

EDITION 4 2017

RED



IN THIS ISSUE

**RESEARCH IN
CYSTIC FIBROSIS**

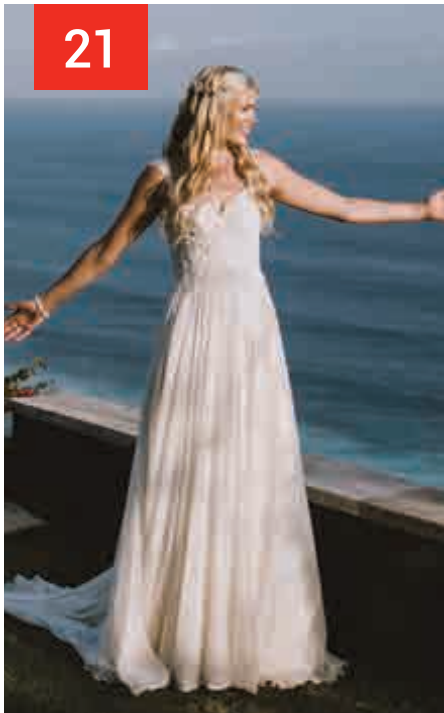
CONTENTS

05

12th AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

12th Australasian Cystic Fibrosis Conference

21



Sophie's Perspective
on Research and Life

12



Clinical Trials and Studies in Australia;
Could it be an Option for You?

29



Fundraising
News

FEATURES

- PAGE03: CEO Message
- PAGE04: Changes in Leadership at Cystic Fibrosis WA
- PAGE06: Positive Outlook from CF Foundation President Preston Campbell III
- PAGE07: There Is No Health Without Mental Health
New Cystic Fibrosis Nutrition Guidelines Released
- PAGE08: Getting Motivated
- PAGE09: Cystic Fibrosis and Pregnancy
- PAGE10: Upcoming New Guidelines for Healthcare Workers with Cystic Fibrosis
- PAGE11: Lauren Rowe: Making Chronic Illness Sexy Since 1990
Quilts Made With Care
- PAGE13: A Brighter Future
- PAGE14: Orkambi Comes at a High Price
- PAGE16: Extending Lives Through Research
Shellabears Cares
- PAGE17: Carers Week
2017 Carers' Dinner
- PAGE18: Infection Control at Princess Margaret and Sir Charles Gairdner Hospitals
- PAGE19: It's War! And the Arms Race is On
- PAGE20: Big Data, Bioinformatics and Cystic Fibrosis
- PAGE22: Brendon Talks About Telehealth
New Resource on the Latest Cystic Fibrosis Knowledge
- PAGE23: Cystic Fibrosis WA Gear Up for the 2017 Telethon
- PAGE25: Red Tie Dinner Dance 2017
- PAGE26: Cystic Fibrosis WA Partner with Swim and Survive
We're off to our Annual Sibling and Offspring Camp
- PAGE27: New Trampolines Thanks to Allens
- PAGE28: Spreading the Word About Cystic Fibrosis in the Community
- PAGE30: Community Champions Get Active for Cystic Fibrosis
- PAGE31: It Takes a Community to Care for CF
Cystic Fibrosis WA Christmas Office Hours



LIKE US ON FACEBOOK
FACEBOOK.COM/CYSTICFIBROSISWA



STAY INFORMED
TWITTER.COM/CYSTICFIBROSISWA

RED CEO MESSAGE

This edition of RED magazine looks at the latest research in cystic fibrosis (CF), and particularly, the issues emerging from the 12th Australasian CF Conference held in Melbourne in August 2017.



NIGEL BARKER, CEO

One of the keynote speakers at the conference was Preston Campbell III, the President and CEO of the CF Foundation in the USA. Never before have I witnessed such an inspiring and uplifting speaker. His message was one of hope for the future and is summarised in this edition of RED. Clearly, we are moving faster than any of us would have dared

hoped toward our vision of 'Lives Unaffected by CF'.

Whilst the CF Foundation is providing some serious financial resources to the drug development pipeline, it's also helping to address some of the cross-infection and mental health challenges we face.

But it's not all about the USA. Here in Australia we continue to punch well above our weight, particularly in the area of paediatric CF research - thanks largely to the AREST CF team led out of the Telethon Kids Institute - and building on the research which has been undertaken in other fields such as Duchene Muscular Dystrophy.

We were also able to launch two more PhD Top Up Scholarships for researchers right here in WA.

At the close of the conference in Melbourne, I was very excited to hear that Perth has won the opportunity to host the 13th

Australasian CF Conference in 2019. We don't have a date yet, but as they say on TV, stay tuned for further details.

We will certainly be looking for volunteers to help out and be part of the conference which is sure to attract speakers from all over the world. We will also be looking at ways of maximising the opportunities for participation amongst our members, without breaching the all-important cross-infection protocols, and help shape the lay component which has been such a unique hallmark of the CF conferences in the past.

Perth is a centre of excellence for CF research and I for one can't wait to showcase it!

All this and more in this exciting edition of RED magazine.

Nigel Barker
CEO

DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our summer issue, please contact us before 1 December 2017

DO WE HAVE YOUR CORRECT DETAILS?

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

DESIGN BY

Catherine Fisher
The Pixelfish Designs

SPONSORED BY

Community Newspaper Group
PRINTED BY Picton Press

ON THE COVER

Telethon Kids Institute Researchers
Tim Rosenow and Emma DeJong

CONTACT US

Cystic Fibrosis Western Australia
PO Box 959, Nedlands WA 6909
08 6457 7333

info@cfwa.org.au

www.cysticfibrosis.org.au/wa/

Subscribe to our e-newsletter online

www.cysticfibrosis.org.au/wa

DISCLAIMER: This magazine is edited and produced for Cystic Fibrosis Western Australia. Articles or advertisements in this publication do not necessarily reflect the views of the editor or those of Cystic Fibrosis WA.

CFA UPDATE: ANN MAREE BOSCH FELLOWSHIP APPLICATIONS NOW OPEN

It is now 18 months since Ann Maree Bosch lost her battle with leukemia. In her honour, and as a tribute to all that she did for the cystic fibrosis (CF) community over more than 10 years, Cystic Fibrosis Australia (CFA) is once again funding the Ann Maree Bosch Career Fellowship up to the amount of \$10,000.

CFA is calling for applications for the 2018 Ann Maree Bosch Career Fellowship grant for early career scientists working in CF research, and the grant will be awarded to one applicant.

The aim of the Fellowship is to facilitate CF researchers learning new techniques and establishing research collaborations. The Fellowship will be offered to a post-graduate student nearing completion of their PhD and to recently graduated (up to 2 years) postdoctoral researchers.

The Ann Maree Bosch Career Fellowship will enable early career scientists to travel to a laboratory in an interstate or overseas institution, such as a university or research establishment, of international standing in the field of CF research.

The recipient of the Fellowship will be able to visit and/or conduct research at the institution and may also have the opportunity to attend an appropriate conference as part of the award.

The recipient of the Ann Maree Bosch Career Fellowship will be required to provide a report to CFA on their use of the award. In addition, and where appropriate, the recipient will be asked to make a presentation at the bi-annual Australasian Cystic Fibrosis Conference.

The maximum amount awarded will be \$10,000 per annum. The actual amount provided will be subject to approval of the applicant's budget. Funding will commence in 2018.

The Governor General, at CFA's Patron Awards on 20 November 2017, will award the grant to the successful recipient.

Please let your community and colleagues know that the Ann Maree Bosch Career Fellowship is now open and applications close 18 October 2017.

For more information and to download the application form: <http://www.cysticfibrosis.org.au/scholarship>

To make a donation to the Ann Maree

Bosch Career Fellowship: <https://donate.grassrootz.com/cysticfibrosis/ann-maree-bosch-scholarship-2017>

Yours sincerely
Nettie Burke
CEO



CHANGES IN LEADERSHIP AT CYSTIC FIBROSIS WA

As an incorporated association, Cystic Fibrosis WA (CFWA) is indebted to a voluntary board of directors who consistently provide leadership and governance to help guide our organisation ever closer to our vision of 'Lives Unaffected by CF'.

Their contribution is often hidden below the line of visibility, but over the last forty years, their leadership has played a pivotal role in transforming CFWA from a small volunteer-based organisation, into a professionally run, incorporated association; an association which delivers

the widest range of services of any cystic fibrosis (CF) association across Australia.

The constitution of CFWA (the rules by which our association operates) allows for seven directors to be elected at the Annual General Meeting (AGM) by the members.

In addition to these elected members, the board can co-opt up to three members at any time during the year to balance the diverse range of expertise required to properly govern the association.

This year, we have said farewell to two



outgoing board members, Jackie Ormsby and Andrew Walsh, and welcomed Tim Sharp and Simon Trevisan.

Jackie Ormsby was first co-opted to the board of CFWA in July 2009 and subsequently elected at the March 2010 AGM. She was elected as Vice President in 2011 and served as President of CFWA in 2012 and 2013, retiring from the board in April this year.

Jackie was a registered psychologist who brought a wide range of skills and leadership to the board during her tenure. This included extensive experience in policy development in the areas of health, culture and the arts and work in the state's rural and remote areas. She was part of the team that investigated attitudes to community-wide screening for CF led by the Department of Population and Health

Genomics. Jackie will be sorely missed but we wish her all the very best in her retirement to her farm in Denmark.

Andrew Walsh joined the board of CFWA in April 2013 and immediately took on the role of Treasurer from Richard Simons. Andrew's strong financial background as CFO at NRW Holdings Ltd, a publicly listed company, took financial reporting and analysis to a whole new level for CFWA. This was publicly commented upon when CFWA won the inaugural Charity Category Award for the Telstra Business Awards in 2016.

Andrew's legacy lives on in the reporting framework that is used to present monthly figures to the board and brings a level of transparency and accountability which is regarded as world's best practice in the sector.

As Treasurer, Andrew was constitutionally restricted to serving two consecutive terms of two years. We wish him all the very best in his future endeavours and will particularly miss his razor-sharp mind and ability to interpret seemingly complex accounts to cut straight to the chase. Current board members include: President Richard Simons, Vice President Carolyn Boyd, Treasurer Simon Martin, Past President Feliciano Sanchez, Rachael Hosking, Ken See, Simon Trevisan and Tim Sharp.

If you would like to find out more, please call Nigel Barker CEO on 08 6457 7333 or email ceo@cfwa.org.au.

2017 12TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

Some members of the Cystic Fibrosis WA (CFWA) team were lucky enough to travel to Melbourne to attend the 12th Australasian Cystic Fibrosis Conference (ACFC) to hear the latest in research, treatment and care of those living with cystic fibrosis (CF).

