

## Car and gifts overwhelming for new mum

*With thanks to the Bay of Plenty Times for allowing us to share the story*

**A Tauranga woman whose car was stolen while she was in labour at Auckland City Hospital has been overwhelmed by the response from those wanting to help. She has received a large donation instigated by a fellow Cystic Fibrosis NZ member in Hamilton and an Auckland woman gave Miss Reynolds and her partner a replacement car.**

Because she has cystic fibrosis, Nikki Reynolds, 20, was sent to Auckland prior to the birth of her daughter, Skyla. When she went into labour she called her partner, Brendan Wilson, 22 and sister Krystie who headed north to be by her side.

About half an hour after they arrived, Mr. Wilson returned to the couple's car, which was packed with a baby capsule and supplies, to find it had been stolen.

Waikato boy Chase Annan, who also has cystic fibrosis, heard about the theft and wanted to do something to help. Late last week, Chase's mother Donna Slater and friend Donna Moxon arrived at Miss Reynold's Greerton home laden with baby clothes and toys and vouchers from Hamilton, Wellington and Cambridge along with a food hamper from the CF Hamilton branch.

Earlier in the week, Miss Reynolds received a phone call from a woman in Auckland, who wanted to give the couple a car.

The woman, who wanted to be known only as Jacqui, had



been planning to sell the vehicle on Trade Me but decided to offer it to the family after reading about their plight.

"I just saw their story and it just broke my heart. They're already struggling so much, especially with her [Ms Reynolds'] health and then this happens to them. The car's just sitting there and it would be just a big help for a young couple just starting out," the woman said.

Miss Reynolds said she was stunned by the woman's generosity.

"I kept asking her are you sure? Are you sure?"

Enjoying being a new mother, Miss Reynolds said she has been "a bit overwhelmed" by the outpouring of support.

"I just can't thank everyone enough. I don't really know what to say," she said.

## Report from the European Cystic Fibrosis Society Conference, Hamburg, June 2011

I was fortunate enough to have been able to attend thanks to the Cathay Pacific travel scholarship awarded to me by CFNZ and the financial support of CFNZ to assist with the conference fees.

My only small concern about travelling to the European meeting in Hamburg was the outbreak of a fatal strain of E. coli in the Hamburg region the week before we were due to arrive. At the time we were there, it was thought to be due to contaminated tomatoes or salad vegetables. As a result, the conference

organisers decided not to have any fresh salad foods. I decided the best way to stay safe was to stick to sausages and beer! (Joking – well a bit anyway).

The CNS special interest day started with an opening address from Professor Stuart Elborn, who gave an overview of CF and current treatments and then discussed new therapies in CF. A focus for new developments in CF care is looking for mutation specific therapies. Professor Elborn discussed two therapies currently in development. Class I mutation



therapies aim to suppress the premature stop codon (PTC) which prevents the manufacture of CFTR. The current therapy in trial is PTC 124 (ataluren) which is a tablet. A phase III trial is currently underway in Europe, USA & Canada. The primary outcome of the study is improvement in

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*Plus a whole lot more!*

## Diary

**Charity Cricket,  
Hagley Oval  
Christchurch**  
November 27th

**CF Office closed  
for Christmas**  
December 22nd  
- January 9th

**Ironman - Taupo**  
March 3rd

## Raffle results

**Thank you to all our fabulous sellers and those who donated prizes for this year's raffle. The lucky winners are:**

**1st prize:** # 1186  
Leigh (no surname)

**2nd prize:** # 5588  
Carol Burke

**3rd prize:** # 8722  
Renee Wilburn

**4th prize:** # 5664  
Dan (no surname)

**5th prize:** # 5989  
Jacky Quinn

**6th prize:** # 3240  
Brian Flashman

**7th prize:** # 1196  
L & M Ashby

**8th prize:** # 1645  
Ron Crate

**9th prize:** # 1040  
Annette Bradley

**10th prize:** # 4565  
Colin & Yvonne Stitt

*Continued from front page...*

FEV1 after 48 weeks.

There are currently two drugs (VX770 and VX809) undergoing trial to correct class III & IV mutations. The aim of drugs to treat class III & IV mutations is to activate the chloride channel with potentiators. Vertex has developed 2 drugs hoping to achieve this, both in tablet form – VX770 and VX809. Each is being trialled separately, then if safe, in combination to see if they are more effective when used together. Christchurch is taking part in this multi-centre trial.

I attended a workshop on transition and annual review, to discover what others were doing and what improvements could be applied to our service.

