EDITION 3 2017

RED

IN THIS ISSUE...

ADOLESCENCE

Picture: The Sunday Times/PerthNow/Ross Swanborough

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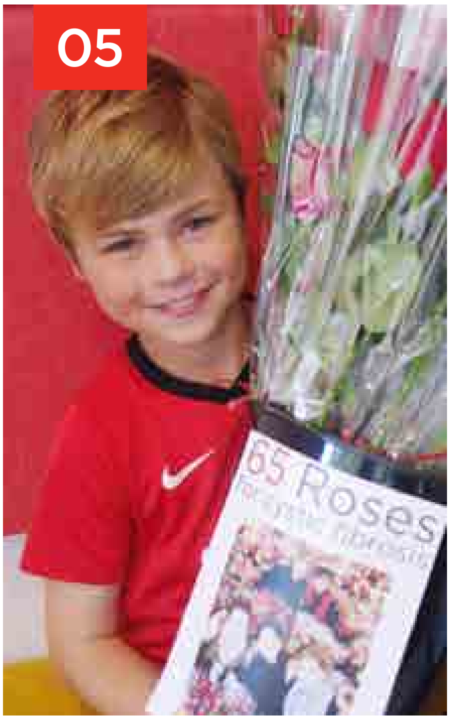
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CEO MESSAGE

The theme of this edition of RED magazine is adolescence. This can be a challenging time for anyone, especially when it is overlain by having to deal with a chronic degenerative disease like cystic fibrosis (CF).


NIGEL BARKER, CEO

I remember my adolescence well. The world was black and white. I had the answer for everything. My mind was not cluttered by facts and I was pretty much the king of all I surveyed. I could not imagine that my parents actually knew anything, except perhaps what went on “back in the day”. I certainly could not imagine that they had ever had an adolescence quite like mine.

So, adolescence is a challenge not only for any young person growing up, but in the case of someone living with CF, it’s also an issue for parents, siblings and carers too. For people with CF, problems with compliance, mental health, body image and peer pressure all add to the normal pressures associated with transitioning to adulthood.

These issues, and others, are discussed in this edition of RED magazine, and whilst we don’t have a magic pill to surreptitiously slip our teenage sons and daughters, there is still hope.

We also reflect on some rather quirky research which looks at how eating in company can assist in calorific intake.

We review the latest developments in CF research and summarise some of the ground-breaking work which is being done right here in WA, building on the work of other researchers in the field of Duchene Muscular Dystrophy.

The annual Evening with CF Scientists, which launched 65 Roses Month, was a great success coming hot on the heels of a fantastic Golf Day and as a prelude to the biggest 65 Roses Day ever. Such was the success of the Evening with CF Scientists, that it is now being duplicated in Bunbury.

In the meantime, our Regional Respiratory Training Program, a collaborative venture with the major hospitals, Diabetes WA, Asthma WA and WACHS, has continued to empower health and allied health professionals in the regions.

Finally, a huge thank you to everyone that responded to our questionnaire for our next strategic plan. This is progressing really well and will target our resources to meet current and future needs of people living with CF over the next few years. It will be placed online as soon as it is available.

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

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our summer issue, please contact us before 1 September 2017

DO WE HAVE YOUR CORRECT DETAILS?
If not, please let us know so we can keep you informed

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ON THE COVER
65 Roses Day ambassador
Dylan Cooper and his mum Karen

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CFA UPDATE

PUTTING A PRICE ON A LIFE

It's almost unimaginable that children and adults with a debilitating disease like cystic fibrosis (CF) can be denied a drug that could quite literally help save their lives because of cost.

Sadly, for the 1,000 young Australians with the CF gene mutation F508del homozygous, this is the case.

Orkambi® goes back to the Pharmaceutical Benefits Advisory Committee (PBAC) for the third time in July 2017, and it is difficult to understand the sense behind this quarrel over dollars.

Australia is a country that prides itself on an equitable and fair health system, but sadly the relevant parties, the government's PBAC and the multinational pharmaceutical company Vertex, have been unable to come to an agreement on costs for this life changing drug.

The CF community must act and put pressure on both the drug company and the government to come to an agreement before lives are lost. Register your support at **http://www.health.gov.au/internet/main/publishing.nsf/Content/PBAC_online_submission_form**

The Federal Health Minister, Greg Hunt, has been supportive, but we still are denied access to this life-changing drug.

Orkambi® is designed to treat the underlying cause of CF and clinical trials in Australia and across the world provide solid evidence that Orkambi® improved lung function and reduced exacerbations, hospitalisation and antibiotic use. 96-week trial outcomes clearly showed that lung damage was slowed on average by 40%, preserving lung function and maintaining lung health.

Exacerbations reduced by 39%, hospitalisations were reduced by 61% and antibiotic use by 56%. These statistics alone are massive improvements for CF sufferers used to lengthy hospital confinement and taxing drug regimes.

Trial participants reported improved nutrition and subsequent Body Mass Index (BMI) increases, both of which have the capacity to stave off diabetes.

Orkambi® had a positive flow-on effect on the mental health of people with CF, leading to social inclusion and a reduction in personal and family stress. Given the toll CF takes on people born with the disease, this emotional, physical and financial burden on families is equally devastating.

The PBAC must realise that Australians with CF need access to life-changing drugs, and if you would like to support Cystic Fibrosis Australia's (CFA) advocacy efforts, go to **www.cfa.org.au** and learn more about why we need access to Orkambi®.

If you would like to tell your story to the media or our politicians in Canberra, contact Vanessa at CFA by email **vanessak@cfa.org.au**

Kind Regards
Nettie Burke
CEO Cystic Fibrosis Australia

CHEVRON CITY TO SURF FOR ACTIV

Registrations are now open for the city to surf!

ALBANY 23 July
GERALDTON 30 July
KARRATHA 6 August
BUSSELTON 13 August

Help raise much needed awareness and funds for cystic fibrosis (CF) in WA by walking, jogging or running in the City to Surf 2017.

With even more locations than ever across metro and regional WA, anyone can get involved and help make a big difference!

Register online at perthcitytosurf.com and nominate CFWA as your charity or email Marnie on events@cfwa.org.au to find out more about how you can help raise funds and awareness for CFWA.

Chevron city to surf WESTERN AUSTRALIA FOR acti

65 ROSES DAY 2017 - THAT'S A WRAP!

The team at Cystic Fibrosis WA (CFWA) have been reflecting on the month of May and 65 Roses Day 2017, and would like to take a moment to thank all the incredible people that helped us achieve success this year. From partners to supporters, volunteers to ambassadors; you all played an important part in this amazing day and we can't thank you enough!

ONE OF THE POPULAR RAINBOW ROSES

Thanks 65 Roses Partners!

Long-time partners of the event, WAFEX, supported 65 Roses Day in an even greater way this year, donating 3,000 beautiful fresh roses free of charge to the campaign and supplying the total 12,600 roses that were wrapped and sold across WA. In addition, several members of their team helped sell roses on the streets of Perth to raise funds and awareness for cystic fibrosis (CF).

New partners of the event, Telstra, added a huge level of support for 65 Roses Day by wrapping over 3,000 roses in their head office in Perth and selling them in 17 of their stores across WA. In their 17 store locations, Telstra volunteers sold our beautiful fresh roses and shared information about CF to customers.

Thanks 65 Roses Supporters!