"Optimism, Opportunities and Outcomes" was the theme, and as you will hear, there is certainly much to be celebrated.

In this edition of RED, we will share some of the outstanding findings from the conference.

For more information about the conference and to watch the presentations, go to www.cflivesmatters.org.au/ Consumer-Connect.

POSITIVE OUTLOOK FROM CF FOUNDATION PRESIDENT DR PRESTON CAMPBELL III



Dr Preston Campbell III is the President and CEO of the CF Foundation (CFF) in the USA. With an auspicious sounding name, Dr Campbell did not disappoint with his opening keynote address to both the lay and medical attendees.

The conference theme was “Optimism. Opportunities. Outcomes”, and using ten key points, Dr Campbell explained how everyone in the worldwide cystic fibrosis (CF) community should be optimistic for the future.

1. There is no community like CF

- We are worldwide, uniquely collaborative and committed
- Includes patients, families, care teams, scientists and industry partners
- All focused on finding a cure and their dedication should never be underestimated

2. CF care continues to improve

- Although we have already come a long way, it has only just started
- Care is guided by evidence-based best practice and increased data allows continuous improvement in quality of care
- Patients are now more involved than ever in co-managing their care
- Technological advancements have the potential to radically improve care, case management and therapies

3. Scientific advances continue

- ‘Money buys science and science buys lives’ (phrase coined by Richard Mattingly, an ex-CFF employee)
- In 1980, CFF financially committed to 10 research development projects, and within 10 years the defect in CF was identified as a defective chloride channel and the CF gene was cloned
- This paved the way to transition from an era of care in the 1960s, to research advances in the 1980s, to ground breaking therapeutic developments in the 1990s

4. The pace of drug discovery and development is accelerating

	2012	2016
US CFF Medical Awards budget	\$87m	\$181m (\$35m internationally including \$8m to Australia)
US Grants Issued	500	1700
Clinical Trials	28	56
Subjects Enrolled	1000	1800

- In 1988, it was unusual to talk to any company about CF research
- In 2016, CFF met with 130 companies about potential opportunities

Industry Sponsored Projects

Note: CFTR= Cystic Fibrosis Transmembrane Conductance Regulator

Therapeutic Area	Active Companies 2016	Funded Programs
Anti-infective	43	7
Inflammation	17	4
CFTR Modulation	13	6
CFTR Nonsense and Restoration	13	6
Mucociliary Clearance	15	5
Gene Editing	8	3
Gene Delivery	6	2
Nutrition	3	2
Total	118	35

- CFF involved in 50 clinical trials in 2017
- Pace is accelerating; things are happening now

5. CFTR modulator development is very exciting

- In 3-4 years, we expect 95% of patients to be on modulators that give them efficacy at or above levels seen with Kalydeco® in

patients with G551D.

6. The therapeutic drug pipeline holds more promising symptomatic therapies than ever before

- Scientific research accelerating in antibiotics, anti-inflammatory, mucus altering agents, anti-microbials

7. There is a strong commitment to make sure no one is left behind

- A commitment to ensure that everyone with CF will be able to access a therapy suitable to them
- Geography should not limit anyone with CF to receive therapies

8. The CFF is now focused on improving lung transplant outcomes

- Collaboration with US and Canadian centres to improve transition, best practice, best therapies and anti-rejection treatment

9. Individuals with CF and their families are creating incredible new programs for others with CF

- The voice of people with CF has never been stronger
- Potential for them to have an impact has never been greater

10. Gene editing advances now allow us the opportunities to focus on a cure

- long-term goal
- Unknown 5 years ago
- Perhaps most exciting science in the world
- Will one day allow people to be cured

“It’s a dream. Are we crazy to do this? I think we’d be crazy not to try.”

In conclusion, Dr Campbell challenged all those attending to work harder, go faster, stay together and finish the story for 100% of people with CF.

Presented by Preston Campbell III, President of CFF.



THERE IS NO HEALTH WITHOUT MENTAL HEALTH!

Dr Alexandra Quittner, PhD from the Miami Children's Research Institute in Florida, USA, presented the findings from her TIDES (The International Depression/Anxiety Epidemiological Study) at the conference.

Dr Quittner has been researching mental health in the American cystic fibrosis (CF) community for over 28 years. She is the lead researcher of TIDES, looking at anxiety and depression in CF. TIDES looked at data from 12,000 participants (CF adolescents 12yrs+, CF adults, and both male and female caregivers of CF children aged 0-18) and took over 9 years to complete.

Data from the TIDES study show:

- **A high prevalence of anxiety and depression in people with CF and caregivers.**
- 2-3 times higher than the general population
- 10% of adolescents, 19% of adults, 31% of male care givers and 37% of female care givers had elevated scores

- **Mental health has a direct link to adherence and health outcomes.**

- New evidence is showing that depression, independent of disease, has a direct correlation to inflammation
- Increased levels of anxiety and depression lead to a drop-in adherence to medications (including enzyme replacement) and airway clearance regimes to around 50%, and possibly lower for adolescents
- Reduced adherence affects health outcomes (increased exacerbations, decreased lung function, drop in weight)
- Decrease in quality of life
- **Direct link between parent-adolescent symptoms.**
- Adolescents were 4-5 times more likely to have elevated levels of anxiety or depression if one of their parents also had elevated levels

- **What is the outcome of this research:**

A set of international guidelines has been developed to provide consistent screening tools for people with CF and their caregivers. If the assessment indicates elevations in anxiety and/or depression, then a referral can be made to access counselling and support.

Implementation has already begun in the USA and Europe, and preliminary findings after the first-year show:

- Increased awareness and identification of mental health issues in the CF community
- A standardisation of worldwide data so that everyone is using the same measuring tools to assess anxiety and mental health
- By screening everyone there is reduced stigma in the community

Presented by Prof Alexander Quittner, Professor of Psychology and Paediatrics, University of Miami, USA.

NEW CYSTIC FIBROSIS NUTRITION GUIDELINES RELEASED

The latest 'Nutrition Guidelines for Cystic Fibrosis in Australia and New Zealand 2017' were released at the 12th Australasian Cystic Fibrosis Conference. They were developed and written by dietitians experienced in the field of cystic fibrosis (CF), including:

- Dietitians Association of Australia (DAA)
- Dietitians New Zealand (DNZ)
- Cystic Fibrosis Australia (CFA)
- Cystic Fibrosis Association of New Zealand (CFANZ)

The guidelines include information on:

- The role of nutrition in CF care
- Service delivery
- Nutrition assessment

- Nutrition interventions
- Macronutrients
- Fat soluble vitamins
- Minerals
- Pancreatic insufficiency and Pancreatic Enzyme Replacement Therapy
- Gastrointestinal and hepatobiliary considerations
- Cystic Fibrosis Related Diabetes
- Bone health
- Pregnancy
- Complementary therapies
- Lung transplant and more

How to find them:

The primary custodian of the

'Nutrition Guidelines for Cystic Fibrosis in Australia and New Zealand Project' is the Thoracic Society of Australia and New Zealand (TSANZ).

Search www.thoracic.org.au then tab clinical documents/current issue/cystic fibrosis. www.thoracic.org.au/journal-publishing/?command=record&id=46&cid=13





GETTING MOTIVATED

Adherence, or lack of, is often talked about. Research indicates that many of us struggle to stay on track with complex treatment regimes, sometimes feeling overwhelmed and discouraged.

We know that if we took all the prescribed medications and regularly did physio we would be much healthier and probably have less hospitalisations. So why don't we do it?

Some reasons for non-adherence include:

- Avoidance of uncomfortable emotions
- Other priorities
- Avoiding failure
- Being "normal"

'Greater acceptance leads to greater adherence' (Moitra, Herbert & Forman, 2011)

Acceptance of uncomfortable feelings and emotions is an internal experience where people are willing to experience difficult and aversive emotions. How comfortable are you to talk with friends, family and colleagues about having CF and some of the difficult things you experience through having CF e.g. treatments, fatigue and worry. It's normal to want to avoid uncomfortable or difficult emotions which CF and its treatment may trigger, however, avoidance can lead to anxiety, and in some cases, depression, and as we know, this often correlates to poor adherence.

Some people state they have other priorities

- "I don't have enough time"
- "I run out of time"
- "I forget when I'm busy"
- "I don't have time before work"

People can feel pressure to stay on track

with their treatment and struggle to get into a good routine or, if in a routine, to remain consistent with the routine. Some people feel a sense of failure around this and may even feel overwhelmed. These are common strategies to avoid feeling failure.

- Procrastination = avoidance
- Start – stop = repeated failure
- Perfectionism

It's important to look at our values and have a positive expectancy that we can manage treatment, however it's also important to admit when we might need some help. Sometimes we procrastinate because it seems too hard, too much to do or we don't understand why we need to do it. Writing down treatment plans and asking questions of your treatment team can really help with this.

Remaining consistent with routines can require a structured plan which may seem easy when feeling well and life is good, however many people struggle with this if struggling with their mood or other life circumstances. People may feel repeated failure with constantly "falling off track". If this is you, you're not alone; it can be a struggle. Building confidence on the things that you do well is a good place to start.

Begin to notice how you think about CF, its treatments and how it affects you. Make an evaluation of what you can possibly do better. You may need help to work on what is most important for you and some strategies to develop a plan or goals.

Perfectionism is also often unattainable and can similarly leave us feeling like we're failing. Give yourself a break; self-care is important and don't beat yourself up if you occasionally miss out on part of your treatment plan.

If you're able to explore the function of non-adherence you may have more clarity around the things that get in the way.

The therapeutic goal is to improve willingness to cope with the aversive internal experiences that the disease and treatment generates. Some people become inflexible in thinking about their CF which boxes them into a way of doing things or not doing things. Some examples:

- "I'm going to be fine"
- "I don't need treatment"
- "I'm too sick"
- "I can't do things that others can"

It's important that you collaborate with your team, including the social worker, and be honest about your struggles to do treatment; they've heard it all before and they may be able to help you work through some issues and help you keep on track with your treatment.

CFWA may also be to assist with general support, motivation or referral. Please contact Kathryn for further information servicesmanager@cfwa.org.au

Presented by Jennifer Kemp, Clinical Psychologist, Cystic Fibrosis Statewide Service, Royal Adelaide Hospital, SA.



CYSTIC FIBROSIS AND PREGNANCY

Nowadays, young women with cystic fibrosis (CF) are showing more interest in having children.

Getting pregnant is very exciting, however for women living with CF, special attention is needed to best prepare them to optimise their gestation time so that both the mother and her baby are healthy.

