karen Murrell, Rachael's wish to visit a make-up factory came true – and with an even better result than expected.

The Make-A-Wish angels visited Rachael in March to tell her that her wish had been granted but she was not told of the secret plans to make a personalised lipstick for Rachael, which would be sold with a 50:50 split between CFNZ and Make-A-Wish.

Rachael had been asked to pick her favourite colour from a colour palette but just thought that meant she might be given a lipstick during the factory visit in Australia. When she was told that the purple/pink lipstick named *Rachael's Lipstick* and with a beautiful sketch of her on the packet, was going to be put in production with funds going to Make-A-Wish and CFNZ, she became overwhelmed with emotion.

“When Karen told me the profits were going to Cystic Fibrosis New Zealand and Make-A-Wish, I full-on cried and it was also very exciting,” she says. “It makes me so happy that my wish has been given back to others.”

Rachael (18) is studying pharmacology and art at Otago University with the help of a \$40K scholarship and waited for years before deciding to apply to Make-A-Wish for her life-changing wish.

“I hadn't wanted to do it as a child because I thought other people were worse off and I didn't want to make a big deal of having cystic fibrosis.

“I was really excited about the idea of visiting a make-up factory. I love make up and am interested in chemistry and I thought seeing the production would be hugely fascinating,” says Rachael, who got to see a big vat of her lipstick being made.

“Everyone was so kind and so generous, it was beyond the reach of my imagination,” says Rachael who left with a bag of her own lipstick. “I want to thank everyone involved. It was a once in a lifetime experience.

“I thought it almost made it worth having cystic fibrosis – and I definitely say ‘almost’.”

Karen Murrell, also pictured on the cover, was delighted to help make Rachael's wish come true. “This was truly such a special day and seeing the look on Rachael's face when she realised what was really going on was absolutely priceless and one that I will never forget.”

The limited edition lipstick will be sold online at [www.karenmurrell.com](http://www.karenmurrell.com) and at stockists nationwide from 8 August at NZ \$32 and all proceeds will be donated to CFNZ and Make-A-Wish Foundation



## CF Awareness Week 13–19 August

Cystic Fibrosis Awareness Week is just weeks away and it's going to be big! This year we have an award-winning creative agency working with us to develop a bold, multi-channel campaign to help raise awareness of cystic fibrosis.

Through this exciting campaign we'll be highlighting the importance of advocacy to support all New Zealanders with cystic fibrosis. It's a great opportunity to acknowledge CFNZ's 50th anniversary and the amazing support provided over the years.

Local CF branches are always on the look-out for more volunteers to help during awareness week. Contact [laura@cfnz.org.nz](mailto:laura@cfnz.org.nz) for fundraising resources and Irene at [admin@cfnz.org.nz](mailto:admin@cfnz.org.nz) for chocolate fish, or if you can volunteer during the week.

This year so many people with CF have been happy to tell their stories but we can always do with more personal stories around Awareness Week because you never know what the media might be interested in. Email [laura@cfnz.org.nz](mailto:laura@cfnz.org.nz) if you'd like us to put your name forward to our PR contractor.

Auckland Branch is holding a **Step for CF** Winter Challenge during Awareness Week. Individuals, groups of friends, schools and businesses are being encouraged to step out for CF. Participants download a steps app, gather sponsorship via Givealittle, then head out during Awareness Week to get as many steps as possible and fundraise for CF at the same time. Contact Kath at [auckadmin@cfnz.org.nz](mailto:auckadmin@cfnz.org.nz) for more information.



## CFNZ Launches New Website and Refreshed Look

Developed over the past year by CFNZ staff and design agency Transformer, the website and refreshed branding is one of the first significant enhancements to be delivered through the charity's new strategic marketing plan. Much of this work was made possible by a generous donation from the Anwhereo Nui Trust.

The site was developed following extensive user research, with many key aspects of the user experience being improved. This includes streamlined navigation, intuitive functions and a cleaner layout, as well as updated information and resources.

Alongside the new website, we recently rolled out a refreshed CFNZ logo and branding to help build a strong visual identity.

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

## New CF resources for parents, schools, family and friends

CFNZ has released four new, user-friendly information guides, to help families on their journey with cystic fibrosis. These guides, made possible through funding from SKIP and The Lion Foundation, include:

- **A guide for parents and caregivers of children diagnosed with cystic fibrosis**
- **A guide to cystic fibrosis for family, whanau and friends**
- **Starting school: A guide for parents and caregivers of children with cystic fibrosis**
- **Starting school: A guide to cystic fibrosis for primary schools and teachers**

These new resources were developed with the help of CF families, who kindly gave us valuable insight into their personal experiences with CF and shared how we could best support them.

They are available to download from the CFNZ website, or you can order a printed copy from your fieldworker or the CFNZ office.

– Laura Huet

# DR ALISON WESLEY REFLECTS

*Dr Alison Wesley was a pioneer for improving CF care in New Zealand. Now retired, Dr Wesley reflects on some of the important milestones in treatment and research over the years.*

It's no wonder that paediatrician Dr Alison Wesley became a cystic fibrosis specialist given that she trained under Professor Bob Elliott - one of the leading CF researchers of our time.

Medical researcher Bob Elliott made a worldwide breakthrough in the diagnosis of cystic fibrosis when he discovered a test to screen newborns for cystic fibrosis – and his research was inspiring for the young registrar.

"It was Bob Elliott who influenced my interest in CF," she says.

And when Dr Wesley won a research post related to cystic fibrosis in 1979 at a leading children's hospital in Toronto, Canada, it led to a career caring for children in New Zealand.

"At that stage everybody thought there must be something different about the mucus in children with CF. Why did they get so clogged up? In fact, we didn't find there was anything different. Now I'm not sure if it's a problem with over-production or a problem with clearance."

Dr Wesley brought home the knowledge from Canada: the message that attention to detail was most important in the care of children – attention to their weight, lung function and growth.

"Virtually every patient was colonised with *Pseudomonas* in Canada but their results were way ahead of New Zealand and a lot of the US clinics in terms of survival.

"They had a great point to get kids to grow normally. Toronto was one of the early places to adopt a new pancreatic enzyme and would say to children 'if you just feel like eating one thing – eat two pieces'. They really monitored growth and had really good growth and nutrition.

"In England, the children were all on low-fat diets – their way of controlling the terrible bowel symptoms was to tell them not to eat fat, whereas in Canada they said eat as much as you like and their growth was so much better than the English children."

This led to Dr Wesley's focus on diet and growth when she returned to New Zealand in 1981.

With the support of the Cystic Fibrosis Association (now CFNZ) she was able to continue her research and clinical work.

"Bob Elliott persuaded the CF Association to fund me almost full time both in research and clinical work," she says.

Dr Wesley was instrumental in organising the annual CF conference in NZ – and at first these were "doctors only" events with invited guest speakers from overseas.

Dr Wesley was also heavily involved in the introduction of the newborn screening programme for cystic fibrosis in 1981.

In 1991 Dr Wesley had a sabbatical to visit many CF and gastroenterology clinics around the world.

These clinics also paid a high attention to detail – they were doing lung function tests, looking at nutrition, culturing sputum.

"There was also an aggressive use of antibiotics – either inhaled, oral or I/V, particularly in Leeds where they were on

permanent anti-staphylococcal antibiotics. In America, they were giving courses of inhaled antibiotics," which Dr Wesley says was something that was only just being introduced in New Zealand.

