

WINTER 2015

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Creating Better Tomorrows

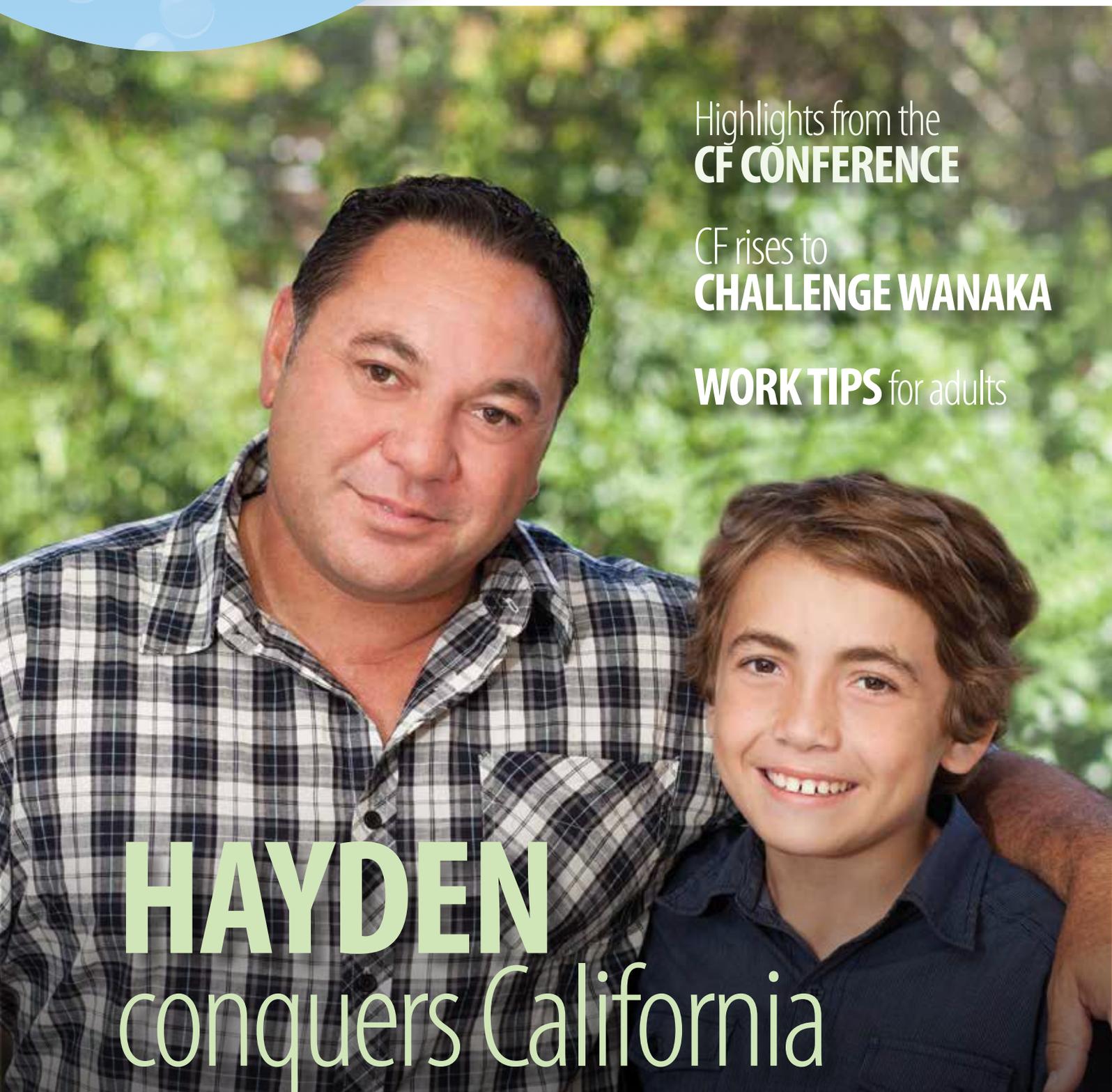
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CF news

Highlights from the
CF CONFERENCE

CF rises to
CHALLENGE WANAKA

WORK TIPS for adults



HAYDEN
conquers California



Update from the Chair

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Lucky for me I have now been on the CFNZ Board for 13 years! Even though that is a long time, for me I still feel I have a contribution to make, it is never boring and best of all – the people are awesome.

We do however face constant challenges. Many not-for-profit organisations in NZ (2000 plus) have been forced to close down over the past two years through lack of financial resources.

CFNZ are also faced with a challenging financial environment. We have a strong network of 12 hard-working branches, a solid financial asset base across all sectors, and yet operational income from year to year can vary dramatically placing real pressure on the services we want to sustain for our members.

Most of you will be aware of the work that Kiwifirst is doing to fundraise on behalf of CFNZ. This work is now bringing in better than expected results and will continue to grow over the next few years. The great thing about this method of fundraising is that it is happening in the wider community and this marketing of our organisation will have positive spin-offs for CFNZ events and CF Awareness Week.

Something I have never had to do in my time on the CFNZ Board is acknowledge the sad loss of

the son of one of our long-standing current Board members. Margaret Nicholls lost her son, Jonathan, earlier this year and we share Margaret and her family's sorrow, and very much appreciate Margaret's ongoing commitment to CFNZ as an active Board member.

The Board has been updating the CFNZ Constitution, we have finalised the Strategic Plan – after consultation with branches and are currently reviewing all CFNZ policies with the CE.

Carmen is now the sole Adult Rep to the Board, and we thank Chloe for her involvement and wish her well with her adventures. Carmen is supported in her role by a small group of AWCf who have made themselves available as a consult/sounding out group.

I would like to take this opportunity to congratulate Belinda Burnett our CE, on her one-year anniversary with CFNZ. It has been a busy whirlwind of a year but I have the feeling that Belinda enjoys a challenge, and may even be quite taken with the community and culture of CFNZ. Thanks Belinda and congratulations on surviving a year of CFNZ.

The Board extends a warm welcome to Hannah, our newest staff member who truly was thrown in at the deep end working at the recent National CFNZ Conference.

The Conference this year was an unprecedented success, with over 100 registrants and the live streaming was just brilliant.

On behalf of the Board I thank all staff and volunteers who made it such a special weekend.

I will finish with the wise words of Michael Carr Gregg (Keynote speaker and founder of Canteen):

“If you can't change something – you can change how you think about it”.

JANE DRUMM, CHAIRPERSON



From left: CFNZ Chief Belinda Burnett, with a volunteer and Administration Manager Julie Clemett. Both Belinda and Julie entered the fun run at the beginning of the event and met many of the amazing athletes who raised money for CF. See report pages 4-6




UPDATE from the CEO

Another new year has arrived and with it many new resolutions and plans.

Here we are almost half way through and CFNZ is as busy as ever working on events for members, such as the recent National Conference, the National Raffle and Awareness Week (17th – 23rd August).

Those of you who did not attend the National Conference would not have had a chance to meet our newest staff member, Hannah Wilson. Hannah is the Grants & Events Coordinator and she is introduced on page 20.

The Board has been very busy creating the Strategic Plan to help guide us through the next five years. It reflects CFNZ's vision of lives unlimited by cystic fibrosis and our values:

- Passionate engagement
- Knowledge is power
- Creating community
- Innovative

The CFNZ strategic plan is a living document and will be regularly reviewed by the Board to gauge how well we are progressing towards our goals.

The National Conference (See report page 18) was a great opportunity for me to meet the members and get feedback on your ideas for our community. Lots of people mentioned what a great atmosphere it was, and they enjoyed the fact we were running concurrent sessions.

There was a suggestion to include a talk on gene therapy in the future and several would like to see the conference divided into ages and stages. One of the feedback comments expressed the desire for something for partners of people with CF – this is an idea that I will be pursuing both locally and nationally with the Board and branches.

Please take the time to read this magazine; there is lots of great information and some very inspiring stories. My contact details are on the back page. Please feel free to contact me at any time.

BELINDA BURNETT, CEO



Shop for CFNZ in June!

CFNZ has been named as charity of the month by one of New Zealand's biggest shopping websites. During the month of June, any orders made through **HealthPost.co.nz** will see \$2 being donated to Cystic Fibrosis New Zealand, so it's a good time to stock up on vitamins and skincare.

The website has a wide range of natural health and beauty products, stocking brands such as *Healtheries*, *Solgar*, *Thompson's*, *Antipodes*, *Trilogy* and *Dr Hauschka*. There are organic food supplements and pet products as well.

BE SURE TO TICK THE CFNZ BOX AT CHECK OUT.

There is free delivery within New Zealand on orders over \$79.

www.HealthPost.co.nz

FREEPHONE: 0800 148 148

HealthPost

Brushing up on the facts

Fact or Fiction: Children with CF need a new toothbrush every week?



