

WINTER 2017

cf CYSTIC FIBROSIS NZ
Creating Better Tomorrows

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CF news



Family Fun Fundraising

Meet our CF Achievers | CF Surfers in Southland
Research News: 3D Printed Lungs? | CF Adult News: CF at 63!



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In February this year the CFNZ Board, Chief Executive, the Chair of the CF Adult Advisory Group and the SILF Trustees attended a Strategic Leadership Day where we were all asked what excited us about CFNZ. My reply was that I believe that from a governance perspective we have certainly come a long way. In the last 5-6 years CFNZ has become much more focused and cohesive, and with our branch volunteers we have gone a long way towards breaking down any “them” and “us” barriers within the organisation. Something else that really excites me is the potential for moving along the path of my favourite CFNZ value – creating communities.

For the last three years CFNZ has had to be focused on business continuity management, for a variety of reasons. Over the last year CFNZ – whilst still ensuring support, services and assistance for PWCF and families, has gone through a time of great change – and our focus has had to be more internal rather than the more outward presence of prior years.

Last year we had four of our six staff leave, including our CE. This prompted a move of the CFNZ office from Christchurch to Auckland and we now (finally) have our full contingent of staff. We have had new external reporting requirements (as have all charities in NZ) and have implemented these throughout our organisation – something we have no choice but to comply with; this has taken considerable resources and time. We have rewritten our CFNZ Policy Documents that are fundamental to the legal, safe and effective operation of our organisation. We are working with the PORT CF Steering Committee to review and strengthen the data collection and reporting with a view to the data providing strategic direction going forward. We have developed and strengthened our collaborative partnerships with the Ministry of Health, PHARMAC, Wellington DHB, the NZ Paediatric Society Clinical Reference Group, and Cure Kids. We have secure and positive relationships with our sponsors – Choice Hotels and Hell Pizza, and of course

with our amazing and hardworking CFNZ Branch committees.

I am confident that CFNZ is in a space where due to the dedication, commitment and hard work by both staff and volunteers; we have strengthened our organisation and are becoming future proofed, even though it is an increasingly difficult time for the charity/NFP sector.

I am really aware that everything that we do, either as a Board or as individuals, can either build up or break down CFNZ and our vital and vibrant NZ CF Community. Sometimes there are difficult decisions to be made that we as a Board acknowledge may not be popular. However, we make these decisions carefully and thoughtfully using quality evidence and robust discussion to ensure that our decisions are as “right as possible”.

The recent position statement on funding Kalydeco/Orkambi has not had a positive reaction from some members of our CF community. The Board recognise that this position is not what many in our community hoped for. However, the Board has decided that CFNZ is not currently well placed to undertake and win a major campaign for high-cost medicines like Kalydeco and Orkambi.

The strategy that the CFNZ Board has agreed on is to resource the gathering of great supporting information (via PORT CF) to establish the most pressing needs – based on real patient data. At the same time CFNZ will align with our CF medical professionals by re-establishing our currently defunct Clinical Advisory Panel, and with this group establish our new medicines and treatment priorities (including Kalydeco and Orkambi, and many other options that are available overseas but not in NZ). From this position of knowledgeable direction, strength and robust information, future campaigns for innovative medicines and treatments will be launched. It will be from this strong position that we believe we will be able to lobby and win as a whole and coordinated CF community.

It is my hope that what I have outlined above has clarified the difficult decision the Board had to make recently. CFNZ staff have

UPDATE FROM THE CEO

I have been fortunate, with the support of Pari (Ebos), to attend the 40th European CF Conference in Seville, Spain.

The conference is attended by over 2000 people across Europe and presents symposium, workshops, and trade stands.

With many countries having access to new generation medications there is a focus here on research into the impact of these drugs plus ongoing research to develop a detailed understanding of activities at a cellular level.

I met up with CEs from Australia and Ireland, together with a representative from Canada, to discuss some of the current issues impacting our CF organisations. Hot topics for our

discussion included the introduction of Kalydeco and Orkambi, and cross infection. I will also meet with the CE of the UK Cystic Fibrosis Trust before I return.

Of interest has been the use of the valuable information held in European data registries to further understand the condition. This highlights the importance of our registry, PORT CF, and the work we are doing to ensure the data is fulsome and current.

With a huge content of medical and scientific presentations, it is pleasing to also attend presentations on care of PWCF and their families and to see that NZ holds its own in this regard.

JANE BOLLARD
CHIEF EXECUTIVE

CF News would like to thank...

Cystic Fibrosis New Zealand and CF News extend their gratitude for two grants that have allowed the publication of this edition of CF News.

We received \$3078 from **First Sovereign Trust** for the printing of CF News and \$1500 from the **John Ilott Trust** towards the printing and postage of the newsletter. We also received \$100 donation from a reader to assist with publication.



The aim of the CF News is to celebrate the achievements of people with CF and provide inspirational stories and updates about the organisation and latest news.

Feedback and story ideas welcome.
Email Vicky at comms@cfnz.org.nz

Update from the Chair continued

resources for individuals to carry out their own lobbying campaign for an increase in funding for high-cost medicines and would be pleased to provide information (based on our dealings with PHARMAC over many years) to any group initiative who wish to lead a specific campaign right now. After all, for me it is about developing our community and using our knowledge to ensure that CFNZ

continues to be a strategic, powerful and successful influence for the benefit of all our PWCF who live in NZ.

As always, I am happy to chat and encourage anyone who has questions to make contact and discuss any issues.

JANE DRUMM
CHAIRPERSON
Email: chair@cfnz.org.nz



Choice Hotels CF Heroes

CFNZ is delighted that **Choice Hotels Asia-Pac** has renewed its commitment to supporting children and adults with CF around New Zealand.

Choice Hotels has reconfirmed as CFNZ's major sponsor and will generously continue to provide free bed nights for our field workers visiting families around NZ, in addition to raising funds and assisting with CFNZ events.

The Choice Hotels website: www.choicehotels.co.nz, also features a prominent banner advertisement to help raise awareness about CF.

Choice Hotels has been CFNZ's major sponsor for the past four years and the team there have been instrumental in raising a significant amount for our organisation. Last year during CF Awareness Week Choice Hotels raised \$15,000 through its 'Take a Breather for CF' campaign where \$2 from every night stayed at any of its New Zealand properties was donated to CFNZ. An additional \$5000 was raised in its successful corporate Choice Hotels Golf Day late last year.

These events all help contribute to the CFNZ's ongoing services to assist with our mission to improve life expectancy and the quality of life for people with cystic fibrosis.





Surfs up in Southland

Although the weather threatened to rain out Southland's Surf Day with the Ultimate Waterman competition the sun came out in the afternoon – allowing three young people with CF the opportunity for surf lessons with the world's best pro-surfers.

The trio of Sophie (7), Stanley (14), Tylah-Ray (12) and his brother Caleb (14) all braved the chilly water in wetsuits to have the time of their lives at Colac Bay near Invercargill after the first day of competition.

"Sophie had a blast," says Sophie's mother Hannah Hutcheson. She was fortunate to ride with Ultimate winner of the competition Zane Schweitzer and also Connor Baxter. Afterwards Zane singled out Sophie in a Facebook post:

"Connor Baxter and I had a lot of fun surfing with Sophie at the Maui Ola Foundation event we got to be a part of here in New Zealand with all the athletes of The Ultimate Waterman. We hosted this event just after finishing the Paddleboard race, and we were all stoked to be out there, share some laughs and what we love with the kids! Mahalo #mauiolafoundation for all the awesome times brought to the keiki! Stoked to be a part of another one here in #NZ!

#MayTheWaveHealUsAll"

Stanley's dad Dave Millwater was impressed with how kind all the pro-surfers were to the kids. There was also a team of volunteers to help keep the children 3-4 metres apart because of cross infection concerns.

"The surf guys couldn't have treated them any better. We were treated to lunch and hung out most of the day. The kids really enjoyed it."

Stanley has kept in contact with his Ultimate Waterman via social media.

Dave says it rained in the morning but the weather cleared for a nice afternoon. It was a bit cold but it didn't bother the kids.

"The water was chilly but I think the pro-surfers were colder than the kids," he says.

Logistics Manager Rebecca Coomer says the athletes and the kids had a great time.

"The athletes were so good with them. It was such a nice thing to see."

She was particularly impressed that some of the young people already knew how to surf.

"Sophie got up straight away," she says.

The day started out nice and calm but waves posed more of a challenge towards the end when the tide was coming in.

That night the athletes heard a first-hand account of cystic fibrosis from an adult woman with CF. She made an emotional speech, thanking them all saying how much the experience would have meant for the kids.

PHOTO CREDIT: Thank you to professional surf photographer Cory Scott / Ultimate Waterman for these fabulous photos. Cory works for New Zealand Surfing Magazine and followed the Ultimate Waterman as they competed in events around the South Island.

"This was my second year being involved with cystic fibrosis kids enjoying the chance to go and surf with some of the world's best water athletes. Up until this point I embarrassingly did not know what cystic fibrosis was and how it affected sufferers! To have the chance to see the joy that surfing brought these kids was heart warming, to see the athletes also giving the day and their time with the kids in a way that was genuine was also amazing."



RUN TO BREATHE

Tania Clark is woman on a mission – to support CFNZ Waikato, her five-year-old niece and to get fit at the same time.

Tania and her sister Sarah Wilson have launched a fundraising operation to raise funds for the Waikato Branch throughout the year which includes running in the Queenstown Half Marathon in November and also running an impressive raffle with even better prizes including those donated by CamJet boat tours, Moments by Mumzee - Sandra Lapworth Photography, BNZ, The Warehouse and many more.



“We’re looking to sell 500 tickets at \$10 a ticket, so hopefully that will raise about \$5000.” Tania says.

Sarah’s daughter and Tania’s niece Heidi who is now five, was born with CF in 2012. It wasn’t until she was diagnosed that the family realised the gene had been passed down on their mother’s side.

“I was pregnant at the time Heidi was born so I was tested and I do carry the gene as well,” says Tania who has three children – none of whom have CF because their father doesn’t have the gene.

