

EDITION THREE 2015

RED

magazine



**BREAKING
NEWS**

USFDA APPROVAL
OF ORKAMBI
See page 11

IN THIS ISSUE

CROSS INFECTION -
AVOIDING THE
NASTIES



What's happening in the world of Cystic Fibrosis Western Australia

RED

DEADLINE FOR NEXT ISSUE

If you would like to contribute to our next issue, please contact us before Friday, 25 September.

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

Ramaa Puvvadi & Daan Coudri of Telethon Kid's Institute.

Cross Infection- Avoiding The Nasties.

Welcome to this bumper edition of Red Magazine which deals with a vast range of issues for people living with CF.

A special welcome too to the recently appointed Rothwell Family Fellow Daan Coudri from Amsterdam in the Netherlands. Daan recently joined the AREST CF Team at the Telethon Kids Institute. This appointment has been made possible through the outstanding philanthropy of our Patron John Rothwell and his wife Denise.

At a more practical level we are pleased to launch our new CF Smart animation.

One of the most important issues for parents who have a child with CF is ensuring that people around them have a good understanding of the disease.

One of the most anxious times is when a child starts a new school. It's important that the whole school community understands some basic facts around the disease itself, (not just that 'no you can't catch it!') and the importance of cleanliness.

Parents may request that the CFWA Education Officer works with the teachers at the school which their child attends to deliver a comprehensive CF education program called CF Smart and includes information packs for pre-primary, primary school and high school.

This program has been developed in WA but branded CF Australia to allow our sister CF organisations to deliver it in their States and Territories. This is a great example of how we have collaborated with our sister organisations to produce a world class product.



Nigel Barker, CEO

The animation funded by Lotterywest is aimed at primary school children with a catchy little tune called Good Clean Hands. You can view this on Youtube by searching for CF Smart Good Clean Hands. It's proved immensely popular but comes with a warning. If you watch it you may find it difficult to shake that tune out of your head for days!

Many congratulations to the Services team and particularly to Natalie Amos our Education Officer in bringing this to fruition.

Building on the theme of cleanliness is a special feature on cross infection and an update from one of the AREST CF researchers on how iron might help fight pseudomonas. We also celebrate some of the fantastic fundraisers that took place over May, Cystic Fibrosis month. If you feel inspired by these fundraisers then why not get together with a group of friends and have some fun designing your own fundraiser to help CFWA.

RED NEXT EDITION - MENTAL HEALTH & WELLBEING

If you would like to contribute to the next edition of RED using the theme above please email marketing@cysticfibrosiswa.org for additional information

CONTENTS



8

ROTHWELL PHD SCHOLAR JOINS THE AREST TEAM

INFECTION CONTROL AND CYSTIC FIBROSIS



14

GOLF CLASSIC A BIG HIT!



12

YOUNG CARERS



30

FEATURES

- 4** > CFA Update
- 5** > CF Conference
- 6** > TED Study
- 7** > Infection Prevention and Control at CF events
- 8** > Rothwell PHD Scholar Joins the AREST Team
- 10** > Telethon Kids Institute Seeks Consumer & Scientific Representatives
- 11** > New Combination Drug Approved by FDA
- 12** > Infection Control and Cystic Fibrosis

SERVICES & EVENTS

- 14** > RED Resources
- 16** > Supporter Spotlight
- 18** > Young Carers
- 20** > Interview with Ashleigh
- 22** > Interview with Jeslyn
- 24** > Ladies Support Dinner
- 25** > CFfood - Request for Submission of Recipes

FUNDRAISING NEWS

- 26** > Fundraising News
- 30** > Golf Classic a Big Hit!
- 32** > Big Bounce Jumping Success!
- > Spring Rose Art Show Set to Blossom
- 33** > 65 Roses 2015 – A wonderful result

CF CORNER

- 34** > CF Diary
- > Get Serving for CF!



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CFA Update

Governor General visits Cystic Fibrosis Centre, Westmead

On Friday 8th May, Cystic Fibrosis Australia hosted our Patron, the Governor General Sir Peter Cosgrove and Lady Cosgrove at The Children's Hospital Westmead. His Excellency and Lady Cosgrove toured the paediatric Cystic Fibrosis Centre meeting with physicians and young patients.

Adult patients from the Cystic Fibrosis Adult CF Service at Westmead Hospital were present, welcoming the opportunity to share their personal story with our guests.

During morning tea, CFA's President, Patrick O'Connor and past President Mitch Messer provided a detailed update on the extensive work currently being undertaken by Cystic Fibrosis Australia with respect to research, advocacy and quality improvement programs.

Before departing, the Governor General was gracious in thanking the Cystic Fibrosis Community for sharing their personal stories and for conveying the medical progress in such an understanding way. Sir Peter and Lady Cosgrove are keen to continue working with Cystic Fibrosis Australia to support the cystic fibrosis community.



Nettie Burke,
CEO CFA



Governor General Cosgrove and Lady Cosgrove
at Westmead Hospital



CF Conference

Cystic Fibrosis Australia is hosting the 11th Australasian Cystic Fibrosis Conference at the Sofitel Wentworth in Sydney from the 15th – 18th August 2015.

The Lay Program designed to inform and update families, carers and support networks is scheduled for the 15th and 16th August.

Themed 'CF-Life in the Fast Lane' the Lay Program will include international speakers from the USA, The Netherlands and UK. These high profile CF experts will be sharing their knowledge on a broad range of CF related topics.

Professor Peter Wark, Respiratory Physician and CF centre Director at John Hunter Hospital is chairing the 2015 Organising Committee and will deliver the Opening Address.

Professor Barry Plant, Consultant Pulmonologist and CF Centre Director at Cork University Hospital, Cork Ireland, will deliver a Key Note address during the cross over with the Medical Program. It is anticipated that the session titled 'New Therapies: Lumacaftor & Ivacaftor – how & why they work; what's next?' will be well attended by both lay and medical delegates.

Other renowned speakers include Francis Hollander, Department of Dietetics and Nutritional Science at Utrecht University The Netherlands, Eleanor Main, Senior Lecturer in Physiotherapy and Course Director at the Institute of Child Health in London and Pradeep Singh MD, Professor of Medicine & Microbiology at the University of Washington School of Medicine.

All attendees are encouraged to register online for the conference and associated events. Further information is available on the website www.cysticfibrosis.org.au/conference or call CFA on (02) 8883 4477 or email general@cfa.org.au



11TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

Lay Program: 15th and 16th August 2015
Medical Program: 16th, 17th & 18th August 2015
Sofitel Wentworth Hotel Sydney

Cystic Fibrosis Australia would like to welcome you to Sydney to hear the world's leading speakers working in Cystic Fibrosis care.

Cystic Fibrosis Australia is a non-profit organisation supported by the CF community in Australia and donors. CFA is committed to providing a collaborative forum where physicians, nurses, allied health professionals and scientists working in CF care can meet to advance education, share experiences and practices and learn about new products. We also remain committed to providing families and carers with information on the most recent drugs, treatments & therapies for CF.

Closing date for Abstracts: 29th April 2015
Register at: cysticfibrosis.org.au/conference
Enquiries: Conference Secretariat **02 8883 4477**

TED Study

Adding Ca-EDTA to inhaled antibiotics for effective treatment of Pseudomonas and other infections



Ramaa Puvvadi of the Telethon Kid's Institute.

The lungs of Cystic Fibrosis (CF) individuals are at risk of recurrent and chronic infections caused by bacteria such as pseudomonas aeruginosa (PsA). After infection, this organism (PsA) adapts to the airway environment by forming a protective mucoid layer (biofilm) around itself. Once established, biofilm-forming bacteria are virtually impossible to eradicate with existing therapies. It has been recognised that iron is essential not only for growth of PsA but also for biofilm formation by this germ. In the CF lung there is increased iron compared to non CF lungs, creating an environment that is helpful for PsA growth and biofilm formation.

Ca-EDTA is a compound that can bind to metal ions such as iron making them unavailable for use by bacteria such as PsA. In humans, it is used extensively intravenously (in high doses with well established safety) for the removal of heavy metal ions, such as iron and lead in iron overload or lead poisoning respectively. In our study, we plan to nebulise a solution of this salt into the airways of patients

with CF (who are infected with PsA) together with their usual nebulised antibiotic - in this case, Tobramycin. The expectation is that the Ca-EDTA will bind the iron in the airway thus making it unavailable for use by the PsA.

In turn this will:

- (1) cause breakdown of existing biofilm;
- (2) render the PsA unable to produce new biofilm, and;
- (3) render the PsA unable to grow efficiently. All of this will make the PsA much easier to be killed by the accompanying antibiotic, and studies thus far (mainly in animals) show that addition of Ca-EDTA can improve bacterial killing of the antibiotic by up to 1,000 times.