Auckland CF Paediatric Nurse Specialist, Jan Tate answers:

"No they don't need to have more frequent toothbrush changes than the average child. I would recommend a new one each season change – seems an easy way to remember. For anyone we need to keep our toothbrushes covered if they are in a bathroom with a toilet – when the toilet flushes the bacteria aerosol into the room – so keep the toothbrushes in a cupboard to dry out between use and away from the toilet bugs!"

That's just the sensible bathroom rules according to Jan Tate – but no they don't need a new toothbrush every week.

A BIG THANKS FOR OUR GREAT COVER PHOTO

A big thank you to Auckland-based photographer Megan Blackwell for volunteering to take the photos of Hayden and Jason for our cover. Megan was really able to capture the essence of their father and son bond. Megan's range of services includes portraits, events and weddings. blackroomphotography.co.nz

CF rises to CHALLENGE WANAKA

It's the second year that Breath4CF has been the official charity for Challenge Wanaka, and the amazing support from athletes competing helped raise more than \$20,000, more than double the total of the previous year. National staff were there manning the Creation Station and handing out drinks to thirsty competitors, and some of the athletes had some incredible stories to tell.

Leanne Ellis' Outstanding Achievement

It would be hard to think of a more deserving recipient of Challenge Wanaka's inaugural Ann Scanlan Memorial Trophy for Outstanding Achievement.

Three years ago, Leanne Ellis was bedridden for a year due to failed spinal surgery. Two years ago she was learning how to walk again, and the fact she managed to cycle the Challenge Wanaka course in under four hours left everyone amazed.

She expected to complete the course in 4 hours 15 minutes but crossed the finish line at 3:33.

"It was a fantastic ride. I was just so proud and I had a little bit of pain but I'm used to pain every day," says Leanne who's courageous story learning how to walk and ride again impressed people at the Challenge Wanaka prize giving in February.



Leanne's back problems stemmed from a car accident in 2000 which led to scoliosis (curvature of the spine) and the need for spinal surgery three years ago. Full Harrington rods needed

to be inserted into her back, but unfortunately four of the screws came loose causing major nerve damage and the loss of feeling in her right leg, flank and foot. A second operation also failed. And although Leanne would never run again she discovered she could cycle.

The 46-year-old, who lives in Dunedin entered Challenge Wanaka with her team, Chit Chat, which included swimmer Theresa Dunn and runner Alena Lynch.

Leanne's teenage nephew Dylan has CF which is why she wanted to help with Breath4CF. Leanne herself has the CF gene but her husband doesn't. They don't have children.

Disappointingly, just days after her Challenge Wanaka high Leanne got more bad news about her back. She would need a third operation to repair her neck which has



Jake at the lake

At just 16 Jake is already a Challenge Wanaka veteran. The teenager with CF has competed twice before. This year Jake cycled the Lake Wanaka Half – and reported that he loved every minute of it:

“For me the Lake Wanaka half was a huge success. My aim was to finish the 90km bike course in 3 hours 30 minutes, and ended up with 3 hours 20 minutes which I was very pleased with. My other team members also put in brilliant efforts, and we finished up in 20th place in the men’s teams and 51st overall out of 268 teams, with a time of 5 hours 23 minutes. I found the training hard as I was trying to fit it in around rugby and squash, but in the end I think that the combination of both worked rather well! The conditions on the day were almost perfect as there was barely any wind and it wasn’t too hot! The hardest part of the ride for me was being out in the saddle for such a long time, but the feeling of crossing the finish line definitely made it all worth it. Also cheers to the CF tent at the event for getting me a nice cold drink and somewhere to rest my aching legs after the ride, and you never know I might be back next year!”

Photo by: www.Marathon-Photos.Com

started to collapse forward over the rods in her back – and that is likely to result in a loss of further upper body movement as well, so she may never cycle again afterwards.

“I haven’t had a good run.

The first op failed because of the screws coming out. The second op failed because they accidentally put the rods in the wrong position and left me tipped forward and that’s caused my neck to tilt.

“The year my back collapsed I did six half marathons and was training for a full. My life is quite different now. I’ve lost my business as a financial adviser and I’ve lost my job.”

Leanne is doing her best to stay positive as she faces the prospect of another long recovery, but she has already learned what can be achieved with quiet determination.

“Who knows? I’m hoping one day I might be able to cycle again. We’re hoping I will be able to walk better than I can now. At the moment I lean forward. But I know there are people worse off. You start to think, ‘why me?’ But you can’t think like that. The Wanaka challenge was the first time I had hope. The cause was something relevant to me and it was just meant to be.”

We love Leif!

When Leif Tippet saw OneRepublic’s music video I Lived he set out to raise \$200 for Cystic Fibrosis NZ. But not only did Leif Tippet make headlines while running for CF, he also ended up raising \$2193, and getting recognised by the rock group itself.

Leif took part in the Central Otago Running Series and Junior Challenge Wanaka while fundraising for CF because the song really struck a chord with the nine-year-old. The music video tells the story of a 15-year-old with CF.

His mother, Megan Tippet, says Leif, who’s also a keen rugby player, never gets tired of watching the OneRepublic I Lived video which includes information about CF.

“He’s at the age when he’s starting to understand things a bit more. He was quite sad about it and we looked up online about cystic fibrosis and ended up going to Cystic Fibrosis New Zealand to donate, and then we started to think about what we could do.

“Leif was going to do all these runs anyway and we thought it would be good to do a bit more than just donate a wee bit of money. We could get our friends to donate with us.”

His efforts also attracted the attention of the local newspaper, the Central



Leif on the red carpet at Challenge Wanaka Junior



With father Kerry at Waiorau Snow Farm.

Otago Mirror, which reported on him three times, and the band OneRepublic who mentioned Leif on their Facebook page.

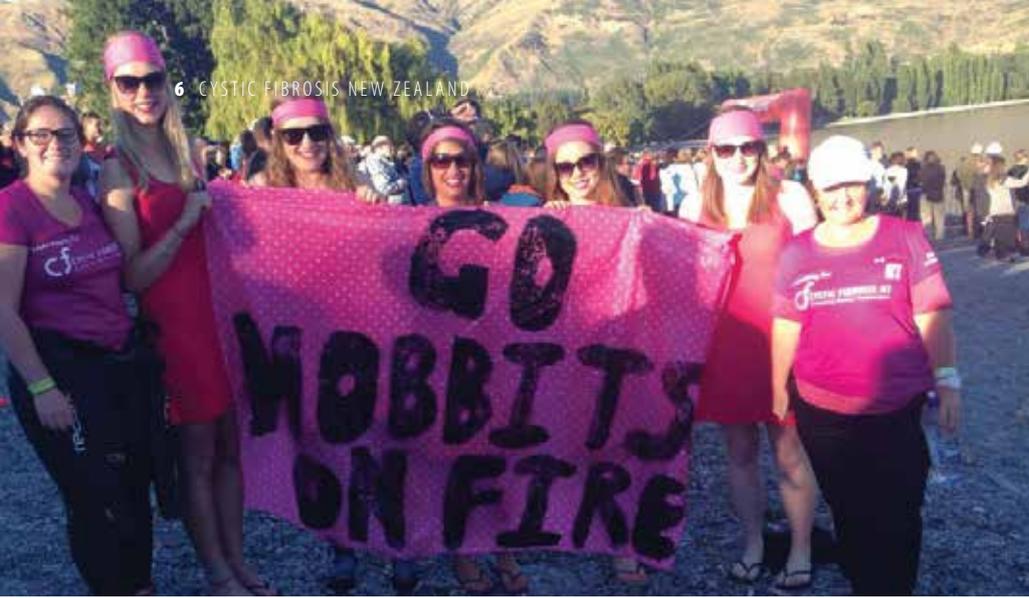
“We came across this very inspiring story by Cystic Fibrosis NZ. 9-year-old Leif Tippet got out there and decided to make

a difference! Way to go Leif!”

Since Leif started fundraising, Megan has discovered her brother’s partner had lost a friend to CF. *“I hadn’t known that and to be honest until this song I had heard about cystic fibrosis but didn’t know the facts. It is an awesome song and even though we’ve seen it a thousand times we still sit down and watch it.”*

OneRepublic are a popular pop rock band in the US. Their third single Counting Stars reached the top five in Australia, Canada, Germany, Ireland, New Zealand, the U.S. and the UK.

Visit Leif’s fundraising page online: www.fundraiseonline.co.nz/LeifTippet/



HALL'S HOBBITS

After spending half her life hoping to lose weight, Deb Hall found that training for Challenge Wanaka was the only weight loss programme she needed – shedding 31kgs and helping to raise more than \$4000 for cystic fibrosis at the same time.

Deb entered her team – Hobbits on Fire – which included her sister Hayley Stevenson who cycled, and her daughter Kate who swam. And found the tough training involved for the event in February saw weight falling off her.

