



Lisa Borkus, CF Adult Rep

Cftalk

NEWS FROM THE CF ADULT REPS DESK

ISSUE 6

NOVEMBER / DECEMBER 2010

INSIDE THIS ISSUE:

Andrew Walklin 1

Situation Critical : Erin and Kat 1

Exercise Again 2

Probiotics and Cystic Fibrosis 2

On a Personal Note ... 3

Helpful Links 3

Raising CF Awareness 4

Andrew (AJ) Walklin

National & Regional Winner of the Kiwi Battler Competition



Congratulations to Cricket Wellington and Onslow College 1st XI coach Andrew Walklin who was recently named as the joint winner of the Wellington and Wairarapa regional and winner of the National Kiwi Battler competition. The Morgan Foundation presented \$20,000 to Cystic Fibrosis Association of NZ, Andrew's chosen charity and \$3,000 to Andrew. I asked Andrew to write a little about himself for this edition.

'In my life there has been routine after routine and the same questions each time. Why? I could give you my history of my 36 years, the good, the bad and the ups and

downs and I would say each to their own path. I don't set myself any long term goals, as I get up in the morning and face the day ahead, then the routine starts to kick in, yes I'm up and I know who I am.

It sounds like I have a black cloud over my head, but I look at the cup half full as that's how I deal with things. So I start with, what if I don't take this pill or miss this treatment this once, the so-called "bad things" that could happen to me and then I can work out the "Why" I must do it.

I have Cystic Fibrosis, Type One Diabetes and now doing Kidney Dialysis, but what

am I going to do about it. "Well talk, that's what I'll do"! As you see, I am not much of a writer, but surround myself with people who will support and give me advice, knowledge (good and bad) and ideas. I've met lots of people (some I call close friends) from school days, college, work (day and night shift), playtime and the young to the old and we just "talk" from a joke, to getting something off your chest (wow wasn't meaning it to come out like that Ha-ha). I like to share when the time is right and I like to listen as well, but I've had some great discussions.

I do a lot for others, more than I do for myself and that's what keeps me busy.'

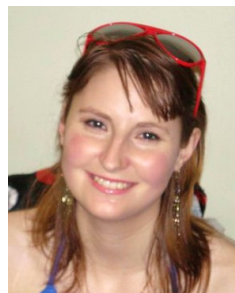
Situation Critical

A new local television series Situation Critical tells the heartfelt stories of New Zealanders in need of organ transplants, as well as meeting families who have lost loved ones and those who have donated a family member's organs in order to give the ultimate gift of life.

Two such individuals were Erin Bartrum and Kat Turner. Incredible women who have undergone lung transplants as their condition with Cystic Fibrosis worsened over the years.



Erin Bartrum is a 40 year AWCF who lives in Wanganui with her husband Rowe. Television of this episode, yet to be advised.



Kat Turner is a 25 year old AWCF living in Palmerston North with her husband Lucas. Her story was televised on Wednesday 10th November at 8pm. This episode can be downloaded online.



Exercise ... Again!!!

Exercise used to be discouraged for people with cystic fibrosis (CF) because it was thought that overexertion would increase breathing problems. Now, we know that the opposite is actually true. Studies have shown that regular physical activity provides many benefits to people with cystic fibrosis.

Why Exercise?

The health benefits of an active lifestyle are widely

recognised for all people, but exercise is especially important for people with cystic fibrosis because it can:

- Increase lung capacity
- Increase strength and endurance
- Increase energy
- Increase life expectancy
- Improve airway clearance, which helps prevent respiratory infections
- Increase bone density and prevent bone loss

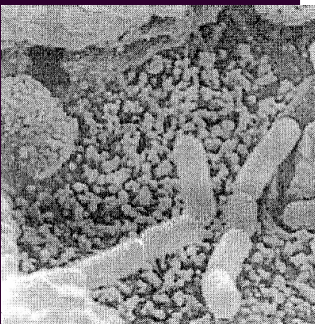
What Type of Exercise Should People with CF Do?

While most people with cystic fibrosis can tolerate some form of physical activity, the amount and type of exercise that a person can tolerate will vary based on the severity of his or her illness. People with CF should work with their health care providers to develop an exercise routine that is right for them.