"Deteriorating growth may be an early indication of deterioration of the lungs," she wrote in a report to the Royal Australasian College of Physicians when she returned from her sabbatical.

New Zealand was vastly lacking in resources in those days. In Auckland it was just Dr Wesley, Professor Elliott and a paediatric registrar seeing children with cystic fibrosis.

"One of the things I asked for, that was needed, was to employ a cystic fibrosis nurse specialist," recalls Dr Wesley, and that's what led to the appointment of Starship's current CF Nurse Specialist Jan Tate.

"I did a paper on survival of CF patients in New Zealand and wrote to every hospital looking for information on admissions of diagnosis of cystic fibrosis. It showed that the mean survival was only 16 years but it was close to 30 in Canada. That was the ammunition that was needed to do something different," she recalls.

Dr Wesley also became involved in the annual review of patients around the country.

Seeing her young patients safely transitioned to the CF Adult Clinic was always a cause for celebration for Dr Wesley.

"It was pretty devastating to lose patients. But from when I started until I finished, at least in Auckland, we hardly lost any patients at all before they turned 18 and I could move them to the Adult Clinic. For me that was a real feeling of satisfaction," she says.

"To me the most important thing was attention to detail – keeping the growth normal and keeping the lung function up."

When the breakthrough CF treatment, pulmozyme, was approved for funding in 1997, Dr Wesley recalls they could only afford to give it to people most severely affected and who could show a definite benefit.

Although she can't see a time when cystic fibrosis will be cured, she can see a time when it will be "managed".

"There's so much research coming out of North America and new medications but they're so expensive that you can't get hold of them," she says.

After a brilliant career in CF care, Dr Wesley (now 71) retired at 60 and decided to move from Mount Eden in Auckland to Whangaparaoa so she could continue to work on conservation projects with the Auckland Botanical Society and the Shakespeare Open Sanctuary Society.

"I knew I didn't want to be in the city. I wanted to be outdoors," she says.



## VAUGHAN SOMERVILLE CF ACHIEVER, SPORT

Vaughan Somerville is off to represent New Zealand in the World University Futsal Championships – just one of the reasons why he has received a CF Achiever’s Award for Sport.



The 25-year-old was also named Tertiary Sportsman of the Year at the University of Auckland Sports Awards last year, after Auckland University won the NZ Tertiary Futsal Championships and where Vaughan won the Golden Glove award for best goal keeper in the tournament.

Now team captain, the team is competing in the World University Futsal

Champs in Kazakhstan in August – Vaughan’s best sporting achievement to date. His CF Achiever’s Award will go towards flights and accommodation for the tournament.

Vaughan says futsal (a form of indoor soccer) is a rapidly growing sport in New Zealand with 700 registered players in 2010 to over 20,000 in 2016 – with a NZ Women’s side launching last year. And he says it’s a perfect sport for his health condition.

“CF has had quite an impact on me during my life, causing me to change degrees and also causing me to take time off sport and university. It was one of the main reasons I moved to goalkeeper, this meant that even when I wasn’t at my optimum health, I could still play and contribute towards my team,” explains Vaughan, who has been described as an exceptional athlete by one of his referees.

Vaughan considers good sports players combine a determination to win while also playing fair.

“I try to strike a balance between passion and humility. You should always want to be pushing yourself and others to perform at the best of their ability but this shouldn’t come at the expense of respect towards the opposition, the officials and your other teammates,” he says.

Although Vaughan once had his heart set on becoming a doctor, he has now found happiness with his new path and success in futsal. Vaughan had to switch from a medical degree because of his CF and is now studying for a PhD in Health Science and an LLB degree, and hopes to pursue a career that utilises both degrees.

With a packed-full schedule, Vaughan admits finding a balance between study, training and treatment can be tricky. “The University has been incredible at allowing me to moderate my workload so I can still push forward with training/competition



and also help with providing me with training facilities. Also the iced coffees are amazing,” says Vaughan.

The effect of futsal on his health has been an added advantage. “I’ve been lucky enough that my health in general is pretty good and hasn’t affected too much of my training. I find the exercise and training I do for futsal helps me stay healthy with a lot of aerobic and resistance training,” says Vaughan, who urges others to keep trying new things.

“Throw yourself at whatever opportunities come your way. I only picked up futsal in 2016 and have made leaps and bounds since. Life doesn’t throw you second chances, catch the first – take it from a goalkeeper.”

## GEORGE BLYTH CF ACHIEVER, LEADERSHIP

Canterbury teenager George Blyth has been recognised for his leadership abilities with a CF Achiever’s Award.

George (18) is described as an excellent role model who has provided leadership and support to younger students at Rangiora High School from his position as House Captain for the Lydiard school house and for being part of the leadership group for the school’s 1st XV and 1st XI sports teams.



George believes having cystic fibrosis has been a positive force behind his leadership and educational success - he also achieved excellence endorsements in both NCEA Level 1 and 2.

“I believe CF has had a positive effect on my education and leadership. CF has taught me that you need to make the most of every moment because you don’t know how many more healthy moments you will have.”

George is particularly happy with the performance of his school’s rugby team during his time with the team in 2016 and 2017.

“Rangiora is not a traditionally strong rugby school and has struggled to compete with big rugby schools. In my second season in the team we finished 6th out of 15 teams, beating some top tier teams including St Andrew’s, St Bede’s, Shirley and St Thomas. I am really proud to have been a leader within such a successful team.

“Leadership is all about leading by example. If you’re prepared to go the extra mile as a leader I believe others will follow and go the extra mile with you,” he says.

After leaving school last year, George began a cadetship at Jeff Farm in Southland where he is learning the skills required for his chosen career in agriculture.

Managing treatment is always a challenge but something he has learned to adapt to.

“As most people reading this will know CF can be extremely time consuming - 2 x 15 minutes nebulisers a day plus 60 minutes of exercise and various other things that you have to do to keep well. You learn very quickly that you have to have good time management skills if you want to do well,” he says.

George is planning to spend his award grant on a new pair of tramping boots. He loves the great outdoors and all his sporting activities assist with airway clearance.

“My hobbies are virtually all based around physical activity. They include rugby, cricket, hunting, tramping, motorbikes, waterskiing and fitness. These physical activities are by far the biggest factor for keeping me relatively healthy. My advice for anyone out there with CF would be to find a physical activity that you are passionate about, whatever it may be, because it is so good for not only your mental wellbeing, but also your physical wellbeing and lung health.

“My own health has been relatively good so far. I have had five hospital admissions throughout my life. I have struggled to put on weight at times but the introduction to Ensure Plus has helped with that significantly. Leaving school and starting full-time work had a hit on my health. I lost 4kgs in a month and my lung function reduced slightly. It took me a while to adjust but I now know what I need to do to keep my health in a good state in my new lifestyle. Getting enough sleep is very important because it gives my body a chance to recover,” George adds.

Pulmozyme has had a big impact on his lung health and George advises anyone not on it to ask their CF specialist about access. “It increased my FEV1 by about 10% which was massive. It has also reduced the amount of time I have to spend on airway clearance because it is so effective for me.”

George admits it has taken him some time to accept his CF.

