

Conference 2011

Yet again, the ‘family reunion thinly disguised as a conference’ was a roaring success as we came together in Wellington to celebrate the year’s successes, share information and learn together, parents, PWCF and their clinical teams.

This year’s event was a ‘home grown’ conference with local speakers taking centre stage to showcase the wealth of knowledge and experience we have within New Zealand.

We are now beginning to see the importance of including speakers from ‘sub-specialities’ in CF Care and this year with Dr. Paul Hofman (Endocrinologist – Starship) and Dr. Campbell Baguley (ENT Specialist – Auckland) speaking on CFRD and sinus care, we see the beginning of a real coming together of ALL aspects of CF to improve quality of care and the level of knowledge amongst PWCF and those who care for them.

The Friday night opening saw the presentation of the Mark Ashford Scholarship to Phoebe Watt. Sadly Phoebe couldn’t be with us as she was unwell, but her Mum, Shelley, accepted the award from DVS and spoke of Phoebe’s resilience and determination to succeed.

Denis Currie presented two of our CF Achievers for 2011 with their certificates,

Tristram Buttner and John Ward, more about these two and the other recipients later in this magazine.

Saturday night’s dinner and Karaoke night saw some real stars come out of the woodwork! Everything from slow ballads to Michael Jackson’s “Thriller” were given the “CF Treatment” and everyone had a heap of fun. Our thanks to our wonderful karaoke master Matt Ryland who kept things going and sang a few songs himself!

A big thank you to our main conference sponsors, Boehringer Ingelheim and Vidcom and trade displayers Pharmaco and Ebos/Pari. We want to also thank the James Cook Hotel, whose staff are a delight to work with and for whom nothing was ever a problem.

As the programme literally had ‘something for everyone’, it is hard to pick out the stand-out presentations. One thing that is obvious is that we NEVER seem to have enough time for questions at the end of people’s talks! If the number of questions is a testament to the interest in a talk, then our speakers were riveting!

Paul Hofman’s lecture on CFRD answered many people’s questions about the key causes and mechanisms of



Shelley accepts Phoebe’s award from Kerry from DVS



Ai Leng Hong, Arthur Booth and Sarah Millwater-Pitt get in the groove!

diabetes in the CF body. He also posed a few questions about the future of CFRD treatment and whether a combination of growth hormone PLUS insulin, earlier in the life of a PWCF might lead to a better outcome overall. Clearly there is more investigation to be done in this area and who knows, it may be something the Shares in Life Foundation can help with!

Hilaire O’Dea’s talk about keeping physio fun for your child could have gone on for far longer than the time allowed as there were SO many questions!

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The Cystic Fibrosis Association acknowledges support for this newsletter from Roche Products (New Zealand) Ltd



Makena takes on Perth!



On the 26th of January, both Mum and I travelled to Perth to set me up for the beginning of my big adventure. Before I left however, we had made contact with the Sir Charles Gardiner Hospital that has a large Cystic Fibrosis centre and a very experienced team.

Leaving NZ was supposed to be the easy part but as it turned out my port-a-cath decided to block itself the week before I was due to leave and I ended up in Auckland Hospital having it replaced so my flights were all delayed. Eventually we arrived in the peak of summer with at least 40° days, which for me was perfect but mum melted somewhat. I had my first clinic appointment 2 days after arriving where we met the team and they helped arranged all my healthcare needs. I was surprised at how much medicine costs in Australia compared to NZ.

I have now been living and working at MLC for almost 5 months. My role here is working in the theatre arts department but I also have weekend and night duties in the boarding house. I live in the boarding house with all the students so I have access to all the school facilities like the pool, sports facilities and cafeteria which makes it a very easy place to live.

I have had one hospital admission so far and will probably have one more before I leave. In 2 months I'm off on the next stage of my adventure – Europe!! On the 9th of July I depart Perth for London where I am meeting up with lots of my high school friends who are on their own gap year and we are going straight into a 29 day European Contiki Tour. I plan to stay on in England after the Contiki until November 1st, staying with friends at their schools, depending on how my health holds up.

From my experiences so far, I would recommend taking a gap year and travelling while your health still allows it, but make sure you contact a CF centre wherever you are going just in case you need them. Take copies of all your notes and some medicines in hand luggage in case your bags go missing.

I finished high school last year with absolutely no idea of what I wanted to study further or do with my life, so a gap year seemed like the fantastic idea.

Many of my friends had applied for and been offered, placements in UK schools to work as tutors. However my dilemma was I HATE the cold and because of my medical needs, wouldn't have been eligible for any of the formal international programmes, so I decided to contact schools directly to see if they took international tutors.

The most obvious starting place was schools in the southern hemisphere - Australia being the closest choice. We started in Perth and located a school that was suitable and after many conversations and lots of paper work I was offered a 6 month placement as a Gap Student (tutor) at the private girl's school; Methodist Ladies College which has 1000 students from kindergarten to year 12 (they don't have a year 13 in Australia).

Continued from front page...

Everyone took new ideas home to try to maintain good adherence in their own families.

