

WINTER 2016

cf CYSTIC FIBROSIS NZ
Creating Better Tomorrows

ISSN 0114-3573 (Print) • ISSN 1179-044X (Online)

CF news

Star Surfers



Meet our CF Achievers & Mark Ashford Scholar
2016 CF Conference Report | Cystic Sisters: Acts of Kindness



Update from the Chair

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Funny isn't it when one sits down to write and then thinks – a little blankly – “now what do I have to tell people?” So I started a list of possible points and in five minutes I had 13 points! So obviously a lot is happening in our CFNZ world.

2016 has thrown a lot at CFNZ. We bid farewell to Belinda our Chief Executive of 18 months and thanked her for her time with us. Belinda streamlined many of our procedures, brought us together with our marketing/fundraiser Kiwifirst, employed two new staff members, got the grants and fundraising programme activated and really made an impact on our branches by visiting regularly and getting a great handle on issues impacting on PWCF and their families throughout NZ.

Although we were sorry to see Belinda leave, the CFNZ Board were delighted to appoint our new CE, Jane Bollard, who started with us in March. Jane (great name by the way) is Auckland based and our thinking was that the CE would work from the Auckland CFNZ office and manage the Christchurch staff remotely – a reversal of what had been happening. Sadly this was not to be for we had two resignations from Christchurch based staff soon after Jane starting with CFNZ. This has left just our lovely South Island Fieldworker, Sue, currently working from our CFNZ Christchurch office.

I am very pleased to welcome our new CFNZ staff members; Natasha Banks-Fowler – Admin Manager, Jude Kelly – Central Fieldworker, Jeanette Franklyn – Grants Coordinator and Allyson Harvey our contracted Accounts Manager. We also said farewell to our Northern Fieldworker, Melinda Coombes, last month and we wish her well with her studies.

Even with all this coming and going we still managed to hold an outstanding CFNZ conference this year. The qualities of speakers left us spoilt for choice as there were concurrent streams, and as always people really enjoyed the opportunity to network and have a few laughs. I was honoured at the Saturday night conference dinner, to be able to introduce everyone at conference to the 20th annual Mark Ashford recipient, Kirsty Parsons, who you will read about in this edition of the CF News. Kirsty is an outstanding recipient and I congratulate all who applied for the scholarship – the standard this year was particularly high. It was touching to be able to watch a short film where previous recipients were featured, and several talked about how receiving this very special award had impacted on their life.

Upcoming Board meetings this year will be in August and October and our AGM will be held during the Chairpersons' Conference to be held in Wellington in October. We will likely have at least two current Board members stand down at the AGM and I would encourage you to think about likely replacements. Often our Board members come from Branch committee backgrounds but this is not a requirement. There may be someone you know who has the kind of skills we are looking for and has yet to get involved with CFNZ. Please contact me drummsj@ihug.co.nz or any of the other current Board members if you or someone you know is interested in finding out more about being nominated for the CFNZ Board.

As I mentioned in the last CF News, CFNZ has faced some very difficult times financially particularly over the last year. This has led the Board, branches and CE to really look at the way in which CFNZ operates and how best to address the issues. Previously CFNZ (National) has raised all the funds required to provide national support and services to each of the branch areas. This has included Fieldworker services, voucher assistance, hospital allowances and other forms of help for PWCF and families who are feeling the impact of CF. CFNZ (National) have also fundraised for and funded all applications for Breath4CF. With the shrinking nationally available charity dollar and limited staff capacity, now more than ever we need to work as a team.

Branches have traditionally raised funds for the support which they provide directly to the members in their region, nebulisers, physio equipment, top up for Breath4CF, parking vouchers, hospital packs etc. What is now happening is that many of the local branches are now kindly raising funds and helping fund various aspects of CFNZ (National) operations in their branch areas, in particular the new Central Fieldworker position and Breath4CF. Some branches prefer to run fundraising events or activities as a way of providing operational support, where they will “profit share” with CFNZ (National) like Waikato Branch's Raise-a-Calf Scheme.

At our Chairpersons' Conference last year we talked a lot about our CFNZ strategic position of “Together we are one” and I am very pleased to be able to let everyone know that I believe we are now starting to live our motto and that together CFNZ is becoming a sustainable organisation working at meeting the needs of the growing CF community we serve.

JANE DRUMM, CHAIRPERSON



Update from the CEO

I was delighted to take up my appointment as Chief Executive in March this year.

With several new staff appointments to be made and the relocation of the office from Christchurch to Auckland my focus has been primarily on sustainability of the organisation in the short and longer term. I have appreciated the support of Jane Drumm, CFNZ Chair, and the Board Members over the last four months.

With the new Health and Safety at Work Act coming into effect on 1 April it has been my immediate focus to develop policies and procedures to ensure we provide a safe environment for our workers (paid and unpaid), contractors and visitors.

Government funding is another priority and while it is only a small percentage of the income received by CFNZ, it is vital. I have been working to secure both Ministry of Health and Canterbury DHB funding for another term with both three-year contracts ending in June. Our other source of income is via grants and fundraising and we are in the process of engaging a fundraising specialist to develop a fundraising strategy for CFNZ. I have been struck by the level of commitment from branch members to fundraise and also the generosity of our supporters and the public to give us donations. This was particularly evident at the sell-out Northland Golf Tournament that I attended.

CF Research is important to everyone in the CF community, and I am pleased to announce the recent collaboration between Shares in Life Foundation and Cure Kids to fund CF research utilising the Cure Kids granting process. This collaboration reflects the close association of the organisations and a commitment to enable the research dollar to be boosted and best utilised.

At the May Board meeting the Board identified priorities for CFNZ over the next 12 months from 1 July. I look forward to discussing these with branch representatives at our Chairpersons' Conference in October.

A standing priority continues to be access to treatment and equity of care. CFNZ staff have been working closely with the Wellington Branch members to campaign for a Paediatric CF Nurse Specialist to be employed by the Capital & Coast DHB – ensuring that our Wellington families receive a similar standard of care to other areas. Auckland families receive excellent support from Jan Tate, Paediatric Nurse Specialist at Starship Hospital and CFNZ was happy to nominate Jan as part of the Ansell Nurse Hero Awards campaign.

JANE BOLLARD, CHIEF EXECUTIVE



WE'RE ALL GEARING UP FOR AWARENESS WEEK 15 – 21 AUGUST

All offers of help are gratefully received. Local branches need volunteers to help with bucket collections with the main collection day being Friday 19 August.

We can help by providing a number of promotional resources. Contact CFNZ on Freephone 0800 651 122.

We are hoping to feature human interest stories in the media and if you haven't already, "Like" us on Facebook @ Cystic Fibrosis NZ, so our posts reach as many people as possible, which is always great for awareness of CF.

Our sponsors **Choice Hotels** are generously helping by hosting their 3rd fundraising week for CFNZ during Awareness Week. This year Choice Hotels will be donating \$2 from every night stayed to CFNZ between 15 and 21 August. Visit www.choicehotels.co.nz to book a stay.

FUNDRAISING IN STYLE

Schwarzkopf's Hair Expert Mall Event proved to be a stylish fundraising method for CFNZ.

The Hair Expert Mall Event, held at shopping malls in Auckland, Wellington and Christchurch attracted 500 people happy to pay \$10 for a dry hairstyle, with the proceeds going to CFNZ.

A total of \$5000 was raised, with many people willing to pay more knowing that the funds were going to charity. The free samples and goodie bags also helped attract shoppers to the Schwarzkopf stands.

CFNZ is extremely grateful to the Schwarzkopf team doing such an amazing job at the malls and to Rachel Elliott of the Auckland Branch for setting up Cystic Fibrosis as the official charity. It was a highly successful event.



Schwarzkopf Senior Brand Manager Priscilla Khor (left), CFNZ Chief Executive Jane Bollard, and Rachel Elliott of the Auckland Branch (right)

TRAVEL WITH CF

While it can be difficult for people with CF to get travel insurance, it is recommended to try to get cover before embarking on an overseas trip – and it is possible in some circumstances.

Some of our members have had success arranging for travel insurance via the travel insurance brokers www.healthinsurance.co.nz/.

They use insurers who will consider cystic fibrosis on a case by case basis and people whose health has been stable for six months with no hospitalisations or changes in their treatment or medication may be approved for medical and evacuation cover with Bupa after medical assessment.

Health Insurance owner Sandra Grant says that hospital "tune ups" where there are any adjustments in treatment or medication might affect the application, but routine visits may be fine. For this reason, all queries are reviewed by Bupa's medical assessors so that there is no confusion about the coverage.

The insurance is for worldwide travel and costs US\$4.50 a day with an administration fee of \$42 for those aged under 37. Over 37s pay \$6.80 a day up to the age of 70.

Contact Sandra@healthandtravel.co.nz for more information.



WAVE RIDERS

New Zealand's first Surf Experience Day for kids with CF sparked a new generation of keen surfers thanks to the lessons provided by world-class surfers and paddle boarders at Orewa Beach, North of Auckland.

Surf Day is run by the Maui Ola Foundation to provide surf lessons for children with cystic fibrosis in several countries around the world, and the event in Auckland was a big drawcard for both the CF community and the media.

The beach was covered in photographers and cameramen from both New Zealand and around the world. It was featured by TV3's Newshub and also filmed by Red Bull TV, and also covered in the local newspaper, and on Stuff.

But it was the excitement on the faces of the children which was the biggest success story. Many of the children want to take surf lessons and have new heroes in the form of the professional surfers who taught them, like big wave surfer Kala Alexander.

The waves were fairly small on the day but it didn't stop the kids from being able to catch a few of them and even stand up on the boards.

He's fizzing – he's on Red Bull," said Keoghan's mum Claudette at the event.