The diploma events and hospitality students from South Metropolitan TAFE Bentley formed the volunteer shopping centre stall management team, helping to spread awareness and raise funds in more locations across WA. The Certificate III students attended wrapping day and acted as a support team for CFWA, helping pack resources, wrap roses and guide other volunteers.

A well-deserved thank you must go to the volunteer team who were tasked with the challenge of designing and wrapping our 'New Look Bouquets'. We were lucky enough to have our very own floral design expert, Felicianna from Fleurt, a local Nedlands business that creates boutique floral designs and grazing platters. Felicianna and her team of incredible volunteers turned 500 beautiful fresh roses into 50+ bouquets in less than a day – amazing! We had so many wonderful comments on our new bouquets and can't wait to make them again next year.

Thanks 65 Roses Volunteers!

We had an overwhelming response to volunteering this year and we simply can't thank everyone enough for giving up their time and energy to help. We set a record on the Thursday of 65 Roses week, wrapping over 8,000 roses in under three hours at the CFWA office. That's more than 40 roses a minute! Thank you to all our amazing community members, CF families and organisations that joined us on wrapping day; we couldn't have done it without you.

With the help of the SM TAFE and Telstra, we were able to sell the roses in more than 30 shopping centres around metro Perth. We had an amazing response to volunteering for 65 Roses selling day as well, and were pleased to be able to have volunteers at every one of our shopping centre locations, spreading awareness for CF and raising funds.

THE KNIGHT FRANK TEAM CYCLING IN THE TOUR DE' 65 ROSES CHALLENGE AT EXCHANGE TOWER

OUR 'NEW LOOK' BOUQUET, DESIGNED BY FELICIANNA

There were also several volunteers who helped us in the lead up to 65 Roses Day; cutting ribbons, sticking stickers and splitting apart the flower food sachets. The team from Activ and UWA Pop Up Volunteering took boxes of flower food sachets, ribbon rolls, stickers and sleeves and prepared materials in April and May. We also had the help of Brooklyn and her mum Tonya, who cut thousands and thousands of ribbons in her spare time – thanks Brooklyn and Tonya! Finally, thank you to Chris, Denise and Desley who helped in the weeks leading up to 65 Roses Day, taking on challenges and coming up with brilliant ideas to get things done.

The feedback we have received from our volunteers has been incredible and we thank you all for sharing in this experience with us. If you volunteered and would like to share your thoughts and experiences, please get in touch with Marnie at **events@cfwa.org.au** or **08 6457 7333** - she would love to hear from you.


THE ALBANY TEAM
WITH THEIR 700 PREPARED ROSES

Thanks 65 Roses Fundraisers!

This year, our friends at Vault Fitness and Exchange Tower came up with a fun way to be involved and raise funds for 65 Roses Day. Vault Fitness set up cycle bikes in the foyer of Exchange Tower in Perth and challenged the tenants of the building to a cycle-off! They called it the 'Tour de'65 Roses' and each competitor donated to CFWA to compete. They fundraised over $5,500 on the day, combined with matched giving from the building owners, Perpetual Trustee Co- the outcome from their fundraiser was incredible!

Laura Bass from Geraldton completed her own 65 Roses Challenge by running 65 laps of the local oval during the month of May. Also in Geraldton, the Iaria family organised a fundraiser with their local basketball team. Orchard Espresso got on board and held a 65 Roses Cake Raffle, and finally there was a CF Quiz Night fundraiser thanks to the hard work of Maggie Di Re. We also had a number of schools and child care centres participate in awareness raising throughout the month of May. Pearsall Primary School did 65 laps of their oval as a school and talked about CF in their classes on 65 Roses Day – great awareness raising!

Thanks Regional 65 Roses Teams!

One of the many achievements of 65 Roses Day this year was being able to connect with so many regional communities to spread awareness for CF and help raise funds to support vital services and research. Thanks for the support of Adele Farina and her team in Bunbury who wrapped and sold roses in Bunbury and Busselton.

Albany saw a large team lead by Lorraine, Simone, and Anne, wrapping 700 roses and selling to businesses, friends and from a stall at the Albany Plaza. Thanks to our other regional members, there were also rose sales at several other locations in WA including: Esperance, Denham, Geraldton, Merredin, York, Northam, Broome and Busselton.

We'd like to thank the transport companies who helped by delivering the beautiful fresh roses to these locations including: Tail Lift, Great Eastern Freightlines, Virgin Air, Southern Regional Transport, Freight Lines Group Geraldton, Freight Lines Group Esperance, Western Independent Foods and Kalbarri Carriers.

Thanks 65 Roses Ambassadors!

We had great presence in the media in the lead up to 65 Roses Day, including an article in the Sunday Times which featured this year's 65 Roses child ambassador Dylan Cooper and his mum Karen. We were also lucky to have stories featured on some of our other members. Thank you Sally Edwards, Sera Taylor, Jason Mears, David Spaapen, Sam Phillips, Austin Delic, Holly Radys and families for sharing your stories and experiences.

65 Roses Day 2018

We know it's very early to be thinking about next year and we know you all deserve a break from your hard work this year, however, we just wanted to say that we look forward to having you all back again for **65 Roses Day 2018, Friday 25 May!** If you'd like to know how to get involved or would like to volunteer again next year, keep your eye out for upcoming opportunities on our CFWA Facebook page and in our e-newsletters, or get in touch with Marnie at **events@cfwa.org.au** or **08 6457 7333.**

WAFEX


TELSTRA VANS DELIVERED
ROSES TO THEIR STORES


TAFE STUDENT, JAMAICA
AT THE WINTHROP STALL


DYLAN COOPER, THIS
YEAR'S 65 ROSES AMBASSADOR


WAFEX TEAM MEMBERS
SELLING ROSES IN PERTH


VOLUNTEER BROOKLYN WITH
THE THOUSANDS OF RIBBONS
SHE CUT FOR 65 ROSES DAY

HOW CYSTIC FIBROSIS CAN IMPACT ADOLESCENCE

A study by Adelaide Withers, respiratory doctor from Princess Margaret Hospital (PMH), looked at how cystic fibrosis (CF) may impact upon adolescence. Here we discuss the main findings from the study, and how parents can help guide their adolescent through this tumultuous and demanding time.

PUBERTY AND BODY IMAGE

Many CF health-related problems become more "visible" during the adolescent years. Unfortunately, adolescence is also a time when teenagers are acutely focused on their appearance, body image, conforming, and comparing themselves to their peers. Self-worth and body image is strongly tied to how well they conform. Any differences from peers can be particularly distressing to an adolescent. Symptoms commonly seen in CF (coughing, flatulence, bowel issues, discoloured teeth from antibiotics, and finger clubbing) are often distressing and isolating for adolescents, especially those that cause visible difference to their peers (pubertal delay, short stature, and low body mass).

Pubertal delay is common in CF, with an average two-year delay in females and one and a half years in males.

How to help:

- Ensure their medical team are aware of any body image issues your teen may be experiencing so they can talk them through any concerns.
- Use an older patient as role model, reassuring them that a normal puberty will occur in the near future.
- Offering to allow friends to attend appointments to learn more about CF may be useful in supporting your child.

RISK-TAKING BEHAVIOUR

Adolescence is often a time for experimentation and risk taking. There are conflicting reports as to whether adolescents with a chronic medical condition are more or less likely to smoke, abuse drugs and drink alcohol. Some studies have found equal or greater risk-taking behaviours, whereas other studies have found that adolescents with a chronic illness are less likely to engage in these behaviours. Regardless of these findings, adolescents in general, and with CF, are likely to experiment with smoking, drinking alcohol, and using drugs, especially if their friends engage in these behaviours. Risk-taking behaviours may be tried as a way to conform, minimise differences from peers, and try to forget about the burden of CF.