Probiotics and Cystic Fibrosis

What are Probiotics?

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



**Lactobacillus
Rhamnosus**

How Can Probiotics Help People with Cystic Fibrosis?

Two recent 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. A few years later, the same researchers decided to take 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 less bouts with respiratory infections than those that didn't take LGG.

Where Can I Find LGG?

Lactobacillus rhamnosus GG is available over the counter at many health food stores and pharmacies in capsule form. It is also available in some brands of yogurt.

There are many products,

including most yogurts 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 getting a product that contains LGG.

(Note: I use a product called Rheutori, which contains *Lactobacillus rhamnosus* amongst other probiotics that are beneficial. I use these in times of extra stress and throughout a course of ABs, as it is well documented that antibiotics not only kill the nasty bacteria, but also the healthy bacteria! Probiotics are not government funded or prescribed by health professionals, although many physicians support their use. They cost approx. \$30 per month.)

On A Personal Note ...

Over the past year or so, my love of photography has been rekindled. I have met many other AWCF who also share this passion. Although, a tad more experienced than me!! Yes, you know who you are!!

I have found to have an interest or passion outside of work, health maintenance, commitments and family has been important for me in maintaining balance. It reminds me of the simple pleasures and allows me the freedom to explore the things that I enjoy. After all, life is to be enjoyed, with or without CF!! Here are some of my latest creative experiments through the lens!!



A Touch Of Christmas Trivia ...

CHRISTMAS CARDS -- "The tradition of sending Christmas cards originated in the mid-1800s when a few people began to design handmade cards to send to family and friends. A man named John Calcott Horsely is credited as being the first to actually print Christmas cards. The card depicted a family enjoying the holiday, with scenes of people performing acts of charity. The card was inscribed: "Merry Christmas and A Happy New Year to You"



Helpful Links ...

- www.cfnz.org.nz CF Association of New Zealand
- www.cff.org American CF Foundation
- www.ccff.ca Canadian CF Foundation
- www.cftrust.org.uk UK CF Trust
- www.IACFA.org Formerly: International Organisation for Adults with CF
- www.sharelifeaustralia.com
- pwcfnz.net Site set up by AWCF, for AWCF

Raising CF Awareness by Public Speaking: Why Do It?

By Shannon Price (CF Adult)



As I sit to write this, I first begin my daily ritual of visiting Facebook to check on my circle of CF friends: Jason had his double-lung transplant in July of last year and recently had quite a setback, landing him back in the hospital. Sabrina has been in the hospital fighting infection and other obstacles for three straight months. Lloyd awaits his transplant but has been temporarily removed from 'The List' as he fights an infection riddling his body. Lindsay has had a rough year, in and out of hospital, and today will see if she will be heading back and the list goes on (there are too many friends to list them all individually!).

Beyond the common link of us sharing the same disease, we are united by the same fierce guts and determination, by the drive to keep going and believing, and united, too, in pain when we lose our be-

loved friends. These people, my treasured extended family, are among my reasons for speaking about and raising awareness of cystic fibrosis today. When I was a child, my family was very involved in fundraising, and for many years, you could say I was a poster kid for the cause. In 2004, after a hiatus, I wanted to get involved again. I had just lost my first close friend to CF and I wanted to do something to honour her. I delivered the first of what would become many difficult but heartfelt speeches. Then an unexpected thing happened: it awakened something inside of me. Public speaking had a whole new meaning for me now as an adult. Having this disease can sometimes make you feel powerless, but public speaking was something – besides my fundraising – I could actually do to feel like I was making a difference. I

have spoken at many different events, including Shinerama kick-off events, the American Thoracic Society Conference, and the Robbie Soccer Tournament press conference. Another unexpected outcome: I found that speaking about CF was cathartic for me, for outside of those events I never gave voice to what living with this disease was like. As I've befriended more people with CF over the years, they themselves add to the reasons why I put myself out there. I want to do it for all of us who are fighting for our lives, and for those we've lost, who I carry with me in my heart every day. The reasons why I do it have evolved over time, but they are always there. I believe that with greater awareness, comes increased funds, better treatments, and ultimately... our cure. That's something I'm proud to be a part of!