“My weight loss was really just a bonus of the training. It’s funny that after spending half my life worrying about my weight and focusing on food I started to focus on exercise, not obsessing about the scales and the weight started to come off. The key is to be consistent. Not have a good week then fall off the wagon the next.”

Deb (49) had regular sessions with her personal trainer at a local gym and trained three to four days a week – often while listening to OneRepublic’s inspirational song about CF, *I Lived*.

And the Southland farmer also had the perfect spot to go running or “wogging” as she calls it – a cross between walking and jogging.

“At the start I was embarrassed to run in public so went around the farm increasing more and more fence posts each week,” recalls Deb who also hired a treadmill for three months during the cold Southland winter.

One of her hardest sacrifices was not drinking wine.



“I was told four of my glasses of Sav were equivalent to seven slices of white bread! Also I found if I went out, and had one glass of wine I would inhale it and want more so I just said no, much to the surprise of a lot of people.”

“I didn’t stop eating out but wasn’t afraid of asking for things maybe not on the menu or sauce on the side for example – they can only say no.”

Deb also cut a lot of sugar from her diet and replaced bread with rice or oats as she dropped from a size 24 to a size 14.

Raising money for CFNZ’s Breath4CF fund gave Deb and her teammates a lot of incentive not to give up. *“We are very proud of the money we raised, we honestly did not expect to get \$4675! Our original target was \$500. I think it helped that everyone could see that we were prepared to do the*

hard work and it wasn’t easy for us. The fact that we inspired people along the way is very humbling. I’ve never inspired anyone in my life.

“Friends were very generous, then people we didn’t know started to donate and we were gob smacked, our Hobbits on Fire Facebook page was being shared and even students were donating what they could afford. Businesses that deal with Hayley started to donate, a lot of my friends, family and people I didn’t know. Whenever I was having a down day (there were quite a few) I went onto the page and read the comments, they still bring me to tears.”

Neither Deb, Kate or Hayley have a personal connection to CF, but were determined to run for charity so as many people as possible could benefit from them completing Challenge Wanaka.

“We like to think we have empathy for people who struggle daily with debilitating illnesses such as CF. I recovered from a stroke in my 30s, and we lost my mother and father to cancer so feel compassion for people who are struggling with health issues.

“Once we signed up we met so many people who have approached us with their stories of family members and friends with CF.

We also we got tee shirts printed with fundraising for CF on them and quite often I was stopped and handed some money for a donation – this was very humbling especially when you meet people with CF and hear how much they have to cope with.”

Deb is now urging athletes entering Challenge Wanaka next year to help raise money for the Breath4CF fund, which helps people with CF stay well for longer.

Deb and her teammates have also signed up for Challenge Wanaka 2016 as “Hobbits on Fire – the Sequel”. Although she’s lost a total of 31kgs, she’s still looking to lose another 10 kilos – and shave half an hour off her running time.

“I was very, very, slow. But I don’t have 30kgs to lose next time.”

INTRODUCING Health Minister **Jonathan Coleman**



Dr Jonathan Coleman was appointed Health Minister after last year's general election. He entered Parliament as MP for Northcote in 2005 and served as Defence Minister from 2011 to 2014. Dr Coleman responded to some questions from CF News about his background and priorities as Minister.

My background

I attended Auckland Medical School. I did my house surgeon years in Hawkes Bay and Auckland. I obtained a Diploma of Obstetrics and went onto train as a GP, working both here and the UK. While I was in London I became interested in the wider issues impacting on the health system so I undertook an MBA at the London Business School. When I returned to NZ I worked as a consultant for PricewaterhouseCoopers and continued to practise as a GP one day per week. I was elected to Parliament in 2005 and am the MP for Northcote. In 2008 I became a Cabinet Minister. Today, as well as being Minister of Health, I am also Minister for Sport and Recreation and I am particularly keen to see greater linkage between these two portfolios.

My priorities

One of my first priorities as the new Minister of Health was to travel to all 20 DHBs to talk with the Chairs, CEs and clinical leaders. As I travelled around the DHBs one thing that has really struck me is that although the hospital buildings are on the same sites as when I was working as a

doctor, the actual health system – what's going on inside these buildings and what is increasingly happening out in the community, is very different.

I am keen to see more people receiving the care they need in the community and away from hospitals. To support this happening we need to further harness the skills of our workforce so we are better utilising the full range of skills of the wider health team.

CFNZ has noted differences in the funding of equipment and treatment for CF patients among the various DHBs. Is this an issue you would like to see addressed?

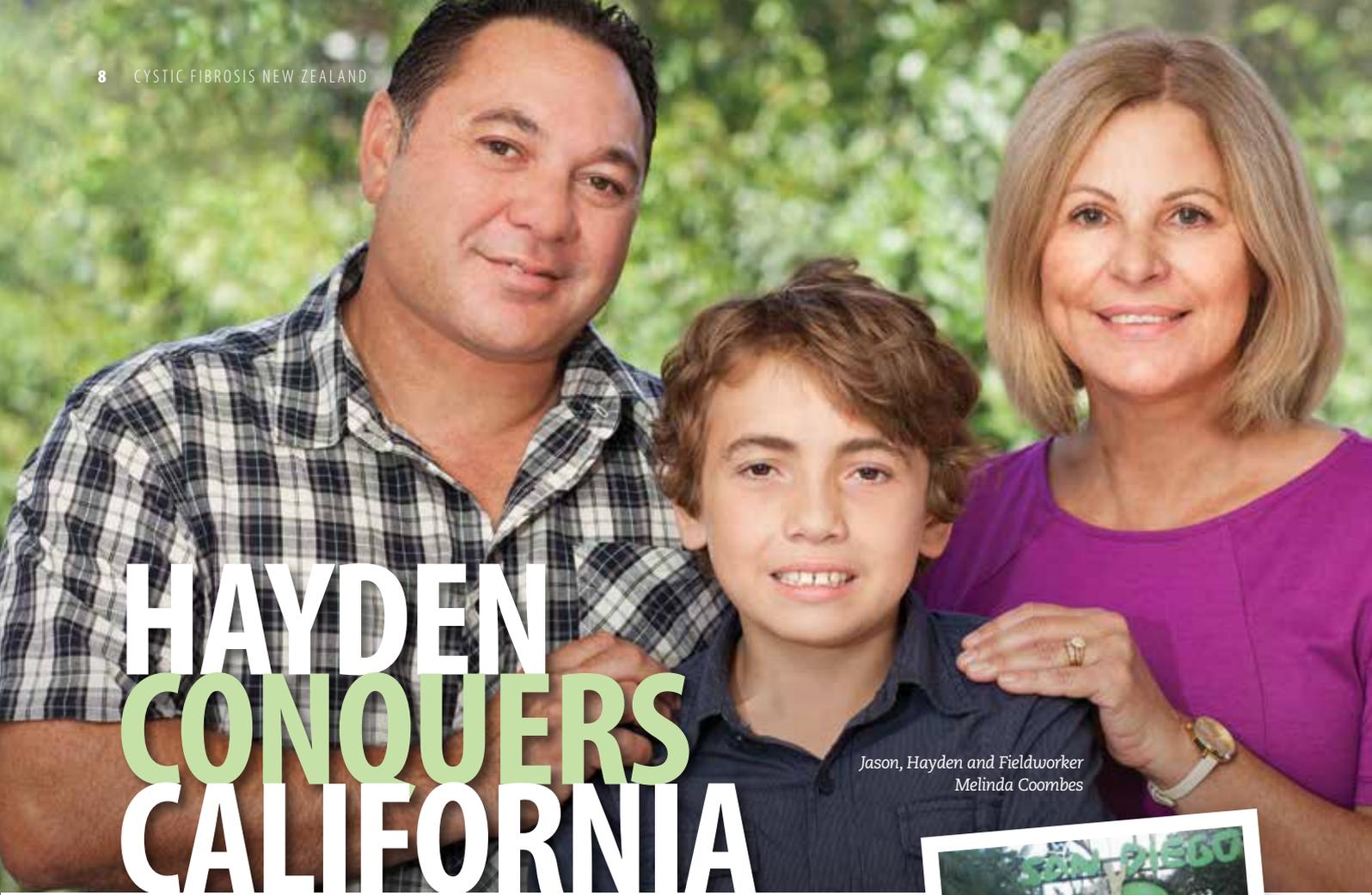
In regards to the equipment available for the treatment of CF across the DHBs, this is assessed by a specialist assessor, which is usually a physio-therapist or occupational therapist from the DHB. The Ministry of Health is not aware of any differences of treatment/assessment by the DHBs.

The Ministry standardise what is supplied by having standard equipment lists, a national equipment prioritisation tool and an accreditation process for assessors.

What is your view about the funding of expensive medications for rare diseases in general? One of the best developments in the treatment of CF has been the new medication, Kalydeco. So far there's been no decision about publically funding the medication in New Zealand, although it has recently received government funding in Australia. Do you see a time when that could happen here?

