

A man with a beard and a black cap with sunglasses on top is smiling. He is wearing a black jacket. Two children are sitting at a white round table. The child on the left is wearing a red hooded jacket and a red cap. The child on the right is wearing a black jacket with red accents and a red cap. They are outdoors in a park-like setting with trees and a paved area in the background.

EDITION 1 2017

# RED

IN THIS  
ISSUE...

EDUCATION  
AND CAREERS



# CONTENTS



65 Roses 2017



Inspirational Teachers



Life after Transplant



CFCooking: Healthy cooking for people with cystic fibrosis

## FEATURES

PAGE03: CEO Message

PAGE04: CFA Update

PAGE09: Cystic Fibrosis WA's 40th Anniversary Celebrations

PAGE10: 2017 Fitness Events for Cystic Fibrosis

PAGE11: Education Services for Schools and the Community

PAGE12: CF and 65 Roses at School

PAGE14: Sibling and Offspring Camp 2016 - Our Biggest Camp Ever!

PAGE15: Supporter Spotlight: CommBank Makes a Difference

PAGE16: Mentoring: Sharing the Lived Experience

PAGE17: Year Twelve is Over - What Next?

PAGE18: What Financial Benefits Am I Entitled To?

PAGE19: Halloween Fun Run: A Spooky Success

PAGE21: Telehealth

PAGE22: Closing the Gaps in Regional Western Australia Through Professional Health Education in the Regions

PAGE23: Fundraising News

PAGE26: Convicts for a Cause: Red Rose Bandits Make Bail!

PAGE28: Save the Date

PAGE29: MRI Scans to Lower Radiation Exposure

PAGE31: 12th Australasian Cystic Fibrosis Conference 2017



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# CEO MESSAGE

As we start 2017, the future for people living with cystic fibrosis (CF), whilst not without its challenges, is nevertheless looking bright and optimistic.



NIGEL BARKER, CEO

Although we did not get Orkambi® listed on the PBS at the end of last year, Vertex Pharmaceuticals are continuing their negotiations with the Government of Australia. I feel confident that they will reach an agreement following re-submission in July. Whilst this delay is very frustrating, it is set within an evolving landscape of innovation, excitement and hope.

Following our rally on the steps of Parliament House in Canberra on 7

February, politicians can be left in no doubt as to the importance of making drugs like Orkambi® available to people living with rare diseases.

No less than 17 CFTR modulators are now in the drug development pipeline. Two of these are in their final phase three clinical trials and one of these, Tezacaftor, like Orkambi® is designed to afford relief for people with one or more copies of the more common F508del mutations. (Details of these drugs, and how you can get involved in clinical trials are available on our site [cflivesmatters.org.au](http://cflivesmatters.org.au))

What's more, at the recent North American CF conference, there was talk of even more drugs being developed to treat the underlying cause of CF. This will put increasing pressure on Vertex to reach agreement on price sooner rather than later as their window of opportunity for skim pricing continues to shrink.

Whilst the development of these small molecules is very exciting for everyone, our own research continues to develop early intervention techniques and re-purposing of existing drugs to keep young lungs healthy and delay the onset of structural lung damage so

that these new small molecules can help us achieve our vision of Lives Unaffected by CF.

The theme for this edition of RED magazine is Education and Careers.

We look at professional development, particularly for health professionals in regional WA, new fact sheets and schools education program, further study, Oz Study, and workplace discrimination. We also highlight the launch of our CF Cooking videos – a collaboration between Sir Charles Gairdner Hospital (SCGH) and Cystic Fibrosis WA (CFWA) - funded by Vertex Pharmaceuticals' Circle of Care Grant, plus much more.

We also look back at our 40th year celebrations and look ahead to some of the exciting fundraising and awareness-raising activity opportunities for 2017.

I hope that you will join us on our journey and if you haven't done so before, make 2017 a year when you step up and organise your own event to help fund our activities and research which will advance us towards our vision of Lives Unaffected by CF. If you would like some ideas, please call Marnie at our offices on (08) 6457 7333 for an obligation free chat.

## DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our winter issue, please contact us before 1 March, 2017

## DO WE HAVE YOUR CORRECT DETAILS?

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

## DESIGN BY

Catherine Fisher  
Community Newspaper Group

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**ON THE COVER** Luke Ioppolo with his student, Jayton, and brother, Patrick

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# CFA UPDATE

Going Federal to Support Cystic Fibrosis.

I hope you all had a wonderful break over Christmas and had the chance to spend some quality time with family and friends. Although Australia has officially been in 'holiday mode' there has been a lot going on, not least of which we have a new Health Minister. Minister Ley has resigned and the Hon Arthur Sinodinos will now act as Health Minister in the short term. Cystic Fibrosis Australia (CFA), has contacted with the Ministers office to ensure cystic fibrosis (CF) does not disappear from the health agenda. We have also invited Hon Sinodinos to the CF Protest at Parliament House on 7 February 2017.

The Canberra CF Protest plans are well underway and already we have more than 50 confirmed attendees. It will be a long day and so we recommend you bring along a seat or a picnic rug. The details of the day are:

## Date & Time

**Tuesday 7 February 2017 at 7.00am until 6.00pm.** Protestors are welcome to arrive and leave at anytime

**7.00am – 9.00am** – Protesters arrive at Federation Mall, Parliament House (grass in front of PH)

**7.00am onwards** – Politicians and media invited to learn about CF and represent their local people

**9am onwards** – CF community speeches, celebrations, life journeys and eulogies

**Noon** – House of Reps sit

**12.30pm** – Senate sits

**1.00pm** – Lunch provided for CF community at protest site

**6.00pm** – Protest ends ... 'Bump Out'

## Venue

Federation Mall at Parliament House (the grass area at the front of PH)

## CFA Support

\$50 petrol subsidy per car, lunch and refreshments, CF flags for cars and protesters and 'CF clappers' (to be revealed on the day). If you would like to be part of this event, please email [sharone@cfa.org.au](mailto:sharone@cfa.org.au)

Each attendee will need to complete an Infection Control Form and a Media Waiver. These documents will be sent out by CFA and we also recommend that people with CF consult their clinician to ensure that they support your attendance and we have the highest level of infection control and health safety. The Canberra CF Protest is an important event for the CF community because the health of our community is our fundamental and ongoing concern.

CFA will be contacting all MPs and Senators to ensure they are aware of the protest and we will be inviting them to join us to learn more about CF and enjoy 'tea and cup cakes' with the CF community. During the Canberra CF Protest, attendees will have the opportunity to tell their stories and express their concerns. If you would like to participate in this part of the event, please let Sharon know by email and we will save you a spot. Testimonials and photos will be collated and presented to the Prime Minister, Opposition Leader, Health Minister and Shadow Health Minister. It will also be shared with the media and place on CFA's website for all to view and share.



We implore you as a valued member of the CF community to reach out to your local federal representative and ask them to visit the Canberra CF Protest. If you or your family member with CF is unable to attend, ask your local member of parliament to represent them at the protest. We recommend you attach a photo to your email for them to bring along on the day. We will be featuring those people with CF who are unable to attend.

CFA is very excited about the Canberra CF Protest and we hope that it will raise the profile of CF and, in particular, give volume to our serious concerns about Kalydeco® and Orkambi® not being recommended for reimbursement by the PBAC. By attracting wider yet informed media attention, this can amplify a loud and powerful voice to the CF community.

I do hope you will either be able to join us in Canberra or compel your local politician to be your representative.

Yours sincerely

Nettie Burke

CEO Cystic Fibrosis Australia

## Official Notice of 2017 AGM



### CYSTIC FIBROSIS WESTERN AUSTRALIA (INC)

Wednesday 5 April 2016 7.30pm

The Niche Conference Room, 11 Aberdare Road, Nedlands WA 6009

Corner of Aberdare Road & Hospital Avenue.

Guest speaker: Clinical Associate Professor Siobhain Mulrennan  
Respiratory Consultant & Director Adult CF Service, Sir Charles Gairdner Hospital  
Clinical Associate Professor - School of Medicine and Pharmacology, UWA

RSVP for catering by Friday, 31 March to **08 6457 7333**

Refreshments served following the AGM





# 65 ROSES 2017

Planning is well underway for 65 Roses Day 2017 on Friday 26 May. Check out how you can get involved this year to make it our biggest and best yet!



May is cystic fibrosis (CF) awareness month and Friday 26 May is 65 Roses Day, our national day of awareness.

Every year, community supporters and businesses join us to raise funds for CFWA by selling beautiful fresh roses on the streets of Perth, in shopping centres, at workplaces, schools and regional centres all over the state.

This money is used to deliver vital research funding and home care services to people living with CF in WA. Taking part is fun and easy. We'd love to have you on board!

## **1. Help us wrap roses on Thursday 25 May 2017**

Every year we wrap thousands of roses to sell on 65 Roses Day, but we can't do it alone!

Get a group together for a great team-building day and help us make this 65 Roses Day the biggest and best yet.

To lend a hand get in touch with Marnie on **08 6457 7333** or **events@cfwa.org.au**

## **2. Sell Roses on 65 Roses Day Friday 26 May 2017**

This year we're challenging ourselves to paint the state with roses with the help of our generous partners WAFEX and Telstra... and you!

Take a bucket of roses to sell in your workplace, school or community or buy a bunch of beautiful fresh roses for that special someone. We're also offering professionally arranged corporate displays that will brighten your office reception.

If you can't sell roses in your workplace, join us at one of our stall locations. There are places to lend a hand all around the state.

## **Regional Rose Deliveries**

We have partnered with a range of couriers to expand our rose deliveries in 2017. If you're in regional WA and would like to sell roses in your community, give us a call to discuss your options.

Visit **www.65roses.org.au** or get in touch at **events@cfwa.org.au** or **08 6457 7333** for more information or to



order your roses.

## **3. Take the 65 Roses Challenge**

Choose your 65 Roses Challenge this May and set yourself a fundraising target for the month. It could be anything from a physical test to run, swim or ride 65km, or you could bake and sell 650 cupcakes. There's no wrong idea, as long as you challenge yourself!

Read more about Paul's cross-continent 65 Roses Challenge in the next edition of RED magazine for some inspiration!

Visit **www.65roses.org.au** for more challenge ideas and to get started.





# INSPIRATIONAL TEACHERS

As this issue of RED is focusing on education, it seems apt to highlight the great work that teachers out in the community do. RED interviewed three inspirational teachers who work with children who have cystic fibrosis (CF) to find out more about the fantastic work they do and what inspires them to excel in their field.

