

EDITION 4 2018

# RED



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A LIFE JOURNEY WITH CF



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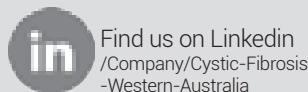
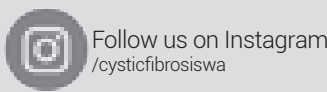
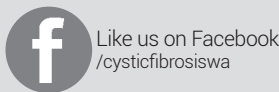
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# RED CEO MESSAGE



NIGEL BARKER, CEO

Since the last publication of Red Magazine there have been developments which I believe will become regarded as historical milestones in the care of people living with cystic fibrosis (CF).

Of course, the success in getting Orkambi listed on the PBS has been one of the highest profile achievements of the CF Federation in recent years. A campaign designed and implemented by CF Australia and supported in each State and Territory has demonstrated what we can achieve if we work together. Congratulations must go to everyone involved and particularly to Nettie Burke the CEO of CFA and her team, and also to the PBAC and Vertex for finding a way forward.

Importantly not only was the campaign successful in obtaining access for people over the age of 12 years but it was also successful in obtaining access for 6-11 year-olds too, who are homozygous to F508del. A more detailed article is included in this edition of Red Magazine and of course can be accessed through CFWA's website [www.cfwf.org.au](http://www.cfwf.org.au)

The other milestone, less heralded but just as significant, is the breaking news that infections, and by association, structural lung damage, in infants under 5 years of

age has been halved over the past 5 years. This is really important because we know that if we can delay the onset of structural lung damage in infants we can add many years to life and they'll be good ones too.

The reduction in infections and structural lung damage is thought to be due to a range of activities including a better understanding of the disease, early intervention and new treatments. We'll have a lot more detail on this in future editions of Red Magazine so watch this space.

We have also had success in raising awareness and funds for CF research and service delivery, particularly the funding of new nebulisers through the Red Tie Dinner Dance in August.

The fight continues and with your support we will achieve our vision of Lives Unaffected by CF.

## DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our first edition for 2019, please contact us before 20 Jan 2019.

## 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

Ruby bouncing on her new trampoline

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# ORKAMBI FAST-TRACKED WITH OCTOBER 1 ROLL OUT AND IMMEDIATE COMPASSIONATE ACCESS

This week the Australian cystic fibrosis (CF) community celebrates after the Prime Minister, Scott Morrison and Minister for Health, Greg Hunt confirmed that the Government would subsidise Orkambi for 1,300 patients with the F508del CF gene mutation.

Orkambi was priced at \$250,000 per year per person and now patients will pay a monthly maximum of \$39.60, with concessional patients paying just \$6.40.

The official listing date for Orkambi was 1 October 2018, however Vertex has agreed to providing free compassionate access immediately, which means that all those who are eligible for Orkambi should start by contacting their clinic to get the process underway.

Thank you to the CF community for

their amazing support and fierce, passionate advocacy. With each knock back, you all got straight back up, grew bigger, louder and stronger.

Whilst the fight for Orkambi has given us a great reason to celebrate, the additional announcement that Vertex will prioritise Australia when filing new CF therapies such as Symdeko and the next generation triple therapy makes it even greater.

Quick access to the best available drugs is what Cystic Fibrosis Australia strive for and we thank The Prime Minister Scott Morrison, Health Minister Greg Hunt, Vertex, PBAC, our colleagues in all CF State and Territory Organisations and of course the CF Community for their commitment to getting Orkambi across the line.



## 13TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

3-6 August, 2019 | Crown Towers Hotel, Perth



## IT'S CF CONFERENCE TIME AGAIN!

The Australasian Cystic Fibrosis Conference is heading to Perth in 2019

We are thrilled to be well underway with the planning of the 13th Australasian Cystic Fibrosis Conference to be held at the Crown Towers, Perth from 3-6 August 2019.

Speakers are currently being confirmed to cover a huge range of topics in what is shaping up to be Australasia's largest ever event dedicated to cystic fibrosis (CF). As

always, there is also a social program that runs parallel to the conference allowing attendees of the Lay Conference to meet fellow community members and share experiences and offer advice, as well as for attendees of the medical conference to chat with their peers in a relaxed and social environment. Bookings for all social

events are limited and can be made when registering for the conference.

Extreme Early Bird registrations are now open and offer a huge discount for both the Lay and Medical Conferences. It saves to book early as prices will rise from 1 December. Register now:

[www.cysticfibrosis.org.au/acfc](http://www.cysticfibrosis.org.au/acfc)





Melissa, Justin, Colby and Toby

# ORKAMBI® AT LAST!

On 17 August 2018 thousands of families waited anxiously to hear the PBAC's decision for the life changing drug ORKAMBI® (lumacaftor/ivacaftor).

This was the fourth Pharmaceutical Benefits Advisory Committee (PBAC) Orkambi® (lumacaftor/ivacaftor) submission for reimbursement in Australia and Melissa, with husband Justin and their two beautiful boys agreed to be the faces to represent our Cystic Fibrosis WA (CFWA) community. Their eight-year old son Toby has cystic fibrosis (CF) and we spoke to Melissa and Justin about this memorable day.

**RED: Can you tell us your motivation in agreeing to meet with the media for the release of the Orkambi® reimbursement decision.**

Justin and I agreed to take part in this as we feel it is important to give an insight into what we go through as a family. Many people still don't know enough about CF, so anything we can do to raise awareness is a positive. Toby is possibly going to benefit from this medication, so we felt it important to take part.

**RED: What were your thoughts while you**

**awaited the decision announcement?**

Whilst awaiting the announcement we were not feeling very positive to be honest. At best, we expected it to be available for children 12 and over which would have given us hope for Toby to receive Orkambi® in 4 years' time. We kept busy and tried not to overthink it.

**RED: With the wonderful outcome, being the PBAC has approved access to Orkambi® (lumacaftor/ivacaftor) for CF patients six years and over who are homozygous (have two copies of) for the F508del gene mutation, how does this impact you and your family?**

Now that Orkambi® has been approved we look forward to speaking to Toby's CF team at PCH. Of course we are keen for access earlier rather than later but understand the processes that needs to be put into place once it is released. We are strong advocates for prevention of lung damage and getting in before this happens is something that you

could only dream about. For us, the timing couldn't be better as Toby's lung function has been down without obvious reasons, so Orkambi® is such a positive for us.

**RED: Can you describe life now and how you see the future for Toby and your family?**

Life now has hope. We can look forward to overseas travel with Toby down the track. We can take him camping more, which he really enjoys. We understand it isn't a cure, but it's a solid step forward that will make life better for Toby. This has a flow on effect through our whole family. He is most excited about less time off school and more time really enjoying fun times with his family and friends.

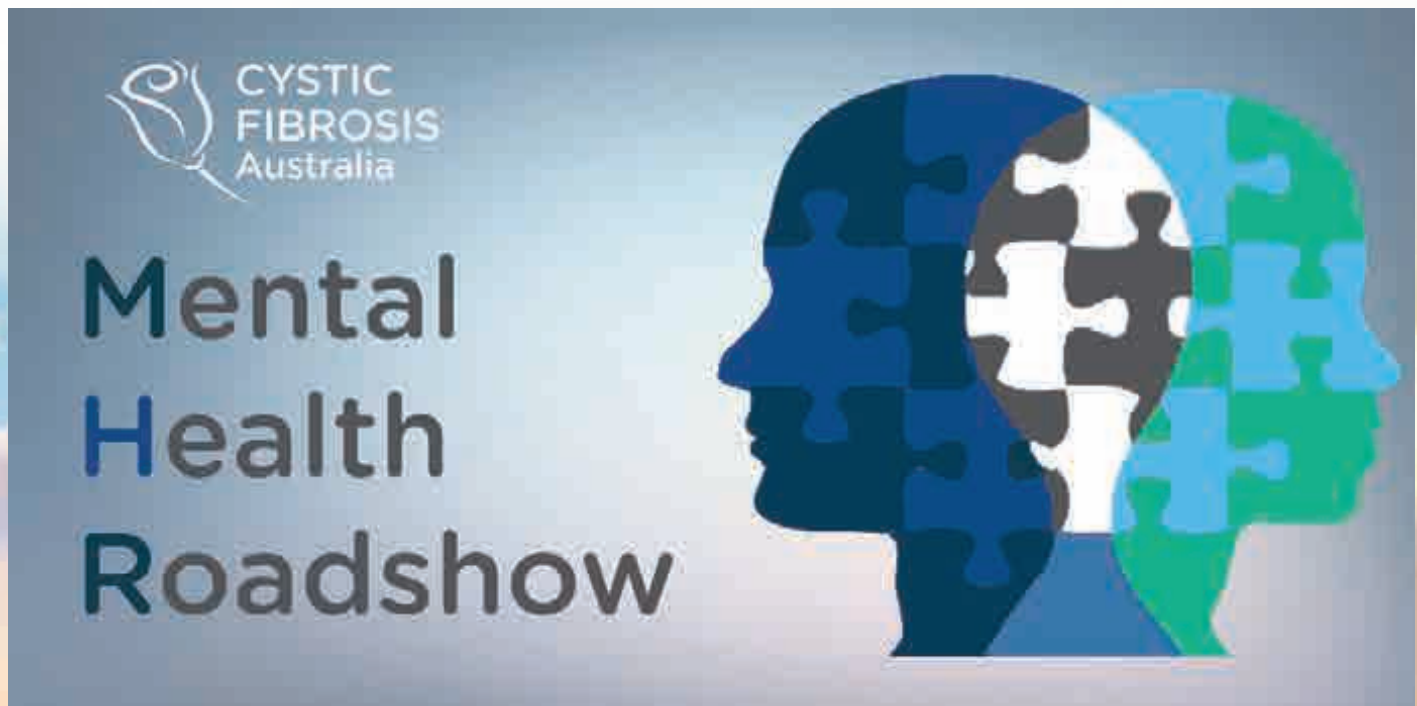
We thank all those that worked tirelessly to make this happen.