Pharmac does fund expensive medicines, including some for rare disorders. In the 2012/13 financial year, 86% of Pharmac's expenditure was spent on 20% of patients. Pharmac is currently trialling a new commercial process to encourage competition amongst pharmaceutical suppliers specifically for treatments for rare disorders with public consultation expected to get underway within the next three months.

You have also asked about the medication ivacaftor (Kalydeco), this is an operational activity for Pharmac, the agency responsible for deciding which medicines to fund for eligible people in New Zealand.



HAYDEN CONQUERS CALIFORNIA

Jason, Hayden and Fieldworker
Melinda Coombes

Going on an all-expenses-paid holiday to California was the trip of a lifetime for Kiwi teenager Hayden, but having CF meant it wasn't all plain sailing for him or his family.

Hayden was one of 16 children picked for Koru Care's California Adventure trip, which included tickets to Universal Studios, Disneyland, Knott's Berry Farm, and California Adventure, all under the supervision of a full-time caregiver.

Despite being excited about getting the chance to travel overseas for the first time, Hayden, who lives north of Auckland, admits he initially had a few misgivings about the two week trip.

He had never been away from his family for so long, or on a plane before, so his dad Jason Simmons took him for his first flight to Wellington to help prepare him for the long flight to LA.

"We spent the day in Wellington," says Hayden. "I went to see my Nana and Poppa and flew back. It was quite fun. The flight to LA was even better because we went faster," Hayden says.

Parents aren't allowed to talk to their children while they're away because of concerns conversations can

spark homesickness. Instead, progress reports are posted on the Koru Care Facebook page. So when Hayden's caregiver phoned not long after they arrived in LA, Jason was filled with dread. But it was nothing that couldn't be fixed – Jason's nebuliser wasn't working.

"They contacted me straight away and said don't worry about it, everything was fine. They ended up having to hire one over there because of the differences in voltages in the US," Jason explains.

In the end Hayden had the time of his life and is thankful that CFNZ North Island Fieldworker Melinda Coombes suggested the trip to Hayden and assisted with the Koru Care application, which requires a full medical assessment.

Jason, who was naturally worried about his son being away, also wants to thank Koru Care's Tracey Curran



and Grant Moore who works for Aviation Security Services at Auckland Airport and was Hayden's caregiver during the trip.

"We had the opportunity to meet Grant and the other child Hayden was paired up with prior to them departing so we could ask a few questions and it put my mind at ease. It was hard watching him fly off but I could tell he was in good hands. But it was the longest Hayden's ever been away from me," he says.

The 14-year-old, who plays, cricket, touch rugby and football stayed well during his overseas adventure – the biggest problem was the Californian heat in October and November, and the jetlag.

"The heat just took me out because I wasn't used to it. My caregiver just gave me heaps of water, and it was good being able to swim in the pool."

Back in New Zealand it wasn't long before Hayden was California dreaming again.

"When I came back I felt like going back over. I went back to school sat in my chair and thought about the roller coaster."

Which kids qualify for Koru Care?

Generally it's a child who has a condition, disability or illness that significantly impacts on quality of life.

- Is between the ages of 7 and 14 years.
- Is capable of mixing with other children and joining in activities planned for the trip.
- Has a family that would struggle to afford the experiences similar to those that would be gained on one of their trips.

On average there are about 40 applications a year for generally 26 spots.

If you know of a child who might qualify please contact your CFNZ Fieldworker.



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Craig and Shelley Crestani

Kiwi Karma is an accommodation booking site which is making the most of one of the biggest trends in fundraising – a concept known as passive fundraising.

Passive fundraising uses shopping transactions to feed a percentage of sales to people's charity of choice, and so far Kiwi Karma has 50 charities that visitors to its website can donate to when they book a hotel or motel.

And Craig Crestani, who created the concept, may never have come up with the idea for Kiwi Karma if it wasn't for some lifestyle changes forced on him and his wife, Shelley, during the economic downturn.

Shelley decided to set up her own marketing business after being made redundant, and when Craig quit his job in the travel industry to help her, he came up with the idea of Kiwi Karma at 3am one morning.

"I had gone to pick her up after an appointment with one of her charity clients and they were saying how tough it had been since the Christchurch earthquake, and the "shaking the tin" revenue had dropped off in the last few years.

"I thought if we could latch into the commission model that somebody uses when they book on Expedia and we were to give a portion of that to charity then

that's a really good thing," explains Craig.

Two years later Craig is pleased with the progress but would like to see more people supporting Cystic Fibrosis NZ – the most popular charities are linked to cancer organisations.

"Understandably someone who chooses Cystic Fibrosis is someone who is predisposed to supporting you in the first place."

He wants to remind our members who are booking accommodation to use the Kiwi Karma website because not only it is often cheaper than booking via international websites, the donations will come through to CFNZ.

"If you book through Expedia suddenly 15% commission is off to the USA – that's money that just leaves New Zealand's economy," he says.

Three percent of the total room cost is donated to charity via Kiwi Karma and amounts over \$20 are paid to charities every three months.

Kiwi Karma's biggest strike rate is with corporates booking travel for their employees.

"You talk to a PA who books the team's travel and realises they're not going to be disadvantaged in any way, and she'll be using it the following day," he says.

Meanwhile, Shelley's business is going from strength to strength, Craig wants to see a time when Kiwi Karma could assist with their retirement.

"What could be better than making an income and doing some good along the way?"

www.kiwikarma.co.nz



BIG WIN for Charity Cricket

CFNZ was the big winner at the charity cricket match in Christchurch.

Charity Cricket is a big part of the Association's heritage. It was the 32nd year of the event and this time the Crusaders took on the Christchurch construction workers, led by Coach Todd Blackadder.

CFNZ raised \$22,000 at the event in December, which is slightly up on the previous year.

CEO Belinda Burnett is especially thankful to the Crusaders and Todd Blackadder who couldn't do enough to help CFNZ on the day.

"They were available to the public, never tiring of having their photos taken alongside their young and not so young fans. Todd Blackadder was an absolute star – he took control and managed his team nicely. They arrived with minimal fuss and fanfare and just got on with it. They seemed to really enjoy playing the game and everyone had a great day," she says.

Crusaders XI Captain Willi Heinz said the event is one that the players look forward to each year: *"There are quite a few of us in the team who have played a bit of cricket, so it's fun to replace the rugby ball with a cricket bat for a day. We're a competitive bunch though so we take it pretty seriously, especially when you're at the crease facing the head coach!"*

In previous years Todd had captained the All Stars XI but hadn't won in a long time. He had been hoping that captaining a team of "real workers" would finally mean a win, but the Crusaders beat Toddy's Tradies XI by a slim margin in the 20/20 game: Crusaders 138 /Toddy's Tradies 122.



A huge thanks to the volunteers and National Office staff who worked extra hard to make sure the day was lots of fun and with some big ticket items up for auction. They want to acknowledge the following sponsors:

- Placemakers
- ASB Bank
- Christchurch Casino
- Russell McVeagh
- Mainland Foundation
- Pitstop
- Winstone Glass
- Cophorne Hotel Commodore
- Choice Hotels
- Harcourts
- No: 4 Bar and Restaurant
- Sharp Corporation
- Andrew and Wendy Oh
- Tariq Kundan, Ray White Next Step Realty
- Gary Cockram Hyundai
- Duncan Cotterill
- March Construction
- Arbor Master Ltd
- NZI Health and Fitness
- PGG Wrightson Turf
- The Nanny Company
- Christchurch Northwest Kiwanis
- Canterbury Rugby Football Union
- The Rock FM
- Christchurch Boys High School
- Labour Party – Christchurch MPs
- CocaCola Amatil
- Eftpos NZ
- Working Style
- Bealey Dental
- Sugarhorse
- Rangoon Ruby
- Dilmah Tea
- The Fitting Room
- DB Breweries
- Armourguard

CHARITY OF CHOICE

update from Choice Hotels

In June 2013, Choice Hotels, Australasia's largest hotel franchisor partnered with Cystic Fibrosis New Zealand. Since then, Choice Hotels has helped raised more than \$16,500 to make a difference to those living with cystic fibrosis.

The money raised has been a direct result of donation boxes housed at each Choice Hotel in New Zealand, sponsoring of The Crusaders Rugby team annual Charity Cricket match and a fundraising week that involved all New Zealand properties donating \$2 from every guest stay. Choice Hotels has also helped to substantially lower travel cost for the Association by providing free room nights around New Zealand.

Olivier Lacoua, General Manager of Comfort and Quality Hotels Wellington and a big supporter of the cause said, "We are particularly passionate about working with Cystic Fibrosis New Zealand to improve awareness of the most common life-threatening genetic disorder affecting New Zealand children. The hotel supports CF by placing collection envelopes in the hotel rooms, volunteering on collection days and creating special events at the hotel. We get a lot of positive feedback from staff – their involvement in the local community enables them to build a stronger relationship with their colleagues away from the office and this ultimately improves our workplace culture. Our staff also carry with them a sense of pride in themselves and their workplace for giving back to the community."

