



**CYSTIC FIBROSIS ASSOCIATION OF NEW ZEALAND**

## *News from the CF Adult Rep's Desk* *February 2010*

Hi Guys

Hope you all had a fabulous Christmas and New Year celebration period.

I enjoyed some quality time in Queenstown and Nelson with my family. Breathtaking views, fun events and good company made for an enjoyable time away. Enjoyed being a little more creative with my camera and caught a fun shot of the typical Nelson sunset!



This year is already shaping up to be an exciting one for the CF community. Some main events coming up are Ironman in March and the CF Conference in May, which promise to be amazing events. Also, there will be other activities and fundraising opportunities throughout the year in your various regions around the country.

### ***PREPARATION FOR IRONMAN, TAUPO – MARCH 2010***

We are very fortunate to be the official charity for this event. Each year, competitors come from all around the world to compete and many to also raise money for CF individuals with Breath4CF. How this works, is that the athletes are 'buddied' with a CF individual and they communicate with each other and share their trials and set a goal to raise a certain amount for Breath4CF. This is my first year of being a 'buddy'. I am so looking forward to heading to Taupo and supporting him as he competes and also catch up with CF friends and families and meet new ones. It is an amazing event to be a part of.

I am reminded of a story sent to me by a friend. Some time ago, at the Seattle Olympics, nine athletes all mentally and physically challenged, were standing on the start line for the 200m race. The gun fired and the race began. Not everyone was running, but everyone wanted to participate and win.

They ran in three's. A boy tripped and fell, did a few somersaults and started crying. The other eight heard him crying. They slowed down and looked behind them. They stopped and came back .... All of them!

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A girl with Down's Syndrome sat down next to him, hugged him and asked, 'Feeling better now?'. Then all nine walked shoulder to shoulder to the finishing line. The whole crowd stood up and applauded. The applause lasted a very long time. People who witnessed this still talk about it. Why? Because deep down inside us, we all know that the important thing in life is much more than winning for ourselves alone.



Many of the athletes who are coming to compete in Ironman are setting high goals for themselves in competing in a very mentally and physically demanding sport. Not only that, but they carry a desire to make things better for people with Cystic Fibrosis in the form of fundraising for Breath4CF.

When I think of the mental toughness and the necessity to stick with training and discipline to do the things that are required, it is easy to see the comparisons between this and living on a day-to-day basis with CF. I asked my Ironman buddy Kyle Jackson, to write a few words on what doing Ironman means to him and his journey in this competition.

### *KYLE JACKSON - IRONMAN COMPETITOR*

My name is Kyle Jackson (34). I live in Taupo and whilst taking part in this year's Ironman New Zealand, I am trying to raise money for Breath4CF. Previously I have competed in three Ironman events.

The reasons that people take on the Ironman or any long distance event are as varied as the individuals themselves. For me it's about testing myself mentally and physically, and it's the mental test that is the hardest. You need to be mentally strong to finish the event but the most important part is to be mentally committed to the training, as the training is by far, the hardest part of the Ironman experience.

During the 10-12 months that most people spend preparing for Ironman you continually push yourself harder than you have ever done before. The training does hurt, you do suffer, you sacrifice time with friends and family and sometimes it's no fun at all. There are many moments, in the middle of a run, or when you wake up in pain in the morning, when you ask yourself why you are doing this or even if it's worth it. And then there are the times, when you are amazed at your own ability to go further, faster and longer than you ever thought you were capable of. It makes you feel strong, invincible and that you can do absolutely anything you put your mind to.

The training distances get bigger and bigger and the time required for the training gets longer and longer until you have your "peak week" around 3/4 weeks before the event. Exactly what this week involves is different for everyone but for me it's a week of around 25 hours of training which will include a 180k ride, a 32k run and swim/bike/run of 2km/50km/18km.

These are long distances and it will hurt, but because of all the training that you have done to get to this point, you learn that these distances are only numbers and that you can and will get through it. This is why its said that Ironman is more about mental strength than physical strength. If you are mentally strong enough to finish the training then you will be physically strong enough to finish the race.

The race day is the reward for getting through the training. My only goal for that day is to finish. I would like it to be in a good time but that is secondary to actually finishing the race.



Once the start gun goes you know that it's you against the course and you against yourself. You know that you will cover 226km if you get to the finish. You know that it may rain, be windy, be hot or cold but what you don't know is how you will react to these things. Success or failure will come down to how well you have trained, what you have learned and how you have managed yourself on that day.

As you make your way up the final rise along the lakefront to the finish line, you can finally relax and enjoy the moment. For you know that the pain, suffering and physical hurt is almost over. And that everything you have sacrificed to finish the race was all worth it. You know that when you make the final turn into the main street, there will be people cheering, calling your name and there is lots and lots of noise.