**Useful links:**

[www.cfwf.org.au/news/pbac-approves-orkambi](http://www.cfwf.org.au/news/pbac-approves-orkambi)

# MENTAL HEALTH ROADSHOW – A FREE EVENT

Free CF Specific Mental Health Events



Cystic Fibrosis Australia (CFA) is honoured to be able to bring two exceptional mental health professionals from the United States, Alexandra Quittner (Miami) and Anna Georgiopolous (Boston), to Australia to brief our community and train our health professionals across the country in cystic fibrosis (CF) specific mental health.

Dr. Quittner has been a professor and behavioural scientist for the past 30 years. Throughout her career, she has conducted clinical research in CF and other chronic respiratory diseases. She led the TIDES Study in nine countries which brought

attention to depression and anxiety among both individuals with CF and parent caregivers.

Dr. Georgiopoulos is a child, adolescent, and adult psychiatrist integrated into the Massachusetts General Hospital CF Program at Harvard Medical School since 2005. She has played a leadership role in developing and implementing the CFF/ECFS depression/anxiety guidelines.

The roadshow will include three sessions to be held in Perth:

Session 1 is for the community, parents, partners and carers. It will be held from

6-8pm on Sunday 11 November.

Sessions 2 & 3 are for those involved in the direct care of people with CF. There is an introductory session for all CF Centre staff, as well as an advanced session for this directly involved in mental health support, diagnosis and interventions.

For more information and to book now visit [www.cysticfibrosis.org.au/mhr#WA](http://www.cysticfibrosis.org.au/mhr#WA)

CFA is very excited about the Mental Health Roadshow and we thank the Cystic Fibrosis Foundation and LJ Hooker for providing us with the funds to make it a reality.



# THANKS AURIZON!

CFWA are extremely grateful to have received funding from Aurizon to provide trampolines to our young members.



Trampolining is a fun way to get some exercise and may also help move mucus from the lungs. Studies have shown that exercise can have positive health outcomes for people with cystic fibrosis (CF), including improved aerobic capacity, lung function and quality of life. Exercise has also been shown to support good mental health so getting into the habit of being physically active is very important.

If you have a child with CF aged 2-10 years who has not received a trampoline in the past, please contact us to get more information. We would appreciate your photos and feedback to pass on to our generous sponsor Aurizon so please send it through to [physio@cfwa.org.au](mailto:physio@cfwa.org.au).

Aurizon is Australia's largest rail freight operator, operating in almost 200 locations across Australia. Aurizon actively supports communities they work

and live in, through their Community Giving Fund. CFWA welcomes the generous funding from Aurizon to extend the reach of our service programs.





# CF TALK SHORT FILMS

These films share the “lived experience” of adults with CF and their reflections on life as a teen growing up with a chronic disease. Share these journeys and be inspired by their humour, resilience and candour.



Justin

Thanks to support funding from Lotterywest and the generosity of six adults with cystic fibrosis (CF) who have shared their story with us, we have produced a series of short films covering different aspects of life with CF.

The films will be released in November 2018, but here's a sneak peek of the film stars!

## Justin

Justin is nearly 18 years old and in the process of completing his high school studies. In the film he talks about some of the difficulties around managing CF with another chronic condition: CF-related diabetes. He talks about the things that are important to him, particularly sport (soccer), mechanics and his friends. Be inspired about his genuine warmth and desire to help others.

## Mitch

Mitch is 58 years old and has been involved at various levels in the CF community since he was a teenager as his parents were some of the founding members of Cystic Fibrosis WA (CFWA). Mitch's wide-ranging experiences both from an older person with CF and as an executive in CF organisations provides an in depth and considered perspective on managing the many facets of CF.

## Caz

Caz is 51 and had a double lung transplant when she was 27. Listen to Caz talk about her full and colourful life, including relationships, intimacy and life in the old lane! Her talk touches on achievements such as becoming President of the CFWA board and skydiving to celebrate her 18th lung



Mitch



Caz



anniversary. Caz as always, is inspirational.

**Sera**

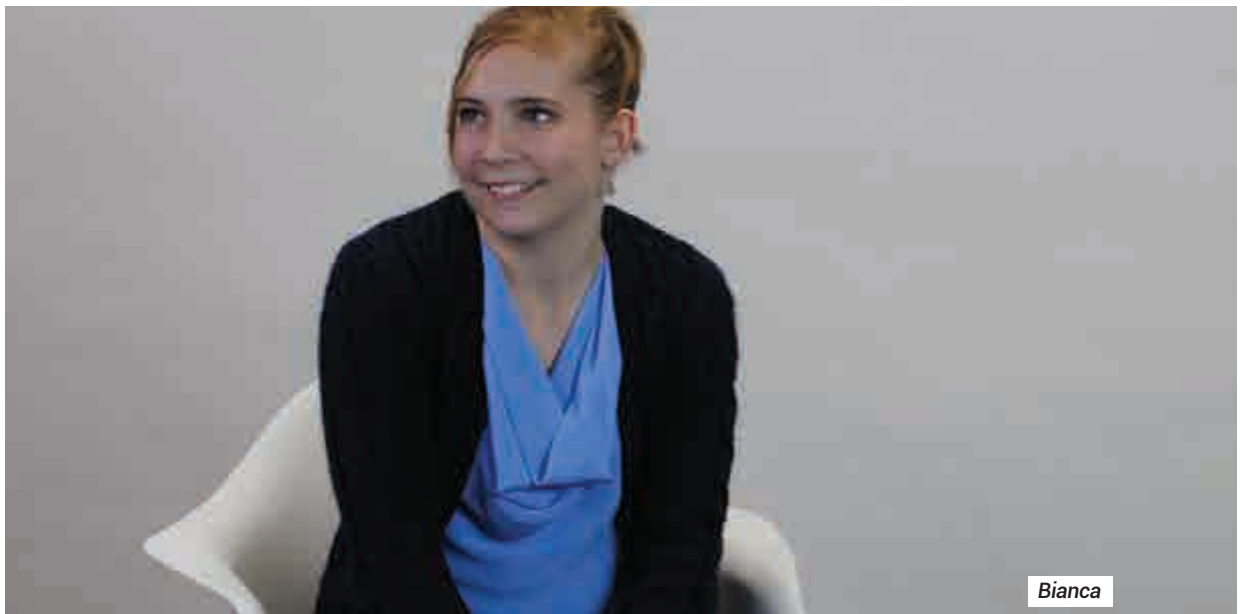
Sera is 28 years old and is renowned for her long gorgeous red hair and as a hip-hop event co-ordinator “extraordinaire”. She reflects on her rebellious teen years offering insights and humour into what can be a difficult time. Sera is highly motivated to keep raising the bar on awareness through community events and her strong sense of self.