Andrea Miller's presentation about her time in the USA, highlighted the vital work being done in that country by the CF Foundation and how important it is for us to support that work through participation in medication trials. As Bob Beall, CEO/ President of the CF Foundation is visiting our shores in August, we will have the opportunity for him to promote the ideals of quality improvement to our wider

clinical community and help us to embed a 'research culture' throughout our organisation.

Our grateful thanks to all of our fantastic speakers and to the delegates who attended, the branches whose grants allowed them to attend and all the service providers who helped to make it a wonderful event.

Next year, we convene in Auckland and this will be a combined conference with our Allied Health family from 11 – 13 May, 2012. See you there!

Diary

**CF Awareness Week
"Bubbles Week"**
August 15 -21st, 2011

**Chairperson's
Conference
Hanmer Springs**
September 10-11th, 2011



Thanks

Thanks to Thomson Reuters and NZFMA for raising \$27,000 for our work from their golf tournament. We are delighted to have been chosen again as the official charity for 2011.

Pictured above are Iain Dixon, CEO of Thomson Reuters and Paul Atmore, CEO of the NZFMA, with our own Kate Russell.

Life is a rollercoaster!



I've never liked rollercoasters. I don't have the desire for the thrill or the adrenalin rush and prefer the ferris wheel at its leisurely pace with a lovely view accompanied by happy fairground music... I think this is a metaphor of my life. However the past year has been anything but a ferris wheel and more like the biggest, scariest rollercoaster you could ever imagine!

I had my lung transplant in January of 2010, I was excited, and not too nervous or scared but looking forward to the new quality of life it would bring. Little did I know I'd be in for the hardest time I've ever had in my 40 years of life with CF.

I could go into huge detail here, but I'll leave that to the memoirs which I'm considering writing at some stage!

To cut a long story short I had many complications including kidney failure, liver toxicity, serious infections and my bowel decided to stop working for 3-4 weeks. (If you are being assessed for a transplant, don't go by my experience, it was an unusual case!)

I remember some days were just minute by minute, willing myself to keep going. It was my husband Rowe sitting beside me, and my family that got me through those dark days. I had them all rather worried on several occasions and they were told to prepare for the worst.

Then I felt I needed more of a challenge, so they found out I had cancer... (insert expletive of your choice here as I did at the time). Even now the thought of it makes me feel exhausted.

So out came my CF warrior, (the hardened, battle-scarred drill sergeant) as



the cancer warrior (this skinny wimpy little snot-nose brat) was standing there bawling its eyes out and so the battle began. That CF warrior really taught the cancer dude a thing or two! The battle commenced and is still rumbling away in the hills somewhere, but relatively under control.

So after 3 months in ICU and a total of six months away I finally came home. I was still very weak and needed a walking frame for a while. I still have cancer as it had spread from my bowel but despite that life goes on with a much better quality. I am doing so much more than I was before my transplant even with all the problems that post transplant brings, so I'll just keep taking it one day at a time.

I have a part-time job at the local dairy but to me I might as well be running Trump Industries! I even enjoy housework, which I couldn't do for years, and enjoy pottering in the garden. I love being able to go for a walk with Rowe and walk around markets etc.

It's nice to remember and feel how life used to be before my lungs were affected by CF. I don't know what's in the future, but I just enjoy today, tomorrow isn't here yet so I don't worry about it. I just live in all the great moments, like sitting in the sun smelling the roses!

I'll leave you with this little thought that I read somewhere... **"Don't be afraid that life may end, but be afraid that you may never begin to live!"**

Erin Bartrum



Powerband

You may have heard of these – lots of athletes at Ironman are wearing them and the claim from the company is that these little silicon wristbands help with balance and strength through a hologram that 'rebalances' your energy field! We have no idea one way or the other but we DO have 5 of these to give away (they retail for \$60) to the first 5 people who would like to give wearing them a go! Snake oil or science – you decide!

Family notices...



Welcome to Kayla Moxon, new daughter of Glen Moxon (PWCF) and Donna Moxon.

Kayla was born on 22/02/11 weighing in at 6lbs, 12oz. She has a big brother, Dean.

If you would like your new arrival, engagement, marriage etc featured in CF News, please send detail to kate@cfnz.org.nz.



Northland golf

For the 4th year running the Northland branch ran its annual golf tournament, raising a whopping \$8,000. They had a record number of teams, with heaps of new contacts for next year made, great weather and a record number of CF families involved. A new car was offered for a hole-in-one sponsored by TW Grant Insurance in Kerikeri. Every player received a prize and all the raffle prizes were kindly donated by local businesses

Raffle time is here!

Our national raffle raises important untagged funds for us each year and we appreciate the time and effort you all put in to selling tickets for us.

We have great prizes this year so the tickets will not be hard to sell.

Tickets have been priced at \$2 each for the past 15 years and we felt it was time to raise the price, so this year, tickets are \$3 – still great value considering there are ten draws!