## Kathleen, Katrina and Alexis

### Kathleen

*Kathleen works as a Year 3 teacher at Assumption Catholic College in Mandurah and taught Alexis, who has CF, in her class in 2016. Kathleen came to teaching later on in life. She was inspired to become a teacher because she was frustrated that she couldn't help her son who has dyslexia. Kathleen has now been teaching for six years. RED also spoke with Alexis and her mum, Katrina, about their experiences with the school and Kathleen.*

**As a busy teacher, how difficult is it to cater for the variety of medical needs that students might have, as well as their educational needs?**

It's not difficult- it's delightful. I just have to be organised and teach my students that they can do lots of things to be organised, too. They are like a corporate body and they all have jobs and they know what they are. The ship sails along beautifully. The kids are brilliant with responsibility.

The medical needs of my students are a top priority. Because I was a mum first before I became a teacher, I do

come from a parents' perspective first and I think "If this student were my child, what would I like the teacher to do?" I think I am always coming from a parents' perspective first and a teachers' second. To me I consider the student's physical and emotional needs first and then their education. With this outlook my students do get good grades too.

In catering for Alexis, we are very careful with hygiene in the classroom. The students are taught about washing and drying their hands properly. If we need to move students away from Alexis due to them having colds, I tell the students "it's time for a move" so they think it's part of a whole classroom thing.

Alexis doesn't specifically tell the students that she has CF, but she has talked to the class about going to hospital.

**How have you worked with Alexis and her parents to cater for her needs as a student with CF?**

I grew up with a couple of children who had CF, so I had a reference point, but my knowledge needed to be updated. Alexis' mum came in and explained about Alexis' needs and our principal also sat in on the meeting.

The school asked Alexis' mum if she would like to be contacted if there happens to be an outbreak of whooping cough or chicken pox, so she is informed as soon as possible.

This year Alexis needed to go to hospital for a few weeks. She then attended a local hospital to get IV antibiotics three times a day and came to school in between those times which helped keep her in a routine.

While Alexis was in hospital, our class sent her emails, pictures and I took photos of the students showing her what we were up to. Alexis sent photos and emails straight back of what she was doing in hospital. We did this every third or fourth day. The school work I gave to Alexis during the time she was in hospital was the same as the class activities but it was a bit modified. I also modified what I was doing in the class so that Alexis wasn't going to miss too much. The messages the students wrote I included as part of the curriculum for their learning.

At our school we follow the Kath Walker Early Life Foundations learning approach, which is flexible and considers the child holistically.

My main aim is to be a help to Alexis

## Celebration of Life Ceremony

Please join us for a twilight ceremony in Kings Park

**Friday 24 February 2017**

**6.00pm - 9.00pm**

**Place of Reflection, Kings Park**

Please come and join us in commemorating the lives of those that have been lost to cystic fibrosis.

Drinks and nibbles provided. If you wish to participate please contact Kathryn on 08 6457 7333 or [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au)





THLEEN WITH HER STUDENT ALEXIS.



LUKE WITH STUDENT JAYTON AND BROTHER PATRICK

and her parents, not a burden. A week without Alexis at school is too much.

### What advice do you have for other teachers who may have a student with CF?

My advice would be to make sure you provide an environment that is helpful and be mindful. It's of course helpful to have a good relationship with the child's parents. Definitely teaching the class proper hygiene is useful too.

#### Alexis

I like writing the narratives and I like maths. I feel happy when I come to school. Taking medications is easy because I have to do it at home too so it's not a big deal. I really liked it when the students sent through their pictures to me when I was in hospital.

#### Katrina (Alexis' mum):

When Alexis was in hospital it was great having the communication between her class and Alexis. It also let the other students see that she was OK. Also, after Alexis had her PICC line (for intravenous medications) she was a bit down. When she received the communication from her class it really

perked her up.

Alexis has a hype about school now. Even when she is really tired I will give Alexis the option to stay at home and she will insist on going to school because she says "I've

got things to do". It's also been great having the same teacher throughout the year too.

### Luke Ioppolo

*Luke Ioppolo is a dedicated sports and health specialist teacher at Cunderdin District High School where he's been teaching for four years. At the end of September 2016, Luke decided to walk non-stop for 24 hours to raise money for Cystic Fibrosis WA (CFWA). He managed to raise \$5,826.50. We wanted to know more about what inspired Luke to undertake*

*such a big challenge.*

### What made you decide to do the 24 hour non-stop walk as part of a 65 Roses Challenge for CFWA?

Jayton, one of my students has CF and he came to the school at the same time I did. Jayton's family are from Cunderdin. I was new to the town, coming from Perth, and I joined the basketball team as a way of getting more involved with the town. I played basketball with Jayton's dad, Gareth. Gareth often brought Jayton and his brother, Patrick to the basketball games so I got to know them pretty well from that as well as at school.

In March 2015, I decided to do a 50km run from Cunderdin to Meckering and back to Cunderdin, to raise money for breast cancer, as a couple of mums had it at our school. I am very competitive and if someone tells me I can't do something, it sets a fire inside me to prove to myself and others that I can do it. So I came up with this idea during dinner after our End of Year Presentation Night in 2014. Watching Shane Crawford (AFL footballer) complete his fundraising work for

Breast Cancer Australia the last few years was a real inspiration for me also.

Jayton's family supported me during the run in a back-up car, and Lisa, Jayton's mum said to me after I did it "Next time you come up with a crazy idea, have a chat to me". I was in fact thinking in my mind at this time that I would like to do another challenge.

During 2015, it was announced at our school assembly that Jayton was going to be the regional Telethon child. It was great to see Jayton's face when it was announced at the assembly; he couldn't believe it. The whole town got involved with fundraising for Telethon by doing raffles and events at the sports club. About 50 or 60 people from Cunderdin came to the Telethon opening night and I presented a cheque to Lisa and Gareth from our fundraising efforts.

I have always admired Jayton's attitude. When it comes to sport he will try everything and not complain. I thought to myself that I should take a leaf out of his book and I thought I really wanted to do something for him.

I came up with the idea that I would like to do a 24 hour non-stop walking challenge to raise money for CFWA. I floated the idea to Lisa and I asked her if it was a smart idea. I said to her "you be the brains and I'll be the brawn". Lisa did lots of organising so the challenge could take place including arranging a back-up car from CFWA that we could use. I am truly grateful for all her efforts and dedication.

In 2016, our school was involved in a GCC (Global Corporate Challenge) where we had to wear a pedometer. My competitive nature led me to do a lot of steps which was great preparation for the big 24-hour walk.

I decided to walk from Hillarys to Fremantle, back up through Claremont to Subiaco, past Princess Margaret Hospital (PMH), across to East Perth and then loop the Swan River from the South Perth Foreshore to the City Foreshore. I wanted to finish at Elizabeth Quay.

Gareth walked with me for 19 hours, my cousin's husband Ryan joined me from midnight until 6am, my uncle Tony walked with me from 6am til midday. Jayton and Patrick walked with me too for a large part of the journey. My friends Lucas, Rob and Kyle walked with me for hour-long stints at different points and Karen and her son from CFWA also walked with me for a bit. So I was only alone walking for about 15 minutes.



The hardest time was from 4am - 6am in the morning when my back seized up. I was in agony. I was so close to stopping but I willed myself to continue and not give up. I put on my backpack and took painkillers, this helped with the pain.

Lisa filmed Gareth and myself as we walked along Rokeby Road in Subiaco at midnight and I thought we were walking at a good pace, but when I saw it back, it looked like we were zombies.

As Ryan and I walked passed PMH at 12.20am an ambulance pulled in with its lights and siren on, and I thought to myself "This is why I am doing this".

We finished the walk on the Friday at midday. I had walked 101 kilometres in total during the 24 hours. People from Cunderdin wondered how Gareth and I would recover from the walk, but we were playing basketball, not necessarily well, on the Monday night.

I actually found the run easier to do than the walk, but I recovered more quickly from the walk than I did the run.

#### **What advice do you have for other teachers who might have a student with CF?**

Jayton has a port (a small device under the skin for easy administration of medications), so he has to be careful when playing contact sports. I keep an eye out for him and make sure he doesn't get whacked. But otherwise I would say to treat a student with CF like any other kid. In terms of sport, I encourage Jayton to go as hard as he can and he can compete the same as everyone else; sometimes he's even better. He's a normal kid. He just needs to control his hairstyle!!

#### **What do you like most about being a teacher?**

My passion is sport. I try to make it fun for the kids and make my classes as engaging and positive as possible. In my class we do lots of different sports instead of the usual. We try things like Gaelic football, Futsal, Ultimate Frisbee and Handball. I also emphasise that sport is all about teamwork and there are rules to follow and many of the skills the students gain from sport they can apply to general life.

The main thing I encourage my students to do is to try their hardest at all they do and set personal best goals that can be achieved. I encourage competitiveness but if we don't win, the students need to be gracious and congratulate their opponents. I always encourage my students and tell them to be proud of all that they achieve.



KERRY LO-PRESTI

Jayton's class is mad about sport and many of them want to be sports teachers when they grow up too!

### **Kerry Lo Presti**

*Kerry is a liaison teacher with the School of Special Educational Needs at PMH, soon to be Perth Children's Hospital (PCH). Kerry graduated in 1986 from Teacher's College and has worked in a number of schools for several years. She took ten years off to raise her sons and returned to teaching in 2001. Kerry began working at the School of Special Educational Needs in 2003. She has been able to work on all the wards in the hospital and began her role of CF Liaison Teacher in 2015.*

#### **What is your role at PMH and what does it involve?**

My role has many facets. Firstly I help to coordinate the educational programs of students admitted to the hospital by liaising with their enrolled school and specialist teachers on the wards. I am based on ward 7teen (teenage ward) so I encourage the patients to attend the school room when they can, or assist them with their work at their bedside.

Also, I can be utilised to support a student's school with regards to the needs of a student with CF and how that can impact on their education. I act as a conduit between the CF multi-disciplinary team here at PMH and their school. I also link schools to CFWA and the CF Smart website and to the Ronald MacDonald Learning Program to access tutoring.

Another part of my role is to coordinate the annual CF for Schools Seminar for teachers, which addresses the impact CF has on student education and classroom management issues.