The event, which adheres to strict cross infection protocols – the children with CF are readily identifiable and are asked to stay 2 metres apart. Sterilising wipes and gel are on hand, and a team of volunteers are there to ensure they do stay safe in and out of the water.

Grants and Events Coordinator Hannah Wilson got into the spirit, and the water, helping kids on and off the surf boards.

There were 10 children aged between five and 16 taking part in the event, along with three brothers and sisters. Most got longer in the water than expected and a few even got rides on a Jet Ski.

Families were also invited to a BBQ after the event, which was unexpected but very welcome. All that surf and sand helped work up quite an appetite.

We have Glenn Bradley, General Manager of Mount Maunganui Lifeguard Service, to thank for the Foundation offering Surf Experience in New Zealand. Glenn had heard about the Foundation's Surf Days for cystic fibrosis in Hawaii before his son Oli (now five) was diagnosed late with CF 18 months ago.

"When Oli got diagnosed I immediately thought of the Foundation because I remembered seeing something about cystic fibrosis on social media. The only thing I knew about cystic fibrosis was that surfing was good for you."

When Glenn heard that big wave surfer Kala Alexander was coming to New Zealand for the Ultimate Waterman competition, he suggested that the Maui Ola Foundation's Surf Experience for kids with CF could also be held in New Zealand, because Kala is the Vice President of the Foundation.

"I said I'd be keen to help out or do anything I could to make that happen and a few months ago they got back in touch and said 'Yes! Surf Experience Day was going to happen'.

"I thought the day was absolutely fantastic on a number of levels – for the CF Association and awareness of the condition in New Zealand, and also global awareness from the worldwide media coverage of that particular day because it was linked to the



Ultimate Waterman, which has a massive global audience, and then the chance to hangout, have fun in the surf, and learn from and be inspired by some of the world's best," Glenn explains.

He would like to see more kids with CF spending as much time in the ocean as they can. "I really believe in the benefits of spending time in the ocean environment and being in the salt water – it's so accessible for most New Zealanders, and hopefully the event sows the seed for other kids to get out there and amongst the waves."

It's certainly given his son Oli a new favourite hobby.

"Oli was fizzing," says Glenn. "When he saw himself on the news he was over the moon. We went for a few surfs afterward and he's really got the bug now."

As a parent, Glenn says he also felt happy about the way the event was run – addressing cross infection concerns by keeping the children with CF at least two metres apart – and using blue rash tops and bracelets.

"It was something Veronica and I were really aware of but had no concerns on the day and we are hypervigilant with Oli. The separation of the kids was fine and it was also an outdoor environment. I'd love to see it happen again and would be happy to help out again."

There were some amazing photos from this event including one of Caleb (8), whose photo is on the cover of this issue of CF News.

Caleb was taken under Tahitian pro-surfer Manoa Drollet's wing, and it wasn't long before Caleb was riding the waves standing up.

"The kids had a ball," says Caleb's mother Larisa Gardner, "I don't know if any of them had surfed before but it was a huge experience for them. I'm not sure they realised they were being

taught by the Ultimate Watermen – the best surfers in the world."

"It was really well run," she adds. "Everyone was conscious about keeping their distance, and boards were being wiped down to avoid any contamination."

Caleb was also lucky enough to train with the West Ham United football team when they were in New Zealand to play the Wellington Phoenix – and now surfing has joined the list of other activities he enjoys including swimming, tennis and mountain biking.

"He did quite well – he's never surfed before. He also got to experience stand-up paddle boarding and quite enjoyed that as well," says Larisa.

A few months later Caleb became the proud owner of his own surfboard – thanks to the Breath4CF activity grant.

Living in Whangaparaoa, north of Auckland, means Caleb doesn't have far to travel to catch some waves.

"It's on our doorstep so we should be taking advantage of it really."

Our cover shot of Caleb (8) was taken by Scott Sinton, professional photographer and surfer, who was one of the photographers covering the Surf Day and the Ultimate Waterman competition. Scott says it was amazing to be part of the Maui Ola day at Orewa Beach.

"I was incredibly humbled by the experience. It emphasised for me how special the ocean is and how lucky I am to surf. Seeing what the kids got out of the day was one of the most moving experiences of my life."

Crusaders pitch in for CF



The BNZ Crusaders Super Rugby Team played ball for Cystic Fibrosis in more ways than one when they hit the cricket pitch to raise funds for CF.

Not only did the annual charity cricket match raise \$21,000 for Cystic Fibrosis New Zealand, the match in December pitched both past and present Crusader's rugby players against each other, ensuring it was an entertaining match for spectators.

The event saw the Crusaders Present team, led by Israel Dagg, opposing rugby stars from the Crusaders Past team, which was captained by Justin Marshall. The Crusaders Present team won the 20/20 match by 20 runs.

Prior to the match, Israel Dagg proved prophetic with his comments – teasing the Past Players saying “I don't think we'll have any problem wearing the old fellas out.

“At the end of the day though, it's not really about us or which team wins. It's about raising funds for this really worthy cause, and that's something we're all really keen to get behind.”

Both team members were happy to sign autographs and sport memorabilia for spectators. Two Crusaders who also represent the Fiji Rugby National Team, donated autographed Fiji Rugby shorts and a Red Crusaders top which fetched the highest bids at the charity auction.

Charity Cricket has been a long-standing tradition for CFNZ, and this was the 33rd Charity Cricket event.

CFNZ would like to thank the amazing businesses that supported Cystic Fibrosis Crusaders Charity Cricket 2015. Their help is key to CFNZ's mission to improve the lives of people with CF:

- Alexanders Marketing
- Armourguard
- Bealey Dental
- BNZ
- Bodyworks Massage Therapy
- Bounce NZ
- BurgerFuel Bush Inn & Spitfire
- Canterbury Weather Updates
- Coca-Cola Amatil NZ
- Christchurch City Council
- Christchurch Boys High
- Christchurch Casino
- Commodore Airport Hotel
- CTV
- Denise Jones—Segway
- EFTPOS NZ Ltd
- Espresso Carwash
- Gary Cockram Hyundai
- Goom Landscapes
- Hang Up Entertainment
- Happy Hire
- Heathcote Cricket Club
- Hellers
- Hell's Pizza Riccarton
- Hilo Decorating
- Hire King
- Inflatable World
- Kiwianis (NorthWest)
- Kookaburra
- Labour MP's
- Loisn Ltd
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- Papanui Youth Development
- Parry Field Lawyers
- PitStop
- Quality Hotel Elms
- Raeward Fresh- Harewood
- Rangoon Ruby
- Sergios Menswear
- Sharp Corporation NZ Ltd
- Sport Canterbury
- St John
- Streets Ice Cream
- The Antarctic Centre
- The Crusaders
- The Fitting Room
- The Rock
- The Star Canterbury
- The Warehouse South City
- Umpire—Brent Watson
- Umpire—Mark Wood
- YMCA Christchurch



WEDDING NEWS

David & Tessa had a Field Day

As a keen rugby fan, it seemed only fitting for David Donohue to kick off married life at a rugby stadium.

David and his fiancée Tessa decided Yarrow Rugby Stadium in Taranaki would be the ideal place to exchange their vows because it combined David's love of the sport with the perfect summer wedding venue. Tessa and her bridesmaids were able to use the Players Tunnel for the bridal march onto the field to the tune of You Raise Me Up sung by Josh Groban, and the big screen in the stadium helped provide some special effects.

The couple got the ball rolling with their rugby theme by sending out wedding invitations designed like rugby tickets, and guests were also seated around tables named after famous rugby teams. And of course some of the speeches couldn't resist referring to David's love of NZ's national sport.

David himself had to stop playing rugby when he was 22 when he had a port-a-cath inserted, but is now just as passionate about coaching rugby teams – most recently in Wainuiomata where he and Tessa lived before moving to Taranaki recently for Tessa's new job.

"I love coaching it," admits David, who met the other love of his life, Tessa, over four years ago.

"We met through my cousin in Taranaki. We saw each other a few times and after about six months we started going out," David explains.

They were only together for nine months before David decided to pop the question.

"We bought a house together and I asked her on our first night there," he recalls. A surprised and delighted Tessa said, 'Yes!'

They now have one-year-old daughter Mya who also made a grand entrance at the wedding in January.

"She had a little remote controlled car – a little Mercedes Benz that she rode down the aisle. I used the remote control to drive her down the aisle," says David.

The couple loved their wedding day, celebrating with 100 friends and family including David's sisters, one of whom also has CF. They were also pleased to put Yarrow Stadium to good use during the off-peak season.



CF TODAY & TOMORROW



Cystic Fibrosis New Zealand's National Conference in Auckland lived up to its theme of CF Today and Tomorrow – providing fresh hope for new treatments in the future.

Well over 100 people attended the conference in Auckland, which included a wide range of topics and speakers.

Keynote speaker Professor Scott Bell's address: "New Therapies in Cystic Fibrosis: 2016" impressed the delegates by providing an overview of some of the main differences with CF genetic abnormalities and how new medication is being developed to target them.

Professor Bell, who is based in Queensland, is the Editor-in-Chief of the Journal of Cystic Fibrosis, Senior Physician of the Adult CF Centre at The Prince Charles Hospital and leads the Lung Bacteria Lab at QIMR Berghofer Medical Research Institute.

He reported that ivacaftor (Kalydeco) produced a 10 percent improvement in lung function in a study which saw people with the G551D gene taking it for one year.

"If you compare that with tobramycin, Pulmozyme, azithromycin – it is two to three times the increase in what we've seen in any of those treatments.

"There was a significant reduction in exacerbations (or flare ups). It may reduce rates of Pseudomonas infection in younger patients and improve glucose tolerance – some patients have even been known to stop their insulin," he says.

"Even lower lung transplantation and mortality has been demonstrated in Ireland," he says.