If you are NOT on our raffle sellers list, all we ask is that you sell 20 tickets (that's 4 books of 5) so contact Caroline to put your name down to receive some caroline@cfnz.org.nz

Special foods – What were they thinking?



A recent Pharmac decision to discontinue full funding of ready-made sip feed supplements such as resource plus, Fortisip and Ensure plus could easily be seen by our membership as the worst decision they have made in many years.

During the consultation phase of the Special Foods review, the Association consistently voiced its opposition to the proposed changes and our dietitians from around New Zealand also sent in a compelling document detailing the serious impact this decision would have. Since the decision was released in March, the Association has sent two further letters with pleas from our members for them to see sense.

Our position is simple:

1. *The powdered alternative does not mix well and only comes in three flavours.*
2. *This reduces flavor choice for a group of people who need variety to be encouraged to eat and comply with taking supplements.*
3. *Powder can NOT be mixed with full fat milk (As Pharmac suggests to boost calories) for those trying to avoid mucous-forming foods.*

4. *If powder is mixed in higher concentrations to achieve higher calories (as Pharmac suggests) it becomes like wallpaper paste.*
5. *Taking a powder to school/ work/ university is inconvenient, time-consuming and also increases the risk of contamination from the water source.*
6. *We have not been given adequate or reliable advice about how far in advance these powders can be mixed and if they need to be refrigerated if they are.*

So what can YOU do? You can write to the following people to express your concern at this very bad Pharmac Decision.

- Peter Moodie – Medical Director, Pharmac, PO Box 10 254, Wellington 6143
- The Hon. Tony Ryall – Minister of Health, FREEPOST, NZ Government, Parliament Buildings, Wellington
- Your own MP

Sadly, it is most likely that Pharmac will not act until we can give them 'hard evidence' about people's health declining as a result of this move. Port CF will be of great value to us in this fight, as we can track BMI and weight percentiles and see if there is a measurable drop after the introduction of the new funding rule.

David's Moonride report

It was certainly a "long day at the office".

Torrential rain 30 minutes before the start made for very challenging riding conditions with mud 2-3 inches deep on many parts of the track.

I just put my head down and kept peddling and I finally finished 14th of the 34 solo riders. I also managed to beat a third of the six-person teams! I managed to complete 29 laps - approx 280kms of muddy, tree-root-infested bush tracks... That's almost from Wellington to Napier! Surviving lengthy endurance races is all about mental toughness and I simply broke the race up into six-hour blocks.

Post-race I had a few sore bits... I won't scare you with the details other than to say we



weren't planning on having kids anyway!

I did have one nasty crash at 2am where I did a Superman impersonation over the handlebars at 30km/h. The attached photo of my destroyed

helmet highlights the importance of wearing appropriate safety equipment.

A big thank you to all those who made supported my recent 24 hr MTB ride and made donations to support Cystic Fibrosis. Together with the matched giving from my supportive employer, BP, close to \$10 000 was raised. I also appreciate the many texts and calls of support I received leading up to the start.

David Lacey, Moonride, 30th May 2011.

News from the CF Adult Reps Desk



by Lisa Borkus

Heading into the silly season of peak bugs, viruses and general increased antibiotic usage, I felt it pertinent to write about the positive effects of probiotics and extras that can help to keep you well and on top of it!

Our bodies are full of bacteria. Some make us sick, some keep us well. Probiotics are foods or nutrition supplements that contain the good bacteria. Most of these organisms are ones already present in our bodies, but not always in sufficient quantity to be of benefit.

Two Italian studies have shown that the probiotic organism, *Lactobacillus rhamnosus GG* (LGG), can benefit cystic fibrosis patients in a couple of ways. In the first study, the researchers just looked at the benefits to the intestines. They found that cystic fibrosis patients who take LGG may have a reduction in the intestinal inflammation that often causes them pain.

The same researchers took it one step further and see how LGG affects the lungs of CF patients. They found that cystic fibrosis patients who took LGG regularly had fewer respiratory infections than those who didn't take LGG. *Lactobacillus rhamnosus GG* is available over the counter in capsule form and is in some brands of yogurt. There are many products, including most yoghurts with active cultures that contain *Lactobacillus acidophilus*. While *Lactobacillus acidophilus* is a beneficial probiotic, it is not the same as LGG. Read the label carefully to be sure you're a getting a product that contains LGG.

We can also help ourselves to keep well by looking at what we are putting into our bodies outside of our normal treatments. Two natural products have caught my attention lately and also some headlines in helping Cystic Fibrosis patients due to their medicinal properties. These are:

- **Coconut:** Coconut is highly nutritious and rich in fibre, vitamins, and minerals. It is classified as a "functional food" because it provides many health benefits beyond its nutritional content. Coconut oil is of special interest because it possesses healing properties far beyond that of any other dietary oil and is extensively used in traditional medicine among Asian and Pacific populations. I have heard from many CF adults that it has been helpful in putting on weight!
- **Turmeric (curcumin):** The medicinal properties of this spice have been slowly revealing themselves over the centuries. It contains anti-inflammatory, anti-bacterial and anti-oxidant properties which may be a helpful addition to have onboard.