How to help:

- Unfortunately, explaining how smoking will cause a rapid decline in lung function and lessen life expectancy is rarely useful, as most adolescents do not have the cognitive capacity to understand future consequences as a direct result of their actions. Instead, sensitive discussion using immediate consequences can be a useful strategy, e.g. discussing bad breath and unattractive nicotine staining can be useful deterrents to smoking.
- Regardless of any discouragement, many adolescents will experiment and if they choose to do so, encouraging harm minimisation is essential.

MENTAL HEALTH

Adolescence itself is a time of great change, and a chronic illness in the mix can render the teen vulnerable to developing mental health issues. Depression and anxiety have a negative impact on health outcomes, adherence to treatment, health-related quality of life, and risk-taking behaviours. Identification of depression and adequate treatment can have a positive impact not only on a patient's health, but their quality of life and compliance with therapy.

Families who are non-supportive have been shown to be the strongest predictor of poor psychological adjustment in patients with CF.

How to help:

- Family functioning plays a huge role in effective care for an adolescent with CF, so ensure your child is well supported.
- Physicians must be vigilant in screening, detecting, and treating any mental health disorder, as it may significantly impact upon quality of life and treatment.

BECOMING INDEPENDENT

Although older adolescents with CF are on the brink of having to function in an independent manner, the demands of the illness may hamper the process. Parents have the difficult and unenviable task of continuing to oversee medical treatment, while allowing the teenager to develop their own independence.

How to help:

- Gentle and sensitive exploration with the adolescent to tease out fears they may have, and identification of barriers to developing independence is required.
- Acknowledgment and affirmation; "I can see how this would be scary for you", and identifying supports to assist the transition towards independence are essential.

NON-COMPLIANCE

Reported barriers to treatment adherence in adolescents with CF include less parental supervision, a wish to conform to peers, not feeling benefits from treatment, forgetting, rebellion, feelings of futility, disagreeing with the physician, and difficulties with time management. In addition, they often have very busy social lives and may not take kindly to the imposition that treatment may bring.

How to help:

- Explore, in a sensitive, non-judgemental fashion, the actual reasons for non-adherence and identify the barriers to change. Explain that some degree of non-adherence and forgetting is normal. Demonstrate to the adolescent that you are genuinely interested in why they do not adhere, as they are more likely to honestly disclose information if they feel that you are working with them and not acting as the "medication police."

- Involve them in problem solving, setting realistic goals, and allowing some compromise increases the chance of adherence. Acknowledging the high treatment burden and the unfairness of the situation can engender a sense of "solving this problem together."
- Drawing attention to the immediate consequences of not taking medication can be useful, as emphasis on immediate quality of life is more relevant to the adolescent.

REPRODUCTIVE HEALTH

Knowledge of reproductive health is often poor in adolescents with CF. Reproductive health includes advice about contraception, pubertal delay, sexuality, avoiding sexually transmitted disease, genetic counselling, and treating low fertility.

In general, patients do not feel comfortable initiating these discussions, and would welcome a physician-initiated discussion and feel relieved when being given "permission" to talk about reproductive health. Parents should be invited to join discussions about fertility if the adolescent consents.

How to help:

- Discussions with their physician about sexuality and reproductive health must occur regularly, with clear and reassuring explanations, no ambiguity and simple language.

TRANSITION

It is well recognised that transition can be an anxious time that some adolescents find extremely difficult. There should not be an expectation that transition must be achieved by a certain age or life event (e.g. completion of secondary school), as transition is an individual process that must be tailored and not rushed. A rough goal is that once the routine developmental tasks of adolescence are complete, transition should occur. The adolescent should be independent enough to appropriately manage all aspects of their medical care, have a clear understanding of the structure of the adult clinic, and have visited the site and met team members.

How to help:

- Providing the adolescent with written material is very useful, such as a "transition readiness checklist".
- Have your adolescent take a tour of the adult hospital. Cystic Fibrosis WA (CFWA) provide orientation tours.
- Joint clinic sessions between paediatric and adult teams.
- A "familiar face" at adult clinics.
- Information about the new adult hospital.

THE FUTURE

Adolescents with a chronic illness often worry about how their disease will affect their future — they may wonder if they will be able to finish school, have a job, have sexual relationships, or start a family. The uncertainty of life expectancy is also a common issue for adolescents with CF. There is often anxiety experienced around what the future may hold for them, including transplant.

Adolescents with CF need to have physicians who are dedicated to addressing and assisting in all areas of health, including medical problems, mental health, reproductive health, and preparation for independent adult life.

You can read the full article here:

https://www.hindawi.com/journals/pm/2012/134132/

MANAGING YEAR 12 AND CYSTIC FIBROSIS:

CASEY HADDOW

Casey is currently in year 12 and recently attended his school ball. Here he talks about juggling study and cystic fibrosis (CF) treatments.

RED: Great Ball pictures, everyone looked fabulous. Was it a good night?

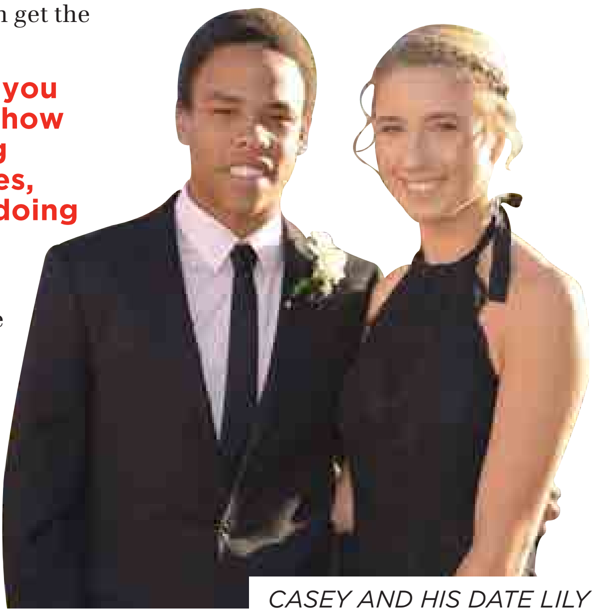
Yes, it was a great night. The counsellors did a great job setting up the whole event so that it ran smoothly the whole night.

RED: Have you got some good tips on how to manage some of the stresses about preparing for a school ball and completing your year 12 studies?

I didn't find it stressful at all preparing for the ball, except for finding a nice suit. My only tip is to pick it out early rather than later. As for year 12 studies, my main focus is on plumbing, so whenever I actually get homework I try to do it as soon as I get it so I can get the focus back to plumbing.

RED: At what age were you diagnosed with CF and how do you manage keeping up with all your activities, including study, whilst doing your CF treatments?

I was diagnosed from birth. I have been very active my whole life while still having time for my treatments. No matter what, I always leave enough space and time for me to do my two treatments every day to stay healthy, which will ultimately help me perform better in school and in physical activity.



CASEY AND HIS DATE LILY

MEET SARAH ‘SERA’ TAYLOR

Sera is a 26-year-old Hip Hop girl from Bassendean; cool, vibrant and insightful. She also has cystic fibrosis (CF). In this interview, she shares some of her story and thoughts around being a teenager living with CF.

RED: What was it like for you as a teenager?