He reported that Orkambi did not have the same effect on the population with the more common F508del gene in a two-year study, providing a "modest" three percent improvement in lung function – less than Tobi or Pulmozyme. But it did significantly reduce the number of exacerbations.

However, Professor Bell reported that Orkambi was the first prototype of this kind of medicine and it's likely that new therapies under development will be more effective.

"It's really the start," he says. "There are many new drugs on the way."

Professor Bell also detailed a new testing technique that could be used in future to determine how a person might respond to a specific drug treatment, and this could be helpful in determining who could benefit from an expensive medicine. It involves taking a biopsy of rectal tissue from young children with CF to grow cells into mini bowel organs, also known as "organoids", to see how they might respond to a medicine such as Orkambi.

"These organoids can be manipulated in the laboratory and different drugs can be added to those. Those cells can be exposed to different drug combinations and demonstrate whether they seem to work or not before applying them to the patient."

Professor Scott Bell's second presentation entitled "What's Emerging in CF Care – Where are we heading?" provided an overview of some of the challenges expected in the future as people with CF live longer lives.

“Our oldest patient was assessed for a knee replacement a couple of years ago,” he told the conference.

An increasing number of Adults with CF are having children, and one survey showed 40 percent of Adults with CF are in a relationship.

A study of four CF centres around the world showed that the average 40-year-old man with cystic fibrosis can expect to live another 13 years.

“We are now facing issues that we never dreamt we would face,” Professor Bell told the delegates. “We may be challenged with newer complications that we haven’t previously seen because people weren’t living long enough.”

He says CF Health Care teams are feeling the strain of dealing with increasing numbers of patients and also increasing complexity. “Therefore, we need to think about ways to develop a more sustainable service.”

Professor Cass Byrnes provided an overview of research in cystic fibrosis, including the FAB and COMBAT studies that she is involved in.

The COMBAT study looks at the role of Azithromycin in young children to see if it can delay the onset of lung disease.

The FAB study follows up the participants of a previous study to identify possible protective factors or risks that could lead to further deterioration, including what impact general anaesthesia has on a person’s intelligence.

She listed some of the pros and cons of patients being involved in research, such as getting access to new medicines on the positive side versus the time commitment and extra tests that are involved on the other.

Physiotherapist Trish Goulter’s urinary incontinence presentation discussed the higher rate of incontinence among females with CF, and also an entertaining demonstration on how to avoid straining to empty the bowel while on the toilet.

Starship Children’s Hospital paediatrician, Dr Paul Hofman emphasised the importance of identifying Cystic Fibrosis Related Diabetes as early as possible to avoid more serious CF health complications in the future.

The Lung Transplant Panel on Day 2 proved popular with Auckland Respiratory Physician Dr Mark O’Carroll providing an overview of the criteria required and the numbers of lung transplants in NZ. There was input from Health Psychologist Iris

Fontanilla who outlined some of the reasons why a transplant could be declined. Cheryl Moffat of Christchurch provided advice as a mother of a daughter who has had a transplant, and personal stories were told by Katherine Stern, and also Troy Stapleton – who has had two lung transplants

Troy said he made the call to go for a second lung transplant when he felt unable dance at a wedding. Now he’s dancing 12 hours a day – Ballroom and Latin.

Starship Children’s Hospital paediatrician Dr Julian Vyas presented an analysis of the scientific literature available for some natural therapies such as colloidal silver, colostrum, curcumin, glutathione, essential oils, and xylitol (sugar alcohol sweetener). Unfortunately, he reported there are no clinical trials on any of these to recommend their use.

There have been only nine clinical trials for using glutathione (which is an antioxidant). However, not all studies showed a benefit, and for those that did, the effect usually lasted less than six months. The only study showing some promise is one from 2015 (by Visca) that used 66mg/kg/day of oral glutathione. In this study, 44 patients had an average improvement of BMI of 17%.

“Whilst this is very promising, the study size (44 patients) is still small, and so we cannot simply advise families that glutathione is used. Clinical trials in many hundreds of patients are needed to help us understand which complementary treatments might be of use in people with CF.

“At the moment, claims for treatment benefit in CF from a wide range of complementary treatments are made on the internet; many of which have no evidence at all, and for the rest, the evidence is too far removed from a clinical trial to be able to say how they will work in humans.”

Dr Vyas pointed out that because alternative therapies don’t attract big investments from pharmaceutical companies, it’s hard to conduct large trials for these products.

Continues on the next page.

FAREWELLS

May our loved ones rest in peace and love

Julian Baker 27/10/2015

Sebastian Bell 30/11/2015

Maddison (Maddy) Stuart 15/06/2016

Katrina (Kat) Turner 17/06/2016

He concluded by saying that PWCF, or their parents, should seek advice from their local CF Teams before starting complementary or alternative therapies - to discuss likely benefit, and also possible side effects risks or interactions with other CF treatments.

There was a lot of interest in the personal stories presented at the conference. There was standing room only at Jamie Archibald's presentation with his wife Michelle where they talked about juggling CF and family life with two young boys.

The conference concluded with a strong presentation from Alex McKay who provided insight into how CF has affected his life from being born a sick baby to graduating with a law degree and working as an Associate at Pricewaterhouse Coopers in Corporate tax.

Alex presented live from a separate room at the hotel because of infection concerns. He provided advice to others with CF – never miss taking Creons or physiotherapy twice in a row, and to live full lives and take every opportunity that comes their way.

The **live stream** of the CFNZ conference was also viewed more than 200 times – 143 times on Day One and 93 times on Day two. CFNZ is grateful to Pub Charity for providing a generous grant to cover the cost of this service.

Mylan, makers of Creon, also provided a grant for the CFNZ Conference. We are also grateful to Purrell for providing hand sanitisers for the conference bags, Avon for the Mother's Day spot prizes, and to Liberty Brewing Company for the cool speaker gifts of craft beer.

MARK ASHFORD CONFERENCE DINNER

This year's CFNZ Conference dinner was a special occasion because it marked the 20th recipient of the Mark Ashford Scholarship Award – Kirsty Parsons whose story is featured in CF Adult News.

Diners embraced the "glitter, glamour and bling" theme, with the Auckland Branch adding a touch of shine to the Jean Batten room, with helium balloons and flowers.

A video produced by Kieran Wright to honour the past award recipients was the highlight of the night. It featured interviews and quotes from Mark's family and from past Scholars, and can be viewed on YouTube using this link: <http://cfnz.org.nz/our-services/library/clips/>

The inspirational messages in the video were both emotional and uplifting for the audience which included Mark's widow Kathryn Ashford, his parents and his children, Megan and Scott Ashford.

Guests enjoyed a generous buffet and a live band helped to entertain guests into the night.



Pharmacies warn of extra charges

Pharmacists have defended charging CF clients extra for dispensing medicine on public holidays, and for passing on freight fees for hypotonic saline in some cases.

Tauranga mum Karen Pope was featured in the Bay of Plenty Times about her concerns that a local pharmacy had added a \$2 surcharge for dispensing antibiotics for her daughter over the Christmas holiday period.

CFNZ Fieldworker Sue Lovelock has also received feedback that some pharmacies have been charging a freight fee for ordering hypertonic saline.

Pharmacy Guild Chief Executive Lee Hohaia provided a statement to CF News, explaining that it's within pharmacies right to pass on extra charges for providing their service, and that the Guild has flagged the extra freight charges for hypertonic saline with government authorities.

"Our position on pharmacies surcharging on public holidays remains the same. Community pharmacies, like all businesses, are able to set their charges to cover the additional cost of providing services on public holidays and after hours.

"If community pharmacy did not charge an additional fee to cover the cost of running their business on a public holiday, many pharmacies would not be able to afford to open on these days, further reducing patients' access to medicine and valuable health care advice.

"Where a patient will incur additional charges, the pharmacy must ensure the patient is advised of these charges in advance, such as through prominently displayed signage. This allows the patient to decide whether they are prepared to pay the extra charge or if they would rather wait to get their prescription filled during usual business hours. Organisations, such as Work and Income, have services available to help patients who are unable to pay for their medicine due to financial hardship.

"Not all services provided by health care professionals are fully subsidised by the Government. If pharmacies do not recoup costs for these services from the patient, the sustainability of pharmacy service provision will be threatened. This is especially relevant on public holidays where overheads are higher, due to higher staff costs."

She explains that hypertonic saline (Sodium Chloride 7%) is made by Biomed and is a section 26 medicine. Pharmacies have to order this medicine separately from their general order.

"This takes extra time and pharmacies are charged a freight fee from the wholesaler. Many pharmacies make a loss dispensing this medicine and will choose to pass on the unreimbursed cost of procurement to patients. The Guild has raised this issue with the DHBs and the Ministry of Health and are working through potential solutions to ensure that pharmacies are fairly reimbursed for the provision of these medicines to their patients."



KAREN POPE AND LENORE
PHOTO COURTESY OF BAY OF PLENTY TIMES

CHALLENGE WANAKA Athletes All Good Sports

A **big thank you** to all the amazing individuals who entered Challenge Wanaka and raised money for CFNZ.

Twins Jake and Emma, and their friend Kate raised more than \$2500 for CF, despite starting their fundraising relatively late in the piece. It was the fourth time that Jake has entered one of the Challenge Wanaka events.

Dunedin Hospital physiotherapist Joshua Woodside entered the Lake Wanaka Half Ironman and signed up to raise money for Breath4CF because until recently he worked with the paediatric CF Clinic and got to know the children and families well.

"I enjoyed working with these children and have seen some of the struggle and the number of treatments they have to complete on a daily basis – even when they are well," he says. "I got to know some of the families quite well. I saw some of the kids grow up and you definitely see all the battles the kids and the families go through."

When Josh noticed that Breath4CF was the official charity for Challenge Wanaka, he knew that fundraising while competing in the Lake Wanaka Half Ironman was something he could do for them and his efforts generated \$1240 for the cause.