“CF is part of who I am. Some days I think ‘Why me? What did I do to deserve this?’ but it's part of who I am. CF has made me enjoy every day as it comes and not look too far into the future,” says George.

“I would like to thank all of the CF team that I have had throughout my youth who have helped me maintain a good level of health, I am truly grateful for them. I would also like to thank my parents for what they have done for me during my 18 years so far. I would not have been able to achieve what I have without them and the continuous support towards my health, sport and school.”

**Note:** Another CF Achiever's Award was awarded for Sport to a teenager who has been named in an NZ Under 19 sports team and wishes to keep his name confidential.

## CLAIRE SCOFIELD

### CF ACHIEVER, EDUCATION

After an early setback in her tertiary studies, Claire Scofield has overcome many challenges to follow her dream in horticulture and win a CF Achiever's Award for Education.

Growing up, Claire (29) had always wanted to become a nurse but was devastated to have to leave her studies after just one and a half years because of a CF-related infection, *Burkholderia cepacia* complex.

However, retraining in horticulture has led to an impressive career in the scientific community, becoming an authority in fruit research in her job as a research associate at the New Zealand Institute for Plant and Food Research in Central Otago. Claire has been asked to present at a number of conferences around the world and is now embarking on a Master of Science.

Claire has been accepted into a two week course in Germany for MSc students from around the world and also has the opportunity to attend an international horticultural congress in Istanbul, which is held every four years.

Just weeks after being granted a CF Achiever's Award, Claire was celebrating her engagement to boyfriend Dan, who proposed at the top of a cliff they climbed in Australia.

“We are very happy,” she says.

Claire's setback in nursing is now a distant memory but she admits it was a very hard time.

“It took a few months and a couple of university changes before I managed to find something that worked, which also meant leaving my friends and family behind in Auckland to move to Palmerston North.”

After getting her science degree Claire was offered a summer studentship at Plant and Food Research in Central Otago – and never left!

Up until recently Claire's health has been good but lately a drop in lung function has had an impact on her lifestyle.

“Some of the things I have previously been able to do are becoming more difficult. I am currently sitting around 37-40% FEV1, and really struggling to keep weight on. But I am pancreatic sufficient, and I count myself very lucky for this. I have always been pretty non-compliant and this is something that I am now focusing on improving. I wish that I could turn back time and teach myself the importance of these.”



Claire uses her many interests to help supplement her physio including rock climbing, mountaineering, snowboarding, split boarding, tramping and surfing. She is also part of the Alexandra Rotary, and Central Otago Search and Rescue.

“I strongly believe in using exercise to supplement physio, it’s the only way I’ve ever been able to build lung function. In 2014 I completed a mountain half marathon, but due to a decline in lung function from 50% to what I am now, running has been very difficult and I miss it a lot.

Her advice to others in the CF community is not to be too hard on yourself when you need to take time out.

“I am the last person who should be giving this advice, as I will probably never take it. Right through university, and my career, I have focused so much on everything, not realising that if you don’t have health first and foremost, that you don’t have life. Sometimes, it’s okay to say that you’ve taken on too much and take a step back for a while. Maybe one day I’ll take my own advice!”

Claire is a wonderful role model for young people with CF and she is extremely grateful for her CF Achiever’s Award.

“I want to thank everyone who is involved in making this award possible. I know that every person with CF deals with what comes at them in different ways, and we all get given very different hands. I hope that maybe telling this story will let people know that you can still live wonderful lives with the hands we’ve been given. I am thankful every day to be included in the CF community, and be surrounded by beautiful, inspirational people that are grabbing life and running with it.”

## CALEB SKENE CF ACHIEVER, EDUCATION

Talented tertiary student Caleb Skene has achieved excellence in his architecture studies with his impressive results and willingness to push architectural boundaries.

Now in his final year, Caleb (21) was offered a part-time job by an architect he studied under during his second year, and who has recently included him in a design team for an architectural competition.

One of Caleb’s referees - a tutor at the Ara Institute of Canterbury, describes Caleb as a positive presence in class. “When given an assignment he consistently goes above and beyond the task with his research to provide an innovative and alternative point of view.”

Caleb is planning to continue his studies to obtain a post-graduate Master’s degree. At this stage he is leaning towards designing homes as a career because of the strong emotional

connection involved for those building a new home. His long-term aim is to start his own firm.

In terms of his health, Caleb is fortunate to have been well enough to complete the Queenstown Half Marathon last year, although in recent years he has been hospitalised with appendicitis and for bowel surgery.

“My biggest struggle at present is dealing with ABPA (aspergillosis). When this rears its ugly head it restricts my ability with breathing and fitness and I must spend many months weening off prednisone.

“Currently my lungs aren’t in their best shape compared to my usual standard, which means running and surfing can become more of a struggle than usual. However, I find that is the best time to keep up the activity to stop the issues from getting worse.” says Caleb, who also enjoys painting.

Caleb believes having CF means he looks at challenges in a different light.

“CF has helped me to enjoy the stresses and experiences of architectural studies rather than be discouraged by them.

“In saying that, CF has, on quite a few occasions prevented me from going to lectures and tutorials when I have been hospitalised. This held me back a few days in my studies but just creates an extra challenge to take on board and overcome.”

Receiving a CF Achiever’s Award is another string to Caleb’s bow and he believes it will be a huge help with his future endeavours within the architecture industry because he plans to use the Award to buy a high-tech computer which will help enhance his architectural designs.

There’s also a chance that Caleb will decide on an overseas trip to experience first-hand some of his favourite works of architecture around the world – such as Frank Gehry’s Dancing House, or Peter Zumthor’s Chapel of Light.

While Caleb is able to fit in his studies around CF treatments and other commitments, it’s not always easy.

“My one tip for any person with CF studying would be to find a balance between study/medication/physio/fitness/sleep and life. With having CF, each and every one of these six steps is crucial to take control of, in order to maintain healthy wellbeing,” he says.

“Overall I never let the issues and health concerns that arise from cystic fibrosis stand in the way of achieving my goals,”

Caleb is extremely grateful to be named a CF Achiever and is thankful to have the opportunity to apply for awards that celebrate the achievements of people in the CF community.

“Studying is very expensive, especially living a student lifestyle, and it is great to be awarded for your achievements,” he says.



# IT'S PARI BOY'S 50TH BIRTHDAY TOO!

The whole CF community in New Zealand have embraced PARI Boy's worldwide T-shirt fundraiser.

As part of PARI BOY and CFNZ's 50th anniversary, PARI launched the T-shirt sporting challenge, offering to donate \$10 Euro for every photo of someone wearing a PARI shirt that is posted to their PARI BOY 50 Years Facebook Page.

New Zealand's had a starring role with everyone from CFNZ's Chief Executive to families and children with CF featuring in some amazing shots.

The promotion has been so successful for PARI, which is also donating to the European Cystic Fibrosis Society, Cystic Fibrosis Australia and the British Lung Foundation, that T-shirts ran out early in the piece, which left many waiting for their shirts to arrive.

Those who did receive a shirt have made the most of them – and don't they look smart!



## Tribute to Anna

Cystic Fibrosis New Zealand has been mourning the loss of one of its greatest champions – Anna Scoullar-Jones who was a parent of a CF son and a long-serving Chairperson of the Central Districts Branch.