Essential inclusion criteria for participation in the study are:

1. CF patients requiring a two-week course of IV antibiotics for treatment of a pulmonary exacerbation.
2. Positive sputum culture for Pseudomonas aeruginosa in the previous 12 months.

This study has started and is being performed at both SCGH and Princess Margaret Hospital. For further information please contact Dr Ramaa Puvvadi or Dr Barry Clements through Princess Margaret Hospital, Department of Respiratory Medicine on 93408222.

Infection Prevention and Control at CF Events

In the past decade new knowledge has been gained in preventing infection in those with CF. This has led to a new challenge in developing guidelines to prevent transmission of infection.

The goal of the infection prevention and control guidelines is to prevent transmission amongst those with CF (Saiman, L et al, 2013).

Planning for the 2015 CF Lay Conference has led to a review and update in the Cystic Fibrosis Australia (CFA) Infection Prevention and Control Policy to minimise the risk of cross infection. This review is a work in progress and the policy will be finalised by August.

It has been shown that pseudomonas can travel up to 4 metres on coughing (Knibbs LD et al, 2014). Overseas, lay conferences have been continued to allow those with CF and their carers an opportunity to gain up to date knowledge of current CF management and research. CFA continues to support the Australasian lay meeting in 2015 and acknowledges that there will be individuals with CF attending, therefore a risk of cross infection will be present. The CFA board has adopted the use of a risk warning and waiver to be signed by those with CF over 18 years prior to attending the event.

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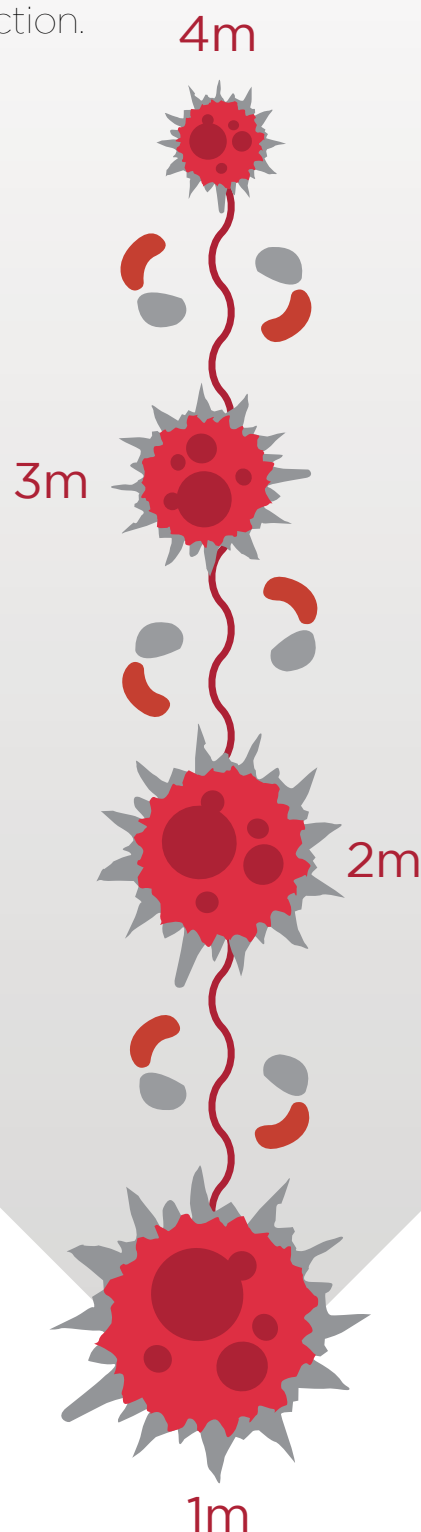


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📖 Saiman L, Seigel J, LiPuma J (2014) *Cystic Fibrosis Foundation Infection Prevention and Control*

📖 *Guideline for Cystic Fibrosis: 2013 Update, Infection control and hospital epidemiology, vol. 35, S1*



Rothwell PHD Scholar joins the AREST Team

Daan Caudri talks to RED about his exciting research.

Cystic Fibrosis (CF) is a very heterogeneous disease, with a wide range in severity and co-morbidities across all ages. There is a great need to find new therapies and follow-up strategies that are tailored to the needs of individual CF patients. Unfortunately many of the currently available treatments use a one-size-fits-all approach. In my research project I want to help in the development of a more personalised approach in follow-up as well as treatment for young children with CF.

I am a paediatrician and epidemiologist from Rotterdam, the Netherlands. This year I joined the AREST CF group as a Postdoc researcher and as a clinical fellow in Paediatric Respiratory Medicine at the Princess Margaret Hospital. I completed my PhD research in The Netherlands focussing on the development of clinical prediction tools. Such tools can help doctors treating children with CF to predict at a very early age who is most likely to experience more severe infections and symptoms. AREST CF is the largest and most detailed database on newborn children with CF in the world. In some of these children we already have a long term follow-up of more than 10 years. This data is very valuable and can be used to look for new prognostic markers. Clinical doctors can use them to decide which child with CF may need more frequent follow-up or more aggressive treatment than others. As part of my project I will try to develop easy to use clinical prediction tools. This can help to change from a one-size-fits-all into a more individualised care plan.

A second reason why it is very important to develop a more individual approach in the treatment of CF, is that not all drugs may be equally effective in all CF patients. Some children with a specific gene defect, or with a more severely decreased lung function, may not benefit from exactly the same drugs as their peers. A recent example with the newly developed drug Ivacaftor clearly showed that it was very effective, especially in a small subgroup of patients. This personalised approach in which the efficiency of drugs is tested in different subgroups of patients is referred to as 'precision medicine'. It offers great opportunities, because it may allow us to develop new and effective treatments using drugs that are already available. Drugs that previously did not show a significant effect when tested in clinical trials in all CF patients, may actually turn out to be very useful in a sub selection of CF patients.

The discovery of new drugs in such a precision medicine approach remains a challenge. It implies that many separate clinical trials need to be designed, each with different subgroups of CF patients. This is very costly and in a rare disease as CF it will be very difficult to find and recruit sufficient CF patients for each subgroup. A promising way to overcome these difficulties is the new concept of performing virtual, i.e. in silico, clinical trial simulations. Rather than running many clinical trials in real life, we can first simulate different clinical trials using virtual computer simulations. The results of these virtual simulations can be compared and used to decide on what



Daan Caudri of the Telethon Kid's Institute.

will be the most promising trial to perform in real life, in actual children with CF. That way the in silico trial simulations can be used to identify the optimal choices for a number of important factors, such as:

1. The most promising drug to be tested;
2. The optimal drug dose;
3. Whether the drug should be taken orally, intravenously or inhaled;
4. Which subgroup of patients is most likely to benefit from the drug;
5. The most efficient design of the trial;
6. The number of patients that needs to be included for a significant trial result.

Obviously, this approach is only useful if we have very good and realistic computer models available. These models need to describe all the relevant pathophysiological processes that play an important role in CF disease. I am involved in an international collaboration with several partners that have put great effort in the development of such mathematical models. There is a mathematical model describing the anatomy of the airways, up to the smallest airway. Another mathematical model describes how inhaled medication flows through these airways and where it is exactly deposited. A model was developed that describes

how the small hairs lining the airways wave simultaneously to push the mucus up from the lungs to the mouth. Combining all these models will create an overall model of the pathophysiology of CF. AREST CF is a very important partner in that project, because the clinical data from the AREST CF database is needed to check the mathematical models and make sure their simulations are very realistic.

This whole virtual approach with in silico computer model simulations will certainly sound a bit futuristic at first. In essence though, it is nothing more than combining all the detailed knowledge we already have on CF and use it to pick the most promising set-up for a new clinical trial. That way we have a much higher chance of finding efficient drugs for exactly the right patient. And importantly at a fraction of the time and costs of running many real life clinical trials. We think that this approach will help us to find new medications that are useful in the children that really need it. The clinical prediction tools developed using the AREST CF database will further help to early identify the children that are more likely to get recurrent infections and early lung damage. Together these projects will hopefully ensure that in the future we can really achieve precision medicine in the treatment of children with CF.

Telethon Kids Institute Seeks Consumer & Scientific Representatives



Expressions of interest are invited for both the Child and Adolescent Cystic Fibrosis Consumer Reference Group of WA and our Scientific Management Committee at the Telethon Kids Institute (TKI).

Child and Adolescent Cystic Fibrosis Consumer Reference Group of WA

This reference group is a formalised representation of parents and patients with cystic fibrosis brought together to:

- Support the development of partnerships between consumers, researchers, research organisations and clinical staff.
- Provide a consumer perspective to both clinical and research aspects of cystic fibrosis.
- Advise about research and clinical priorities, practice and policies.
- Enhance the quality and relevance of research and clinical activities through consumer participation.