"Knowing the daily challenges that people with cystic fibrosis face every day gave me the motivation to train harder.

"I thought it was an awesome opportunity to be able to raise some money for a good cause such as Breath4CF. Getting children into activities they will enjoy was always a passion of mine, and seeing how Breath4CF can help facilitate this is great."

The team "Half Pie – mmm Pie" decided to help fundraise for CFNZ after learning about the amazing Good Dead Sisters in Tauranga who performed a good deed for 65 days in a row last year.

Hayden Wingfield was another CFNZ fundraiser who had a more personal connection to CF because his cousin was born with the condition. He entered with his workmate Sam and her sister Shelley.

It wasn't the first time that Hayden has helped out CFNZ. His previous employers, Deloitte, donated laptops for people with CF in the past.

Hayden, who does have the CF gene, says there's not much awareness of cystic fibrosis in New Zealand and believes our small charity needs a lot of support.

On Event Day, staff watched our former CFNZ Administration Manager Julie Clemett cross the finish line after she cycled 90kms in the wind. She entered the Lake Wanaka Half with her son, and helped fundraise for Breath4CF while training.

A Challenge Wanaka flag signed by the athletes was auctioned for \$2500 and the winner of the Women's Challenge, Yvonne van Vlerken, kindly donated \$1000 of her prize money to Breath4CF, which helped contribute to CFNZ's total of over \$9000 from the event.



WIRED FOR FUNDRAISING

While Cystic Fibrosis New Zealand has witnessed some remarkable attempts to raise money for the community, Auckland mum Lorna Anderson is believed to be the first one prepared to brave the possibility of an electric shock to do so.



When Lorna entered the Australian-based obstacle course challenge called Tough Mudder where her and her teammates were forced to navigate a series of obstacles in the mud including:

- Electroshock Therapy – Live wires hanging over a field of mud which athletes had to transvere
- Arctic Enema – Plunging into a dumpster filled with ice water and pulling themselves out on the other side
- Funky Monkey – A set of monkey bars slicked with butter and mud over a pit of cold water
- Everest – Running up a pipe slicked with mud and grease

It's not the first time that Lorna has competed in this type of event, nor is it the first time she's raised money for CFNZ. Lorna ran the Auckland half marathon in 2014 and raised over \$3000. This time the mum of two, Raphael (5), and Sadie (now 2) who has CF, raised almost \$2000 taking part the Tough Mudder event, and she enjoyed every second of it.

"I was super nervous leading up to the event as I thought I might injure myself on any of the more challenging obstacles. A few of the obstacles were tough physically and mentally, but I surprised myself with how well I completed them," says Lorna.

"It did help that I completed the event side by side with a group of eight fabulous ladies from my gym. We helped and encouraged each other the whole way and this made a great difference to the enjoyment of the course."

She admits that the electric shocks did hurt but not for long and her family also helped cheer her on.

"Raphael and Sadie did brilliant supporting me at different obstacles along the way and putting up with the intense Gold Coast heat that day."

In the Arctic enema volunteers continuously threw bags of ice into the water to keep it freezing cold.

"You had to get in the ice water and dive down and under a barrier in the water and come up the over side. My head hurt afterwards from the cold.

"Funky Monkey was one of my favourites. I didn't think I would make it all the way across the monkey bars, but surprised myself. Everest was tough and I definitely needed my team mates to grab my hands to help pull me up to the top," she says.

The first mud run that Lorna entered was in Rotorua called "Tough Guy Tough Gal", and she's also taken part in Mudd Rush in Auckland.

Tough Mudder is based on an obstacle course designed by British Special Forces to test all around strength, stamina, mental grit and camaraderie. It is not a race, and the athletes are expected to put teamwork before their finishing time. "There are obstacles you can't do by yourself – you need people to help you," Lorna explains.

"Some people don't like the mud but I love the fact that I'm getting dirty and exhausted and challenging myself. You get wet and muddy, and it's in your nails and everywhere."

Lorna wanted to raise money for CF because she's aware of how much help some families need.

"We're middle class and don't really struggle but we do appreciate the parking tickets for the hospital and the Subway vouchers and there're lots of things they help us with – and it's really appreciated. I'm sure there are families out there who struggle and it really helps them."

While Lorna was upset when her daughter tested positive for CF, she says finding out what she could do to help has been beneficial.

"The Cystic Fibrosis Team at the hospital drip fed me information, they didn't bombard me which I appreciated. I tried my best to stay away from the internet. To me every case is different and I try to be positive," she says.



➔ To visit Lorna's fundraising page go to: <https://give.everydayhero.com/nz/lorna-gets-tough-for-cystic-fibrosis>

Meet our fabulous CF Achievers

Our CF community continues to impress with their remarkable achievements – often in the face of adversity.

JAKE (17)

Achievement in Education



Jake has been awarded a CF Achiever's Award after excelling at both NCEA Level 1 and Level 2 – something few of his fellow pupils managed to achieve.

Jake, who received the Rector's award for being top student in PE in 2014 and 2015, also achieved an Excellence endorsement in both Level 1 (2014) and Level 2 (2015) at Waitaki Boys' High School – an honour he shares with six other students in his year.

Having CF means Jake has to work hard at school, and catch up with any missed lessons due to hospital visits. Jake doesn't complain if he has to spend the school holidays in hospital, and organises extra tutorials and field trips outside of school time to complete exam requirements.

Along with representing his school in the 1st XV rugby, cricket, tennis and badminton, Jake was made Prefect and Head of Lee House this year, and represented the High School at the Russell McVeagh debating competition in Dunedin earlier this year. He has also earned his Bronze Duke of Edinburgh Award – all this on top of nebulising twice a day and taking all his medication and keeping up with his calorie intake.

Jake plans to put his grant towards books or course fees for when he attends University next year where he plans to study sport science.

Emma (17)

Achievement in Sport



Emma represents Waitaki Girls' High School in Hockey and Squash and is Captain of the Hockey team.

Emma has been praised for silently shouldering a debilitating disorder without complaint. There are times that it can impact on her speed on the hockey field but she has pushed herself physically and has learned to "think smarter" to achieve, according to one of her referees.

Aside from Squash and Hockey, Emma has played Badminton and Touch for Waitaki Girls' and competed in the school's Multi-sport team.

An important recent achievement is signing up to compete in the Challenge Wanaka triathlon along with her friend Kate and her twin brother Jake, raising more than \$2500 for Cystic Fibrosis New Zealand.

Emma plans to use her award to buy a Fitbit to monitor her fitness, and possibly a power board, which is a vibration platform which assists with muscle strength and is believed to be helpful for shifting mucous in the lungs.

Christina (15)

Achievement in Sport



Christina entered the CF Achievers' Awards on the advice of her CF specialist in Waikato who was impressed with the goals she achieved over the past year.

Christina came 2nd overall in athletics in Year 11 at Fairfield College in Hamilton, and won 1st place in all her running events.

And she's achieved an important health goal of having her feeding tube removed, which allows her to play more sports.

It was first inserted five years ago when Christina weighed just 26 kilos. In the past two years she has put on 19kgs and now weighs a healthy 55kgs.

"I'd always wanted to get it out because I want to play rugby and I couldn't play it while it was in," Christina explains.

She can now play rugby and Touch over the winter and wants to use her CF Achiever's Award money to buy a pair of hiking boots for her outdoor adventures. She is now urging other teens with CF to embrace sport as well.

"Try you best when you do physical activity because that's what helped me," she says.

Natalie (32)

Achievement in Leadership



Natalie Wineti of Rotorua has been awarded a leadership award for her ability to complete her degree in Applied Social Science and balance her busy home life with a young child and partner, along with the added challenges of CF including two hospital admissions.

During her study Natalie completed and gained an A average in every assessment, and gained a three month placement at Karlton Trust Mental Health and Addiction Services, working alongside Tangata whaiora in their journey to recovery, which led to a permanent position once her study was completed. She is currently working as a Mental Health and Addictions Support Worker and is described as a very conscientious and hard-working employee.

The judging panel praised Natalie for her perseverance and resilience, which they considered an inspiration to others. She is also well respected by her peers for her strong morals and integrity.

Her grant will go towards attending the Olympic Games later this year to watch her cousin compete in the top NZ Sevens women's rugby team.

CF Achievers continued

Kirsty (22)

Achievement in Education



Kirsty Parsons was named a CF Achiever in education for her impressive academic achievements - completing her Bachelor of Science with an A to A- average, and being named in the 2014 and 2015 Massey University merit lists.

She lived away from her home in Hawke's Bay during her tertiary education and focused on living a balanced lifestyle – studying, competing her horse, and maintaining her health. "My strong work ethic and determination has not let any of these take a back seat," she says.

Kirsty also won the Mark Ashford Scholarship due to her outstanding grades. She is using her CF Achiever's grant for post-graduation course fees at Lancaster University in the UK. You can read a full interview with Kirsty in the CF Adult News section.



Read more about Kirsty on page 26



SOPHIE FIGHTS4CF

Good luck to Sophie Lester who is literally fighting the battle against Cystic Fibrosis in the boxing ring.

She has entered the Canterbury Student Association Charity Fight Night on 22 July and has nominated Cystic Fibrosis New Zealand as her official charity because she says it's an excellent cause that often goes unnoticed. "CFNZ does wonderful work for some inspirational New Zealanders facing the hurdles of CF every day."

Entering the boxing ring for the first time is definitely out of Sophie's comfort zone, but she wants to push herself physically and mentally for the cause.

Visit her fundraising page for more info:
<https://givealittle.co.nz/fundraiser/sophfightsforcf>



PHOTO CREDIT: BAY OF PLENTY TIMES

SOUL SISTERS GOOD AS GOLD

It's been a year of media attention for the Good Deed Sisters from Tauranga Nikki Reynolds-Wilson and Kristie Purton who carried out 65 days of good deeds in the lead up to Awareness Week last year.