As stated by Annie Kroushev, doctor in Obstetrics and Gynaecology at Monash Health in Melbourne, a pre-pregnancy visit is highly recommended to:

- Discuss the potential challenges for pregnancy
- Discuss prognosis of pregnancy
- Arrange genetic testing of partner and offer counselling
- Provide information on the importance of good nutrition, stable lung disease and diabetic screening and control
- Discuss possible adjustment to medications while stressing the importance of treatment compliance
- Emphasise physiotherapy regime

Following the visit, if a pregnancy is to go ahead, a multidisciplinary health approach between the CF specialist unit, the Obstetric

Unit and Tertiary Labour ward will be put in place.

What to Expect During the Pregnancy?

- (While most of the CF medications are safe) a change in treatment regime and the inclusion of pre-natal vitamins/folate.
- A weight gain of 0.5 to 2kg in the first term is a must and nausea is to be actively managed. In the second and third term weight gain should be 0.5 kg per week. Additional nutritional supplements are often needed.
- (If there is no pre-pregnancy CF related diabetes), Gestational Diabetes in CF is a high risk. Diligent screenings are conducted at the onset of pregnancy, at 12-16 weeks and 24-28 weeks, and if needed, personalised treatment and education given accordingly.
- Pulmonary monitoring, reviewing FEV₁, trends and frequency of exacerbations, sputum microbiology for optimum preventative therapy and prompt treatment in time of acute exacerbation.

What about the delivery?

- Labour and delivery are usually not a problem.
- Vaginal delivery is the preferred option.
- To take pulmonary medications and monitoring of O₂ saturation.
- Epidural for pain control is offered.
- Immediate post-delivery pain control to promote coughing.

In conclusion

- Many women with CF wish to have the option of having children.
- Pregnancy does not have a negative impact on CF prognosis, however there is a higher risk of gestational diabetes than in the overall population.
- There is an increased health care utilisation during pregnancy and in following years.

Good outcomes are possible with collaborative interdisciplinary relationships and communicating effectively with the woman living with CF.



UPCOMING NEW GUIDELINES FOR HEALTHCARE WORKERS WITH CYSTIC FIBROSIS

New guidelines for inspiring individuals living with cystic fibrosis (CF) to join the healthcare professions are soon to be released.

In response to a growing number of people with CF pursuing careers in health care (currently 7% in Australia), and a lack of guidance as how to safely manage training and the workplace environment, the Royal Australasian College of Physicians commissioned a working group in 2012 to prepare a position paper for healthcare workers with CF (HCWCF). The multidisciplinary working group included expertise in adult and paediatric CF care, infectious diseases, infection prevention and control, ethics and consumers who were HCWCF and currently in training. Appraisal of the evidence of risk both for the HCWCF, the patients they care for and the staff they work alongside was undertaken.

The aims of the guidelines are to:

- Help protect both the patients and the HCWCF from infection
- Facilitate dialogue between HCWCF, CF clinicians and employers regarding risks of infection to and from HCWCF
- Help protect HCWCF from discrimination in the workplace
- Allow HCWCF to navigate training and work without too much disruption

Infection prevention and control is a major feature of the guidelines.

The framework provides ways to navigate work/training whilst minimising risk of infection for both the HCWCF and the patients. The guidelines highlight that:

- HCWCF is accountable for his/her own health
- HCWCF is responsible in managing their own physio/hospitalisations
- HCWCF is responsible and accountable for self-protection and protecting their patients and colleagues, i.e. use of Personal Protective Equipment and Hand Hygiene.

Tips for HCW/trainees with CF:

- Decide level of disclosure – who to tell and when
- Contact employee liaison
- Know the risks of infection to you and your patients
- Take personal responsibility for own health and your patients health
- Any issues – talk to your CF team, your supervisors/health services

Rebekah Divakaran, an anatomical pathology registrar living with CF, says that:

- “Being a HCWCF is challenging but worth it”
- “Having the guidelines gives a framework to work around, but also encourages personal responsibility”
- “Clinical work isn’t the only branch of medicine – it is good to explore all options...”

So, if you are thinking of becoming a health professional and/or you know someone who may be interested please check our next RED magazine for an update on how to access the new guidelines for Healthcare Workers with Cystic Fibrosis*.

*The guidelines are currently in the process of peer review.

Presented by:

Rebekah Divakaran, Anatomical Pathology Registrar, Dorevitch Pathology, Ballarat VIC.

Rhonda Stuart, Infectious Diseases Physician, Medical Director of Infection Prevention & Control, Monash Health, VIC.



LAUREN ROWE: “MAKING CHRONIC ILLNESS SEXY SINCE 1990”

Delegates at the lay conference were treated to a moving opening address from keynote speaker, Lauren Rowe, who is a 27-year-old adult with cystic fibrosis (CF) who refuses to be invisible.

In 2016, Lauren, who lives in New South Wales (NSW), won the People's Choice Awards for Women's Weekly "Women of the Future" competition, for her dedication to a not-for-profit organisation she started up: "Gifted Life". The aim of the organisation is to raise awareness of organ donation and support people under 30 years of age who have had transplants.

At age 19, Lauren had a double lung transplant, and so she knows full well what the experience is like and how it can affect a person, both physically and mentally.

In her speech at the conference, Lauren posed the following question about people with CF: "Why are they worth fighting for?", and explained that health care workers should consider this question and ask the 'why' before the 'how', when treating people

with CF.

Lauren discussed how she found her high school years particularly difficult, but it wasn't the treatments or hospitalisations that she found the hardest, it was the feeling of being isolated, invisible and disconnected from her peers. Lauren said that what got her through high school was her gymnastics training, where she was able to excel.

Lauren's idol from the age of 11 was the character Satine, played by Nicole Kidman, in the film *Moulin Rouge*. Satine was a courtesan who was very glamorous, however, had a bad cough as a result of suffering from tuberculosis. Seeing such a strong character on the big screen, who was unwell but so glitzy, made Lauren feel less alone and even inspired her to pursue acting.

Lauren completed an Advanced Diploma

of Acting, but due to poor health and her lungs facing rejection, she hasn't been able to pursue an acting career. Instead, she has put her acting skills to great use in becoming a CF vlogger, with her own YouTube channel, www.youtube.com/c/giftedlife. Lauren's videos wittily and candidly address various aspects of living with CF.

It was so insightful to hear Lauren speak about her experiences and to appreciate how her strength, humour and determination have enabled her to spread awareness around the world about CF, chronic illness and organ donation, and doing it all with her own style and glamour.

Presented by: Lauren Rowe, adult with CF and 2016 Australian Women's Weekly "Women of the Future" People's Choice Award Winner.

QUILTS MADE WITH CARE

Cystic Fibrosis WA (CFWA) has many special supporters who use their talents and passions to help make a difference to the families that are affected by cystic fibrosis (CF) here in WA.

Over the years, quilting groups and individuals all around our state have used their skills to craft beautiful, unique quilts for newly diagnosed babies and children with CF. Newborns who are diagnosed with CF are gifted a handcrafted quilt as part of CFWA's newly diagnosed program.

The wonderful people to thank for these quilts belong to our quilting community: The Sue Bates Angel Quilters, Sandra Barton, Mary McAuliffe, Denise Hopkins, Lori Baker and Lin Maddy have all been

supporting CFWA for many years by donating dozens of custom-made quilts.

Another group of quilters from Esperance, called the Grass Patch Patchers, raised over \$3,500 for CFWA this year by crafting and raffling off a queen sized '65 Roses' quilt valued at \$2,000.

We are often told by our families that the quilts they receive are loved and treasured for many years. On behalf of all our families and CFWA, thank you!



Mary McAuliffe, Sandra Barton and Denise Hopkins making a quilt for CFWA

Lin (middle) presenting CFWA with newly donated kids quilts

CLINICAL TRIALS AND STUDIES IN AUSTRALIA; COULD IT BE AN OPTION FOR YOU?

Clinical trials and studies are major contributors in cystic fibrosis (CF) research and treatment development. Nowadays there are many opportunities to participate, however what should you consider before you or your child get involved?

Clinical trials, also referred to as Interventional Clinical Studies, apply specifically to testing a treatment method. It can range from a potential drug to a treatment or even an exercise study. Participants receive one or more treatments (interventions), or a placebo, so researchers can evaluate the effects on the participant's health.

The interest in Adaptive Clinical Trials, that evaluates a medical device or treatment by observing participants outcomes on a prescribed schedule, is an approach of interest to clinical trial in Australia. These adaptive designs reflect very much on our client/personalised centred-care, where the parameters of the trial protocol can be modified in accordance of the observations made on the participants. However, for this flexibility to redesign clinical trials at interim stages, the trial protocol is set before the trial begins.

Overall, the aim of an Adaptive Clinical Trial is to move more quickly, identify drugs or devices that have a therapeutic effect, and to zero in on patient populations for whom the drug is appropriate. A key modification is to adjust dosing levels, which in traditional clinical trials, were not considered until a trial was completed. So, let's watch the space to follow on Adaptive Clinical Trials becoming available in Australia.

Other studies called Observational Clinical Studies that are not to test potential treatments are also available. During these studies, researchers keep a close eye on participants throughout their current treatment plan and track health outcomes. These observational studies are used to develop new ideas about CF and how the disease might best be treated.

Under these two types of clinical studies there are many sub-types. For example, behavioural studies, where researchers try to identify and understand how factors such



as self-management, mental health and social support are associated with health outcomes.

All clinical trials and studies have a specific sponsor and they all follow an explicit regimented protocol that encompasses signing the informed consent form, the process of joining a clinical trial after meeting all criteria, and following all necessary steps to the project's conclusion.

Participating in a clinical study is a personal choice.

Some of the benefits include:

- Taking an active role in managing your own CF, or that of your child
- Gaining access to new treatments before they are more widely available
- Helping advance our knowledge of CF

Some possible risks include:

- Side effects of the studied medications or treatments
- Unwanted events during the trial
- Failure of a treatment to work

Prior to the trial you will be supplied with a patient/consumer information form that will clearly explain the aims and the

requirements of the trial. Remember that by signing an Informed Consent Document you are not signing any form of contract and you can leave the study or trial at any time. In turn, those who are monitoring the trial, such as the principal trial investigator or the study medical monitor, can withdraw you from the study if they believe your health is at risk.

Finding a clinical study and staying informed:

If you would like to participate in a clinical trial, talk to your CF care team. Your CF doctor can help you find trials you or your child might be eligible for. If there are no current studies at your CF centre, a referral can possibly be made for you to participate in a study at another CF centre.