**Bianca**

Bianca is 25 with an impish smile and a big laugh. She shares her story of spending her childhood on the Solomon Islands before returning to Perth as a young adult. She has a beautiful connection, particularly with her Mum who she recognises as the strength that has got her through, however also acknowledges that the rest of her family, friends and church have also been vital to her.

**Toby**

Toby lives in Bunbury and is 21. He has been involved in Sea Scouts with his brother for many years, more recently being involved in a leadership capacity. He shares some funny stories about managing “gas” at work and the importance of mates.





# CF RESEARCH NEWS – ORKAMBI® UPDATE

The following articles bring you some of the latest information published in the Journal of Cystic Fibrosis about the use of ORKAMBI® (Lumacaftor/Ivacaftor) in patients with advanced lung disease and a case study during pregnancy and breastfeeding.

The aim of CF Research News is to bridge the gap between people with cystic fibrosis (CF) and the researchers investigating CF, providing access to patients, parents, relatives, friends and caregivers to all scientific work published in the Journal of Cystic Fibrosis.

## **Nov 2017: Lumacaftor/ivacaftor in patients with cystic fibrosis and advanced lung disease homozygous for F508del-CFTR**

Authors: Jennifer L. Taylor-Cousara, Manu Jainb, Tara Lynn Bartoc, Tarik Haddadd, Jeffrey Atkinsone, Simon Tianf, Rui Tangf, Gautham Marigowdafa, David Waltzf, Joseph Pilewskig.

### **What was your research question?**

Is combination therapy with lumacaftor/ivacaftor safe, tolerable, and effective in patients with cystic fibrosis (CF) aged 12 years and older with advanced lung disease?

### **Why is this important?**

Patients with CF and more severe lung dysfunction have a greater disease burden and risk of death than patients with better lung function. No FDA (Food and Drug Administration) - regulated studies have been conducted to determine the safety, tolerability, or efficacy of lumacaftor/ivacaftor in patients with CF who also have advanced lung disease. These patients may be at more risk of side effects from lumacaftor/ivacaftor treatment.

### **What did you do?**

We conducted a clinical study that included patients with CF aged 12 years and older

who had two copies of the F508del-CFTR gene mutation and who also had advanced lung disease. All patients underwent medical tests, including spirometry (which measures how well the lungs are working) before and after taking lumacaftor/ivacaftor. Patients received lumacaftor 400 mg/ivacaftor 250 mg every 12 hours (full dose) for 24 weeks. To improve study drug tolerability, dose modification to half-dose for 1 to 2 weeks was permitted at the discretion of the study doctor. Safety, tolerability, and efficacy were assessed in this study.

### **What did you find?**

Treatment benefits associated with lumacaftor/ivacaftor were observed in patients with CF and advanced lung disease similar to those seen in patients with CF without advanced lung disease. Patients receiving lumacaftor/ivacaftor had less need for antibiotics to treat their symptoms and fewer hospitalizations. An increased incidence of side effects (including dyspnea and chest tightness) was observed in patients receiving full-dose lumacaftor/ivacaftor. However, patients who initiated treatment with half-dose lumacaftor/ivacaftor prior to increasing to full dose experienced fewer side effects and did not discontinue study drug treatment.

### **What does this mean and reasons for caution?**

Although this study had only a small number of patients, these data demonstrated that lumacaftor/ivacaftor is safe and tolerable in patients with CF and advanced lung disease. The findings from

this study suggest that patients with CF and advanced lung disease might benefit from treatment initiation at a lower dose of lumacaftor/ivacaftor, with a gradual increase to full dose. This study should be interpreted with caution because no direct comparison was made to patients with CF and higher lung function.

### **What's next?**

This study showed that lumacaftor/ivacaftor can potentially be a safe and effective therapy in patients with CF and advanced lung disease. Additional studies are needed to observe a larger patient population over an extended study period in order to provide more evidence for our findings.

Original manuscript citation in PubMed:

**[www.ncbi.nlm.nih.gov/pubmed/?term=Lumacaftor%2Fivacaftor+in+patients+with+cystic+fibrosis+and+advanced+lung+disease+homozygous+for+F508del-CFTR](http://www.ncbi.nlm.nih.gov/pubmed/?term=Lumacaftor%2Fivacaftor+in+patients+with+cystic+fibrosis+and+advanced+lung+disease+homozygous+for+F508del-CFTR)**

## **June 2018: Measured fetal and neonatal exposure to Lumacaftor and Ivacaftor during pregnancy and while breastfeeding**

Authors: Aaron T Trimble, Cameron McKinzie, Mary Terrell, Elizabeth Stringer, Charles Esther Jr

### **What was your research question?**

CFTR modulators represent an important new class of medication to improve CFTR function, but little is known about their effects on pregnancy. After one of our





patients decided to remain on lumacaftor/ivacaftor both while pregnant and to breastfeed following birth, we wanted to know how much drug the baby would be exposed to.

#### **Why is this important?**

As health improves for people with CF, more people are choosing to have families of their own. CFTR modulators are an important part of this progress, but little is known about how their use may affect a pregnancy. To date, there is one published report of a woman carrying her pregnancy to term while taking ivacaftor, and there are no such reports for lumacaftor/ivacaftor.

Because many women prescribed these drugs will undoubtedly consider pregnancy, it is important for the scientific community to describe and report any experiences to inform patients and providers to develop a medication plan while considering pregnancy and/or breastfeeding.

#### **What did you do?**

We reported on the clinical outcome of a mother and her infant daughter from pre-term through six months of age who remained on lumacaftor/ivacaftor during her pregnancy and while breastfeeding. We also measured drug levels in the mother, the infant, as well as breastmilk and cord blood.

#### **What did you find?**

The pregnancy was normal and

the infant was born without CF and healthy. There were some mild fluctuations in the infant's liver function that we did not believe were due to exposure to lumacaftor/ivacaftor. We also found high levels of both drugs in cord blood; lumacaftor levels in cord blood were higher than the mother's blood levels, and ivacaftor levels were similar. We found drug present in breastmilk as well, but at lower levels. The drug was present in infant blood for several months after birth but were about 1-5% of the mother's levels.

#### **What does this mean and reasons for caution?**

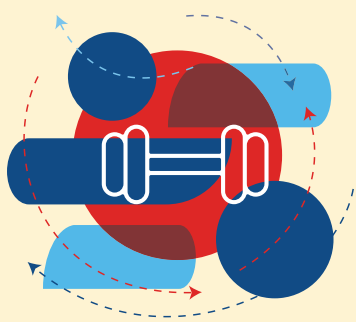
Although the patient and her daughter seemed to suffer no ill-effects, this one case report is insufficient to alter the current recommendation that these drugs should be avoided in pregnancy and breastfeeding. Our findings do suggest that both lumacaftor and ivacaftor readily cross the placenta, and that infants may be exposed to the same levels of drug as their mothers during development. Our findings also suggest that the drug is present in breastmilk, and that infants who breastfeed are exposed to low levels of drug. It is also possible that the drug may cause transient abnormalities in liver function in infants.

#### **What's next?**

Because the promise of new treatments will likely enable more people with CF to enjoy healthy lives and relationships, it is very important to collect information about people's experiences with these drugs with pregnancy and breastfeeding. Although not discussed in this paper, a registry has been created to collect information which will help patients and their providers make informed decisions with regard to CFTR modulators and pregnancy.

#### **Original manuscript citation in PubMed:**

[www.ncbi.nlm.nih.gov/pubmed/?term=Measured+fetal+and+neonatal+exposure+to+Lumacaftor+and+Ivacaftor+during+pregnancy+and+while+breastfeeding](https://www.ncbi.nlm.nih.gov/pubmed/?term=Measured+fetal+and+neonatal+exposure+to+Lumacaftor+and+Ivacaftor+during+pregnancy+and+while+breastfeeding)



# NEW CF FIT RESOURCES

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## Have you seen our new CF Fit resources?

These booklets, including a guide for people with cystic fibrosis (CF), Personal Trainers guide and an exercise diary, have been produced to assist people with CF to exercise safely at home and in the gym.

Visit [www.cfwa.org.au/what-we-offer/resources](http://www.cfwa.org.au/what-we-offer/resources) for a free downloadable copy of these resources





# BEAT-CF PROJECT IS SEEKING PEOPLE TO JOIN THEIR NATIONAL REFERENCE GROUPS

Do you have cystic fibrosis (CF) or care for someone who does? Would you like to have a say about a new way of trialling treatments for people living with CF?