At the time Heidi was born Tania was living in Ashburton feeling completely helpless and sorry she couldn’t be with her sister Sarah in Waikato to support her after Heidi’s diagnosis.

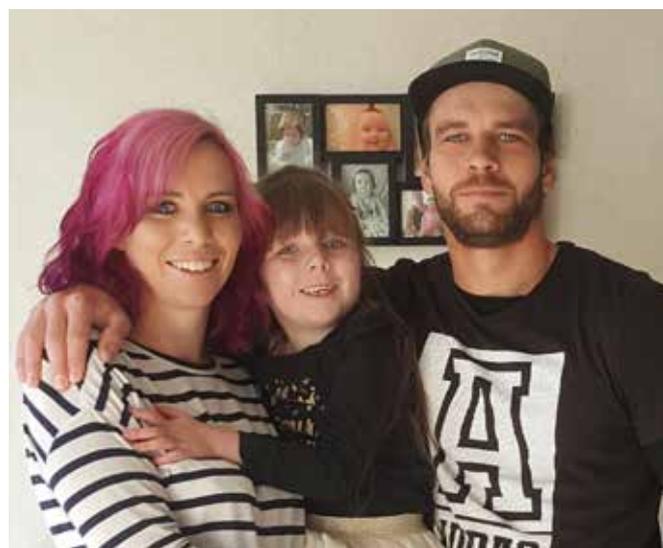
“It was a big shock to everybody involved. But Sarah is a very strong woman,” Tania says.

Tania knew about CF as she had worked for Waikato Branch Chair Deb and Mike Wood when she was 16 as a relief milker and still keeps in touch with them. Sarah (25) also knew about cystic fibrosis because she had gone to school with a pupil who had it. “I didn’t know what exactly it was then,” Sarah says.

“We’ve been fortunate – Heidi has kept amazingly well and we haven’t had any hospital admissions in the last three years. Heidi had a rough start with the first month of her life spent in hospital having procedures for her blocked bowel, and then having her colostomy bag removed when she was two and half months old,” Sarah says.

“There are a lot of challenges when it comes to CF. It’s just how you manage them,” says Sarah who recently had to work with the school about potential dangers in the environment and ensuring Heidi was taking the right amount of enzymes.

Tania (32) started training for the Queenstown Half Marathon at the start of the year and is approaching local businesses in Waikato to sponsor her for this event. She goes to a personal



trainer 3-4 times a week and does a 10km walk/run once a week on the weekend. So far Tania has lost 13.5kgs but is determined to lose more.

“I feel stronger and fitter and it’s been good for my health. But it hasn’t been an easy journey. There’ve been a few tears. But I’m looking forward to it. It’s going to be a great effort for a great charity which does great things and I feel blessed to be able to help,” she says.

And Sarah is hugely impressed with her sister’s efforts.

“She is an amazing woman. I couldn’t be any more proud of her.”

The two sisters are very close and Tania can see one of the biggest issues with CF is the daily treatment regime.

“When everyone is leading such a busy lifestyle – Sarah runs her own business; her husband Jesse works fulltime as well so the physio, PEP, nebulisers etc add extra into an already busy life.

“But it’s awesome to see that Heidi just gets on with it – she knows what she has to do and is okay with it.”

And Sarah wants other mums to know that CF does not define their children.

“Your child lives with CF – it’s not CF that defines your child.”

Donate to Tania’s fundraising campaign by online banking:
Set your champion free, Run to breathe
BNZ / 02-0368-0143122-097

Visit her Facebook page:
Set your champion free. Run to Breathe.
@setyourchampionfree



Family Fun Fundraising

There's almost no stopping the Fisher family in their mission to help raise funds – in just a few months they've been involved in the Hawke's Bay Marathon, a fun Railway Day for CF and an apple orchard fundraiser.

And the whole family have loved it. The Railway Day at Havelock North's Keirunga Park miniature railway saw the Fisher family of Claire, Andrew, and Isaac (8) cousin Euan (2) and Amber (11) join in the fun and help wave balloons and raise awareness for CF as you can see by the CF News cover shot.

Recently, Claire's father, Kelvin Taylor, also opened the doors of the family apple export business, Taylor NZ, to visitors interested in visiting the site in return for a donation for cystic fibrosis. See report in Hawke's Bay Branch News page 20.

Amber and Isaac also ran in the 3km kids' event at the Hawke's Bay Marathon. They raised a total of \$1305 for Breath4CF through a Givealittle fundraising page and Amber finished the race quicker than her brother or mother, Claire. Last year Amber also ran a very successful Pyjama Party at her school which made the front page of the local newspaper. There are hopes more local schools will get on board with Pyjama Parties for CF this year.

Claire is Hawke's Bay Branch Secretary and the biggest reason for her whole family's strong support is because of Amber's diagnosis. "I totally recommend being involved in your local CF committee and branch – it's great to help out and being involved has so many benefits.

"The whole CF community rallying around us has been hugely beneficial. For me, when Amber was younger I shouted CF from the rooftops at any opportunity. It's always been part of the kids' lives. Friends and family want to help in any way they can and unless you talk to them they don't know what you are going through and how they can help you.

"And because we have put ourselves out there it has meant that people have come to us with offers to fundraise - friends and family are looking for ways to support us and CFNZ. It is awesome to be able to give back to an organisation (CFNZ) that has been hugely supportive and beneficial to our family."

While Amber is not particularly sporty and is at an age where she has a say in who knows about her CF, she does enjoy the fundraising events. Isaac is the sporty one but Claire notes there are times he can feel left out of the attention his sister receives – getting time off school for clinic, support via Breath4CF activity grants and also when the family talk about Make a Wish.

"Upon saying that Isaac is not envious of all the treatment Amber has to do and he's very quick to remind me to do PEP with Amber. We make an effort to include him in our fundraising efforts, which he loves."

Claire is keen to bring up Amber knowing a genetic condition is nothing to be embarrassed about.

"That's what I want to teach Amber. Communication is key. It's key for her to keep well so she doesn't have to hide her CF. We teach our kids that everyone is different and everyone has stuff happen to them. I tell Amber 'CF is part of who you are but ONLY part of who you are' and she laughs at my choice of words but totally gets it."



COVER PHOTO: Thanks to Claire Fisher's sister Natalie Hartley for taking this superb cover shot. It really captures the essence the fun children

had at this event. Natalie remembers it was a super-hot day. "The ice blocks went down a treat. It was great to see so many families out enjoying the sunshine and supporting CF."

MEET OUR CF ACHIEVERS!

Three young people have been honoured with CF Achievers' Awards for their impressive records in sports, education and the arts.

Rachael

Rachael of Otago received a CF Achiever's Award for her achievements in music and the dramatic arts.

This year Rachael (17) was named a drama and music prefect at Logan Park High School and received Excellence endorsements for both these subjects in NCEA Level 1 and 2. Rachael has played the clarinet for over eight years and been singing for five years. She is also a dedicated member of the school orchestra as head of the wind section. In drama, Rachael has attended the Toi Whakaari New Zealand Drama School intensive summer programme and also the National Youth Drama School during Easter.

Rachael impressed the judging panel with her impressive achievements in art while also struggling with multiple hospital admissions.

Logan Park School Principal, Jane Johnson, described Rachael as a role model for others and noted her loyalty to her clarinet teacher, Nick Cornish, who suffered a serious mountain bike accident in 2016. When he was well enough to return to teaching the principal asked Rachael to pose for a photo and article in the Otago Daily Times.

"Rachael is also a very polite, steady and reliable student," she wrote in her reference. "Rachael also has a big heart for helping in the community. She fits in very well with others and is very aware of equality and justice issues."

She is thrilled to be named a CF Achiever and plans to use her award for University fees at either Otago or Victoria University where she plans to major in music and drama.

Angus

Auckland Liston College pupil **Angus** was able to gain Excellence endorsements for both Level 1 and Level 2 NCEA in spite of some of the challenges that CF cast his way.

Angus (18) says maintaining good grades at school is a challenge, particularly with CF.

He had one hospitalisation in 2016 and had to add another two treatments to his daily routine taking the total time up to an hour and a half twice a day. "It is a lot of time but it helped me stay well enough to achieve my Level 2 NCEA Certificate endorsed with Excellence," he says.

Last year Angus achieved second overall in his Liston College group of around 120 boys and this year he was named a Prefect.

Liston College Director of Curriculum Development and Pedagogy Sarah Hooper describes Angus as an exemplary role model for fellow members of the school. "He is highly capable and he demonstrates a drive well beyond his years," she says.

Angus is now focused on achieving an Excellence endorsement for his Level 3 NCEA Certificate and his goal to study law next year with a conjoint of a Bachelor of Arts in history and politics. He plans to use his Award to help fund a six-month student university exchange – in the US or Europe.

Joe

Joseph Voyce has received a CF Achiever's Award in sport after his mother nominated him for the hard work he's put into reaching his goals over the past few years.

Joe placed 2nd in the NABBA South Island body building champs in 2014 and won 1st place in his category at the NABBA champs last year.

Hi mother Janet Camplin says CF took its toll on Joe while he was training in 2014 but it hasn't stopped him from achieving his goals.

"Joe is an inspiration to a lot of people including those he has trained. Joe inspires me daily. I'm proud of this young man I have raised, his dedication, enthusiasm, courage and sheer guts."

Along with managing CF, Joe (26) also managed a gym in Dunedin before deciding to move to Auckland this year to be closer to his sister and father who live there. Joe recently started a new job at ID Electrical working in the sales team.

Family friend Don Stroud describes Joe as someone with a very determined nature. "When he sets his mind to something he will achieve it no matter what."

Joe continues to pursue his goals in health and sport and plans to use his Award for an overseas trip in October.



Rachael



Angus



Joe

AWARENESS WEEK

14 – 20 August

Not long to go until CF Awareness Week – CFNZ has produced a number of resources available on the website to help people with collections or activities during the week. There are posters including the Help Those Living with CF Become Invincible superhero, chocolate fish order forms and sponsorship forms.