Their efforts received nationwide coverage when they were featured in the NZ Herald and on TV One's documentary My Perfect Family: Cystic Sisters.

Lately Nikki and Kristie have had even more media exposure, especially since deciding to do their 65 days of good deeds again this year. They've featured in the local newspaper Bay of Plenty Times, the local radio More FM, and the latest appearance will be as contestants on Family Feud on TV3 on 12 July.

Kristie and Nikki's good deeds have been helping to raise awareness of cystic fibrosis and although their efforts are not improving their physical health, Kristie says doing good deeds for others helps to boost their spirits.

Unfortunately their health has declined as anyone who watched their Cystic Sisters documentary will know. Nikki's lung function is particularly low and she is on the list for a lung transplant and Kristie is also being assessed for a transplant.

But this hasn't stopped them from taking the time to brighten other people's days with their random acts of kindness.

Some of their deeds include helping to keep the Waterfront in Auckland clean, giving muffins to hospital security guards and posting lotto scratchy tickets to random addresses. They were also offered pocket money from some big-hearted children so they could buy vouchers and treats for children in hospital.



You can keep up to date with their adventures on:



Facebook: <https://www.facebook.com/cysticsisters/?fref=nf>

Full Steam Ahead for Nebulisers

A recent report in the *Journal of Cystic Fibrosis* has identified the safest way to disinfect a nebuliser – by steam cleaning.

The article in the January issue of the *Journal* reported there was a lot of conflicting information about the best method to clean a nebuliser, but good maintenance was key to avoiding bacterial contamination and helped to improve people's health.

"We have to maintain a high vigilance to minimise our patients' exposure to potential environmental sources of *Pseudomonas aeruginosa* including contaminated nebulisers," the *Journal* reported.

The *Journal* published the results from research in Austria which aimed to determine the best method for steam cleaning nebulisers.

A previous study had found that contaminated devices were frequent (57 percent) but patient education reduced this to 43.5 percent.

The Austrian study found that steam disinfection is a very potent method for killing bacteria. "It reduces bacterial populations more effectively and is less complicated than other methods.

"Chemical disinfection requires preparation of a solution which is a risk, both for contamination and faulty measurement."

The authors found no differences in the performance of the disinfection process regardless of the bacterial strain, the steam disinfection device or the contaminated nebulisers pieces used."

The results suggest that towel drying after steam cleaning is not necessary. "This limits recontamination opportunities and reduces cleaning time for the patients by simplifying the process."

But if "active drying" is necessary, then the use of paper towels seemed like the best option.

The study did have some limitations – the researchers pointed out they did not measure the residual amounts of water in the steam disinfector and on the nebuliser parts after disinfection. "This water could lead to a dilution of the medicine subsequently applied with the nebuliser."

They add that some materials are not heat-resistant enough for steam cleaning.

The *Journal* reported that recent innovation in dry power inhalers such as the Tobi PodHaler (not yet available in NZ), negates the need to use nebulise antibiotics and use disposable devices but so far there is little data relating to the contamination rates of these inhalers.

The authors' recommendations for the best way to steam clean nebulisers:

AFTER EVERY USE:

1. Wash the assembled nebuliser with water, with or without dish-washing detergent.
2. Steam disinfect the assembled nebuliser using tap water.
3. Open the steam disinfector after disinfection only for a short time if it is desired to let some steam out; otherwise, leave the lid closed until the nebuliser is reused (a maximum of 24 hours).
4. Wash hands and dry them with a clean paper towel (a) (e.g. the inner side of a leaf of kitchen roll) and place another clean paper towel (b) next to the steam disinfector.
5. Open steam disinfector and assemble the parts if dismantled.
6. If the parts are too wet, shake off the water, or tap it off on the clean paper towel.
7. Place the nebuliser only in the steam disinfector or on a clean paper towel.

AT THE END OF THE DAY: Dismantle the nebuliser parts, wash them with or without dish-washing detergent and steam disinfect them. Leave them inside the steam disinfector overnight and assemble just before use.

WEEKLY: Clean the area around the steam disinfector and the steam disinfector inside and out with a detergent and let it dry. Clean the steam disinfector outside with a disposable, singly packed, alcohol-based disinfecting wipe.

If more water than usual remains in the disinfector after the process, replace the steam disinfector with a new one.



CF Kidney Study at Starship

Research to identify early kidney damage in young CF children is about to get underway at Starship Children's Hospital. The Shares in Life Foundation, which is the research funding arm of Cystic Fibrosis New Zealand, has approved a grant of \$10,000 towards Dr Mirjana Jaksic's study to measure urine protein to check for early kidney damage in children with cystic fibrosis.

DR JAKSIC HAS PRODUCED THIS REPORT FOR CF NEWS ABOUT WHAT THE STUDY INVOLVES:

"The one-year study, expected to start in July this year, aims to collect urine samples from children during their annual reviews.

The study titled, 'Measuring Urine Protein to Indicate Early Kidney Damage in Children with Cystic Fibrosis', will try to determine the children who could be at risk of kidney damage, which could lead to an adjustment of medicine doses to help reduce the possibility of any damage in future.

The main clinical feature in Cystic Fibrosis is chronic lung disease. Severe chest infections in CF are mostly caused by very resistant bacteria, especially *Pseudomonas aeruginosa*. The antibiotic of choice for those infections has been for years – Tobramycin, given intravenously or nebulised.

For keeping infection under control, many patients have numerous courses of antibiotics. With increase use, there is an increased risk of side effects. The main side effect of Tobramycin is nephrotoxicity (kidney damage) and/or ototoxicity (hearing problems).

We are looking for a simple and sensitive test for early diagnosis of kidney damage. Knowing early kidney damage is occurring will allow us to modify the medications and/or the dose that we use. This may well improve kidney function of children and adults with Cystic Fibrosis.

The other investigators involved in the study are: CF Paediatrician - Starship Associate Professor Cass Byrnes, Ms Jan Tate – Starship CF Nurse Specialist, Dr John Lewis – Biochemist at Canterbury Lab, Christchurch, and Dr William Wong - Paediatric Nephrologist at Starship Hospital.

The samples of about 1 mil of urine will be collected in clinic, sent to ADHB laboratory to be stored and then to the Canterbury laboratory for analysis by Dr John Lewis. He will be testing the samples for a kidney protein called 'retinol-binding protein' (RBP), which gets released in urine in cases of early damage to kidney cells. The test is more sensitive than albumin creatinine ratio, which is what we check for currently, and is also easy to do in children.

The study has received approval from the Auckland District Health Board and Ethics Committee, and the samples will be labelled with an identification number only.

Families will be asked for their permission to collect urine samples from their child for the study during their annual review at Starship Hospital."

By Dr Mirjana Jaksic

PGD in NZ

CFNZ has recently noticed an increase in inquiries about PGD (Preimplantation Genetic Diagnosis) to assist with having a baby not affected by CF. This article has been written by Cindy Zaitsoff a Senior Genetic Counsellor at Genetic Health Service NZ.

When both individuals in a couple are carriers of cystic fibrosis (CF), there is a 1 in 4 chance that any pregnancy they conceive together could be affected with CF. We meet these couples in the Genetics Service to discuss all the various options available to them when it comes to having children. More and more of these couples are interested in the option of preimplantation genetic diagnosis.

The aim of preimplantation genetic diagnosis (PGD) is to help a couple conceive a pregnancy that would not be affected with CF. To do this, IVF technology is used to create embryos for a couple. This involves the female taking medications to stimulate her ovaries to produce a large number of eggs. These eggs are then fertilised. Three to five days later, either a single cell or a number of cells are removed from each embryo and tested for their specific gene changes in the CFTR gene. Only embryos that are unaffected are chosen for transfer into the female partner's womb. These embryos may or may not be carriers of CF. Only one embryo is transferred at a time and any other unaffected embryos are frozen for later use.

Some couples who have IVF treatment have great success with few, if any, hurdles. However, some couples face numerous challenges and may not be successful after many attempts. The same is true for PGD. At the start of a PGD cycle, there is about a 25% chance that the couple will have a baby. The further they get through the cycle, the greater the chance for success. If a healthy embryo is transferred, the chance of having a baby increases to about 35-45%.

There are a number of steps for a couple to complete before they can start a cycle of PGD. The first step is to meet with a genetic counsellor to discuss the genetics, genetic testing, PGD process and whether or not this is the best option for the couple. It is essential that both individuals in the couple have had genetic testing and that we know the type of gene they each carry. The couple are then referred to the fertility clinic.

There is public funding for a limited number of cycles of PGD each year in NZ. The demand for PGD, for various genetic disorders, exceeds the available funding and therefore, there is a substantial waitlist in most regions. There are some criteria that a couple need to meet to be eligible for funding: the female partner must be less than 40 years when referred, must be a non-smoker and have a BMI of under 32. Each eligible couple receives funding for two cycles, unless they have a baby born following the first cycle. If a couple wishes to access PGD quicker, they have the option of paying privately. The cost of a cycle varies but is approximately \$16,500.

Whilst on the waiting list, the couple will have general fertility work-up and feasibility studies done. DNA (taken from a blood sample) from the couple is sent to the laboratory that will do the PGD analysis. They need to go through a specialised test development for the couple to ensure that their laboratory technique will work on single cells. The laboratory usually requests DNA from other family members, such as parents. This allows them to ensure their test is robust – like adding in another check. However, we know that getting DNA from family members is not always possible and this would not prevent a couple from being able to have PGD.

The feasibility studies will also tell us the accuracy of PGD for that couple. Usually we say that PGD is 95-98% accurate for each embryo, and this is clarified for each embryo at the time of testing. This means that there is a 2-5% chance that an embryo transferred could actually be affected with CF. There is the option of having a CVS or amniocentesis in pregnancy to confirm the diagnosis in the pregnancy.