### **The role of the paediatric CNS in transition is to:**

- *Talk about goals with patient and family*
- *Encourage the parents to let go*
- *Assess the patients knowledge of CF medications, treatments and adherence*

### **The role of the adult CNS**

- *Be aware of the potential reluctance of family*
  - *Encourage families to let go and promote self care*
  - *Encourage self advocacy and autonomy*
  - *Assess patient competency/knowledge of CF medications, treatments and adherence*
  - *Health behaviours*

### **What kind of parental support do adolescents with CF want? (Denmark Study)**

The research was conducted to see if reasons could be found why there is often a drop in the lung function and health of adolescents with CF. It emerged that adolescents wanted:

- *Parents to learn to trust them. They felt like parents were always checking up on them "have you taken your pills?" This made them not want to take treatments*
- *The transfer of responsibility of treatment from their parents to themselves*
- *Their parents to forget about CF now and then and just treat them like normal teenagers (have a "day off")*
- *Parents to give reasons and explanations for treatment/ meds*
- *Parents to involve them at an early age about treatment and healthcare*

No one asked the parents of adolescents with CF about how they felt about parenting and whether they felt they were doing the "right" thing. The authors of this paper felt that authoritative parenting

was the best method of child rearing to promote independence and responsibility in adolescents (there is lots of information available online regarding this). There may be a role for the CF team or regional CF branches to arrange some workshops for parents on parenting children and adolescents with CF.

### **Using registry data to improve daily care**

*M Stern, University Children's Hospital, Tubingen, Germany*

The real value of data registries is that information can be easily gathered and used for quality initiatives. This helps improve outcomes for our patients.

It is important for a clinic to know where they sit:

- Individually (e.g. how many patients have a BMI less than 20, FEV1 <30% predicted etc),
- By centre (compared with other centres)
- Regionally (e.g. within Australasia)

When looking at centre or regional data, gains can be made by sharing of information – e.g. asking the centre with the best nutritional profile to write guidelines for others. This could include how they provide basic follow-up, risk groups, how to solve specific problems, what alarm signals to look out for etc. That way all can gain from their knowledge.

Quality improvement requires:

- *Intensive team and group work*
- *Leadership to improve*
- *Readiness to change*
- *All teach – all learn*
- *Improved measuring of outcomes*
- *Improved patient recall (intensive follow up)*
- *Having sufficient time to see patients*
- *Counselling to individual needs*

### **The key things I took from the conference were:**

- *Reviewing the data we capture at annual review and our process in clinic to see what we can improve so that patients get the most out of it*
- *Continuing to work on improving the nutritional status of our clinic – we are now able to monitor this with the use of the Port CF database*
- *Continuing education for the team as a whole on sexual and reproductive issues*
- *It's all about continuous quality improvement – looking at the way we do things, the results we are getting and ways we can improve. The Port CF database is an invaluable tool to give us the information to be able to do this.*

I'd like to thank CFNZ for their ongoing commitment and support of health professionals involved in the care of people with CF.

**Robyn Beach**





## Vicki's transplant story so far

drain tubes in my chest out.

I was moved across to Hearty Towers the rehabilitation centre on the 30th June, 14 days after my lung transplant. The last five days I have been resting and I seem to be sleeping a

lot I am still on morphine because of my broken sternum which takes up to 8 weeks to heal.

On Saturday 2nd July I woke up feeling very unwell I had really bad nausea and slept all day. I woke Sunday even worse. By Wednesday 6th I was readmitted to Auckland Hospital. I will keep the details to a minimum as the next 2 weeks were really bad, far worse than the lung transplant. Because of all the morphine it had blocked the intestine it took them 5 days of numerous tests to decide that it was the intestine and not the bowel. They finally came to a decision and decided to drain my stomach with tubes stuck down my nose and they finally gave me a pain pump. (This all happened after Wayne had a meltdown that caused things to happen!)

Because I had been nil by mouth for 6 days when my bowels finally worked, I went to the bathroom at 3am I passed out and woke to the damage... landed on my left cheek completely closed my eye and bruised all my face! Not a pretty sight!

We have received some lovely cards and presents that have been very helpful and our family really appreciate the support we have received. The support certainly made my day when Wayne brought all the lovely cards up to the Hospital for me to read, and it certainly lifted my spirits.

To the people who were visiting Auckland who made the effort to call and visit, thank you, it was nice to see a familiar face, the text messages and phone calls were also inspiring to help with my recovery.

I was finally discharged back to Hearty Towers on the 22nd July, here's to onwards and upwards from now on, we are so ready for the next chapter in our lives.