Anna joined Central Districts Branch as Co-Chair not long after Lockie was born with CF 18 years ago. Initially she co-chaired the Branch with her childhood friend Erin Bartrum who had CF and who passed away at the age of 42 from liver cancer following a lung transplant. Anna remained sole-Chair of the Branch until she stepped down last year.

It was Anna and Erin who organised the first Ballentynes Fashion fundraiser for Cystic Fibrosis in 2010, which became a popular annual fundraiser with local women modelling latest fashions and it was often a sell-out. Anna had no problem talking friends and colleagues into modelling for the event and also managed to persuade the Whanganui Mayor to appear on the catwalk a few times.

Anna passed away unexpectedly in April from a pulmonary embolism. She is remembered for her smile and her

generous and friendly nature. She was dedicated to improving the lives of people with CF and also very active and encouraging to others on CFNZ Facebook pages.

Anna's sister Katy Scoullar was instrumental in getting CFNZ named as one of 10 charities to receive a \$10,000 donation

from Mercury Energy last year after writing a heartfelt letter about Anna's own fundraising efforts.

"My sister gives her time as chair of a local branch. She has organised raffles, bake sales and fashion shows, and even talked KFC into having a donation box on their counter! Hours of work are done out of love by these people who are already under incredible pressure caring for an unwell child, to raise a few hundred dollars at a time," Katy wrote.

A number of people from the CF community attended her funeral, including CFNZ Chief Executive Jane Bollard. Her funeral was live streamed so we also got to tune in from the office. Anna was farewelled to the sound of the Crowded House song Always Take the Weather played by Frazer's band, The Noodles. And Frazer has since thanked the CF community for all the love and support the family has received.



## Kimmy's Caps' Tribute to Talented Coach

The Capital Punishment Women's Ultimate Frisbee Club has been honouring the memory of their much-loved coach Kimberley Bryant by wearing caps dedicated to her.

The Club has created "Kimmy's Caps", with players wearing a cap with Kimberley's name and player number embroidered on it, which they say allows them to carry her spirit with them in every game they play.

Kimberley was committed to the Ultimate Frisbee sport and represented New Zealand in the women's U23s at the Ultimate Frisbee World Champs in Toronto.

She was instrumental in founding the Capital Punishment Women's Ultimate Frisbee Club in Wellington and nurtured young talent with her coaching ability.

"Kimberley was a fundamental part at the heart of this club," says Anka Kuepper who is part of the leadership team.

Kimberley, who passed away in January, aged 26, also played Ultimate Frisbee for Victoria University's Ultimate Frisbee Club for more than six years until she was no longer able to fully participate on the field, at which time the CP Women's Ultimate Club was well established and she stepped into coaching and development.

The Club has held a number of fundraisers this year to support CFNZ, with Kimmy's Caps playing a starring role.

Kimberley is fondly remembered for her spirited nature and the club thanks her for all she has done to help foster young talent.

She won a Mark Ashford Scholarship award in 2012 for her studies in Biomedical Science and Cognitive & Behavioural Neuro Science. Also a CF Achiever Award for leadership in 2010 after being named a Tukana Prefect at Wellington East Girls' College, leading a buddy system for Year 9 students. She was also a co-leader of the Wellington City Council After School programme, teaching arts and crafts to young people from underprivileged backgrounds.

The Capital Punishment Club has created a memorial award in her honour – Player of the Year for Women's Ultimate, which is a supreme award to the player who has represented the club's values and spirit throughout the year. This trophy incorporates a relatively new Maori symbol in the form of a glass "twist" or "pikorua". This design has its roots in nature and is said to represent the path of life and symbolise the strong bond between two loved ones. It is a powerful expression of loyalty because the arms of the twist have no end point – just like lifelong relationships.

Aptly, New Zealand Ultimate Championships this year dedicated their Most Spirited Player award to Kimberley in March this year. It's wonderful to hear that Kimmy's Caps ensure that her spirit lives on.



## Kelcie Wins OSH Award

Massey University student Kelcie Mills has become the first recipient of a \$15,000 Zespri Health and Safety Scholarship Award.

Kelcie, who is studying Occupational Health and Safety online from her home in Hamilton, won the Scholarship after completing an essay on the subject.

Zespri is offering the Scholarship as part of an agreement with WorkSafe NZ, as an alternative to prosecution for a workplace accident involving a quad bike at a Tauranga orchard in 2016. It will voluntarily pay a total of \$250,000 towards health and safety measures. It is known as an “enforceable undertaking” and is increasingly being used as a positive alternative to prosecution when a workplace contravention has not directly been the cause of an accident.

Kelcie (19) and her fellow students were advised to apply for the Scholarship and Kelcie was over the moon to be the lucky winner because it will be a huge help towards completing the three-year course.



She did not mention having CF as part of the application process and believes her youth helped her selection. “I think my age helped because you don’t find many young people studying health and safety.”

She plans to use most of the Scholarship funding for her three-year course, but may treat herself a little. “I might do some shopping but 90 percent of it will go on the course,” she says.

Kelcie originally enrolled in business studies at Waikato University but decided to switch to a Bachelor of Health Science at Massey University - which she finds is better for her own health and future career.

“It’s a lot easier than going to classes at Uni but it can be hard not to be distracted by Netflix and Facebook,” she smiles.

“It’s quite nice being able to stay home and warm. I got quite sick attending University last year. Also I found business studies a bit boring.”

Getting a part-time job at Hauraki District Council, where her father works, led to her interest in health and safety. She was placed in the health and safety department and still works there two days a week.

Kelcie is flatting in Hamilton with two good friends who are extremely supportive – reminding her of her appointments and sitting with her at hospital.

She recommends online degrees to others with CF who may find lecture theatres too tough to handle.

“My health took a huge hit when I was at Waikato University and I was so stressed. I am so much better now,” she says.

## Welcome to New Office Manager Irene Vanderlaan

### What drew you to CFNZ?

*I have spent the last 12½ years working for an innovative NZ biotechnology company which reached Phase 2B trials for an immunomodulating drug for people with progressive multiple sclerosis, creating and managing a compassionate use programme for over eight years for ex-trial patients across New Zealand and Australia who wished to continue to use the drug. Through close contact with them as I documented their physical and emotional progress over the years, I became very familiar with the issues faced by PWMS and came to understand the need for networking and support and advocacy. I hope I present the same understanding attitude to our CF community.*



### What are the best parts of the job?

*The team and Board are all professional, discreet and caring and have been supportive as I come to grips with the complexities of dealing with the grant making process as well as the documentation involved in recording our services to the CF community. Meeting some of the CF professionals involved in the various CF sub committees has been enlightening and stimulating and I look forward to meeting the people at the branches who are so important to the work of the organisation. I look forward with great interest to learning about the new drugs, equipment and techniques being developed.*

### What is on your wish list for the next five years for CFNZ?

*Top of the list would be to see the Ministry of Health and DHBS recognise the value of CFNZ knowledge and services with inclusion in their information sharing and with ongoing funding. I would also love to see CFNZ develop a reliable ongoing funding base which would allow long-term planning and the ability to provide expanded Fieldworker services and greater advocacy services. This might also allow bigger office space with easier parking so that our volunteers find it easier to visit and also provide greater storage facilities for the many gifts and projects we are involved in.*

### Favourite music?

*I am a great fan of NZ’s Lyttleton sound (Marlon Williams and Eldous Harding) and follow NZ talent quite closely.*

### What do you like to do in your spare time?

*I am a keen gardener with an interest in natural medicine and herbs. I also belong to a large, vibrant Dutch family who get together regularly, sing, and make a lot of noise! (It’s called being “gezellig”).*

### Best piece of advice?

*Laughter is the best medicine.*

### You’re happiest when?

*I am on the couch with a good book and my pussy cat sitting on me.*

## NZ Joins Worldwide CF Liver Disease Study

It's hoped a new research project to assess the effectiveness of a medication used to treat CF Liver Disease will lead to the medication being funded in NZ.

