

A person is riding a bicycle on a paved path that stretches from the foreground into the distance. The path is flanked by rows of corn plants. In the background, there are some houses and trees under a warm, orange-hued sky, suggesting a sunset or sunrise. The overall scene is peaceful and rural.

EDITION 2 2017

RED

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PAIN
MANAGEMENT

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CEO MESSAGE

The theme of this edition of RED Magazine is pain management.



NIGEL BARKER, CEO

It won't come as a surprise to you to find out that pain has been around for quite some time.

What may be news to you however, is that human beings have been seeking out ways of treating pain for tens of thousands of years.

Researchers from University of Adelaide's Australian Centre for Ancient DNA (ACAD) and Dental School, along with the University of Liverpool in the UK, recently found traces of aspirin and penicillin in the tartar on the teeth of Neanderthals dating back 50,000 years. For those interested, their results were published in "Nature" on 8 March 2017 and can be found online.

Of course, there weren't any pharmacies around at that time but clearly early man recognised that willow bark and certain types of fungus could help ease their pain and fight their infections.

Today, our approach is a little more sophisticated, but still 25% of the drugs used in modern medicine owe their origins to plants and animals. Our understanding of a whole of body and mind

approach continues to grow and the importance of healthy mind, healthy body, is gaining more and more weight. We also look briefly at dragon's blood and the race to find new antibiotics.

This edition of RED is also appearing on the shelves during our busiest month, the month of May. This year we hope to sell more roses than ever before on the last Friday of May, our national 65 Roses Day, and we have some great organisations and volunteers to help. If you are one of them, thank you! If not, please call us for more information, and if you and your friends would like to get involved this year or next, we'd love to hear from you.

We'd also be interested to hear from you if you are doing a challenge themed around the number 65. In previous years, we've had people walk 65km, bake and sell 65 cup cakes, sell 65 kisses and swim 650m. What will your challenge be?

DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our winter issue, please contact us before 9 June, 2017

DO WE HAVE YOUR CORRECT DETAILS?

If not, please let us know so we can keep you informed

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ON THE COVER
Paul Fowler on his 65 Roses
Challenge across Europe

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CFA UPDATE

OUR THANKS GO OUT TO EVERYONE

It began under grey skies. It ended in sunshine and smiles. And for that our thanks go to everyone in the cystic fibrosis (CF) community, absent and present on the day.

The CF community banded together on Tuesday February 7 to stage a peaceful protest on the lawns of Australia's Parliament House in Canberra. It was the first sitting day of parliament for the year and all the politicians had gathered to the fray.

Our cause was clear – to let our nation's elected leaders know unequivocally they could not evade public scrutiny when it came to bringing life-changing drugs like Orkambi and Kalydeco into the hands of those who really need them.

This congregation of families, friends, advocates and supporters from right around the nation were quietly riding a wave of increased awareness in Canberra's most powerful inner circles of the travesty afforded by the PBAC's decision to deny access to these drugs in December 2016.

So, at 11.00am that morning, when the Federal Health Minister Greg Hunt stepped forward into the boisterous but friendly sea of red-shirted supporters, his proclamation that Kalydeco would now be

available on the PBS was greeted with roars of delighted approval.

Minister Hunt was one of a steady stream of politicians and their advisors from all parties who responded to the community's persuasive appeals. Each in turn was warmly greeted with tea and cupcakes and introduced to members of the CF community with their uniquely compelling stories to tell.

The protest was imagined and implemented to generate awareness of CF and bring an amicable but persuasive focus on the need for Kalydeco and Orkambi. As a result, our nation's leaders are now indelibly more informed of the shattering effects of this 'rare disease', and the herculean efforts of those who suffer, their families and their carers.

To everyone who contributed in any way to the success of this day, particularly those who could attend, the Australians with CF who bravely greeted Minister Hunt and others and won over their hearts and minds, you have Cystic Fibrosis Australia's (CFA) profound thanks.



By all measures the day was a success and this was due to a collaborative effort from CF state organisations, the CF community and CFA.

Our next target- reimbursement of Orkambi for the 1,000+ Australians who desperately need it – is now firmly on the Health Minister's agenda; something that adds a significant impetus towards reaching our goal.

Finally, and to reiterate, thank you. It is times, and events, like these that bring the best out in all of us. And in the CF community we see and experience the best of the best!

Yours sincerely
Nettie Burke
CEO Cystic Fibrosis Australia



PROTESTORS AT THE ORKAMBI RALLY

HELP US PAINT WA WITH ROSES

We need your help to make 65 Roses Day 2017 the biggest and best yet!



WILLOW,
2016 AMBASSADOR FOR 65 ROSES

May is cystic fibrosis (CF) awareness month and the last Friday of May is 65 Roses Day.

Every year, community supporters and businesses join us to sell roses all around the state and raise funds for Cystic Fibrosis WA (CFWA). This year we're thinking BIG, but we need everyone to play a part and help us paint the state in roses for CF!

There are three ways you can lend a hand:

1. **Wrap Roses: Thursday, 25 May 2017**

We're selling thousands of roses all over the state but we'll need plenty of helping hands to get the job done!

If you're available to help wrap roses, please visit www.cysticfibrosis.org.au/wa/65roses

2. **Volunteer: Friday, 26 May 2017**

Wrapping the roses is only half the job; we've got to sell them all on 65 Roses Day.

Lend a hand to sell roses from our stall in Murray St Mall or volunteer at one of the other 15+ locations we've organised. Visit www.cysticfibrosis.org.au/wa/65roses to choose your stall location and time slots.

3. **Sell Roses: Friday, 26 May 2017**

Why not bring 65 Roses to you? Order a bucket of roses to sell in your workplace, office or school at \$5 a stem, or gift a beautiful rose bouquet to that special someone.

Beautiful corporate displays are also available for your office reception to support 65 Roses Day. These orders will arrive Monday, 22 May to allow you to enjoy them for the full week.

Visit www.cysticfibrosis.org.au/wa/65roses to place your order now. Metro and select regional delivery is available. If you're in a regional area and would like to be involved, we'd love to talk to you!

The funds raised from this event will help support our vital home care services and research funding for people living with CF in Western Australia.

For more information about how you can get involved in the 65 Roses campaign, please get in touch with Marnie at events@cfwa.org.au or on 08 6457 7333.

GET A TEAM TOGETHER
TO WRAP OR SELL ROSES



WAFEX SUPPLY OUR
BEAUTIFUL FRESH ROSES

CYSTIC FIBROSIS IS A PAIN TO TREAT!



A review of the literature in 2016 found that pain is a problem affecting many people with cystic fibrosis (CF) and has a significant impact on quality of life and health outcomes.