Scientific Management Committee

The role of this Committee is to implement the research priorities of the AREST CF collaboration through activities such as:

- Progress review of current projects, including the Early Surveillance Program.
- Review and approval of new projects, collaborations and Chief Investigators.
- Review and approval of requests for access to AREST CF biological samples/data.
- Progress review of research outputs, including publications, conference presentations and grant applications.
- Monitor and align research efforts to ensure research will lead to meaningful benefits for patients in clinical practice.

For more information or to express an interest in joining either of these groups please visit the AREST CF website. Please note expressions of interest are due by the 24th July 2015.

New Combination Drug Approved by FDA

Independence Day in the USA brought exciting news for people living with CF in the U.S. The Food and Drug Administration (FDA) approved a new combination drug called Orkambi, for people with cystic fibrosis (CF) homozygous for the F508Del CFTR mutation who are aged 12 years and over.

The Cystic Fibrosis Federation in Australia celebrates and supports this decision and plans to continue the momentum of the Orkambi approval campaign here in Australia.

Two large phase three clinical trials were conducted internationally and 10 trial sites were located in Australia.

Trial data shows that FEV1 improvements in many participants were observed from Day 15, sustained throughout the 24-week trial and to 48 weeks in the open label follow up period. The mean improvement in lung function was 3% though pulmonary exacerbations for patients on the drug combination were 39% less than the placebo group.

The drug combination not only initially improved FEV1 but a significant percentage of Orkambi trial participants also experienced weight gain, a reduction in hospitalisation and a reduction in the use of additional antibiotics.

It is important to note that Orkambi's impact has been variable, according to some trial participants, who did not identify any noticeable changes to their CF symptoms.

Approximately 1,500 Australians have the F508del homozygous gene mutation and if approved by the Australian Therapeutics Goods Administration (TGA) and the Pharmaceutical Benefits Advisory Committee (PABC), Orkambi will be available to 1,000 of this cohort in 2016. Vertex is planning on using a parallel approval process by engaging both the TGA and PBAC simultaneously.

Cystic Fibrosis Australia (CFA) will be tracking the progress of Orkambi in Australia and overseas and regular updates will be available at cysticfibrosis.com.au and via our social media platforms. CFA is committed to maximising every opportunity to get the voice of the CF community heard and will be working with CF clinicians, and Australian government regulatory agencies to improve access to treatments for patients with CF. CFA will announce details of how to get involved in due course.

This exciting news is yet another step closer to our vision of Lives Unaffected by CF and we welcome your involvement in achieving that vision.



Infection Control and Cystic Fibrosis

Infection control is an important issue in CF clinics worldwide. Infection control impacts on both the patient with CF and health care staff working in this field. It has also influenced interactions between individuals with CF.

A program to minimise the risk of a person with CF acquiring a 'bug' from another person with CF requires involvement by both staff and patients. It is based on the concept of 'standard and transmission-based precautions'. This is to minimise contact and reduce the risk of cross infection between all people who have CF and to have safe procedures for health care staff and facilities.

To minimise the spread of their infection people with CF can exercise some simple precautions such as:

- Covering mouth and nose when coughing or sneezing using tissues, disposing of soiled tissues immediately.
- Washing hands after coughing or sneezing and after physiotherapy.
 - Keep a distance from other people with CF – greater than 1 metre (A recent study published in 2014 indicated that when CF patients harbouring *Pseudomonas aeruginosa* cough viable organisms which are capable of travelling 4 metres and persist in the air for 45 minutes).

<http://thorax.bmj.com/content/early/2014/04/17/thoraxjnl-2014-205213.full.html>
- When unwell with a viral infection / influenza, arrange a separate appointment rather than come at a clinic time.
- If concerned, ask health care workers to hand wash or use alcohol hand rub before contact.

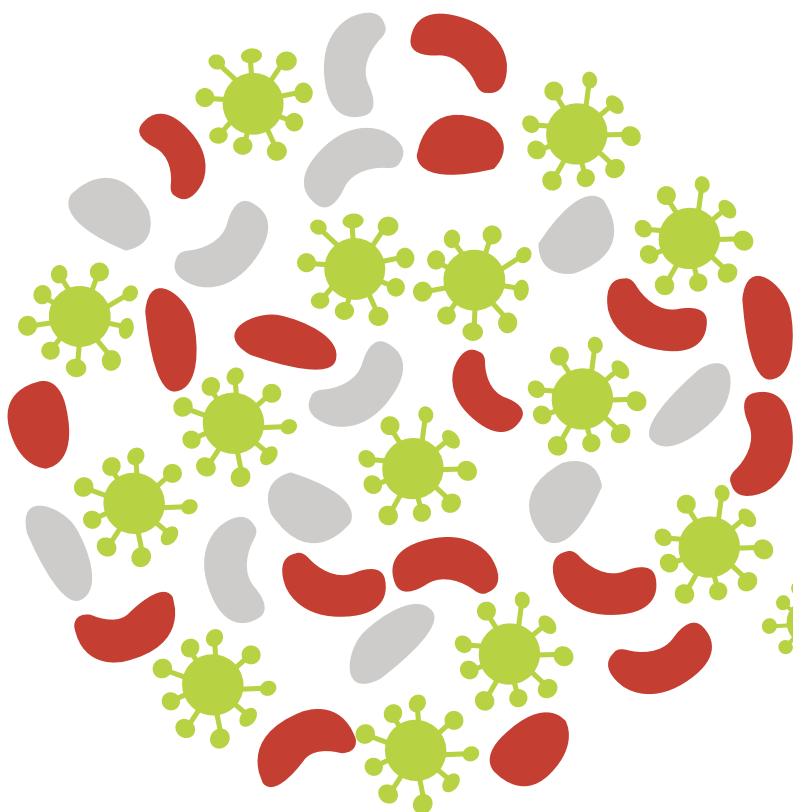
CF health facilities can manage infection risk with measures such as allowing people with CF to be easily separated from other people with CF or viral type infections. Equally important is the sterilisation and disinfection of equipment including breathing test equipment and office furniture in consulting rooms.

At SCGH there are a number of ways our health care professionals aim to prevent and control infection in our outpatient clinic, including those described below.

- Standard hand hygiene for all health care workers –the use of alcohol hand rubs or antimicrobial soaps before and after contact with patients.
- Sterilisation and disinfection of equipment.
- Segregated clinics – set clinic date and times for different respiratory infections.
- Ensuring minimal patient to patient contact during the clinic.
- Sputum microbiological surveillance – monitoring what 'bugs' are present in sputum.
- Influenza vaccination.

People with CF are prone to certain lung infections which can prove harmful to others with the condition. To avoid the risk of cross-infection people with CF are advised not to mix with each other. In recent years social media has helped to overcome this barrier to CF patients socialising and supporting each other whilst minimising any risk of cross infection.





FUTHER INFORMATION ▼

The websites below give further information on CF infection control.

http://www.cysticfibrosis.org.au/media/wysiwyg/CF-Australia/PDF_files/02_CFA_InfectionControlGuidelines_LowRez.pdf

http://www.cysticfibrosis.org.uk/media/132906/CB_Cystic%20fibrosis_what_exactly_Mar_13%20%28PDF%20330KB%29.pdf

<https://www.youtube.com/watch?v=peWm76uYxFE>

<http://www.safetyandquality.gov.au/our-work/healthcare-associated-infection/national-infection-control-guidelines/>

If you have any questions or require any further information regarding this article please feel free to discuss this with members of your CF team.



RED Resources

Good Clean Hands

Finally after a year in the making, thanks to the generous support of Lotterywest, and the work of Elephant Productions, our animated film “Good Clean Hands” is ready to hit schools around Australia. The main purpose of this film is to encourage children (and adults) in a school setting to have good hand washing and infection control practices, to reduce spreading germs. The film also mentions a little about CF and why it is not so great for people with CF to catch things like colds and the flu. The film has been shown to classes of school children around Perth and has been a real hit, with its catchy hand washing jingle. Some of the classes have asked to watch the film a couple of times! “Good Clean Hands” is targeted towards children aged 3 to 8.



So have a look on Youtube <https://youtu.be/d-WVOBTW6iA> for 'Good Clean Hands' and encourage your child's teacher to show the class this fun, informative and vibrant film.



Regional Professional Education

Regional education sessions were provided in Geraldton and York for nurses, physiotherapists, several doctors and a group of school teachers.

School and Community Education

During May, 640 children and 94 adults received school based education on CF, raising lots of awareness through this very special month.