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/>

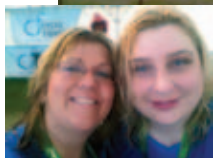
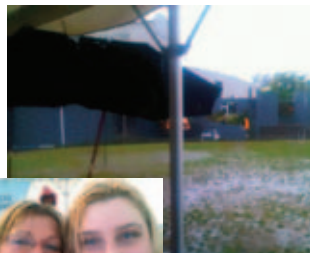
Ironman - Noah's Ark Revisited

From a fundraising point of view, this year's Ironman was great! \$89,000 made in total which was a big improvement on last year.

We had a good number of athletes, many of whom started fundraising for us fairly early on and this made all the difference to the bottom line at the end of the event!

But, for only the second time since we began our Ironman journey, rain totally marred the day and the marquee became a swamp!

We were amazed by how all our CF families 'stuck with it' during the day, even getting pretty wet and persevering with the selling of balloons, pens and chocolate fish. They went out in shifts and plied the streets



and despite the weather, managed to move a bit of stock! Our BBQ team were also on fire, in a good way, this year! With the weather being pretty cold, our yummy fare went down a treat and the team had a steady stream of customers from midday.

Once again, Aaron Fleming successfully completed the event and Cory De Kort, partner of Chantelle Donohue (PWCF) also completed his second Ironman for Breath4CF.

Our top fundraisers this year were Christopher Lee and Olivier Monnard. Our thanks to all the Ironman Directors, Destination Taupo, Mainfreight, Blue Seventy Wetsuits, Timex and Mighty River Power for their loyal support.

Damien's wedding



Saturday March 11th Damien Bell (PWCF) married his sweetheart, Alice in a lovely ceremony at Mystery Creek in Hamilton. Damien's wedding story is a pretty amazing one that we will feature in the next issue of the CF news, along with a few more pictures.

Suffice it to say for now, that the lead-up to the event, the day itself and a few weeks after, involved collapsed lungs, special undies (you'll see what we mean when you read the story) and a heap of love and support from the wider family. Congratulations Damien and Alice – don't they look lovely!

Thanks BP

It's fantastic when someone decides to raise money for us.

It's even MORE fantastic when their employer agrees to match what they raise!

BP is such an employer. They match their staff's fundraising efforts for charity, dollar for dollar (to agreed maximums) and use this as a part of their drive to care about the planet, its people and some very worthy causes.

So when David raised \$5000 at Moonride, BP were only too happy to match it to make it a whopping \$10k from one person's sporting effort.

Well done BP – you should challenge other businesses to do the same!



CF Achievers Awards 2011

Ironman buddies needed!

Can you believe it? Ironman 2012 has already SOLD OUT!

The field has been increased to 1600 and we are already getting registrations from athletes who want to raise money for us while they are training for the 'big race'.

That means that we need buddies NOW and will need a heap more this year as we anticipate uptake to be much higher this year with increased promotion.

If you want to be an Ironman Buddy, just send us your profile: name, age what you do and don't like doing, a wee bit about your CF and a recent picture. We will buddy you up with an athlete so you can share stories and let them know a bit more about CF! Email caroline@cfnz.org.nz

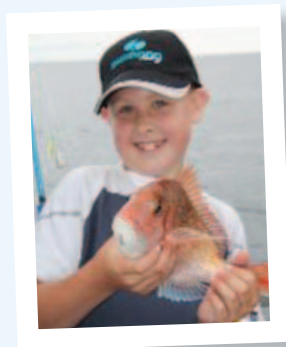
Each year we honour high achievers in the Association across a number of areas, with a CF Achievers Award, sponsored by Boehringer Ingelheim. This year we had eight people recognised for their determination and achievement in sport, education and leadership.

Oliver Carran - 16 years old - Endeavour in Sport

Oliver has played tennis, touch and soccer at rep level. He now coaches and referees touch and plays cricket in the summer. In 2010 he was awarded the Eastern Southland Cricket Assn. trophy for Most Improved 1st XI Cricketer of the year. Basketball, however, is Oliver's real passion with a long list of achievements in the sport since 2006. Oliver plans to use his award to help fund an Outward Bound course in summer 2011.



McMahon Elliott (Mac) – 10 years old - Endeavour in Sport



Mac is a sports enthusiast extraordinaire with a long list of sporting credits to his name: representative rugby, karate, hockey, athletics, Kiaido Ryu, sports fishing are only the tip of the iceberg with this sports whiz! Mac now has his brown belt in Kiaido Ryu which is his real passion. For 2009/10 he was awarded Top Junior Male for his Dojo. Mac also won Top Junior Angler at the Bay of Islands Swordfish Club in 2009/2010. Mac also has Coeliac Disease as well as CF and his parents characterise him as managing these two challenges with maturity beyond his years. Mac was also awarded the Citizenship Award for his school in 2010. He is saving toward a small boat.