Pain relief should be an important goal and will involve a multidisciplinary approach to assess and treat symptoms, in addition to medication, complimentary therapies and self-management strategies.

Over 70% of adults and 42% of children with CF reported some form of pain, many suffering with chronic pain for at least three months before reporting symptoms. Pain was associated with poor disease management, increased psychological symptoms, more pulmonary exacerbations, and lower health-related quality of life.

Over the past 10 years, studies have shown that pain assessment and treatment in CF is vital, as pain has been associated with survival. The assessment of pain should be undertaken as part of routine care in CF centres and good pain management should be a priority to enable effective treatments. Musculoskeletal pain is commonly reported to be a barrier to treatment adherence, particularly with airway clearance and exercise. No two people have identical pain perception so each person with CF will need a review to enable an individualised approach to their pain management.

Pain relief medication can play an important role for patients experiencing pain that is limiting their ability to complete their treatments. Timing of pain relief medications in relation to airway clearance or exercise needs to be considered to enable these treatments to get done.

Physiotherapists play a crucial role in assisting people with CF to manage pain. Management techniques may include manual therapy, electrical stimulation, heat or cold therapy, ultrasound, exercise, education, and modification of unhelpful behaviours. Preventative measures that address any contributing factors, such as posture, are important to address.

Joint abnormalities and postural changes start to develop in the early years and as patients age, these changes, and the associated pain, may affect their ability to do required treatments. In CF, an increase in the forward curvature of the upper spine (thoracic kyphosis) can occur as a result of the posture adopted for breathing and coughing. Postural education and incorporating stretches into everyday routines is important

to prevent postural changes from occurring. Improving posture can have a positive impact on body image and self-esteem and also improve pain and lung disease. CF physiotherapists can suggest stretches and positioning for airway clearance and nebulisation to help address any posture and pain issues. They can also assess the need for referral to a specialist physiotherapist for extra interventions such as hands-on therapy and other pain management techniques.

Complementary therapies can be very helpful for managing pain when used in conjunction with medication and other pain relief strategies. These alternative, or holistic, therapies often claim to treat the whole person, rather than the symptom of the disease and can include homeopathy, naturopathy, meditation, yoga and acupuncture.

There have been some studies examining the benefits of complementary therapies in CF which have had positive results. Three studies that used biofeedback, music, and massage therapy to assist with physiotherapy found some effectiveness, and a study published in 2016 found that yoga may reduce immediate anxiety and joint pain in patients with CF.

Complementary therapies can be used alongside conventional medicine in a belief they can 'complement' treatments, but should not replace medical treatment prescribed by the CF team. It is important to discuss any alternative treatments with the primary care team to ensure there are no contra-indications to treatment.

Self-management of chronic pain is an important strategy to empower people to manage their condition proactively and independently. Training in self-management for people with pain aims to provide education about why they have pain, and suggest possible lifestyle modifications to optimise function and independence. One of the first steps when introducing pain self-management strategies involves the patient recognising that they need to take control and make some changes to their current way of doing things. This may involve discussions with the CF team to develop a collaborative plan for managing the more painful days.

Some other self-management strategies that people may find useful when dealing with pain are:

- setting small achievable goals for treatment with plenty of rests
- learning how to ease tension and relax using things like breathing, gardening, or reading
- gentle exercise
- improve sleep
- distraction
- planning activities that are enjoyable and improve mood

Pain in CF is a complex issue that requires a multi-targeted approach to management, including medication and other therapies. Early identification and treatment is vital to ensure pain does not interfere with other CF treatments.

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JO DISCUSSES PAIN MANAGEMENT USING TAI CHI

Jo Giles underwent a double lung transplant 18 months ago, at the age of 47. She has an intimate knowledge of pain and shares her management strategies in this interview.



JO GILES

How did you come across Tai Chi?

A friend with cystic fibrosis (CF) recommended it because I had been trying different types of exercise which had all become too tiring or difficult for me as I was too unwell.

It's a very old Chinese exercise system that uses slow, smooth body movements to achieve a state of relaxation of both body and mind.

What was your first class like?

Good, in that I was able to follow the moves and I instantly felt relaxed and felt like everything was connecting. Tai Chi has a lot of moves. I was told to just let go and go along with it. When I learnt to let go and not worry so much about the moves, it was more relaxing. I learnt the whole set by the end of the beginner's class.

Did Tai Chi help with managing pain?

I had pain associated with breathing, particularly before transplant, and it helped in the form of relaxation. It doesn't necessarily focus on breathing, but the movement encourages a type of breathing that is meditative and relaxing, and that helps with the pain of breathing and the anxiety around that. It's a bit of a cyclic thing; breathing-pain-anxiety, but the Tai Chi helps to intersect that cycle. As you focus your breath on the moves, the moves distract you from the pain and the anxiety around that.

When I was nearing transplant, I was very sick and every breath caused pain; headaches, chest, shoulder and abdominal pain, and some pleural pain (muscular and skeletal due to inflammation in the airways). Tai Chi has many levels depending on fitness. It was something I could do standing, in a chair, even in bed when I was too sick to get up. I could either do hand movements or practice visualising movements. When I couldn't sleep, I would visualise doing sets of Tai Chi and would still get relaxation out of this.

Does Tai Chi help with posture and strength?

Tai Chi helps to develop core muscles. A natural response to coughing is to restrict inwards. Tai Chi helps to expand and open up the joints, the fascia and the muscles. A simple stretch out actually massages the internal organs.

Were there other benefits from this practice?

When I became really unwell, I couldn't handle people hugging me; it became painful, and when super unwell you withdraw inside as well. To look out requires energy. Towards the end, every ounce of energy needed to be saved for myself. It would have been easy to stay inside. It's like closing a door but being

aware that you still need to leave a crack open to let people in. Tai Chi was a way for me to keep interacting with people. I could still go to a class and do exercise in a chair. They created a "Health Recovery" class at the Bayswater group to help support me through transplant. A similar class existed in Fremantle so it was great that they were able to start one close to me.

Where are you now in terms of your health?

I'm now 18 months post-transplant and teaching Tai Chi. I did teach about five years ago, but had to stop due to becoming unwell, so it's great that I am able to do this again. I became reaccredited in August 2016 and I practice every day; it's more active now.

Do you use other strategies to help manage pain?

I like to do puzzle solving such as Sudoku and video games. I also enjoy reading.



JO GILES

PAUL'S AMAZING 65 ROSES CHALLENGE

PAUL COULDN'T RESIST
A QUICK SELFIE AS HE SET
OUT ON HIS INCREDIBLE RIDE

When Paul Fowler decided to undertake a massive bike ride across Europe, little did he know what he was taking on. Paul, from New Zealand and living in Broome WA, had recently turned 30 and felt he had a statement to make about living with cystic fibrosis (CF).