CF Smart Program

CF Smart is a program which comprises a set of resources designed for parents, teachers and students to use in a school setting, to improve awareness and understanding of CF. The resources are available as PDFs on the CF Smart website: cfsmart.org and hard copies are also available at CFWA. To keep up to date on new resources and other things school related we also have a CF Smart Facebook page.



Some of the resources available on the website and in hard copy form are:

- Information booklets about CF for early childhood, primary school and high school teachers.
- Hand washing posters.
- "Hand washing and About CF" bookmarks for early childhood and primary school students.
- Enzyme bookmarks.
- Lesson plans for early childhood teachers.
- "Good Clean Hands" film.
- CF Summary for relief teachers.
- Letter to other parents.
- Student Health Support Plan (blank) and an example of one filled out.
- A summary for managing CF in the classroom.

CFWA also has an Education Officer available to deliver education sessions to teachers, students and parents in the school community.

For more information about our resources or to book a school visit please contact; Natalie Amos, Education Officer on 9346 7337 or 9346 7333 or email education@cysticfibrosiswa.org

Regional Respiratory Training Program (3rd - 8th May)

Thanks to the Department of Health this program has continued to grow in strength since its inception in 2010. Since that time we have facilitated comprehensive respiratory training for 145 regional nursing and allied health professionals from all across WA; including Kununurra, Esperance and smaller centres such as Northampton and Narrogin. Full accreditation was received from the Australian College of Nursing "CPD 30.5 hours according to the Nursing and Midwifery Board of Australia – Continuing Professional Development Standard" which has established this program as a bench mark of high clinical standing which engages a diverse and broad community of presenters and participants. Feedback from participants was extremely positive, one comment: "Absolutely fantastic course. Presenters were great, information was useful, and it was thoroughly enjoyable. Thanks for all your great work".

Function Creative

RED chats to Damon Carter from Function Creative, who provide some of our graphic design services.



RED: Welcome to RED Damon, you have been working behind the scenes for a few years now. Tell us about Function Creative and how you came to start the business.

Function Creative is a digital and print design consultancy, based in Perth, however we venture interstate on occasion.

Having spent several years working in tech start-ups, I was looking for a new challenge. I've always felt a bit entrepreneurial, and the timing felt right, so I founded the business. It's now been over 3 years and I'm still here so I must be doing something right!

RED: What types of graphic design do you do and what is your greatest design passion?

Having started my career in graphic design working in print and branding, I moved to London and transitioned into digital design, specifically user experience (UX) and interface design (UI). This is the area of design I find most exciting as the future of design (and the world!) is digital, and building apps that make life better is very rewarding.

That said, I just love crafting something new, and as I have a broad range of skills in most areas of graphic design, and am willing to take on most challenges - my motto is 'If it's visual, we can help make it reality'.

RED: What sets Function Creative apart from your competitors?

Flexibility. As a design consultancy practice rather than a traditional agency model, we can work on-site with our customers, bring in specialist skill sets as required and generally be more nimble when it comes to scoping and delivering work for my customers.

Our philosophy is 'fun follows function', which in practical terms means generally we will first design for practical outcomes, then ensure the work is still enjoyable and engaging to interact with.


RED: As a boutique operation do you have plans to expand or grow in the next few years?

As I mentioned earlier at the moment I bring in specialist skill sets on demand. I do have a few casual employees which has worked well to date, however I'm always keen to see operations expand and am always looking at ways to make this happen.

RED: When you aren't designing what do you like to do away from work?

I have a 2 year old daughter who occupies most of my spare time, which I love. She is at a really fun stage in her development, so it's great to get out and about and watch her learn!

Outside of family time at the moment it's DIY home renovations, as my wife and I are expecting our second child in October, so I'm racing to get as much done as possible before then.



I do enjoy a good game of football (soccer) most weekends and enjoy getting out to see live comedy every now and then, so it's not all work and no play!

RED: What specifically have you worked on for Cystic Fibrosis?

I've worked on a wide range of materials including the magazines RED, Rozee and TeenRED, to online fundraising campaigns, annual reports and even branding for events such as CFSibs'.

Two of the largest projects I've completed for CFWA have been the CFsmart and CFfit assets, which were so well received they were produced nationally, and have lead to opportunities with CF associations in other states.

It's always great to hear that your work has been well received, and it's doubly good when you're working alongside such dedicated people, like at CFWA.

RED: Thanks Damon we look forward to working with you for years to come.



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functioncreative.com.au



Young Carers

A young carer is “a person under the age of 26 who helps to look after a family member with a disability, mental illness, chronic illness, or drug or alcohol problem” (Carers WA). Children who have a sibling or parent with CF fall within this category of being a ‘young carer’.

Even though they are unlikely to be the primary carer, they usually have extra responsibilities at home compared to other people their age. For most young carers, helping to look after their sibling or parent is just a normal part of life, however, when inadequately supported, their own health and wellbeing can be affected. Young carers can miss out on opportunities to go to school, do homework, spend time with friends, have a job or further their studies; they can experience high levels of stress and worry; they can feel confused and uninformed, and often they need some help and support.

Here are some ideas on how to support your child:

Keep them informed:

Even young children in a family can sense when something is different or wrong. Talk openly (although age appropriately) with your child and encourage them to ask questions and talk with you about any issues or concerns that they are having.

Help them to feel safe:

Young carers need to feel safe and secure. They may worry about the health of their sibling or parent and what will happen in the future.

Help them to feel that they are not alone:

Young carers often find it really helpful to connect with other carers; to know that someone else understands and that they aren't alone.

Enable time away from the caring role:

Sometimes young carers feel very responsible for the person they are caring for and may need some encouragement from their family to take a break. It is important to remember that they are children who sometimes take on adult responsibilities.

Offer support when they need it:

Encourage them to think about their extended support network and support them in making links.

Support Available:

CFWA provide support through the annual Sibling and Offspring camp held in the October school holidays each year. They aim to create networks and offer a supportive environment to enjoy respite and ask questions.

There are other organisations that can also offer support to young carers.



Livewire

www.livewire.org.au

Livewire is a safe online environment for young people aged 10-20 years living with a serious illness and their siblings. It's a place for them to meet new friends, share experiences and know that they are not alone in their situation.



Siblings Australia

www.siblingsaustralia.org.au

This is a unique organisation committed to providing support for brothers and sisters of people with additional needs; including disability, chronic illness and mental health issues. They provide workshops, resources and networking opportunities for families.



Carers WA Young Carers Program

www.youngcarers.net.au

This program offers young carers access to specific information, service referrals and counselling, plus social support in the form of camps, school holiday activities and outings. The Young Carer website provides information and advice about self-care, coping with school and the caring role and available supports.

Sibling and Offspring Camp- Save the Date!



The Sibling and Offspring Camp is held each year to provide support and respite to young carers. This year's camp will be held at Bickley Outdoor Recreation Camp on the 8th and 9th of October. Activities will include canoeing, flying fox, mountain biking, team building activities, vertical challenge and search and rescue. The event is open to siblings and children of people with CF aged 8 to 16 years. Further information will be mailed out closer to the event.

For more information, contact Gillian on recreation@cysticfibrosiswa.org

Thank you to Commonwealth Bank Staff Community Fund for sponsoring this important event.



Proudly funded by Commonwealth Bank Australia

CommonwealthBank



Interview with Ashleigh

RED first recognised Ashleigh through her participation and growing leadership in four sibling camps. She is an active (particularly in netball) 14 year old and a sibling to Jordan who has CF. She lives in Port Hedland with her family.

RED: Could you tell us a bit about what it's like living in a place like Port Hedland?

Port Hedland is in the far north of WA. It is an Iron Ore Mining Town and it also mines salt. The weather gets quite hot, it doesn't usually get cool and when it rains it rains a lot. We also have cyclones, although this year we didn't have any. I have been in Hedland for over three years and we moved here from Broome because of my mum and dad's work. There is not really much to do in Hedland so I keep myself entertained by hanging out with friends and playing sport. I also like to get away and go camping and fishing. Some things are really good; there is no traffic or traffic lights and I like the heat.

RED: We have heard that you're a serious netball player, whereabouts do you play and how much time does this take up?

I play 3 games of netball a week, 2 games are played on Tuesday night, under 16's and B Grade. I play mixed adult netball on Thursday night. I train on Monday night and Thursday nights. I play in Goal Defence and Goal Keeper. I also belong to the Shooting Goals program at school and we play competitions against Newman, Tom Price and Karratha. We have to travel to each other's towns to play. I have just finished playing in the North West Netball Championships, which were held in Broome. I played 4 full games on Saturday and 2 full games on Sunday: we won the grand final! I also play mixed touch rugby on Wednesday nights and I'm in the same team as my brother Jordan which is good.