Researchers at Telethon Kids Institute are looking for 24 people - 8 adults, 8 young people and 8 parents, partners and carers, to join one of three national community reference groups for this exciting new project.

## About the project

The Bayesian Evidence-Adaptive Trial in Cystic Fibrosis (BEAT-CF) is one of the first Australian platform trials, which is aiming to improve the quality of life for people living with cystic fibrosis (CF) through better management of lung infections.

A platform trial is quite different from a traditional clinical trial. Usually trial designs are fixed from beginning to end and only one or two treatments are tested during a trial, which may not be effective for some patients involved.

A platform trial allows a more flexible design. Importantly, researchers can change parts of the trial while it is in progress. The researchers will regularly review information gathered during the trial and can modify the treatments for some or all of the patients. Adjusting the treatments that patients receive in the trial is likely to improve health outcomes (including by reducing the chance people receive treatments with unwanted side effects). Researchers are also able to compare multiple treatments against each other. This is expected to greatly speed up the process of getting effective treatments approved so they can be available for use in all patients.

This new design has the potential to transform the medical care that people living with CF will receive in the years to come.

**TELETHON**  
**KIDS**  
**INSTITUTE**  
Discover. Prevent. Cure.

Applications close: Friday 12 October 2018  
and can be made via this link:

[www.involvingpeopleinresearch.org.au/vacancies/402-cystic-fibrosis-beat-cf-project-national-reference-groups-ref-tk785](http://www.involvingpeopleinresearch.org.au/vacancies/402-cystic-fibrosis-beat-cf-project-national-reference-groups-ref-tk785)





# GRAINKING – CHASING THE CF VISION

Rural machinery innovator GrainKing will be chasing the CF vision this harvest with CFWA branded chaser bins working in the wheatbelt

When Gareth Button and his boss Colin Jorgensen sat down for a discussion around corporate support Gareth's personal connection with cystic fibrosis (CF) quickly came to focus. For Colin the opportunity for GrainKing to support a not for profit that had such strong attachment means that they can make a difference.

CFWA Business Development Manager, Karen De Lore, was excited to see the finished product at the recent Dowerin Field Day, having driven through the beautiful cropping region with this year's crops full of promise.

Karen later spoke with Colin about GrainKing's commitment to local communities and the charities that support families in regional areas.

**Would you like to explain GrainKing's community ethos?**

Being part of the lives of Aussie farmers and their local communities is what makes us

love what we do. Being able to give back to these communities and the organisations that support them keeps our farming regions vibrant and healthy.

**Why CFWA?**

The child of one of our employees has CF. We see the juggling act that families have with this chronic condition and know that living regionally adds to the burden of care. We understand how organisations like CFWA can help CF families, and we want to be part of making a difference in the lives of CF families across WA.

**Tell us about the chaser bin initiative?**

We make chaser bins, and we strive to help farmers innovate and improve their harvest. Time is money during harvest. Once a crop is ready to harvest the best place for that grain is with the grain buyers. Our bins help farmers move their grain efficiently between the harvester working out in the paddocks and their storage and haulage solutions.

Harvest 2018 and seeding 2019 will see two CFWA branded 18T chaser bins available for farm hire. Through a percentage of hire fees and other fundraising initiatives we have pledged a \$10,000 donation to CFWA by the end of 2019.

We are very proud that our distributorships have come on board too and will be supporting CFWA with collection tins and awareness brochures in their regional locations.

Together we want to achieve a brighter future for families impacted by CF and for children and adults living with the condition.

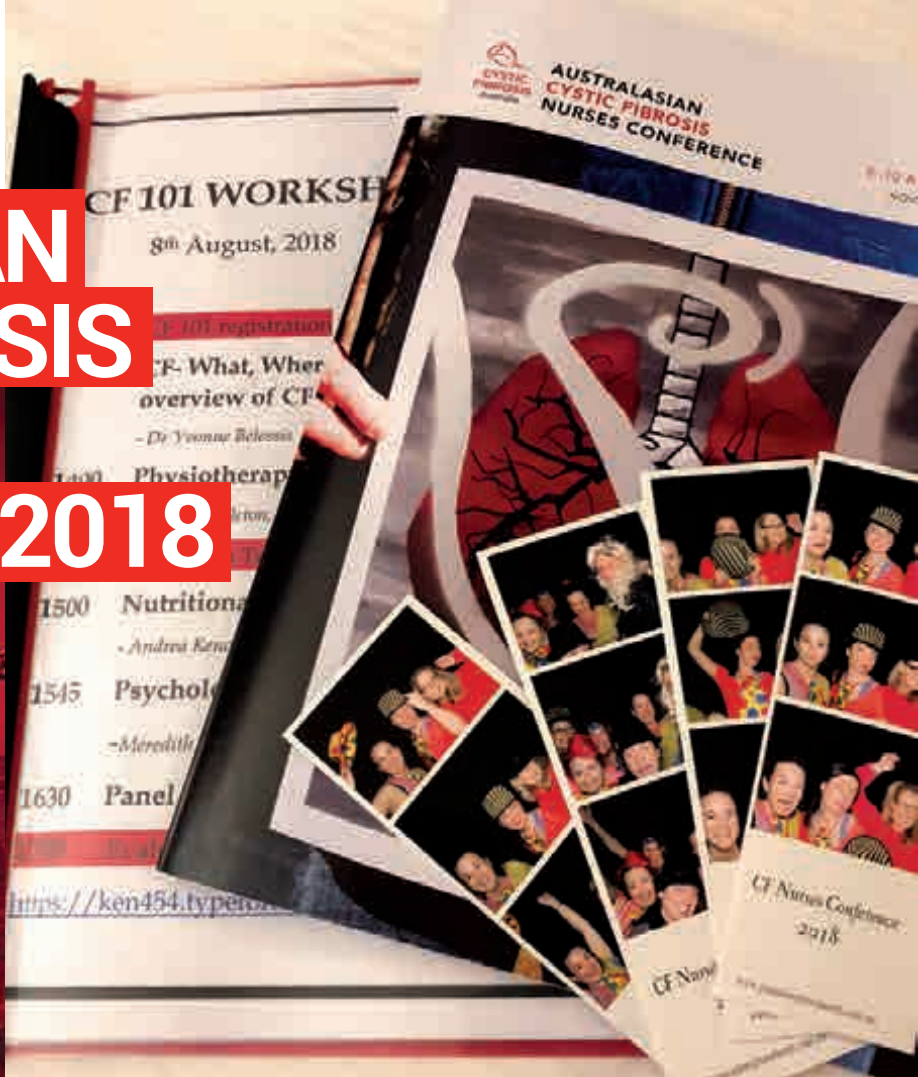
**How can farmer's get involved with this initiative?**

Each year we hire out chaser bins to farmers for the harvest period. Farmers looking to hire a chaser bin can contact Trent at GrainKing on 08 9635 2300 or at [sales@grainking.com.au](mailto:sales@grainking.com.au).



# AUSTRALASIAN CYSTIC FIBROSIS NURSES CONFERENCE 2018

FROM NOVICE TO EXPERT!



Recently our nurse, Sharon joined nurses from all over Australia and New Zealand who have a special interest in cystic fibrosis (CF). The conference was held at the Novotel, Parramatta and the program covered key areas of paediatric and adult CF patient management.

Jennifer Stewart, a Family Nurse Practitioner specialising in CF from Utah spoke on the importance of empowering CF patients through education. Additionally, she spoke on recognising and promoting the role of nurses in the lifelong management and support of people living with CF. Professor Barry Plant, a Consultant Respiratory Physician and the Director of the Adult CF Centre at Cork University Hospital in Cork, Ireland, provided updated information about infection control in CF clinics and practical approaches to CF challenges.

Dr Keith Ooi, Consultant Paediatric Gastroenterologist at Sydney Children's Hospital and a leading expert in CF gastroenterology and childhood pancreatic disease presented a comprehensive overview on specific CF and non-specific gastroenterological conditions in CF. He discussed future recommendations in the assessment and diagnosis of these conditions including the importance of the gut microbiome and having a holistic approach to management.