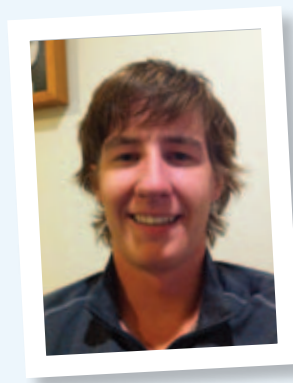
Vaughan Somerville – 17 years old – Education

In his last four years at Auckland Grammar, Vaughan was in accelerated streams and passed Cambridge exams with Excellence. He was awarded the Ian MacKinlay Scholarship last year, awarded for personal excellence in every field of endeavour within the school. He also received the top prize for physical education. During his final two years, Vaughan had several hospitalisations and he worked these in-patient stays to coincide with mid-term breaks and school holidays to minimize his absence from school. In 2010 Vaughan rallied the other school prefects to sell 10,000 chocolate fish for the CF Awareness Campaign. Vaughan plans to use his grant to support his studies.



Alexander McKay – 19 years old – Education

In his final year at Sacred Heart College, Alex won several awards; Excellence in English and Statistics, first place Physical Education, Economics, Religious Education and Accounting. He also gained excellence in his NCEA results that year with a scholarship for Economics and Physical Education. He also maintained a senior leadership role in the school throughout this time. Alex has now completed his first year at Uni, being offered a place in the UoA Law programme. Alex says he will use the award to help him with his education.



A big thanks!

Many thanks to these funders for their recent support...

Foodstuffs South
Pelorus Trust
Lion Foundation
Lottery Board
First Sovereign
ASB Trust

Ashley Watson – 17 years old – Endeavour in Sport

Ashley's passion is clay-bird shooting. In 2010 he made the NZ Junior Skeet team and shot for the NZ Skeet Postal Challenge. He won gold in the 2010 NZ Skeet Doubles C Grade and Silver in the NZ Skeet C Grade alongside many other victories in local competition. As he has only been shooting for two years, this is quite an achievement and shows some amazing talent! He works part-time milking cows and all the money he earns goes on ammunition and entry fees. He says the award will help with travel to events and will propel him toward goal to make the 2012 World Championship DTL Team.



Tristram Buttner – 26 years old – Leadership

Tristram has been working within his community for the past two years, as assistant coach for a junior soccer team and becoming a committee member of the Taita RSA. Tristram is a qualified electrician but sadly he was made redundant in early December 2010. Not content to sit around and wait for opportunity to come knocking, Tristram has now started his own electrical business. He is also an active member of the CF Association in Wellington and helped with the 2010 Christmas Tree Festival by providing electrical services onsite. This award will help Tristram in his new business.



Shane Hill – 33 years old – Leadership

Shane has had a varied academic career, gaining a Diploma in Sport, a degree in Computer Graphic Design and then settling into his career with a Post-Graduate Diploma in Secondary teaching. Shane states that he realised that teachers can be important positive role models and as such he has been body-building for 14 years and teaches PE alongside Design. Due to his condition, he was not well enough to gain full registration as a teacher until now. This is a huge achievement for Shane and a testament to his perseverance. Shane was married this year, to Rachel, whom he credits with 'changing his life'. He is looking forward to buying a home and starting a family. One day he hopes to write about his life with CF.



John Ward – 24 years old – Education

John has completed a degree in Audio Production, is a guitarist and songwriter and with his degree would like to start his own production company, with kiwi musicians and bands. The degree took John four years to complete due to numerous hospital admissions. He has worked fulltime as well as teaching music classes to school students. Like many people with CF, John has faced many challenges to his dreams but with attitude and tenacity, he has completed his goal of a degree. He plans to pay his student loan with an award.



Thanks America!



When the February quake hit, Kate reached out to our overseas affiliates for assistance, knowing that fundraising was about to get incredibly difficult for us at a national and local level.

CF Worldwide answered our call by featuring us on their website for the month of April and putting out a call for international donations.

Even better, our good friends at the CF Foundation in the USA, without hesitation, offered us financial assistance in the form of a \$50,000 USD restricted grant. The grant will be used to offset costs for Port CF and to help with the administration of the Shares in Life Foundation over the coming couple of years.

An amazingly generous gesture from the Foundation, with whom we are forging ever closer links with each passing year.



Because it happens and matters...

Skylight foundation

Don't forget that our friends at the Skylight Foundation have some fantastic books dealing with grief and change available to buy at very reasonable prices.

We carry some of their books in our own library but if you want copy to keep, you can visit them at their website to order www.skylight.org.nz/shop/



Who do I go to?

We often get told that PWCf and their families are not sure whether to go to national or their branch for certain kinds of support. So, although this is not an exhaustive list, here is a general guide as to who you should go to if you need help with yours or your child's CF.

National

- Vouchers for home IV's (needs assessed)
- Transplant assistance
- Hospital allowance
- Breath4CF
- Funeral assistance
- Fundraising for national projects
- Information on research
- Library
- Education materials
- Social worker help
- Confidential advice
- Conference

Branch

- Assistance with equipment (nebulisers etc)
- Assistance with general welfare
- In-hospital vouchers (needs assessed)
- Local fundraising
- Peer support

If you are not linked into your local branch and would like to be more involved, tell us kate@cfnz.org.nz



Awareness Week AUGUST 15 – 21ST

This year's Awareness Campaign is going to be a 'doozy' as we launch the new Bubbles Week campaign all over New Zealand.