If you want to be notified when a new CF trial is posted, you can sign up by sending Cystic Fibrosis Australia an email, and alerts will be sent directly to you when new trials are posted or when results from a trial are released.

For more information go to:
www.cflivesmatters.org.au
www.cflivesmatters.org.au/Clinical-Trials-Finder

A BRIGHTER FUTURE!

The decision to join a clinical trial is an individual and personal one. Benefits and risks of participating, as well as the time commitment required, must be considered. For the Donaldson family, this decision has been a positive one.

You may remember the Donaldson family and their two daughters, Isobel and Ruby, who have cystic fibrosis (CF) and who created their own fundraising campaign during Easter of 2016. Entitled 'Crack A Cure', this community fundraiser stretched across the nation, not only raising considerable funds for future research and service provision, but creating awareness with each Facebook post.

It is with this drive and enthusiasm that the family tackle life with CF. Recently we had the great pleasure of interviewing Isobel, almost 12, Ruby, 9, and mum, Christine, to gain some insight into their experience participating in a clinical trial.

RED: Please explain your main reasons for participating in a clinical trial.

For Christine and her husband, Gerard, participating in a clinical trial had always been a big part of their journey. With both girls being involved in the AREST CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis) program from diagnosis, the benefits of being on a trial rang loud and clear. Not only did it provide invaluable information in regards to the girls' health status and management, but it was contributing to future research and treatments. From this time, Christine and Gerard made it known to the CF team that they would be happy for the girls to be considered for future trials.

Isobel and Ruby have been involved in a few trials over the years. Christine stated that she is comforted in knowing that by the time clinical trials come to Australia, they have already had outcomes in other centres across the world and safety standards have been clearly established and tested. Another important factor considered is that the clinical trial is not too invasive.



RED: What clinical trial are the girls currently on and how did you go about joining this trial?

Isobel and Ruby are part of a study involving the drug Orkambi® for people with CF homozygous F508del-CFTR mutation. As mentioned earlier, we made it quite clear to the girls' CF team that we were interested in being involved in trials. We also made the message clear to the staff at the Telethon Kids Institute (TKI) as not only would it assist with research, but hopefully, the girls would access new treatments before they were readily available.

RED: Please explain the selection process.

Our CF team and members of the team at TKI identified the girls as a possibility to be selected for the Orkambi® drug trial as they appeared to fit the strict selection criteria. With this, and being aware of our interest to participate in clinical trials, they gave us a call. From here, the girls were brought in to the Children's Clinical Research Facility (CCRF) at Princess Margaret Hospital (PMH) for further assessment to clearly identify if they qualified to be included.

The selection process involved many tests such as blood tests, sweat tests and lung function. Ruby and Isobel were successful in qualifying and were part of the first group of children in WA to participate.

RED: How long is the trial?

The trial is for a period of two years. The first six months was a 'blind trial' which means we were not told if the girls were on the Orkambi® or a placebo.



Ruby and Isobel came up with the Crack a Cure challenge to raise money and awareness for CF

RED: What did the trial involve?

At first, fortnightly blood tests were required. Now the girls have 6-8 weekly assessments which involve blood tests, spirometry and ECGs (electrocardiography). Sweat tests are required every 4-5 months. Interestingly though, Isobel doesn't produce enough sweat, so is now exempt from this test.

Eye testing is also a requirement. An eye test is performed prior to commencement of the trial and twice during the course of the trial.

RED: How has this impacted your lives?

The more frequent testing at the beginning of the trial obviously required more frequent trips to the hospital and to TKI, but has always been manageable. The assessments take about an hour. With appointments now being 6-8 weekly, it is much easier these days.

Honestly, the impact has been a positive one. When considering the time commitment, travel time, time off school



Ruby and Isobel with mum Christine

and expenses involved, with both girls experiencing an improvement in health, this has not been an issue. Isobel, who would normally be hospitalised frequently, has only had one admission in two years and Ruby has kept well too. So, less stress and manageable appointments.

RED: Please discuss the benefits of the trial, personally and in regards to future advances (e.g. did you feel any different? were there any improvements in your health?)

Ruby: I don't really feel any different. I can now cough up mucus when I do my physio though. Before the trial I always had a dry cough and couldn't cough anything up. My appetite has improved too. My last admission was about five years ago.

Isobel: I am not in hospital much now. I have an appetite and have gained 20% of my body weight. I now weigh 36kg and am growing well. Before the trial I always struggled to gain weight and I was frequently unwell. I can now really appreciate the feeling of wellbeing.

Christine: Being part of this trial has given us hope and optimism; it is a game changer. To watch the girls with their increased appetite and energy levels, no longer looking at the necessity for a port or a PEG,

it's just amazing. One of the parents at netball made a comment about how much energy Isobel had running around the court!

Another benefit is being able to address Isobel's needle phobia. Isobel has worked closely with the clinical psychologist from PMH to assist with the blood tests required on the trial, and this has helped immensely. Needling is no longer such a fear for Isobel. Being on the trial means we are in regular contact with the researchers and clinicians. For example, if there is a change in one of the girl's cough we are required to inform them. This provides the opportunity for different medications to be prescribed straight away if required.

A big positive of the trial is the impact it has had on our family. With the girls' improved health, we are all less stressed. Our sons, Jackson and Angus are no longer having to manage while we juggle lengthy hospital stays and all that came with the girls being so unwell, with family life. It is just so much easier on everyone now. We are all enjoying the 'feeling of wellbeing'.

RED: Would you participate in other trials in the future?

Definitely, yes. We would be happy to be



part of trials in the future. We are hoping that Orkambi® will hold us until new drugs come through. The benefits of all the research is going to be amazing.

RED: Do you have anything that you would like to share about your experience on the trial?

Ruby: Having CF gets easier as you get older and I am happy to have had a chance to be on a trial. Just remember to take your tablets!

Good luck!!!

Isobel: Being on a trial helps. Do it!!!

Christine: Clinical trials are so beneficial. I know some parents have found that if there are no obvious improvements they question the benefits. For us, we could see the positives straight away in Isobel; with Ruby it wasn't so apparent. We just understand the drugs are doing good things.

We are hoping that Vertex's submission for reimbursement for Orkambi® will be approved by the Pharmaceutical Benefits Advisory Committee (PBAC). If not, let's hope the girls can stay on Orkambi® on compassionate grounds.

Reference:

<http://www.cflivesmatters.org.au/Clinical-Trials/Clinical-Trials-101>

ORKAMBI® COMES AT A HIGH PRICE

Once again, the Pharmaceutical Benefits Advisory Committee (PBAC) refused to recommend Orkambi® to be put on the Pharmaceuticals Benefit Scheme (PBS).

For patients age six and over who have the two copies of the cystic fibrosis (CF) F508del mutation, the only drug available in Australia to treat this genetic underlying cause is Orkambi®. However, this drug, Orkambi® comes at the high price of \$250,000 per patient per year and is not yet included on the PBS.

On 18 August, the PBAC decided to refuse - for the third time - to recommend Orkambi® be put on the PBS. In its

attempt to negotiate with Vertex (the drug company), the government failed to obtain more clarity on Orkambi's® long-term effectiveness, and was unable to obtain a reduction on the cost of the CFTR modulation drug.

In a statement, Vertex senior vice president Simon Bedson called on Federal Health Minister Greg Hunt to intervene; "we

urgently want to find a solution that provides rapid access to our medicines and call on the Minister to intervene in the best interest of patients," he said.

Mr Hunt will not go against the recommendations of the PBAC and has called on Vertex to resubmit an application and to consider running further clinical trials to give more patients access to the drug.



SAVE THE DATE

{ THE CORPORATE
BATTLE OF THE BANDS
IS BACK NEXT YEAR! }

DATE: 10 FEBRUARY 2018 **VENUE:** THE CHARLES HOTEL
MORE INFORMATION COMING SOON!



EXTENDING LIVES THROUGH RESEARCH

This is what drives the passionate group of volunteers behind Conquer Cystic Fibrosis (CCF). It is also what enticed more than 600 people to attend this year's Capel Vale Conquer Cystic Fibrosis Grand Ball held at Crown Perth in May.

This glamorous event, in combination with Bingo for Conquer Cystic Fibrosis and other CCF fundraising events, raised more than \$509,000 (profit!) for cystic fibrosis (CF) research and services.

While the principal focus of CCF is research, the committee is also keen to continue its support of the important work Cystic Fibrosis WA (CFWA) do.

As a result, CCF has recently donated another \$10,000 to CFWA.

CCF chair Wendy Endebrock-Brown said the donation was made possible through the support of generous Perth businesses,

its passionate team of volunteers, and friends and families impacted by CF.

"We have been fundraising for CF for over 15 years now. We are so lucky that the generosity of family, friends and loyal businesses continues, year after year," she said.

"As the mother of a son with CF, I am aware of the desperate need to keep supporting the researchers who hold the key to saving the lives of those we love. We are also very grateful for the work CFWA do to support individuals and families, and to raise awareness of the ongoing fight against this disease."

As well as supporting CFWA, CCF donates to CF research through the Institute for Respiratory Health, the Australian Cystic Fibrosis Research Trust and Telethon Kids Institute.

For more information, find Conquer Cystic Fibrosis on Facebook or visit www.conquercysticfibrosis.com



SHELLABEARS CARES

Helping to make an impact in the community is very important for Chris Shellabear and his team at Shellabears Real Estate. They chose to raise funds and awareness for Cystic Fibrosis WA (CFWA) in support of one of their colleague's grandson, who has cystic fibrosis (CF).

Drop in to Shellabears Real Estate in Cottesloe on any week day and you'll meet a team of hard-working real estate professionals. Cheryl Hatt is one of these team members. Shellabears represents and sells beautiful homes in the western suburbs of Perth.

On Tuesdays, she takes a break from the office to care for her two grandchildren. Hudson is just four years old and has CF. He already has a good grip on his routine, reminding Cheryl of which tablets he needs to take and the physio that he needs to stay healthy.

Inspired by Hudson's story, the team at Shellabears decided to come up with an

innovative way to raise funds and awareness for children and adults living with CF in WA.

They created a colouring competition for local children, with the winning design featuring on their 'For Sale' signs during June and July. A donation was made to CFWA each time one was placed.

The team raised a generous \$5,000 for CFWA through their efforts and helped to increase awareness of CF in their community.

Thank you to the whole team at Shellabears for their incredible support of children like Hudson, and others, living with CF.



Shellabears staff Cheryl, Daniel, and Chris with CFWA CEO Nigel



2017 CARERS' DINNER

Please come along to our 2017 Carers' Dinner and enjoy a three-course dinner, meet other parents and chat with Cystic Fibrosis WA staff.