**Thank you, Vicki**



**It is now 6 weeks since I had the most wonderful gift a new set of lungs. I flew from Oamaru on the 15th June. I needed to be there by 5pm, so an air ambulance was fuelled up in Timaru and sent to pick us up at 1.30pm at Oamaru Airport.**

We arrived at Auckland Hospital at 4.45pm I was prepped for the operation. It was really quick, no time for a shower or to be shaved (thank goodness) and they wheeled me into theatre at 6.30pm.

The surgeon phoned Wayne at 3am and said it went really well. The lungs were a bit bigger than my old ones but they managed to fit them in. (Similar to a V8 in a mini) and I was in ICU on 16th June Thursday morning connected up to all the bells and whistles drains, tubes and monitors. By 11.45pm on the 16th June I was taken off the respirator and breathing on my own with my new lungs.

Wayne and Renee became really good at charades while I had the tubes down my throat, it was really bizarre because I was asleep but could hear everything that was going on around me. Two days after the transplant I was moved to Ward 42 and over the next few days they gradually took the



*Kate and Caroline sharing a pre-dinner drink with Paul Atmore and Jenni Walsh from NZFMA*

## NZFMA Ball

**A big thank you to the Team at the NZ Financial Markets Association, Jenni Walsh and Paul Atmore for a fantastic night at their biennial Financial Markets Ball.**

This year, they chose the Association as their official charity and held an auction during the night to benefit our cause.

We were told that they usually make around \$5,000 and we were very pleased to be chosen. But we found some pretty awesome



auction items between us and the amazing supporters of the auction and as a result we made \$29,500 on the night!

We were blown away by the success of this event and we are hopeful we can get these kind folks to invite us back in 2013! We already have a great relationship with the organisation through the NZFMA Thomson Reuters Charity Golf Tournament and this new event has helped to cement us as close friends.

# Bob Beall visits New Zealand

**Late in August we were lucky enough to have Dr. Bob Beall, CEO and President of the CF Foundation in the United States, stop off in New Zealand on his way back to the States from the Australian Conference.**



We set up a fairly packed programme for Bob as, naturally, there were heaps of people who wanted to hear him speak, ask him questions and benefit from his 40 years of experience in the sector. We also allowed a little bit of relaxation time, to show him some good old Kiwi hospitality!

On the Saturday, Bob spoke to a packed room at the Rendezvous Hotel, as we used his visit to re-launch the Shares in Life Foundation. Bob spoke about the genesis of the US Medications Pipeline and the venture philanthropy strategy that has led to them investing over \$600 million US dollars into CF medications research over the past few years. He also spoke about the US efforts to promote a culture of quality improvement in US CF centres, that has led to 'across the board' improvement in patient outcomes.

Bob was ably supported by Andrea Miller – Chair Shares in Life, who spoke about the Foundation, its goals going forward and the strategic projects such as Port CF and Quality Improvement, where it will be concentrating most of its effort and resources over the next few years.

Guests came from across our network, with Specialists, Allied Health, Researchers, Families, PWCF and donors all represented. Everyone got the chance to sign a lovely new Shares In Life (SILF) banner to demonstrate their support for the push toward a world where CF is not life-limiting.

On Sunday, we took Bob to Waiheke Island, where we were all fabulously hosted by the Auckland Branch, with the Thorrat family providing a friend's bach for a superb BBQ catered by Jane Drumm, Jill Thorrat and Robyn Somerville – thank you ladies, it was SUPERB! Bob was still raving about the trip (we had perfect weather) when Kate dropped him off at the airport to go home!

Monday saw Bob having meetings at Starship and Auckland Hospital and speaking to a group of specialists and allied health from various sub-specialties that afternoon. Again, his talk was on the pipeline and centred greatly on quality improvement, the importance of involving patients and their families in those processes and what we can do to lift the game here in NZ.

Finally Bob met with the CFANZ Board to bring everything we had learned over the preceding days, together to form a plan for how CFANZ could, in partnership with the Shares in Life Foundation, develop a NZ-wide quality improvement programme and ultimately work to accreditation of our centres according to accepted international standards.

We were delighted that Bob was able to spend some time with us and everyone who met him was inspired and educated about the amazing work of the CF Foundation. The CF movement, globally, has a great deal to thank Bob and his team for as it is through their work and the medications pipeline that we have seen the greatest progress in CF care in the past decade. We are now able to support this work through our local patients taking part in stage three trials such as Cayston and Vertex.