PGD isn't for everyone and certainly is not the easiest way to achieve a pregnancy. However, many couples feel PGD is the best option for them for various different reasons. If you are interested in exploring whether or not PGD is a good option for you, please ask your GP to refer you and your partner to Genetic Health Services NZ.

Cindy Zaitsoff
Senior Genetic Counsellor

FIG. 1
THREE DAY
OLD EMBRYO
(APPROX. 8
CELLS)



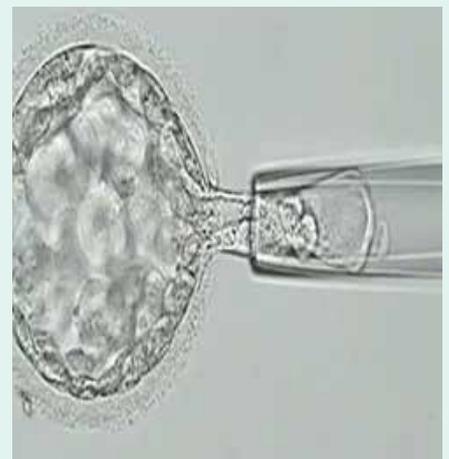
FIG.2
BIOPSY OF
A THREE DAY
OLD EMBRYO



FIG. 3
FIVE DAY
OLD EMBRYO
(BLASTOCYST)



FIG.4
BIOPSY OF A
BLASTOCYST



CONTACT GENETIC HEALTH SERVICES NZ

GENETIC HEALTH SERVICE – NORTHERN HUB

Toll Free: 0800 476 123

GENETIC HEALTH SERVICE - CENTRAL HUB

Toll free: 0508 364 436

GENETIC HEALTH SERVICE – SOUTH ISLAND HUB

Toll free: 0508 364 436



Introducing... Jude Kelly



Cystic Fibrosis New Zealand has a brand new fieldworker, Jude Kelly, who is our Central North Island Fieldworker. It's a new position which aims to improve services in Wellington, Central Districts, Taranaki, Hawke's Bay and Bay of Plenty, with the hope of freeing up the Northern and Southern fieldworkers so they have more time for members in their regions.

LET'S MEET JUDE WHO IS BASED IN WELLINGTON:

What drew you to CFNZ?

I had been working in hospitals for quite a number of years, most recently in Christchurch, and recently took some months off to return to Wellington and renovate my cottage. During this time I realised it was time for a complete change, something different that I could really get stuck into, specialise in and hopefully make a difference – meeting people and with a bit of travel etc, so was absolutely delighted when this position came up.

What are the best parts of the job?

Being on the road and meeting the people.

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

- For Wellington PEADs clinic to get a CF Nurse specialist.
- More medications to be made available in NZ for our CF community.
- More organ donors in New Zealand.

Favourite film?

That's hard, love so many art movies – possibly Ben Sombogaart's Twin Sisters, or Jean de Florette, Manon des Sources. Most probably Ken Russell's 1993 Lady Chatterley.

Hobbies?

The Film Festival (have been known to see five-a-day for a week), travelling, listening to music, watching rugby, playing crib – especially on train trips, picking roses. And eating and drinking good wine.

Best piece of advice?

"Ask for a dream, imagine your ideal scenario, put together a wish list and don't accept anything that doesn't make you feel excited."

Pet peeve?

Standing in queues...

You're happiest when...

I'm with my loved ones – possibly in the South of France, or most recently with my brand new granddaughter.

✉ Contact Jude: jude@cfnz.org.nz

☎ Ph: 021 192 6234



FUND
RAISING
NEWS

Running every day of the year might not be everyone's idea of fun but Taupo man **Paul Riedel** has found a good cause to motivate him to complete his goal – raising money for Cystic Fibrosis New Zealand.

Paul came up with the idea of Run365 just before the start of 2016 and so far he hasn't missed a day.

"I woke up on Boxing Day and thought, 'I've got to do something'. I thought if I commit to something every day I've got no excuse not to do it," says Paul who is aiming to raise \$2500 for CFNZ via his Everyday Hero fundraising page.

So far Paul's been running a minimum of 5kms a day – usually around Lake Taupo, but he has also entered various events such as the Piha to Muriwai Hilary 34 km run in Auckland, and is averaging 50kms a week – the equivalent of running from Auckland to Pukekohe.

Sometimes Paul (46) is joined by his wife or a friend but is generally happy to run on his own.

Paul works in the building industry and prefers to run first thing in the morning.

"If I do it in the morning, it's done and out of the way, and then I can relax," says Paul, who has a close family member with CF, which is one of the reasons he wants to raise money for CFNZ.

Paul registered his Facebook Page "Run365" on 27 December 2015 after coming up with the idea but says he wasn't alone because on 1 January 2016 Facebook founder Mark Zuckerberg registered his own Run Everyday Facebook Page.

"He got 100,000 members straight away – I got 40," Paul laughs.

If Paul's having an off-day he won't push himself to complete a 5km run, and ran 2kms in a pool when he experienced back pain.

"If I feel sick I try and drop it down to 2kms. But if I was really sick then I know I can't run. And if I injured myself – say break a leg or something – that will be the end of it I guess."

Once running around the coast, Paul got caught by the tide and had to wade in up to his waist to get back to the track.

"Running over summer I ran in so many beautiful places. I carry a little camera with me to capture some of the great sights.

"I am getting fitter but I am also extremely tired," he admits.

"Some people ask me, 'Why don't you have a day off?' But people with CF don't get a day off."

Visit Paul's fundraising page:

➔ <https://give.everydayhero.com/nz/run365/posts/573173>

Happily Ever After in Hamilton



CF Waikato are thrilled to be hosting a production of the Broadway musical **Beauty and the Beast** which is being performed in Hamilton in August.

The benefit night on 5 August at Riverlea Theatre in Hillcrest will see all proceeds used to support the children and adults with CF in hospital.

Tickets are only \$25 and can be purchased by emailing Robyn at grmcbride@hnpl.net or texting **027 374 4044**.

There's also a raffle, a special supper available for a gold coin donation – and of course the chance to see a handsome prince.

Gangster's Paradise in Hawke's Bay

There are three important fundraisers for CF Hawke's Bay on the go – there's the popular Casino Night, the Napier City Pak'nSave Half Marathon and a cool real estate offer of \$500 to CF for every house sold.

This year's **Casino Night** looks like heaps of fun. There's a gangster theme so look out for Bugsy Malone and his gang at the Speakeasy at the Havelock North Function Centre on 3 September.

Tickets are \$100 and can be bought from EventFinda.co.nz. (Search for Cystic Fibrosis).

The Art Deco bus is being put on for those living in Taradale, Marewa and Napier so gangsters can enjoy their "illegal"



Casino Night

drinking and gambling within the bounds of the law.

The Branch was thrilled to be named

as the official charity for the **Napier City Pak'nSave Half Marathon** for a second year running. This will be held on Sunday 16 October and will include 5 & 10km courses plus a relay.

CF Hawke's Bay have also had a cool offer from **Tremains** real estate agent Sherry O'Sullivan. She will donate \$500 to cystic fibrosis from every house sold that's listed with her. Ph: 06 845 9055 or mobile: 027 277 4336. Email: sherry.osullivan@tremains.co.nz



Jonathan Coleman



Steve Tew

Money grows on trees for CF Wellington

The **Wellington Christmas Tree Festival** (XTF) attracted some big name speakers and some welcome donations for CF Wellington.

Health Minister Jonathan Coleman was there and also New Zealand Rugby Union CEO Steve Tew. Mayor Celia Wade is photographed with the winning tree designed by Kiwibank.

The XTF made a record \$35,000 profit, and the festival was also particularly helpful for awareness of CF. Decorating Wellington Airport with a range of trees designed by local businesses meant it was a highly visible campaign. The great news is Wellington Airport has confirmed it will host it again this year, so Welly Branch members will be rocking around the Christmas Trees again.



Wellington Christmas Tree Festival



If you are thinking about moving, let's work together to help both YOU and Cystic Fibrosis (Hawke's Bay branch) achieve a great result.

For every property that is listed and sold with us, we will give \$500 back towards Cystic Fibrosis (Hawke's Bay branch) for them to use to benefit your children.

Give me a call today, I would love to hear from you.



Sherry O'Sullivan

Direct: 06 845 9055 Mobile: 027 277 4336
sherry.osullivan@tremains.co.nz



Tremains Real Estate (2016) Ltd Licensed Real Estate Agents WkA 2016

Fundraising **Movie Night**

Auckland Branch's annual fundraising movie night took place in May this year at the Capitol Cinema in Mount Eden. About 120 members, family, friends and clinical staff gathered for a glass of wine and to watch the quirky story of Florence Foster Jenkins. A great time was had and around \$2000 raised for the branch. Thanks to those who generously supported this event – Barkers of Geraldine, EasiYo, Villa Maria Wines and Andrea McKay.



Jan Tate – CF Nurse HERO

We are very excited to hear that Starship Hospital CF Nurse Specialist Jan Tate has been nominated for the Ansell HERO Nurse Service Award. This award celebrates nurses who selflessly dedicate their lives to improving the quality of patient care.



Jan has touched so many lives in her 24 years as CF Nurse Specialist and this is a great way for us to show how much she is appreciated.

Voting for the nominees runs until 22 July. People can vote up to three times a day, every day on Facebook, the website and Twitter. When

voting began Jan had surged ahead and received many compliments for her patient care on Facebook. The top three nurses with the highest number of votes will receive a donation of \$1 per vote made to their chosen charity. For more info and to vote go to: <http://www.ansellhero.com.au/en/About-HERO.aspx>

Please share with your family and friends and encourage them to vote too.