RED: What sorts of things have you done on the sibling camps and how do you think these camps might benefit siblings, particularly those from regional centres?

The activities are always different each time and the places the camps are held have been different every time so far. I love going to the camps and I really like to meet everyone. I have made some really good friends there. We keep in contact all the time now by the internet, Skype, snap chat and instagram. The siblings on camp all understand what it's like to have someone in the family who has CF and this is really great and you don't feel alone, you know, like you're the only one. Everyone on camp is in the same kind of situation. Maybe because I live so far away I don't really meet anyone else like us, so I really enjoy going to the camps. My favourite activity so far on all of the sib's camps has been the water biscuiting, which was so much fun. I would like to go to camp again this year.

RED: Do you feel being a sibling to someone with CF has made your life a bit different and if so in what ways?

Yes, I think it does make you a bit different; sometimes I'm late to school because physio takes so long. Everyone else that is late for school just says yeah I'm late because I slept in. Sometimes my friends ask why my brother has to take so many tablets and I'm not always sure what to say because he doesn't tell many people he has CF. When Jordan goes to hospital it sometimes feels a bit weird. Sometimes I get worried about him wondering how he is going. Port Hedland is so far away from Perth and I don't get to see him while he



Ashleigh at
netball

is in hospital. It also means that mum has gone with him and I then miss them both. It feels like he does get more attention because of his CF and I do understand he has to, so sometimes I feel like I'm just in the background. I am kind of used to that now though. My brother is older than me so I don't really know what life would be like if he didn't have CF.

**RED: THANKS ASHLEIGH
FOR SHARING YOUR STORY
WITH US!**

Interview with Jeslyn

RED interviewed Jeslyn about being a sibling to Joel who has CF. Jeslyn shared some of her experiences of being a sibling, and how it has impacted her life. Jeslyn is 11 years old and lives in Bunbury with her Mum Lee, Dad Craig and brother, Joel Boy.

RED: What are your favourite things about your brother?

He makes me laugh.

He never complains about CF or being sick, ever.

He's really brave.

I love how he helps little kids with CF by making videos and messages on Facebook.

RED: How does having a brother with CF impact you?

It doesn't really. I'm used to it because I've grown up with CF. Mum and Dad always tell us the truth about CF and if they don't know the answers they tell us that too.

I was really upset the first time Joel got haemoptysis. It was really scary. Mum explained he probably burst a blood vessel from coughing so hard and that he'd probably have to fly to PMH (we live in Bunbury), and he did. I stayed at Auntie Dawny and Uncle Alan's house. I thought he was going to die and it was really scary. I told Mum on the phone I will help more and he'll never get that sick again. Mum always talks to us and tells me what a great job I'm doing, so I don't think that way anymore. I know I'm doing all I can.

Once when I had a bad chest infection I felt so sick it made me think 'this is what it's like for Joel'. I can't compare the flu to CF, but it was what made me realise what life must be like for Joel boy.

RED: Do you help look after your brother?

I have always helped Joel with his medies. I used to clean his PEG and flush it. I gave him bolus feeds and helped with night feeds. I used to help wash and sterilise his neb pots and stuff but we need him to learn to do it all himself and not be lazy LOL.

These days I mostly exercise with him. We do Muay Thai with Jenny our trainer. She is lovely. At home Joel helps me practice skipping for 'Ripper Skippers' but he doesn't realise it is good exercise for him too LOL. We love trampolining, and we have scooters and bikes and a basketball ring. When he is sick I help by getting his Ventolin or tissues and stuff.

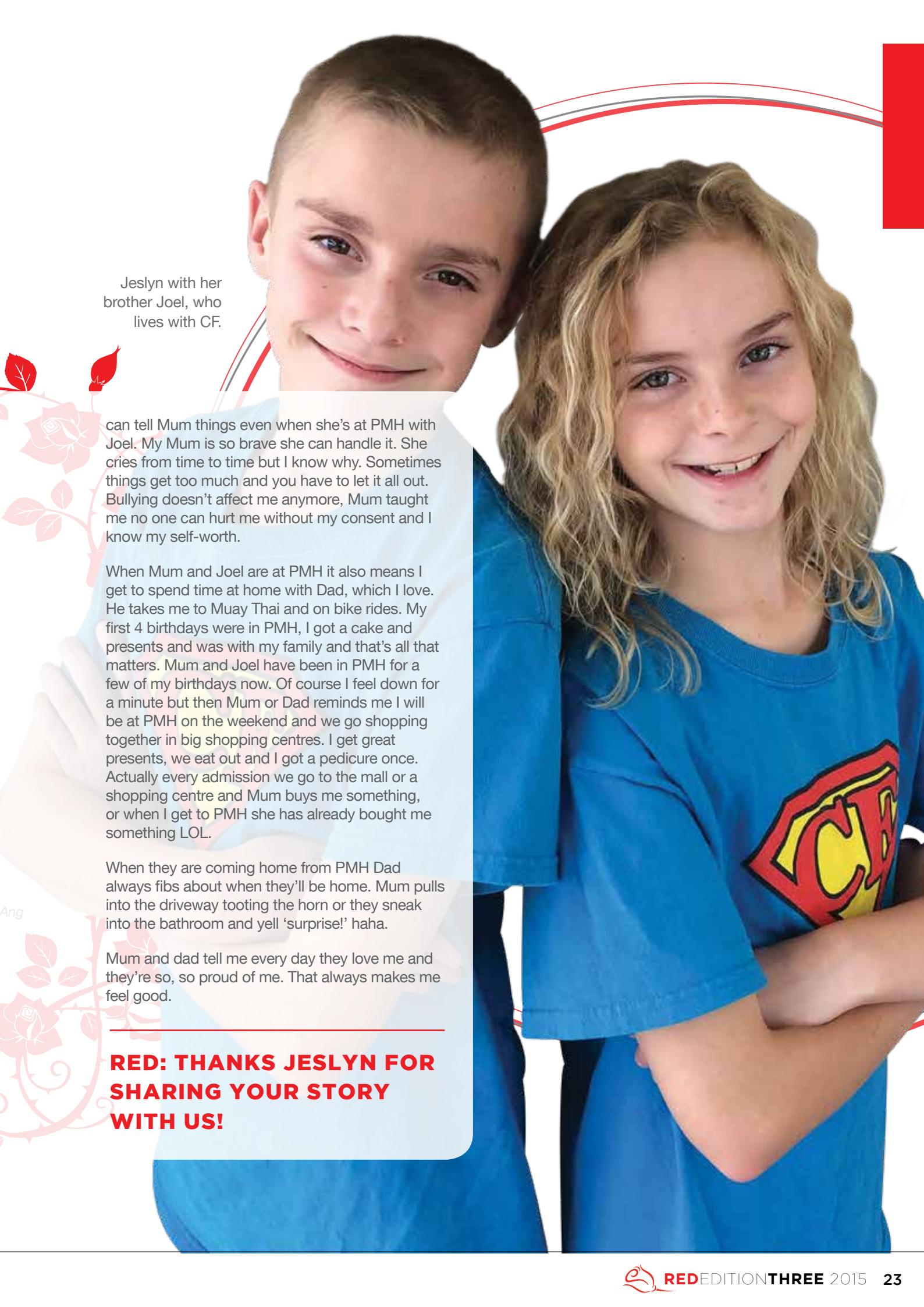
RED: What do your friends think?

All of my friends, the teachers and Mr Harvey the principal love Joel. They always ask how he is. They think it's cool when he's on TV or in the newspaper. I have great friends.

RED: How do you cope being away from Joel and your mum when they have to go to PMH?

I cope very well. Joel has been admitted every 3 months for 2-3 weeks since 2011 I think. In 2010 he got a Naso-Gastric tube and spent 6 weeks in PMH. Then he got a PEG, then a button, so I'm quite used to time apart.

Last year was hard because I was getting bullied at school. I didn't want to bother Mum because Joel was unwell. I now know that I



Jeslyn with her brother Joel, who lives with CF.

can tell Mum things even when she's at PMH with Joel. My Mum is so brave she can handle it. She cries from time to time but I know why. Sometimes things get too much and you have to let it all out. Bullying doesn't affect me anymore, Mum taught me no one can hurt me without my consent and I know my self-worth.

When Mum and Joel are at PMH it also means I get to spend time at home with Dad, which I love. He takes me to Muay Thai and on bike rides. My first 4 birthdays were in PMH, I got a cake and presents and was with my family and that's all that matters. Mum and Joel have been in PMH for a few of my birthdays now. Of course I feel down for a minute but then Mum or Dad reminds me I will be at PMH on the weekend and we go shopping together in big shopping centres. I get great presents, we eat out and I got a pedicure once. Actually every admission we go to the mall or a shopping centre and Mum buys me something, or when I get to PMH she has already bought me something LOL.