#### **What do you like most about your**

#### **work?**

The thing I like the most about my job is the people I work with. I meet the most amazing kids who inspire me every day. I am always left in awe of the amazing nursing staff and their endless compassion and dedication to the job. I feel very proud to be part of the CF health team who dedicate their time and incredible desire to help their patients to have the most rich and fulfilled lives they can possibly have.

#### **What tips would you give to students who have CF for keeping up with their school work while in hospital?**

1. Use us!!! Make the most of the time you have in the hospital to keep up with your school work. We have amazing, supportive teachers.
2. Allocate time to school. We understand how full of therapies your life is, but we are here to help you when you have those free moments.
3. Try to bring your school work with you, especially those assignments you are part way through. We can help you to complete and send back to school.

If you wish to contact Kerry Lo Presti for more details about school services in the hospital her details are;

**Phone: 08 9340 8529**  
**Email: [kerry.lopresti@education.wa.edu.au](mailto:kerry.lopresti@education.wa.edu.au)**

If you know of an amazing teacher who has gone above and beyond to inspire and also assist your child with their needs while they are at school, we would love to hear about them. We want to share stories on the new up and coming CFsmart website. You can contact **Natalie** at [education@cfwa.org.au](mailto:education@cfwa.org.au) for more details.







# 2017 FITNESS EVENTS FOR CYSTIC FIBROSIS

Plan your fitness events for 2017 early and nominate Cystic Fibrosis WA (CFWA) as your chosen charity.

## **HBF Run for a Reason Sunday 28 May**

Tie your laces tight and walk or run the 4km, 12km or half marathon course around Perth in the HBF Run for a Reason. With entertainment and cheer zones along the way, it's easy to see why this is one of Perth's favourite fun runs.

Visit [www.hbfrun.com.au/](http://www.hbfrun.com.au/) to find out more.

## **Swan River Run Date to be confirmed**

A part of the City Run Series that occurs across Australia, the Swan River Run is Perth's fun run that highlights the beauty of the Swan River and Kings Park by featuring both in its course.

More information coming soon to the website; [www.swanriverrun.com.au](http://www.swanriverrun.com.au).

## **City to Surf Perth Sunday 27 August**

The City to Surf offers a 4km, 12km, 21km and 42km running course and attracts participants from all over WA.

Contact Marnie at [events@cfwa.org.au](mailto:events@cfwa.org.au) or phone **08 6457 7339** to find out more about nominating CFWA as your chosen charity. Or jump online here [perthcitytosurf.com/](http://perthcitytosurf.com/) and register to run.

Check out these regional City to Surf locations!

**Karratha** – 23 July  
**Geraldton** – 30 July  
**Albany** – 6 August  
**Busselton** – 13 August

## **Halloween Fun Run Sunday 29 October**

Dress up in a spooky Halloween costume and come to Perry Lakes Reserve for a family friendly stroll, walk or run for CF. With entertainment along the 3km and 6km course as well as a fun carnival setting, the Halloween Fun Run promotes fitness, family, friendship and fun! Stay tuned for more details in the year through CFWA E-news and Facebook page.



## **Looking for something else?**

Visit [www.obstacleracers.com.au/race-calendar/](http://www.obstacleracers.com.au/race-calendar/) to see more upcoming fitness events including ROC Race, Miss Muddy and the South West Mudfest.

If you want to know more, please contact our Events and Community Fundraising Coordinator Marnie at [events@cfwa.org.au](mailto:events@cfwa.org.au) or on **08 6457 7333**.

# 2017 CYSTIC FIBROSIS WA WORKSHOPS

Parenting can be challenging at the best of times, however, having a child with cystic fibrosis (CF) can add another element of complexity. Cystic Fibrosis WA (CFWA) are hosting a short series of informal, fun workshops throughout the year to assist parents manage behaviour, set routines and boundaries, and communicate positively with their child.

### **SOOTHING AND SETTLING BABIES**

Facilitated  
by Ngala  
Friday 3 March  
10.00am –  
1.00pm

### **SETTING ROUTINES (INCLUDING PHYSIO) WITH TODDLERS**

Facilitated by  
Ngala, Friday 28  
April 10.00am –  
1.00pm

### **PLAY, LEARNING AND SETTING BOUNDARIES**

Facilitated  
by Ngala  
Friday 28 July  
10.00 am – 1.00  
pm

### **STARTING SCHOOL WITH CF**

Facilitated  
by CFWA  
education  
officer, Tuesday  
5 September  
6.30 pm

### **TALKING TO YOUR TEEN**

Facilitated  
by CFWA  
Thursday 19  
October 7.00  
pm

If you would like more information about these workshops, please contact [Kathryn.servicesmanager@cfwa.org.au](mailto:Kathryn.servicesmanager@cfwa.org.au) or **08 6457 7333**.



# EDUCATION SERVICES FOR SCHOOLS AND THE COMMUNITY

Cystic fibrosis (CF) education and awareness raising have always been very important priorities for Cystic Fibrosis WA (CFWA). In the late 1970s, some of the organisation's founding members provided community groups around WA with CF education using a 16mm film and a projector. The first education officer was employed in 1982 and throughout the 1980s and 1990s, CF education has been delivered using tools such as overhead projectors, in-house developed brochures, videos and information booths.

35 years later, CFWA continues to provide an education officer who is available to deliver face to face CF education to teachers, parents, students, community groups and families. Hard copy information packs are available upon request and the resources are available online too. In 2014 CFWA developed and launched a website called CFSmart, [cfmart.org](http://cfmart.org), which is a portal that stores teacher information booklets, student health plans, a short animation about having good hand hygiene (Good Clean Hands- also available on YouTube) and other handy items. CFWA collaborated with its sister organisations around Australia to develop the CFSmart resources.

In 2016, Cystic Fibrosis Victoria (CFV) gained a grant from the Ian Potter Foundation to update the CFSmart website and include an e-learning component for teachers all around Australia to access as professional development regarding the needs of students with CF.

Staff at CFV and CFWA have been collaborating on the updates for the new website and the content for the e-learning. The website should be ready to launch in late February 2017, so keep a look out for this exciting new development to the suite of CF educational resources. To keep updated please like the CFSmart Facebook page.

The education officer at CFWA is Natalie Amos and upon request from parents, students or teachers, she can arrange school, community or family visits, send out school information packs or answer questions. For more information about CFSmart or to book an education session, please contact Natalie at [education@cfwa.org.au](mailto:education@cfwa.org.au) or on 08 6457 7333.

## DETAILS ABOUT CF PRESENTATIONS

Type of presentation	Duration	Information
Teacher Professional Development	30-45 min	A summary on CF and how it affects a student (according to age) in the school environment.
Teacher/ Parent Case Conference	60 minutes	The education officer can attend a case conference between the parent and teacher or deputy/principal to provide general information about CF and available resources for teachers, parents and students.
Students	45-60 min	A lesson tailored to the age group, involving a presentation about CF and an activity.
Other Parents	30-45 min	Can be done at a parent information night at the beginning of the year. A brief summary of what CF is, how it affects the student, and what this means in a classroom situation.
Family Groups	45-60 min	Can be done as a PowerPoint or more informally.



EDUCATION OFFICER NATALIE AND EVENTS AND COMMUNITY FUNDRAISING COORDINATOR MARNIE



# CF AND 65 ROSES AT SCHOOL

Looking for a way to raise awareness about CF. Check out all the fun and simple ways to involve your school or day care in CF education and fundraising!

May is CF's national awareness month and on the last Friday of the month, CFWA hosts 65 Roses Day, where we sell thousands of roses to raise funds and awareness for the genetic disorder. Why 65 Roses? The 65 Roses story dates back to 1965 in the USA, when a young boy pronounced cystic fibrosis as 65 roses. Since then, 65 Roses has been synonymous with our cause and the rose has been adopted as the national symbol for CF.

Many schools in the community love to get involved in our awareness and fundraising events during the month of May and throughout the year. There are plenty of opportunities to support CFWA and help make a difference to the lives of those living with CF.

## Fundraising is as easy as 1, 2, 3!

1. Decide on a fundraising idea; you could do a 65 Roses Challenge, Go Red for CF Day, a Crazy Hair Day or come up with your own idea!
2. Pick a date in May, which is 65 Roses month, or any other time that suits you.

3. Contact Marnie, our Events and Community Fundraising Coordinator at [events@cfwa.org.au](mailto:events@cfwa.org.au) or on **08 6457 7333** to discuss your idea or visit [www.cysticfibrosis.org.au/wa/fundraise-for-us](http://www.cysticfibrosis.org.au/wa/fundraise-for-us) to register your fundraising idea.

## Want to get started right away?

Check out our ready to go fundraisers and register today to get started! Once you register, our Events and Community Fundraising Coordinator, Marnie, will be in touch to create a fundraising pack for you and your fundraiser.

## 65 Roses Challenge

Host your own 65 Roses Challenge and fundraise for CF in any way that you like! You could try to collect 6,500 5c coins, bake 65 biscuits for a bake sale or walk 6.5 laps of the oval. Your school

doesn't have to focus on the 65 Roses theme though, anything is possible; just come up with an idea and take the challenge. Get started at [www.65roses.org.au/#wa](http://www.65roses.org.au/#wa)

## Go Red for CF

Stand out by hosting a Go Red for CF fundraiser and encourage your school or day care to dress in red for a gold coin donation. Jump online and visit [everydayhero.com.au/event/goredforcf](http://everydayhero.com.au/event/goredforcf) to create your fundraising page.

## Crazy Hair Day for CF

Gel, tease, scrunch, spike, colour and style your hair in a crazy way for school or day care and donate to CF to participate. It's easy and fun, just visit [everydayhero.com.au/event/crazyhairdayforcf](http://everydayhero.com.au/event/crazyhairdayforcf) for more information.



Masters of Menu 2  
Now on Sale!

Masters of Menu 2 has now arrived!

This brand new hardback cookbook is packed full of tasty recipes from some of Perth's best restaurants and includes a special CF section!

The book is available for sale online at [www.cysticfibrosis.org.au/wa](http://www.cysticfibrosis.org.au/wa) or via phone order on **08 6457 7333**. Pick up your copy now for just \$50 while stocks last!

# LIFE AFTER TRANSPLANT

Tina received her transplant just over a year ago. After recovery, Tina wasted no time getting back into life. She and her partner have been living their dream of a twelve-month Australian road trip. Whilst travelling, Tina has also been completing her online degree in education and running her business, dispatching stock and responding to customers from the outback.