Good in the Hood



Our busy committee began the year applying to be part of Good in the Hood. Auckland Branch managed to secure five Z stations across Auckland. For the month of May, Rachel, Steph, Amanda, Robyn and Rebecca

spent many an hour at their respective Z stations, promoting CF in the hope that we would gather as many tokens as possible. This year Auckland Branch will receive over \$5000, which is a great result. A big thank you to those from CF Auckland for all the time and effort they put in, to the staff at the Z stations and to Z Good in the Hood for involving us in this fantastic community initiative.

Filming with Z

In April, we were visited by a film crew who were keen to put together a 30 second video about CF Auckland Branch and Z Good in the Hood. Our star for the day was Brody who made it through the traffic to demonstrate his daily treatments. Brody was a natural in front of the camera and kept us all entertained with his chit chat and boundless energy. After a couple of hours of filming, and many retakes, the crew finally managed to get enough to put together the video. It was a great experience for us to see how much work goes into just a short clip.



Auckland Marathon

Auckland Branch wants to recruit as many runners as possible to join their team in the Auckland Marathon, which will be happening on Sunday 30 October 2016. This year runners have a variety of events to choose from, including the half marathon and the 12 K traverse – both allowing runners to jog over the beautiful harbour bridge. Runners will be able to join us in the CF tent after the race and will be treated to massages (by a physio) and delicious hot fresh bacon butties. If you or someone you know is keen to take part go to www.aucklandmarathon.co.nz to register and then choose CF as the selected charity, we will then send you information about how to join the CF fundraising team.



Awareness Week and voluntary recruitment

Auckland Branch is hoping to attract as many volunteers as possible for Awareness Week. In April, Committee member Sarah and Auckland Branch Coordinator Kath took part in the Auckland University Volunteer Expo with a number of other organisations. This was a great opportunity to talk to the students about CF and we had a good response from people who are keen to lend a hand.

GBB...baking

For the last couple of months, every Thursday morning, the CF Auckland Branch office has been delivered delicious home cooked goodies from Good Bitches Baking (GBB). The baking is delivered with the hospital packs to inpatient PWCF. Good Bitches Baking is a network of people who want to show kindness to those in their communities having a tough time by treating them to home baked treats. We have had a fabulous array of brownies, cream cakes, biscuits, slices and choc-chip mint cookies baked by Good Bitch Annalise Davies pictured here. The feedback has been overwhelmingly positive. Thank you to all the bakers and Rebecca at GBB for their support of CF Auckland.

TOBERLONE CHEESECAKE (RECIPE COURTESY OF CF IRELAND)

INGREDIENTS

Top
200g Philadelphia cream cheese
100g Icing sugar
500ml Cream
6-8 Small Toblerone bars (depending on how much you want)

BASE

175g Digestives
75g Butter

Nutritional Content (Per slice)

Energy: 550 - 631kcal
Protein: 8.5 - 10g
Carbohydrate: 40.5 - 50.6g
Fat: 33.6 - 42g

METHOD

1. Preheat the oven to 180c/gas 4. Butter the sides and base of a 24cm baking tin.
2. Blend the biscuits in a food processor until it resembles rough breadcrumbs, or place them in a plastic bag and bash with a rolling pin.
3. Mix the crushed biscuits with the melted butter and press down into the base of the tin. Leave to chill in the fridge.
4. Chop up the Toblerone into small chunks. You can use a blender but best not to make them too small.
5. Blend the Philadelphia and icing sugar together to form a paste.
6. Add in the cream – about 50 - 100mls at a time and keep beating.
7. Fold in the Toblerone when the mixture resembles thick whipped cream.
8. Pour onto base and leave overnight if possible.

RECIPE
ROUND-UP



PAULA'S TICKET TO RIDE FOR CF



There's not much Timaru mum Paula Thompson wouldn't do for the CF community in Canterbury – including cycling the equivalent of Christchurch to Dunedin in a bid to win a share of the substantial amount raised in the Central South Island Charity Bike Ride.

Paula led the charge to ensure that CF Canterbury was named an official charity in the Central South Island Charity Bike Ride, which raised a huge total of \$148,000 for charities in the region.

It's the third time that Paula has cycled for CF in the event, and her reasons for wanting to raise money for cystic fibrosis really hit home after finishing the race, when her son, who has CF, was hospitalised for two weeks the following day.

Paula has two children Ambar (24) and Logan (16) and both were there to cheer their mother on, with Logan's best mate Chris also riding in the fastest team – The Mice – for CF.

Paula's brother-in-law headed their more moderate-paced team – The Bears – and Paula also roped in four members from her Seido Karate club to ride for CF in another. Their efforts have more than paid off for the local branch which has been donated \$11,100 as a result.

"The Canterbury Branch are fantastic since the day that Logan was diagnosed. They've been awesome," Paula says.

Some of the larger charities such as Hospice and Alzheimer's received a larger share of the funds raised in the Bike Ride.

Last year Paula also entered. Although CF wasn't named as an official charity then, she hoped her participation might help CF Canterbury get picked again this year.

"We usually apply every second year," Paula explains. "It's popular. Everyone has the opportunity to apply for it and it is just luck whether you get accepted."

It's compulsory for riders to raise at least \$500, and to do three training rides starting at 40 to 60km, and going up to 80 to 100km, to help riders get in shape.

"It's the length of time that you're on the bike – it's not so much the riding," Paula adds.

The cycling circuit runs from Timaru to Kurow the first day, then to Tekapo on the second day and back to Timaru on the third, with volunteers also needed to drive support vehicles.

One of the positive outcomes from Paula's mission has been meeting another mum who had twins with CF who sadly passed away. Linda Callaghan has been an inspiration to Paula, she also rode in the Bike Ride and helped speak on behalf of CF. (See Linda's story).

Along with the Bike Ride, Paula has helped with Awareness Week collections, and many successful fundraisers including an annual Swim-a-thon.

"When it's in your own home of course you're driven," says Paula. "Nothing drives me more than my children. You would do anything for them."

"When you think about what kids with CF go through every day. I only had three days of hard work riding a bike. It's a bit easier to catch your breath then going up a hill."



"WE HAD THE BEST TEAM EVER AND MADE SOME GREAT FRIENDS."



FUND
RAISING
NEWS

CHARITY BIKE RIDE



There's a good reason why Timaru mum Linda Callaghan decided to get on a bike for the first time since high school to ride for CF.

Linda works for the YMCA and initially agreed to help with food during the Central South Island Charity Bike Ride, but when she realised that CF Canterbury was also one of the official charities she had a strong feeling that she should be riding and raising money for them as well.

For years Linda had a very close association with Cystic Fibrosis New Zealand. Her twin girls, Emma and Charlotte, were born with CF in 1991 and received lots of ongoing support from the organisation until her daughters tragically passed away. And she believes it was their spirits that helped spur her on to get on a bike for the first time

since high school – for their sake and the sake of other families still struggling with the condition.

“Those kids pushed me all the way to the finish line. I never would have done it without their help,” says Linda.

What Linda didn't expect was to make a great new friend in Paula Thompson, the mother who is the driving force behind the CF team in the Charity Bike Ride.

“Paula is just fantastic. It was really cool to meet her. I must admit I was a wee bit apprehensive because I was a mum who had lost children as opposed to being a mum who still has a CF child. I remember Paula looked at me and said, ‘you do realise that I've got a million questions for you.’”

“We just clicked and I got to meet her son Logan – poor boy. I just got off my bike and gave him a huge hug and he's never met me in his life,” she laughs.

What she did expect is that the 369km ride would be a massive physical challenge – and it was.

“I didn't even have a bike so I had to buy one. After my first kilometre I thought I was like Lance Armstrong. After that it got worse and worse. I had to do 10kms and then 20kms. I had a few moments when I thought, ‘I really can't do this.’ But I thought about the girls and that this was nothing compared to what they went through.

“It was damn tough but it was probably the best thing I've ever done. For me I think I got a lot of closure. It's been really good because I was out of that CF loop for a long time. And now it's good to be back in it.”

Linda herself raised \$2500 and was talked into giving a speech about cystic fibrosis at the dinner at the end of the Bike Ride, which helped all the riders understand the nature of the condition and the importance of supporting families who are affected.

Linda and Paula plan to keep in touch, and Linda's even prepared to ride again in honour of Emma who passed away in 2006, and Charlotte who died in 2009, and those who are living with CF.

“I can now choose whether to throw my bike in the shed, my battle is over. But for the lives of others who have lifelong battles, they have no choice but to continue riding. Their journey continues every day.

At the dinner, Paula thanked Cystic Fibrosis New Zealand for all the support she received over the years. “Without these people and everything they provide to the patients and their families, life would not be the same and thank you to all the sponsors who have supported this cause and of course the other charities also. It does make a difference to the lives of those who need the continuous help and support.”



Living their Dreams

We meet three inspirational young people who are following their dreams across the ocean. Georgia got valuable work experience overseas after winning a scholarship, Sam has been accepted as a counsellor and to lead mountain bike courses in Camp America, and CFNZ's 20th Mark Ashford Scholar Kirsty Parsons who is now studying for her Master's degree in Data Analysis at Lancaster University.

GEORGIA DRUMM

Georgia Drumm (20) of Auckland travelled to Wales this year after winning a scholarship to undertake work experience for her Early Childhood Education degree.

What did you do in Wales?

I won the Aitken Early Childhood Education (ECE) Travel Award Scholarship to gain experience overseas working in an early childhood centre. It didn't count towards my degree but it was so worthwhile.

Where were you based?

I stayed in a gorgeous little village called Caerleon with Catherine, the

owner of the Owl and Pussycat Nursery, which launched the scholarship programme for New Zealanders to gain experience working in an early childcare setting overseas because New Zealand didn't have any scholarships for that purpose.



Catherine and Georgia

I was there for three weeks working with babies and children up to four years.