When: Saturday 21 October 2017 at 7pm

Where: Steve's,
30 The Avenue, Nedlands

Cost: \$20 per person

For more information or to RSVP, email services@cfwa.org.au or phone 08 6457 7333.

This important event is part of Carers Week. Many thanks to both Carers WA and the City of Nedlands for supporting this event.



City of Nedlands

CARERS WEEK

Sunday 15 to Saturday 21 October 2017 is Carers Week. A week designed to celebrate and raise awareness of carers, the caring role and carer supports and services.



"A carer is someone who provides unpaid care and support to family members and friends who have disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue, or who are frail aged" (Carers Australia, 2017).

Carers can range in age from as young as eight to people well into their nineties. More than one in eight Australians are carers. Two thirds of carers are women and most carers provide care for a parent, partner, child or friend.

Caring may include help and support of daily activities and management of medications, as well as providing emotional, social or financial support. It can also involve helping the person they are caring for to be organised, reminding them to attend appointments and dealing with emergencies.

Carers can be:

- Parents
- Spouses

- Siblings
- Grandparents
- Friend or other relative

If you are caring for someone with cystic fibrosis (CF), you are a carer and are entitled to various supports.

Carers WA

Carers WA is a non-profit, community-based organisation and registered charity dedicated to improving the lives of the estimated 320,000 family carers living in Western Australia.

Carers WA helps carers in any caring situation. To qualify as a carer:

- You do not need to live with the person you care for
- You do not need to be the main source of care and support
- You do not have to provide care every day or over many years
- You do not have to receive the Carer Payment or Allowance from Centrelink

Services:

- Counselling
- Information and advice
- Education and training
- Social support
- Young carers program and more

For More Information:

W: carerswa.asn.au

P: 1300 CARERS (1300 227 377)

Carers Counselling Line: 1800 007 332

Government Carer Payment

Did you know that when a child is born with CF, parents automatically qualify for the Carers Allowance, which entitles you to the health care card until your child turns 16. Outside of this, if your caring needs meet a certain level or criteria, then a carer could qualify for the Carer Allowance or Payment which would assist with the ongoing costs of the person with CF.

This is accessible through Centrelink.
www.humanservices.gov.au/customer/services/centrelink/carer-allowance



INFECTION CONTROL AT PRINCESS MARGARET AND SIR CHARLES GAIRDNER HOSPITALS

Following the latest research on cross infection, Dr André Schultz, Cystic Fibrosis (CF) Centre Director at Princess Margaret Hospital (PMH), and Professor Siobhain Mulrennan, Cystic Fibrosis CF Centre Director at Sir Charles Gairdner Hospital (SCGH), have collaborated to provide an overview of the precautions being taken at the WA centres and what you can do to help.

Infection control precautions, the steps that health-care professionals put in place to reduce transmission of infections from patient to patient, is currently highly topical in the international cystic fibrosis (CF) community.

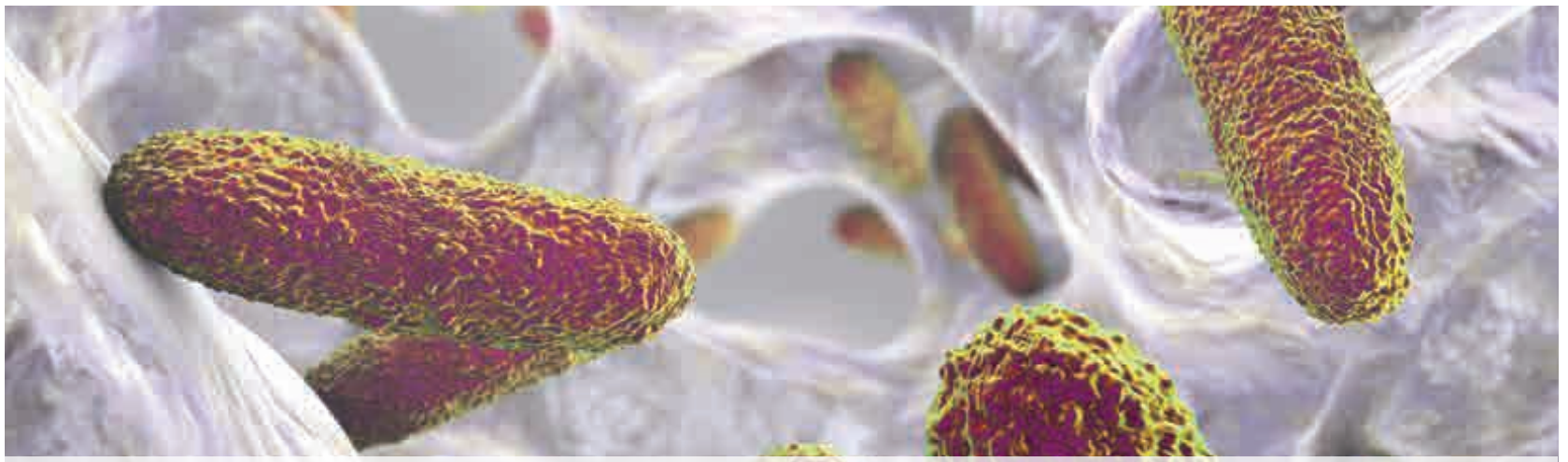
Fortunately, there has been no known outbreaks of infection in WA amongst the CF community in recent years, but we have not been complacent. Well before the recent media attention, CF teams in WA have been working to optimise infection control practices. Issues around transmission of bugs are complex and require close interaction between respiratory physicians, microbiologists, infectious disease physicians, nursing and allied health members of the CF team, as well as general nursing, cleaning services, outpatient coordinators and many more stakeholders.

An important, and perhaps less known fact, is that the best documented type of infection transmission in CF is not via airborne transmission but via droplets. Respiratory droplets are generated by talking, coughing or sneezing. Droplet spread has been related to *Pseudomonas* outbreaks in overseas centres, as well as a relatively recent transmission of *Mycobacterium* infection from one patient to others through a hospital inpatient room in the United Kingdom. Respiratory droplets are large and do not remain suspended in the air, but rather land on surfaces a short distance away. Infection therefore may spread when people with CF are in close physical proximity to each other, or when surfaces with droplets on are touched.

Hence, people with CF should not have

close physical contact and are encouraged to stay a few metres away from each other. Fortunately, modern technology can be used to allow people with CF social interaction.

A main focus for CF centres has been to prevent indirect droplet-based infection transmission in the hospital environment. Strategies include well known infection control methods, like encouraging hand hygiene for patients and staff and making access to hand sanitisers easy at all points of care. Importantly, a large part of infection control happens behind the scenes and involves surface and equipment cleaning in outpatient clinics, guidelines around and coordination of inpatient room allocation, extreme room cleaning of inpatient rooms in between patients, infection guided segregation of patient groups etc. Infection control will remain a priority for CF teams.



IT'S WAR! AND THE ARMS RACE IS ON

In recent editions of RED magazine, we have looked at the issue of Antibiotic Microbial Resistance (AMR) in "Microbial Monsters" Summer 2015, and more recently, "Dragons Blood" Autumn 2017. These articles recognised the importance of finding ways to fight the rise in AMR using two very different approaches. This is not only important for people living with cystic fibrosis (CF) because of the high doses of antibiotics patients regularly receive, but also for the whole of mankind.

Deaths from AMR infections today are estimated at around 700,000 per annum. Jim O'Neil, a UK-based economist, estimated last year that by 2050, AMR infections will kill over 10 million people a year.

As bacteria develop more and more resistance to antibiotics, scientists predict that there is a real danger that we will revert to a situation common in the 19th century where relatively common infections were untreatable and led to death. It is estimated that around 14% of the world's population were dying of a bacterial infection that caused tuberculosis in the late 19th century; a disease subsequently treated effectively by antibiotics.

Infections treated by mainstream antibiotics today may become untreatable within our lifetimes. Elective surgery will carry a much higher risk of fatality from post-operative infections.

So how do these nasty bacteria fight back and what are we doing about it?

We have all heard of Darwinism; how natural selection can weed out the more vulnerable of a species. We know that some bacteria have a natural resistance to some antibiotics so they can flourish when others die. The resistant genes which these bacteria have are carried on rings of deoxyribonucleic acid (DNA) called plasmids. What's more, some of these bacteria can exchange plasmids with other unrelated bacteria, thus spreading the resistance between types of bacteria and

these can, in turn, jump across species from farm animals to man, for example.

As we exhaust the range of effective antibiotics, we need to look at developing new weapons in the arms race.

Some bacteria have the ability to sense each other's presence, a mechanism called quorum sensing, and move towards each other to form defensive extracellular DNA reinforced masses called biofilms. These resist the penetration of antibiotics. Current research sponsored by the Australian Cystic Fibrosis Research Trust (ACFRT) is looking at using nitric oxide to disrupt quorum sensing and allow hitherto ineffective antibiotics to mop up the now free swimming (planktonic) bacteria.

Other researchers are looking once again at using viruses to kill bacteria. These viruses, called bacteriophages, or 'phages' for short, appear to have been around as long as bacteria themselves. They are small; generally 10 to 100 times smaller than the bacteria they infect, and there's a lot of them. In fact, they are the most abundant life form on the planet. They also appear to be constantly evolving so that as bacteria evolve resistance to phages, the phages themselves evolve to overcome those defence mechanisms. No need for human intervention to continually upgrade to the newest version.

The idea of using phages to overcome bacterial infections is not new. It was first trialled successfully in 1919 to treat children with dysentery, but subsequently

abandoned in western medicine in favour of antibiotics. The development of antibiotics and phage occurred at relatively the same time. The rise in popularity of antibiotic use combined with the establishment of the Cold War caused the decline in phage use.

The thing with phages is that they are very specific to the type of bacteria that they infect. In theory, this makes them very safe for us to use as they cannot attack beneficial bacteria in our bodies or indeed other beneficial cells. Recently, trials in Bangladesh have highlighted the very specific nature of phages. In this instance, a phage known to attack *E. coli* was administered to children with diarrhoea, only to find that a third of the children were infected with another bacterium unaffected by the phage.

Phages look like spaceships with legs that lock onto the surface of bacteria. Each bacterium has a specific landing site which the phage recognises and locks into. It then drills through the cell wall of the bacteria and injects its DNA or RNA into the bacteria and uses the contents of the bacterial cell to create replicants of itself. These replicants then use an enzyme called a lysine to disrupt the cell wall and escape to infect other bacteria.

Lysins are very effective killers of bacteria and some scientists are looking at bypassing phages entirely and using lysins to specifically target certain groups of antibiotic bacteria.