Choice Hotels Australasia has more than 270 hotels across New Zealand, Australia and Singapore, with over 11,000 rooms.

Choice Hotels looks forward to working with Cystic Fibrosis New Zealand in 2015 and beyond.

www.choicehotels.co.nz



CHOICE HOTELS
AUSTRALASIA



Chicken pie with herb crumble

Recipe courtesy of Michele Wilson (who has a daughter with CF) and Tracey Jones of Wellington who run the personal catering business, Wilson Jones.

Serves 8 to 10 easily, can be halved, but a big favourite in my family with extras eaten for lunch.

Ingredients:

- 2 whole chickens
- 2 onions
- 4 cloves garlic crushed
- 50g butter
- 1 large tetra pack chicken stock**
- 2 tablespoons flour
- 250g bacon
- 4-6 thinly sliced zucchini
- 1 red pepper
- 6 slices day-old bread
- Extra 50g butter
- Large handful of parsley

Directions:

1. Bring large pot of water to simmer add an (onion, whole pepper corns, a bay leaf and salt and a carrot, to create a nice poaching liquid, these vegies not included in ingredients above). Poach chickens in liquid about 40 minutes until completely cooked. Remove and cool.
**Add some of chicken bones from shredded chicken below to liquid and bring to boil reducing to about half. This can then be used instead of the Campbell's stock if desired.
2. When chicken is cool enough to handle, shred meat off bones. Sauté finely sliced onions and garlic and chopped bacon together, set aside finely sliced red pepper. Slice and sauté zucchini. Set aside.
3. Melt 50g butter in pot; add 2 tablespoons of flour and cook stirring constantly for 2 minutes. Add small amount of warm stock, stirring well. Continue to add stock and stir until sauce of a good consistency is made. Should have about 2 cups of sauce.
4. Place shredded chicken, all vegetables and sauce in a large ovenproof dish and mix thoroughly.
5. In a food processor pulse bread, extra butter and herbs together to form a crumble consistency. Careful not to go too far. Place crumble in a pan and heat gently in oven or on stovetop stirring regularly until crumble just starts to colour. Sprinkle crumble over chicken pie.
6. Cook pie for about 20 mins until heated through and crumble is golden and pie bubbling, can be made in individual pie pots for something special.



Hair-raising donations IN MEMORY OF KENNETH

Kenneth O'Sullivan was the sort of guy who made each day count. Born with CF, Kenneth inspired many people with his positive and open attitude to life before he passed away last year.

His partner Freya Lance (20) has paid tribute to her boyfriend for making the most of his life.

"He did what he wanted to do in the time that he was here, and touched a lot of people's lives. He was a strong one," says Freya Lance who shared two very special years with Kenneth before his unexpected death in Tauranga in August.



He had impressed many people with his positive attitude, including Freya's brother-in-law Sam Morton who is raising funds for CF Auckland in memory of Kenneth by waxing a body part every time \$1000 is reached.

Kenneth had been enjoying good health after a lung transplant three years previously but he developed lymphoma, and a virus saw his condition worsen. He died of a suspected brain haemorrhage in hospital after what his family expected to be a brief hospital admission.

Freya will always be grateful for the two years she and Kenneth had together, although they never got to fulfil their dreams of building a house and getting married.

"We were already talking about children and we were going to build a house together as well. And we always had marriage and kids in the back of our minds.

"He had a lung transplant three years ago and had cystic fibrosis his whole life. He was never afraid to tell people. It was a well-known fact that it was him – he was sick but he didn't care and he just got on with his life."

Freya hoped to have many more happy years with Kenneth, and when they first got together his health had never been better.

"The first year we got together he didn't have one night in hospital. He said it was the best year he ever had and he put it down to me, but I don't think that's true," Freya says. "I loved taking care of him. It made us stronger. I wouldn't take anything back."



Sam Morton getting a body wax

Sam bares all for CF

It's a case of no pain no gain for CF as one of Kenneth's friends decides to sacrifice his body hair for charity.

Sam Morton, who is Freya's sister's partner, had decided to help raise funds for CF before Kenneth passed away, and never expected he would be doing it as a tribute to his mate.

Sam (34) had only got to know Kenneth a year before he died when Sam got together with Freya's sister Emily, but he quickly identified with him - impressed with Kenneth's attitude to life.

"I got to hang out with him one-on-one and he was such a down to earth, kind person; very straight up and would tell it like it is. He was just a likeable person," he remembers.

Sam decided that he wanted to fundraise for Kenneth, and has since

vowed to wax one body part for every \$1000 raised, and so far he's waxed one leg. "It was painful at the back of my leg and the top. But I wasn't screaming or anything," says Sam who also intends to shave his hair off – and that will be the last to go.

Sam would like to see the money he raises go towards supporting families who need to travel for clinic and hospital appointments.

"I know that Kenneth and Freya struggled a lot, particularly with travel. So travel, accommodation and food vouchers are the kind of thing that really helps the family."

You can follow Sam's fundraising efforts online: givealittle.co.nz/fundraiser/redbullking



Shippo's 2800km for CF

Auckland man Greg Shipton combined the trip of a lifetime with raising \$5000 for Breath4CF by taking on a bucket challenge on behalf of a late family friend who had cystic fibrosis.

Greg Shipton, also known, as Shippo, wanted to honour the memory of Makenzie Perry who passed away in 2013, so he made the decision to cycle from Cape Reinga to Bluff, while raising funds for those with CF along the way.

His journey began over a year ago at Cape Reinga and by taking roads off the beaten track, Greg met some incredible people, made new friends with fellow travellers, and learned more about New Zealand's history.

He made the cycling trip in six stages while completing short-term contracts in his job in the food packaging industry.

"We set out to ride the length of New Zealand in under 100 days, and do it in stages over 18 months, to manage work commitments. We covered the 2,800 kilometres in 52 days over a 13 month period," Greg explains.

He now hopes to inspire others to follow their dreams – happy that he's achieved his own goal, fulfilling a promise to Makenzie.

FAREWELLS

May our loved ones rest in peace

Michelle Walsh – 15/12/14

Ian Patterson – 2/1/2015

Jonathan Nicholls – 10/3/15

Ngaroimata White-Winiata – 25/3/15

Dylan York – 19/4/15

Reece Brown – 26/4/15

HISTORY OF CF

The gene that causes cystic fibrosis is believed to exist in modern times because it once helped humans to survive, providing protection against deadly tuberculosis.

The CF gene itself has affected the human population for thousands of years, and because it didn't gradually fade out, researchers have speculated that there must be some benefit from being a carrier of the gene.

According to researchers at Yale University in Connecticut, US, between 1600 and 1900, tuberculosis caused 20% of all deaths in Europe, and it was at that time the number of CF genetic carriers in the population jumped.

"The TB pandemic starting in the seventeenth century allowed CF to really take off" one of the researchers explained.

CF patients and carriers of the gene have some natural resistance to tuberculosis because TB bacteria need a nutrient that CF patients don't produce.

The researchers believe that CF rates will gradually fall in places where TB is controlled but only at a very slow rate of 0.1% per year.

Before this study there had been a theory that the CF gene

protected against cholera and typhoid but the researchers say little evidence of this has been found.



Dorothy Hansine Andersen was the first person to describe the characteristic cystic fibrosis of the pancreas and to correlate it with the lung and intestinal disease prominent in CF. She also first hypothesised that CF was a recessive disease and first used pancreatic enzyme replacement to treat affected children.

(source: Wikipedia)

Jenna rebuilds after robbery



When Jenna Harris' home was ransacked by thieves during her lengthy hospital stay she couldn't believe the injustice.

Jenna was being discharged in time for Christmas when her family had to break the news that most of her prized possessions had been stolen.

Since then friends, family and the CF Community rallied to help, with her best friend setting up an online fundraising page in Australia, which raised \$3000 for Jenna.

She's been able to replace her television, stereo and game consoles, but will never be able to replace her late Nana's cross or the rings her mother had given her for her 21st birthday.

The 29-year-old had been in Palmerston North Hospital for almost three weeks with a serious chest infection when burglars climbed through a window three days before Christmas. A small tomahawk was left outside.

The story appeared in the Manawatu Standard on Christmas Eve, outraging residents in the area.

Since then Jenna has noticed many more items that must have been stolen in the burglary. It's estimated more than \$5000 worth of her stuff is gone.

"They took make-up, hair straighteners, some of my clothes, my MP3 players, videos from TV shows, some toys of my nieces, and my vacuum cleaner. They had time to pick through everything. They stole all my food and my car stereo that was inside," says Jenna who is unable to afford insurance. *"There have been a few little things that*

I've gone to look for and they're not there."