Supporting the campaign, we will have a TV Commercial on TV 3 (being aired free of charge) Orly Productions here in Christchurch have been incredibly kind in offering to make the ad for us free of charge which in today's economic climate is a fantastic offer!

Thanks TV3 and Orly!

We will also have APN billboards in the main centres and "AdShell" bus shelter advertisements. Both the billboard and bus shelter space has been gifted to us and we are incredibly grateful for APN and AdShell's generosity.

The national office is busy scoping some amazing merchandise which will be available through branches and directly from our website, including mugs, umbrellas, pens, bubble kits and much more!

Grace Patterson from Taranaki will be our poster girl for this year's campaign. Grace lives with her Mum Jess and Dad Sean on a farm in 'rural naki'. She will be seen in our posters and ad, blowing bubbles and showing the world the importance of healthy lungs for a full and active life.

And of course, because they were such a HIT last year, we will, once again, be selling chocolate fish which made

branches a lot of money in 2010.

There are so many ways you can support the campaign. You can buy merchandise, sell a box of chocolate fish for your local branch or even run a small event yourself!

What about a sausage sizzle?

A Bad Hair Day at your school?

A Mufti Day at work?

A 'wear your PJs' day?

What if you had several friends round for dinner and instead of

asking them to bring

something to eat, ask them for a \$20 per head donation to CF!

You could approach your local paper and ask them if they will run a story about CF in our week.



If you want to run a bubble-themed event, you could have a bubble gum blowing competition! Blow the biggest bubble with soapy bubble mixture!

However you decide to support our efforts to increase awareness in 2011, we can assist with stickers, posters and advice. Often for little charities like us, it isn't one big thing that raises money but lots and lots of little events that ALL ADD UP!

So talk to your local Chairperson or give us a call at the national office on 0800 65 1122 to talk about your idea. We LOVE all new ideas about how we can teach NZ about CF.



Pulmozyme® (dornase alfa 2.5mg/2.5mL solution for inhalation) is a **Prescription Medicine** used to improve lung function in cystic fibrosis patients.

Possible unwanted effects: voice hoarseness, sore throat, hayfever-like symptoms, conjunctivitis (sore, red, weeping eyes), high temperature, indigestion, skin rash, itchiness or hives. Chest pain, breathlessness, and cough. When you first start using Pulmozyme, your lung function may get worse and you may cough up more mucus.

Ask your doctor if Pulmozyme is right for you. Use strictly as directed. If symptoms continue or if you have side effects or would like further information please talk to your doctor or pharmacist or visit www.medsafe.govt.nz for Pulmozyme Consumer Medicine Information. **Pulmozyme is funded by Special Authority for patients approved by the Cystic Fibrosis DN'ase Advisory Panel. A pharmacy charge and normal doctor's fees will apply.**

Roche Products (New Zealand) Ltd, PO Box 12-492, Penrose, Auckland. TAPS# PP6366 - JAN 2009

Canterbury ...battered and bruised

It seems everytime we switch on the telly, there is a new flood, earthquake or tornado somewhere. But by far the one that has had the biggest impact in NZ is the earthquake that struck Christchurch on February 22nd.

The National Office was turned upside down, but miraculously, the only thing damaged was one filing cabinet! But, the ongoing aftershocks have certainly had the effect of making everyone at the national office tired, stressed whilst dealing with their own, damaged homes.

The bigger impact on the Association, both from a national office and a local Canterbury Branch point of view is in our fundraising. So much philanthropic money has been sucked out of the market, that donations are down across the board.

The national association is considering options for the Crusaders Cricket match and Canterbury have had to cancel their Christchurch Casino Golf Masters and their Christmas Tree Festival – both expected to be the biggest earners for the branch for this year.

Melissa Skene, Canterbury Chair told us "The welfare issue has not yet begun, I have talked to a lot of the families and the issue is going to be winter heating! What good is putting in heat pumps as the main source of heating in a home that you can see

daylight through the walls and around the window frames? Winter has already begun here and mums at home with children need to keep warm as do adults keeping well, so we are preparing for many requests for assistance.

We have already had our first claim for firewood, so I am forecasting that the need is going to be huge and we will have to manage it. People are putting on brave faces but this is going to change. The masks will slip especially as the cold sets in, people are now starting to realise that there is no quick fix and people with severely damaged homes are in limbo. The stress on families is bad now but is going to get a lot worse with peoples' personal wellbeing status dropping. The earthquakes have affected every person in Christchurch whether your home is damaged or not."

Congratulations to the Hayes family

MORE FM Canterbury teamed up with Falcon Construction to help them find a deserving family or person in need of a modular house after the 22nd February Earthquake.