**Bob, we hope you can join us again in 2013 and that perhaps you can bring the family and spend some more time in our beautiful country!**



## I've learned...

That life is like a roll of toilet paper. The closer it gets to the end, the faster it goes.

I've learned that we should be glad God doesn't give us everything we ask for.

I've learned that money doesn't buy class.

I've learned that it's those small daily happenings that make life so spectacular.

I've learned that under everyone's hard shell is someone who wants to be appreciated and loved.

I've learned that the Lord didn't do it all in one day. What makes me think I can?

I've learned that to ignore the facts does not change the facts.

I've learned that the less time I have to work, the more things I get done.

## News from the CF Adult Reps Desk



by Lisa Borkus

**As I began to write this article for the National Newsletter, I was hooked up to an IV infusion. This was my 5th round of IVs for the year, alongside orals and nebs. The harshness of this year's events from earthquakes to slipping health, have caused me to reflect on the simple pleasures in life and what is the most important things for me to be investing my time and energy in.**

For us, living in the Eastern suburbs which was badly hit in both the September and February earthquakes, has meant adjusting to chemical loos, bouts of no power and water and difficulty getting to places due to liquefaction and damaged roads. However, the strength and camaraderie of those around us has cemented the reality that the people in our lives help us to stay strong and can overcome many obstacles.

Due to this year also being filled with extra hospitalisations and undergoing aggressive, long term treatment to tackle Mycobacterium Abscessus and MAI/MAC, without the supportive network around us, undergoing this would have been so much harder on me and my family.

As a parent, the tendency is always to put the children's needs first, but when you are unwell and need to be hospitalised, you have to step back and get yourself well. I find great relief in knowing that my husband and children are supported when I am away, from a car pool system to take the kids to school, after school play dates to meals being dropped off, etc.

Having to rest more has allowed me more time to investigate CF sites and draw encouragement from other people's experiences around the world in the CF community. Here is one I would like to share:

One name that always seems to crop up in international CF circles is Josh Mogren. He is a 32 year old adult with CF living in Minnesota. He has quickly become one of my Facebook buddies and has been working towards helping children with CF understand their disease. Not only that, but he is a skilled puppeteer, who uses his puppet Moganko to help tell the story and make the children with CF laugh, especially when undergoing treatment. Children from all over the world regularly watch his shows and videos. In essence, Josh's mission is to take the 'edge' off CF and make treatments a more fun experience, rather than traumatic ones. This link shares a little more of his story:

<http://www.myfoxtwincities.com//dpp/health/maplewood-puppeteer-cheers-children-with-cystic-fibrosis-aug-15-2011>

**The newsletter 'cftalk' is available for everyone (including parents) to read and is found on our website by following this link:**  
<http://www.cfnz.org.nz/news-from-the-adult-rep/>



### Welcome

To wee cutie **Skyla** – daughter of **Nicola Reynolds (AWCF)** and partner **Brendon Wilson**. Skylia's entry to the world was pretty dramatic (see story on page 1).

### Policy change Breath4Cf Fund

**We have made some changes to the grants we are giving each year for Breath4CF. Please take note of these changes that have now come into effect.**

Age 0 – 5 years:  
\$150 per annum

6 years and above:  
\$300 per annum

We realize this represents a reduction for many people but the Board has decided that, if we are to sustain this fund (which currently costs CFANZ \$90,000 per year) we do need to make some changes now to avoid the fund running out in the next few years. If you have any questions don't hesitate to call Kate on 0800 65 1122.

## Merchandise

All our lovely merchandise for Bubbles Week (and beyond) can now be purchased from the CFANZ website, or direct from us using the flyer inserted in this edition of CF News.

Please note that we DO have children's sizes for the teeshirts!

We are very proud of our new theme and we are getting great feedback about it on our facebook page at <http://www.facebook.com/#!/pages/Cystic-Fibrosis-NZ/171499682890863>

If you are a Facebooker and haven't 'LIKED' this page yet, get to it!



\$17.50



\$2



\$3



**CYSTIC FIBROSIS** 

# Bubbles Week

**15-21 AUGUST 2011**

**Support Kiwis with CF. Make an instant \$20 donation phone: 0900 FOR CF (0900 367 23) [bubblesweek.co.nz](http://bubblesweek.co.nz)**

Grace Paterson  
Kaimata



Calls cost \$5 plus GST per minute. Kids ask parents first.