I also went to Cardiff for a day and London for one weekend. It was an amazing trip. Apart from going to Australia with my family, I've never been overseas before.



What precautions did you take regarding CF while you were there?

In my carry-on luggage I took a full supply of everything I needed. I was going in winter so I made sure that I kept up with my medication and my physio – I did that twice a day every day because it's a great experience and you don't want to get sick. I took the Pari Mobile portable nebuliser which is really good.

What did you do about medical insurance?

New Zealand has a reciprocal health agreement with Australia and the UK. I did get medical insurance just in case.

What new skills did you learn?

Apart from holidays in Australia with my family, this was completely out of my comfort zone. This was travelling half way around the world by myself, so it definitely gave me more confidence.

I also learned a lot about the Welsh early childhood curriculum. How they teach in Wales is completely different to how we teach here. Children in Wales stop early childhood education at four and then there's a smooth transition to



school. I thought it was a lot smoother than here in NZ. It was great to be able to compare the teaching styles as well.

Was your own experience studying for your degree in NZ helpful for them?

It was good to talk to the Welsh teachers who work there and share opinions. In Wales they use checklists for child development and in New Zealand we use a form of documenting called learning stories that provides more detail about the children's progress. They also thought it would be worthwhile providing parents with more details about what children are learning.

What are your long-term plans with your career?

Next year I plan to graduate and then I have to work for two years to be registered. From there I want to go back overseas and learn more about different teaching styles in other parts of the world. I've heard that Italy's childcare centres are amazing, and I'd also like to see what centres are like in Scotland and other countries.

Advice for other young people?

Be prepared for the worst case scenario. Have a back-up supply of medication, and keep up with physio.

Don't let fear stop you from travelling.

SAM STEVENS

Sam Stevens (18) of Auckland is off to Camp America in Pennsylvania where he will be working as a counsellor and leading mountain biking courses.

What will you be doing at Camp America?

I will be a "Camp Counselor", instructing in mountain biking. I'll be leading the kids through their mountain bike courses and keeping the bikes maintained. Other than this, I'll be having a whole lot of fun doing all kinds of activities with the kids, while also serving as a mentor, or big brother if you will.

Where will you be based, and for how long?

The camp I'm going to, called Golden Slipper, is in Pennsylvania. I'll be there for about six weeks as a counsellor. After that, I'm off on my own for 30 days. I might do a cross country trip visiting everywhere I can.

What drew you to the Camp America experience?

I was struggling to find something that I was passionate enough about to want to go and study after high school. I tossed up personal training, and actually applied for South Seas Film and Television School. Unfortunately I didn't make

the cut for that, and decided that going back to school right after finishing school wasn't for me. Mum actually suggested Camp America to me; she reckoned it'd suit me better than Uni, for now anyway. I figured that at this stage in my life I'm just looking for a wee bit of adventure, and Camp America seemed like the perfect opportunity. I want to travel, that's why I'm here, and I'll figure the rest out later.

How did you get in?

First I had to apply with a list of skills that I could bring to a camp and teach kids, along with a whole profile and description of myself. Once that got accepted, I had numerous interviews with people from Camp America who helped me refine my application and get me seen by camp directors. After that, it was a waiting game, hoping that a camp would come and snatch me up for my exceptional skills. Camps would contact me, interview me, and decide whether they wanted me. I was tossed up by three camps before I was accepted at Golden Slipper.



Sam

Did you have to fundraise for the trip?

It was all me baby. I made the hard grind working full time at a Subway, while getting all the hours I could at my second job at the North Shore Events Centre. Oh, and of course my wonderful parents are helping me out – they still love me after all.

What skills do you hope to share with the children at Camp?

Of course I have so many amazing skills that it would take years to teach the kids all of them! Honestly though, I want to teach kids about how to simply enjoy their time, they've got plenty of it, don't take it too seriously. I've made my own journey to this realisation and I know it's sure not easy, but I'm confident that I'm going to make a difference with these kids. That's what I want to teach them.

What are some of the experiences you hope to have while there?

I want to have that full-on cultural experience – you know, that cliché thing everyone says while going overseas? That's me. That's the whole point, I want to live for a while in a whole different place, "doing as the Romans do". Specifically though? Travelling alone - I want to have that total independent feeling, fending for myself, figuratively of course.



What precautions will you be taking regarding CF while you are there?

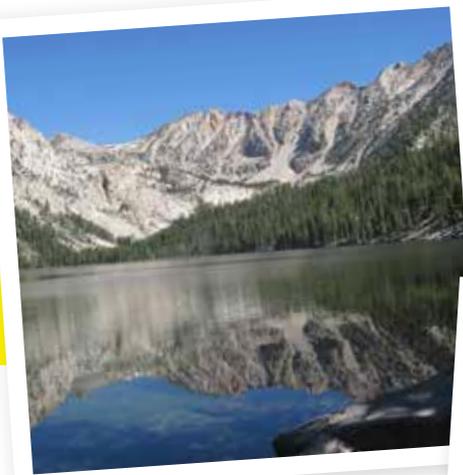
“STAY AWAY FROM SICK CHILDREN” says Mum, “STAY PERFECTLY HYDRATED” says Dad. Of course, I’m taking all the necessary precautions, thanks Mum and Dad. I’ve got scripts for all the meds I’ll need while over there, and I’m covered by medical insurance quite soundly. Luckily, there’s no need for me to bring any antibiotics except a round of Cipro - Just in case. Other than that, Mum’s gone online and found all the nearest medical centres that will help with any CF-related issues that I hopefully won’t encounter.

What happens with medical insurance?

As I previously mentioned, I’m pretty well covered by medical insurance actually supplied through Camp America. It was only an extra \$50 to count in my “chronic or previous illness”, and I’m counting on my current state of good health to keep me from needing to make any claims.

Have you been overseas before? Any plans to visit other countries?

Only on family holidays to Australia and Hawaii – never by myself like this. And yes, I definitely intend to travel to many different countries – let’s say all of them before my time is up.



KIRSTY PARSONS – MARK ASHFORD SCHOLARSHIP AWARD WINNER

Kirsty is the 20th Mark Ashford Scholarship

recipient and was presented with her award at the CFNZ Mark Ashford Conference Dinner just days before jetting over to the UK to study for her Master’s degree in Science at the University of Lancaster. Kirsty answered these questions before changing flights at Singapore.

The Mark Ashford Scholarship is Cystic Fibrosis New Zealand’s premiere study award, presented to the person who gains the highest achievement in tertiary education while also overcoming the challenges of CF.

What did you receive the Mark Ashford Scholarship for?

In 2015 I gained a Bachelor of Science majoring in Biochemistry and Statistics from Massey University, passing with excellence. I have now headed over to England to carry out a MSc in Data Analysis at Lancaster University.

What are some of your proudest achievements in your tertiary education so far?

Definitely gaining a BSc with a mark I am proud of. I think it shows me that I can balance university studies, socialising, sports, and most importantly looking after my health so I’m still able to do all of these things. Picking up statistics and really enjoying it, having never done it at school, was also a surprise. I’m glad I gave it a shot as it ended up being very worthwhile!

How did you feel when you received the Scholarship?

Over the moon! I heard that there were many strong applications this year. So being told the news gave me a great boost of confidence. Also, the background behind the award and learning about Mark’s character and the work he achieved made the award so much more special.

What did you think of the Mark Ashford video screened at the conference dinner?

It was great! There were definitely some tears in the room, but it was a great way to recognise Mark, the award, and all the past recipients in a very meaningful way. Their achievements are incredible.



Summer work adventures
since 1969



well as the cause and effects of everything to do with CF. It's pretty fascinating.

Do you believe the Scholarship will be of assistance in your career and studies for the future?

Yes. Now I will be able to leave university with a lower student loan which in the long run is less restricting when it comes to taking advantage of any opportunities that may come my way. Also the application process itself taught me a lot of skills I'll use later on in my career. I highly recommend anyone interested to apply. You never know what might happen!

What impact has CF had on your education?

During school I had many days off when admitted to hospital. That put more pressure on me to catch up on work. Also factoring in nebulising and physio around school work isn't always easy. I had the mind-set that my CF came first, because if I was sick then trying to do school would have been a waste of time anyway.

What will you use the money for?

The money will go towards funding my MSc for the 2016/2017 year. An invaluable help to student life in the UK.

Why do you want to further your studies in the UK?

I was interested in the area of data science as it is relatively young and growing rapidly. Two universities in NZ have Masters Courses in Data Science, but I felt they weren't quite as strong yet compared to the courses offered in the UK. I also had a "gap year" after school, which gave me the travel bug! So I am looking forward to being able to go on lots of adventures.

You've also been named a CF Achiever and it's impressive to get both awards in the same year. Did you expect to get both?

Not at all. I was hoping to be named as a CF Achiever but after hearing that I was awarded the Mark Ashford Scholarship I had no expectations at all. So it was the icing on the cake and will also help fund my masters a great deal.

Some of your papers involved genetics. Is that a career path you are interested in? And if so, is it because of CF?

I think having CF makes genetics and biochemistry a lot more meaningful. Science is my strong point but now knowing about genetics I can understand how the medications work as

Do you have any advice or tips for other young members about studying?

There is a lot of help available, through Cystic Fibrosis New Zealand, your local branch, schools and universities. Each person finds the best way for themselves, which can sometimes take some trial and error. But ultimately have fun and make sure you are enjoying everything you're doing!

Is there anything else you would like to add about the Award, the impact on your life, or CF in general?

I'd like to thank Mark Ashford's family. I was lucky enough to have a great dinner with them at the conference. They are so passionate about CF and have a great interest in all of the award winners. And also to Pink Batts who are extremely generous in providing this award.

I have been fortunate to have very supportive parents which have made the biggest impact on my great health. So I'd like to thank them too.



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