Email office@cfnz.org.nz if you need any assistance.

Visit: cfnz.org.nz/cystic-fibrosis-awareness-week-2017/

Hell Pizza Moves Heaven for CF

We had an amazing response to CFNZ's Hell Pizza voucher giveaway on Facebook. We asked the CF community why they support CFNZ and had almost 50 responses. Many were very personal and provided further insight into the unique nature of the CF community and the far-reaching effects of the condition. All the comments struck a chord including this one from Kerry Scherer.

"I support CFNZ because they have supported my son and our family for over 30 years through good times and bad times including two double lung transplants the first in 2013 and the second in 2015. He's still going strong second time round. The assn was there for me as a new mother many years ago and are still there for us all today."

Thanks to **Hell Pizza** and the voucher winners for sending us these pics.



Introducing...Gretchen

A warm welcome to **Gretchen Kitching** who is CFNZ's new Northern Fieldworker. She covers Northland, Auckland, and Waikato. Gretchen works Monday to Thursday.

You can contact Gretchen on Freephone **0800 651 122** or email: Gretchen@cfnz.org.nz.



Let's meet Gretchen who is based in Auckland:

What drew you to CFNZ?

I have worked in the health and disability sector since I was 16 years old, working predominantly with individuals living with intellectual and physical

impairment. This work entailed time in both private and institutional settings. I believe the time I spent working in people's homes allowed me to form close working relationships, the precursor to best outcomes. The role at CFNZ incorporates working in both the community and hospital environments, providing the opportunity to work holistically with a focus on all aspects of health and wellbeing alongside the medical terrain. My understanding of CF to date is that it is different for every person, this means that I will never stop learning and be constantly challenged to identify and address the unique needs of the individuals and families I work with.

What are the best parts of the job?

It is an autonomous and flexible position, meaning that I can develop my role to where I see best fits and prioritise certain aspects of my work load. I also like the travel as one of my favourite things to do is go on road trips. Another highlight for me is working under Sue Lovelock, she is supportive, encouraging, informative and professional all whilst making me laugh. But really the whole team is amazing.

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

Definitely more organ donors, I think education and awareness of the importance of donors is limited in New Zealand.

For my role in particular I would like to hear the voices of the community express how CFNZ can support them to achieve goals, wants and the outcomes important to them.

In general, for the lay community to have a greater awareness of what cystic fibrosis is and what it means to individuals and families living with CF.

Favourite Film?

Not so much a particular film but a genre, Thriller.

What you like to do in my spare time?

Hang out with my girls (21 and 10) and family, walk my dog (Mabel), eat (Vegetarian), cook (Food that doesn't make too many dishes) and sometimes just simply do nothing.

Best piece of advice?

Appreciate the small things.

You're happiest when?

The house is tidy, my girls are home, my tummy is full, the fire is on, I have a cup of tea, a peanut slab and a good movie to watch.



MANY PATIENTS – ONE VOICE CONFERENCE

CFNZ staff were invited to attend the Many Patients One Voice Conference in April along with a wide range of patient organisations.

The Conference provided an avenue for bringing a number of charities and patient groups together to focus on how to ensure patients views are taken into consideration in all aspects of the healthcare system.

There were several interesting speakers including Health Minister Jonathan Coleman who urged lobby groups to keep knocking on the doors of politicians, bureaucrats, and clinicians if they wanted changes to the current system.

“At the heart of what we are trying to do is build services around the needs of patients and their families in the community. You can’t do that unless the patient voice is being heard,” he said.

“Advocacy groups and those who are lobbying for different approaches and new treatments – those people are a very important part of the health debate.”

Mr Coleman said there was a focus on how the health system can meet the needs of the largest percentage of the population as possible, and the Government was developing electronic patient records to help better identify needs and where more resources are needed.

“There never seems to be enough money in healthcare that is a problem that faces every government of every type right across the western world. The issue is how do we work together to deliver services in a smart way that meet the needs of the largest percentage of the population possible.”

He said the current model is not sustainable. Current health spending was 7 percent of GDP with projections of it rising to 12 percent, which would be unaffordable.

However, this statement was challenged at regular intervals at the conference. Another speaker Simone Leyden, CEO of the Unicorn Foundation in Australia, said the level of spending on health in a country should be linked to the needs and beliefs of the population.

The Unicorn Foundation supports patients with neuroendocrine cancer and Simone spoke of the importance of having patient representation on committees that decide on the funding of pharmaceuticals. She called for two consumers to be appointed to Pharmac’s Pharmacology Therapeutic Advisory Committee (PTAC), which is what’s happened in Australia – something the Foundation campaigned strongly for.

She also called for more importance being placed on a patient’s personal perspective of new medicines under research – along with strong data which proved effectiveness. She pointed to a patient with cystic fibrosis who had spoken at a drug hearing in Australia. She had been on a drug trial which had not made any statistically significant improvement.

“Her results didn’t actually meet the primary endpoints of the clinical trial but in person she had gone from somebody who couldn’t get out of bed to someone who had gone back to work – was doing so many incredible things but the PBAC (Australian drug funding authority) would have just looked at the clinical trial data which showed it didn’t make that much of a difference.

“What you see on paper is different to what you see when hearing from a patient. Before taking it she had not been able to get out of bed in the morning. But they didn’t look at this.”

In a controversial presentation, Principal Economist of the New Zealand Institute of Economic Research Todd Kriebel spoke in favour of reducing the number of DHBs from 20 in an effort to save costs. He said money saved from reducing the cost of administration linked to some of the boards could be ploughed back into the health system.

He said there was a low turnout of voters for the 2016 elections (41 percent nationwide), 33 percent in Auckland to a high of 55 percent in Whanganui. And said it has to be asked whether the DHBs are doing enough to outweigh the cost of administration involved.

Professor Kathryn McPherson, CEO of the Health Research Council, said a 56 percent increase in government funding for research was announced last year.

Diabetes New Zealand Chief Executive Steve Crew reported that New Zealand has the second highest level of people giving to charity – the highest is the US but some of their religious groups are defined as charities.

He outlined some of the barriers to a patient's voice getting through to clinicians:

- Giving information in a cold, tactless manner
- Using medical terms that are unfamiliar
- Pressing patients to make a serious medical decision without adequate knowledge
- Belittling patients who ask questions that are important to them.

He said patient organisations can help by:

- Providing information
- Raising awareness about screening and prevention
- Provide a forum to share experience and support for family and friends
- Patient organisations represent the patients' views on issues surrounding healthcare
- They make their collective voices heard

Steve also spoke of the level of medicine funding in New Zealand which meant 10 high priority medications that had been recommended for funding had to wait 6.75 years for funding.

Cystic Fibrosis Conference 2017 Report

Cure for CF on the horizon

CYSTIC SISTERS – WELCOME TO THE CONFERENCE

Tauranga's Cystic Sisters **Kristie Purton** and **Nikki Reynolds-Wilson** were beamed into the 2017 Cystic Fibrosis Conference in Christchurch by video – providing their unique view of CF and some great advice for others.

Kristie described cystic fibrosis like a hand of cards dealt to her at birth and needing to “play it the best that you can.”

Nikki, who has now moved to Australia following her lung transplant, advised people to “keep their body healthy and their mind strong and to remember that tomorrow is a new day.”

DR JOANNE DIXON – GETTING DOWN TO GENETICS

It was predicted a cure for Cystic Fibrosis could be as soon as 10 years away by speaker Christchurch geneticist Dr Joanne Dixon.

Dr Dixon was at the announcement for the discovery of the CF gene in Toronto in 1989, and is now preparing to retire after working as a geneticist in New Zealand including as the National Clinical Director of the Genetic Health Service.

She has previously spoken at CFNZ Conferences in New Zealand and the last time she spoke she was asked about a cure for CF. “Not in my lifetime,” she told the conference then.

But now in 2017 Joanne can now see a time when CF could be cured with therapies such as gene therapy which she expects to show more promise in coming years and from gene editing technology known as “CRISPR” which has already been used to repair the CF gene. And also by editing the RNA molecule which is what reads the genetic code and produces the protein.

“I do think a cure is coming – probably in the next 10 years – then the problem will be how early will these new treatments be started?”

Joanne expects the future treatment for limiting the effects of CF will actually involve a combination of therapies and not just one.

“I think there are really exciting things coming,” she said.



KENOTE ADDRESS – ANYTHING IS POSSIBLE

Keynote Speaker Olympian Rob Hamill had the audience on the edge of their seat when he spoke of being at sea for 41 days in a row boat to win the first ever Atlantic Rowing Race in 1997 while also coming to terms with the grief of losing his two brothers.

Rob's theme of "Anything is Possible" encouraged people to step outside their comfort zone.

Many people thought Rob was crazy to join the ocean race from the Canary Islands to Barbados, but Rob believes there is a lot to be gained from achieving goals.

"What if someone told Sir Edmund Hillary that he would be mad to leave his bee keeping business to climb Mount Everest?" Rob asked.

"What if that negative sentiment had infiltrated Sir Edmund's thinking at that time? Would he have done it? Absolutely Not. And how did Sir Edmund climb Mount Everest? He climbed it one step at a time."

Unexpectedly Rob's time spent at sea during the rowing race with two companions gave him plenty of time to reflect, which brought back some of the grief related to the loss of his eldest brother Kerry who was imprisoned and killed by members of the Khmer Rouge in 1978, and also the suicide of another brother nine months later.

Rob decided he had to take action to help make peace with the death of his eldest brother by travelling to Cambodia to find out more about tragedy.

He discovered that Kerry was forced to admit to a false confession that he had been a CIA agent when actually his boat had simply strayed off course into Cambodian waters before he and his companions were captured.

Rob found his brother's so-called "confession" which included lots of references to his life in New Zealand and growing up with his brothers such as working under "Colonel Sanders" and CIA Intelligence Officer "Major Ruse".

Not only did Rob's experiences capture the audience's imagination, he also encouraged people to follow their own paths. He used the analogy of providing children with the tools to climb their tree.