When they are coming home from PMH Dad always fibs about when they'll be home. Mum pulls into the driveway tooting the horn or they sneak into the bathroom and yell 'surprise!' haha.

Mum and dad tell me every day they love me and they're so, so proud of me. That always makes me feel good.

**RED: THANKS JESLYN FOR
SHARING YOUR STORY
WITH US!**

Ladies Support Dinner

The Ladies Support dinner was held on the 5th of June and was a great success, with 53 ladies from the CF community coming along for a night of 'Hollywood Glamour'.

The ladies donned beautiful dresses and enjoyed a three course buffet dinner and drinks, a photo station with props, and lots of positive chatter. This year the carers were able to hear from Amy Lauren, who spoke from her point of view as an adult with CF, and bravely shared some of her journey and inspired us all to 'Carpe Diem'!



During the evening, carers also worked in groups to brainstorm both the positives and challenges of being a carer and then shared some of their coping strategies.

This important event provides an evening of respite, while allowing female carers the opportunity to develop networks within the community and have a night of fun. This is an annual event and is open to all female carers within the community.

The Ladies Support Dinner attendees



CFfood - Request for Submission of Recipes

As part of the CFfood program that CFWA are currently creating, we are including a member based recipe book. We would love members to submit their favourite CF recipe. This could be a main meal, snack, drink, dessert etc. It may be a high calorie smoothie, a well-balanced dinner full of healthy fats, a breakfast that you can eat on the go, and so on.

If you also have tips on how to keep the meal lower in fat for the rest of the family please also include these at the bottom of the recipe. E.g. Serve up the soup and then add a dollop of cream into the person with CFs bowl.

We will also scatter useful recipes and tips throughout the rest of the resources we are developing for the program, so if you have specific ideas for babies, toddlers, school lunches and other niche groups, please send those to us too.

If you have calculated the calories, fat, protein and/or carbohydrates please include this with the recipe (per serve).

If you have time to also cook the recipe at home, please send in some photos to go along with the recipe. To ensure best quality, please send in photos with a minimum 2MB, taken with a digital camera if possible. If using a smart phone, it needs to be at least an iPhone 5 or Samsung S4 to ensure the picture quality is high enough. Please send a minimum of 3 photos.

CFfood
cystic fibrosis nutrition program

 CYSTIC
FIBROSIS
Western
Australia

Name of Recipe: _____

Prep time: _____

Cooking time: _____

Number of serves: _____

Ingredients & Measurements: (use tsp, tbsp, gms, cups - Please dot point the ingredients)

Method (Step 1, Step 2, etc.)

Nutritional information per serve

Calories:

Fat:

Protein:

Carbohydrate:



The recipe and photos should be emailed to Gillian on recreation@cysticfibrosiswa.org using the form that can be downloaded from www.cysticfibrosiswa.org/resources/cffood



Fundraising News

Thanks so much to everyone who stepped forward to raise funds since the last edition of RED. There has been an amazing show of support, especially during the month of May, our CF month of awareness. So many supporters are making a real difference in the lives of people living with CF and your ongoing support will help realise lives unaffected by CF.

CF AT SCHOOL

The Western Australian school community have outshone themselves by stepping up to the challenge to educate their students about CF and hold fundraising activities such as Crazy Hair Days and Go Red for CF. It has been great to hear the stories and unique ideas that students and teachers have come up with to raise funds. The collective effort of the Western Australian school community reached a remarkable \$13,119.25! Thank you to all the teachers, students and parents that participated.

Marmion Primary School undertook several fundraising activities under the Go Red for CF and 65 Roses theme and raised \$3,934.10! Marmion Primary School were also the lucky winners of the sporting goods voucher, being the school that raised the most funds during the month of May.

Wanneroo Primary School raised \$500.00 and **Busselton Primary School** raised a total of \$400.00. **Wattle Grove Primary School** achieved an amazing result of \$1,589.60 by hosting a Crazy Hair/Go Red for CF day and selling raffle tickets and baked goodies!

Clifton Park Primary School raised money through gold coin donations with a Go Red for CF Day and reached \$226.00, while **Willetton Primary School** had a gold coin donation day and sold wrist bands, raising \$559.40.

Peter Moyes Anglican Community School had an assortment of fun activities, gold coin donation day and Crazy Hair Day, raising \$1,258.65.

Weld Square Primary School held a Go Red for CF and Crazy Hair Day, raising \$220.

Baynton West Primary School had a Crazy Hair/Go Red for CF day raising \$740.25 and **Glen Forrest Primary School** raised \$446.80. **Rostrata Primary School** had a gold coin donation day and raised a total of \$632.45.

Ellenbrook Christian College raised \$612 by holding a uniform free day, while **Williams Primary School** walked their way to \$2,000 by having a school walkathon.

Applecross Senior High School held a bake sale, selling delicious goodies and raised the total amount of \$531.00.

RUN FOR CF

Ben Younger, \$6,045.75 and still counting!

Ben and Lisa are very fortunate to have two beautiful children Joshua, two and half years of age and six month old Chloe. Joshua was born with cystic fibrosis and whilst he is a robust high energy child, he endures significant daily treatments and ongoing health challenges. So this year Ben decided to take on the challenge to run in the Gold Coast Marathon to generate awareness about cystic fibrosis and to raise



Caption





*Alex Inkster
cup cake day*

funds for Cystic Fibrosis WA. Ben's ultimate aim is to extend and improve the quality of life for his son Joshua, as well as other people living with cystic fibrosis.

As part of his conditioning and fitness plan, Ben participated in the HBF Run for a Reason half marathon on the 24 May. Then on Sunday 5 July Ben ran the gruelling Gold Coast Marathon and smashed his fundraising goal of \$5,000 raising \$6,045.75 and still counting!



*Christina Posselt's
Sean the Sheep -
Cake Raffle*

65 ROSES CHALLENGE

The month of May is always a month when many from the CF community will do the 65 Roses Challenge. Whether it's a running challenge, a community challenge, a baking challenge or one of the many other challenges we've seen, thank you so very much to everyone who took part. And if you can't wait for May 2016 for your next challenge, you can always do the 65 Roses Challenge whenever it suits. Visit www.65roseswa.org.au to check it out.

The **Pingrup Community Centre**, **Kate Bishop** and **Mary Bock** put their talents together to hold a community fundraiser selling cupcakes, roses and various other goodies. The event raised a total of \$6,799.15, with the **Lions Club** contributing \$2,100 towards the overall amount. Thank you to everyone in the Pingrup community, a small town achieving big results.

Deidre Murphy raised an amazing \$1,136.00 for CF by holding a sausage sizzle, while **Joel Boy**, our 65 Roses Junior Ambassador, took on his own 65 Roses Challenge and raised an incredible \$844.75! Thanks Joel!



*Marmion PS -
How many Lollies*



Claire Ridley raised \$154.74 by placing collection tins in Karrinyup Shopping Centre and **Melissa Gibson** raised a total of \$326.50.

*The team at Exchange
Tower & Vault Fitness
doing their spin challenge*

Alex Inkster had a very busy month of May by participating in the HBF Run for a Reason and then selling cupcakes and other goodies to reach an impressive fundraising total of \$5,724.97!

Katherine White raised \$65.70 by shaking collection tins, while **Casey Shepherd** and her family held her annual Roses in the Park event and raised a total of \$3,425.

Kate and Paul Spaapen cooked up another storm this year by hosting four different dinner parties during the month of May, raising \$2,674.90. A great result!

Sue Williams and Janelle Realle teamed up to raise funds by selling chocolates and placing collection tins at their local Coffee Clubs and raised \$473.50.

Christina Posseltt approached Mitre 10 to hold a sausage sizzle at **Mitre 10 Northam**. Christina also baked a spectacular birthday cake which she raffled. The total for the day reached \$656.00.

The team at **Exchange Tower and Vault Fitness** sported a challenge of the fittest by setting a spin challenge. Together the team raised \$3,883.50.

Alisha Glenney and the team from Georgiou put their love of chocolates and roses to good use and raised a very sweet \$1,150.00!

And there were even more 65 Roses Challenges during the month of May.

Thanks to **Tim Strutt** for raising, \$31.50 and **Phyllis Byrne** for the amount of \$52.50. **Frances Stone** raised \$65.00 and **Denika Donnelly** raised \$25.00. **Café Boranup** raised an amount of \$31.50 and **Walter Van Praag** for raising, \$20. **Carina Needham** raised \$71, **Jade Keogh** for raising, \$592 and **Jaxon DeVos** who raised \$221.25. Thank you!