## At what age did you receive your transplant?

I was 30 when I had my transplant and my wait was relatively short- only 5 months.

## What sorts of things did they assess you for to get onto the waitlist for transplant?

- Compliance to existing treatment and medications
- Lifestyle factors, i.e. smoking, drugs, drinking
- The capacity of my other organs; were they strong enough for transplant treatment?
- The transplant team do regular blood tests to check for any possible diseases; cancer, STDs, STIs, to make sure they have the full picture of my overall health
- Dental check
- Pap smear
- Bone scan
- Skin check for cancers
- Psychology evaluation to ensure that I was mentally prepared
- Liver and kidney scan
- Have all vaccinations

## What was the decision-making process around getting a transplant?

The transplant subject had been spoken of occasionally with my doctors over the years. Once I started to deteriorate to a point where I was struggling to maintain a good quality of life due to frequent hospital admissions, Dr Mulrennan, Sue Morey and myself had THE talk. We discussed options regarding new treatments and trials that I could participate in, to no avail. I was simply too weak to even qualify for any trials. We agreed to look at the transplant prospect and a referral was made for me to see the team at Royal Perth Hospital (RPH). The journey had begun.

**What happened when you were on the list for transplant? i.e. did you have to work hard to meet requirements e.g. go to physio, attend appointments etc.?**

To get on the list is a marathon event. Once you are there life becomes much simpler as most of the tests have already been completed. Once listed, it was a matter of attending weekly physio appointments, meeting with the surgeon and seeing the transplant team once a month for check-up and blood tests.

## What sorts of changes happened to your body after transplant?

Quite a few that I was not expecting:

- My face was no longer bright red due to lack of oxygen
- I no longer had blue lips
- Initially I was very puffy, like the Michelin Man, due to the steroids but it went away after about a month or two
- My skin started to peel, like I had bad sunburn
- I have a constant tremor due to the Tacrolimus (anti-rejection medication). This has improved over time however, gets worse if I'm anxious
- My hair started falling out, partly due to Tacrolimus and stress (I had a few complications plus an extreme needle phobia)
- I learnt how to cope with some really difficult situations. I set aside 12 months for any complications to occur, that thought process got me through. Luckily, 12 months on all seems to have settled down.

**Some people report weird dreams or other strange experiences e.g. suddenly liking beer. Did anything like this happen to you?**



I'm not sure if it's relevant, but I've developed a love of the gym and fitness. To be able to complete a class with the healthy folk is an incredible feeling. I love the fact that I have little muscles now instead of just being skin and bone like I once was.

**There is some evidence that people experience some trauma after coming out of the Intensive Care Unit (ICU) post-transplant. Do you remember anything about this?**

No I didn't. My only trauma was that I was only allowed to eat ice!



### Where are you now in terms of your health and outlook on life?

I'm very happy. Quality of life has improved dramatically. For me, life began at 30. Health has been wonderful for the past 6 months; I maintain regular contact with the transplant team which helps to alleviate any concerns. Keeping healthy is definitely a team effort.

Currently, 13 months post-transplant, I'm travelling around Australia which will take approximately 12 months. Prior to transplant, this would never have been possible. Loving life!

### What are your future plans?

At the end of the year, I will be graduating university after completing my Bachelor of Education. Next year I plan to return to work full-time and start our surrogacy journey to have a family. I'm sure this will be followed by



more travelling and hopefully building a new house! It's a wonderful feeling being able to make plans now. That was once a cruel thought.

### What words of wisdom can you offer other people considering transplant?

The transplant process can be tough, but the outcome and the life you have afterwards is better than you can

possibly imagine. It really is the most incredible gift of life.

Surround yourself with strong people - you will need to lean on friends and family more than ever as you make your journey through the process.

Start setting goals NOW... It helps to have a visual motivator! I hope this helps.

# SIBLING AND OFFSPRING CAMP 2016 – OUR BIGGEST CAMP EVER!

A huge shout out to the Commonwealth Bank Staff Community Fund grant for their continued support of the Sibling and Offspring Camp.



Raft making, Laser Quest and the much-loved flying fox, were just some of the activities on offer this year at the Point Walter Recreation Centre which hosted this year's two-day camp. James Sleight, our evening entertainer, proved particularly popular with the younger kids and a few budding Robin Hoods emerged after quickly locating the bullseye in the archery session!

The Sibling and Offspring camp is an annual event, run during the October school holidays. The camp gives this cohort of young people a chance to feel special, relieve stress and bond with other children in a similar situation. The activities are designed to improve resilience and coping skills and the camp provides them with an opportunity to build new friendships and networks. As a result, they gain an

understanding that they are not alone in living with a family affected by cystic fibrosis (CF).

If you have a child aged between 8-16, please encourage them to come along. Contact Paula on [recreation@cfwa.org.au](mailto:recreation@cfwa.org.au) to find out more information. Invitations to attend the 2017 camp, to be held at Woodman Point Recreation Centre on 5 and 6 October, will go out later in the year.



# SUPPORTER SPOTLIGHT: COMMBANK MAKES A DIFFERENCE

The Commonwealth Bank provides banking services for Cystic Fibrosis WA (CFWA) but not many people understand the wider reach of CommBank support and where they are making a difference at CFWA.

It is not often that Commonwealth Bank's John Sgambelluri has had to put a call out to his mates and family to bail him out of prison, but in the lead up to CFWA's Convicts for a Cause John took up the challenge. John, the General Manager for Business Banking in WA and SA, took up the challenge to raise funds for CFWA at the annual event held at Fremantle Prison. The support from John's friends, family and CommBank colleagues resulted in John becoming the highest fundraiser for this event. John is ready to pass the handcuffs on to another CommBank colleague for 2017!

CF families also see Commonwealth Bank support through our annual Sibling and Offspring Camp. A grant sourced through the CommBank Staff Community Fund means the siblings and children of CF members can participate in the camp run by our services team each year. For further information on the camp, see the Siblings and Offspring Camp article in this edition.

CommBank Merredin adds a regional flavour to CommBank's support. The Merredin branch took up the 65 Roses Challenge in 2016 decorating their branch in CF colours and balloons, and raised funds through merchandise boxes and collection tins. With members far flung across our huge state, support from organisations in the regions is fantastic.

#### Want to be involved?

Does your workplace want to help make a difference to CFWA? Please contact Karen on 08 6457 7336 or email [marketing@cfwa.org.au](mailto:marketing@cfwa.org.au) to discuss opportunities to be part of our journey towards finding a cure for CF.



JOHN SGAMBELLURI - COMMONWEALTH BANK, GENERAL MANAGER BUSINESS BANKING WA & SA, DONNED HIS COWBOY GEAR FOR CONVICTS FOR A CAUSE

## AN EVENING WITH CF SCIENTISTS.

Join us for an annual research update from WA cystic fibrosis (CF) researchers. The evening includes presentations, laboratory tours and the opportunity to chat with researchers.

To be held in early May at the Telethon Kids Institute, the date will be confirmed in upcoming RED E-Newsletters and the next edition of RED magazine in April.





# MENTORING: SHARING THE “LIVED EXPERIENCE”

A mentor is seen as a “wise guide”, and in the case of our cystic fibrosis (CF) community, someone who has a “lived experience” of having CF and who is able to be a positive role model to someone younger or less experienced.

The mentee is someone who perhaps needs a bit of guidance and support through a particular issue or someone just to connect with.

Mentoring at its core guarantees that there is someone who cares about them and “gets them” and assures them that they are not alone in dealing with everyday challenges. Research indicates that quality mentoring has a powerful effect on a variety of personal, academic and social growth issues.

Young adults who were at risk of falling off track but had a mentor are:

- 55% more likely to enrol in further study
- 78% more likely to volunteer regularly
- 90% more interested in becoming a mentor

- 130% more likely to hold leadership positions

Studies also indicate that most people are more likely to turn to a friend or family member first for advice or support rather than a health professional. The mentor has a different role to either of these; someone that you can tell “just how it is”. If the mentor also has CF they would be able to use their own “lived experience” as a common point of understanding.

Mentoring is a planned activity that focuses on specific challenges facing the mentee. It is typically a one-on-one relationship based upon encouragement, constructive comments, openness, mutual trust, respect and a willingness to learn and share.

Cystic Fibrosis WA (CFWA) are developing an information and training package for future E-mentors to commence early 2017. If you would like to be a future E-mentor or receive mentoring, please contact Kathryn on [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au) or on 08 6457 7333.

## References and further reading:

Mentoring for Success  
[http://www.nrm.wa.gov.au/media/7140/mentoring\\_guide\\_final\\_print.pdf](http://www.nrm.wa.gov.au/media/7140/mentoring_guide_final_print.pdf)

Mentoring Works  
[www.mentoring-works.com](http://www.mentoring-works.com)

CFWA Youth Survey (More information available if required)  
[Zero2Hero www.zero2hero.com.au](http://Zero2Hero.com.au)

## YEAR TWELVE IS OVER – WHAT NEXT?

Finishing school is exciting but can be frightening or overwhelming. You are not alone, whether you have cystic fibrosis (CF) or not.

### Things to consider when thinking about higher education

1. Most people don’t know what they want to do when they leave school.
2. Choosing the right course is not all about marks. Think about part time study if it will be easier for you to manage treatment. Consider if the course is made up of modules that could be easily done if you had time off during the semester. Having

lectures available online may be a priority.

3. Location – It is important to consider what is influencing you. It is common for people to enrol in a course simply because it is based where their friends are going. Travel time will be important if you need extra treatment if unwell.
4. Timetable/schedule – It may not be wise to select early morning classes if

there are other options available. This will allow time to do your airway clearance before class. Try to select a timetable that does not involve long distances across campus between lectures/labs.

5. If you decide on a gap year, use it wisely. Try to get some experience in a field of interest or related to your planned career.



Looking for something to do in your gap year? Check out the link to The Green Army below:

<http://www.environment.gov.au/land/green-army>

### Flexible study options

There are many options available in a variety of study modes. Using different study modes may allow your study to fit in with your lifestyle and treatment load.

Apart from full-time and part-time options, other pathways are available:

- External studies/distance education – this maybe something worth considering. This type of education means that usually students are not required to be physically present in the classroom. This will result in more freedom to study when and where you want. Some programs will still require some face-to-face contact. It would be ideal if materials are available online and lectures are downloadable.
- Summer school – classes may be available in the summer period when your health may be better.