"Obviously be there if they fall and we have to let them go. We all have our own trees to climb as well and some trees might be pretty dodgy but if we want to climb them we need to learn how."

He also urged people not to compare themselves with others: "You can only compare yourself with the person you were yesterday."

"Life is an adventure and if we treat life as an adventure it will help us get through the challenging times," he said.

"With passion and belief anything is possible."



ASSOCIATE PROFESSOR CASS BYRNES AND PROFESSOR IAIN LAMONT – SCIENCE IN SUMMARY

Auckland University Associate Professor Cass Byrnes had some good news to report with the announcement of a new treatment for CF that is expected to be approved in the US, and also her own research with a new physiotherapy game to improve the rates of physiotherapy for children in New Zealand.

Dr Byrnes explained that results of a new combination therapy which included the medication tezacaftor had shown promising results and the drug manufacturer Vertex would be seeking FDA approval for the new drug.

A 24-week study of people with two copies of the F508del gene showed the tezacaftor combined with Kalydeco improved lung function by four percent, reduced infection rates, increased weight gain and improved quality of life.

She also reported that a second gene therapy trial is expected to begin this year. The first trial in the UK showed that nebulising a gene to correct the CF defect could become a realistic treatment option in the future.

"They were able to stabilise lung function and there were some other benefits – weight gain and also reduced infection rate," she reported.

One of Dr Byrnes own research projects, partly funded by the Shares in Life Foundation, involves testing a new game device called BreatheHeroes which is connected to an Acapella device where children use their breathing as the game controller – with the aim of winning points. A six-week study of 20 children at Starship Hospital aims to find out whether the game could improve rates of chest physiotherapy for children.

"The game also records how long they are doing physiotherapy," Dr Byrnes explained.

It's hoped the game could make physiotherapy more fun for children. Dr Byrnes pointed to research which showed that children with CF considered that physiotherapy was the worst thing about the condition.

"Physiotherapy is worse than not feeling well and also having CF. It's boring and repetitive and we have to do something about that," she said.

Otago University Professor Iain Lamont has also received Shares in Life funding for his research into how oxygen affects antibiotics to treat Pseudomonas. He presented the possibilities in the future for eradicating the bacteria.

- New delivery options for antibiotics
- Reduce the resistance of Pseudomonas to improve the effectiveness of antibiotics
- New treatments – nano particles and different compounds

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Mylan
Seeing
is believing

REBECCA SCOONES – CF MY WAY

Starship Paediatric Physiotherapist Rebecca Scoones recommended the five “R’s” for encouraging physiotherapy.

- **Routine** – making it part of everyday routine
- **Reward** – only give them rewards when they are sticking to physio (examples include DVDs, dinner out, mobile top-ups, money for the shops or sticker charts and marshmallows for smaller children).
- **Reassure** – reassure that it will be making a difference to their health over time
- **Relinquish** – let them take some responsibility for doing physio
- **Remind** – reminders framed in a positive way without nagging

“Avoid power struggles with your tween and teen because they don’t work. Just give one warning and then follow up with a consequence – loss of a privilege,” Rebecca advises.

She emphasised the importance of exercise and encouraged the people attending to share any top tips for improving adherence.

CROSS INFECTION IN THE REAL WORLD

The Cross Infection Panel sparked an interesting discussion about cross infection in the real world.

The Panel featured Paediatric Infectious Disease Specialist Dr Tony Walls, Clinical Nurse Specialist Viv Isles, Parent and Canterbury Branch Chair Melissa Skene, and Lung Transplant recipient Alana Taylor.

The Panel outlined the evidence of multi-resistant Pseudomonas, cepacia complexes and mycobacteria passing through hospital clinics.

“We know that can be fixed because as soon as these clinics actually put in cross infection procedures the rates of cross infection dropped,” Viv Isles explained.

In Christchurch CF clinics there is a 30 minute timeframe between each patient with CF during which time the area is wiped down.

“Hand washing is the number one thing to stop cross infection and infection from the environment,” Viv said. “If parents and people with CF take responsibility to hand wash on arriving at clinic, leaving places and going in and out of rooms, into lung function, out of lung function – you probably should wash your hands to eight to 10 times before you’ve got in and out of clinic. And be careful to stay at least two metres away from others with CF at clinic.”

Dr Walls agreed with hand washing being the best protection because most viruses are transmitted on surfaces.

“Most are from people picking them up from leaning your hand on a surface and then rubbing your nose a bit later. Hand washing will protect you more than anything else.”



In terms of two children with CF at the same school, Viv said it was important for the children not be in the same class, to stay 3-4 metres apart, be seated at different sides during school assemblies and to use different toilets. She said if they are kept apart then it’s likely they have more risk from a child sitting next to them with a virus than from a person with CF somewhere in that room as long as precautions are taken such as separation and handwashing.

“Don’t sit next to people who are coughing. It is the virus that’s going to cause the majority of the problems not the child or adult with CF in the room,” said Viv who also advised against babies and children sharing toys if they are still at the stage of sucking on them.

“What we don’t want is a whole lot of children living in plastic bubbles and not living. Everything has to be looked at in terms of whether it’s got more benefit than risk.”

She also recommended the Royal Brompton Hospital website which outlines environmental risks for people with CF: <http://www.rbht.nhs.uk/healthprofessionals/clinical-departments/cystic-fibrosis/clinical-cf-guidelines-care-of-children/appendix-3-risks-of-getting-p-aeruginosa-from-the-environment/>

Alana works with pre-school children and is often exposed to many germs and viruses but she observes general hygiene rules with frequent hand washing and has built up an immunity over the years.

She said she loved watching adults on social media who had CF and believes a “big brother” or “big sister” system using social media could work well for children.

Melissa also supported the use of mask wearing at Christchurch Hospital appointments.

“It gives you that feel-good factor that you’re not only protecting yourself, you’re protecting others,” she said.

DR CHRIS TAUA – KEEP CALM AND STRESS LESS

Pumahara Consultants Director Dr Chris Taua recommended that people learn their limits and not feel guilty about saying no, take time to laugh, embrace the support of close family and friends, and also seek financial assistance if it’s needed.

Top 10 stress minimisation tips:

- Recognise you are not alone
- Managing feelings of guilt about being stressed
- Learn to accept
- Having a family care plan
- Making your health a priority
- Educate others
- Try to sleep
- Let some things go
- Take only the advice that you value
- Learn to say no



FALLON EARL – LIVING LIFE WITH CF

The advances in CF care were underlined when Fallon Earl – a 32-year-old woman with CF and her mother Karen Gill concluded the conference with their personal perspective on life with the condition.

Born in Nelson, Fallon’s mother was told that Fallon would not make her first birthday.

“Clearly, they didn’t know what they were talking about,” Karen told the conference.

Fallon recalls having a normal childhood apart from having to sit with other kids at school to take tablets. Her friends envied her for lunch boxes filled with high-fat sweet foods and also her “chocolate drawer” in her bedroom.

In recent years there’s been a move towards encouraging a high-fat diet of healthy foods for people with CF. “Now there are healthy options for higher-fat foods,” Fallon says.

There’s also now more evidence regarding cross infection.

“I remember CF camps which I thought were amazing and great fun. I made some amazing friends and it was place you were made to feel safe and were the same as all the other kids there.”

Lately Fallon has enjoyed a good period of health – something she puts down to an increase in exercise. “I’ve just had my longest 18-month stint without a hospital admission – I put that down a lot to fitness. Four times a week I get up at 5.30am and workout.”

Fallon prefers to keep her health status private and be the one to tell people she has CF if she chooses to. “I’d rather that someone who knows me hear it from me,” she says.

She did tell her husband of nine years Roger that she had CF just a few weeks into their relationship.

“He jokes that I got him genetically tested pretty much straight away.

“I wanted to have kids so I felt like he needed to know because that was such a big part of him having to give up the possibility of not having children,” explains Fallon who used fertility treatment to help conceive both her daughter Olivia in 2010 and son Hunter in 2013.

“My life today I feel is very busy, being a wife and a mother.

“Having children myself it’s given me much more respect and understanding of what my own parents went through.”

The close relationship Fallon has with her mother Karen Gill who shared Fallon’s presentation was also apparent as Fallon revealed she still calls on her mother for any of her own health concerns, preferring that her husband concentrate on caring for their children if she needs to be admitted to hospital.

“It’s also important to have a good relationship with your doctors, nurses, and dietitian – they really treat me like a person.”

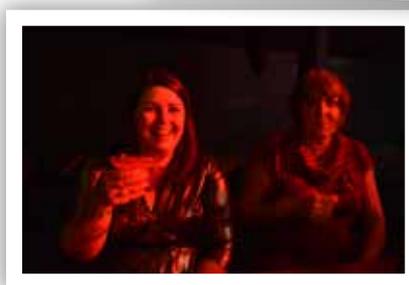
*Some of the Conference videos are available to view on the CFNZ website: <http://cfnz.org.nz/our-services/library/cfnz-national-conference-presentations/>

MURDER MYSTERY DINNER – DISCO INFERNO

As you can the CF community got into the spirit of the disco theme at the Murder Mystery Dinner – with plenty of flares, afros and sequins on display.

The dinner hosted by Canterbury Branch required teams to guess the murderer from a complex set of clues played out on the night.

A spooky train ride helped teams get into the murder mystery mood, and people had lots of laughs dressing up one of their male team mates with dresses, handbags and lots of make-up.



Wanita goes Ape for E-flow

Wanita from Auckland Zoo may not always like using her nebuliser but has become surprisingly tolerant with her treatment.

Orangutan Wanita has been diagnosed with Pseudomonas after developing a chesty cough. And when Primates Team Leader Amy Robbins consulted

with overseas orangutan experts and a leading CF specialist in the United States Dr Jennifer Taylor-Cousar. It was advised Wanita be treated with the antibiotic, Tobramycin delivered with an E-flow rapid nebuliser.

“Pseudomonas can be common in orangutans and presents similar symptoms to humans who have CF,” Amy explains.