Starship Hospital Paediatric Gastroenterologist Dr Jonathan Bishop is taking part in a worldwide research study to assess the effectiveness of the medicine, ursodeoxycholic (UDCA), which is commonly used in many countries around the world either to prevent liver disease from developing or reduce the progression of the illness.

UDCA is form of bile that is believed to help thin thick bile in the liver that can occur in the CF population. The acid, derived from bear bile, was used in some form of traditional Chinese medicine, but Dr Bishop says at this point there is not a lot of evidence that it actually does improve long-term outcomes in CF such as transplant and life expectancy. The aims of this study aims to determine whether it does improve CF care.

"You can understand the rationale for Pharmac limiting this prescription because whilst it's relatively inexpensive and relatively non-toxic, the evidence base for its use to date has been fairly limited. There's some evidence that if you've got cystic fibrosis and you've got abnormal liver blood tests then yes, ursodeoxycholic acid can make the liver blood tests look better. There's some weak evidence that if you had a biopsy which showed CF Liver Disease and use ursodeoxycholic then the biopsy may improve with time. But there is no good robust evidence to show that it makes any difference in the long-term outcomes of either the need for a liver transplant or life expectancy," Dr Bishop explains.

He recently received Ethics Approval for the study and sought CFNZ's permission to access data on the patient registry, PORT CF, for 250 people born between 1990 and 2007 which will be sent to the lead Italian-based researcher Dr Carla Colombo to compare to other anonymous data from several other countries around the world including US, Russia, Italy and Australia.

The data will be compared against three different CF patient groups – those who have taken UDCA from the diagnosis of CF, to the population who take it from the diagnosis of CF Liver Disease, and those that have never had it (NZ and Australia).

The medicine has been available for over 20 years in the US and the UK, and was a normal medicine to prescribe when Dr Bishop worked in the UK.

"This study will be valuable – both if it shows the drug does not work because it would suggest that it won't need to be prescribed. It will also be valuable if it does prove to be effective," he says.

If it does show that it's effective at preventing or developing CF Liver Disease or that people who take UDCA once diagnosed do better than those who don't have, then this new data could be presented to Pharmac as evidence to start funding it here. "It provides much greater strength to our argument that we would like to prescribe it for this indication. It is funded for other indications but not cystic fibrosis," Dr Bishop adds.

It costs around \$100 a month and Dr Bishop says understandably many parents of children being diagnosed do want access to it because it is also considered a safe medication. He knows of a number of families which personally cover the cost.

"One of the concerns is that by the time you start taking it the damage has been done and the liver has been scarred so it will be interesting to see if the countries that start it in infancy have less prevalence of CF Liver Disease," he says.

CF Liver Disease is most common in boys and generally detected towards the age of 10. It is also the most common CF-related death following respiratory causes and transplant complications.

The development of new innovative medicines available overseas, such as Kalydeco, won't have any impact on these results because they were introduced after 2007 which is when the study ends.

"Generally speaking, the care that the CF patients in New Zealand get is excellent and have probably benefited from screening and very early diagnosis which is not standard around the world," he explains.

In the past some children with CF have accessed UDCA under Pharmac's named patient application scheme but not in recent times.

"In the last three or four years we've made submissions to Pharmac to reconsider the indication for funding ursodeoxycholic acid, and they did, but felt CF Liver Disease did not meet the criteria.

"There are no other specific medications that we can offer for liver disease in cystic fibrosis. We can talk about general health advice which is maintaining overall CF care and nutrition, to avoid excessive alcohol use when they're older and being immunised against hepatitis viruses, but there are no other specific drug treatments.

"Pharmac obviously have to think about funding and resources but actually it's a cheap medication, been around for many, many years and is essentially side-effect free," he says.

A new generation ursodeoxycholic acid has been developed overseas which has been show to be more effective in some forms of liver disease but not in CF so far. Dr Bishop is also interested to see if long-term use of precision medicines like ivacaftor (Kalydeco) may help prevent or slow progress of CF Liver Disease.

If Pharmac does reconsider funding for UDCA then it may be for a target group of patients who are more at risk of liver disease such as boys, those with more serious genotypes, and those who had meconium ileus at birth requiring surgery and a long hospital stay.

Dr Bishop says the study results are expected sometime next year.

“It is important to be part of multi-centre studies like this. Dr Carla Colombo is the leading light of Cystic Fibrosis Liver Disease internationally so it’s good for New Zealand and our patients to be part of this study and hopefully it will improve patient care in the long run.”

## Kalydeco Continues to Impress

Latest research on the effects of Kalydeco has shown positive results – with a significantly lower risk of CF-related complications.

The study of data from the US and UK cystic fibrosis registries shows people treated with Kalydeco had a lower risk of exacerbations, hospitalizations, transplant, and death, along with an improvement in lung function.

The therapy was first approved in both the US and European Union in 2012 to treat CF patients over the age of 6 who specifically had the G551D gene. Overseas it is now prescribed for the treatment of several other genetic types of cystic fibrosis and for many under the age of 6.

In the study, published in the medical journal *Thorax*, researchers investigated the effects of Kalydeco treatment on the progression of CF and clinical outcomes of CF patients, using data from the U.S. and U.K. CF registries.

The study compared 1,256 patients who started Kalydeco treatment in 2012 with 6,200 patients who had never taken Kalydeco from the U.S. registry, and 411 patients who began Kalydeco treatment in 2013 with 2,069 people from the U.K. registry who had not taken it.

Different outcomes were compared, including risk of death, pulmonary exacerbation, hospitalisation, transplant, lung function changes, and prevalence of CF-related complications and infections.

Outcomes (US)	Kalydeco	Non-Kalydeco
Pulmonary exacerbation	0.6%	1.6%
Hospitalisation	27.5%	43.1%
Transplantation	0.2%	1.1%
Risk of death	0.6%	1.6%

Similar results were found in the U.K. registry.

The treated group also had less CF-related complications, such as diabetes and depression, and pathogenic microorganisms. These patients’ lung function also improved after treatment with Kalydeco.

No additional safety concerns for the therapy were reported in this study.