There were many experts who shared their knowledge and experiences. Professor Peter Wark from John Hunter Hospital, Newcastle,

discussed the new modulator therapies for CF. He highlighted modulator therapies which are now a reality for most people with CF and are likely to transform care and early intervention and may prevent the development of significant lung disease. Despite this, a high burden of care remains and is likely to be a reality for the current generation with CF, especially those older than 12 years of age, and cost remains a potential barrier for access.

Nursing experts in CF were also well represented at the conference, presenting and motivating innovation by sharing their research projects, paving the way to improve patient care outcomes and advances in data collection.

One of these projects, inspired by the CF Services Team at The Children's Hospital at Westmead, NSW, was the 'Patient portals to their medical health record-new technologies for families and staff'. The "My Health Memory App" was launched to a trial group as a new patient portal. The aim being, to communicate with families in a timely, comprehensive and uncomplicated manner. The app allows text communications between the patient and clinical staff via the e-Medical Record (eMR). Appointments are integrated with the eMR scheduling system allowing a patient to request an appointment reschedule and appointments to be synced with their phone calendar and provide automated appointment reminders. The app has been enthusiastically embraced by

the CF team and families and has now been implemented across the Children's Hospital at Westmead.

Another interesting abstract presentation by CF nurse Elizabeth Shevill was 'The Sunshine Vitamin: Are the CF nurses and their patients getting enough?' Vitamin D deficiency is widely reported worldwide, and it is known that around 80% of shift workers and 43% of nurses have low vitamin D levels. Are CF nurses monitoring their own vitamin D levels while they ensure their patients are receiving the fat-soluble vitamin supplementation? vitamin D deficiency is also common in people living with CF and historically this has been associated with bone health, however there is now concern that it contributes to other comorbidities. A preliminary review of vitamin D levels in newly diagnosed babies at the Lady Cilento Children's Hospital in Brisbane has raised discussion and prompted more proactive treatment to maintain adequate levels.

Special thanks to the Organising Committee of the 2018 CF Nurses Conference for organising an excellent program and the opportunity for nurses to network and share their knowledge. Also, a special thank you for arranging a fun conference dinner and 80s Karaoke Night.

Conferences such as these not only empower our staff at Cystic Fibrosis WA but assist with future planning, inspire new ideas and support the provision of best practice.



# RELATIONSHIPS AND ROUTINES GET THE JOB DONE

Sharon, one of our homecare workers, works holistically with the family, developing routines around physio and making it a fun experience



Sharon and Emma

## **What do you do when you get a new referral?**

If the new client is a child I always ring and make contact with the primary carer and ask their advice on how they would like physio done and their expectations. I want to find out about the child's favourite things, so I can establish a relationship even before I meet them. I always reassure parents that physio will be fun and lots of laughs and make sure the kids know it's their time and make them

feel special. They are my priority and it's all about them.

My routine is always the same, as that works best. The greatest feeling is when you arrive for physio and you get this amazing greeting from the child, it's priceless. The smile and hugs and screams of delight when you arrive is amazing. It's the best feeling in the world when you just make a difference in the family's day and take the pressure off around physio treatments from the carers.

## **Is it difficult connecting with a new child or young person, particularly when they know you are there to do physio with them?**

Kids enjoy routine, so I stick to that. I plan physio visits in advance and engage with the kids as we establish our relationship. Once you get their trust and make their time all about them it becomes really awesome. The challenge of building this relationship is so personally rewarding. I love when they fully



trust you and they tell you funny stories. Boy, the mums and dads and I have had some laughs from kids' comments; they mirror image everything. It's not just about the kids with CF, you have to engage with siblings, the extended family and pets and build relationships with all of them. They like to feel important in their own special way and be included and part of physio.

### **What are some of the strategies you use to get children and young people to do physio?**

Lots of challenges and goal setting between me and the person with CF; with verbal promises, contracts and pinkie promises. The kids love positive encouragement and cuddles and sometimes a space where they can just voice their opinion and for us to listen to them.

We always do physio first and then the reward is after. I establish a personal connection with everyone and listen to what they like to do. For example, it could be ok if I buy an ice cream at McDonald's as a treat for great physio and working hard but we agree that we walk there and back, which obviously includes exercise, fresh air and a good chat. Sometimes it could be bubble play or ten minutes on the iPad, cards, art work, baking or a favourite story just whatever they like to do to put a smile on their face.

### **What do you do when someone refuses to do physio?**

Everyone has challenging days. I don't push the issue straight away to do physio but focus on what's bothering them. I let them chat and give them lots of reassurance and cuddles and keep letting them chat away. Before I know it, we are at a great happy level again and we do physio and the challenge is done. Sometimes it's harder than other days but it's just time and patience and we get there in the end.

Positive encouragement is important, always playing and having fun and sometimes a surprise on the next visit and thinking of something special just for them. I also check with mum and dad that they are happy with the services and if they would like any changes or need help with things that are

happening with physio. Parents enjoy the time to themselves and a break from routine.

### **Do children and young people ask you lots of questions about CF?**

Some kids ask more questions than others. I always check with the parents what they have told their kids and respect their wishes about what they would like their kids to know. As our relationship establishes I start to get them to do things on their own in preparation for physio. I listen and answer their questions as simply and honestly as possible and am always guided by the parents.

I also care for older kids, teenagers and young adults. I have introduced FaceTime physio for young adults which works great. You can do it at a time that works for everyone.

This is the best job in the world! I love what I do and being welcomed into the families' homes. It's different every day and so personally rewarding seeing the kid's and adults develop and create their dreams. I am so lucky to be a part of the CFWA Team. Thanks so much to all the families.




FaceTime physio with Holly



Samantha and Sharon enjoying some bubbles





# *You're invited to the 2018 Cystic Fibrosis WA Carers Dinner*

If you are a parent or carer of someone with CF, then we would love you to join us for dinner to chat with other parents, share stories and meet some of the CFWA team

We're hosting this event during Carers Week to celebrate the important work you do and give you a chance to relax and take a break for the evening.

**Where:** Captain Stirling Hotel, 80 Stirling Hwy, Nedlands

**When:** Friday 19 October 2018

**Time:** 7pm **RSVP:** [tinyurl.com/jxk94cb](http://tinyurl.com/jxk94cb)

Thanks to the generous support of Carers WA, Lotterywest and City of Nedlands we are able to offer this dinner at just \$20 per person.







# FREMANTLE SAILING CLUB ROCKED BY RED TIES & GLAMOUR

Now in its 4th Year, Fremantle Sailing Club (FSC) Power Section once again hosted the Red Tie Dinner Dance to raise much needed funds for Cystic Fibrosis WA (CFWA).

At the sell-out event, over 260 people rocked the night away with Tod Johnston's Band; Peace Love and raised funds for CFWA whilst they enjoyed stunning food from FSC's head chef Richard Potheary, wines from Oakover and beers from Gage Roads.

The event was the best ever and gave a fantastic opportunity not only to raise funds but also to celebrate the recent listing of Orkambi on the PBS the day before, a new drug to treat the underlying cause of cystic fibrosis (CF) for people over the age of six with two copies of the F508del mutation.

The Commodore of FSC Graeme Allen, said how proud he was of the club's place in Fremantle and the way in which it was fulfilling its corporate social responsibility, not only raising funds for CF but also for prostate and breast cancer too.

Caz Boyd, President of CFWA and herself a double lung transplant recipient, talked about her life living with CF and the courage of the couple who had given up the lungs of their daughter upon her death so that Caz

could live. This was followed by a stunning video produced for the event by the Telethon Kid's Institute.

This year, for the first time, the event organisers decided to include a 'fund a need' in the live auction. The need identified was the provision of new nebulisers, used to deliver vital medication to people with CF. We were blown away by the generosity in the room, with funds raised for nebulisers far exceeding our expectations.

Ms Jessica Shaw MLA attended representing the Deputy Premier and Minister for Health and said how she had great hopes for people living with CF in WA and recognised the outstanding support that CFWA has received through successive governments over the years.

Thank you to the generous event sponsors



Croker Construction, Vertex Pharmaceuticals and Robinson Insurance Broking Services, as well as event supporters Oakover Wines, Boat Parts Australia, Fiori, WAFEX and Tail Lift Transport, who all helped make the night such a success.





# OPTIMISING RESILIENCE

In the CF community we constantly meet amazingly resilient people and wonder just how they do it. The great thing is these people inspire us and research indicates that such skills can be learned and developed in all of us.