Wanita needs to use her nebuliser twice a day for a month and then she has the following month off. It takes 10 to 15 minutes per session with the E-flow – longer than Auckland Zoo staff had been hoping for which was 7-8 minutes.

“She breathes it via a mouth piece through her nose and we hold it to her nose. She has been trained to use it with positive reinforcement training,” Amy explains.

Coconut water or some unsweetened almond milk or fruit is used to tempt Wanita to stay compliant with the device – but even then it’s not easy getting an orangutan to use a nebuliser.

“We are asking a lot of her. She enjoys sitting with us and the attention that comes with it, but try and keep it interesting for her. Animals won’t do something unless there’s something in it for them. Like a child, she can get a bit impatient because it does take a long time so we’ve been stopping at around 12-13 minutes if it hasn’t run its course,” Amy says.

“Orangutans are very similar to humans – they share about 97 percent of the same DNA so it makes sense what works for humans works for these guys. There’s been a lot of research into orangutans and how the genetic markers compare with humans with CF,” Amy adds.

Treatment with Tobi has so far been able to keep Wanita’s symptoms at bay but she will now need treatment for life. “Her symptoms are fairly mild,” Amy says. “The experience has given Zoo staff an appreciation for what people with CF and their families go through in their daily lives.

“I used to look after a little girl with CF in a previous job but it’s helped my team realise the seriousness of it,” she says.

Amy has been working with Wanita for the past 17 years she’s been at the Zoo and training her to use a nebuliser has allowed staff to become friendlier with the great ape.

“This has brought all of us a lot closer to her. She’s quite aloof and she’s not an orangutan that needs or wants a lot of attention whereas the others do. It’s been really nice to spend time with her.

“What we would love is for someone to invent a ‘rapid, rapid’ E Flow that delivers the medication in five minutes,” Amy says.

Hear, hear to that we all say!



CFNZ Turns 50!

Next year is our 50th year as a charity and we will be marking this occasion with a year of special activities.

We’ll kick-start the year with the launch of a new CFNZ website with heaps of new features to make finding information easier.

There will be a greater emphasis on story telling in 2018 – with plans to introduce new CF ambassadors during 2018.

We’ll also be working closely with businesses and schools to help raise awareness and funds, including a parliamentary function in Wellington.

CFNZ is calling for volunteers to be part of the 50th Anniversary Planning Committee. We’ve had some interest but are keen to get more people involved.

Please contact Laura at office@cfnz.org.nz if you would like to help plan CFNZ’s birthday celebrations.

Talent Spotting – Meet Max!

Looks like Max of Riversdale could be a future CF Achiever if his determination is anything to go by.

The Southland five-year-old will give anything a go and loves sport including Ripper Rugby, running, cricket, hunting AND fishing.

Max recently came 2nd in athletics for sprints and 5th in the school cross country running with 6-year-olds, and is also rightly proud of this impressive Kawhai he caught. Go Max!



PORT CF Data Registry in Focus

Nidha Khan has been instrumental in improving the PORT CF data registry. Nidha, who has a post-graduate Diploma in Public Health began work on the project as a summer studentship with the University of Auckland. Here she reports on the importance of the registry and the results of her research.

In 1955, the creation of the first CF Foundation was spurred on by a group of parents whose children had CF. They banded together with the mission of creating a better life for people with CF and their families. They recognised that, to achieve this mission, data collection and measuring outcomes are vital and later created a CF registry in 1966.

Patient registries are powerful tools for change and are particularly valuable for rare and progressive diseases, such as CF. They provide information regarding health and long term statistics which can then be used to improve treatment, services, funding, and ultimately health outcomes. Just take this one example, after using the registry for benchmarking (a process of comparing performance characteristics between clinics), making CF outcomes publically available, and generating new clinical practice guidelines, the annual incidence of *Pseudomonas* across 115 certified CF clinics in the US dropped from 59.3% in 1999 to 51.7% in 2009. To put this into perspective, the annual incidence of *Pseudomonas* only decreased from 60.3% to 59.3% in 1999 and was expected to reach only 57.3% by 2009.

In New Zealand, our CF registry is called PORT CFNZ. It's a project that's owned by CFNZ and guided by a multidisciplinary steering group. Every person with CF in NZ is provided with the opportunity to be a part of this registry, but only those who give their permission will have their data recorded in the registry and this remains confidential. Throughout the person's lifetime, data is collated from their current clinical tests and hospitalisations by nurses, specialists, allied health professionals (dietitians, physiotherapists, psychologists) and administrators. At the end of the year, the registry data is analysed and a report is produced and uploaded on the CF Foundation's website in the US for everyone to see.

Having a CF registry is only as useful as the data being entered. Anecdotally, it seemed that doctors and nurses were having some difficulties using the registry.

Over the recent summer, I investigated these issues under the supervision of two members of Starship Hospital's CF clinical team - Cass Byrnes (Paediatric Respiratory Specialist) and Jan Tate (Cystic Fibrosis Nurse Specialist). We examined the 2014 report and confirmed that not all of the data is being entered. Shortly after, we developed a short survey which looked at 1) the value that doctors and nurses place on PORT CF, 2) the issues they have with the registry, and 3) characteristics of the clinics, such as the clinic size and type (paediatric or adult). This was sent to 54 doctors and nurses across the country who are known to be involved in CF care and run CF clinics. We received 33 surveys, though some people filled in surveys on behalf of everyone at their clinic. The results showed that 100% of respondents regarded PORT CF as necessary to improve future care and outcomes (life quality) and 56% of those who completed questions on issues with the registry (15 out of 28 people) experienced difficulty when entering data. Common issues were a lack of time to enter the data, clinic-specific issues, such as problems with local IT systems, lack of funding and resources, and database-related issues. For example, the questions in the registry are being interpreted differently by health professionals. There weren't any distinct differences in response patterns between paediatric and adult clinics or between small, medium, or large clinics.

These findings were presented to the University of Auckland's School of Medicine, and Starship and Auckland Hospital's CF clinical teams. This kept people informed, generated discussions regarding PORT CF's issues, and will provide CFNZ and the Steering Committee with greater direction regarding the improvement of the registry. The aim is to get the most comprehensive data capture nationally for 2016 - allowing the most accurate snapshot of the health of all persons with CF in NZ to date!

CFNZ has employed Jan Tate for one day a week to work on maximising data input for 2016 and beyond.

"Accurate and comprehensive information is vital to CFNZ in order to work towards equitable care and access to treatment," says CFNZ Chief Executive Jane Bollard.

Note: Are you or your child registered with PORT CF? Check with your CF Nurse or Specialist.

3D Printed Lungs Could Happen

From ears to bones – 3D printing is producing made-to-order titanium implants, but how far away is the possibility of 3D printed lungs and hearts?

Dr Khoon Lim is a biomaterial scientist and Research Fellow at University of Otago based in Christchurch while studying the combination of biomaterials and cells that can be used for 3D printing. His aim is to help solve the current problems faced with organ donation in New Zealand and worldwide.

“Not all materials can be printed,” he explains. “My research involves developing ‘bio-ink’. Like any printer you need ink, and biomaterials and cells are combined to make the ink. So we want to print them and make sure the cells can survive the printing process and after printing it will still be functional.”

3D printing for artificial limbs such as hip joints is available in Christchurch but they use customised titanium orthopaedic implants that are still metal. However, Dr Lim can see a future when live cells can be used to generate body parts.

“Research is progressing but it could be another 10 to 20 years before artificial limbs can be produced using a person’s own live cells.” And Dr Lim says it will take much longer for 3D printing of organs such as lungs and kidneys.

“I hope that by 2030 we should be able to 3D print a functional organ. A lot of research is on cartilage right now because it only has one cell. But if you want to move to a complex organ you need to have the material and process to keep a lot of different kinds of cells happy.

“There’s a lot of hype about 3D printing and people think you can 3D print a heart or kidney but the main challenge is functionality. You can 3D print something that looks like a heart but it doesn’t mean that it’s functional – it’s not beating and pumping blood, but that is what the heart is there for,” Dr Lim says.

“The majority of research groups around the world are trying to make it a reality but it is challenging, and requires a lot of collaboration. It would be awesome to go to the clinic and say ‘my lung is failing, please print me something from my own cells,’” he says.

Even when 3D organ printing does become a reality, Dr Lim warns the technology will still be in its infancy and any problems will need to be ironed out.



DR KHOON LIM

In Dr Lim’s view the 3D printing of a new pair of lungs will likely remain one of the last treatment options for cystic fibrosis – so it’s unlikely to be something a young person with CF would consider.

“But it would change the whole scenario of lung transplantation – you won’t need to go on a waiting list if a 3D printed organ works just as fine.”



Farewells
May our loved ones rest in peace and love

Glen Moxon
19/1/17 Waikato

Santana Daniels-Pakau
4/2/17 Bay of Plenty

Vicki Kennedy
17/2/17 Canterbury/Otago

Riki Towers
24/2/17 Auckland

Nicholas (Nic) Ramsden
27/3/17 Australia

VOGMASK CONCERNS

The Cystic Fibrosis Foundation in the US has expressed concerns about the use of Vogmasks at hospital.

The Foundation's Director of Clinical Communications Paula Lomas has written to health professionals there emphasising that Vogmasks are not intended to protect against germs.

"Please note that these masks are NOT approved to protect against the spread of pathogens in the clinic or hospital setting. These masks are intended for use against environmental particles such as dust, pollen, and other particles found in air pollution.

The Vogmask does NOT meet the CF Foundation recommendation that 'all people with CF wear a surgical (procedure, isolation) mask when in a health care facility to reduce the risk of transmission or acquisition of CF pathogens'.

Concerns related to the use of these masks in clinical settings stem from questions we've received about the masks and the increase of social media posts of individuals with CF wearing the masks while in clinic."

The Foundation asked health professionals to let patients and families know that Vogmasks do not protect against infection and to urge those who arrive at care centre appointments wearing a Vogmask to wear a surgical mask instead.