## Aerobika – New Device Advice

CFNZ has heard positive reports about the new Aerobika device, which combines nebulising hypertonic saline and PEP – and Rebecca Scoones, Paediatric Respiratory Physiotherapist at Starship Children's Hospital is trying to get them into NZ. :

*“The Aerobika is a relatively new device used for airway clearance. The Aerobika is a type of oscillating PEP that clears secretions producing oscillations or airway vibrations that shears secretions off the airway walls. Secretions are then cleared with a huff and cough.*

*The Aerobika also has an element of positive pressure that splints airways – holding them open, allowing more airflow to shift secretions. While there is minimal evidence around the Aerobika and airway clearance, it is thought to be as effective as other types of oscillating PEP such as Acapella or Flutter.*

*Several people with CF in New Zealand have these devices through Starship due to a small survey done in Australia and New Zealand. This survey found that those using the Aerobika found it easy to use, and some users reported being able to clear more secretions and do more physiotherapy than they were previously.*

*The Aerobika is not available in New Zealand yet but I am currently working to access these devices through an Australian supplier. I am hopeful we will be able to access these in the near future.”*

– **Rebecca Scoones**, Physiotherapist, Starship Hospital

## PATIENT VOICE TALKS SENSE

CFNZ is playing a key role in a new organisation aimed at improving the healthcare of all New Zealanders.

Patient Voice Aotearoa, is a group of many health-related patient groups, which aims to speak out against the lack of patient representation in decisions related to medical care and the funding for new medicines.

A steering group to outline how Patient Voice will operate has been formed and includes CFNZ Chief Executive Jane Bollard along with representatives from Cure Kids, Canteen, the Lung Foundation, the Unicorn Foundation, and Breast Cancer Aotearoa. The group intends to find common objectives that all patient organisations in NZ can lobby for.

A recent Patient Voice conference in Auckland looked at some of the important issues related to health care in New Zealand and featured speaker Cathy Scott of the NZ Institute of Economic Research who painted a grim picture of any improvements in the short term – largely because of the change of government and also staff changes at the Ministry of Health.

She said it would take the Health Minister some time to come to grips with many of the issues and also long-term staff had left the Ministry of Health which meant new staff also needed time to settle into their roles.

In addition, there were a number of emerging problems likely to impact the health system. There is a shortage of health professionals, staff pay disputes and a large number of senior GPs reducing their hours, leading to an increase in part-time GP positions.

It was her belief that the best people to lobby for changes are senior policy advisors at the Ministry of Health and the Health Minister's private secretary.

One of the biggest problems facing patients is that the current health policy directs funds at what can improve the health of the most people.

"The things the government is focusing on are not the ones that cause the largest health burdens," she said.

Cathy said the new minister had met with very few patient groups, although the Cancer Society has had a meeting. She didn't expect any big changes in cancer treatment until towards the end of the current government's term in 2020.

She explained there was little related to health in the Labour/NZ First coalition agreement, apart from these points:

- Free health checks for seniors
- Re-establish the Mental Health Commission
- Free doctors visits for under 14s
- Increase the age of breast screening to 74

She spoke about the number of DHBs in New Zealand and asked whether the voting of their boards was really a democratic process. She said merging some DHBs would help to reduce administration costs.

Meanwhile, a representative of Pompe Disease, Samantha Lenik, who lives with the condition, said the enzyme replacement therapy called Myozyme is funded in 76 countries. The drug company which produces it is now providing compassionate access to some patients with the disorder in New Zealand – something the drug company normally only provides to "third-world" countries.

## Update from Pharmac Chief Executive Sarah Fitt



I'm delighted to lead PHARMAC as it continues its work for New Zealand. Our broader funding work continues with work in community medicines, vaccines, hospital medicines, and medical devices used in DHB hospitals. In line with our strategic goals, we have a strong interest in activities to eliminate inequities in access to medicines.

We are currently considering a funding application from CFNZ for the TOBI Podhaler and this will be given full consideration by our clinical experts and economic advisers. We will first be seeking advice from our expert Respiratory Subcommittee, who will in turn provide their advice to our main clinical committee, PTAC. Should the recommendation be positive, PHARMAC would rank the funding proposal alongside other medicines seeking funding. We always have more options to fund than we can afford, so careful choices need to be made.

Some recent funding changes include the shingles vaccine being funded from 1 April, for people aged 65, with a catch-up programme for people up to 80. We're also funding an influenza vaccine this year that, for the first time, offers protection against four strains of influenza. People with CF are eligible for a funded vaccine, and we encourage people to use the opportunity to prevent influenza infection.

I know there is some interest in our rare disorders work from people with CF and their families, as there are some sub-types of CF that could be considered rare.

At the end of 2017 we announced the formalisation of a process for considering medicines for rare disorders, which includes establishing a new clinical advisory subcommittee, to specifically consider funding of medicines for rare disorders. This work started in May and we hope the committee will be able to have its first meeting before the end of the year.

We are calling for funding applications from suppliers of medicines for rare disorders. This process could lead to even better access to medicines for people with rare disorders.

Our earlier contestable funding process led to decisions to list 10 medicines for rare disorders on the Schedule.

– Sarah Fitt

## Beach Kids Moved Mountains to Raise Funds

Beach Kids Early Learning Centre in Waihi has been overwhelmed by the support received from the Climb Everest for CF Challenge in support of pre-school student Frankie-Lee.

The Challenge, organised by Emma Overdevest and Sara Harris-Ellis, from Beach Kids, raised \$2500 before it even started and finished with a whopping \$14,043 for CF Bay of Plenty.

The challenge involved walking the Waihi Beach Trig 48 times over a 60 day period – the same length as Mount Everest.

There was amazing support from the community, including business sponsorship and a number of other fundraising spin-offs.

Beach Kids also helped raise awareness about cystic fibrosis by producing two compelling videos we were able to post on the CFNZ Facebook Page.

A big celebration was held at the end of the challenge which included raffles, spot prizes and an auction which helped push up the total raised, with the organisers expressing their gratitude for people's "generosity, kindness, respect, thoughtfulness, love and friendship".

Bay of Plenty Branch Chair Yvonne Rooney has sincerely thanked Beach Kids for their efforts.

"We were overwhelmed by Emma and Sara's efforts – their passion and energy! They had an idea and it took off and energised a whole community. The whole BOP branch has been amazed at how much they achieved in such a short time – they deserve a huge round of applause.

"We can't thank them enough – for both the raised awareness of cystic fibrosis and the fantastic fundraising they achieved. Champions!"



## All Charlie's Easters Come at Once!

Charlie's eyes lit up with delight when she unpacked the goodie bag she received just after Easter at Ronald McDonald House in Auckland. The 10-year-old was up in Auckland for her annual check-up at Starship Hospital and couldn't believe her luck arriving just after Easter when there were still a few goodie bags left in the cupboard.



## Peter Tinholt Hits \$100,000 Target



It's been a labour of love for 10 years but it's all paid off for the CF community as Peter Tinholt and several key supporters achieved Peter's dream of raising \$100,000 for cystic fibrosis.

Peter reached his goal at his Rotary Club's Breakfast at the Tauranga Readers and Writers Festival, which featured historian Vincent O'Malley as guest speaker who provided an in-depth look at the Waikato land wars in the 1800s. The event organised by Rotarian Sally Morrison raised a massive \$10,000, bringing the total amount raised in 10 years to \$103,000. At the breakfast Peter and Sally were both awarded a Paul Harris Fellow – the highest award in Rotary.

Peter started fundraising for CFNZ when he entered Ironman in 2008 and with support of his Rotary club his goal of raising \$100,000 grew over time. Once he had raised around \$70,000, Peter decided he wanted to reach the \$100,000 target which is why he kept fundraising both for Breath4CF and his local Bay of Plenty Branch including holding quiz nights, raffles, charity auctions with sports memorabilia, and what have now been three CF fundraising breakfasts.