This time last year I didn't own a bike. In fact, I probably hadn't even sat on one for the 15 years prior. I've never been a big fan of cycling, partly because of bike pants, but mostly because my legs are smaller than a 10 year olds' arms, and cycling is hard work. For these reasons, it was a surprise to me that one night late in 2015, I found myself unable to sleep and becoming increasingly obsessed with the idea of flying to Europe, getting on a bike and riding it from one side to the other.

At the time, I was nearing the end of my days as a 20-something-year-old and, while the idea of turning 30 may fill most people with dread, it was a much anticipated occasion for me. Not because I like finding new grey hairs on a daily basis, but because of a Reader's Digest article I read when I was 12. The article was about CF and it told me that I could expect to live to 30, if I was lucky. Until that point, I don't think it had dawned on me that what I had was so serious, or permanent. But at that young age I made a decision that, not only was I going to live past 30, I was going to do something significant to mark the occasion.

I spent the few months after that sleepless night planning, saving and fundraising, and on 18 August last year I found myself at the start of the Eurovelo 6 cycle trail in Nantes, France. I was feeling very apprehensive on day one, probably because my 'training' had consisted of three rides around Broome on a little girls' bike, occasionally involving the humiliation of being overtaken by actual little girls on their own girls bikes. But, after a few obligatory selfies, I made a start and after a few hours I had 50km behind me and I'd arrived in Ancenis - stop number one. The next day I managed 80km before setting up my tent for the

night. That was to remain my daily average for the next two months as I followed the Loire River through the French countryside, the Rhine through Switzerland, then met up with the Danube in Germany and rode alongside as it grew and lazily twisted through Austria, Slovakia, Hungary, Croatia, Serbia, Bulgaria and to its mouth at the Black Sea in Romania. Ten countries and 4,000km in all.

PAUL FACED MENTAL AND PHYSICAL
CHALLENGES ON THE ROAD



PAUL IS ALSO A TALENTED PHOTOGRAPHER AND USES A DRONE FOR THESE SPECTACULAR AERIAL SHOTS.

I cycled with my 20kg of luggage through major cities such as Vienna, Budapest and Belgrade, through the quaint villages of France, past Europe's largest waterfall in Switzerland and even picked up a girlfriend in Germany. I rode past thousand-year-old castles, through stunning river valleys and vast fields of corn, over seemingly endless hills and across the borders of countries that were not so long ago at war with each other.

I faced physical challenges such as getting lost on a regular basis (at times cycling up to 20km in the wrong direction), the constantly changing

languages and (I'm sorry Europe) awful coffee, the rough and busy roads as I got further east (not to mention crazy drivers and frequently having to share those roads with horse-driven carts), carrying my bike up hundreds of steps after cycling 135km through rain one day, and even cramping up completely in 40 degree heat.

I usually try not to worry so much about my health on a daily basis, but I'll admit that before setting off I was scared about ending up with a nasty infection somewhere in the back-blocks of Eastern Europe. However, I can't remember

a two-month period where I've had consistently better health. Ever. Even on the days I woke up feeling a little rough, the fact that I had no choice but to get on the bike meant that I was forced to push through, and within an hour I'd usually forgotten about it and was feeling great again. This, aside from raising over \$20,000 for Cystic Fibrosis WA (CFWA) and the desire for bigger legs, was the real reason for my trip. I wanted to prove, as much to myself as to anyone else, the importance that remaining physically active plays in fighting CF, and I'm now more convinced than ever.

TAKE THE 65 ROSES CHALLENGE FOR CF



Did you find Paul's story inspiring? Do you have your own unique challenge you've been thinking of undertaking?

It could be a physical challenge like Paul's incredible cross-continent bike ride, or you could organise an event with proceeds to Cystic Fibrosis WA (CFWA). No idea is wrong, as long as you're challenging yourself!

Visit www.65roses.org.au for some challenge ideas to get you started. What are you waiting for? Challenge accepted!

SUPPORTER SPOTLIGHT

When we told Daniel Stean, General Manager from WAFEX, that we wanted to sell even more roses on 65 Roses Day 2017, he stepped up to the challenge.

The WAFEX rose journey with Cystic Fibrosis WA (CFWA) began in 2009 when they were engaged to supply roses for 65 Roses Day. What started as a small supply, which included donated roses and the others at a reduced cost, is now growing each year. On 26 May 2017, we will paint the state of WA in roses for our biggest national awareness campaign for cystic fibrosis (CF), 65 Roses Day. In 2012, we sold 2,000 roses in and around the city; in 2017, we are aiming to have rose sales in the city, outer suburbs and several regional locations.

At every step, WAFEX have been with us with ideas and suggestions on how to increase awareness of CF through the event. They were so committed to this event in 2016 that the WAFEX team downed tools and joined our 65 Roses volunteers in the city and at suburban locations to sell roses.

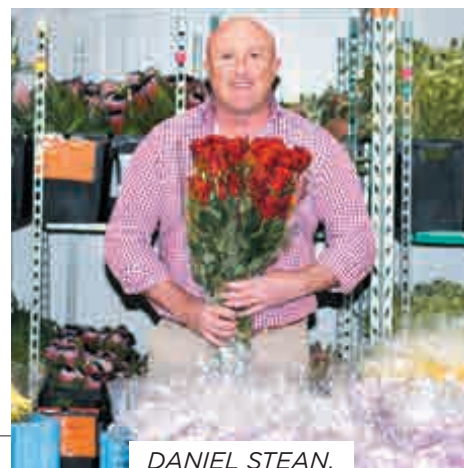
Established in 1991 by Craig Musson, 2003 finalist of the 40under40 award held by Business News, WAFEX has become the leading flower exporter and importer in Australia. With offices in Perth, Melbourne, Sydney and Los Angeles, WAFEX specialises in

shipments of fresh and dried native flowers, and has created a flower breeding company called Helix, who have become world leaders in breeding Geraldton Wax.

Craig and Daniel, along with their dedicated team at WAFEX, have joined CFWA in our mission to raise awareness for CF right around our state, and in doing so are supplying our roses, lending their expertise in flower preparation and transportation, as well as joining us to sell roses.

In addition, WAFEX is a significant supporter of other CFWA events including supplying roses for our CF Scientist's Night, George Jones Family Foundation Cystic Fibrosis Golf Classic, Spring Rose Art Exhibition and Red Tie Dinner Dance.

Over the years, we have seen our rose sales grow significantly thanks to generous supporters such as WAFEX, and wish to see it continue to grow in years to come. Together with our partners WAFEX and Telstra, let's make 2017 an even bigger year for raising awareness and funds.