The theft of her family's Christmas presents was particularly gut-wrenching for the 29-year-old who was diagnosed with CF at the age of four.

"I had no presents to give my family on Christmas Day. My family understood and knew but it was just not the same," she sighs.

Jenna's only been able to replace the most important items.

But Jenna's dad was able to see her television listed on a local second-hand goods website, but didn't have time to buy it before it was swiftly sold. They gave the seller's "user profile" to police but

believe it's likely a fake name was used.

Although her health was good over the summer, she's found the temperature change has been affecting her chest.

One of the worst consequences has been Jenna's fear that the burglars could return, although the home is now more secure with an alarm system and security locks on the windows.

"They didn't take any of my antibiotics or the drugs used to manage my condition. Because they would have seen it all, it worries me they could come back to get them. I sleep with night lights on through the house now."

On the plus side, Jenna has made new connections in Palmerston North because of the theft. She had only been in the area for six weeks after moving from the Hawke's Bay to be closer to her family.

"My neighbours are really good looking out for me, and it's become a friendlier neighbourhood now."

And Jenna has been heartened by the generosity of people who have donated and wants to thank everyone who has supported her.

"People were so generous. It was frustrating me because everyone was giving me donations and I had no way to thank them personally. I wanted to give them all individual hugs."



Photo by: Fairfax NZ / Manawatu Standard



Wishing well bride

Before Nicky Murphy exchanged vows with her husband to be – there was a third person they had to thank first.

Without her new lungs Nicky would never have got the chance of a new life – living and breathing well, so both Nicky and groom Blair Hatton wanted to say a special thanks to the lung donor, by reading a poem dedicated to her.

“We wanted to acknowledge her first - if it weren't for her gift our dream of becoming married may not have happened,” Nicky says.

After the reading, the 100 guests at the wedding ceremony released heart-shaped balloons, filling the sky with good wishes.

Nicky and Blair also decided to feature a wishing well at their wedding held at Cana Gardens in North Canterbury to raise money for Cystic Fibrosis Canterbury Branch because of the support Nicky and her family received during the lung transplant operation, which involves many weeks away in Auckland.

“Loved ones still have a mortgage and bills to pay and miss out on working. The CF branch helps out with paying for things like airfares and grocery vouchers. So I've asked that our money go specifically towards helping transplant patients' families,” says Nicky.

The CF wishing well raised \$575. And there was another wishing well for guests who asked

to donate to Nicky and Blair's future together.

Nicky, whose wedding was also featured in Woman's Day in February, says Blair proposed when Nicky was going for a lung transplant follow-up in Auckland.

“We were celebrating going unconditional on the house we bought and we went to the Sky Tower restaurant Dine, and Blair got down on one knee and proposed,” says Nicky who replied, *“yes of course!”*

The couple have been together for five years, meeting through Nicky's sister's partner who is best friends with Blair. Blair did know that Nicky was unwell but she had to explain what cystic fibrosis was.

“He googled it when we first started going out so he didn't have to ask me so many questions.”

Blair also helped care for Nicky during her transplant and of course before it when she felt so exhausted. *“It got to the point when he would actually do my home I/Vs for me, he learnt how to do them,”* Nicky recalls. And Blair flew to Auckland every weekend that Nicky was in Auckland recovering from her transplant.

“He'd brush my hair, lift my arms, would go on a mission to get food I felt like,” Nicky says. *“He's one of a kind. I'm so lucky to have him.”*

DONOR POEM

We received a gift this time 2 years ago
from someone we didn't even know.
It came with no card, ribbon or bow
But sent to me that's all we know.

It didn't arrive in a box or sack
And is a gift one would never send back.
The gift in size is rather small
Compared to its power to conquer all.

This beautiful gift has set me free
What a precious gift and given to me.
This gift was given out of selfless love
And delivered to me with help from above.

This gift is so precious and was very timely too
When you know of this gift,
I'm sure you will agree too.
This gift will not be taken in strife
The gift we speak of is that of life.

With this gift we stand here today
as we become husband and wife
all thanks to this second chance at life.
May we all stand tall as we thank thee above
as a sign of our love let our balloons rise above.



THAT'S THE SPIRIT!

Jake and his twin sister Emma also had the trip of a lifetime when they were granted a voyage on the Spirit of New Zealand. Emma discovered the City of Sails in February and Jake embarked after completing his Lake Wanaka Half at Challenge Wanaka.

Emma:

I had the amazing experience of going on the Spirit of New Zealand 10-day youth voyage at the beginning of February.

During the 10 days you do all sorts of things. The days start at 6:30am with a morning swim before breakfast and clean up. It was then straight into the day's activities doing things like sailing the little yachts and the ship itself, learning all about the ropes and everything it takes to control a massive sailing ship like the Spirit.

We also did things like playing beach cricket, rafting, swimming and yard swing, played silly games, we saw dolphins and whales. We did a beach cleanup on a Coromandel beach and climbed to the top of the mast and so much more.

It's a pretty full-on 10 days but every second is heaps of fun. The second to last day is called Trainee day and it's our job as trainees to sail the ship back to Auckland. This day is one of the main goals of the trip and why we learn about

ropes, navigation, leadership and teamwork. Personally, it was my favourite day as we got to plan the day and it felt really good arriving back in Auckland and being able to say we sailed here by ourselves without the crew's help.

At the start of the trip it's just 41 strangers but by the end we are all life-long friends who feel like we have known each other for years. The things I did and the people I met made it some of the best days of my life and I'd like to thank the National CF Association and the Otago Branch for sponsoring me. Also to my parents for making it possible for me to go.

I would recommend this trip to everyone, you won't regret it for a minute!

Jake:

Thanks to the generosity of the New Zealand CF Association and the Otago CF Branch, and also my parents, for an amazing 10-day voyage on the Spirit of New Zealand.

I was on the ship with 39 other teenagers that I didn't know from all

around the country, and have hopefully made life-long friends with them.

The voyage started off at Princess Wharf on the Auckland Viaduct and went all around the Hauraki Gulf, from Waiheke Island, to Great Barrier Island and the Coromandel.

Things we did on the voyage were activities such as a day walk on Great Barrier and a beach clean on Waiheke Island. I found the beach clean quite interesting, but also quite shocking because of the amount of rubbish that we picked up in only a couple of hours!

Each day started at 6.30am with a swim in the ocean, which was actually quite nice believe it or not! I also got to climb right to the top of the mast and out to the end of the yards which was quite a unique experience too.

The weather was great for the first eight days with a nice breeze for sailing, and on the last day, which was Trainee day we had 25 knot winds which made the sailing very exciting!

For Trainee day I got voted in as one of the mates (the captain's right-hand man) which made the day a real highlight for me as it meant I got a decent leadership role and had the chance to steer the ship.

I think that this voyage was probably one of the best things I've ever done, as I have possibly made life-long friends, and I would recommend it to anyone and everyone!

Concejal muere ahogado tras naufragio de lancha

Chileno: El hombre dejó volar la embarcación de Claudio Sarrasa Barrientos (80), quien viajaba junto a su hijo de 12 años, que resultó herido.

Accidente ocurrió en las cercanías del puerto de Aguilera. Los guardas escucharon los gritos de los tripulantes y pidieron ayuda a Carabineros. Pág. 2



VETERINARIA NEOZELANDESA SE ENAMORÓ DE PERROS PUERTOMONTINOS
La australian Nicole Doriguzzi, de 26 años, está impactada por la realidad de cientos de abandonados en Chile. Pág. 2

Permisos de circulación ya se pueden cancelar
Se viene a cancelar. El trámite se realiza en oficinas y por Internet. Pág. 2

Defensores a dos personas por causar accidentes
Resolución. Cinco días de prisión y multa que se pagan al día. Pág. 2

Mujeres recibirán apoyo para emprender
Resolución. El monto depende de la actividad. Pág. 2

CMT abrirá nueva ruta en la Carretera Austral
Comunicación. Será la primera entre Santa Leocadia y Puerto Cisneros. Pág. 2



NICOLE'S RESCUE MISSION TO SAVE THE CHILE DOGS

Wellington Co-Chair Nicole Doriguzzi has returned from her three-month mission to raise awareness about the plight of abandoned and abused dogs in Chile where she made headlines and appeared in newspapers, and on live television and radio shows.

Nicole volunteered at shelters throughout Chile, ran free sterilisation clinics, treated animals on the streets and at landfills needing medical help, and met with officials in the local governments to discuss the plight of these animals and how they can help.

Nicole is a qualified Veterinary Nurse and has always loved animals.

"There are millions of streets dogs in Chile and a culture that does not promote their welfare, it is heart breaking and I am going to do everything I can to help these animals," she says. *"Every city I visited it was the same problem: unsterilised street dogs everywhere with only a small number of locals trying to help. Many are starving, have mange or other ailments, or have been hit by cars. All these dogs want is a loving home but the reality is that most of these dogs will never get that."*

Recently, the Parliament of Chile announced a law allowing the shooting of dogs in Chile, which Nicole has been protesting against with local

shelters. A few weeks after these protests the President announced this law was now on hold.