It was hard because I didn’t want to feel different. I didn’t really want to bring my medications or nebuliser to school and I didn’t have many sleep overs because I didn’t want to do nebs in front of people. No one really ‘got it’. I was known as the “sick girl”. I sort of guarded myself because of the fear of being excluded. I felt like it was hard to keep up with friends.

People were OK with it; it was more my burden.

RED: Were you compliant with taking your medications and keeping up with your treatments?

Adherence was a bit of an issue. It stopped being such an issue when I was around 21 years old. I got my first real partner and he was supportive, so I settled down and did my treatment. I also ‘came out’ at this time about having CF, doing my first charity event with a DJ to raise awareness about CF.

RED: How did your siblings deal with your CF?

My siblings had always been extremely supportive when I was growing up. It wasn’t so much that I got extra attention, it was that my CF got attention, it was hard for my sisters to see the difference. I’m still really close with them. Some of my siblings chose to be tested to see if they were CF carriers and some didn’t.

SERA AT OUR RECENT LADIES HIGH TEA EVENT

My sister-in-law Rhonda has been a huge support with my awareness raising events. She helped me plan my first event in 2012 and has helped me establish my annual fundraising event, Hip Hope for Roses. I couldn’t have done it without her and the help and support of my family.

RED: Did you know anyone else with CF?

No, I never really knew anyone else.

I became friendly with other people with CF in hospital but never knew anyone outside of hospital with CF. I now have heaps of people with CF on my social media for support. Since ‘coming out’ about having CF, and being able to talk openly about my illness, a lot of people have said to me they have known or do know people with CF. Awareness helps.

RED: Was there anything else that would have helped when you were a teenager?

Teenagers just rebel. Maybe trying to find an active hobby or activity that they really enjoy. Learn to multi-task when doing nebs e.g. I do my nebs when I’m straightening my hair or listening to music etc.

RED: Would it have helped to have talked to someone else?

I think at any age it helps. To see someone else doing nebs would have been great, and to know I wasn’t alone with this. I would have liked to talk to an older person; someone to reframe things from their own experience.

RED: What would you say now as a mature lady of 26?

Don’t sweat the small stuff. I’m not a complainer; I try to stay positive and get the best out of life.

You’re either going to feel down about it, or accept what you have. If you can accept it, you become happier and realise most drama is insignificant. We deal with so much. No matter how weak we may feel, we are strong!

RED: Have you at times struggled with mental health? And if so, what things have you done to work through it?

At least once a year I get a bit down because my health changes so much. Things constantly change and then you get used to it again. Speaking to people and keeping a good social network is important to me and really helps. I like to meet new people and get excited about things.

Having people around you that are OK about CF is really important, but mostly I think it was about accepting that I’m OK, accepting that I have CF, and having no shame about that. I continue to be healthy and try to stay on top of my treatments. If low in mood it’s easy to stop treatments, so it’s really important to get back on top of it.

I also put myself ‘out there’. I like to create awareness so lots of people know about CF and support it. The more you talk about it, the more support you have. Everyone with CF is their own support network, and it’s easier now with social media.

I also have a very loving and supportive partner. He makes me want to be healthy. I need to keep up with all the fun and exciting things he has planned for me and our future. He’s ticking off my bucket list. He is so supportive, which is so important and fulfilling.

RED: What are your future plans?

I would love to become a wife and mother; I’m only human. I would love to travel and experience everything. Becoming a makeup artist is my dream.

STUDIES SHOW BOTH PHYSICAL AND MENTAL BENEFITS OF EXERCISE FOR PEOPLE WITH CYSTIC FIBROSIS

The importance of exercise in chronic disease has been well documented in research over the years. Exercise plays an important role in both airway clearance and overall quality of life. Structured exercise programs for people with cystic fibrosis (CF) may enhance airway clearance, slow the rate of pulmonary decline, and improve overall wellbeing (Physiotherapy for Cystic Fibrosis in Australia and New Zealand: A Clinical Practice Guideline).

A study analysing the benefits of a three-year home-based exercise program found that lung function declined more slowly in the exercise group and that compliance was associated with a positive attitude towards exercise. Another study published in 2014 examined the relationship between physical activity and lung health, and found that patients with higher levels of physical activity in daily life (encompassing all activities, not just exercise programs), had a slower rate of lung function decline than those who were less active. A review published in 2011 discussed the role of exercise in maintaining health in CF and found that there was substantial evidence to support the benefit of exercise in reducing the rate of lung function decline by increasing mucus clearance.

There are many studies examining the benefits of exercise as airway clearance and comparing different types of exercise to see which has the most impact on airway clearance. In 2011, a study was published comparing the use of treadmills and exercise bikes in patients with CF. Both types of exercise increased ventilation and expiratory airflow, which are essential components for shearing secretions from airway walls, and may stimulate a cough, but noted the importance of including forced expiratory techniques (FET), or huff, to maximise the airway clearance benefit.

Another study in 2011 compared exercise bike or treadmill use with gaming console exercise and found no significant difference in heart rate or energy expenditure. Both interventions provided a hard workout, however gaming console exercise was rated as more enjoyable than formal exercise which may result in better adherence.

In 2017, a study was published comparing treadmill exercise and the flutter device as airway clearance techniques. The flutter is a small, handheld, positive expiratory pressure (PEP) device that combines vibration and positive pressure on expiration. The results of the study showed that both techniques increased peak expiratory flow rates but only flutter increased the expiratory bias. Expiratory bias is essential to move mucus towards the mouth and is the basis of the huff technique, again emphasising the importance of including huffing in an exercise program in CF.

A review published in the Journal of Internal Medicine in 2010 found that exercise training improved anxiety in patients with chronic illness, with minimal negative side-effects, and was particularly useful for patients who prefer non-pharmacological treatment. They found that adherence to exercise was a key indicator of its effectiveness, but noted that adherence to an exercise program may be particularly difficult for patients during an exacerbation.

In 2014, a study found that improved

NEW EXERCISE EQUIPMENT PURCHASED FOR OUR PERSONAL TRAINER PROGRAM

quality of life was associated with physical fitness in CF, highlighting the role of physical activity in overall wellbeing in the CF population. Exercise therapy was found to improve both mental and physical health in patients with depression according to another study published in 2014. The effect of exercise was found to be comparable to anti-depressant medication and psychotherapy for people with mild to moderate depression, and was a valuable complementary therapy for those with severe depression.

New PEACH grant to support Cystic Fibrosis WA (CFWA) Personal Trainer Program

The benefits of physical activity and the importance of including exercise in treatment routines are well recognised for all people with CF. CFWA offer support with exercise through many programs including an equipment subsidy, CFfit resources and our homecare workers (see page 14 for more information). We have also recently employed a personal trainer who can work one-on-one with clients, taking them through a suitable, targeted exercise program. Participation in this program is done in consultation with your hospital care team. (Please note this program is currently only available to members in the southern suburbs, but we hope to make it available to those in the northern suburbs as soon as possible).

This new service has been made even better by the generosity of employees at Alcoa, who awarded CFWA with a $7,400 PEACH grant. This has enabled us to purchase a huge range of exercise equipment for use in this program.