At times being a carer, or having cystic fibrosis (CF) can bring up a whole host of emotions such as anxiety, sadness, guilt, anger, frustration and even depression. These feelings are probably quite “normal” and remain fairly situational, for example, initial diagnosis of CF, hospitalisation, clinic or specific medical procedures. See our procedural anxiety factsheet for more information: [www.cfwa.org.au/wp-content/uploads/2018/07/CF-Fact-Procedural-Anxiety.pdf](http://www.cfwa.org.au/wp-content/uploads/2018/07/CF-Fact-Procedural-Anxiety.pdf)

Often for carer's and people with CF these feelings will remain in check until the next health issue occurs, which is again quite normal. However, research indicates that these feelings often spill over to affect other parts of our lives with 2-3 times more depressive symptoms than the normal population.

**Outcomes of unchecked anxiety and or depression include:**

- Parents suffering from elevated anxiety

and depression are less likely to administer medication and or treatment to their children

- Young people and adults with elevated anxiety and depression are less likely to understand their CF and have less motivation to manage treatment regimens

## **Building resilience to manage stress**

So, what exactly is resilience and why should we have it? As mentioned, many of us are stressed, however developing good resiliency



skills helps us to bounce back despite trauma or with difficult health or relationship issues.

Martin Seligman, positive psychology author, has researched how people recover from trauma and asserts that for some people they are able to have post-traumatic growth, to not just bounce back to a previous self but to grow beyond with a whole new set of skills and thrive despite life's setbacks.

Five key resiliency skills are:

- Optimism skills
- Willpower
- Communication and social support
- Organisation and practical preparation skills
- Meaning and life purpose

### Optimism Skills

Optimistic people or those that see the glass half full tend to be more resilient, less anxious, depressed and generally healthier. Seligman breaks these skills down to three elements:

- **Permanence:** Optimists tend to believe that the tough stuff has an end point and generally they can find a silver lining in each situation, whereas a pessimist may believe that things will always stay difficult. More info:

[www.silverlinestories.com/about](http://www.silverlinestories.com/about)

- **Pervasive:** If something difficult happens an optimist may think, "ok that's tough" but it's confined to one area and they are able to reflect on other good things in their life, whereas a pessimist may let one negative event spread to the rest of their life.
- **Personalised:** Optimists learn to not take things personally, whereas pessimists tend to blame failures or problems on themselves even when they shouldn't.

### Take advantage of opportunity

Opportunity is a word that inspires HOPE. New drugs, new treatments, new programs, dating, skydiving or whatever gives your life meaning. Edison apparently tried about 2000 substances before having success with carbon wire to invent the electric light bulb. "Opportunity is missed by most people because it is dressed in overalls and looks like work." – Thomas Edison

Keeping the balance between realism and hope is also vitally important and learning to surrender when things are out of your

control or beyond your capability whilst maintaining hope is essential.

### Creativity and Mindfulness

There is a reason that creative pursuits are often used in rehabilitation centres as it helps people reconnect with "flow", stay in the moment, find joy, new ideas and use parts of our brain that perhaps haven't been used for a while. Creativity can be applied to anything, not necessarily just art, music or writing but to other aspects of our life such as cooking and work.

Resilient people know that stress and pain is part of life and usually something that will come and go. When things are really difficult, breaking it down into "one day at a time" makes it possible to get up and get moving. There are plenty of creativity and mindfulness sites that can help with this, see the "Connecting, Creating and Looking After Yourself" article later in this edition of Red Magazine for some useful links.

### Dealing with uncertainty

Studies have shown that most people would rather get an electric shock now than at some other unknown unpredicted time, so if there is going to be bad news it's better to know what it is rather than live with the uncertainty.

"Uncertainty is the only certainty there is and knowing how to live with insecurity is the only security" - John Allen Paulos

The question is: "how much do we need to know"? Studies have shown that people who have a better understanding of their health feel more confident to ask questions and manage treatment. The Australian Bureau of Statistics report that approximately 50% of Australians have poor health literacy which directly affects their ability to manage their health or that of their children, directly resulting in poorer health and hospitalisations.

It's your health, learn about it, ask the health professionals what certain things mean. Take a notebook to clinic appointments. CFWA also have lots of educational resources to help explain different aspects of CF. [www.cfw.org.au/what-we-offer/resources](http://www.cfw.org.au/what-we-offer/resources)

### Loving compassion

To connect well with others, we need to have a good sense of self, feel worthy and lovable. Brene Brown in her TED talk discusses her

research on people that live "Wholehearted" and successful lives. These are her tips:

- **Courage-** tell your story with your whole heart and have the courage to be imperfect
- **Compassion** – have compassion towards yourself and others
- **Connection** – let go of who you think you should be to connect well with others
- **Be vulnerable** – what makes you vulnerable makes you beautiful. It's the willingness to do something first, to invest in something with no guarantees e.g. to ask someone on a date, invest in training, to share feelings without necessarily getting anything back
- **Stop controlling and predicting** – develop spiritual awareness and trust
- **Practice gratitude** – learn to find the good in each other and each situation

### Trauma recovery and social support

Many people with CF and their families experience a level of trauma around diagnosis, medical treatments and illness. Research indicates that trauma can make people feel disempowered and disconnected from others. Herman (1992) discusses how healing can only take place in relationships not in isolation. We need to build trust and a sense of competence, identity and intimacy.

All six people in the CF Talk short films discussed their strong social connections and the importance of family, friends and at times the CF community. Happiness author and business coach Alvah Parker notes that resilient people "are strong people who realise the importance of having good social support systems".

### Life meaning and purpose

"We are at our best when we dedicate time to something bigger than ourselves. This might be religious faith, community work, family, politics, a charity, a professional or creative goal" – Martin Seligman

### References

[www.ted.com/talks/brene\\_brown\\_on\\_vulnerability?share=1a2a1d0045http](http://www.ted.com/talks/brene_brown_on_vulnerability?share=1a2a1d0045http)

<https://www.cff.org/Life-With-CF/Daily-Life/Emotional-Wellness/Coping-While-Caring-for-Someone-With-Cystic-Fibrosis/>

Quittner et al., Thorax. 2014;69 (12): 1090-7  
Seligman M. A Visionary New Understanding of Happiness and Well-being 2011





# FINISHED READING YOUR RED MAGAZINE?

Ask your doctor, dentist, hairdresser etc. if you can leave a copy in their reception.  
A great way to "save a tree" and spread awareness of CF in your community!

# Regional Evening with CF Scientists

Friday 23 November



## You are invited to the 2018 Bunbury cystic fibrosis research update

Join us for an annual CF research update from the Telethon Kids Institute (TKI) AREST CF Team.

We're delighted to announce that Professor Stephen Stick who heads the team will be guest speaker, presenting the team's latest research.

This is an amazing opportunity to hear from a world renown expert in the field of CF.

### EVENT DETAILS

**Date:** Friday 23 November

**Time:** Drinks and nibbles from 6:00pm, dinner and presentations from 6:30pm

**Venue:** Lord Forrest Hotel 20 Symmons St, Bunbury

This event is proudly supported by Telethon and is a FREE event for members. Please note, RSVP is essential for catering purposes.

To RSVP please contact Kathryn

email: [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au)  
phone: **08 6457 7333**

If you have CF, please be aware that there may be other adults with CF at this event. We request that you follow our Infection Prevention guidelines, for further information visit [www.cfw.org.au/about-us/annual-reports-policies](http://www.cfw.org.au/about-us/annual-reports-policies)





# CONSULATE COURT CHRISTMAS LIGHTS FOR CYSTIC FIBROSIS

A dedicated community of people will be raising awareness and funds for cystic fibrosis (CF) through their incredible annual Christmas lights display this year.



Every year, the residents of Consulate Court select a charity to support through street festivities and colourful christmas lights. This year they have chosen to support Cystic Fibrosis WA (CFWA).

One of the families who lives on the street said “given Christmas is such as family time and how much children love the christmas lights, we feel it’s a great opportunity to raise awareness for CF. It’s difficult to know

how to help a family facing these challenges every day, and this is just a very small gesture to let them know we think about them”.

From the 1 to 25 December, this very merry cul-de-sac in Thornlie will be lighting up their street in flashes of colour to raise funds to support important services for families living with CF and critical CF research.