The Hayes had a lovely heritage home which sadly was badly damaged and to date a decision has still to be made on whether the home can be repaired or will have to be bowled and rebuilt. The Hayes' business, located within the quake cordon was also badly affected and it only got back up and running in early May.

Falcon were looking for a severely disadvantaged family, who had an unliveable house, ie red stickered or needing to be demolished, that were without or struggling for accommodation and had existing land that can be built on. The mayor contributed all tip and building consent fees, with everything else being contributed by Christchurch sub trades and suppliers. Truly a



The Hayes family accepting their gift from Falcon and More FM

Canterbury effort. We would specifically like to acknowledge, Falcon Construction, More FM, Placemakers, Avon Roofing, Smiths City and all the other amazing businesses that helped with this project.

Deb told us "what is so fantastic is that eventually, we will rebuild our home and then the house that Falcon have given us can go to Charlotte (PWCF) so she doesn't have to worry about where to live, a mortgage etc"



Thanks a lot!

Each year, some of our branch executives change and new people step into the governance roles that are so important to the healthy functioning of our local branches. In some branches however, the Executives can stay unchanged for many years, for a variety of reasons.

In Waikato, Claudette van Niekerk is stepping down after several years in the role of Chair. Claudette has had a challenging last 3 years and has bravely continued in her role despite at times, having a huge amount on her plate. Claudette is now in training as a Social Worker and has decided that she needs to concentrate on her studies, so thank you from everyone in Waikato and at National Office

In Otago, Janet Camplin has been an active committee member for 15 years, in the Chairperson's role for most of that time. With few people to call on for help, Janet has made sure that the people with CF in Otago get extra assistance when it is most necessary. Janet is stepping down to have a well-earned rest from single-handedly running the branch and is looking forward to some new people in the Otago area stepping into governance roles.

Quote of the day

"True heroism is remarkably sober, very undramatic. It is not the urge to surpass all others at whatever the cost, but the urge to serve others at whatever the cost."

ARTHUR ASHE



2013 Australasian Conference

Earlier this year we received the great news that we had won our bid to host the 2013 Australasian Conference here in New Zealand.

This will be the largest conference we have attempted with a lay and medical/scientific track. Around 600 delegates will come from around New Zealand and Australia with a few coming from even further afield.

We have decided, in light of the quakes in ChristChurch to bring the conference to Auckland where we will showcase the best NZ has to offer and one thing is certain - the conference will attract international speakers and trade like we have never seen in this country before.

This conference will replace our own conference in 2013 and will be held in late August – dates to be confirmed.

Make sure you apply!

Just a reminder to you to make sure you use



your Breath4CF grant for the year in good time. Our financial year runs from July 1 to June 30 each year and if you don't use your allowance you can't carry it forward! So make sure you apply. If you are unsure how, ask your local field worker.

CF Achievers Awards will close on 1 April NOT 1 March as in previous years. If you would like to know more about the CF Achievers Awards and how to apply, visit <http://www.cfnz.org.nz/grants-and-awards/#GrantsAwards/Achievers>

Why do I do it?

Each person has their own unique and special reasons for putting up their hand and helping us to win the fight against CF.



"It took me 6 years before I got involved because I wanted to get to grips with it first myself. I also have a strong feeling that CF isn't what makes my son special; it's just something he has. But I would say it has also been important to me to meet others walking the same path.

Overall it's my way of fighting. I can't fix CF for my child but I can try do what I can by raising money, looking after our people with CF and lobbying as hard as we can."

Nicky Churton – Branch Secretary - Canterbury

"It's simple for me. It's part of healing to do something about a disease that gives you no choices. You can educate others and support those who need it. Make a difference, feel a part of a group of people where it doesn't matter what they have – they are able to stand together.

I want to see children grow to be adults who are as capable as anyone else and see them live their lives alongside the rest of us. I want to help them to put things together and ensure they always have somewhere else to turn and the life skills to GO FOR IT! Together we are mighty - that's our strength."

Janet Camplin – Branch Chairperson, Otago

"For me, the passion to be of service to the community is very personal. I lost my brother at the age of 26 to CF. After years of running away from anything to do with CF, other than my own CF treatment, I reached a cross-roads. The growth and development of our Association is a direct result of many people serving tirelessly to make things better for those with CF and their families. I want to be a part of that. To do my bit in making this journey for all of us a little easier.

I have learnt many things and have found a wealth of support and understanding that is like no other community and feel proud of how we have developed to fight this disease. I have learnt the power of lobbying, development of processes to assist where there is financial need, education through conferences and literature and most of all support and understanding from like-minded people tackling the same hurdles."

Lisa Borkus – Adult Rep to the Board

"I first heard the name CYSTIC FIBROSIS was 38 years ago when our second son was born 8 weeks premature. With Colleen's background as a Physiotherapist, she has been the most important support person for Cameron over all the challenges he has faced with CF. Like most mums, her role has been on-going and of immense importance.

Feeling inadequate in the day-to-day practical support area, it really became a question of 'where can I help?'. At the time there were many good parent support groups spread throughout NZ, but no effective focus as a National Association. It was here I was able to utilise my business skills to assist, with others, to develop what we now have as an effective national body.