Equipment purchased includes:

- Dumbbells
- Kettlebells
- Weight plates and squat bar
- Resistance bands
- Boxing gloves
- Bosu balls
- Medicine balls
- Slam balls
- Plyo boxes
- Battle ropes
- Power bag
- Skipping ropes
- Yoga mats
- Agility ladder
- Kick shields

If you would like more information about exercise or more specifically, our new personal trainer program, please contact us on **08 6457 7333** or **physio@cfwa.org.au.**

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PEACH
PERSONNEL EMPLOYED AT ALCOA CHARITY HELP

CYSTIC FIBROSIS WA (CFWA) TEAMS TOOK OVER PERTH FOR THE HBF RUN FOR A REASON

There were more than 45 runners who raised funds and awareness for cystic fibrosis (CF) in the HBF Run for a Reason on Sunday 28 May 2017.

There couldn't have been a better way to finish off the national month of awareness for CF and 65 Roses celebrations, than to have so many amazing participants challenging themselves in the HBF Run for a Reason.

We had two big groups participating in this year's run, Team Norah and the Busy Bee's: and several individuals who were raising awareness and funds for CF.

Of the 45+ CFWA participants, there were five runners who raised over $1000 each – what an amazing effort!

CF AWARENESS TAG AT THE HBF RUN FOR A REASON

Clementine	**$5,086.00**
Nyssa	**$4,796.14**
Sharon	**$3,590.94**
Katelyn	**$1,313.93**
Joe and Debbie	**$1,042.00**

A massive thank you to everyone who fundraised and donated; altogether an astonishing $27,404.88 was raised for CFWA through all your efforts, and we can't thank you enough!

Now it's time to put your feet up and rest, you deserve it!

THE BUSY BEE'S TEAM

TEAM NORAH BEFORE THEIR 12KM CHALLENGE

GOLF CLASSIC 2017

From a near miss at the hole-in-one to a laugh-a-minute act from Mick Colliss, this year's Golf Classic was a big hit!


LYLA AND THE HOLE-IN-ONE PRIZE

The 2017 George Jones Family Foundation Cystic Fibrosis Golf Classic was a wonderful day of friendly competition, good sportsmanship and generosity. It was a glorious sunny day on Friday 28 April as 32 teams played a game of Ambrose Golf on the championship course at Lake Karrinyup Country Club to raise funds and awareness for cystic fibrosis (CF).

There was plenty of entertainment on the course, with an opportunity to stop at the Gage Roads tasting tent to try some of their premium beers, and the chance to win a red 2017 Ford Mustang, thanks to Range Ford, by hitting a hole-in-one. Paul Larsen was the closest player to winning the car when his golf ball rolled over the hole instead of rolling in it – so close!

In the evening, guests arrived and joined their partners and friends who had played golf to enjoy some refreshments and entertainment on the terrace. The Sweet Teas trio sang as the Oyster Shucker served fresh oysters and the guests enjoyed Capel Vale sparkling wine and Gage Roads beer.

The formal part of the evening included a delicious three-course meal, comedic act from Australian legend Mick Colliss and heart-felt messages from Mitch Messer and Dr André Schultz, respiratory physician and director of the Cystic Fibrosis Centre at Princess Margaret Hospital (PMH). Dr Schultz highlighted some of the current CF research that is occurring in WA and the need for fundraising to support research projects.

This year Cystic Fibrosis WA (CFWA) received incredible support during the live auction which raised over $22,000 in a matter of minutes – a phenomenal amount of funds which will go towards supporting research and providing services for people living with CF in WA. This added to the total funds raised of over $100,000!

We'd like to extend a special thank you to the dedicated volunteer golf committee, who worked tirelessly to ensure the event was a success. We'd also like to thank our naming sponsor, the George Jones Family Foundation and gold sponsors including: Gillard Builders, Aerodrome Management Services, Brookfield Rail, Qube and Risbec.

We hope everyone enjoyed the day and we look forward to seeing you at the 2018 Golf Classic!

QUBE

RISBEC
DESIGN AND DRAFTING

Brookfield
Rail

GILLARD BUILDERS
(1977) PTY LTD

AMS
Aerodrome Management Services Pty Ltd

George Jones Family Foundation


TEAM AMS

SUPPORT FOR YOUNG PEOPLE AT CYSTIC FIBROSIS WA

At Cystic Fibrosis WA (CFWA) we have a range of resources and services in place to provide support to young people living with cystic fibrosis (CF).

Personal Training

We currently employ a personal trainer (PT) based in the southern suburbs who can come to your home and take you through a suitable, targeted exercise program. All referrals are accepted in consultation with your hospital CF team. We are planning to employ another PT in the northern suburbs as soon as possible.

Home Care Worker (HCW)

HCWs are great for helping you maintain a routine, stay motivated with your health and can even be someone to talk to about managing CF. They can provide flexible and supportive services including:

- Airway clearance support
- Assistance with exercise programs
- Nebuliser support

Subsidies

- Patient Support Subsidy- An annual subsidy of up to $200 to assist with the purchase of items such as medical or exercise equipment.
- Country Patient Travel Subsidy- $50-$150 per clinic or hospital visit to assist with fuel, parking and food (regional members only).

Community Nurse and Physiotherapist

Available for support with:

- Treatment routines
- Nebuliser assistance
- Motivation
- Assistance with pill swallowing
- Health coaching

Counselling and E-Mentoring

Counselling is available for support with a range of issues associated with living with CF. Our social worker can come to you, you can meet for an informal coffee or even chat over the phone.

Our e-mentoring program is a new program which is now available to link young people up with an older, more experienced person with CF who can provide general structured support.

Transition Support

Our Transition Support Program provides assistance for young adults transitioning from Princess Margaret Hospital (PMH) to Sir Charles Gairdner Hospital (SCGH). CFWA staff can take transitioning young people on a tour of SCGH to see the ward and meet with their new CF care team. This is done in liaison with both PMH and SCGH staff.

Hospital Support

CFWA staff visit inpatients during hospital admissions to offer support and deliver a hospital support bag, with a range of useful items such as toiletries, food and magazines.

Information and Resources

CFWA have developed a range of resources relevant to young people. All resources are available online or in hard copy from our office (can be mailed out upon request):

1. **Exercise: CFfit (www.cysticfibrosis.org.au/wa/cffit)**

A set of three exercise booklets to assist with exercising at home or in the gym:

- 'A Guide for People Living with CF'- information on getting started, motivation, types of exercise and their benefits, considerations during exercise, exercise and food and more.
- 'My Exercise Record'- includes exercise examples, exercise log and a place to record your goals and exercise precautions. Take to your physio for approval and guidance.
- 'A Guide for Personal Trainers'- an information booklet to give to your personal trainer or coach.

2. **Nutrition: CFfood (www.cysticfibrosis.org.au/wa/cffood)**

A set of booklets about food and CF:

- 'Nutrition and Cystic Fibrosis: A Guide for Young People'- Information on enzymes, salt, vitamins, how to eat for sport/exercise, explaining CF to your school, eating when you don't feel well, diabetes, supplemental feeding, feeling different, body image, meal ideas and more.

- ‘CF Bites: Snacks and Meals for those with Cystic Fibrosis’- Recipe book

3. **Nutrition: CFcooking (www.cfcooking.org)**

Short films featuring people with CF, led by CF dietitian Paul O’Neill, cooking healthy CF food. Video topics include:

- ‘Healthy Fats’
- ‘CF Meals Everyone Can Enjoy’
- ‘CF and Exercise’
- ‘Healthy Food for Tired Busy People’
- ‘Salt and Fluids’
- ‘Retro with a Twist’

5. **Education: CFsmart (www.cfsmart.org)**

Includes resources for students and teachers:

- ‘Tips and Ideas for High School Students with CF’- Information on telling teachers about CF, medication at school, keeping up with school work, exams and more.
- ‘A Guide to Cystic Fibrosis for High School Teachers’- Information about CF for high school teachers.
- Videos and interviews from teenagers about living with CF.