## Bubbles Week POPS!

**Our Awareness Week this year had more than one interesting element to it! Our new bubbles theme was warmly received by everyone as a relevant and attractive new addition to our branding. The bubbles theme will continue to be developed as the years roll by as we know we are onto a winner!**

The lovely Miss Grace Paterson, a vibrant, outgoing four year old with CF from Kaimata in Taranaki, was our poster girl for this year's campaign. Grace and her Mum Jess and Dad Sean flew down to Christchurch for the day, to have the filming done by our friends at Orly Productions and stills for the poster and print campaign. You can see

the results were simply stunning and the public has responded to the billboards (kindly supplied by APN Outdoor) and the Bus Shelter ads (courtesy of AdShell).

We wish to thank Harvey Cameron for their ongoing support of our cause and the genius of their creative team in developing this campaign.

Most branches took up the challenge of running street collections in various forms and a myriad of other events all wrapped around the bubbles theme. Our new merchandise went 'gang busters' with the most popular items being our new bubble pens and the ever-yummy chocolate fish.

Otago branch reported that their most



Left: Otago's BIG bubbles  
 Below left: Paula's family swimming for CF  
 Right: Kaiya and Mum Glenny collecting in Matamata



successful sites were outside supermarkets and interestingly, the University! Seems those 'scarfies' might be a generous lot!

Paula Thompson from Timaru (mother of Logan, PWCF) and her family, competed in a local swimathon and raised just over \$900! A fabulous effort from one family. Pictured above is Paula's sister Lynn and hubby Mike.

The national office ran a successful collection at the ChCh Airport (the only place that was really sheltered from the snow!) and our thanks go to the Northwest Kiwanis and Girl Guides for helping us to man the donation stations.

Facebook played a major part in our efforts this year and the CF Facebook page at <http://www.facebook.com/#!/pages/Cystic-Fibrosis-NZ/171499682890863> was utilised to drive traffic to our website where the public could purchase our great merchandise. We even had other businesses, like "Cupcake Princess" 'liking' our page and running small fundraisers of their own for us!

LJ Hooker Matamata used facebook to promote their sausage sizzle – this LJ Hooker branch are very committed to the CF cause.

Glenny Bowes of Matamata (is it something in the water there?) created a lovely film about kids with CF and the challenges they face, using One True Media and this video went viral around NZ – you can view the video by visiting here <http://www.facebook.com/video/video.php?v=1883200841537>

Yet again, sadly we encountered collectors from the Cancer Society in some centres out on our collection day. This is disappointing as charities around NZ sign up to the Appeals Calendar administered by the Fundraising Institute and the agreement is that we do not collect on each other's days. When contacted, the Society denied having its collectors out but given that we had several reports from our own people, in centres around the North Island, we are inclined to believe our own people. Next year, we will be encouraging our volunteers to take pictures of the Cancer Society collectors if they are out and about in our week again, so we can send the pictures to the Society management to prove to them that it is happening.

Auckland led the way again with a varied programme of events, including Bubble Days at kindies, a Trade Me auction and the sale of recipe journals as well as the official CF merchandise. Northland held a skateathon which was a fantastic success and gained them media coverage.

Thanks to everyone for their great efforts in making our first Bubble Week a big success!



\$10



\$2



\$2



\$2

## Cordbank

**Sadly our three free cordblood collections per year with CordBank NZ came to an end this year, but CordBank are still offering a discount off the cord collection kit for all CF families as follows:**

CordBank would like to offer you \$200 off the price of your CordBank cord blood collection kit. All you have to do is complete your registration by clicking on this link - <http://www.cordbank.co.nz/register/payment-options/> and choosing 'Option B' to register a sibling (even though this is the first child you are registering with us). Then simply enter 'CF' in the promotional code field.

1. To qualify, you must be a new CordBank customer with a child with Cystic Fibrosis.
2. To qualify, you must complete the registration, including payment of applicable registration fees.
3. This offer cannot be used in conjunction with any other offer, is not transferable or redeemable for cash.
4. CordBank will not be responsible for failure of your registration to qualify for this offer, whether or not as a consequence of incomplete or misdirected registration, including as a consequence of internet or other technical difficulties.



## Damien's wedding challenge

**Well I guess it all started in 2009 when I decided to go to Canada for a year with my then girlfriend. While we were camping our way through The Rockies I asked her to marry me. We decided we wanted a summer wedding, so once we returned to NZ in Sept 2010, we booked our venue and had 6 months to plan ready for March 2011. We pretty much went to bed dreaming about wedding stuff... as those of you that are married will know!**

Just to add to the situation, I ended up in hospital in Jan 2011 with a collapsed lung. A chest drain was put in for a week which inflated it, and then I had a 6 week recovery period of not being able to do much at all! This meant no work and no income (not even any help from WINZ, turns out nurses earn too much!). So wedding planning it was! Well, at least trying to anyway...