In New Zealand, the Paediatric Clinical Network infection control guidelines recommend the use of **surgical** masks for children with CF. The clinical guidelines state:

All people with CF should wear a surgical mask (or mask as per local hospital policy) when in the hospital setting to reduce the risk of transmission or acquisition of CF pathogens. Masks should be worn throughout the facility, including in the toilets/restrooms. Masks should not be worn during lung function testing, in the clinic exam room, or in the patient's hospital room. (Young children, especially under the age of three, may not tolerate wearing a mask, however they should be gently familiarised with the mask and encouraged to wear it as they become used to it).

Note: These guidelines recommend that surgical masks be used to stop cross infection in healthcare settings by children and young people with CF. Surgical masks are designed to prevent the release of potential contaminants from the user into their immediate environment. Surgical N95 masks, will in addition, help reduce wearer exposure to certain airborne

biological particles. However, if the N95 mask is not correctly fitted or becomes contaminated through incorrect use they offer no benefits over the surgical mask. Environmental masks (such as Vogmask) are products designed to prevent inhaled contaminants. They are not designed to prevent germs from being exhaled and are therefore not recommended to prevent cross-infection in CF healthcare settings."

Vests Not Necessarily Best

CFNZ regularly gets inquiries about using a Vest for physiotherapy, so we asked Starship Hospital Paediatric Physiotherapist **Rebecca Scoones** for her advice:

Over the last two decades, there have been many advances in airway clearance techniques or physiotherapy techniques and now there are many options available to people with CF. Widespread access to the internet and social media pages means that the CF community can easily find out what is happening in other places around the world with respect to the treatment and management of CF.

One question that is often raised both to CFNZ and to physiotherapists is about High Frequency Chest Wall Oscillation (HFCWO) or 'the Vest' and would this be an option or be beneficial for people with CF here in New Zealand.

The Vest is a machine attached to a "vest jacket" which delivers vibrations to the chest wall mimicking mini coughs and is meant to shake the mucus out of the airways so it can be coughed up. There are different sized jackets and these need to be changed as your child grows. Vest machines cost between \$10,000-\$12,000 dollars here in New Zealand if purchased new. The Vest is commonly used in the USA due to health insurers covering the cost but is less commonly used in Canada, Australia, the UK, and Europe.

When investigating different options for airway clearance, it is important to discuss your thoughts with your clinical CF team and to refer to the evidence around each option. Over the last few years, there has been more evidence regarding the vest and it is important to know this information if people with CF and their families are considering the Vest as an airway clearance option.

In 2013, a research article was published in the medical journal 'Thorax' by McIlwaine et al comparing the effectiveness of the Vest compared to PEP (positive airway pressure) as airway clearance techniques for CF. This study is a long-term randomised control trial of 107 people in 12 CF centres across Canada and involved adults and children. This was the first large, long-term study conducted on the Vest to compare it to another technique. The study found that those participants using the Vest experienced almost double the amount of chest infections requiring antibiotics and less time in between infections. Both of these measures are associated with poorer lung function over time. People in the Vest group were also three times more likely to need IV antibiotics (rather than inhaled or orals) to treat the exacerbation. Participants in the study also reported that they preferred PEP over the Vest in terms of flexibility and treatment time. The conclusions from the authors was to continue with PEP as the main form of airway clearance in people over six years in Canada.

Another study in Thorax by Osman in 2010 compared the Vest to usual airway clearance techniques such as PEP, Flutter, ACBT in the short term. The authors reported that that participants in the Vest group produced less sputum in the physio session and 24 hours after.

Authors have suggested reasons why the Vest was found not to be as effective as other techniques. This can be because the Vest provides no positive airway pressure which can help to hold floppy airways open. Positive pressure also helps to get air behind trapped sputum and forces it out of the small airways. Another reason suggested is that the Vest is a passive technique and doesn't engage your breathing muscles as much as other techniques do and doesn't create the same muscle workout.

In the research we have available, the Vest does compare favourably to percussion and postural drainage and could be an option for those using this as their treatment technique from 2 years of age. Most children in New Zealand are recommended by their physiotherapist to change from doing percussion to do PEP at around 5-8 years of age.

Physiotherapists in New Zealand are always looking at international best practice and evidence based practice when working with families and people with CF. If you are thinking of purchasing a Vest or starting any new treatment, it is strongly recommended that you discuss this with your CF team so they can advise you on the best course of action. If you feel that your current physiotherapy regime is not meeting your needs or that you may want to try something different, then please have a chat to your physiotherapist in clinic. They will be more than happy to help.

By **Rebecca Scoones** (physiotherapist)

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EASY ITALIAN ROAST CHICKEN

Ingredients

- 4 chicken Maryland's (thigh and leg)
- 2 rashers of bacon cut in half
- 1 onion peeled & diced
- 1 celery stick, washed & diced
- 1 clove of garlic, peeled & crushed
- 3 tins tomatoes
- 1 ½ tins of extra water
- Italian herbs (Oregano, basil or thyme)
- Salt pepper
- 2 Tbsn. Olive oil
- Non-stick spray

Put all the ingredients in the tray and roast the chicken while you relax, or do something else.

Using a timer will help you relax while the chicken cooks.

Cook extra and enjoy left overs. Simply double the recipe and cook enough to freeze or reheat.

Method

1. Preheat oven to 180c
2. Spray a roasting tray with Non-stick spray
3. Add chicken to tray drizzle with olive oil, then season with salt & pepper,
4. Add onion, celery, garlic, herbs, tins of tomatoes
5. Add a half tin of water to each tin & swirl, then pour it into the next tin & repeat until you have all of the tomato juice out of the tins
6. Roast for about 45-60 minutes until almost cooked
7. Cover Maryland with bacon and roast for another 15-20 minutes



Recipe courtesy of www.cfcooking.org in Australia, Healthy Food for Tired and Busy People



Liam's Field of Gold

In March this year Liam (7) (PWCF) and his brother Cooper had a mammoth task set out in front of them – to sell 1,500 cobs of sweetcorn in a week!

With help from Mum, Dad, good friend Boydie and the powers of social media the boys managed to sell out in five days and raise \$604 for the Taranaki CF Branch.

Taranaki Branch has issued a huge thank you to all the sponsors and helpers in getting this fundraiser the ground. "Your help is always appreciated," Chair Nicola McCarthy says.



Raise a Calf 4 CF

Liam also helped with the Raise a Calf for CF fundraiser. He's pictured here with Alfred the calf donated to the Taranaki Branch.

Families reared calves to help raise funds for CFNZ branches around New Zealand. More than \$4000 was raised in Taranaki, and funds of around \$3000 for the Nelson and Waikato Branch areas. Thanks to RD1 Livestock for being involved with the initiative and to Allflex NZ for the tags and Bruce Fowle from NZ Farmers Livestock for coordinating the sales.



WAIKATO BRANCH NEWS

Cystic Fibrosis Waikato would like to take this opportunity to thank all our amazing supporters here in the Mighty Waikato!

The Warehouse stores that are supporting us, and Z Te Awamutu for supporting us too!



Our amazing adult CF nurse Jo, showing her support for CF!



A quick trip to The Warehouse Morrinsville from Olivia to put her token in for CF Waikato.

Z recipients selected



COMMUNITY recipients, from left: Alice and Damien Bell, of Cystic Fibrosis, Z site leader Steve Comber, Michael Maloney, of Lake Ngaroto Sailing Club and Clare St Pierre, of Pirongia Te Aoroaro o Kahu Restoration Society.

BY BETHANY ROLSTON

Z Te Awamutu is giving away \$5000 to local community groups – and votes from the public will decide how the money is split.

Good in the Hood is a community funding programme that awards over \$1 million every year to around 100 Kiwi groups doing good for people or the environment.

Every Z service station has chosen four groups who will share \$4000 between them.

Locals will determine what percentage of the funding goes to each group by voting with an orange

token each time they shop at Z during May.

Z Te Awamutu has selected Cystic Fibrosis' Waikato branch, Huggable Hearts NZ, Lake Ngaroto Sailing Club and Pirongia Te Aoroaro o Kahu Restoration Society as the four beneficiaries.

Cystic Fibrosis Waikato branch provides information and support to all families of children who are born with cystic fibrosis as well as supporting adults with cystic fibrosis.

Huggable Hearts is a free service that provides grieving families who have lost a baby with a fabric heart made to their baby's birth weight.

Lake Ngaroto Sailing Club provides sailing for those with a disability.

Pirongia Te Aoroaro o Kahu Restoration Society is restoring the native biodiversity on Mt Pirongia.

Z community manager Christine Langdon says the range of needs highlights the scope of help needed across New Zealand. "Good in the Hood empowers communities to come up with solutions to these needs."

On top of the \$4000, every Z service station has an additional \$1000 to use for discretionary Good in the Hood neighbourhood support.

Damien and Alice Bell, pictured with Z Te Awamutu with the other lucky recipients of the Z Good in the Hood Initiative!

Heather, Megan, and Briar at the Warehouse Te Rapa to show their support!



Tribute to Janet Parsons

Earlier this year CFNZ farewelled one of our strongest CF champions – Janet Parsons who has been a huge support nationwide and for her local Hawke's Bay Branch. This is Hawke's Bay Branch Secretary Claire Fisher's tribute to one of the most inspiring woman she ever knew.



"I am sure many of you know that John and Janet have been involved with the Cystic Fibrosis Association for some time. Many of you probably know that they have helped our organisation at both a local branch level as well as at a national level. However, due to John and Janet's modest personalities I am not sure if you are aware just how significant their roles have been in the cystic fibrosis community. I struggle to find

words to describe just how meaningful their input has been.

Not only have John and Janet been active members of our local CF branch – working tirelessly on the committee, at fundraising events and creating awareness – they have also ensured our branch has stayed strong during tough times and they have given other CF families amazing support. I have always known that Janet had an open door policy and if I needed support, she was just a phone call away. Her advice was always both honest and kind.