Like their Facebook page to keep up to date:

[www.facebook.com/consulatecourtlights](https://www.facebook.com/consulatecourtlights)

We are looking for volunteer “elves” to help the families of Consulate Court to take donations and help spread awareness of CF during December. Get in touch with us on [events@cfwa.org.au](mailto:events@cfwa.org.au) or phone **08 6457 7333** to find out how you can get into the festive spirit and help make a difference.

# CROSS INFECTION, WHAT'S ALL THE FUSS ABOUT?

Cross infection, or the transfer of infection from one person to another, poses a threat for people living with cystic fibrosis (CF) and can have adverse health consequences.

The Australian Cystic Fibrosis Director Group is currently developing a National Cross Infection Policy for National and State CF events to minimise the consequences of cross infection. This article is based on the draft policy, providing an overview of the implications for people with CF.

**Background:** People living with CF should be concerned about the possibility of transmission of respiratory pathogens between individuals and the subsequent serious outcomes.

Chronic infection with certain bacteria such as *Pseudomonas aeruginosa* (Pa), *Burkholderia cepacia* complex, methicillin resistant *Staphylococcus aureus* (MRSA), and non-tuberculosis *Mycobacterium abscessus* (NTM) have significant health implications and are associated with reduced lung function, poor growth, increased need for antibiotic therapy, increased hospitalisations and may impact on life expectancy.

The potential for certain pathogens to pass from person-to-person, or environment-to-person was first reported in the 1980s. A strain of *Burkholderia cepacia* that caused rapid respiratory deterioration in many individuals was found to have originated from one individual with CF. This strain spread throughout CF communities in two countries following social contact and shared social spaces. Similar experiences have now been observed with other pathogens such as *Mycobacterium abscessus* and *Pseudomonas aeruginosa*. Whilst these pathogens are renowned for their potential for patient-to-patient transmission, the CF scientific community now recognises that any respiratory pathogen could be transmitted from person to person.

With the increased use of a technique called molecular typing we have the technology to identify strains that are shared among people with CF.

Research has now confirmed that respiratory pathogens can be projected into the air with coughing and sneezing to a greater distance than originally recognised; up to four metres and possibly further. They can exist in the air as aerosols and droplets or contaminate surfaces and survive outside in the environment for hours.



In addition, while persons without CF rarely carry the bacteria that typically cause chronic infection in CF, they can carry other bacteria such as *Streptococcus pneumoniae* or viruses such as RSV, influenza and adenovirus that can cause coughs, colds and chest infections in the community. Infection with these pathogens may have greater implications for people with CF. These acute bacterial and viral infections are also transmissible between individuals with or without CF.

In the past, people with CF were asked to provide a recent sputum for culture and sign a waiver in order to attend an event or a CF conference. However, there are no tests that will guarantee 100% the culture status of a person with CF and this former practice is no longer considered safe because some pathogens are 'slow growers' and may not be identified until after the person has attended the event. The concept of 'less threatening' bacteria is also no longer accepted, and all pathogens should be considered as potentially transmissible and harmful.

In view of the growing body of research and evidence surrounding how and which pathogens are transmitted from person-to-person, new strategies to safeguard the health of people with CF attending events are needed.

The goal of the policy being developed is to reduce the risk of transmission and acquisition of pathogens between CF individuals in non-health care settings. Cystic Fibrosis WA expect to adopt the policy

once it has been finalised. As soon as this happens, it will be placed on our website at this link:

[www.cfwa.org.au/about-us/annual-reports-policies](http://www.cfwa.org.au/about-us/annual-reports-policies)

It is important that we apply this knowledge as soon as possible. There are people who may find it difficult to adapt to these changes but with new and emerging communications technologies such as live streaming of conferences, no one with CF need miss out.

This could be a sensitive and controversial issue for people with CF. If you find this raises concerns for you, please contact CFWA to discuss further 08 6457 7333 or [info@cfwa.org.au](mailto:info@cfwa.org.au)

References:

1. **Cystic Fibrosis Foundation, USA 2014:** Saiman L et al, Infection and Control Guideline for Cystic Fibrosis: 2013 Update. *Infection Control and Hospital Epidemiology* 2014; 35 S1-S67.
2. **Cystic Fibrosis Trust, UK 2013:** 'Cystic Fibrosis why we are here. Cross Infection Policy. Guidance for people with CF at events and meetings'. CF Trust website [www.cysticfibrosis.org.uk](http://www.cysticfibrosis.org.uk)
3. **Cystic Fibrosis, Europe 2013** 'Cystic Fibrosis conference / meeting anti-cross infection requirements for people with CF'. [www.cf-europe.eu](http://www.cf-europe.eu)



# MEET MAGGIE!

When times get a little tough it's good to know support is there for you.

My name is Maggie and I am a cystic fibrosis (CF) social worker at Sir Charles Gairdner Hospital (SCGH)!

I am originally from Northern Ireland (with an accent you'll either love or hate) and have been a social worker for about 12 years. I have really enjoyed the past 6 years working with CF patients at SCGH and understanding how I can best support you.

It's hard to say what social workers do... a lot depends on what you need. I can support with issues such as relationships, finances, employment, health and treatment, emotional well-being, family and more. If in

doubt... ask!

Myself or my colleague, another social worker called Dan, can see you when you are in hospital – please just tell any staff member on the ward that you want to see us. I also run a CF out-patient clinic on Wednesdays at the Social Work Department at SCGH. If you have any questions or would like to book an appointment, please just call on **08 6457 4666**.

Hopefully this provides a snap-shot of what CF social work is about. Please shout if you think I can help!

Maggie :)



## FUNDRAISING NEWS

This edition we thank our City to Surf runners and two kind-hearted girls who chopped their locks for people living with cystic fibrosis (CF). We also say good luck to some of our community members who are continuing their awareness and fundraising efforts right up to the end of 2018.



### City to Surf

Thank you to all the participants who ran in the City to Surf and fundraised for Cystic Fibrosis WA (CFWA) including Ella, Sally, Sean, Rebecca and Perry.

One of our teams, Team Awesome from Diplomantik, raised \$500 and shared their fundraising story on their organisations website.

To read their story visit [www.diplomatik.com.au/diplomatik-for-cystic-fibrosis-wa](http://www.diplomatik.com.au/diplomatik-for-cystic-fibrosis-wa)

### Hair Today, Gone Tomorrow

Matilda and Tayla, two special girls with very kind hearts, have raised funds and awareness for cystic fibrosis (CF) during August by cutting their long hair. They held an event at a local sporting club for friends and family to watch their courageous act and raised funds online for those who couldn't come along.

In addition to supporting CFWA, the girls also donated their freshly cut locks to the Australian Alopecia Foundation to help make wigs for children who have lost their hair to this condition.

Tayla's mum Megan says "Tayla and

Tilly absolutely love their new cuts, they still have no idea how much their selfless act will help many more children".

Thank you Tayla and Matilda, your new hairstyles look fantastic!

### Trekking Nepal

Siblings Shari and Matthew have set themselves a 65 Roses trek challenge in Nepal this November to raise awareness and funds for CF. The inspiration for this challenging adventure is a close family friend that they grew up with who lives with CF.

In 2016 they did a Kokoda trek and raised over \$9,000. This year they are getting the gang back together to trek in Nepal. Shari says, "we are hoping to do this trek for those who can't – we are passionate about raising both money and awareness for CF".

Their fundraising page has already raised over \$3,100 of their \$10,000 goal. To get behind Shari and Matt, visit [65roseschallenge.everydayhero.com/au/nepal-trek-cystic-fibrosis](http://65roseschallenge.everydayhero.com/au/nepal-trek-cystic-fibrosis)





## CF Talk (adults) Facebook Group

This is a closed space for adults with CF to share their stories and their “lived experience” as only they know how. It’s also a safe space to ask the questions that you probably wouldn’t ask of a health professional.

Join us here [www.facebook.com/groups/cftalkadults](https://www.facebook.com/groups/cftalkadults)





# BUSSELTON GOLF DAY 2018

*The winning team of last year's Busselton Golf Day*

The Rotary Club of Busselton Geographe Bay is once again holding a Golf Day for cystic fibrosis. Last year's event was a great success for our first time and we are hoping to grow it even bigger this year.

Teams of golfers from across the state are invited to join in this fun event on Friday

30 November at the Busselton Golf Club. As well as prizes, there are quirky things you can participate in on the course, cheats you can buy and best of all a 'Wall of Wine' raffle.