For more information about any of these services, please contact Kathryn on **08 6457 7333** or **servicesmanager@cfwa.org**

CFWA MEMBER ALEX INKSTER AND CF DIETITIAN PAUL O’NEILL WORKING ON THE CFCOOKING PROGRAM

NEW YOUTH RESOURCES

We are planning to put together more online resources for young people with CF. To do this we would love to gather input from young people in our community about what information they would like and how they would best like this presented. If you are a young person living with CF and would like to be involved, please contact **education@cfwa.org.au**

MEET OUR NEW NURSE EDUCATOR

This is the “new face” at Cystic Fibrosis WA (CFWA). Please meet Christine Smith, our new nurse educator.

Originally from France, Christine has a wealth of experience and knowledge in clinical and educational settings. She has worked in hospitals in Paris and WA (Fremantle Hospital, The Mount Hospital and Hollywood Private Hospital). She has also worked as a school nurse in two WA private schools and has taught at Edith Cowan University, Curtin University and the University of WA.

Christine is passionate about empowering people to learn and develop. She is innovative in her teaching approach and seeks to cater for her colleagues’ specific development needs and ensure it reflects current knowledge and best practice. As a lifelong learner herself, Christine is not only attentive to delivering workshops and programs, she is also very much interested in learning from the CFWA community how to better meet their health requirements and expectations.

“I feel very grateful and excited to be joining CFWA and I look forward to learning and engaging with the multidisciplinary WA expert teams. I am committed to provide the best educational support to my health professional colleagues in the regions to maximise the health benefits to the whole CFWA community.”

To contact Christine email **nurseeducator@cfwa.org.au** or phone **08 6457 7333.**

AN EVENING WITH CF SCIENTISTS RECAP

In May, 65 Roses Month was launched to a packed audience at the Telethon Kids Institute (TKI) at the annual Evening with CF Scientists. This year's event, hosted by Cystic Fibrosis WA (CFWA) and TKI, saw seven speakers cover a range of issues from gene therapy to the importance of involving consumers in research.

Much of the data presented has not yet been published and is at the cutting edge of cystic fibrosis (CF) research. Consistent across all the presentations was the strong theme of hope for the future.

One of the researchers, Kelly Martinovich, explained how she was looking at using small molecules to patch up flaws in CF genes. Kelly completed her undergraduate biomedical degree at Murdoch University in 2008 and honours in medical science at The University of WA (UWA) in 2009. She has worked as a research assistant in the epithelial research group at TKI for three years prior to her enrolment in further studies, and began her PhD in March 2016.

Kelly explained that "genes are like the recipe book for the production of proteins in our bodies. These proteins determine how our cells work by virtue of their shape. When the gene is damaged, or mutated as we say, the recipe gets mixed up and the protein that's made is not quite right. If it's not right, then either it doesn't work quite the way it should, or not at all."

Kelly explained that her research is looking at using small molecules (called antisense oligonucleotides) to effectively put a band aid over the damaged part of the CF gene to get a partially functioning Cystic Fibrosis Transmembrane Regulator (CFTR) protein.

"By using a band aid to mask the damaged part of the gene, we should still be able to make our cake. It may not be perfect but the aim is to make it edible. We think that we might only need a relatively small percentage improvement to provide an effective treatment for people living with CF" she said.

Kelly's work has built on work undertaken by Professor Steve Wilton in the area of Duchene Muscular Dystrophy (DMD) which, like CF, is also a recessive genetic disease. It is being undertaken in collaboration with the centre for comparative genomics based at Murdoch University.

Professor Wilton took 20 years to develop the first compound to treat the underlying cause of DMD with miraculous results. Our hope is that by building on this work we should be able to accelerate the process to get something for CF a lot sooner.

Dr. André Schultz is a CF scientist and CF Centre Director at Princess Margaret Hospital (PMH), soon to be relocated to Perth Children's Hospital (PCH). He talked about his work in the area of unresolved grief around diagnosis, which may influence a parent's ability to deal with their child's diagnosis of CF. This study was borne out of feedback from the Consumer Reference Group at PMH who asked for more research around psychological aspects at diagnosis.

A highly specialised screening process is used to determine if parents have unresolved grief in relation to their child's diagnosis. Parents who have unresolved grief are then offered a combination of five hours, spread over a few weeks, of insight oriented psychotherapy, followed by five hours of CF related upskilling/education with expert CF clinicians, or vice versa. After each intervention (psychotherapy or education), unresolved grief is again screened for.

Preliminary results suggest that unresolved grief is widely prevalent amongst parents of children with CF and can be present for many years. Fortunately, it appears that such grief can be resolved with appropriate intervention.

Daan Caudri was trained as a paediatrician and epidemiologist in the Netherlands and finished his PhD in 2010. In 2015, he came to Perth for a Fellowship in Respiratory Medicine and Sleep Medicine, supported by the Rothwell Foundation Fellowship. During that fellowship, he has contributed to several research projects using the AREST CF database.

Daan presented insights from data collected at the Perth and Melbourne paediatric CF centres, linking practices with clinical outcomes and identifying implications for intervention. Doctors are always trying to decide whether your child needs more or less medication, and they make use of all the information they can get; the symptoms you tell them about, the blood and bronchoscopy test results, problems in previous years. Despite all that information, it remains quite difficult to predict the future. Will the cough resolve with oral antibiotics and physio, or is an admission with intravenous antibiotics needed?

The AREST CF data base contains a wealth of knowledge on which factors are best for predicting the risk of lung problems in individual children. But it is not easy to analyse such a large dataset. Daan used complex statistical and mathematical models to develop personalised risk scores in children with CF. A score was developed to predict if a child will need an admission in the following six months, and another score was developed to estimate the long-term risk of developing lung damage.

"Obviously we do not just want to predict future problems. If we know a child is at increased risk for lung damage, we want to use that information and do something about it, for example, a doctor could then ask for more investigations, arrange more frequent follow-up, or start some stronger medication. Using a personalised approach means we can do this only for the children who really need it. If your child was doing fine on his/her current treatment, why would you want to change anything?"

In an innovative development, the evening also encompassed an inspirational presentation from Ben Horgan from the Involve Program. Ben talked about the importance of involving consumers in research.

Ben Horgan was diagnosed with Juvenile Rheumatoid Arthritis in 1973, aged 2. The disease quickly consumed every joint in his body, changing his and his families' lives forever. Not expected to live past the age of 10, Ben's story is one of determination and courage.

Ben is currently working for the Consumer and Community Health Research Network as a Consumer Advocate. A seasoned consumer representative, working on several state and commonwealth health initiatives. His current role enables him to utilise all his experience and evidence based best practice models to improve collaboration between researchers and the community.

"Consumer and community involvement in research is more than just a good idea, it is actually the right thing to do. Lived experience is invaluable to understanding what we research, how we research and what we do when we finish. I was lucky to have a determined mother who decided soon after my diagnosis to find out as much as she could to help me and others in similar situations. She conducted two large research projects which ultimately enabled her to write a book entitled Arthritis in Children; A Practical Guide. It was the first book of its kind in the world in 1983 and gave me an early understanding of what research is all about. Mum never went to university or got a PhD, she was just a mum who had a real-life experience and wanted to make a difference.