When John messaged me to say that Janet had passed away and that I could inform the others, I took the liberty of digging out some old email addresses so that I could inform both past and present members of our local CF branch. I knew John and Janet had been on the local CF committee a long time and that they will have touched the lives of many. Here are a few of the comments I have received:

- *The contribution both Janet & John have made to HB CF Association has in my opinion, assisted in keeping this branch so active through the last 20 years.*
- *Our heart goes out to John, Kirsty and family, they were both a good support and 'go to' people when my daughter was a baby. We are really sorry for their loss.*
- *John and Janet have both been long standing and tireless supporters for CFNZ over many years.*
- *Janet was an awesome and loyal CFNZ supporter both at branch and at national level and John has been a major strength on the CFNZ Board and branch for many, many years.*

As you can see John and Janet have touched the lives of many within the cystic fibrosis community. We are all saddened by Janet's passing and this strong yet gentle lady is going to be missed by us all.

John, Kirsty, Duncan and Sophie – our thoughts are with you at this time. May your wonderful memories, give you comfort now and through the years ahead."

CF gives Hot Rods a Run for their Money

A 100-year-old family apple business in Hawke's Bay got more than it bargained for when it opened the doors to visitors in a return for a donation to support people with cystic fibrosis.

Taylor Corporation is used to taking small groups through the facility but everyone's eyebrows were raised when a group of hot rod enthusiasts drove up the road wanting to use the site for part of the annual Hot Rod and Classic Car Festival meet.

Taylor Corporation Managing Director Kelvin Taylor and his grandchildren Amber and Isaac were delighted to host the visitors and receive a cheque for \$1000 for providing use of the property.

Other groups that have made use of the company include Tsubaki (a chain manufacturing company) that wanted to do some promotional filming – so it's been a creative little money spinner for the branch.



Save the Date

CASINO NIGHT Sat 2 September

This is Hawke's Bay Branch's biggest fundraising event of the year and will be held at the Havelock North Community Centre. The theme this year is 60s! Yes, those were the days of hippies, The Beatles, Elvis, Marilyn Munroe and Jackie O – something for everyone!



SPECIAL EVENT

Chair Paula Richards reports:

On the evening of Monday 13th March we held a special event at the CQ Hotel where we were presented with a donation of nebulisers from the Freemasons. We also said farewell to Robyn Lange, Paediatric Physiotherapist.

James Martin from the Waihenga-St Johns Lodge Martinborough along with his colleagues from the Zetland Lodge in Wellington presented us with 10 nebulisers plus three travel nebulisers for CF Wellington Branch. We are incredibly grateful for this generous donation which takes the financial burden off the branch having to buy nebulisers for at least a year. Once again, thanks to the Freemasons for their kind donation and continued support for CF Wellington.

We also said farewell to Robyn Lange who retired at the end of last year. Robyn has been the Paediatric Physiotherapist for nearly 15 years and has developed firm relationships with our CF children and families over these years. We will miss Robyn and wish her all the best in her retirement.



CF Symbol Star of Bake Sale

The ANZ Finance Team in Featherston St baked up a storm for CF – making creative use of our CF symbol.

Using a CF blue theme, these tasty treats raised a total of \$2050. Thanks to CFNZ Wellington Branch member Katrina Fletcher for organising.

Raffle winners received “Coffee and Chocolate” themed gift baskets – Coffee products kindly donated by Coffee 32 The Terrace, and Coffee 86 Lambton Quay.



Xmas Tree Festival fights like Hell for CF

Hell Pizza came out on top at the Xmas Tree Festival at Wellington Airport and you can see why.

The spooky tree won the best tree out of many other amazing trees on display to help raise funds for CFNZ Wellington.

There was also an All Blacks tree this time and NZ Rugby CEO Steve Tew spoke at the gala opening about how much support the XTF brings to CFNZ and how the wider Wellington CF community has embraced the Festival and the CF cause.

Hell is so confident it will win again next year it will pledge \$1000 to CF if another business can beat the Hell Pizza tree this year.



AWARENESS WEEK

Auckland Branch is busy preparing for Awareness Week (AW). We always endeavour to make each year's AW even more successful than the last. This year we are trying to get more schools supporting our fundraising effort. As part of this we have created a CF coin trail image that we will send to schools/kindys to assist them in running a coin trail for CF. These are currently being printed but once we have them we will be making contact to see if any of the other branches around the country could use them for their fundraising efforts. The star will measure 1000mm x 1000mm and will be printed on a piece of large white card that can be folded for posting.



Good in the Hood has just finished, this year we were part of this at two service stations, Milford on the North Shore and Newton, on the edge of the CBD. There was some stiff competition this year but it was still a great opportunity to get some Awareness out about CF and do some fundraising at the same time. We are waiting to hear what the final amount is but in the meantime a big thanks to Z Energy for supporting CF Auckland Branch.

The Warehouse supported CF Auckland in two stores for the second half of 2016 and donated just over \$2,700 to our branch. Our appreciation to those shoppers who dropped a token in our box and a big thank you to The Warehouse for their generosity in supporting CF Auckland Branch.



Grant News

Auckland branch has recently received a \$10,000 grant from Louisa and Patrick Emmett Murphy Foundation to purchase parking vouchers to cover the cost of parking for PWCF attending clinic appointments. Many thanks to the foundation for this generous grant.



The Auckland Marathon is an iconic running event and this year it will take place on Sunday, 29th of October. CF Auckland is planning to have a group of fundraising runners taking part. Thank you to WillisTowersWatson (risk assessors and insurance brokers) who had a team in the event last year and did some impressive fundraising

for our branch. They have already recruited a team of 20 to run and fundraise for CF Auckland in the 2017 Auckland Marathon. We are now busy trying to encourage as many other people as possible to join the team. We are planning delicious bacon butties, treats, drinks and a sports massage to entice people to take part.



Auckland Branch recruiting volunteers at the University of Auckland Volunteer Expo

Auckland committee members, Jane Drumm (pictured left) and Sarah Cahill, joined Branch Coordinator Kath Sanderson at the University of Auckland Volunteer Expo to recruit volunteers to assist in our fundraising efforts. This was a great opportunity to spread the word about CF and to link with people who are enthusiastic about volunteering their time to help with **CF Awareness Week 14-20 August.**



The bake sale at Macleans College in June went down a treat



THE PARKERS TAKE MANHATTAN, DISNEY WORLD, THE GRAND CANYON – AND DISNEYLAND!

The Parker family of Christchurch saved for seven years so they could afford their five and half week trip around the US. Kevin Parker submitted this article for CF News.



Let me introduce our family, I'm Kevin, my wife Kathryn our two daughters Elizabeth and Jennifer and our son Thomas. Thomas was diagnosed with cystic fibrosis from the Guthrie's test and as with any parent the last thing you want to hear is that your child has a health condition. This was the first time that we had really heard about CF, it was a real shock as there was no history in our families.

A couple of years after Thomas was born Kathryn and I were talking in bed late one night, I brought up the idea of going to Disney World in Orlando because I'd been backpacking there in 1996 and promised to return when I had a family.

With three children and a mortgage we needed to start saving, even \$5-10 a week makes a big difference six to seven years out. We wanted to wait until the kids were old enough so they got the full benefit of going on rides as well as remembering the experience.

We were doing well then in 2010-11 the quakes hit Christchurch, the holiday was put at the back of the bookshelf. There was a couple of hard years after the quakes, but we were lucky than others, we didn't get hurt and our house was still standing.

Around 2014 I got the holiday off the bookshelf and started to do a bit of pricing. What was going to be a three-week holiday to Orlando now included five nights in New York and we ended up including San Diego, Las Vegas, the Grand Canyon and LA - a total of 5 ½ weeks.

With only six months before our departure we still had no travel insurance for Thomas, but then an email came through about a health and travel insurance broker. Two weeks later,

with much delight, Thomas was covered through Bupa Insurance.

Two weeks before our departure Thomas had his last check up before our holiday. Unfortunately, he had traces of a bug growing even though he wasn't showing any signs of it. It was straight



onto antibiotics and a week of 'shall we stay or shall we go?' Departure day arrived and still no signs of a cough (thank goodness). However, we still almost missed our flight to Auckland as we couldn't find our dog and we spent 20 minutes looking for him!

The internet is full of bad stories of the US customs and as we were taking a medical bag on board (antibiotics, needles and nebuliser). I called all the airlines we were flying and they made a note in their systems. Every time we went through security we just told them what was in the bag, they had a quick look inside and let us on our way, no problems at all.

In New York we enjoyed all the main attractions and never felt unsafe on the subway or walking along the streets day or night. NY is actually a beautiful city.

Next stop was Orlando for three weeks. We rented a 3-bedroom apartment (The Mouse Pad) at Windsor Hills Resort through VRBO.com.

Thomas was still having antibiotics through the nebuliser two weeks into our holiday when the machine stopped working. I found the number for Cystic Fibrosis America and explained what we needed and within 30 minutes they got back to us with places where we could purchase a new machine. They suggested to call ahead to see if they had the machines in stock which saved a lot of time. We picked up a new nebuliser for \$260 NZ.

In Orlando we did all the Parks including Disney's four main parks, Universals Studio, Legoland, Sea World and Kennedy Space Centre. Thomas liked the Jurassic Park River Ride the best, the girls both loved Harry Potter World, Kathryn and I loved Epcot. I could go on forever about Orlando, so I'll sum it up in one word UNBELIVABLE.

Our next stop was San Diego where we stayed right on Mission Bay in a room overlooking the bay. We went to San Diego Zoo in a day but you could easily spend 2-3 days there. In Vegas we took a helicopter ride over Hoover Dam and Lake Mead, and landed at the bottom of the Grand Canyon for a morning tea. The next day we walked along the strip of casinos, the one thing we noticed straight away was that they still smoked inside even if it was in the gambling area.

On Christmas Day we drove to LA for two nights. Our second to last day was spent at Disneyland and California Adventure parks – yes, two parks in one very long day. Tip - get to the parks before the advertised time as they sometimes open up 30mins beforehand. There were a couple of rides at Disneyland that weren't at Disney World so it was still worthwhile going.

On our last day we drove to Hollywood and watched the sunset at Santa Monica Pier before a late flight home. We couldn't have asked for better last day and to top it off, we saw the Santa Monica Pier out the window as our plane climbed into sky, just MAGIC.