Find out more about online learning options in the links below:

<http://www.australianuniversities.com.au/distance-learning/>  
<https://www.open.edu.au/>

### Support for students with a medical condition

Higher education institutions provide free services and a range of support for students with a medical condition. The variation between the health of

people with CF means some people may not think they have a disability. However, the legal definition of disability is broad and includes medical conditions, physical disabilities, mental illness, temporary disabilities, illnesses or injuries (Commonwealth Discrimination Act, 1992).

### Disclosing CF

Having CF does not need to stop you from chasing your dream of studying further. It may be difficult for you to tell people at university about your CF and it may not be necessary to give all the details. It may be worthwhile talking with lecturers and tutors about why the quality of your work may fluctuate. It is important to let the staff know how CF could impact on your study. You could say:

*"I have a medical condition that requires some treatment in the morning before class. This means I would like to attend tutorials/labs that are run in the afternoon."*

Advisors at the student support/disability services area at the institution will be able to help you gain assistance and support, especially if you are having difficulties meeting submission dates and sitting exams. These discussions and arrangements need take place well before the exam/assignment due date. You and your family can even talk to staff prior to enrolling.

There are useful online resources for those planning on further studies. Hannah, 19 years, has developed some YouTube videos that offer advice about developing a plan for talking to lecturers about missing classes because

of CF or another chronic illness:

College with CF: How to be "normal"  
<https://www.youtube.com/watch?v=8PJHZc-0fVc>

College with CF: Professors and absences  
[https://www.youtube.com/watch?v=EY\\_LiPyFaLE](https://www.youtube.com/watch?v=EY_LiPyFaLE)

### Types of support

Some of the support that could be available to you include:

- Accessible parking
- Alternative test/exam arrangements
- Assignment extensions
- Accessible course materials, i.e. online
- Lecture recordings

Applications for support will need to have a doctor's report. Talk to your CF team

Try to work around having flexibility in your study semester so that your treatment does not drop as you become involved in university life.

**All institutions have information on their website in relation to student support, as shown below:**

University of Western Australia: <http://www.student.uwa.edu.au/experience/health/uniaccess>

University of Notre Dame: [http://www.nd.edu.au/academic\\_support/disability-support-services](http://www.nd.edu.au/academic_support/disability-support-services)

Edith Cowan University: <http://intranet.ecu.edu.au/student/support/student-equity>

North Metropolitan TAFE: [https://central.wa.edu.au/current\\_students/services/Pages/default.aspx](https://central.wa.edu.au/current_students/services/Pages/default.aspx)

# WHAT FINANCIAL BENEFITS AM I ENTITLED TO?

Studying, looking for employment or working as an apprentice can entitle you to a few concessions or allowances. There are also several support services to assist you with accessing these benefits.



The Department of Human Services (previously Centrelink) are responsible for a wide range of financial payments including those for people studying, looking for work or doing an apprenticeship.

### Youth Allowance

Financial help for people aged 16-24 years who are studying full time,

undertaking a full time Australian apprenticeship, training, looking for work or sick.

### Eligibility Basics:

- 16-21 years of age and looking for full-time work or undertaking approved activities
- 18-24 years of age and studying full-time

- 16 or 17 years of age and have completed year 12 or equivalent, or undertaking full-time secondary study and need to live away from home in order to study, or are considered independent for Youth Allowance
- 16-24 years of age and undertaking a full-time Australian Apprenticeship

## Austudy

To receive Austudy you will need to be:

- 25 years or more
- studying full-time in an approved course at an approved educational institution, or undertaking a full-time Australian Apprenticeship or traineeship
- meet a personal income and assets test, and
- meet residence requirements

You can earn extra money (up to \$433 per fortnight) before tax, before your payment is affected.

If you are a student and receive Austudy you may qualify for a Low-Income Health Care Card.

## Student Start-Up Loans

These are available:

- if you are studying full-time
- receiving Youth Allowance, Austudy or Abstudy
- not receiving or have previously received a Student Start-Up Scholarship

## Student Start Up Scholarships

These are available if:

- you are studying full time in an approved scholarship course delivered by an approved higher education provider

## Education Entry Payment

This is available if:

- you receive Newstart Allowance, Parenting Payment partnered, Partner Allowance or Widow Allowance and have received this payment continuously for at least 12 months
- have started or will start an approved education course, and
- have not received Education Entry Payment in the last 12 months

## Vocational Education and Training (VET) and Registered Training Organisations (RTOs)

### My Skills

Aims to connect students and employers with training organisations and provides information about VET and RTOs in Australia (see link).

### Australian Apprenticeships

Provides information and resources about Australian Apprenticeships and the support available (see link).

### Student Edge Card

Provides several concessions, discounts and information on accessing employment, study and different forums for students.

## Student Budget

Managing finances is always important, however, even more so if you are on a low budget and a student income.

### Budgeting

There are several apps, online tools or free community financial counsellors that can assist with budgets. For more information look at the budget planner in the link below that helps you calculate income and expenditure.

### Banking

Bank accounts have different fees so shop around to get the best account/s for you. Some ATMs are free, whereas others have fees. Internet banking is also quick, easy and generally doesn't attract fees, however be careful to keep your password safe and watch out for fake bank emails.

## Bills

### Direct debit

Most companies including government agencies, can set up a direct debit whereby you can make regular payments. This can be useful for rent or paying off bills, however, you can be charged default fees if you don't have enough money in your account.

### Smooth your bills

Bill smoothing can help you deal with those big bills over the year by estimating the average amount of consumption over the previous twelve months and making the same regular payments either weekly, fortnightly, or monthly. This can also be arranged through direct debit.

## Accommodation

### University campus rooms

If you are regional or leaving home this can be a cheaper option as some costs can be included in the accommodation such as water, heating and internet.

### Homestay

This is now very popular and can be cheaper to rent with a family. Meals and internet can also be included.

### Share House

Set up some rules. There are also some good websites on things to look out for. Here are a few tips:

- Respect, privacy and space
- Set up a joint kitty for expenses
- Share the cleaning
- Manage rent and bills
- Have a plan if things go wrong

## Transport

Compare different travel options

When you are budgeting for transport to university, compare the costs of travel by bus, ferry, train, bike or car. Get a student travel card or try carpooling with others.

### 2017 CFWA Subsidies

We are pleased to announced that subsidies are now open for 2017.

If you have CF, you are able to make a claim up to \$200 for exercise/activity, equipment or obtaining a driving license. Reimbursements will only be provided upon evidence of a tax invoice of the item or activity purchased. Please note, only one application per person per year.

Thanks to Telethon, we are also able to subsidise travel for regional children for each clinic visit or hospitalisation. There is also a subsidy for regional adults for each clinic visit or hospitalisation.

For further information please contact Kathryn [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au)

## References and Further Information

### Centrelink Payments

<https://www.humanservices.gov.au/customer/services/centrelink/austudy>

### Australian Apprenticeships

<https://www.australianapprenticeships.gov.au/>

### My Skills – VET training

<http://www.myskills.gov.au/>

### Budgeting

<https://www.youtube.com/user/MoneySmartAu>

<https://www.moneysmart.gov.au/life-events-and-you/under-25s/studying/living-on-a-student-budget>

### Bill Smoothing

<https://www.agl.com.au/residential/help-and-support/billing-and-payments/bill-smoothing>

### Student Edge

<https://studentedge.uservice.com/>

### Share Housing

<http://www.youthcentral.vic.gov.au/housing-accommodation/sharehousing/5-tips-for-living-in-a-share-house>

### CFWA Subsidies

<http://tinyurl.com/q4ccbpn>

You can also contact Kathryn on [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au) for further information.



# HALLOWEEN FUN RUN: A SPOOKY SUCCESS

Perry Lakes Reserve was transformed into a spooky wonderland for the Halloween Fun Run!



Witches, wizards, warlocks and ghouls descended on Perry Lakes Reserve on Sunday 23 October for the Halloween Fun Run, proudly supported by Community Newspaper Group.

Participants arrived early to grab their free witches hat and a Halloween-tastic face paint makeover, thanks to the ladies at Funky Face Painting. We were thrilled to see so many people getting into the spooky theme!

The new family friendly course was a big hit with the brand new Halloween hunt, featuring spooky signs and creepy clues with plenty of prizes to be won.

There was plenty to see and do at the finish line with a live DJ, freaky photo booth, roving performers, fun family activities, a spectacular trampoline raffle, yummy food, refreshing drinks and a special performance from escapologist Ghupi.

Congratulations to our prize winners from the day: the 3km and 6km champions and best-

dressed boy and girl, who all received a Fitbit thanks to The Good Guys Malaga.

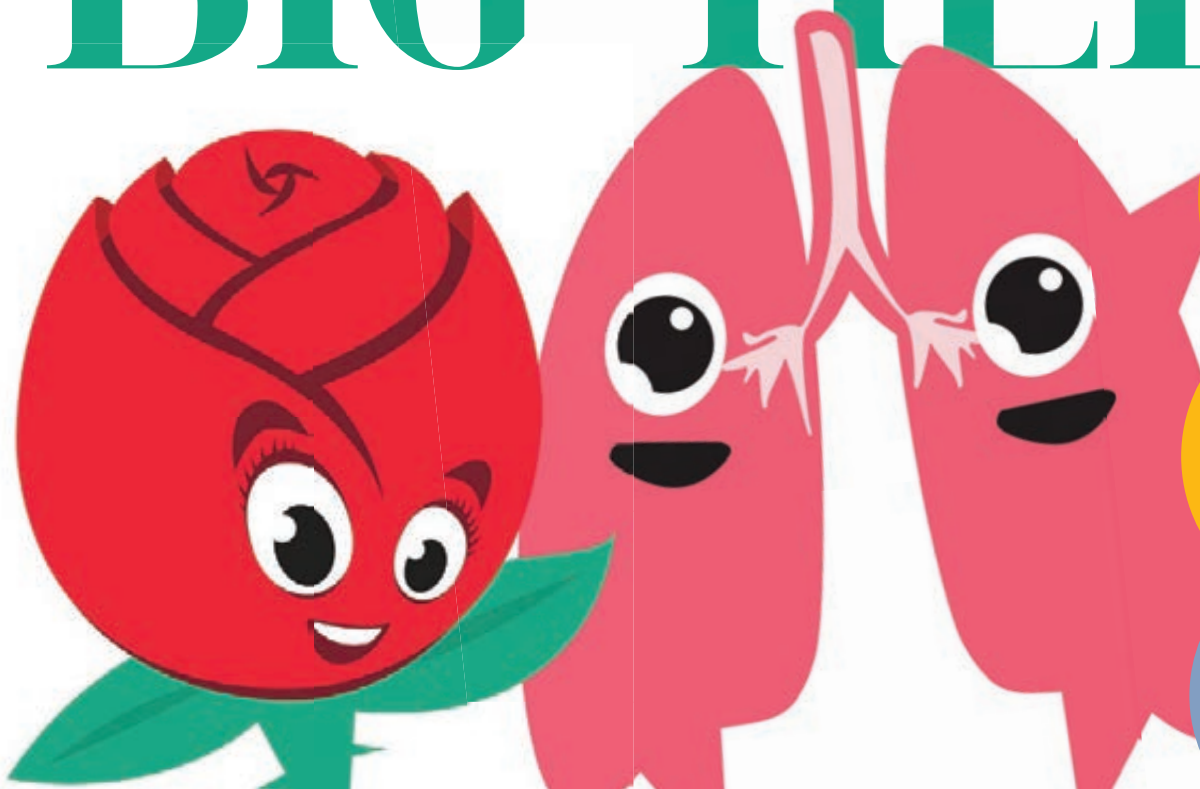
We'd particularly like to acknowledge our top fundraiser, Ceri Ovans, who completed the course less than 2 months after receiving her lung transplant. What an amazing achievement!