DANIEL STEAN,
WAFEX GENERAL MANAGER



WAFEX DELIVER THOUSANDS OF
ROSES ON ROSE WRAPPING DAY



THE WAFEX TEAM HELPING OUT
ON 65 ROSES DAY



ABDOMINAL PAIN IN CHILDREN WITH CYSTIC FIBROSIS

Children with cystic fibrosis (CF) commonly experience abdominal pain. We discuss possible causes, diagnosis and management.

Abdominal pain in children with CF is often chronic pain and can come as a result of malabsorption, despite the use of pancreatic enzyme replacement therapy. Acute abdominal pain, however, may be a sign of the following disorders: appendicitis, constipation, gastroesophageal reflux (this occurs in up to 60% of the CF population), coeliac disease, inflammatory bowel disease (increased incidence in CF), intestinal pathogens, pancreatitis and biliary disease.

Distal Intestinal Obstruction Syndrome (DIOS) should be one of the first considerations in disabling abdominal pain in CF. DIOS is an obstruction of the distal part of the small intestines. DIOS is reported to occur in 15% of patients with CF per year, while pancreatitis (1%-2%), biliary tract pain (4%), and kidney stones (6%-7%) also occur with a higher incidence in the CF population. Appendicitis has an incidence rate of 1% to 2% in CF, lower than the 7% in the general population (Britton & Saeed, 2007).

The location of the abdominal pain is an important detail. Right lower quadrant pain may indicate appendicitis; left lower quadrant pain may indicate pancreatitis and epigastric (upper abdomen, below the ribs) pain could indicate gastroesophageal reflux or gastritis (including *Helicobacter pylori* gastritis). Pain that radiates to the shoulder may indicate pancreatic or biliary problems. Constipation or DIOS in people with CF causes diffused pain or pain anywhere in the abdomen, depending on the location of the constipated stool. Most commonly in DIOS, the pain is in the right lower quadrant and a firm regular mass may be felt (Britton & Saeed, 2007).

If fever is present with abdominal pain, there is increased likelihood of appendicitis (Bundy et al., 2007). Decreased appetite, nausea and vomiting are associated with most causes of severe abdominal pain, however, the child who complains of abdominal pain but maintains their appetite, probably does not have a serious condition. Bilious vomiting can be the first sign of appendicitis if a small bowel obstruction is present, as well as with other causes of small bowel obstruction such as intussusception (which is the inversion or telescoping of one portion of intestine within another section of intestine). In the context of CF, bilious vomiting may also be a sign of DIOS.

It is important to note that children with CF frequently continue to have large, bulky stools even if they are constipated or have DIOS, however, this is usually accompanied with abdominal distention or a history of previous episodes of either constipation or DIOS. Blood in the stools increases the concern of intussusception.

Because abdominal pain in children with CF can have multiple causes, basic laboratory tests can be helpful to screen causes of the pain. Liver function tests including bilirubin can help rule out biliary or gallbladder pain. Amylase and lipase can help diagnose pancreatitis. Full blood counts and other specific blood tests, urinalysis and urine cultures can assess infectious causes of pain such as appendicitis and urinary tract infections.

Decisions about abdominal imaging are more complicated. A basic abdominal X-ray will screen for constipation and DIOS. Depending on symptoms and other findings, abdominal/pelvic ultrasound or CT scan may be performed.

There is an increased risk of DIOS in those children with CF who were born with meconium ileus, have had bowel surgery or had previous episodes of DIOS. DIOS often occurs with a change of routine that slows down bowel function or reduces fluid content in the bowel. For example, change in diet, illness, chest exacerbation and increased physical activity. Change of social situation, such as starting school or moving to a warmer climate can also contribute. These changes are usually associated with decreased fluid intake and/or inadequate amounts of enzyme supplements. The bowel contents become thicker and stickier and can result in an obstruction of the distal part of the small intestine.

Treatment of DIOS consists of rehydration combined with laxatives. Mild cases of DIOS are treated with the laxative PEG 3350 – polyethylene glycol (Movicol or Osmolax). In more severe cases, Golytely or Gastrograffin is used and can be given via a nasogastric tube or gastrostomy. These laxatives work by drawing fluid into

the bowel to soften the contents of the impacted bowel. Rehydration is achieved via increasing oral and/or intravenous fluids. In most severe cases, Gastrograffin can be given as an enema. In these severe cases the child may be reviewed by a gastroenterologist and surgeon and further investigations may be requested. However, with early aggressive medical management, surgery is seldom required.

As a previous episode of DIOS is a risk factor for reoccurrence, prophylaxis is the key. Maintaining laxative therapy is generally considered, along with avoidance of dehydration, ensuring adequate fluids and sufficient salt intake and reassessment of adequate pancreatic enzyme dosage.

Unrecognised and untreated chronic abdominal pain may negatively impact on and reduce the quality of life of children with CF. If your child is complaining of abdominal pain or discomfort, please seek the advice of your CF team.

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COULD DRAGON'S BLOOD HELP FIGHT INFECTIONS IN CYSTIC FIBROSIS?

Komodo dragons living on the islands of Indonesia are the largest lizard in the world. They are a fearsome apex predator nearly as big as a crocodile which, if you believe the tour guides, regularly take out Japanese tourists for lunch.

Their saliva contains slow-acting venom and a huge range of nasty pathogenic bacteria including *Pseudomonas aeruginosa*, a bacterium commonly found in the lungs of people living with cystic fibrosis (CF).

When hunting their prey, which it must be said, are mostly goats and the occasional cattle (hardly any tourists at all), they will often inflict fleshy wounds from rows of sharp shark-like teeth. These wounds in themselves are not fatal but are laced with venom and bacteria which quickly set to work to poison the poor victim. As the animal eventually succumbs to blood poisonings, it is then eaten by the dragons.

Researchers in the field noticed that even a small wound will quickly become infected and lead to death. Yet Komodo dragons often fought each other and inflicted significant fleshy wounds on each other but these wounds didn't appear to get infected.

This led researchers from the College of Science at George Mason University (GMU) in Virginia, who had previously done work on alligators, to speculate that there were some special things going on in the blood of the dragons which was acting as a hugely powerful antibiotic.

Finding new ways of treating bacterial infections is critical not only to people living with CF but the whole population, as commonly found bacteria develop antibiotic resistance (see article Microbial Monsters Edition 4 RED Magazine 2015).

On 6 February 2017, the researchers at GMU published their findings in

the *Journal of Proteome Research*. They identified 48 substances known as cationic antimicrobial peptides (CAMPs) in the dragon's blood. These CAMPs are found in the immune systems of nearly all living creatures that can fight bacteria. Seven of these were found to be particularly effective in fighting off *Pseudomonas aeruginosa* and *Staphylococcus aureus*, while one specifically and exclusively targeted *Pseudomonas aeruginosa*.