Other scientists are looking at 'de-fanging'

bacteria. Dentistry for Dracula. This involves using a chemical called regacin to disarm nasty bugs. Whilst still in its early days, so far we have not seen any resistance developing to this novel approach.

Since the discovery of antibiotics in the 1920s, we have enjoyed unprecedented health as a species, but that is coming to an end. It's been 30 years since a new class

of antibiotics was introduced, and whilst there are around 40 antibiotics in the drug development pipeline, there are no new classes.

The antibiotic war is a war we are losing. We need to outsmart the nasty bacteria using new weaponry, like quorum sensing dispersal agents, smart bombs like phages, lysins and 'dentistry' to defang.

It's a global race and Cystic Fibrosis WA (CFWA) and the ACFRT cannot win this race alone, but we can play a part. If you would like to find out more or help fund research being undertaken by CFWA, please contact **Nigel Barker CEO** on **08 6457 7333** or **ceo@cfwa.org.au**

All donations over \$2 are tax deductible and can be made online at <http://www.cysticfibrosis.org.au/wa/>

BIG DATA, BIOINFORMATICS AND CYSTIC FIBROSIS

You may or may not have heard of the term "big data" being thrown around and wondered what it means, and what it has to do with cystic fibrosis (CF)

According to Baker (2015), one of the best uses for big data, in terms of potential benefit for humanity, is in healthcare and the medical sciences. But what exactly is 'big data'?

Although the term 'big data' had origins in the mid-1990s from Silicon Valley, it didn't gain traction as a concept until 2013, where it was more commonly used in business, popular media and scientific fields. In the areas of government, industry and academia the belief in 'big data' is strong, with the overarching idea that it is set to "alter fundamentally how science and business are conducted" (Kitchin, 2014).

'Big data' is defined not just by the amount of information involved, but also by its variety and complexity, as well as the speed with which it can be analysed or delivered. 'Big data' comes from online sources, such as from websites, social media activity, emails, photos, videos, smartphone apps, wearable technologies such as Fitbit watches, electronic health records and from scientific research. In just a few days the amount of data collected is now larger than the data combined from all of mankind since the beginning of recorded history up to 2003 (Kuchenreuther, 2014). With the increasing processing power of computers, there is greater capacity to store enormous amounts of data cheaply, and there are more advanced statistical methods and analytics available to interpret the data. Analysis of data sets is useful in all areas, such as business, government, science and medicine.

Large quantities of data in healthcare and

medical sciences have already existed for a long time, but in a siloed way. Whereas now it is much easier and cheaper to share health and medical data between organisations and researchers all over the world.

Bioinformatics is "an interdisciplinary research area at the interface between computer science and biological science" (Xiong, 2006) and the increased capacity to access 'big data' is allowing the area of bioinformatics to thrive.

The main goal of bioinformatics is to have an increased understanding of living cells and how they function at a molecular level (Tsongalis et al, 2013).

Bioinformatics is having a major impact on many areas of biotechnology and biomedical sciences and has applications in knowledge-based drug design (Xiong, 2006). Large datasets are now also being repurposed to ask new biomedical questions, which ultimately leads to finding out whether drugs that treat certain conditions may also be repurposed to treat other conditions.

The drugs Ivacaftor® and Orkambi®, developed by biotech company Vertex are examples of what bioinformatics research can achieve. Ivacaftor® is the first medication to treat the cause of CF, at the cellular level and is suitable for 5% of the population of people with CF.

The Telethon Kids Institute (TKI) has a bioinformatics department, where their bioinformatics team "aim to deliver great research outcomes primarily by empowering bench researchers to perform

their own data analysis and interpretation" (Telethon Kids Institute, 2017). A software has been developed called Virtual Pooling and Analysis of Research (ViPAR), which allows researchers from TKI to share and analyse data securely, with colleagues from around the world.

The impact of using big data and bioinformatics is poised to revolutionize the health care industry by being instrumental in the development of personalised and customized medicine (Xiong, 2006). Bioinformatics is providing medicine with new, more effective methods for physicians to treat genetic disease.

References:

- Baker, P. (2015). *Data Divination: big data strategies*. USA: Cengage Learning.
- Kitchin, R. (2014). *The Data Revolution: Big data, open data, data infrastructures and their consequences*, Sage Journals. vol: 10.4135/9781473909472
- Kuchenreuther, M., & Crawford, K. (2014). *Marrying big data with personalised medicine data analytic strategies can help companies capitalise on personalised medicine*. *BioPharm International*, 27(8)
- Telethon Kids Institute. (2017). *Bioinformatics*. Retrieved from <https://www.telethonkids.org.au/our-research/expertise-and-technologies/bioinformatics/>
- Tsongalis, G., Chao, E., et al. (2013). *Bioinformatics: What the clinical laboratorian needs to know and prepare for*. *Clinical Chemistry* 59 (9).
- Xiong, J. (2006). *Essential Bioinformatics*. UK: Cambridge University Press.

SOPHIE'S PERSPECTIVE ON RESEARCH AND LIFE

Sophie is a young woman with cystic fibrosis (CF). As you can see from these beautiful photos she recently got married in Uluwatu, Bali. She is also the adult representative for the Child and Adolescent CF Consumer Reference Group of WA and a participant in research.

RED Have you participated in any research programs or drug trials?

In 2014/2015, Sophie took part in one of the research studies, which was being done at the Institute for Respiratory Health (IRH), to look at the safety and effects of an exciting CF drug which is used to treat the underlying cause of CF. The study she took part in was for people with the heterozygous F508del mutation.

RED What was the process like?

Sophie went through a screening process at the IRH. This included quite a few different examinations and tests, including CF genotyping. When she started the study she had regular appointments and tests conducted to monitor her closely, which included: blood tests, sweat testing, ECG, spirometry, pregnancy tests and urine samples.

The visits to the IRH were quite time consuming, but she was given the visit schedule in advance so could plan her time off work. She completed questionnaires at every visit which looked at her overall health, quality of life, daily activities and CF symptoms. She also had to keep a study diary card every day. Sophie advised that it was really interesting taking part in the study and the staff at the IRH were really friendly and kind.

Unfortunately, the results of the study she took part in did not show benefit for her genotype and the study was stopped early. While this was really disappointing at the time, she is hopeful that other studies will prove more successful for her genotype and new treatments will be available soon for all

CF mutations.

RED What made you want to join the consumer reference group and what value do you see that the group offers to research and clinical practices?

Sophie is from the UK, and prior to moving to Australia five years ago, she was very involved with the UK CF Trust as an ambassador. She likes to raise awareness and share her experiences of living with CF. Joining the group has allowed her to advocate from a patient's perspective. The group offers valuable insight into things that researchers and clinicians may not have thought of.

One of the benefits of the group is that they have the opportunity to highlight things from a family/patient perspective and outline important aspects that researchers and clinicians may have overlooked. She likes attending the meetings because having CF can feel very isolating at times and being around a group of people that understand what it's like and being able to talk and share experiences is really beneficial.

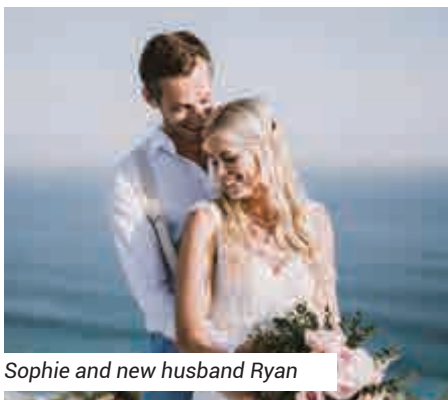
RED Lastly, congratulations on your wedding. It looks like you had an amazing day. How did you manage to keep healthy in the lead up so you could enjoy your beautiful wedding?

Planning a wedding is a stressful time and she was anxious that she was going to get unwell and not be in her best health to be able to fully enjoy her wedding day. Sophie advised that she has been seeing a psychologist to help with her anxiety and managing her CF. She also found it really helpful leading up to the wedding as she

helped her to work on some mindfulness and self-compassion strategies.

Sophie planned ahead with her CF team at Sir Charles Gairdner Hospital to have a proactive course of home IV antibiotics to give her a pre-wedding boost. She finished the course of IVs the day before she flew to Bali. Sophie advised that she has an incredibly supportive work place and her manager and colleagues helped her to reduce her case load so she could focus on her health leading up to the wedding.

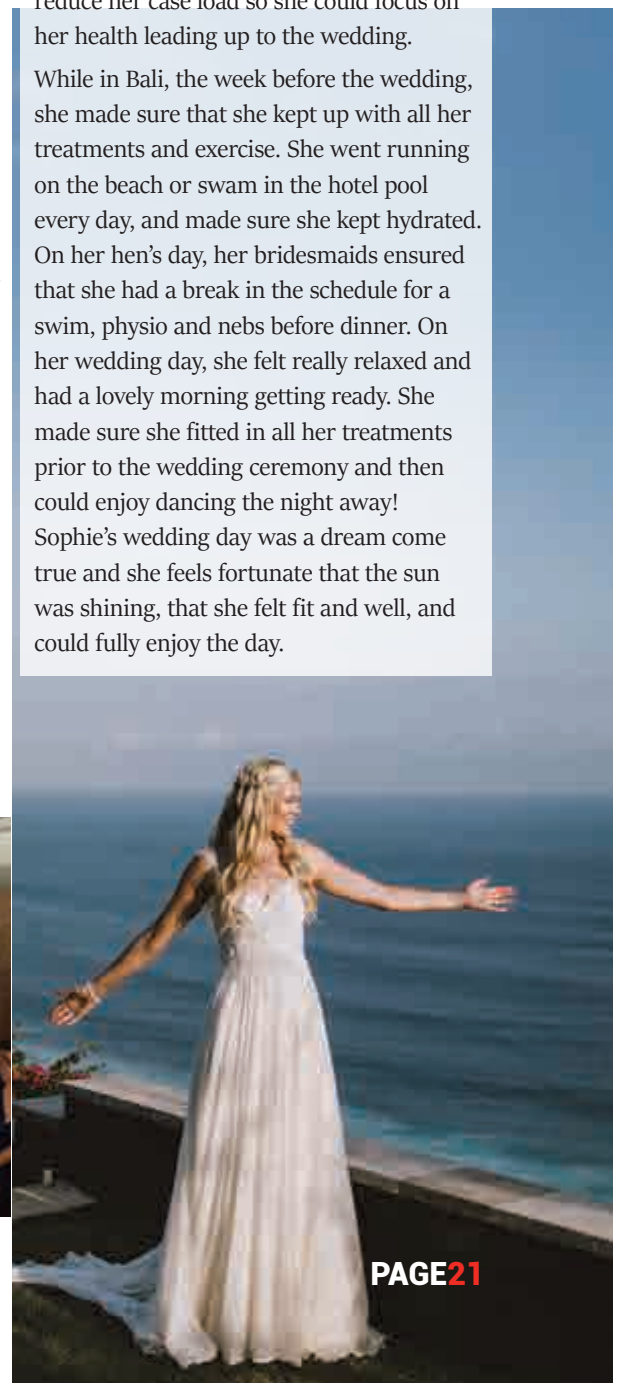
While in Bali, the week before the wedding, she made sure that she kept up with all her treatments and exercise. She went running on the beach or swam in the hotel pool every day, and made sure she kept hydrated. On her hen's day, her bridesmaids ensured that she had a break in the schedule for a swim, physio and nebs before dinner. On her wedding day, she felt really relaxed and had a lovely morning getting ready. She made sure she fitted in all her treatments prior to the wedding ceremony and then could enjoy dancing the night away! Sophie's wedding day was a dream come true and she feels fortunate that the sun was shining, that she felt fit and well, and could fully enjoy the day.