As you enter the finishing chute and finally cross the finish line you realise that time and those moments are something that you won't ever forget and something you want to feel again and again. As your name is announced over the loudspeaker that you are an ironman, you know that all the effort, the pain and the suffering to get to that point in time was worth it, and that the day you have had is something that will live with you forever.

I got involved with Breath4CF to raise a little money but mostly to be able to share the experience of what it is like to finish Ironman with someone that wouldn't be able to experience it for themselves. I hope that through my efforts that Lisa and her daughter Analise, get to feel some of the exhilaration of being involved in an event like Ironman and that they too will remember it for the rest of their lives.

I can appreciate that for all the suffering I experience during my training, and on the day of the event, is not only a choice I make but it is also temporary ie. not only is over when I finish my race but I am stronger and fitter for the experience. After reading through your newsletters and being involved with Lisa, I would like to say that I admire and respect the courage those of you have living with CF to work hard to lead what we would call a 'normal' life in a positive and dignified way. I realise that there is no finishing line, with spectators and a medal but just know that I applaud each and every one of you!

# ***INSPIRING NEW ZEALAND CF ADULTS***

*Tribute to:*

*Jonathan (Jono) Fowler*  
*12<sup>th</sup> April 1982 – 27<sup>th</sup> December 2009*



It is with great sadness that we lost Jono at the end of last year. It seems only fitting to write this tribute for a dear friend who had a huge impact on other CF adults and the wider CF community. He had an ability to hold onto the positive things in life and courageously fought some pretty tough battles simply to stay alive. Since Jono's double-lung transplant on 19<sup>th</sup> December 2008 he has been an inspiration to many and had a larger than life personality that made it easy to get swept up in his zeal and enthusiasm for life and a desire to give back to the CF community. He completed the 'Beaters and Breathers' Taranaki Mountain Relay only 6 weeks before he died and was in good health and good spirits, so his passing has come as a great shock to many.

Jono was my 'partner in crime' on many occasions. He was my co-admin in starting up the CF Adult Network, CFANZ Network and also was a member of the CFACT group. He was very proactive in promoting organ donation awareness and was often asked to present talks at various places about his journey. He wrote a helpful leaflet that can be found on our website regarding the things to think about when you are accepted onto the 'active' waiting list for a lung transplant.

Jono held a deep empathy for those living with CF and those embarking on the transplant road and made himself available to chat and help whenever needed. Although his passion was supporting those with CF, he also had a heart for those suffering from any form of illness and was always there ready to support them or lend a listening ear.

Jono also possessed a wicked sense of humour, which balanced what was often a very heavy load. On a personal level, this was tremendously helpful to me in balancing difficult issues and like with many of you, Jono was available to chat at those odd hours of the morning when you couldn't sleep. He was a bit of a computer wiz and also had embarked on studies on Cranial Sacral Therapy, which he had found helpful in his walk with CF.

One of Jono's favourite quotes was: 'All you need to decide is what to do with the time given to you'. We are grateful that Jono chose to give so much to the people around him and inspire so many people with the time he was given and to live life to the full, despite CF and the tough journey it was for him.

## **CIPROFLOXACIN**

After talking with many CF adults recently, I am aware that Ciprofloxacin (Cipro) tends to be a significant oral antibiotic that is used by CF individuals because of its broad spectrum capacity to deal with a number of bacteria and the only one effective against Pseudomonas. This is a fantastic antibiotic to have in our artillery, but one that can sometimes have a few side effects. We all experience side effects differently and some of us may not have any, but thought it interesting that many people have not been aware that this drug interferes with the body's ability to eradicate caffeine.

Cipro may increase nervousness, sleeplessness, heart pounding, and anxiety caused by caffeine. All drinks containing caffeine are advised against whilst on this drug to minimise the build up of caffeine in the system.

Your medical team can provide you with things you need to be mindful of when using this drug, i.e. hypersensitivity to sunlight, etc. However, the issue regarding the interference with caffeine eradication may be influential in the degree of some side effects you experience whilst using it.

### ***FOR THOSE KEEN GARDENER'S AMONGST YOU - POTTING MIX WARNING***

I was watching Close-Up last night and was alarmed as to how many people are unaware of the dangers of Potting Mix due to being exposed to Legionella. In the CF community, we are acutely aware of the risk of compost heaps, but sometimes the simple potting mix can slip under the radar. Simple precautions should be put in place when using this product. Although health warnings are generally placed on the bags, these are often small and easy to miss. Some basic guidelines are:

- Use a face mask covering nose and mouth to reduce the risk of inhaling the dust
- Always open potting mix bags at arms length in a well ventilated place with care to avoid breathing in airborne particles
- Damp down with water to reduce dust before handling
- Always wash hands thoroughly after working in the garden

***'A day without laughter is a day wasted'***  
*Charlie Chaplin*

*Lisa Borkus*