Volunteering as a vet nurse to sterilise animals was a big eye opener for Nicole because the operations were done without the luxury of normal surgical equipment such as surgical tools, anaesthesia machines or even a surgical table. Nicole says: *"The vet and I sterilised over 60 dogs in one day. We worked in a community hall and had an office table to operate on and only one set of surgical tools. It was incredibly unsterile but when you have no money and no resources you have to use what you have available"*.

The young New Zealander, who also volunteers at the SPCA was named a finalist in the Wellingtonian of the Year Awards last year, has had several media interviews in Chile, and made the front page of several newspapers there. Her story was also featured in the Dominion Post and in the New

Zealand Lucky Break magazine.

Having CF meant Nicole was unable to get travel insurance so she had to be extra careful to not get sick in Chile. She got a bit of a chest infection after visiting the freezing cold city of Punta Arenas but a veterinarian prescribed her antibiotics for free to help clear it up.

"I was feeling pretty good for the majority of my trip. When I got back to New Zealand I think the three months of hard work and the unhygienic landfills I visited caught up with me though. The day after I arrived I was admitted to hospital for three weeks of IV antibiotics and when I discharged myself to continue injecting them from home myself, I then collapsed with a blocked bowel and had to call an ambulance. After a bit of time in hospital I think I am now luckily on the road to recovery," says Nicole who plans to return to Chile in October this year to continue her mission to improve animal welfare there.



ASPIRE to inspire

The 2015 National Conference delivered on its promise to inspire. It was a highly successful conference with more than 100 people attending and informative speakers. The main sessions were livestreamed over the CFNZ website for the first time. It was heartening to see so much support for the CF community.

Official Opening

Deputy Labour Leader and Spokesperson for Health, Annette King, officially opened the conference with a warning about the Trans Pacific Partnership Agreement which may allow pharmaceutical companies to extend the patents over its products. She says this would lead to a delay in generic medicines entering the New Zealand market, making the drug budget even more expensive.

Ms King said New Zealand has under-performed in the management of chronic illness and New Zealand has a small health budget in relation to pharmaceuticals. "It's one part of the health budget that has only grown marginally over the years," she said.

Ms King said Pharmac has managed to get access to many new medicines that other countries have not, but believes there is a hole in Pharmac's policy in relation to its funding of medicines for rare disorders. She favours the new funding system introduced in Scotland which would set aside about \$25 million for rare disorders.

"It would help address some of these issues where New Zealanders are unable to get access to drugs that countries like Australia and others do."

Dr Michael Carr-Gregg

Keynote Speaker Dr Michael Carr-Gregg kept the delegates captivated twice during the first day. The child and adolescent psychologist's keynote address looked at how technology could empower children with CF, and the second focused on encouraging



The Pari workshop in action.



Dr Michael Carr-Gregg



Dr John Wyeth and CFNZ Board member Margaret Nicholls reunited after going to school together in Southland.



“For a young person to get help they don’t need to see a doctor, they don’t need any money.”

He warned against sleep deprivation and said adolescents needed nine hours sleep a night. One school in Australia has introduced three different start times to recognise the importance of teenagers getting the required sleep. He spoke of the increasing trend for practising mindfulness – meditation to still the mind.

In one study an eight-week mindfulness course actually saw a large increase in grey matter in the brain. Some companies are now using mindfulness for their employees, including Google staff who perform 15 minutes of mindfulness before they start work every day.

Some of the apps for teenagers he recommended included:

- MoodKit – which tells teens how they can improve their mood.
- MoodGYM – has shown to reduce symptoms of depression and anxiety.
- Happify – happiness action pack

In the afternoon, Dr Carr-Gregg spoke of compliance in young people – or rather “adherence” which is considered a more diplomatic term. In this session, he pointed to a study which found that adherence to treatment occurs less than 50% of time in patients with CF.

Interviews with teenagers and young adults revealed

that the main factors for non-adherence were treatment burden, forgetting and time management, and unwilling to take medication in public.

The app www.pillboxie.com is helpful for reminding people to take their medicine.

Pharmaceutical panel

The Pharmaceutical Panel included Dr Cass Byrnes of Auckland Hospital, Philippa Williams of EBOS, Pari’s Wieland Paul of Germany, and Pharmac Medical Director Dr John Wyeth.

The questions focused on the medication Tobi, Kalydeco, and new devices being considered for funding.

Dr John Wyeth reported that Kalydeco was being reconsidered by the Pharmacology and Therapeutics Advisory Committee (PTAC) for funding but “don’t hold your breath because of the cost”.

Dr Cass Byrnes noted that the majority of people with CF are likely to need a combination of two drugs to help correct their genetic defect, which is likely to cost even more.

Battling bugs

Dr Stephen McBride of Middlemore Hospital and Dr Mirjana Jaksic of Starship Hospital ran a popular session about strategies for avoiding CF-related infections.

Dr McBride, who has a child with CF himself, explained some of the bacteria that can affect people with CF, and how they can become resistant to antibiotics.

His recommendations for avoiding infections with dangerous bacteria that can affect PWCF include:

- Regular hand washing
- Social distancing – not physically socialising with other people with respiratory illnesses when possible.
- Having a flu injection each year and other routine immunisations.
- Physiotherapy
- Good nutrition
- Mucus clearance techniques
- Clean environment

Some of the following things should also be avoided:

- Spa pools
- Decaying / rotten plant matter
- Onions
- Vapour such as water blasting

continued on the next page



Annette King opening the conference



compliance in teenagers and young adults. He said adolescents love technology, and now some smart phone apps have been proven to improve their mental health.

Dr Carr-Gregg recommended the Reach Out website – one of the most visited in Australia, which helps young people access information about mental health.

A sincere thank you

to the following service clubs who have supported Cystic Fibrosis New Zealand in the past year – their assistance goes a long way to assisting PWCF fulfil their potential.

[Lions Club of Kaponga](#)

[Lions Club of Riccarton Waimairi](#)

[Lions Club of Lower Hutt](#)

[Lions Club of Waikanae \(Inc\)](#)

[Lions Club of Titahi Bay](#)

[Lioness Club of Motueka & Districts](#)

[Dannevirke Host Lions](#)

[Rotary Club of Hutt City](#)

[Wairoa Lighthouse Lions](#)

[Lions Club of Balfour](#)

[Lions Club of Johnsonville](#)

[Lions Club of Motueka](#)

[Lions Club of Amberley District](#)

[Greymouth Riverside Lions Club Charitable Trust](#)

[Beavertown Blenheim Lions Club Inc](#)

[Ashhurst Pohangina Lions Club](#)

[Lions Club of Howick Inc](#)

[Lions Club of Huntly](#)

[Lions Club of Auckland Hillcrest](#)

[Lions Club of Kowhai Coast](#)

[Lions Club of Christchurch Ferrymead Inc](#)

[Hawera Mt View Lions](#)

[Lions Club of Paeroa](#)

[Christchurch North Lions Club Inc](#)

[Oxford & District Lions Club](#)

[Waiau Valley Lions Club](#)

[Amuri Lions Club](#)

[Onerahi Lions Club Inc](#)

[Lions Club of Tokoroa District](#)

[Lions Club of Blenheim](#)

[Hauraki Plains Lioness](#)

[Lions Club of West Auckland](#)

[Lions Club of Morrinsville](#)

ASPIRE to inspire CONTINUED

Personal stories

Two people with CF shared inspiring stories during the conference – Will Polson and Vaughan Somerville.

Will spoke about his lung transplant while Vaughan revealed the impact that CF has had on his life including his teenage years and how it forced him to change his career course. Conference feedback showed that Will and Vaughan were in the top five list of speakers (with Michael Carr-Gregg at the top), and that delegates wanted to see more speakers with CF in future.

Picky eaters

Main presenter Fiona Leighton, dietitian at Christchurch Hospital, highlighted the importance of children maintaining a healthy weight, pointing to a study which showed a good weight led to better lung function, growing taller, fewer CF complications, and improved timing of puberty. Some of the strategies for picky eaters included structured meal and snack times:

- Use the same place for meals
- Routine – the child helps to prepare, serve and clean up
- Present only three foods on the plate
- At least one preferred food on the plate
- Limit snacks to 15 minutes and meals to 30 mins

Conference webcast

The CFNZ National Conference was livestreamed over the internet thanks to a generous grant from Pub Charity. We had an estimated audience of 350 people. It's wonderful that we could provide timely information to our members who couldn't attend the conference. The sessions that were livestreamed are now available to view.