"It's been so rewarding to see children with cystic fibrosis grow up. I'm fortunate because I haven't got kids with CF. I just wanted to do this for a good cause and it's been so wonderful to be able to give money and give back to the community and see the difference it can make," says Peter who is now on the Board of the local Community Foundation which he attributes to his commitment to the CF community.



## Awareness Week – All Hands on Deck

Auckland Branch is aiming for the biggest and best CF Awareness Week yet. After identifying our priorities as a branch we have set up a number of subcommittees including a fundraising subcommittee. This subcommittee is hoping to do bigger and better fundraising this year, get our community more involved and of course increase the awareness of CF as much as possible. For this year's Awareness Week, as well as our street collection, coin trails, and chocolate fish selling, we are also doing a 'Steps for CF – Winter Challenge'. We are encouraging groups of friends, schools, and businesses to step out for CF. Participants download a steps app, gather sponsorship, then head out during Awareness Week to get as many steps as possible and fundraise for CF at the same time.

## Movie Night Sell-Out!

Thanks to Waverley Brett from our CF Auckland committee who recently organised a fundraising movie screening of the Charlize Theron movie *Tully*. The event was a sell out. We are still waiting for a final amount raised from ticket sales and raffles, but it was a hugely successful evening that enabled us to reach out to the wider community. A big thank you also to Delish Cup Cakes which donated some scrumptious mini cupcakes to give away on the night.



FUND  
RAISING  
NEWS

## Branch on the Run

The Auckland Marathon is an iconic running event and this year it will take place on Sunday, 29 October. CF Auckland is planning to have a group of fundraising runners taking part. Thank you to **Willis Towers Watson** (risk assessors and insurance brokers) who have supported CF Auckland for a number of years and this year plan to have about 30 runners as part of the CF team in the Auckland marathon event. The Branch is also hoping to have a number of runners from the wider community join our team on the course over the Harbour Bridge and are planning delicious bacon butties, treats, drinks and a sports massage to entice people to take part and to give them something to look forward to at the finish line.

Willis  
Towers  
Watson

## New Developments in CF

In March we hosted an evening for our community on *New Developments in CF*. We were fortunate to have Starship Associate Professor Cass Byrnes who discussed the latest research results and gave an insight into what we are likely to see in the future. Following on from the talk was a panel discussion with some of the medical team that provided an opportunity for attendees to ask questions. The talk was screened on Facebook live at the time of the event and was also professionally videoed.

If you would like to view the video you can find it on the [www.cfauckland.org.nz](http://www.cfauckland.org.nz) website or contact Kath at [auckadmin@cfnz.org.nz](mailto:auckadmin@cfnz.org.nz). The Branch is intending to run this on a regular basis, to keep our community updated on the latest international CF news and research.

## Tokens for CF

Many thanks for the ongoing support from **The Warehouse Bags for Good Campaign** and **Z Energy Newton's Good in the Hood** in May. CF Auckland is currently one of three recipients at **Sylvia Park, St Lukes** and **Atrium** in Auckland. Get a token when you pay for a shopping bag and vote for CF. The Warehouse is ditching single-use plastic checkout bags and replacing them with fully compostable bags, with all net proceeds going to charity.

## RECIPE – CHICKEN SATAY

### Ingredients

- 1 onion - chopped
- 2 cloves garlic - crushed
- 180 gm crunchy peanut butter
- 35 gm soy sauce
- 50 gm sweet chilli sauce (or to taste)
- 80 gm oyster sauce
- 1 can (400ml) coconut milk
- 600gm chicken cubed
- 300 gm of mixed veggies of your choice

### Method

Fry onion in a little oil until transparent, add garlic and fry for a minute. Then add peanut butter, soy sauce, sweet chilli sauce, oyster sauce and coconut milk and simmer over medium heat for 5 minutes.

In a separate pan or wok, cook chicken and your choice of vegetables. Add the chicken and vegetables to the satay sauce and serve over noodles, rice or cauliflower rice.



RECIPE  
ROUND  
UP

# 2018 Fundraising Superstars

FUND RAISING NEWS



Macleans College in East Auckland continue to do amazing fundraising for CF Auckland. So far this year they have run a bake sale and a car wash and they have plenty of other ideas for ways they will continue to support us for 2018.

Jonny Simons who was challenged by his mates to run the Waterfront Half marathon and in doing so raised an incredible \$2614.50 for CF Auckland!



Jamie's Golf day – friends and family ran a golf day to help Jamie and family as he recovered from his lung transplant. On one hole the golfers that participated were able to pay \$5 to challenge Jamie in a putting competition with the \$540 raised donated to CF Auckland.

– KATH SANDERSON, AUCKLAND BRANCH COORDINATOR

# NIGEL LATTA

## *Adventures in Parent Land* The First Ten Years

*"There's no doubt that raising kids is hard work. Large parts of the journey are covered in worry, confusion, and guilt. In this entertaining, and unflinchingly honest evening, Nigel will deal with some of the myths about raising children, and offer some ideas for a kinder, simpler, more enjoyable approach to parenting."*

**21 August 2018**  
**Isaac Theatre Royal, Christchurch**  
**Doors 6:30pm | Start 7:30pm**

Tickets available from [ticketek.co.nz](http://ticketek.co.nz)  
Facebook page @ [bit.ly/2tcytkn](https://bit.ly/2tcytkn)

Supporting  
**cf** CYSTIC  
FIBROSIS NZ  
CANTERBURY



## Night Out with Nigel Latta

Canterbury Branch is grateful to have secured **Nigel Latta** for a special appearance to mark its 50th anniversary this year.

Canterbury families were instrumental in the formation of Cystic Fibrosis New Zealand and are welcoming Nigel to Christchurch on 21 August to support other Kiwi families bringing up children to mark the 50th anniversary.

His talk “Adventures in Parentland – The First 10 Years” will look at how to raise children with the least amount of stress that’s humanly possible – always handy to know!

Nigel’s latest show *Mind over Money* recently screened on TVNZ. He is also the host of the popular TV shows *Beyond The Darklands*. His presentation at the Christchurch Isaac Theatre Royal is sure to be entertaining and insightful. Tickets \$45–\$55 and available at [ticketek.co.nz](http://ticketek.co.nz).

◀ SEE OPPOSITE PAGE FOR FURTHER DETAILS

# HAWKE’S BAY BRANCH NEWS

## Gambling to Win in Hawke’s Bay

It will be a **black and white casino night** in the Hawke’s Bay this year – marking the 5th anniversary of the popular event.

Gamble the night away on the roulette and black jack tables at the Havelock North Function Centre on **1 September** – all for a great cause – to raise funds for the local CF community in Hawke’s Bay.

Come along to party dressed in black and white – gamblers worried about what to wear can try The Tabard Costume Hire (Napier Operatic Society) which has offered a discount if you mention the CF Casino Night. Ph **06 835 8775**.

Tickets are limited and the price includes canapés, five drinks, gambling loot and the chance to bid on some amazing auction items at both the live auction led by John Kingston and a silent auction during the evening. Tickets available on [eventfinda.co.nz](http://eventfinda.co.nz). Email: [cfcasinohb@gmail.com](mailto:cfcasinohb@gmail.com) for more information.