The researchers also created a peptide known as DRGN-1 that showed wound-healing ability and the power to bust the biofilms which our own researchers are working on as reported above.

The GMU researchers hope that they will eventually be able to manufacture compounds to fight microbial infections in humans. In the meantime, however, they must first catch their dragon.

MEET THE VOLUNTEER: CHRIS BRAMBLEBY

Our 2016 Volunteer of the Year talks about the reasons he chooses to volunteer and gives us an insight into his weekly efforts to raise awareness and funds for Cystic Fibrosis WA (CFWA). In 2016, Chris volunteered an incredible 259 hours and raised over \$6,900 for CFWA, winning him the prestigious title of 2016 CFWA Volunteer of the Year. We are so grateful to receive the tremendous support Chris gives us in the community and in the office.

How did you come to volunteer at CFWA?

I have been volunteering for over 15 years for various organisations in the medical and health industries. I have mainly helped by driving for them; assisting with patient transfers at hospitals and delivering special packages. I noticed an advertisement in a magazine or on the internet and came in to see if I could volunteer. I had seen the building before and so I just popped into the office and offered my help. Since then, I have been coming into the office a few days a week and helping with all kinds of things.

What do you do when you volunteer at CFWA?

Mostly, I look after the collection tins that go out into the community; dropping them off, swapping them

over and maintaining them. I have also helped at some of CFWA's events like 65 Roses Day and Convicts for a Cause. They were both a lot of fun.

What is your favourite thing about volunteering?

Meeting a cross-section of people out in the community. I like to meet different people who have unique stories and characteristics. When I volunteer, and go out into the community, I talk to a mixture of people and that is great.

What do you do in your spare time?

I have a few hobbies, but I especially like to play chess and garden. I grow flowers and vegetables in my garden at home, like broccoli, onions and carrots. I also have a pond with fish in. I am always talking to people about CF, even

when I'm not volunteering as such, to raise awareness and hopefully get them to take a tin or join one of the events.

Why do you like to volunteer?

The "money" is good, and it's a worthwhile cause, but not necessarily in that order. I like to support charities and when I volunteer, I give it everything I have. I eat, sleep and live the cause.

Any additional thoughts?

Two cows are walking down the street and one cow says to the other "moo moo". The other cow says, "I was going to say that."

If you would like to know more about volunteering for CFWA, please email Marnie on events@cfwa.org.au or phone 08 6457 7333.

**2016 CFWA
VOLUNTEER OF THE YEAR
- CHRIS BRAMBLEBY**



MANAGING PROCEDURAL PAIN & ANXIETY

Between forty to sixty percent of children report feelings of mild to intense anxiety before an invasive medical treatment. This can also be an ongoing issue for adults.

These methods have been identified as being effective in reducing procedural anxiety:

- Topical agents to numb the skin and alleviate pain such as lidocaine and prilocaine (EMLA) can help.
- Distraction techniques can be useful and may include: blowing bubbles, counting backwards, watching TV, playing computer games, and guided visualisation (depending on age).
- Providing age-appropriate information about the procedure is important. This helps alleviate the stress of the unknown and builds trust between medical staff, parents and the patient.
- Deep breathing can be a quick and effective way to calm the child down and prepare them for the procedure or draw their attention away from their worried thoughts. Yoga breathing techniques are one example of how to do this.
- Parents are role models and, therefore, need to model calm, coping behaviour for their child before, during, and after the treatment procedure.

Ongoing Anxiety Associated with Medical Procedures

Children can experience longer term behavioural and psychological issues associated with regular medical procedures. These may include: sleep disturbance, nightmares, separation anxiety, increased irritability, and aggression and temper tantrums.

Anxiety or trauma associated with medical treatments can present differently in children depending on their developmental stage. Having an illness, or how the illness is perceived, can also cause regression to a child's development. If a child is experiencing ongoing anxiety and distress associated with their medical treatment, and it can't be managed with the strategies mentioned above, then it is important to seek professional help provided through the hospital.

Infant – Toddler (0-2 years):

Language is limited; however, their understanding is often greater than

what they communicate. Feeling safe and secure is often dependent on how their parent is responding, so it is crucial that parents are able to seek support independently and discuss their feelings so they are able to provide security and a calming influence for their child.

Toddler to Pre-Schooler (3-5 years):

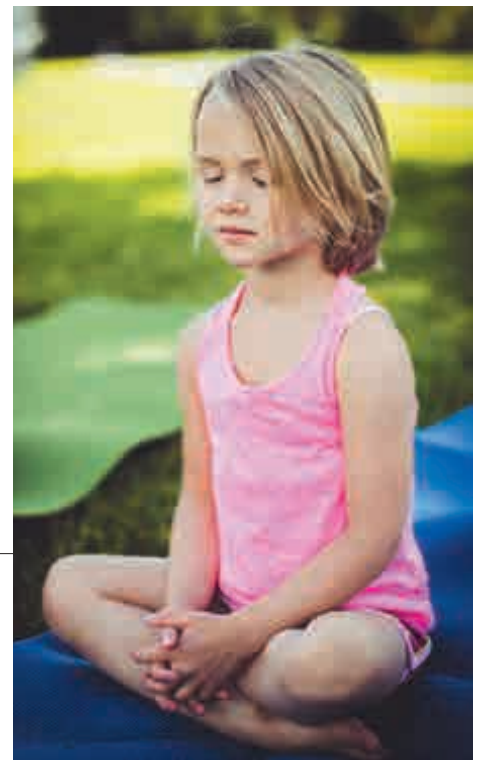
Although the toddler often seeks independence, parental involvement is still very important at this age. Children of this age often engage in imaginative play to help understand their world. They can have difficulty understanding other people's perspectives and cannot think in abstract ways, such as imagining their future, and have a limited understanding of time. Parents need to keep things simple, use concrete language when explaining procedures and let the child know what to expect to see, hear, taste and feel. It is also very important to help the child manage anxious feelings by remaining calm, encouraging them to talk about their feelings and supporting ways to reduce their anxiety.

Primary School (6-11 years):

Comparing themselves to their peers and a growing awareness of what their illness means to them increases at this age. Medical interventions can cause children at this age to feel like they are losing control e.g. having to undress and be examined, do airway clearance, take medications and have IVs. Children may try to regain control through non-compliance, avoidance or aggression. Teaching and modelling coping strategies is very important, e.g. distraction, relaxation, calming self-talk, and providing the child with some choice, where possible, whilst still setting boundaries.

Early Adolescence (12-15 years):

Self-image, identity development and drive for independence are important developmental tasks of this age group. Young people are often very self-focused and want more say in how things are done, which can lead to conflict with doctors, parents and other key people involved in their care. The medical team start to involve the young person more in the medical decision making process which increases their sense of control and independence, and respects their views and choices.