Thank you to all our generous partners who made the event possible including our dedicated team of volunteers, Community Newspaper Group, Spirit Events, The Good Guys Malaga, Perth Prop & Party Shop, McDonalds, Jump Star Trampolines, Telstra, Town of Cambridge, Nadam Events, Laser Electrical Greenwood, Sensational Stilt Walking, HelFit Training Studio, Ghupi Entertainment and Rich Amos for the photos.





# 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](mailto: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>



# TELEHEALTH

Telehealth is a program that is helping improve access to care for adults with cystic fibrosis (CF) in rural and remote WA.

The Sir Charles Gairdner Hospital (SCGH) adult cystic fibrosis (CF) team identified a significant opportunity for improving treatment options and access to care for adults with CF living in regional WA. CF carries a significant daily treatment burden which may take many hours to complete. Combined with professional, academic and/or family responsibilities, individuals with CF are placed at a significant lifestyle disadvantage. Despite this, adults with CF living in rural and remote WA were still expected to travel to SCGH to attend CF clinics.

In 2012, prior to the commencement of

this project, only 22% of adults in rural and remote WA met the recommendation of attending four outpatient clinics per year with the specialist CF team, compared to 79% for those living in Perth. This potentially had a negative impact as scientific evidence shows that those with CF receiving care in a specialist centre have better outcomes. CF clinics also allow for the early identification of signs of exacerbations, which is important as recurrent and/or severe exacerbations negatively impact rate of decline in lung function and health related quality of life.

The team implemented Telehealth via video conferencing which had an

excellent uptake and led to increased clinic attendance in adults with CF living in rural and remote WA, meeting the recommendations of the Australian CF Standards of Care (four or more per year). Satisfaction with Telehealth was very high, and the increase in treatment provided will likely lead to improved long-term outcomes. This service is now part of the routine care of adults with CF living in rural and remote WA.

**Reference:**

Jamie Wood  
Senior Physiotherapist Cystic Fibrosis  
Sir Charles Gairdner Hospital

## REGIONAL RESPIRATORY TRAINING PROGRAM 2017

Cystic Fibrosis WA (CFWA) is hosting their annual training program for nurses and physiotherapists from regional Western Australia from 30 April to 5 May 2017.

This program is in its seventh year and is funded by the Western Australian Department of Health.

It offers comprehensive education on a range of respiratory issues including an overview of cystic fibrosis

(CF), bronchiectasis, chronic obstructive pulmonary disease (COPD) and asthma. The strength of the program is in its multi-disciplinary approach to chronic illness, with sessions on spirometry, nutrition, pulmonary rehabilitation, diabetes and

more. A bonus for participants in 2016 was attending An Evening with CF Scientists hosted by the Telethon Kids Institute.

For further information or to register your interest, contact Kathryn on [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au) or 08 6457 7333.



Government of Western Australia  
Department of Health

### Feedback from previous program participants:

"The training was intensive - I gained a lot of knowledge"

"The night with the CF scientists was very inspiring, hearing about the latest research"

"Best week of education"

# CLOSING THE GAPS IN REGIONAL WESTERN AUSTRALIA (WA) THROUGH PROFESSIONAL HEALTH EDUCATION IN THE REGIONS

GAPS IN HEALTH PERSIST WITHIN THE STATE OF WA. THERE ARE ALWAYS NEW CHALLENGES - NEW INFECTIONS, TREATMENTS AND ENVIRONMENTAL RISKS. CYSTIC FIBROSIS WA'S (CFWA) REGIONAL EDUCATION PROGRAM IS AN ATTEMPT TO SHARE THE ADVANCES IN CYSTIC FIBROSIS (CF) MANAGEMENT EQUITABLY.

The high staff turnover on regional health campuses offers a challenge to keep staff up-to-date in CF care. The Outreach Health Professional Education Program is a step in the right direction to improve regional care for those with CF, by closing the knowledge gap to improve health outcomes.

In 2016, health professionals in Kalgoorlie, Esperance, Merredin and Albany attended CF education sessions.

Contact CFWA on [services@cfwa.org.au](mailto:services@cfwa.org.au) to enquire about having an education session in your hospital or school if you are a school health nurse.

# NEW WEBSITE



## CF LIVES MATTERS

**CF LIVES MATTERS** is a digital resource that empowers people with CF and their families to access up to date information about clinical trials and developments in new drugs and treatments in Australia and around the world.

Visit CF Lives Matters: [www.cflivesmatters.org.au](http://www.cflivesmatters.org.au)





# FUNDRAISING NEWS

2017 is here and already it's shaping up to be a fantastic year! In this edition, we thank the final fundraising champions from 2016 for their amazing fundraising efforts and introduce some exciting upcoming fundraisers.

## Challenges

### Riding to find a Cure

Paul, from New Zealand, who now lives in Broome WA, turned 30 last year and felt he had a statement to make about living with cystic fibrosis (CF). Paul took on his own 65 Roses Challenge in 2016 and set himself an incredible task of riding from the Atlantic in France to the Black Sea in Romania. Paul started riding mid-August at the height of the European summer and finished in chilly Romania in November; riding over 4,000km in that time. He sighted 3 major rivers, crossed 10 countries and raised over \$15,500 for Cystic Fibrosis WA (CFWA). The incredible journey was recorded in his blog [paulmichaelcycle.com](http://paulmichaelcycle.com) and includes photographs and insights into the difficulties and triumphs of taking on a challenge like this while having CF. Paul will share more on his experiences in the next edition of RED, so stay tuned!

### 24 Hour Walk

Inspired by his student Jayton, who has CF; PE teacher Luke Ioppolo set himself a challenge to walk around Perth for 24 hours straight. Backed by a team of dedicated supporters, including Jayton and his family, Luke walked from midday 29 September to midday 30 September to raise awareness and funds for CF. As the hours tallied up on Luke's incredible challenge, the funds rose to \$5,826.50, smashing the initial goal of \$3,000. Well done to Luke and his supporters, you deserve a rest!

### Kokoda Trail Trekkers

Inspired by their friend Warrick, who has CF, Shari Douglas, Nicole Forgone and Mathew O'Brien have taken the challenge to trek the Kokoda Trail in Papua New Guinea. So far, they have raised \$9,005.35 of their \$10,000 goal online at [65roseswa2016.everydayhero.com/au/cystic-fibrosis-kokoda-challenge](http://65roseswa2016.everydayhero.com/au/cystic-fibrosis-kokoda-challenge). What an amazing achievement. Thank you and

travel safe!

## Community Fundraisers

### Soiree for CF

Terry and Frances held a soiree of dancing, singing, musical performance and poetry on 26 November 2016 for CFWA. Caz, a CFWA board member who has CF, attended and shared her experiences of CF with the guests. The evening was a wonderful success and raised \$400! What a creative way to raise awareness. Thank you Frances, Terry and the guests.

### Hip Hope for Roses

The Civic Hotel filled up with Perth hip hop artists, DJs and supporters of CF on 16 September 2016 for Sera Taylor's Hip Hope for Roses event. Sera, who is a member of CFWA and has CF, organised and ran the event herself raising \$1,800 for CFWA. Thank you for your effort and well done for organising such a fantastic event.

### Addams Family: A New Musical

Dark Psychic Productions entertained Perth with their spooky, kooky Addams Family musical. With ten shows over two weeks, the musical delighted audiences with its new take on the old Addams Family stories. Thank you to the whole production and acting crew; your donation from program and raffle sales will make a big difference to the lives of people living with CF.

### York Health Expo

Thank you to Cathy North and Hayley Norrish who represented CFWA at the health expo in York again this October; spreading awareness for CF and raising a fantastic \$519 in raffles, donations and merchandise sales. Congratulations to these wonderful regional members and their supportive towns!

### Wedding Congratulations

Congratulations to Kobi and Alex on

their wedding this year and thank you for fundraising for CF on your special day. The newlyweds raised \$807.36 in donations from their friends and family in lieu of wedding presents. We wish you all the best for your future together!

## Upcoming Fundraisers and Challenges

### 2017 Rottnest Channel Swim

Congratulations to Kate O'Halloran for taking the challenge and swimming for CFWA in this year's Rottnest Channel Swim. Go to Kate's fundraising page at [rotnestswim2017.everydayhero.com/au/kate](http://rotnestswim2017.everydayhero.com/au/kate) and help support her with a donation or by sharing the page with friends and family.

### Battle of the Bands

The Corporate Battle of the Bands is back at the Charles Hotel on February 25 from 7pm. Come on down with your friends and family to watch live bands such as Grid Monkeys, Covenado, Smashed, St Johns Ambulance and Mandurah Catholic College battle it out in support of Youth Focus and CFWA. Tickets are available for \$30 at the door or online at [www.eventbrite.com.au/e/battle-of-the-bands-2017-tickets-29566128085](http://www.eventbrite.com.au/e/battle-of-the-bands-2017-tickets-29566128085).