Sophie and new husband Ryan



Sophie doing her nebuliser during wedding preparations



BRENDON TALKS ABOUT TELEHEALTH

Brendon is an adult with cystic fibrosis (CF) who was brought up in regional Western Australia (WA) and has lived and worked in several regional locations. He is a family man, and as such has had a lot of commitments in his local community. When the chance of using Telehealth was offered he was very keen.

RED: Could you tell our readers a little bit about Telehealth?

Telehealth, for me, was a blessing in disguise. The metro hospital would organise the time and date and book the room. At district and regional hospitals, they have certain rooms set up for Telehealth conferences. It was great as you would get a phone call from the Telehealth coordinator telling you there was a Telehealth appointment and confirming the date and time, and you can schedule your life around this and simply rock up.

Telehealth was a chance to be able to engage with specialists from the metro hospitals and be able to stay on track with the appropriate care plan. It was a way to be able to chat with everyone; the whole team that is looking after you. They even post scripts to local pharmacy which saves so much time, money and stress on patients and their families.

RED: How did you manage to get onto this program?

I was contacted by the team at Sir Charles Gairdner Hospital and Cystic Fibrosis WA to see if I would be interested in pursuing the opportunity.

RED: Did Telehealth make things easier for you?

Telehealth was more flexible for me to be able to manage my life, whether it be work commitments, studies, volunteer role (as a volunteer ambulance officer with St John Ambulance) and also my family, as we have two children with special needs. It saved me that stress of having to take time off and be able to schedule things for the kids; I can simply go off and do Telehealth at the local hospital in my lunch hour.

RED: Would you recommend Telehealth for other regional adults?

Yes. Having that option there for you is something I would totally recommend to remote or regional patients, both children and adults.

Brendon with wife Shane and son Connor



RED: I also understand that you were lucky enough to go on a drug trial, was this difficult to manage whilst living regionally?

Drug trials are great, but living in a regional town or city is a real strain as the commitment involves you being available 100% of the trial, and that consists of going to Perth for some of the required treatment. With a full-on life, it can be a bit of a challenge but with preparation and time management, it can be done.

NEW RESOURCE ON THE LATEST CYSTIC FIBROSIS KNOWLEDGE

To bridge the gap between people with cystic fibrosis (CF) and the researchers investigating CF, and how best to treat those with the condition, the European Cystic Fibrosis Society (ECFS) has created 'Cystic Fibrosis Research News'.

This free publication presents, in everyday language, summaries of the key findings of the scientific work published in the Journal of Cystic Fibrosis, which is the official journal of the ECFS, and is devoted to promoting the research and treatment of CF. The aim of Cystic Fibrosis Research News is to provide access for patients, parents, relatives, friends and caregivers of patients with CF to the latest knowledge on CF disease and care.

The Cystic Fibrosis Research News articles are published in PDF format on the ECFS website www.ecfs.eu/publications/cf-research-news. All publications in Journal of Cystic Fibrosis are required to have an everyday language summary submitted. These are reviewed for readability by a voluntary editorial board and at least one CF scientist/clinician and one CF community member. On average, Cystic Fibrosis Research News publishes everyday

language summaries within two months of the scientific publication, ensuring readers are being informed of the latest developments in CF.

If you are on Twitter and would like to keep up-to-date with publications by both Cystic Fibrosis Research News and Journal of Cystic Fibrosis, follow @JournalofCF (<https://twitter.com/JournalofCF>). Links for all publications are tweeted within 24 hours of becoming available online.

REGIONAL 'MINI' EVENING WITH THE SCIENTISTS

Following the success of the 'Evening with the Cystic Fibrosis (CF) Scientists' held at Telethon Kids Institute (TKI) back in May this year, Cystic Fibrosis WA (CFWA) and TKI decided to collaborate to share the information with regional members in Bunbury.

CFWA gave an overview of current services, fundraising events, scholarship grants for researchers and other research currently funded through CFWA fundraising.

Dr Luke Garratt from the AREST CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis) team provided a snapshot of current research undertaken at TKI.

The evening also included a presentation from regional member Elle Lawrance who talked about her role on the CF Consumer group. This is an important role as it informs clinical and research practices

from a regional consumer's perspective.

Comments from members who attended the evening:

"Very thankful for your support of rural areas. Tonight was fantastic and very helpful to see the progress for our children."

"Hearing from experts in the field has been awesome! Keep it up!"

"The combo of dinner with an educational component is fantastic - better than a straight social night".

This event was proudly sponsored by Telethon.



Dr Luke Garratt from TKI

CYSTIC FIBROSIS WA GEAR UP FOR THE 2017 TELETHON

On the weekend of 21-22 October, Telethon will once again take place at the Perth Convention and Exhibition Centre.

Cystic Fibrosis WA (CFWA) are particularly grateful to Telethon for the wonderful support they provide to children with cystic fibrosis (CF) in regional WA. Their support funds our Outreach Program, which enables us to provide education, travel subsidies, equipment, one-on-one care and social events to families living in regional and remote areas. This year we were also able to host our first research seminar, a 'mini' Evening with CF Scientists in Bunbury, where attendees

were updated on the latest in research developments.

We encourage you to support Telethon and the fantastic work they do, and if you're coming to Telethon, don't forget to visit us at our booth on the first floor of the Convention Centre. If you would like to volunteer at our stall, please contact events@cfwa.org.au or phone **08 6457 7333**.

Thank you, Telethon, for your continued support!



**REGISTER AT THE
BUSSELTON GOLF COURSE**

**REGISTRATION CLOSES
24 NOVEMBER 2017**

REGISTRATION ESSENTIAL

**FRIDAY 1ST DECEMBER 2017
AT THE BUSSELTON GOLF COURSE**

277 CHAPMAN HILL ROAD • PH. 08 9753 1050

TEE OFF 10AM

**LOTS OF ACTIVITIES AND FUN ON THE DAY
HOLE IN ONE • LONGEST DRIVE • PUTTING CONTEST
HIRE A PRO • BEAT THE PRO**

LUNCH PROVIDED • SAUSAGE SIZZLE AND PRESENTATION

Rotary

Club of Busselton
Geographe Bay



INAUGURAL AMBROSE

**GOLF
TOURNAMENT**



Proudly Supporting
**CYSTIC
FIBROSIS**
Western Australia

PROUDLY SPONSORED BY



**CAPE TO CAPE
TILING**



FOR SPONSORSHIP AND GOLF DAY DETAILS CONTACT

Ross Johnston

Director of Community and Projects

Rotary Club of Busselton Geographe Bay

Ph: 0409 883 986 • Email: ross@sanros.com.au

RED TIE DINNER DANCE 2017

The Red Tie Dinner Dance for Cystic Fibrosis WA (CFWA) returned for its third year in a row, and it was better than ever. Guests were spoiled with live entertainment, a whisky raffle and incredible presenters who spoke about their unique and inspiring journeys of living with cystic fibrosis (CF).

On Saturday 1 July, the Fremantle Sailing Club (FSC) Wardroom filled up with finely dressed ladies and gentlemen for the third Red Tie Dinner Dance for CFWA.

Guests were welcomed with a glass of champagne and dazzled by up-and-coming magician Sam Parrish. The evening began with a showcase of incredible raffles and silent and live auction items. A new whisky raffle sold out in minutes, with guests jumping at the chance to win one of the generous prizes, including a bottle of premium Limeburner's whisky and a \$600 Oceanic Bar and Grill voucher.

The formal part of the evening begun with a welcome speech from Nigel Barker, CEO of

CFWA, followed by a delicious three-course meal prepared by the talented chefs of FSC. After dessert, special guests Caz Boyd and Mitch Messer shared their personal journeys of living with CF. Dr André Shultz also spoke about the current CF research being carried out here in WA and around the country.

The live auction boasted a spectacular cruise, dinghy, Dockers VIP box and framed Eagles and Dockers memorabilia. Thanks to the generosity of the donors and bidders, over \$18,000 was made from the silent auction – a fantastic result!

Later in the evening, when the formalities were over and all the prizes were claimed,

The Amplifiers took to the stage to get everyone onto the dance floor. A wonderful night was had by all and a significant amount of funds and awareness were raised for children and adults living with CF in WA.

Thank you and well done to Wendy Barker and the FSC Power Section committee for putting on another amazing event. Also, a big thank you to Caz Boyd, Mitch Messer, Dr André Schultz, Sally Edwards, Michelle De Nicolis, Jasmine Koong, Fin Koong, Darren Heath and the WAFEX team for offering up time and effort to make this night a big success.



The Amplifiers in full swing



Beautiful WAFEX rose centrepiece

Royal Life Saving is pleased to be partnering with Cystic Fibrosis WA (CFWA) to promote the health benefits of swimming to the cystic fibrosis (CF) community and provide opportunities to those families that face financial barriers to access swimming and water safety programs.

The Swim and Survive program identifies 16 critical stages in a child's development. The lower stages focus on teaching efficient support and movement in the water. The higher stages include skill and knowledge in safety, survival and rescue, all while developing a strong and effective swimming technique.

In many communities, swimming and water safety education is simply not accessible. Children and adults from lower social or economic families, Indigenous or culturally and linguistically diverse backgrounds, or from regional and remote communities, are more likely to miss out, making them extremely vulnerable to drowning. These groups are the focus of the WA Swim and Survive Fund.

- Swim and Survive lessons that best suit the needs of the applicant
- Aquatic development and training in regional and remote areas
- Partnerships with key stakeholders to promote the swimming and water safety message
- Provide sustainable Swim and Survive

Or contact Kathryn on
servicesmanager@cfwa.org.au
or phone **08 6457 7333**.



achieve more events like this. If you have a contact that may be able to assist please contact Karen De Lore at marketing@cfwa.org.au or call 08 6457 7333.