Late Adolescence to Early Adulthood (16+ years):

Anxiety can still be present at this age which can be expressed in a variety of ways, including anger, hypervigilance or non-compliance with treatment. Coping strategies such as effective communication, problem solving and calming strategies should be supported if appropriate.

It is normal for all children and families to experience some level of anxiety which can peak at different times, e.g. first bronchoscopy, hospital admission, lung infection or other hospital procedure. At times, these feelings can feel overwhelming and it's important to establish good coping strategies, and if feelings persist, to seek professional assistance through your treating medical team or community-based counselling.

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Written by Pekin. K CFWA, Contributions by Joanna Elliot Specialist Clinical Psychologist. Paediatric Consultation Liaison Program, Acute Services Directorate, Child & Adolescent Mental Health Service Princess Margaret Hospital

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USING HYPNOBIRTHING FOR PAIN MANAGEMENT

Sam Connors first came across hypnobirthing when she was pregnant with daughter Olivia, now 4, and still uses the technique for medical procedures today.

Hi Sam, could you explain in your own words what hypnobirthing is?

Hypnobirthing is a way of preparing for what your body's going to be going through during labour. It teaches you how to stay calm and relaxed in order to have a positive labour experience.

You're still present in the room but go deep within yourself into your own 'zone'. It allows you to stay in control and avoid feelings of anxiety and fear.

When/how did you come across it and why were you drawn to it?

My whole life I wanted to be a mum, and having a natural labour has always been so important to me. Having cystic fibrosis (CF) and constantly being on medications, I really wanted my labour to be drug free. My sister, who is currently pregnant with her fifth child, suggested hypnobirthing to me as a way of achieving this. I started by reading books about it and picked out the aspects of it that I liked best and began practising these techniques.

Screaming takes energy, which having CF, I couldn't afford to waste, so wanted to conserve all my energy for labour. I didn't want to lose control. That leads to fear and anxiety. Hypnobirthing allowed me to achieve the labour I had always dreamt of and I really loved Olivia's birth.



SAM & BABY OLIVIA

What aspects of this skill did you use during labour?

The main aspect of hypnobirthing I used during labour was visualisation. I would visualise a black dot that I would use to focus my energies on. Teachings often suggest visualising a calming environment, such as the ocean, however, I felt this was too busy, and a black dot was simple and easy for me to imagine.

You need to stay focused in order to stay in the 'zone' and if I started slipping out of my 'zone', I had to harness it and refocus my attention to the black dot. At times, I had to ask everyone in the birthing suite to stop talking so that I could maintain my focus.

Other skills I used were positive self-talk; telling myself I could do it and thinking about what I will get out of it once it's all over. I also used controlled breathing (slow measured breaths) and rolling with the pain rather than fighting it; embracing it and understanding what the body is doing.

How did you learn the techniques for hypnobirthing? And how long did it take to master the skills?

I taught myself the skills I needed. When I was first learning, I had to have complete silence to be able to focus, and initially it would take me a few days to be able to get into the 'zone'. I would use the skills when I had a procedure, such as a blood test, and would use positive self-talk and visualisation in the days leading up to it. Over time, my ability to go in to the 'zone' improved and became easier and quicker.

If I were in a situation where I felt panicked or like I was losing control, I would draw little circles on my leg with my finger. This technique allowed me to calm down and regain control of the situation. I will also use positive self-talk e.g. 'you can do this' and 'it's OK'.

Were the midwives supportive of your birthing plan?

Yes, they were. At one stage during my labour, the midwife had to monitor the baby regularly so had her hands on my belly every 30 minutes for 10 minutes at a time. There were also quite a few people in the room, including a student, and during this time I became very distracted and struggled to stay focused. The midwife could see I was getting frustrated and had the student leave the room and



OLIVIA'S FIRST DAY OF PRE-PRIMARY

then readjusted how she was monitoring me. Instead of standing in front of me, she would stand behind me so she wasn't in my line of vision and she remained very quiet so that I could remain focused.

What aspects do you still use today with medical procedures?

I still use the same techniques as I did for labour. It's easier to go into my zone now and I can control how deep I want to go, depending on the procedure. It's all about control and self-strength. It gives me confidence to go through any procedure now, whereas before I would fight or run out of the room. I can even give medical staff multiple goes now (e.g. finding a vein) and even embrace the pain because I'm able to control it.

Would you recommend hypnobirthing to other people dealing with pain?

Yes absolutely. It can be applied to anything, not just labour. For managing any pain, anxiety and even poor sleep.

People with CF often don't know what's next; where their health is going. We might suddenly have to be admitted to hospital, to have a procedure, and the techniques of hypnobirthing can allow you to have some control back.

I taught myself, but I know you can do classes; just Google Perth Hypnobirthing.

FUNDRAISING NEWS

We have had a fantastic start to the year with the massive success of the Pink Boot Ball in March and the Corporate Battle of the Bands in February. We've also had two great sporting fundraisers, with our swimmer Kate competing in the Rottnest Channel Swim and a soccer match between Kwinana United and Warnbro Strikers clubs.

Corporate Battle of the Bands

On Saturday, 25 February, the Charles Hotel in North Perth was packed wall-to-wall with roadies, rock stars and groupies for the Corporate Battle of the Bands. The judges had a hard decision to make as each band proved as talented as the next, but in the end the Channel 9 Band 'Loud Bastards' won and took the title. The event raised over \$13,000 for Youth Focus and Cystic Fibrosis WA (CFWA), a fantastic sum of money which will help two very worthy causes. A massive thank you to sponsors, musicians, volunteers and guests, and congratulations to Phillip Russo, Roger Blow and Tamara Blow, for organising a real crowd pleaser!

Northam Linedancing and Pink Boot Ball

The Northam Linedancers held a sausage sizzle and linedancing demonstration at the Northam Mitre 10 on Saturday, 25 February in support of CFWA. They raised over \$800, of which \$300 was donated directly to CFWA and the rest donated to the Pink Boot Ball, another fundraising event for cystic fibrosis (CF). Thank you to the dancers and everyone else involved for continuing to prove just how amazing regional communities can be!

The Pink Boot Ball was held on 4 March in conjunction with the West State Line Up dance event, where line dancers from all over Australia got together for a full day of dancing. Participating line dance groups from all over Australia sponsored and donated to the event, with 100% of the funds raised this year being donated to CFWA.