65 ROSES DAY COMMUNITY FUNDRAISERS IN ACTION

CFWA had a team of faithful community fundraisers making their presence known in their local communities on 65 Roses Day. You may have spotted them selling merchandise, roses, cooking sausage sizzles, baking cakes, holding raffles and doing various other activities to raise funds to improve the lives of people living with CF.



Make Sell Stall

This year the fundraising activities went from Broome to Esperance, Busseton to Kalgoorlie, Northam, York and Margaret River. Thanks so much to **Catherine North** who raised \$2,011.00, **Tammie Rafferty** for raising, \$1,685.65 and **Kelly Haynes** who raised \$2,235.00. **Cherie Bennie** raised the amount of \$905.30, **Melissa Campbell** raised \$1577.00 and **Rachael Chapman-Knapinski** for raising, \$652.35. **Carolyn Stokes** raised \$984.95, **Wilfred Lynch** for raising, \$325 and **Fabianne Brown** who raised \$2,000. We're so very grateful for your support!

COMMUNITY FUNDRAISING AT ITS BEST

A great big thank you for all the hard work, hours given and tireless support from our exceptional fundraisers. Thanks so much for your support, every dollar raised makes a real difference. And we always love to hear the stories about your fundraising adventures!

Echo Clothing and Jacqueline Hodson held a Fashion Parade and VIP night at the Echo Clothing Store in Busseton which raised \$450. A fantastic result for a fundraiser that was a last minute idea!

Peak Trampolines and Nikki Wood bounced up the grand amount of \$113.95 and **Lisa Hopkins** held a Bingo night, passed around the collection tin and raised \$445.75.

Maggie Di Re held her annual Garden Party for CF, raising \$1,678.75 and then went on to raise an additional \$649.00 for the 65 Roses Challenge.

Wendy Chatfield hosted a morning tea and raised \$160, while **Morning Anyur Atak** sold pre-loved clothing, raising a total of \$156.75. **Deanne Heeling** organised an office collection at **PTTE** which raised \$56.00 and **Catherine Staszewski** teamed up with **Celebrations Harvey and Metcalf** raising, \$371.00.

Krystal Burton wasn't put off by rainy weather and went ahead to hold a sausage sizzle at **Jetts Fitness** in Bassendean which raised \$220.

Tegan Mulcahy held a movie night with the proceeds going to CF. Tegan's movie night included popcorn plus a drink and raised a total of \$665.60.

THE RED RUN FOR CF

Ciara Taylor, \$4,980.50 and rising!

Ciara Taylor is a Year 10 student at Presbyterian Ladies' College and as part of the International Baccalaureate Program, students were required to complete a project as their final challenge for the Middle Years Program. Ciara decided that her personal project would be to organise a fun run to raise funds for Cystic Fibrosis WA.

Ciara has a family friend living with cystic fibrosis so she is extremely passionate about raising funds to support research into finding a cure. Understanding that exercise is extremely important for those living with CF, Ciara wanted to organise a fun run and name it The Red Run for CF.



Pre-Primary Art Auction

Frances Stone raised \$65.00, **Joseph Martino** raised \$105 and **Eureka Wu** and the **Northbridge Taxation Social Club** sent the collection tin around, raising \$73.00.

HBF RUN FOR A REASON

After months of training and preparation the HBF runners took to the streets to run to raise awareness and funds for CF.

Thank you to all the runners for your time and effort spent training and running. The voice you gave to our cause, your sweat, calories and kilometers, and of course, thank you for the \$33,631.81 funds you raised!

Thanks so much to all the fundraisers and donors who made a contribution to the grand total!

Here are their individual fundraising results:

Alex Inkster \$3,387.12, Alan Cooper \$2,023.50, Braden Gillespie \$1,749.50, Holly Edwards-Smith \$1,607.95, Marc Phegley-Giura \$1,554, Andrew Cuff \$1,274.90, Catherine Woods \$1,255.61, David and Kristy Wills \$1,243.40, Karl Tulloch \$1,178.50, Joanna Chalmers \$1,159, Ronnie Stewart \$1,058, Holly Sinnot \$904.45, Gordon Wallace \$865, Karen Cooke \$814, Cindy Louise Adams \$784.35, Mite Micevski \$710, Deonne Van Der Westhuizen \$600.75, Tammie Rafferty \$573.50, Matthew Docherty \$553.50, Jessica Anning \$536.55, Bianca Evans \$502.50, Sarah Anderson \$494.55, Gavin Domhahn \$387.75, Daniel McEntee \$365, Louise Woodhams \$387.50, Claire Nunes \$309, Raymie Kiernan \$350, Sara Rice \$306.50, Callee \$284, Emily Balcombe \$264.25, Natasha O'Sullivan \$237.64, Megan McNeil \$161.40, Kris Carvell \$200, Melissa Rowe \$120.75, Emer Davis \$104, Knobby Hunt \$62.50, Jonathan Petal \$59.80, Lykke Borup \$31.50, Bec Miller \$10.50.

Alex Inkster at the HBF Run for a Reason event



GREAT STRIDES CUNDERDIN

CF 65 Roses Day 2015

6.5 kms for 65 Roses

Lisa Carter, \$3,000 total raised!

On Sunday 31 May, the small community of Cunderdin came alive with runners who flocked from the surrounding region to participate in Great Strides Cunderdin – 6.5 kms for 65 Roses.

Lisa Carter and her team of trusty volunteers took on the challenge of organising the event, which was held in the heart of Cunderdin and attracted 101 runners. To add to the excitement, Lisa and the team also organised a Red Party in the Park, commencing directly after the run. The party featured a bouncy castle, face painting, sausage sizzle, raffles, lucky dips and an assortment of other fun filled activities.

65 KMS FOR 65 ROSES

Hunter Jackson, an endurance challenge!

Read about Hunter's endurance run of 65 kms and the inspiration for his challenge in the next edition of RED Magazine.

Have we omitted your fundraising efforts from RED? From time to time, we receive 'unknown' donations without any information. Please contact our fundraising team on 08 9346 7333 to make us aware of your contribution.



Golf Classic a Big Hit!

A little over five years ago the inaugural golf classic organising committee would not have anticipated the successes that were to be achieved by the fledgling fundraiser.

Since the golf classic appeared on the fundraising calendar in 2011 the fortunes of the event have rolled like the fairways of Lake Karrinyup. However the 2014 and 2015 events have produced a stunning financial result exceeding expectations with the net result topping \$107,000 for consecutive years.

"I'm very pleased to be the chairman of the organising committee, the people who serve the event are a truly committed and fantastic group of people", commented Brad Coutts. "As a parent of a child with cystic fibrosis it is very rewarding knowing that the work we do in fundraising assists the delivery of services and funds important life extending research".

Over \$470,000 has been generated from the prestigious Lake Karrinyup Country Club hosted event in its five year life. This would not have been possible without naming rights sponsor the George Jones Family Foundation. Philanthropic leadership demonstrated by the foundation has given the golf classic a solid footing from which to build the confidence of corporate supporters and the fundraising effort itself.

"With sustained effort using our well-developed model I'm sure we can still achieve our ten year target of raising \$1M", said Brad Coutts.

With almost a week of pre-event rain the sky opened up on the day of the golf classic to provide yet another perfect day for golfers to enjoy the premier course. A field of 33 teams enthusiastically embraced the

challenging layout of Lake Karrinyup Country club followed by pre-dinner refreshments, including an oyster shucking experience.

Proudly supported by Capel Vale, evening guests enjoyed pre dinner refreshments before host Steve Mills commenced proceedings introducing PhD scholar Luke Garratt who gave insight into the latest research work being undertaken to improve the lives of those living with cystic fibrosis.

Scott Draper gave a heartfelt and very emotional recount of his personal experience with cystic fibrosis. Marrying his then wife Kellie who had cystic fibrosis and managing the many challenges of being a pro tennis player on the world circuit, inspired the audience. His story moved all in the room prior to the live auction.

Master of ceremonies, Steve Mills, created a buzz of excitement with his energetic auctioneering skills attracting some wonderful bids for a 5 day Kimberley coral atoll cruise donated by North Star Cruises, Trip aboard Champagne Kiss fully catered by Domain Catering, Aaron Sandilands framed boot, Nathan Charles & Nick Cummins signed Western Force jersey, Giant Toblerone & Capel Vale Imperial Cab Sav and more!

Special thanks is extended to our gold, silver and iron package supporters. Without the valuable contribution made by each the success of the event would not have been possible. The logos of these supporters appear on this page and we look forward to seeing them again in 2016!