A Trip, Wedding and a Christening



A trip to Cape Town in South Africa was more than just a chance for a great family holiday – it also set the scene for a second wedding for the Silverwood's.

Shelley Silverwood and Richard's first marriage ceremony was a casual registry office affair in Christchurch, but their wedding in Cape Town in February allowed the family to enjoy a more formal celebration with Richard's family all present, Shelley in a wedding dress and the children Bella (9) Ben (8) who has CF, Jaxon (2) and Violet (1) all playing a part, including the christening of youngest daughter Violet.

The ceremony was held at a country house called Leipzig on a burning hot 36 degree day. It was a great day for the whole family and the trip to South Africa allowed Richard to spend time with his family.

They spent the majority of time exploring the tourist hot spot of Cape Town and visiting nearby destinations such as Table Mountain. Shelley says they were relieved to secure health insurance for Ben through the travel insurance brokers, www.healthinsurance.co.nz, but thankfully there were no medical concerns while away.

"The criteria was they can't have had an admission within six months of travelling. We've been really lucky with Ben. He's been really well for the last year and a half now," she says.

In fact, it was Ben's coeliac disease which provided much more stress because there are fewer gluten-free options available in South Africa.

"We don't have to worry about a nebuliser. We take his medication and a stack of augmentin if he gets a cough but he was really healthy," says Shelley who says the trick to travelling with a CF child is in the planning.

"I talked to Viv and Phil before we went to check they were okay with it and we got a letter from Dr Phillip Pattemore just in case anything happens and you need to front up to a hospital. I had a letter that gave Ben's medical history," Shelley explains.

"It was important to get enough salt into his diet and make sure he was well hydrated because it's really hot over there.

"I took a lot of food over with us because they aren't so concerned about quarantine. We took a whole suitcase of medication and gluten-free food like cereal and rice cakes."

They stayed with Richard's family in Durbanville north of Cape Town, which kept the cost down and one of the advantages of travelling to South Africa is that it's much cheaper than New Zealand – especially eating out. Shelley estimates it's up to a third of the price of restaurants here. They had a family dinner before leaving which included their own family of six and another six members of Richard's and it cost \$200 including drinks and desert.

"Wine is really cheap as well. You can pay \$5 for a good bottle of wine," she says.

Voting for Viv

Canterbury DHB CF Nurse Specialist Viv Isles was nominated twice in the Ansell Hero Nurse Awards – once by CFNZ also by another strong supporter. Viv got off to a great start in the voting, with lots praise for her care of CF families.

Canterbury Chair Melissa Skene considers Viv part of the family and believes she does not treat her care for CF families as a job.

"Viv always goes the extra mile, we have been very lucky and privileged to have her as part of our hospital team and she has always only been a phone call away to offer that sensible needed advice or a home visit to carry out a cough swab, sputum sample or a health assessment. Her CF knowledge is so valuable."

"Her level head in a crisis episode is also to be commended. She seems to be very good at calming stressed parents and also dealing with an unwell child," Melissa adds.

Viv's dedication was particularly evident when Melissa's son Caleb became seriously ill at the age of six. He was admitted to the high dependency unit and suffered a cardiac arrest.

"Our CF specialist was away in India and we were so happy to have Viv's help and guidance during this stressful time. Because things were so stressful she stayed hours after her shift had ended."

Voting ends 1 July. Vote for Viv at:
www.ansellhero.com.au/en/Vote.aspx



PETER'S JUST TURNED 63!



New Zealand's CF population ranges from newborns to over 80. According to CFNZ figures there are at least 12 over-60s in the CF community and one of those is Peter Wookey who has recently celebrated his 63rd birthday.

Peter lives in Auckland, is retired and under the care of the CF Adult Medical team. He takes Creon to aid digestion and inhales hypertonic saline through a nebuliser and has stayed remarkably well for someone with CF.

It wasn't so very long ago that Peter had no idea that he had a serious health condition. He suffered from pneumonia a few times as a child but children weren't screened for cystic fibrosis when he was born in 1954. It was his yearly bouts of bronchitis that eventually led him to seek further treatment in 2011.

Peter's first inkling that his breathing may not be up to par was

when he failed a lung function test during a medical exam for his physical for his pilot's licence while living in South Africa where he was born. At the time he was diagnosed with COPD (chronic obstructive pulmonary disease), which was put down to him being an ex-smoker. Treatment with the medication Seretide eased his symptoms and he was able to keep his licence.

But years later Peter still suffered from chronic bronchitis. He would treat this by buying antibiotics over the counter which he could do in Europe during his flights overseas during his career working for airlines.

By this time Peter had moved to New Zealand to live permanently in 2008. He eventually sought more treatment from his GP on Auckland's North Shore. Peter was referred to a respiratory specialist and subsequent tests found a microorganism in his lungs which Peter was told could have indicated HIV. But a subsequent upper body scan discovered the inevitable signs of cystic fibrosis because Peter's pancreas was also affected.

"I needed to go for sweat tests which I failed. At least I knew what was wrong with me. I had to go and look cystic fibrosis up on the internet because I had no idea what it was all about," he says.

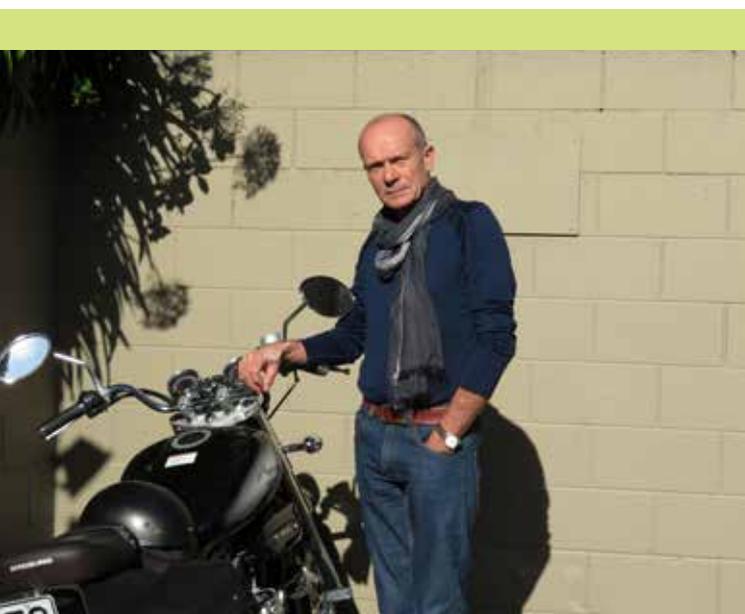
A nine-month course of intravenous antibiotics was necessary to help treat his specific type of lung infection. (The particular organism that Peter had requires much longer treatment than the more usual infections that occur in CF). At this stage Peter had already retired from his job as an airline safety official.

Now being cared for by the Adult CF Service in Auckland, Peter says he's never received such good clinical attention in his life.

"I've never been treated so well in my life by any doctor," he says. "I feel a bit of a fraud sometimes because I don't feel like I have cystic fibrosis.

"I've looked at life expectancies and I'm way beyond that."

Peter sees the CF Multi-disciplinary Team every three months and his regular treatment involves daily chest clearance with saline solution and taking Creon with food.





The diagnosis of cystic fibrosis made a lot of sense, says Peter. His family funeral plots show a lot of young deaths in the 1880s – which Peter only partly puts down to CF. In those days there was a risk of death from many causes. Also Peter’s uncle died at 63 and had suffered ongoing chest problems.

“I was always hungry as a child. It was quite normal for me to eat four meals a day,” Peter recalls. “And after exercising I would wonder why my shirts were full of salt.”

Peter would rather the support offered by Cystic Fibrosis New Zealand and the Auckland Branch, including hospital packs, go to others who require assistance.

“I can afford stuff. I don’t need it, so I say give it to those who need it more.”

Now retired and living on Auckland’s North Shore, Peter stays active and eats a CF diet that includes lots of cream and thick Greek yoghurt.

“The only takeaways that I have is maybe fish and chips once a year. Otherwise I prepare it all myself and grow a lot of my own vegetables in the summer.”

And he remains extremely thankful for the medical care he has received in NZ.

“The treatment and service you receive in New Zealand is incredible,” he says.

PARMESAN BAKED EGGS

Ingredients

- 4 egg
- 4 tbsp cream
- 1 tsp butter
- 2 tbsp Parmesan cheese
- salt and pepper to taste

Instructions

1. Preheat oven to 180 degrees.
2. Butter 2 large ramekins (or 4 small, then have one egg per ramekin). Crack 2 eggs in each ramekin.
3. Add 2 tbsp of heavy cream in each ramekin. Salt and pepper the eggs.
4. Grate some Parmesan cheese over the eggs.
5. Bake for about 10 to 15 min (depending on how runny you like your eggs)

You can easily add spinach, ham or herbs. Serve with toast fingers for dipping.

Recipe Courtesy of Auckland Branch E-News.



Georgia Drumm – Mark Ashford Scholar



Congratulations to Georgia Drumm who has been awarded the 2017 Mark Ashford Scholarship. Georgia (21) has achieved excellence for her early childhood education degree at the University of Auckland including winning the Aitken Early Childhood Education Travel Award in 2016. There will be a formal award ceremony for Georgia in late June and the next issue of CF News will feature an interview with Georgia.

The Mark Ashford Scholarship provides a grant of \$3000 to the person with CF who has achieved excellent results in tertiary education and/or showed tenacity to overcome the trials of CF while studying. Big thanks to Tasman Insulation, manufacturers of Pink Batts, for its on-going sponsorship of this award.

She is pictured here after her graduation ceremony in Auckland.



CFNZ PANUI

Sign up to CFNZ’s electronic newsletter, the Panui, to get the latest in news and views once a month. Email: comms@cfnz.org.nz to get on the list. CFNZ also provides immediate updates on our Facebook Page: [@CysticFibrosisNZ](https://www.facebook.com/CysticFibrosisNZ). Please “Like” us on Facebook if you haven’t already.



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