NEW TRAMPOLINES THANKS TO ALLENS



The Chitty family enjoying their new trampoline thanks to Allens

Many thanks to Allens who gifted Cystic Fibrosis WA \$3,000 for our exercise program.

With this money, we were able to purchase 8 Jumpstar trampolines for families with young children with cystic fibrosis (CF) to help facilitate both incidental exercise and airway clearance in a fun environment. The aim of the program is to assist in establishing good exercise habits in childhood, as this can impact patterns of physical activity in later years.

If you have a school-aged child with CF and are interested in a trampoline, please contact physio@cfwa.org.au or phone **08 6457 7333**. Once this is exhausted, we also have an annual equipment subsidy of \$200 to put towards the cost of exercise equipment if you would like to purchase your own trampoline.

Thanks also to Jumpstar for your continued support.



Allens > < Linklaters

SAVE THE DATE FOR OUR 2018 PARENTS' RETREAT

When: Friday 16 to Sunday 18 March 2018

Where: Gallery Serviced Apartments, Fremantle

More details will be made available closer to the event. For any other information please contact Paula on services@cfwa.org.au or **08 6457 7333**.

SPREADING THE WORD ABOUT CYSTIC FIBROSIS IN THE COMMUNITY

2017 has been a very busy year for cystic fibrosis (CF) education. Since January, our services team has delivered 47 education sessions to teachers, school nurses, students, parents, community groups and families, speaking to 859 people in total. We have also provided 34 education sessions to health professionals from regional hospitals, with more sessions booked for the coming months.



As well as being able to provide face-to-face education, Cystic Fibrosis WA (CFWA) has worked with Cystic Fibrosis Community Care in Victoria (CFCC), to update our CFSmart website (www.cfsmart.org) to include e-learning modules that are designed specifically for teachers in early childhood, primary and high school. The e-learning modules are especially handy for teachers located in regional areas, as well as teachers in high school. Feedback from teachers who have already accessed the modules has been very positive.

"I enjoyed the combination of slides and use of YouTube clips. This was very informative and it is great that you have a general module about CF and then targeted modules specific to the age of the students at various school environments"

"The modules were great, it suited the high school I work in. We are recommending all our staff complete module 1 and 4. The resource was easy to follow, engaging and informative. Thank you!"

The e-learning modules are particularly useful if your child's school is in a regional area and you would like the teachers to know more about CF.

If you would like to be kept up-to-date about CFSmart resources and want your child's school to receive information about our school education service, complete our online form: <https://www.surveymonkey.com/r/cfschoolform>



We are planning to develop e-learning modules on our CFSmart website to assist health professionals located in regional areas, so watch this space!

For further information about our Health Professional education service, contact our

nurse educator at nurseeducator@cfwa.org.au.

For further information about our CF school education service, contact our education officer at education@cfwa.org.au.

FUNDRAISING NEWS

We are so lucky to have had many amazing fundraising and awareness champions in 2017. In this edition, we thank the incredible regional town of Merredin for their huge efforts in raising awareness and funds for Cystic Fibrosis WA (CFWA).

Small Town, Big Support

The small regional community of Merredin has created big awareness and raised an incredible amount of funds for children and adults living with CF in WA this year.

In May, the town was involved in 65 Roses Day and raised over \$1,500 through donations and the sale of roses. Kat White, a mother of a child who has CF, and her supportive friends sold 200 roses on the last Friday of May.

Then in July, Merredin got involved in Dave McAdam's bike ride challenge for CF research, and hosted the Merredin Family Fun Day. Dave, a Queensland cyclist and uncle of a child who has CF, rode through the town as part of his 'Race to the Stars' campaign. Kat, her friend Chesney Maloney, Two Dogs Home Hardware and many other community supporters raised over \$600 for CFWA through family friendly activities.

In addition to this, St Mary's P & F raised over \$170 for CFWA through a school disco, and Brad and Liddy Atkinson donated firewood for an auction which raised \$335. Also from Merredin, Chelsea Willis hosted an afternoon tea fundraiser and raised \$252 for CFWA. Chelsea was inspired to do something meaningful for a charity that would support members of

her community. What an inspirational and generous young woman Chelsea is! That's over \$2,850 from one incredible regional community in a matter of months! Thank you Merredin!

Going Crazy for CF

The Homebuyers Centre Osborne Park hosted a Crazy Hair and Hat Day for CF in August and raised over \$100 for CFWA. Their team styled their hair in weird and whacky ways or wore a funky hat to raise awareness and funds for families affected by CF in WA.

Turning the School Red

Rostrata Primary School raised over \$740 by hosting a Red Free Dress Day in support of one of their students, Thomas, who has CF. To say thanks, our Community Fundraising Coordinator, Marnie attended the school's assembly and presented them with a certificate and special CF book for their library.

Host Your Own

If you'd like to be involved in raising awareness and funds for CF, but aren't sure how, contact CFWA's Events and Community Fundraising Coordinator, Marnie on events@cfwa.org.au or o8 6457 7333.

NEW RESOURCES IN 2018!

Keep your eyes peeled for our new community fundraising resources, which will be released in the new year! We have been working on a new guide and plenty of other fun, free resources to use when hosting your own fundraiser.



DAVE MCADAM ARRIVES AT THE MERREDIN FAMILY FUN DAY



THE HOMEBUYER'S CENTRE TEAM WITH THEIR CRAZY HAIR!



DAVE MCADAM AND HIS SUPPORTERS AT THE START LINE



CHELSEA WILLIS WITH HER CERTIFICATE OF APPRECIATION



BROTHERS, THOMAS AND RYAN, HELPED THEIR SCHOOL RAISE OVER \$740 FOR CFWA - THANKS BOYS!

COMMUNITY CHAMPIONS GET ACTIVE FOR CYSTIC FIBROSIS

Are you looking to set yourself a challenge for the new year but aren't sure what to do? Be inspired by Cystic Fibrosis WA's (CFWA) 2017 community champions who set, and smashed, their own fitness and fundraising goals. There are plenty of opportunities to run, swim, walk and ride to support children and adults living with cystic fibrosis (CF).



The Busy Bees team, made up of 28 people, participated in the HBF Run for a Reason in loving memory of family member and friend Bianca, who was affectionately nicknamed Bee. They raised an incredible amount of awareness for CF and over \$3,840 for CFWA.



Nyssa and her partner Cody signed up to the HBF Run for a Reason this year after their daughter Norah was diagnosed with CF. They were joined by numerous family and friends who helped to raise funds and awareness for Norah and other children who live with CF. Together their team raised over \$5,700 for CFWA. The HBF Run is a family friendly event and is suited to large groups of all ages and abilities.



Kate O'Halloran competed in the Rottneest Channel Swim at the beginning of the year. She nominated to raise funds for CFWA after reading about CF when searching the internet. She raised a phenomenal \$885 for CFWA and helped to share awareness of CF with her friends and family who hadn't heard of the disease before.



Starting with Lisa Lough and her three young boys, the Nedlands Primary School team for the Chevron City to Surf quickly grew to be a team of 40+ students and parents. This brilliant bunch of kids trained every Friday morning before school in the lead up to the big day, proudly wearing their red CFWA shirts to raise awareness in their local community. They raised over \$1,840 for CFWA and had an awesome time walking and running the course together. The City to Surf have free kid's fitness resources available, making it the perfect event for a school or community group.



Cousins Clementine and Essie ran in the HBF Run for a Reason for their cousin and brother Wil. Their efforts raised over \$5,000 for CFWA to support research funding into finding a cure for CF.

Rottneest Channel Swim
24 February 2018
rotnnestchannelswim.com.au
HBF Run for a Reason
May 2018
www.hbfrun.com.au
City to Surf
August 2018
perthcitytosurf.com

The Colour Run

For the first time ever, The Colour Run has teamed up with GoFundraise to help participants raise awareness and funds for their favourite charities. If you have already registered for The Colour Run and would like to fundraise for CFWA, simply visit thecolorrunperth2017.gofundraise.com.au and login with your registration details to set up your own fundraising page. Visit

thecolorrun.com.au for more information or to register.

These events not your style?

If you have another challenge in mind but aren't sure how you can raise funds, get in touch with CFWA's Community Fundraising Coordinator via events@cfwa.org.au or **08 6457 7333** who will help you with a fundraising page and resources.



IT TAKES A COMMUNITY TO CARE FOR CF

You might recognise little Norah and her mother Nyssa from our last RED magazine. Cody, Norah, Cole and Nyssa will be the faces of Cystic Fibrosis WA's (CFWA) 2017 Christmas Appeal.

Every year CFWA work with other state cystic fibrosis (CF) organisations to create a national Christmas appeal. Working collaboratively helps to convey a clear message across Australia and keep costs down. The appeal will be launched in November through Australia Post, electronic mail outs and social media.

This year, one of our own WA families will be sharing their story and helping to spread the message that it takes a community to care for CF.

Norah, who has CF, was born at 33 weeks with her twin brother Cole. She was diagnosed after returning home from

hospital and her parents juggled the early days of being parents to newborn twins with a supportive network of friends and family.

Nyssa says, "thankfully we had such great support from both our families; looking after Cole where needed, so Cody could still try and get to work or come to see us, cooking for both of us and even spending some nights in the hospital with Norah so that I could go home and see Cody and Cole".

At CFWA, we are very grateful to families like Norah's, who share their journey with us to help raise awareness and funds so that we can continue to provide services and programs for WA families, and contribute to

research with the aim of finding a cure for CF.

We are also very lucky to have a network of volunteers and pro bono supporters. Thank you to Curtin University graphic design student, Jade Koch, who is working with us on our appeal design. Thanks also to Carrie of Still Moment Photography for the beautiful photo taken as part of a family photography session she did with Nyssa, Cody and their gorgeous twins.

Above all, thank you to Nyssa, Cody, Norah and Cole for sharing their life with us.

Cystic Fibrosis WA Christmas Office Hours

Cystic Fibrosis WA will be closing over the Christmas period, from Wednesday 20 December, reopening on Thursday 4 January 2018. We wish everyone a wonderful and safe Christmas and New Year.





Sponsors and Volunteers Awards Night

Join us for our Annual Sponsors and Volunteers Christmas Party, where we celebrate all that's achieved in the year, and award our some of our most deserving supporters and members.

When: Friday 8 December 2017

Where: The Niche Building, 11 Aberdare Road Nedlands

Drinks and light supper provided. More information to come.