After the 6 week period was up and I was just about to go back to work, I woke up one morning and thought, hmm something doesn't feel right in my chest. But with me being me, I thought 'nah I'll leave it for a few days it might come right'. Unfortunately however it didn't, and I ended up in hospital again with a second collapsed lung. It was March 7th, less than two weeks before our big day which was all booked for March 19th.

As it would happen, this time the lung didn't want to re-inflate as quickly as the

first time. So here I was, sitting in a hospital room not being able to do anything two weeks out. We had friends arrive from Canada, who were thankfully able to run around and help Alice out with all the last minute to-do-lists! Some might say I did it on purpose haha. The docs didn't want to do anything too major as the wedding was creeping up so they just put drains in and hoped my lung would cooperate.

The days ticked by, Thursday March 17th came around, and I was still in hospital with a big bore drain in and the lung still hadn't re-inflated! However, the docs were nice and decided to let me out for our wedding with the condition that the big drain remained in! They said 'come back at 7am on Monday morning', I said, 'bugger off, I've got 2 nights planned, booked and paid for already, will see you Monday arvo'. On Friday there was lots of stuff that needed doing obviously, but I wasn't much help at all and Alice just kept saying just relax and conserve your energy!

Saturday March 19th 2011 - the big day. I still hadn't really written my speech so I jotted a few points down on some paper in the morning and slowly got up and had breakfast. Me and the boys were meant to be at my parents about 10am, but I think it was about noon when we rocked up to start getting dressed, so of course mum was a bit stressed and the photographer was already there, oops. The wedding was at 3pm, but being boys we got sorted

pretty quickly and had some photos. It was then time to leave.

The groomsman and I forgot to put our special undies on so when we got to Mystery Creek (the venue) we had to do a quick restroom stop and change. My bestman (who already had his undies on) couldn't find us. Eventually we got sorted and were walking down to the

by then I was pretty knackered. I had found a boutique B&B on the edge of Hamilton which I booked 2 nights at so we got dropped off there. It was a surprise for Alice. It was very nice if I do say so myself, very luxurious, bottle of champas and all that.

The weekend went SUPER fast and come Monday I had to go back to the ward. It was about 12 or so by the time we got



ceremony site (outside by the lake) and I looked at my watch, oh crap it's 2.50! Once I got down there I got wired up by the celebrant and popped some morphine as the drain was giving me a bit of pain.

Alice wasn't too late, I told her not to be, otherwise I wouldn't be there (you've just got to be firm sometimes men! Haha.) She looked beautiful. Thankfully the morphine kicked in, and I managed to make it through the ceremony without needing to sit down or a coughing fit. Afterwards, quite a few people said I looked quite nervous, but I think it was more the fact I was just trying to breathe and stay standing as the drain was uncomfortable and I was having trouble breathing.

So after the ceremony we said hi to everyone and then it was photo time... that was a slow process as I couldn't move very fast and had to stop every now and then to catch my breath! It was then onto the reception, which we had at the same venue so that was nice not having to travel anywhere. I couldn't really drink much as I was on painkillers so that was a bit of a bummer!

I managed to stick it out until 11pm, but

there. A few days later I had another drain put in so I had two! It took another few weeks but it FINALLY resolved. So they took the drains out and a week later, you guessed it... the lung went down again, for the third time.

So then it was serious, I ended up being transferred to Auckland for surgery. The same team that does the transplants saw me and the surgeon decided to do a talc pleurodesis. When they went in to operate, they found two holes in my lung, so they were stapled and then stuck my lung to my chest wall. No wonder it hadn't been staying up if it had two holes in it. I ended up being in Auckland hospital for 3 weeks! What a start to married life.

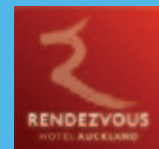
The weekend before I got out we moved to a new house, so again, I planned that well with not being there... Alice had lots of help though which we are very grateful for.

Amongst it all, Alice had managed to surprise me with a "welcome home and now you better stay home" present which consisted of a 50" 3D T.V. I think we've seen enough of hospitals for awhile and now looking forward to starting our married life!