The venue had a makeover for the evening with red and white theming of tables and decorations, with guests dressing in red and white for the evening entertainment. CFWA's Karen attended the event, and was incredibly moved with the presentation of a cheque for \$14,750, along with the opportunity to speak about CF to the guests. CF had touched the lives of some people in attendance, however, for others, participation in the ball is driven by the mixture of fun, dance and a

strong desire to make a difference in the community. Thank you to the organising committee, sponsors and dancing groups involved in this fantastic event; the team at CFWA are so thankful for your generous donation.

Kwinana Football Match

The Warnbro Strikers and Kwinana United soccer clubs took to the pitch at Kelly Park for a game of soccer in support of CF on Saturday, 11 March. Kwinana United planned the fundraiser for a fellow team mate who has a son with CF, and have made a charity game plaque to support more organisation in the future. Funds were raised through generous donations from players and spectators as well as games and challenges at the clubhouse. Well done to Craig, the Kwinana United team and Warnbro for organising a winner of a fundraiser!

Rottnest Channel Swim

Although the weather was very hot, reaching 36 degrees, the wind, swell and other conditions were looking good on 24 February for the 2017 Rottnest Channel Swim. Kate O'Halloran and her team mates, Nathan Chandler, Stephanie Ness and Troy Hancock made it to the finish line exhausted but very happy with their swim. Well done to Kate who raised \$885 for CFWA in the lead up to the event; your support is greatly appreciated.



JOSEPH & HIS CHILDREN AT THE KWINANA FOOTBALL CHARITY MATCH



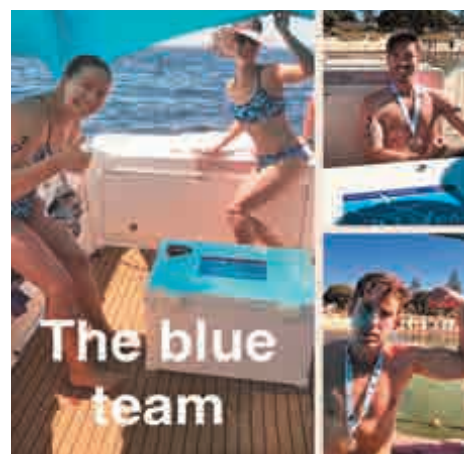
FRED & FIONA FROM THE NORTHAM LINE DANCERS GROUP



ROGER & PHILL AT THE CORPORATE BATTLE OF THE BANDS



BILL, KAREN, GLEN & RHYS HOLDING THE MASSIVE CHEQUE FOR CFWA AT THE PINK BOOT BALL!



KATE O'HALLORAN & HER TEAM AT THE ROTTNEST CHANNEL SWIM



NYSSA'S REASON TO RUN

Nyssa Woodward is running with her family in the HBF Run for a Reason this year. We asked her to share a little bit about her story and motivation to challenge herself with the run.

"It has only been 8 months since our little girl was diagnosed with CF, but we are already in a better place than we were. Norah's medication and physio is now just a part of our everyday routine and Norah is a little champ!"

I do have days where I feel very isolated at home with our twins. I haven't been able to do all the normal things my friends have done with their babies, because while Norah is so small, we are trying to protect her from becoming unwell. Luckily, she has a twin brother for company.

When I read the last Cystic Fibrosis WA (CFWA) newsletter and noticed the HBF Run for a Reason, I thought this was a great opportunity for me to share our story with others and help them to understand what happens each day in our lives and why we haven't been out and about as much as others might be.

I really want this run to be successful and encourage people to join our team 'For Norah' or donate to our page and hopefully meet our target of \$1,500."

Thank you to Nyssa and our other 20 runners who are fundraising for CFWA. If you are inspired by Nyssa's family or have your own reason to run, sign up to the HBF Run for a Reason on Sunday 28 May at www.hbfrun.com.au and select CFWA as your chosen charity.

NYSSA &
BABY NORAH

THE CFSMART WEBSITE HAS BEEN RENOVATED

Cystic Fibrosis Victoria (CFV), in conjunction with Cystic Fibrosis WA (CFWA), and with generous funding from the Ian Potter Foundation, have put their efforts together to renovate the original CFSmart website to include a larger range of great educational resources for educators, parents, students and health professionals.

The most exciting and important addition to the CFSmart website is a free online teacher training resource consisting of four separate professional development modules.

The modules contain key information about cystic fibrosis (CF), delivered through videos, images and text. Our aim is for teachers around Australia to use this resource as a go-to reputable source of information about how to best support their students with CF.

Teachers will be expected to complete two modules; Module 1 and a second Module specific to the age of student they teach.

- Module 1 provides a detailed overview of CF and the day-to-day implications of living with CF, how this impacts on the school environment and the

child.

This module would also be useful in educating family members and other people in the community who work with people who have CF.

- Module 2 covers early childhood
- Module 3 is for primary schools
- Module 4 for high schools

A quiz is provided at the end of each of the two modules taken by the participant, and on successful completion of the two quizzes, a certificate of completion will be provided which can be used towards professional development hours.

The website will be continually updated with new ideas and examples of what is working well for children with CF in their different educational settings.

CFWA would particularly like to acknowledge and thank Felicia Welstead, Operations and Special Projects Manager at CFV, for successfully gaining the grant for the website and for managing the CFSmart renovation.

We would encourage your child's school to access this wonderful resource, as our aim is to educate more teachers about CF than ever before. The website address is still the same: **cfsmart.org**

Face-to-face education sessions are also available for teachers, students, other parents, community groups and families. Please contact our Education Officer Natalie Amos at **education@cfwa.org.au** if you would like to arrange this service.



OUR BIGGEST EVER PARENTS' RETREAT

Thanks to funding from Lotterywest, we hosted our biggest Parents' Retreat to date, with 39 parents attending the weekend getaway.

This important event provides a weekend of respite for parents with a child with cystic fibrosis (CF). Held at the Dolphin Quay apartments in Mandurah from 10 to 12 March, the weather proved to be just perfect!

Parents were treated to a rare trip to the movies, as well as time to relax and recharge, enjoying the beautiful surrounds of the Mandurah Marina. There were also plenty of opportunities to meet with

other parents to chat and share stories. Cystic Fibrosis WA (CFWA) staff were also on-hand to provide any support required.

Many parents look forward to this annual event, returning each year. They provide a wealth of experience to our new parents who may be attending for the first time. New and often long-term connections are made amongst attendees during this important event.



lotterywest
supported

Join Our Champagne High Tea

All female carers of people with CF are invited to frock up for a fabulous afternoon of champagne and high tea.



Venue

CFWA Office,
The Niche

Time

3pm - 6pm

Cost

\$20 per person

Date

Sat 20 May

rsop

recreation@cfwa.org.au



**CYSTIC
FIBROSIS**
Western Australia

TELETHON AERONEBS AND SUBSIDY FOR REGIONAL KIDS!

Thanks so much to Telethon for providing support to our families living in regional WA once again in 2017.