Score Card

WINNERS

1ST	Lighthouse Capital 2	Bernard Schortinghuis	Julia Schortinghuis	Scott Bruce	Mike Currie
2ND	MTM	Gary Kemp	Nick Ward	Matt Burton	Ian Grijsin
3RD	Seashells Hospitality	Gareth Thomas	Ken Torrance	Colin West	Cameron Knapton

NEAREST THE PINS

5TH	Colin West
8TH	Vin Ryan
12TH	Mick Keny
17TH	Duncan Wyatt
10TH	Matthew Burton
14TH	Glen Ticehurst

TARGET DRIVE

16TH	Nick Iustini
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LONGEST DRIVE (MEN)

3RD	Garry Kemp
16TH	Colin West

LONGEST DRIVE (LADIES)

3RD	Peta Roberts
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LONGEST PUTT

9TH	Wayne Burton
18TH	Jason Whiteman



Big Bounce Jumping Success!



Earlier this year CFWA launched its BIG BOUNCE campaign encouraging the community to support our fundraising efforts by hosting a “bounce-athon” or bounce party with friends, family, community, club or school.

For those that visited the Karrinyup shopping centre you would have seen national Big Bounce supporter Springfree displaying one of their larger products. Children passing by could have a bounce for a gold coin donation with proceeds totalling almost \$1,000 for the week.

Peak Trampoline Club based at Lords in Subiaco also raised over \$100 in support of the Big Bounce. National and state champion trampolinist, Abbie Watts who is based at the Peak facility provided local press with a great photo opportunity at Karrinyup to promote the fundraiser. Thanks also to Gymnastics WA which helped spread the word about the Big Bounce to all clubs in WA.

Whilst every contribution is appreciated the most impressive result, not only in WA but in the whole country, came from the wonderful town of Denham in the heart of Shark Bay.

With the whole community getting behind the bounce fundraising and with 19 children jumping in rotation for 12 hours a whopping \$12,592 was raised. This included ancillary fundraising such as the hotdog and drinks stall which fuelled the hungry and thirsty jumpers and supporters.

Thank you to all who participated and a very special thanks to the Oakley family and the town of Denham for a superb national result! And thanks also to Springfree, Karrinyup, Gymnastics WA, Peak Trampoline and everyone else who made the campaign such a success.



**KOTT
GUNNING**
LAWYERS

Deloitte.

Spring Rose Art Show Set to Blossom

Get set for another amazing Spring Rose Art Show headlined by exhibition feature Brendon Darby and supported by a selection of forty leading Western Australian artists.

Kindly supported by event sponsor Deloitte in the foyer of the prestigious 240 St Georges Terrace building, the exhibition will be open to the public from the 15th – 25th September.

This year we also welcome leading law firm Kott Gunning which have joined Deloitte in supporting the event by sponsoring the exhibition catalogue.

For further information contact Shelley Farrell on 9346 7339 or email fundraiser@cysticfibrosiswa.org

65 Roses 2015 – A Wonderful Result

It is difficult to believe a year has passed since May 2014 but we have just experienced another successful 65 Roses campaign!

With our own 65 Roses Challenge set to sell 6,500 roses, 1,200 more than in 2014, confidence in achieving the record number of sales through the invaluable support of our corporate and community supporters was high.

Following the humble beginnings of the WAFEX supported rose campaign a few short years ago when numbers totalled just 2,000, 65 Roses Day 2015 surpassed the 6,500 sales. Amazingly, over 8,000 cystic fibrosis roses were sold raising money and awareness for our cause.

This year the sales increase was in part fuelled by distribution and product diversification strategies including the facilitation of community based rose sales at local shopping centres and the extension of product offerings including corporate reception displays. Also for the first time we were able to negotiate the transport of roses to regional centres throughout WA extending from Broome to Kalgoorlie, York, Northam, Cunderdin, Pringrup, Busselton, Margaret River, Esperance and more with the kind assistance of TOLL.

The extension of the sale of roses into regional WA was a wonderful success and we owe a debt of gratitude to those community supporters that set up stalls, visited schools and town centres to make 65 Roses Day a state wide event! We look forward to many more of our country supporters joining the fun of 65 Roses Day 2016.

Armed with cystic fibrosis community human interest stories throughout May the media gave fantastic exposure calculated to be worth over \$1.2M in public relations value. From the north west to the great southern great stories featuring our 65 Roses activities helped raise awareness via the radio, television, online news and press.

Thanks is also extended to the many people who took up their own 65 Roses Challenges. Running, baking, hosting dinner parties, pedalling and holding movie nights were just a few of the many activities which supported the fundraising campaign.

Some of the top fundraisers included:-

Kate Bishop & the Pingrup Community Centre	\$6,799.15
Exchange Tower & Vault Fitness	\$3,883.50
Kate Spaapen	\$2,548.90
Hunter Jackson	\$1,354.10
LeeLee Schaeche-Odine	\$844.75

If you would like to know more about the sale of roses for 2016, how you can support that initiative or perhaps conduct your own 65 Roses Challenge, please call the marketing team on 9346 7333 or email marketing@cysticfibrosiswa.org

CF Diary



Please note these dates were correct at the time of printing but are subject to change

JULY

- 26** > Swan River Run
31 > Coffee Morning-Mandurah

AUGUST

- 15-16** > CF Conference Sydney: Lay Program
16-18 > CF Conference Sydney: Medical Program
29 > Red Tie Dinner Dance
30 > City to Surf

SEPTEMBER

- 1-30** > Serve It Up for CF
14-15 > Spring Rose Art Show
21 > Starting School with CF info night
25 > Coffee Morning-Scarborough

OCTOBER

- 8-9** > Siblings' & Offspring Camp
14 > CF Expo - Mental Health
17-18 > Telethon
20 > Starting School with CF Information Evening
25 > Great Strides

NOVEMBER

- 7** > Convicts for a Cause

Get Serving for CF!

Does your Restaurant Rule? Are you a Master Chef? Can you organise your own Restaurant Revolution?

In 2014 the Serve it Up for CF "host your own dinner party" fundraising concept kicked off with great success. Hosts invite and organise a dinner party for which guests can make a donation equal to the sum they might spend if they were to go to a restaurant.

For the second successive year Adam D'loia is hosting his very own Serve it Up for CF with a spit roast for 50 friends and relatives! "It's a lot of fun" said Adam, "I'm really looking forward to hosting the event this year, it's going to be bigger and better than last year".

With the support of CFWA marketing material, online fundraising pages, invites, posters and more the task of assisting the cause with your own fundraiser is much easier. And we have a few incentives for the hosts thanks to our supporter, Menu Magazine.

For more information why contact Shelley via email fundraisier@cysticfibrosiswa.org or on 9346 7339.



**NATL
BREWING
AUSTRALIA**

HOUGHTON
WESTERN AUSTRALIA



**FERAL
BREWING
-COMPANY-**

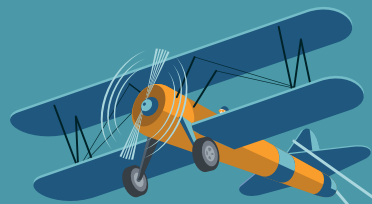
MATSO'S
BROOME BREWERY

**NORTHSIDE
BOOKS**

**TORRE
BUTCHERS**

ADRIATIC BUTCHERS

HARRISON STREET BALCATTA



FSC Power Section Proudly Presents
RED TIE DINNER DANCE
for Cystic Fibrosis WA

SATURDAY 29TH AUGUST 2015

VENUE: FREMANTLE SAILING CLUB WARDROOM
TIME: PRE DINNER DRINKS 7PM, SIT DOWN 7:30PM
THEME: RED TIE
PRICE: \$ 95 PP, 3 COURSE MEAL, BEER & WINE PLUS CASH BAR
ENQUIRES: FREMANTLE SAILING CLUB 9435 8800



PEMBERLEY



Proudly Supporting
CYSTIC FIBROSIS
Western Australia



THE CAPEL VALE
CONQUER
CYSTIC FIBROSIS
GRAND BALL 2015

Saturday 12 September 2015, 7pm – 1am
BelleVue Ballroom, Perth Convention and Exhibition Centre.

Master of Ceremonies:
Lachy Reid, plus live entertainment....

For further details: www.conquercysticfibrosis.com or Email: info@conquercysticfibrosis.com

Proudly supported by:



Will You Paint a **RED** Rose for CF?



Deloitte Spring Rose Art Show

Woodside Plaza, Perth CBD

14th - 25th September 2015

The Deloitte Spring Rose Art Show is a major fundraiser for Cystic Fibrosis WA and a well-established event on the art scene.

CFWA members affected by cystic fibrosis are invited to have their work displayed alongside nationally renowned artists by painting a red rose on a canvas we provide. Both children and adults are welcome to take part.

If you'd like to contribute, please contact Shelley at events@cysticfibroiswa.org or 08 9346 7339.



Deloitte.