### Top Tins

#### October

1. Xpresso Code	\$105.00
2. Good Guys Rockingham	\$41.20
3. Warnbro Pharmacy	\$39.30

#### November

1. Jewell-Mend Jewellers	\$316.00
2. Dr Martin Stuckey	\$81.90
3. The Sunday Times	\$49.90

### Want to be involved?

Have you got a fundraising idea but you're not sure how to make it work? Do you want to volunteer at CFWA events this year? Contact Marnie on **08 6457 7333** or email [events@cfwa.org.au](mailto:events@cfwa.org.au) to find out how you can easily get involved.





# CAPEL VALE

WESTERN AUSTRALIA  
*love wine, love Capel Vale*

Capel Vale Winery & Match Restaurant  
proudly supporting Cystic Fibrosis WA



Each of the Regional Series wines are grown where the optimal expression of its variety can be achieved. Site and varietal selection is the result of more than thirty years of research, trial observation of vine performance in Capel Vale's various vineyards.

These elegant and graceful wines display refined fruit character and a degree of ageing appropriate to the variety. Perfectly approachable upon release, they will however, reveal their strength and pedigree with further appropriate cellaring.

*love wine, love Capel Vale*



# CF COOKING: HEALTHY COOKING FOR PEOPLE WITH CYSTIC FIBROSIS

In December 2016, we were excited to launch CF Cooking, a new online resource for the cystic fibrosis (CF) community.



**CF**cooking



## Who are we?

CF Cooking was a collaborative project between Cystic Fibrosis WA (CFWA) and the Sir Charles Gairdner Hospital (SCGH) dietitian Paul O'Neill. The project was made possible by a successful grant application through Vertex Pharmaceutical.

## What is CF Cooking?

CF Cooking is a series of six professionally filmed cooking demonstrations that were made especially for people living with CF and their carers. In each video episode, Paul and a guest living with CF cook the meals and share their experience around the food. The videos which are approximately seven minutes long each and are 'live' on their own website, focus on healthy, nutritious and delicious recipes for people with CF.

## Background:

We hear a lot about and understand the importance of nutrition and growth for people living with CF, however, there are some barriers to optimising nutrition in CF.

There is a lot of information about nutrition in the community and on the internet, and there is also a lot of misinformation. At the same time, video is increasingly being used as a means of education and learning and could also be used to provide credible nutrition advice

to the CF community.

Traditionally, the dietary recommendation has been for people with CF to consume a diet that is high in fat and salt. Initially this recommendation seems opposite to the nutrition recommendation for the general population and therefore a problem to the friends and family who share meals with someone with CF.

## The process:

The recipes and topics of the videos were designed after a telephone survey of adults with CF. Themes that were nominated were:

- Healthy fats
- Cooking for someone with CF when not everybody in the family has CF
- CF and sport
- CF and salt
- Healthy food when you are tired or busy, and
- The overall importance of CF nutrition and how to obtain that in meals and snacks.

After some stringent 'recipe development' occurred, where all of the recipes were tested, we were ready to film. We were lucky to have a very experienced, professional media company, Myriad Images, work with us on the video production.

The videos were filmed at 'The Cooking

Professor' in Mount Hawthorn. This fantastic commercial kitchen venue has a Mediterranean atmosphere that was perfect as a background for the videos.

We also received some beautiful Australian Extra Virgin Olive Oil from Cobram Estate for use within the videos. Cobram Estate also generously donated a 200mL bottle of EVOO for everyone living with CF in WA to get them started with their CF cooking recipes. If you have CF, or care for someone with CF, you can collect your bottle from CFWA.

The videos are available online now. You can watch each recipe being demonstrated as well as download in PDF format, for printing, or simply view upon your mobile device while you cook.

Check them out at:  
<https://www.cfcooking.org/>

The recipes contain quantities of energy, fat, protein, carbohydrate and salt for reference if needed.

We would like to build upon this foundation with more videos that meet unmet needs in the CF community. So your feedback and suggestions would be invaluable. There is a contact link on the website for feedback.

Thanks to Vertex Pharmaceuticals, Myriad Images, The Cooking Professor, Cobram Estate, Coles Subiaco and especially our CF stars who appeared on each episode.



# CONVICTS FOR A CAUSE: RED ROSE BANDITS MAKE BAIL!



The Red Rose Bandits took on the Wild West in November for a night of 'heels up' fun(d)raising. Cystic Fibrosis WA (CFWA) members, staff, board and supporters donned their wild west gear and hitched their ponies to the rail at Fremantle Prison for a night of entertainment.

Convicts for a Cause is an annual CFWA fundraiser that has been part of our calendar since 1994. Our 2016 event was a collaboration between Rotary, Diabetes Research WA, Reflections Through Reality (RTR) and CFWA, with Rotary taking on the event management role through the wonderful efforts of Alison Dalziel and the event committee.

CFWA's Henshall family rode into the event with Ruby taking on the role of CFWA ambassador, and mum Kerry becoming part of the convict crew called the 'Red Rose Bandits'. CommBank staff John Sgambelluri, along with CFWA board members Feliciano and Rachael, and CFWA staff Nigel and Karen, rounded out the posse. Thanks to our generous bail sponsors, all our convicts managed to be freed to join partners and friends and participate in a night of pantomime, auctions and raffles.

With generous support from individuals and organisations including MC Steve Mills from 6PR, backdrops provided by Perth Prop and Party Shop and wines generously supplied by Capel Vale, Fremantle Prison came alive with the western saloon theme.

Marnie, CFWA Events and Community Fundraising Coordinator, rounded up our fantastic CFWA volunteers – including board member Caz Boyd, CFWA staff member Paula, as well as regulars and new volunteers including Chris, Ingrid, Louise, Ian, Sam, Liam and Fiona who

kept the evening running. Thanks for your brilliant support and we hope to see you back in 2017 at our events!

The event raised awareness and funds for all organisations involved, helping to maintain the spotlight on diseases for which we continue to strive towards cures for. Thank you to everyone who participated and those who sponsored our convicts to make their bail!

## Vale Barry Knowles

It was with sadness following Convicts for a Cause, and in the lead up to Christmas, that CFWA received the news that Barry Knowles, from one of our Convicts partner organisations, passed away from mesothelioma. Barry, who formed RTR as a result of contracting mesothelioma, lost his six year battle with this insidious disease. Barry's fight against this asbestos-related disease (ARD) stunned doctors and drove Barry in his quest to find a cure.

RTR was formed with the objective of promoting medical research into asbestos-related diseases, to provide support and connections for ARD sufferers, network with like-minded organisations and increase awareness of the inherent dangers of asbestos in our community.

We extend our sympathy to Barry's family and know that, with daughter Jo in the role of Operations Manager for RTR, Barry's legacy will continue.







# *Serve it up for CF this Summer*

Serve it up for CF this summer by hosting a get-together and asking guests to donate what they would have spent on a night out. It could be anything from a casual BBQ to a three-course banquet!

.....

[www.serveitupforcf.org](http://www.serveitupforcf.org)



# SAVE THE DATE

**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.**

## FEBRUARY

24 Celebration of Life  
25 Corporate Battle of the Bands

## MARCH

TBC Crack a Cure Challenge  
3 Ngala Soothing & Settling Babies Workshop  
10 - 12 Parents' Retreat  
16 Volunteer Training and Awareness

## APRIL

5 Annual General Meeting  
28 George Jones Family Foundation Cystic Fibrosis Golf Classic  
28 Ngala Routines & Boundaries for Toddlers Workshop  
30 - 5 May Regional Respiratory Training Program

## MAY

TBC Evening with CF Scientists  
TBC Albany Outreach  
20 Ladies High Tea  
25 Rose Wrapping Day  
26 65 Roses Day

## JUNE

TBC Geraldton Outreach  
TBC Mandurah and Bunbury Outreach  
30 Ngala Play and Learning Workshop

## JULY

1 Red Tie Dinner Dance

## AUGUST

5 - 8 CF Conference  
TBC Kalgoorlie and Esperance Outreach

## SEPTEMBER

5 Starting School Seminar  
14 Transplant Support Dinner  
TBC Deloitte Spring Rose Art Exhibition

## OCTOBER

4 - 6 Sibling and Offspring Camp  
20 Teen Workshop  
29 Halloween Fun Run

## NOVEMBER

24 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](mailto:events@cfwa.org.au) to find out more about a specific event or sign up for our E-newsletter.

## NEW EDUCATIONAL RESOURCE FOR NEWLY DIAGNOSED PARENTS AND FAMILIES

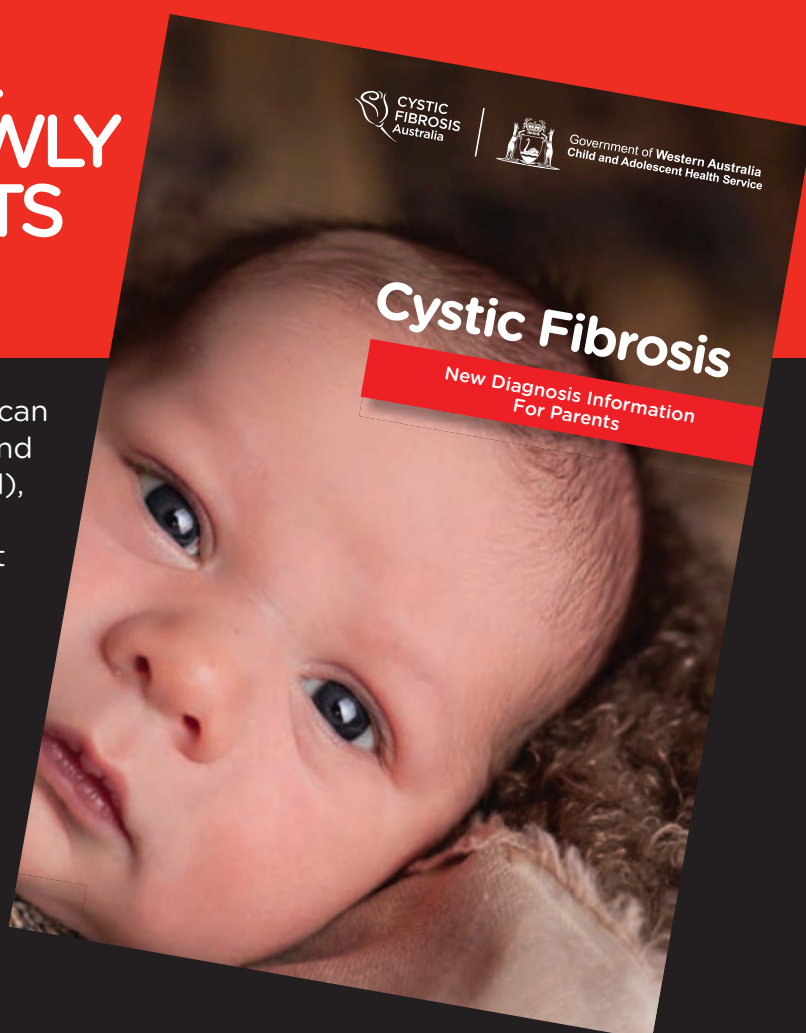
Learning that your child has cystic fibrosis (CF) can be overwhelming. Cystic Fibrosis WA (CFWA) and the CF team at Princess Margaret Hospital (PMH), with input from the CF consumer group, have collaboratively published an information booklet for parents of those newly diagnosed with CF.