## Thanks to...

**Our huge thanks to the following businesses that have helped us in the past few months...**

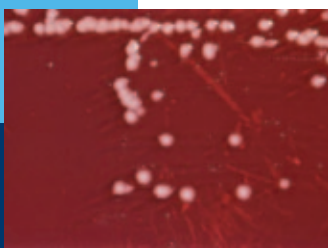
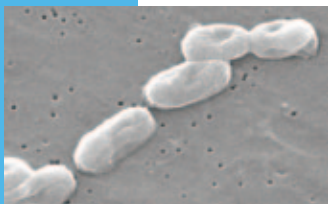
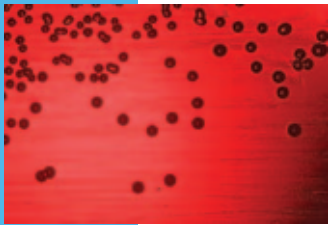
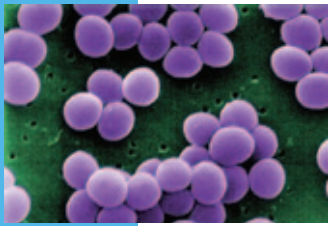
**Westpac** for their very generous \$10,000 donation to our work



**Rendezvous Hotel** for generously donating the venue for Bob Beall's visit



**Hanmer Thermal Pools** for free passes for Chairperson's conference



# Know your bacteria

**Most people with CF have bacteria in their lungs that do not cause inflammation or damage. The number of bacteria in the lungs is relatively small, and the body's immune system is able to keep them under control. But when something happens to offset this balance; e.g. a virus, the bacteria can multiply and cause inflammation leaving lungs open to potential damage.**

Presence of a cough (or increase in cough) is usually the first sign that there is new infection. It is important to know what organism is growing so that the correct antibiotic can be prescribed. This is why a sputum, cough swab/suction is obtained with each new infection.

Staphylococcus aureus and Haemophilus influenzae are the most common bacteria seen in childhood. With age, infection progresses to involve the bacteria Pseudomonas aeruginosa, Burkholderia cepacia, and Stenotrophomonas maltophilia.

## Common bacteria in CF

### **Haemophilus influenzae**

Common in the throat of most healthy people. It is associated with infections of the respiratory tract and is often the cause of acute infections in CF.

### **Staphylococcus aureus**

Present in the nose and on the skin in a number of healthy people. S. aureus is not a common cause of significant deterioration in CF but can result in scarring, tissue damage and airway obstruction, making the lungs more susceptible to P. aeruginosa infection.

### **Pseudomonas aeruginosa**

P. aeruginosa has the ability to live in many environments, from water and soil to plants and animals, including humans. P. aeruginosa is an opportunistic and highly adaptive bacterium. When it becomes established in the airways, the bacteria produce a protective 'biofilm' which surrounds the bacteria and allows it to stick to the airway lining. This biofilm makes it difficult for either the immune system or antibiotics to

effectively clear P. aeruginosa from the lungs. We can prevent long-term or chronic establishment of the bacteria, in most people, by intensive treatment when first detected, using a combination of intravenous, oral and nebulised antibiotics. Once the biofilms are established, P. aeruginosa produces toxic proteins which cause tissue damage and can interfere with the immune system. Antibiotics are able to hit the bacteria hard enough to turn off their production of toxins and help prevent further damage.

### **Burkholderia cepacia complex**

The bacteria previously known as Burkholderia cepacia has now been reclassified into nine closely related species or 'genomovars', collectively known as B. cepacia complex. The bacteria's natural environments are moist soil around plant roots and freshwater environments. It does not occur widely in homes, hospitals or other environments. The occurrence of B. cepacia complex amongst CF patients is usually low, but increases if infection spreads from patient to patient. B. cepacia complex likes to live in biofilms, like P. aeruginosa, and is much more resistant than other CF bacteria to antibiotics, making it more difficult to treat. Although most CF patients do not become very ill when they contract B. cepacia complex, there are some genomovars that can cause very severe chest problems. Some strains of B. cepacia complex can be successfully treated with early aggressive antibiotic therapy before chronic infection becomes established. It is also imperative that all patients with B. cepacia complex are strictly isolated from each other at all times to stop spread of infection.

### **Stenotrophomonas maltophilia**

S. maltophilia is widespread in the home and hospital environments, particularly in water sources. The main risk of infection appears to be repeated exposure to antibiotic therapy. The reported occurrence of S. maltophilia in CF is around 20%, although most people appear to be only intermittently rather than chronically infected. Studies have failed to show a clear clinical impact of S. maltophilia on people with CF, therefore the need for, and optimum approach to treatment, remains uncertain.

In the next newsletter we will look at ways to reduce the risk of contact and/or infection with respiratory bacteria/organisms.