## Raise-a-Calf for CF Brings Home the Bacon

The Taranaki CF Branch have now banked all the money raised from the popular “Rear a Calf for CF” fundraiser and raised about \$9,400. A huge thanks to Bruce Fowlie who collected all the animals, arranged sale and even on reared some for us until the sale prices picked up. Also sincere thanks to Allflex who donated the calf tags. But the biggest thanks of all goes to all those generous people who donated the calves to a very worthy cause!

We are gearing up to run the same fundraiser again this year, so if you are interested in donating a calf, or helping out in any way, contact a member of the Branch.

## Bridging Finance

We were lucky enough to secure the catering rights to a charity bridge tournament run by the Hawera Bridge Club. They donated their entry fees and we ran a couple of raffles. After the tournament they ran an auction for the left over baked goods and raised a whopping \$180! Someone even generously paid \$40 for 6 cupcakes. We were very humbled by how kind and generous their members were.



FUND RAISING NEWS

## Branch Birthday Bashes

The Taranaki Branch was offered two tickets to the TSB Community Trust to celebrate their 30-year-celebration of supporting Taranaki community organisations, which we are lucky to be one of. Two of our members went along for a night of entertainment and celebration and to offer our thanks to the Trust.

It is not long now until Awareness Week and our 50th anniversary event. If you are able to help out in any way with collection week, selling chocolate fish or any other fundraising ideas please contact either Nic, Shelley or Joan.

– By Chair, **Nicola McCarthy** ([Nicola.McCarthy@fonterra.com](mailto:Nicola.McCarthy@fonterra.com))

# SHANE'S BRUSH WITH FAME

CF  
ADULT  
NEWS



It was heartening to see Shane Hill helping to raise awareness of CF on *First Dates NZ*. He talks to CF News about his experience.

Wellington's **Shane Hill** may not have found love when he appeared on *First Dates NZ* but his willingness to share information about his health condition on national television has impressed many in the CF community.

Shane (40) originally applied for *Married at First Sight* but they couldn't find him a good match so referred him to the producers of *First Dates NZ*. Shane says being treated like a star for a day was an exciting experience and he was happy to chat to his date about having CF.

"I've been really pleased with the feedback I've received. They edited it in such a way that it really got the message about cystic fibrosis across. They portrayed me very well and I was pleased to come across as a nice person.

"It was an amazing experience. We were almost treated like celebrities. We were put in 'Green Rooms' and mic'd up and they brought us food and drink. We were told we could wear anything we liked – just no black, stripes or ripped jeans."

Shane was willing to talk about having CF because he says he never saw anyone on TV talking about having cystic fibrosis when he grew up.

"The whole nation knows I have CF now and I get recognised from the show. When I go out people have come up and asked for photos," he laughs.

The producers asked him to reveal his health condition to his date, who was fine about it. In fact, Shane says having CF hasn't affected his ability to find love in the past. He has a four-year-old daughter, Emily, from a long-term relationship. He also discussed the IVF process on *First Dates NZ*.

"Normally you wouldn't bring up that on a first date. When you meet someone in a more typical way and the chemicals are there you might potentially bring it up in the first week because people are a bit more open at that stage. After three or four times I've seen them I usually tell them. I've been in three or four serious relationships and my partners have all been fine with it."

At the end of the show, Shane and his date decided to see each other again but he says it didn't end up happening.

"I didn't really feel that spark but I definitely knew that on paper we could have something. A few days after the show I realised we didn't have what was needed to continue."

The pair did not meet up again and Shane is relaxed about finding the right person.

"I don't need another person to make me feel whole. I am much happier now," he adds.

Shane had initially wanted to apply for *Married at First Sight* because of his goal to find true love. He got through to the final stages of the interview process for *Married at First Sight* and wonders if having CF may have had an impact on him not being selected.

"A couple of weeks later they rang me and said we really liked you but we don't want to marry people unless we can find them the perfect match. They said the producers of *First Dates NZ* really liked my audition and wanted me on their show. They already knew I had CF from the interviews I'd done for *Married at First Sight*.

"There had already been a couple of other people on *First Dates NZ* – one with Asperger's – who I think helped people realise that not everyone is deemed as 'normal', and it's okay to speak out and be proud of who you are, and that's the message I wanted to get across.

"When I grew up I was embarrassed and ashamed of being ill. It affected me quite a lot. I hated having to take tablets when



# NICK AND NATALIA'S HAPPY DAY

They met at the Backstreet Boys' concert so it's no wonder that the band featured in Nick Laing and Natalia Holden's recent wedding ceremony.

Nick and Natalia married at the Elim Church in Hastings that Nick has grown up with, and signed the register as husband and wife to the Backstreet Boys' song *As Long as You Love Me*.

"When that song came on everybody clapped and cheered. My two groomsmen were singing and dancing along," says Nick.

There were 90 guests to witness the ceremony led by Nick's church pastor.

Natalia wore a pink satin wedding gown from the **boohoo.com** website and Nick wore a dark navy blue suit and matching pink tie. It was lucky he looked as sharp as he did because his stag do was the night before the wedding where he was forced to wear a tutu and wig.

Nick had been in hospital for a tune-up to increase his weight a few weeks before his wedding to help prepare him for the couple's honeymoon in Disneyland and Phoenix, Arizona, where Nick's living donor lives, who has offered to donate a kidney or portion of liver, if Nick ever needs a transplant. Nick was pleased to get travel insurance from the travel insurance brokers **www.healthinsurance.co.nz** for the trip.

"The honeymoon was awesome," Nick says.

The couple, who live in Te Awamutu, got engaged after lots of questions from Nick's family and Natalia's five year-old son about when they were going to get married.

After asking for Natalia's father's permission, Nick got down on one knee during a candlelit dinner to propose.

Fortunately Nick's health has been great ever since getting together with Natalia. He's gained weight and his lung function rose from 18 percent to 45 percent.

"I made a conscious effort. I went to a personal trainer and said I need to do something," says Nick. "I now have a responsibility to stay well for her and her five-year-old son who adores me."

The pair met at a Backstreet Boys' concert in Auckland during a soundcheck that people with VIP tickets were able to attend.

Nick saw Natalia leaving the soundcheck and decided to talk to her. Afterwards Nick contacted her on Facebook and they stayed in touch.

"We Skyped every day for literally hours," says Nick but it was still some time before their friendship turned to romance. "But I knew I was going to marry her the minute I saw her."



I was eating, the coughing, and I couldn't go to camps, so it was hard. I hope that by voicing myself that other people can see that they can have a fulfilling life and to not be embarrassed," he says.

Although the Wellington teacher's lung function is fairly low at around 30-40 percent, Shane says he still feels well in himself.

"It doesn't seem to affect me at work or at the gym. I don't feel sick all the time or have any barriers to my lifestyle.

"Physiotherapy twice a day is religious with me. I barely go a day where I don't do it twice and if I don't do it twice, I do it once. I know there are different severities of cystic fibrosis but I think mine must be fairly severe," says Shane who refuses to feel sorry for himself.

"I hate having CF, believe me, and I do have sympathy for people having any medical condition but you have to accept it. I never look for sympathy and I think you just have to get on with it. You do whatever you have to do to keep yourself alive and you need to find someone in your life to want to fight for and for me that's my daughter.

"I want to live not only for me but for my daughter as long as I possibly can."

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