A new part of our grant application for this year was the provision of an AERONEB for each regional child, as we understand how difficult it is for our regional members to access our nebuliser loan system.

The AERONEB is a vibrating mesh nebuliser that is quiet, quick and portable, helping to reduce the stress around nebulisations for families with young children.

If you would like more information or you think your child may be eligible for an AERONEB, please get in touch at physio@cfwa.org.au

If you haven't accessed your Telethon travel subsidy for kids yet, please contact Kathryn at servicesmanager@cfwa.org.au

We look forward to seeing you in the regions soon.



SAVE THE DATE:

2017 EVENTS

Cystic Fibrosis WA (CFWA) has a huge year of exciting events planned that you won't want to miss; so, grab your diary and save these dates! With training workshops, dinners, support sessions and awareness days, there is an event for everyone in 2017.

APRIL

5TH

Annual General Meeting

28TH

George Jones Family Foundation
Cystic Fibrosis Golf Classic

28TH

'Routines & Boundaries for
Toddlers' Workshop

30TH TO 5TH MAY

Regional Respiratory
Training Program

**HELP US PAINT THE STATE
WITH ROSES FOR CYSTIC
FIBROSIS THIS MAY**
www.65roses.org.au



MAY

3RD

An Evening with CF Scientists
at Telethon Kids Institute

20TH

Ladies High Tea

25TH

Rose Wrapping Day

26TH

65 Roses Day

TBC

Albany Outreach

JUNE

9TH

Transplant Support Dinner

TBC

Geraldton Outreach

TBC

Mandurah and Bunbury Outreach

JULY

1ST

Red Tie Dinner Dance

AUGUST

5TH - 8TH

Australasian CF Conference
- Melbourne

TBC

Kalgoorlie and
Esperance Outreach

SEPTEMBER

5TH

Starting School Seminar

TBC

Deloitte Spring Rose
Art Exhibition

OCTOBER

4TH - 6TH

Sibling and Offspring Camp
- Woodman Point

TBC

Halloween Fun Run

NOVEMBER

TBC

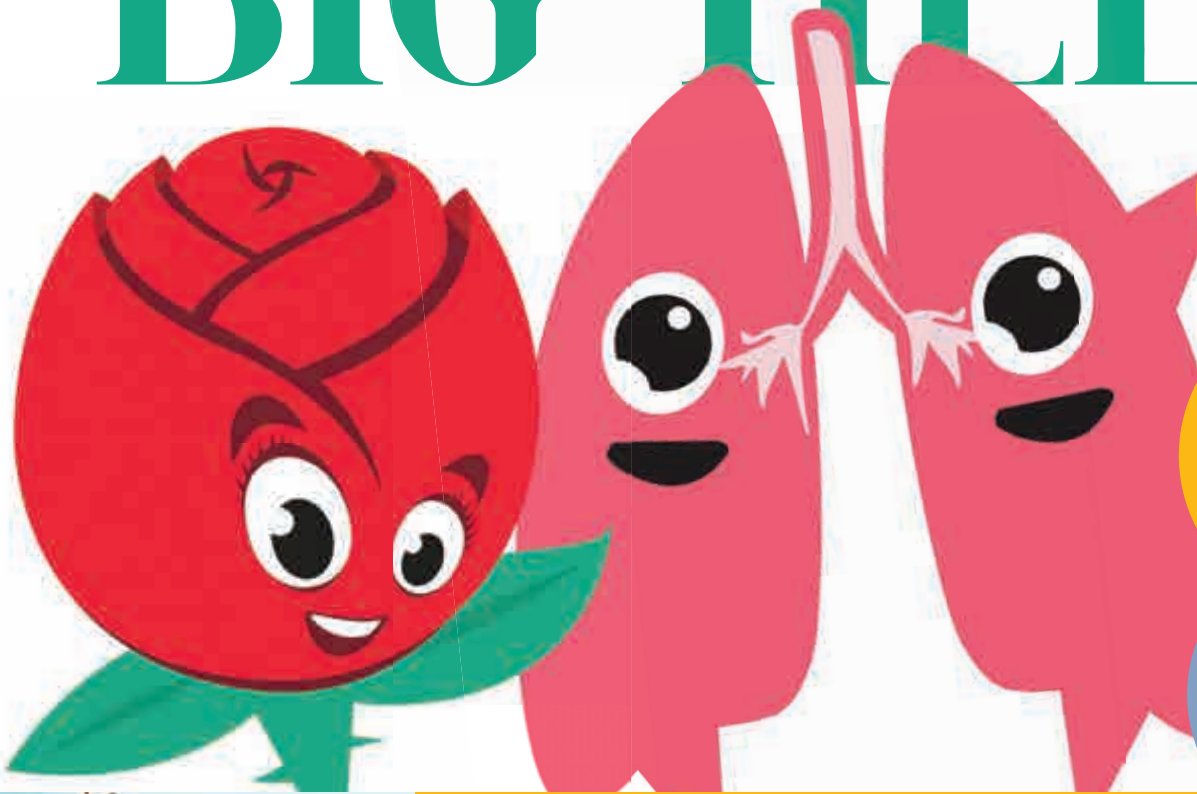
Sponsors and Volunteers
Thank You

TBC

Convicts for a Cause

More information about each event will be made available closer to the time via our Facebook Page, future RED magazines and E-newsletters. Email events@cfwa.org.au to find out more about a specific event or sign up for our E-newsletter.

LITTLE BAG BIG HELP



Quick! While
registrations
are open!

Can you
help make a
difference?

Time to
get
crafty!



**Get your class involved
for a chance to win a
\$200 voucher from the
Teacher Superstore!**

It's simple, just get your students to design and create the contents of up to 10 bags full of fun activities that would help entertain a child who has cystic fibrosis (CF) while they are in hospital.

Registrations are open from 1 March to 1 May 2017. Submissions close by 23 May. Winners will be announced 12 June 2017.

Email education@cfwa.org.au or phone **08 6457 7333** to find out more and register your interest. Or register online by visiting: <https://www.surveymonkey.com/r/LHHQHFF>



ROUTINES & BOUNDARIES

for Babies, Toddlers & Pre-schoolers



Join us for a workshop on daily routines and boundaries for children with cystic fibrosis, including:

- routines and boundaries around mealtime and physio
- strategies to cope with challenging behaviour
- self-care for 'carers'

WHEN

28 April 2017
10am-1pm

WHERE

The Niche Building
11 Aberdare Road
Nedlands

RSVP: Kathryn Pekin at servicesmanager@cfwa.org.au or 08 6457 7333

65 Roses

FOR CYSTIC FIBROSIS



Help us paint WA with roses
for people with cystic fibrosis

www.65roses.org.au