The booklet will be available online and is given to parents on diagnosis by the PMH team.

### Information includes:

- Advice from other parents
- Information on diagnosis and newborn screening
- Effects of CF on the body
- Support services available from CFWA and PMH

If you would like a copy of this booklet, please contact Kathryn on [servicesmanager@cfwa.org.au](mailto:servicesmanager@cfwa.org.au)





# MRI SCANS TO LOWER RADIATION EXPOSURE

Clara Mok is the recipient of Cystic Fibrosis WA's (CFWA) George Jones Family Foundation Golf Classic PhD Top-Up Scholarship. In this article, she talks to CEO Nigel Barker about her research.

Clara forms part of the AREST CF research team and her research is targeted at understanding the characteristics of trapped air on CT scans in children with cystic fibrosis (CF)

**So Clara, what first got you interested in CF research?**

Prior to joining AREST CF, I worked as a research assistant with the Metabolic Research Centre at Royal Perth Hospital (RPH) and became interested in clinical research. My fascination with CF research actually began after joining AREST CF. I particularly love how medical imaging in paediatric CF is a rapidly advancing field and I have been constantly impressed by the way AREST CF works with CF patients and their families to achieve a common goal - to improve children's health and wellbeing. I'm really grateful for the opportunity to join this awesome team.

**The title of your PhD is "Characterising the trapped air appearance on CT scans in children with CF." What's it all about in lay terms?**

My project is based around four propositions. We call these hypotheses in research. You start off with a supposition and then carry out investigations to rule out other possibilities and hopefully what you are left with, having discounted all other probabilities, is right or alternatively, your propositions are debunked!

My first proposition or hypothesis is that I can reliably use MRI images to measure abnormalities in children's lungs in much the same way as CT images have been used in the past.

**That's interesting. We know that the AREST CF team have been pioneers in using CT scans to measure otherwise undetectable changes in lung disease progression, so what's the advantage of using MRI scans over CT scans?**

There are two main advantages of using MRI in CF. First, MRI can be performed without the risk of radiation exposure associated with CT. This is highly beneficial to children with CF because their respiratory health status can be monitored more frequently, enabling early treatment to be pursued.

Unlike CT, MRI can independently assess how well the lung ventilates and how evenly blood flows through different areas of the lung. Not only will this lead to a greater understanding of the disease, but treatments that specifically target these aspects of lung function based on

the MRI results may be developed in the future and used for increased treatment personalisation.

**What are your other hypotheses?**

My second hypothesis is that I will be able to match MRI observable changes to other clinical measures of CF lung disease to see how they relate. We want to validate functional MRI in children with CF because we know that lung disease can manifest before it is detectable by techniques such as spirometry. We also know that the sooner we intervene, the better our chances are of keeping young lungs healthy for longer.

My third hypothesis is that persistent trapped air (trapped air which persists into the next CT scan) is more clinically relevant than transient trapped air on CT scans (trapped air seen on the initial CT scan but not the next). Lastly, I'll investigate whether the trapped air appearance on CT is caused by an uneven blood supply throughout the lungs.

**That sounds very technical and in some ways, it's a real eye opener. There is clearly a huge amount of knowledge being gathered in CF research and I guess that much of the research today is incremental building on that knowledge rather than the eureka moments we are used to seeing in the movies. So, how's it going?**

Yes that's right. eureka moments are few and far between and more likely to start off with a "mm that's interesting" sort of response than leaping up and down in the lab. I'd like the leaping up and down bit but I suspect that comes later. It's obviously early days but I'm making good progress thanks in part to the financial support raised by CFWA's George Jones Family Foundation Golf Classic.

I have now completed the specialised training for CT analysis and I'm learning to use the software for statistical analysis whilst getting up to speed with the literature surrounding structural lung damage and early surveillance. The next step of my project is to validate the use of functional MRI in childhood CF.

At the moment, I am assisting in the collection of CT scans, lung function measurements and sputum samples. These are just some of the clinical measures I'll compare to the functional MRI outcomes. We hope that by recruiting 50 children in the study, we

will be able to determine even the slightest correlation between functional MRI outcomes and clinical measures of CF lung disease. As part of my research, I'll be spending eight months with the Erasmus Lung Imaging Group in Rotterdam, Netherlands to gain more hands-on experience in CT and MRI techniques. This group is world-renowned in the field of paediatric lung imaging and our group (AREST CF) has ongoing collaborations with them.

**OK so what will that mean for children involved?**

This research will improve our understanding of CF lung disease in childhood, leading to better clinical management and consequently, improved lifespan and quality of life for patients with CF.

**So how do parents find out more and sign up their children for this important research?**

I'll be looking to recruit school-aged children from the AREST CF group who will undergo a single MRI scan in addition to their normal clinical management. Eligible children will be identified in the AREST CF database and parents will be sent a letter with detailed information about what the study involves. We will contact parents a few weeks before their child's next annual review appointment to discuss the study and find out if they are willing to participate. If they are interested, then we'll arrange the research appointments.

The 2017 George Jones Family Foundation Golf Classic will be held on Friday 28 April at Lake Karrinyup Country Club. For details call Karen on 08 6457 7333.







# CORPORATE BATTLE OF THE BANDS

**7PM Saturday 25th February 2017**

**CHARLES HOTEL, NORTH PERTH**

**Tickets online \$25 or available on the door \$30**

**FEATURING**

***up to 6 Bands battling for first prize***

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**CYSTIC  
FIBROSIS**  
Western Australia



# 12TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE 2017

The conference will be hosted in Melbourne, from Saturday 5 August to Tuesday 8 August 2017.

Dedicated to cystic fibrosis (CF), this is Australasia's largest conference bringing together lay people, medical, allied health and nursing delegates and CF researchers from across the region and around the world.

Lay and medical sessions will be held over the four days, presenting the very latest CF research and innovations in treatment and care. As Chair of the 2017 Australian Cystic Fibrosis Conference (ACFC), Associate Professor Sarath Ranganathan, Director of Respiratory

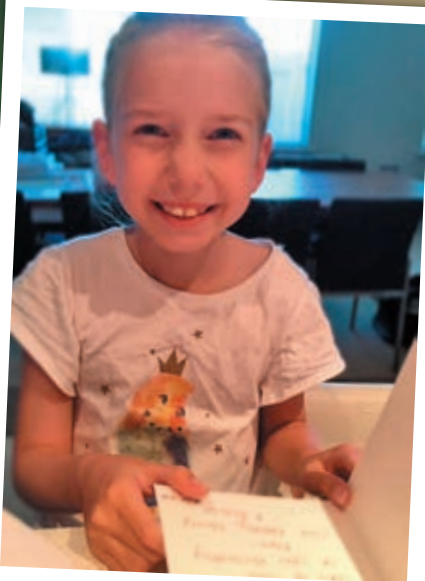
Medicine, Royal Children's Hospital Melbourne, has brought together a committee of CF specialists of whom have planned a valuable and vibrant program that celebrates both Australasian and international breakthroughs, innovative treatments and research.

The CEO of Cystic Fibrosis Victoria (CFV), Karin Knoester, will chair the lay committee with opportunities for education, peer support and consumer engagement in what will be compelling sessions.

The 12th ACFC promises to be a highly informative and stimulating event for our CF community, clinicians, health professionals and researchers.

We are also excited to announce that the 13th ACFC will be held in Perth, Western Australia in 2019! This will provide a wonderful opportunity for all of us at Cystic Fibrosis WA (CFWA) and our West Australian communities.

To register to receive updates on the conference, go to the CFA website: <http://www.cysticfibrosis.org.au/conference>



## Cystic Fibrosis Golf Classic 2017

Cystic Fibrosis WA is proud to present the seventh annual Cystic Fibrosis Golf Classic, to be held on Friday 28 April 2017 at the exclusive Lake Karrinyup Country Club.

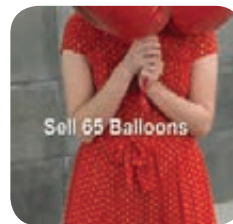
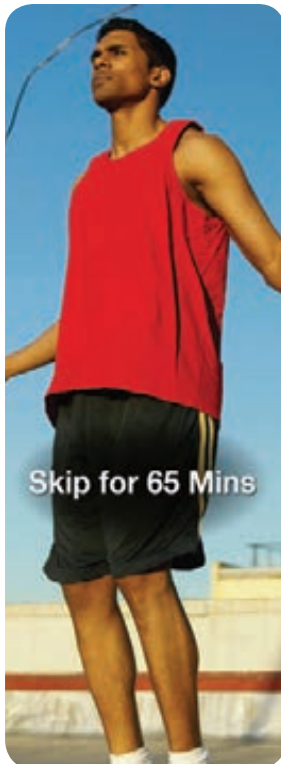
Enjoy a professional golf demonstration, friendly game of Ambrose golf, pre-dinner drinks, a three-course meal with live entertainment and plenty of auctions and prizes.

For more information and to register contact Karen De Lore at [marketing@cfwa.org.au](mailto:marketing@cfwa.org.au) or on 08 6457 7333.

All proceeds from this event helps support vital home care service and research funding for people with cystic fibrosis like Lyla.

# Take the **65** ROSES CHALLENGE

FOR CYSTIC FIBROSIS



## Choose Your Challenge

Choose your challenge this May. Visit the website for ideas!

Funds raised will support our vital home care services and research funding for people living with cystic fibrosis in Western Australia.

What are you waiting for?

[www.65roses.org.au](http://www.65roses.org.au)