To view the videos of the conference sessions, visit <http://cfnz.org.nz/our-services/library/dvds-cds/>

INTRODUCING Hannah Wilson



It was a baptism of fire for our new Grants and Events Coordinator, Hannah Wilson who attended the CFNZ National Conference within two weeks of starting. She's now organising the raffle, and focusing on Awareness Week and other fundraising events like charity cricket – all while making grant applications.

After graduating from CPIT with a Bachelor of Applied Management in Marketing and Event Management, Hannah became experienced in making grant applications and running events for community groups such as the Streets Children's Day event in Christchurch for the last two years.

She works Monday-Friday 9am to 3pm, and you can contact her about any upcoming events.



The last issue of CF News featured NZ's first Kalydeco Kid, Sinead. Now, after more than six months of treatment with the breakthrough medication, Sinead's been enjoying much better health.

In particular, her mother Andrea Neame says Sinead is much more active than she was prior to taking Kalydeco and isn't missing as much as school as she used to.

"Sinead is participating in aikido and rangers. She rides her bike 11km around a track and attends school regularly. We continue to collect data from her monthly and will submit that data to Pharmac to further our campaign," says Andrea who has been lobbying Pharmac for several years to get Kalydeco fully-funded for Sinead. It is currently being supplied to her on compassionate grounds from the pharmaceutical manufacturer, Vertex.

However, Sinead did need to be admitted to Starship Hospital in March for IV antibiotics, which Andrea says is a timely reminder that Kalydeco is not a cure.

"It has and continues to greatly improve her life, and dramatically increase the energy and stamina needed to undertake the daily activities of a regular 13-year-old, which is my dream come true," Andrea says.

Getting a puppy has also given Sinead an extra boost. Andrea says that Trixie, a Sydney Silky cross, will add to Sinead's exercise regime.

"We got her to enhance Sinead's activities as she plans to undertake agility training with her next summer," says Andrea.

Kalydeco is approved to treat people with CF who have the G551D gene. It has also shown promise when combined with the drug lumacaftor in the group of people who have two copies of the F508del gene.

Another combination therapy (Kalydeco + VX-661) is also hopeful. Latest results have indicated that this combination has a good safety profile, but it did not improve lung function as much as expected in the study group of people with two copies of the F508del gene. However, the study only involved a small sample of 15 people taking the drug combination. Now Vertex has announced it plans to study that drug combination in a large group of patients with one copy of the F508del gene plus a second genetic fault.

Watch out for the screening of the controversial show **The Red Band Society** on TV2 later this year.



The show, which revolves around a group of teenagers living in hospital (including one with cystic fibrosis) has screened in the United States, and attracted plenty of comment from the CF community there.

Dash, who plays the guy with CF is portrayed as a risk taker.

He is also one of the smokers and one reviewer who has CF was extremely concerned that the dangers of someone with CF smoking hadn't been addressed.

She also commented on some of the show's technical failings related to the illness, but was pleased to note that one episode did spell out that having a lung transplant is not a cure for CF.

So far Red Band Society episodes have been available at TVNZ On Demand. The show was cancelled in the US after one season.

Astro, the actor who plays Dash, says he was pleased to get the part because it was a strong script. "It was selling the story of the teenager from the teenager's perspective. It wasn't like, old man from middle of nowhere trying to tell our story like a lot of TV shows do."

Astro got to meet some people with CF and was impressed with their attitudes to life.

"As much as they were going through, they weren't sad at all. They were enjoying every moment of their lives."





STUDY HIGHLIGHTS

disagreement over early warning signs

Identifying the signs of an exacerbation can be key to preventing further health problems but new research has shown big differences in what these signs are - especially among patients and clinicians.

Pulmonary exacerbations are experienced by a large proportion of patients with CF, but a UK study recently published in the Journal of Cystic Fibrosis shows there is uncertainty about the most important indicators of an exacerbation.

The researchers surveyed 13 CF centres in UK and Ireland, and found that there were clear differences among health professionals and the CF community regarding the early signs of an illness about to strike.

Minimising exacerbations are key for improving the long term health of adults because they are associated with a rapid decline in lung function and wellbeing.

In the study patients were asked to list the most common signs they experienced before an exacerbation. Health professionals were given the same list to rate in order of importance.

It was found indicators from health professionals that were rated high were commonly rated lower by patients with CF. For example, blood streaked sputum was rated higher by CF health professionals (rank order 13) and lower by adults with CF (rank order 33).

Few statements were rated high by both groups. In fact, only four statements were ranked in the top 10 by both groups. These included:

- A large decrease in lung function
- Feeling more short of breath than usual
- Producing more sputum than usual
- More coughing than usual

The research reports that objective measurements were of higher importance to health professionals. Feelings of increased debility were rated most important by adults with CF.

The study recommends further research into these findings and suggests patients and clinicians discuss some of the early signs of an exacerbation so PWCF seek medical treatment as soon as possible.

CF patients' top 10 signs of an exacerbation (ranked in order of importance)

1. A large decrease in lung function (greater than 10% FEV)
2. Feeling more short of breath than usual
3. Trouble breathing
4. Feeling the need to do more airway clearance than usual
5. An increase in symptoms at night
6. Producing more sputum
7. Finding it harder than normal to exercise
8. Finding it harder than normal to perform usual activities
9. Feeling more exhausted than usual
10. More coughing than usual

Health professionals' top 10 signs of an exacerbation (ranked in order of importance)

1. Increased sputum
2. A large decrease in lung function (greater than 10% FEV)
3. More shortness of breath than usual
4. Increased inflammatory markers (identified from blood tests)
5. Fever or increased temperature
6. Increased breathing rate at rest
7. Decreased oxygen saturation
8. Hypoxia/hypoxemia (low oxygen levels)
9. Change in the colour of sputum
10. Increased coughing + changes on chest X-ray (10th equal).



Balancing work life and CF isn't always easy, so CFNZ Adult Rep Carmen Bradstreet asked our adult community for some tips on how they manage the juggling act, and received some great advice...

1. Rest and relaxation

1. I make sure my weekends are very relaxed or at least one day is for sleeping. I also try to have a back/shoulder massage once a week (focused on my lungs) and I find that really helps with lung pain from working and sitting at a computer all the time.
2. Often, sitting in traffic I will do a feed (pre-set up and insulin taken before I hop in the car), but I am in traffic for over an hour and I can do 3 bottles in a 1.5 hours, so the rest is just finished off at work, and then my nights are free.
3. Work and hospitalisations: The first two days in hospital I just rest, then the rest of the time I work remotely from hospital on my laptop and phone. I find I actually get more done then as I have more time on my hands. And my boss will come visit and we have a work meeting at the same time.

2. Flexibility and honesty

I've worked part time all the way up to five months prior to transplant and I am now back to working full time... Here are some of my tips:

1. First of all (and MOST important) - do something you love. Life is too short to be stuck in a job you don't enjoy. I always struggled with energy levels, but I love going to work - it wears me out but it is worth it!
2. Be honest with your boss, and realise that flexibility is key. I let my boss know that when I was well I would work harder than anyone in the building. However, I would need time off here and there for 'tune ups'. Usually I would do my first three days of



IV's in hospital and then do home IV's. This meant I could go into work (laying out the syringes at lunch was always a great topic for conversation).

3. I've been in my current job for 10 years (apart from the eight months I had off to sort out the lung transplant). Prior to that I was lucky enough not to have any issues with employers and my CF. Honesty has always worked well for me!

3. Pace yourself

1. If you're unsure about how much you can take on, start small. Commit to a few hours in a week, and build up from there. It's much easier to extend your hours and feel good about it, instead of biting off more than you can chew at the beginning.
2. Get up from your desk every hour

or so to walk around, go to the bathroom or have a drink of water. Being deskbound isn't terribly good for anybody, let alone a PWCF. Sometimes when I head to the bathroom, I do some airway clearance exercises while there, so I can have privacy when I cough etc.

3. At the end of the day, your health has to come first, because if you aren't healthy, then you can't work. Be realistic about your needs and do what you can.

4. Save time

1. I worked full time all of 2013, part time 2014 and now nearly full time (four days a week). I know that CF shouldn't restrict you too much with friends etc, but in reality it does to some extent. I find myself having to make choices of what to do on the weekends. For example, when I was working full time I would try and limit myself to one 'event' on the weekend so I did not get too tired and could rest up a bit before the next week started.
2. My group of friends like to get together on the weekends with dinner and a few wines and tend to stay up until all hours of the night talking. I just could not handle my two weekend nights being late nights so I would tend to leave a bit earlier. I hated it, but I found this helped me get enough rest and as it stands now, everyone else's lives have got busy and they all leave early too!
3. I also find that having my nebuliser in the car on the way to work allowed me to sleep in a little later in the mornings. This is imperative to my day as I have to try and fit three nebulisers in and when you have CF, an extra 20 mins of sleep in the morning really makes a difference. This is also a godsend as I have to travel nearly an hour every morning so every saved minute counts!

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