### **Viv Isles (RN, MN)**

### **Clinical Nurse Specialist**

*There is no disease so rare that it does not deserve attention*

## Bill walks Hadrians Wall



**Bill Nelson, at over 60 years old, is our 'most mature' person with CF in New Zealand! Bill didn't find out until pretty late in his life that he even had CF!**

Bill enjoys the great outdoors, and this year he decided to take a holiday with a difference, by walking across Hadrians Wall in Britain, with his wife Heather. Here is his account of their trip.

*We had a one night stop in Singapore, on our way to UK, to ease the jet lag a bit, and it really helped. Arriving into Manchester on a glorious warm spring morning, we took a train to Carlisle, an interesting city with many historical buildings including the castle and cathedral, both dating back to Roman times.*

*Whilst on the wall we stayed at the most amazing bed and breakfast, Brookside Villa, where the proprietors would pick you up, when you felt that you had walked enough for the day, and drop you off again the next day to continue your walking. Denise, who runs the B & B also makes lunches, so that solved another problem, as there are often no shops for miles and nowhere to buy food.*

*Day one was spent mostly walking on the roads out of Carlisle and in the vicinity of where the wall once was. We eventually walked along part of what had once been the sod wall, and were fortunate that being spring the bluebells were out. They made a very pretty scene, and we enjoyed the change. We had intended to walk as far as Gilsland from Carlisle the first day, but this was a bit ambitious for us, and when we got to Banks a call was made for a pick up.*

*On our second day we walked from Housesteads Fort, back to Gilsland, an extremely interesting and well preserved part of the wall.*

*Housesteads is the only place where walkers are allowed to walk on top of the wall.*

*It never ceased to amaze me how the wall was built, out of dry stone, so long ago, and without the tools of today, and so beautifully square, and straight sided. It was over 2 metres high and wide enough to take a chariot along the top. Along the route there are many Mile Castles, and forts all dating from AD122, when the wall was built.*

*We spent 4 days walking along the wall, and enjoyed it immensely. We walked the wall as independent travellers, however there are a number of companies that will organise the walk for you, and transport your luggage from place to place for you as well.*

*The wall runs from Carlisle to Newcastle, but there are a number of parts that can be visited easily, and it can be seen from the road as you drive past Twice Brewed on the road between Carlisle and Newcastle.*

*It was a great achievement, and I went on to do many more hikes, in Scotland and the Yorkshire Dales as well, before returning home. All this had no ill effects on my health and I am now planning a much longer trip for next year walking Britain's Coast to Coast.*

*Good on you Bill – you're a real inspiration to everyone living with CF!*

## Kaleb meets his idol



*Just before my 14th birthday in January, Sue Lovelock came around to my house and gave me an envelope with the best present in my life, when I opened it I was speechless, she had organised for me to meet my favourite person in the world.*



*On February 16th, I was extremely lucky to meet my idol Travis Pastrana at the Nitro Circus Tour of NZ. It was amazing*

*and I didn't realize he was so tall! Travis was very friendly and welcoming and he signed lots of items for me and I also got lots of photos with him.*

*My other idol is Levi Sherwood, I also got signatures*

*and photos with him. He gave me a bit of advice, he told me not to bother getting a foam pit as you can't get enough rhythm to land your tricks properly. On saying that he has broken a lot of bones!*

*I also got to meet the rest of The Nitro Circus team and the show was awesome as we had great seats right in front of the main 50 foot gigantator ramp. Levi Sherwood and Travis Pastrana were the main attraction and the crowd went crazy whenever they came out on their bikes.*

*The ramp was huge - skateboards, bikes, trikes, skis, chilly bin, boogie board, wheel chair and scooters all went down it with some big crashes!*

*I would really like to thank Sue Lovelock again, SUE YOU ROCK! This has been the best night of my life so far. My new goal is to one day go to The X Games in Las Vegas.*

**Kaleb Skene**



## Laptop for Canterbury

As well as being very busy on the CF Canterbury Committee, Nicky Churton also serves as Secretary for her boy's league club!

***"Shell Kaiapoi have been very good about supporting our league club with petrol vouchers and a big donation towards our building fund. They asked if we could use a laptop for our league club committee. I said yes of course! Then he said he had another to give away and I said "have I got the charity for you!"***

I explained about CF and that our treasurer would be an ideal person to receive one and he agreed to this. It will be just so useful for Viv as now that Ben is older he is using their computer a lot and it is hard for her to get on and use it. She will be able to put the whole accounting package on and even bring along to meetings."

**Awesome stuff Shell Kaiapoi! Thanks to Jeff Waghorn & Team**

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## Next issue

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