We are looking forward to many teams entering which will enable us to maximise

our fundraising for Cystic Fibrosis WA. Team entry of 4 players is \$200, but individual players can register for \$50 and will be placed into teams on the day.

For more information or to register please contact Chris White at [rotarybusselton@iinet.net.au](mailto:rotarybusselton@iinet.net.au) or on 0450 152 068.



*The team of volunteers on the day in 2018*



*Presenting the donation to CFWA*





# CONNECTING, CREATING AND LOOKING AFTER YOURSELF

The old saying “you need to put the mask on yourself first before you can help anyone else” is true. Here are a few ideas on enhancing self-care, however don't forget the usuals.... sleep, exercise and diet!!

**Join a club and learn something new**

[www.actbelongcommit.org.au](http://www.actbelongcommit.org.au)  
[www.dsr.wa.gov.au/clubs](http://www.dsr.wa.gov.au/clubs)  
[www.linkwest.asn.au](http://www.linkwest.asn.au)  
[www.meetup.com/cities/au/perth](http://www.meetup.com/cities/au/perth)

**Make something different**

[www.remindawa.com](http://www.remindawa.com)  
[www.cleverpatch.com.au](http://www.cleverpatch.com.au)  
[www.craftonline.com.au](http://www.craftonline.com.au)  
[www.artshedonline.com.au](http://www.artshedonline.com.au)

**Join a community choir, see some music or karaoke**

[www.voicemoves.com.au/groups](http://www.voicemoves.com.au/groups)  
[www.catchmusic.org.au](http://www.catchmusic.org.au)  
[www.theurbanlist.com/perth/a-list/best-karaoke-bars-perth](http://www.theurbanlist.com/perth/a-list/best-karaoke-bars-perth)

**Start journaling or blogging**

[positivepsychologyprogram.com/gratitude-journal/](http://positivepsychologyprogram.com/gratitude-journal/)  
[thehappinessplanner.com/pages/printables](http://thehappinessplanner.com/pages/printables)  
[www.pinterest.com.au/](http://www.pinterest.com.au/)  
[www.adventuresinguidedjournaling.com/p/  
printable-journal-pages.html](http://www.adventuresinguidedjournaling.com/p/printable-journal-pages.html)  
[www.writingwa.org](http://www.writingwa.org)

**Mindfulness and relaxation**

[www.smilingmind.com.au](http://www.smilingmind.com.au)  
[www.mindful.org](http://www.mindful.org)  
[www.freemindfulness.org/download](http://www.freemindfulness.org/download)



# THE PRACTICAL STUFF

Being organised really helps reduce stress and build resilience for the tough times, don't wait until you're sick or for a crisis

Life can send you “curlies”, particularly when you have something like CF, so be prepared to shift your goals and stay flexible. Goal setting, even small goals, can make a really big difference to staying motivated.

- Tips on motivation and goal setting can be found in the CF Fit booklet [www.cfw.org.au/wp-content/uploads/2018/06/CFWao86-CFfit\\_A-Guide-for-People-Living-with-CF-A5\\_WEB.pdf](http://www.cfw.org.au/wp-content/uploads/2018/06/CFWao86-CFfit_A-Guide-for-People-Living-with-CF-A5_WEB.pdf)
- Reward charts to help motivate children with medications and food can be found in the CF Nutrition for Children booklet [www.cfw.org.au/wp-content/uploads/2018/03/CF-Food-Nutrition-for-Children-2.pdf](http://www.cfw.org.au/wp-content/uploads/2018/03/CF-Food-Nutrition-for-Children-2.pdf)

Develop good routines and be willing to shift the goal posts

“CF is just part of my life, not the whole of it. When I’m well I just do stuff automatically, when I’m unwell I give it more attention” Mitch

## Finances

- Money smart has a great online budget planner [www.moneysmart.gov.au/tools-and-resources/calculators-and-apps/budget-planner](http://www.moneysmart.gov.au/tools-and-resources/calculators-and-apps/budget-planner) or if you’re really struggling to manage finances see a financial counsellor [financialcounsellors.org](http://financialcounsellors.org)
- Get legal documents in order. Citizens Advice Bureau offer one free session [www.cabwa.com.au](http://www.cabwa.com.au). You can also contact Legal Aid and get free advice on 1300 650 579

## Looking after yourself and family

- Learn as much as you can about CF if you

haven’t already [www.cfw.org.au/what-we-offer/resources](http://www.cfw.org.au/what-we-offer/resources)

- Connect with other parents of children with CF for general support and advice on how they handle their responsibilities [www.cfw.org.au/what-we-offer/events](http://www.cfw.org.au/what-we-offer/events)
- Tips on staying organised from a Mum with a CF child [www.cff.org/CF-Community-Blog/Posts/2018/3-Tips-for-Staying-Organized-When-Your-Child-Has-CF](http://www.cff.org/CF-Community-Blog/Posts/2018/3-Tips-for-Staying-Organized-When-Your-Child-Has-CF)
- Make time for yourself and others who are important to you, such as your spouse or partner, friends and family. Practice gratitude, it’s an essential part of happiness [au.reachout.com/articles/the-how-and-why-of-practising-gratitude](http://au.reachout.com/articles/the-how-and-why-of-practising-gratitude)

## ARI & HIS FAMILY LOOKING FORWARD TO CHRISTMAS 2018

Ari Gough and his family are looking forward to Christmas 2018 and at CFWA we welcome them as this year’s national Christmas Appeal family



When Cystic Fibrosis Community Care NSW contacted Ari’s mum Jodie, she jumped at the opportunity to share her family’s first year journey with cystic fibrosis (CF). Ari, 18 months, will be celebrating his second Christmas this year and as every month goes by his family learn a little more about managing their lives with CF.

Ari was diagnosed after results from his heel prick test were reviewed. Jodie and her husband had no idea what CF was

and had no family history. With many hospitalisations during his first year, Jodie says the CF services they receive have really helped and that it has been “nice to have the support of someone who truly understands”. We are very grateful to CF families across Australia who share their personal journeys to help raise awareness and funds that continue to support and expand our services and programs, fund research initiatives, and advocate on behalf of our CFWA families.

Working together with state CF organisations strengthens our brand and impact, whilst reducing campaign costs. We also appreciate the ongoing commitment of our suppliers Action Words and Jade Koch Creative Services for their part sponsorship of our campaign.

If your family would like to participate in awareness and fundraising campaigns in the future, please contact Karen at [marketing@cfwa.org.au](mailto:marketing@cfwa.org.au) or on 08 6457 7333.



# event calendar 2018

## MARK YOUR DIARIES FOR THESE 2018 EVENTS

### OCTOBER

2-4 – SIBLING AND OFFSPRING CAMP  
19 – PARENTS' DINNER  
20 - 21 – TELETHON WEEKEND

### NOVEMBER

2 – CYSTIC FIBROSIS GOLF CLASSIC  
4 – THE COLOUR RUN  
23 – REGIONAL CF SCIENTISTS NIGHT  
30 – BUSSELTON GOLF DAY

### DECEMBER

2 – CHARITABLE ACTS MUSIC SHOW  
1-25 – CONSULATE COURT CHRISTMAS LIGHTS

### FEBRUARY 2019

16 – CORPORATE BATTLE OF BANDS  
23 - ROTTNEST CHANNEL SWIM

\*PLEASE NOTE, DATES MAY CHANGE IF CONFLICTS ARISE.

TO FIND OUT MORE ABOUT THESE EVENTS OR TO GET INVOLVED, VISIT THE UPCOMING EVENTS SECTION OF OUR WEBSITE AT [WWW.CFWA.ORG.AU/GET-INVOLVED/UPCOMING-EVENTS](http://WWW.CFWA.ORG.AU/GET-INVOLVED/UPCOMING-EVENTS) OR CONTACT MARNIE ON [EVENTS@CFWA.ORG.AU](mailto:EVENTS@CFWA.ORG.AU) OR ON 08 6457 7333



# CF MENTAL HEALTH ROADSHOW

Cystic Fibrosis Australia (CFA) is honoured to be able to bring two exceptional mental health professionals from the United States, Alexandra Quittner (Miami) and Anna Georgiopolous (Boston), to Australia to brief our community and train our health professionals across the country in CF specific mental health.

The Perth session for the CF community including parents, partners and carers will be held on Sunday 11 November.

For more information and to book now visit

[www.cysticfibrosis.org.au/mhr](http://www.cysticfibrosis.org.au/mhr)