Hardly exciting stuff. But I think that in our own different ways, whether on a large or modest scale, there will always be opportunity for each and everyone of us to assist where we can in the fight against CF. It is not the size of the commitment that matters, but that the commitment was made at all!"

Denis Currie – CFNZ President

Stories needed!

Do you have a great story that could serve as inspiration to others?
Do you want to say something about CF or have an interesting story to tell?
We want to hear from you! CF News is all about you, our members and we want to tell your stories.

If you have something to tell everyone, email kate@cfnz.org.nz

Nebulisers - it's horses for courses!



Recently we canvassed nurses from around NZ to see which nebs they were using. Here's what they told us:

Otago

Most of our patients use the eflow for hypertonic saline and also nebulised antibiotics when needed. The families like them as they are portable and the time for the drugs to be nebulised is much quicker than others hence better compliance. The only disadvantage is replacing the headsets every year the parts are expensive .

Hawkes Bay

All our kiddies are using Pari Boy SX (Sprint) for antibiotics and hypertonic saline. Good delivery easy to use. Easy to get consumables. Inline with Starship.

Auckland – Starship

Pari Sprint nebuliser bowls for nebulised antibiotics and hypertonic saline. These bowls are used with the Pari Turbo Boy compressors (supplied by the Auckland Branch for the Auckland children). The ADHB supply the first and annual Pari Sprint bowls and filter valve sets and the Homecare teams in the 3 Auckland areas supply the ongoing supply of consumables.

The advantages of the Sprint bowls when used for antibiotics are they are easy to put together, nebulise fairly quickly, good particle deposition, easy to clean, few parts to the system.

When using Hypertonic Saline and the Pari Sprint bowl together, the chest physio (using the Pari S-PEP) is done at the same time – the S-PEP and the Sprint bowl connect together and the whole treatment takes about 15 – 20mins if done properly. The SPEP is easily assembled and easy to clean and maintain.

Eflow not used– initial expense, rust easily if using with Hypertonic Saline, break down more easily, expensive consumables – fast time of nebulising – but if using Hypertonic Saline & e-flow the Saline is inhaled first and the PEP done following – so the time is the same as the Sprint bowl and Pari S-PEP combined.

Canterbury adults

The Eflow is portable, fast and quiet but it is expensive and the ongoing parts cost is high. Some patients have reported that it is 'too fast' for hypertonic saline, making them cough too much! It can be difficult to clean and we have had problems with rust on the mesh.

The PariBoy is a reasonable price and has a relatively quick nebulising time when used with an LC Sprint. It is easy to clean but it is not portable and is noisier than the Eflow.

Auckland adults

Pari Boy Turbo – better distribution of particles / medications to lung fields. They also have a portable battery charged option for travelling – very good too... although they take longer to nebulise they are quicker to clean than the Eflow, which we have also had rusting problems with.

Canterbury paediatrics

The compressor most commonly used at our clinic (Portaneb, Pariboy Turbo N, Pariboy SX) have a flow rate adequate to drive modern Venturi type nebulisers. Venturi nebulizers enhance drug delivery during inhalation, reducing treatment times and drug wastage. We currently use the Sidestream and Pari LC Sprint nebuliser. The Sidestream, which can be used for bronchodilators, Pulmozyme and hypertonic saline uses the compressors airflow to allow extra air through the nebuliser, increasing the output from the nebuliser and drug deposition, reducing nebulisation time. The Pari LC Sprint, directs the patient's inspiratory flow through the nebuliser chamber, increasing the effective inhaled nebuliser output. The Pari LC sprint can be combined with Pari PEP so that hypertonic saline and physiotherapy can be done at the same time.

A small number of patients may have an eFlow electronic nebuliser – these have revolutionised nebuliser treatment and work on membrane/mesh technology. The units are quick and quiet, however they are expensive.



Peanut butter & jelly french toast

This twist on the traditional breakfast favorite is easy to make and a great way to start the day. In the States they call jam 'jelly' so no, it isn't going to wobble on the plate!

Prep time: 20 minutes

Ingredients:

4 slices whole wheat bread
¼ c. peanut butter
2 tbsp. jam (raspberry is especially nice)
2 eggs
¼ c. heavy cream
3 tbsp. butter

Directions:

1. Spread peanut butter on two slices of bread and jam on the other two slices.
2. Put one slice of each together to form sandwiches.
3. In a mixing bowl, lightly beat eggs and cream together.
4. Melt butter in large skillet over medium heat.
5. Dip sandwiches in egg mixture, coating well.
6. Place in skillet and brown both sides. Serve immediately.

Serves: 2

Serving size: 1 sandwich

Nutritional analysis (per serving):

703 calories
20 g protein
53 g fat
738 mg sodium
99 mg calcium

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New Zealand CF information
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Sources can be accessed on the
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Suggested improvements
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Post to: Cystic Fibrosis Association, PO Box 8241, Christchurch

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