My first personal experience involving research was with an international clinical trial OMERACT (Outcome Measures in Rheumatoid Arthritis Clinical Trials), and a project trying to define flare. Researchers and consumers were separated and given de-identified core set results, including a Quality of Life score, Patient Global, Physician Global, number of inflamed joints and blood results. From these results, we were asked to make two piles: one in flare and one not, in our opinion. Both groups were then brought back together and the results were compared. Interestingly, the results were almost opposite. The consumers were prioritising the Quality of Life score and the Patient Global, and the researchers were prioritising the number of inflamed joints and blood work. A discussion followed coming to the conclusion that neither group were wrong, simply looking at the problem from a different point of view. From the consumers point of view, bad blood results or a high number of inflamed joints does not mean a flare. A good Quality of Life score seems clear that the consumer is not experiencing flare despite adverse test results. Having consumers involved in research brings a 'lived experience' to a project that can add value and bring a perspective that is empowering for all involved.

For more information about consumer and community involvement, visit the website **www.involvingpeopleinresearch.com.au**. Whether you're a researcher or a person with lived experience we can support you in research".

Other presentations were made by Dr. Anna Tai, Tim Rosenow and Prof. Stephen Stick. Unfortunately, space does not allow for these to be reproduced here, but a video of the evening is being put together by TKI and will soon be available. Please keep an eye out on our Facebook page and e-news for the link.

Much of the work done by the AREST CF team is being funded through the Little Lungs Big Futures research campaign which has already raised over $2.7m here in WA thanks to major gifts from Stan Perron, John Rothwell, the Allingame family, Conquer Cystic Fibrosis and the CFWA Golf Committee. For more information on our research please contact the CEO Nigel Barker on **08 6457 7333** or **ceo@cfwa.org.au.**

STAN PERRON AND PROF. STEPHEN STICK

BUNBURY ‘MINI’ EVENING WITH CF SCIENTISTS

Members in Bunbury and surrounding areas are invited to join us for an overview of up-to-date research from cystic fibrosis (CF) researchers.

Luke Garratt, senior scientist from the AREST CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis) team, will provide a snapshot of current research undertaken at the Telethon Kids Institute (TKI).

The evening will also include a small presentation from regional member Ella Lawrance about the CF Consumer group, an update from Cystic Fibrosis WA about services and programs, and dinner.

When: Thursday 27 July 2017
6.00pm–9.00 pm, for a 6.30 start

Where: Lord Forrest Hotel
Conference Room
20 Symmons Street, Bunbury

If you have CF, please be aware that there may be other adult people with CF at this event. We request that you follow standard cross-infection guidelines. For further information visit **www.cysticfibrosis.org.au/cfa/infection-control** For members in the south west outside of Bunbury, accommodation may be arranged if requested.

This event is proudly sponsored by Telethon and is a FREE event for members, however RSVP is essential for catering purposes. Contact Kathryn at **servicesmanager@cfwa.org.au** or on **08 6457 7333** to RSVP or for more information about the event.

LOOKING IN THE MIRROR WHEN YOU ARE EATING CAN INCREASE YOUR APPETITE

We know that many parents find it challenging getting sufficient calories into children living with cystic fibrosis (CF). Cystic Fibrosis WA (CFWA) and Sir Charles Gairdner Hospital’s (SCGH) previous dietitian Paul O’Neill (thanks to a grant funded by Vertex), recently published a series of online cooking videos, CFCooking, to help address this. But could new research from Japan add another string to our bow?

According to the lead author of the research from Nagoya University in Japan, food tastes better and people eat more of it when eaten with company than alone.

Although several explanations have been proposed for what is known as social facilitation of eating, they share the basic assumption that this phenomenon is achieved by the existence of co-eating with others.

Using mirrors, the researchers demonstrated a similar “social” facilitation of eating effect in the absence of other individuals.

Elderly participants tasted a piece of popcorn alone while in front of a mirror (which reflects the participant themselves eating popcorn) or in front of a wall-reflecting monitor, and were found to eat more popcorn, and rate it better tasting, in the self-reflecting condition than in the monitor condition. Similar results were found for younger adults.

The results suggest that the social facilitation of eating does not necessarily require the presence of another individual. Furthermore, they observed a similar “social” facilitation of eating even when participants ate a piece of popcorn in front of a static picture of themselves eating, suggesting that static visual information of “someone” eating food is sufficient to produce the “social” facilitation of eating.

REFERENCE

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TRANSITION: PAEDIATRIC TO ADULT CARE

Transitioning from paediatric to adult health care can be a difficult and confusing process, particularly with the challenges of adolescence.

As advancements in medical technology and health care are made, survival of children with chronic disorders continues to improve and it is estimated that 90% of children with a chronic disorder, such as cystic fibrosis (CF), will reach adulthood. This highlights the need to implement the transition of care from paediatric to adult medical care. The goal of a planned transition is to achieve a reduction in the interruption of care, maximise well-being and improve quality of life.

Unfortunately, this transition period typically occurs during adolescence when patients are already struggling with the physical, emotional and psychological changes, made particularly more stressful when you have a chronic illness. It is also a time when the young person is trying to develop self-sufficient disease management skills and facing the ongoing expectations of the health care teams. The goals of a planned transition are to be well-timed and specific to each person, thus aiming to maximise lifelong functioning and well-being for all youth.

A structured transition program should include coordination and preparation between the paediatric CF centre, the patient, family and the adult CF centre. Allowing patients to interact with the adult team prior to transition and addressing specific issues can lead to a successful transition process.

Over the last five to six years a transition clinic has been established at Princess Margaret Hospital (PMH) in Western Australia. Patients attend the transition clinic up to three times, where they and their family meet the adult team in the familiar, secure surrounding of their paediatric centre. Here, issues about transition are discussed, anxieties are allayed and preparation for the move to the adult centre begins. Fertility and sexual health education is also included in these transition clinic sessions. These appointments are commenced and continued throughout the teenage years in order to optimise the best possible outcome for a timely, sensitive and uninterrupted transition.

When appropriate, the first appointment at the adult centre, at Sir Charles Gairdner Hospital (SCGH), is arranged.

CFWA NURSE SHARON AT SCGH'S CF CLINIC

The actual transition period ranges from 17–25 years, again centred around the needs of the individual.

The transition process in WA is a collaborative project between PMH, SCGH and Cystic Fibrosis WA (CFWA). A transition booklet, also part of the collaborative project, is used to give basic information. It provides guidelines such as; what to expect at the adult centre, what happens when a hospital admission is required, what to do in an emergency, how to get medications, home treatment and other helpful advice.

CFWA offer a transition tour, where a member of the CFWA services team take individuals and their family on a guided tour of the areas they are likely to visit as part of their treatment plan, and other areas of interest such as the newsagent, coffee shops and ATMs.

The future brings exciting changes. With the foreseeable move of PMH to the Perth Children's Hospital (PCH), transition should continue to thrive with the potential for increased collaboration between the CF centres and CFWA.

For more information about the transition process or to arrange a transition tour, contact our community nurse Sharon on **08 6457 7333** or **nurse@cfwa.org.au**.

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CFSIBS

SIBLING AND OFFSPRING CAMP 2017

When: Thursday 5 October to Friday 6 October 2017

Where: Woodman Point Recreation Camp

Who: Siblings and offspring
Aged 8 to 16 years

Keep an eye out for registration packs going out in early August

For more information contact Paula on recreation@cfwa.org.au or 08 6457 7333

TRANSPLANT SUPPORT DINNER

As part of our Transplant Support Program, we held our annual dinner for individuals who have undergone a double lung transplant, and their partners.

ADAM AND LEXI

Held at the Metro Bar and Bistro on Friday 9 June, 15 members attended the event. It was a wonderful success and provided a great opportunity to connect and share stories with one another.

The dinner is just one aspect of our Transplant Support Program. We also offer:

Post-transplant support, which may include:

- Personal training
- Access to counselling from our social worker
- Links to further supports where required

Pre-transplant support, which may include:

- A home care worker for assistance with airway clearance and exercise, as well as support with light cleaning.
- Access to counselling from our social worker.
- A 'buddy program' where you can be mentored/supported by someone who has already been through the process.
- Our 'Positive Profiles' booklet, where 15 inspirational West Australians share their lung transplant journey. We have hard copies of this wonderful resource available from the office, or you can view it online here:

www.cysticfibrosis.org.au/media/wysiwyg/WA/Positive_Profiles_Low.pdf

For further information about the Transplant Support Program please contact **servicesmanager@cfwa.org.au** or phone **08 6457 7333**.

SUCCESSFUL 8TH ANNUAL REGIONAL RESPIRATORY TRAINING PROGRAM

Regional nurses and physiotherapists travelled across WA, from Kununurra to Albany, to participate in our Regional Respiratory Training Program (RRTP) from 1-5 May.

This program aims to improve regional hospital outcomes for cystic fibrosis (CF) patients through improved awareness, knowledge and connection to our metropolitan counterparts. The course covers information including, but not limited to: CF education, bronchiectasis, Chronic Obstructive Pulmonary Disease (COPD), respiratory physiotherapy, oxygen therapy, non-invasive ventilation, spirometry, pulmonary hypertension, pleural catheters, pharmaceuticals, Percutaneous Endoscopic Gastrostomy (PEG) tubes, continence, nutrition, diabetes, lung transplant and psychosocial aspects of chronic disease. This program is endorsed by the Australian College of Nursing.

Comments from participants:

- "Absolutely fantastic course. Presenters were great, information was useful, and it was thoroughly enjoyable. Thanks for all your great work".
- "Overall a fantastic course, very well organised and informative. Would highly recommend the course to others in the future".
- "This is a very well organised course. All the presenters are very knowledgeable in their area and all presentations were delivered at a high standard. All facilitators are extremely professional and helpful. Thanks a million for everything".

2017 PARTICIPANTS

We are grateful to the Department of Health WA who generously fund this program. Special acknowledgement is also made to our key sponsors, Mylan and Technipro Pulmomed.

Many thanks to all of our very knowledgeable presenters from Sir Charles Gairdner Hospital (SCGH), Princess Margaret Hospital (PMH), Royal Perth Hospital (RPH), Fiona Stanley Hospital (FSH) Lung & Heart Transplant Department, Asthma Foundation, Diabetes WA, Silver Chain and Black Swan Health.

If you're a regional member, our nurse educator is available to do specific CF health professional education at your local hospital, with your general practitioner (GP) or other health provider. For further information please contact Kathryn on **08 6457 7333** or **servicesmanager@cfwa.org.au**

Mylan

TPM

Government of Western Australia
Department of Health

FROCKED AND FABULOUS AT OUR LADIES HIGH TEA

This year, 48 deserving women from the cystic fibrosis (CF) community attended our sell-out 'Ladies High Tea' and enjoyed an afternoon of guest speakers, party games, yummy food, champagne, tea and coffee.

This important support event for mums, partners, female relatives and supportive friends was held downstairs at the Cystic Fibrosis WA (CFWA) offices where we transformed our conference room into a lovely 'restaurant' fit for high tea!

Guest speakers included Sera Taylor-Coker, a young woman with CF who talked about how she has raised both funds and awareness of CF within her Hip Hop community. She also provided some useful tips for our parents on how to encourage their kids to do physio – thank you Sera, you really were a hit!

We were also lucky enough to have established WA artist and philanthropist Di Taylor come along and address our audience. Di spoke about female empowerment and how this theme was prolific in her highly successful exhibition 'Angry Sexy Hot Chicks'.

Di continues to provide both financial and hands-on support to CFWA and we are very grateful Di for all the effort you put into our organisation!

BIANCA, MAGGIE, LINDA AND JUSTINE

KATRINA AND GUEST SPEAKER DI TAYLOR

DEIRDRE AND SHARON

HELEN, KAREN AND KIM

VISITING THE REGIONS

The Cystic Fibrosis WA (CFWA) team have been busy visiting members, volunteers and health professionals in the regions to provide support and education.These trips are always a great opportunity to connect with members and discuss how we can best support those living in regional areas.

Great Southern Outreach

Members of both the services and marketing teams enjoyed catching up with members and volunteers in Collie, Albany and Narrogin on the 17 and 18 May. It was wonderful to have a marketing perspective to engage volunteers in 65 Roses Day, which was a fantastic success.

We also had the opportunity to arrange further health professional education sessions for the Albany and Narrogin regional hospitals for later this year.

Merredin Outreach

Part of the services team travelled to Merredin on the 29 May to deliver an education session to kindergarten teachers at the local primary school. They also had the opportunity to catch up with members to discuss how we can best support them.

CFWA are also planning trips to Geraldton, Kalgoorlie and Bunbury later in the year.

We would like to thank Telethon for providing a generous grant to facilitate education, nebulisers and social opportunities for members in regional areas.

MEMBERS DINNER IN ALBANY

KAREN WITH OUR WONDERFUL VOLUNTEERS IN ALBANY, WHO WERE PREPPING FOR 65 ROSES DAY

KATHRYN AND CHRISTINE DROPPING OFF SOME FUNDRAISING CHOCCIES TO WARRICK AT HIS WORKPLACE IN COLLIE

INNOVATIVE SMARTPHONE APP FOR YOUNG PEOPLE WITH CYSTIC FIBROSIS

As an extension of the psychosocial work initiated by AREST CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis), the Health Promotion and Education Research team at the Telethon Kids Institute (TKI) have gained a grant from Vertex Pharmaceuticals to proceed with their innovative online program to support young people aged 10 to 16 with cystic fibrosis (CF).

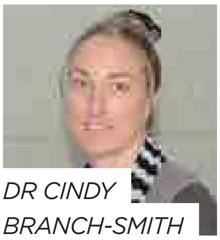
In 2016, Dr Cindy Branch-Smith, the principal coordinator of the project, and Rebecca Nguyen, associate investigator, along with their other colleagues at TKI, surveyed young people aged 10 to 16 with CF about their social and emotional experiences when at school.

From the initial research, the team then worked with young individuals as co-designers to develop a mock version of a smartphone app, with the aim of assisting with the social isolation of CF, linking in with school during hospital admissions, and improving mental health and wellbeing.

With funding from Vertex, further research on the app can be achieved in terms of testing and piloting its usability and effectiveness.

Additional input is being sought for this app project from young people with CF aged 10 to 16 years, so watch this space for more details.

Cystic Fibrosis WA can't wait to see where this exciting venture will go in the coming year.



DR CINDY BRANCH-SMITH

REBECCA NGUYEN

THE WOMEN OF CYSTIC FIBROSIS: SALTY GIRLS

Salty Girls is a collection of real-life stories from women living with cystic fibrosis (CF). In this book, the Salty Girls challenge the norms around body image and strive to put an end to body shaming. No more feeling embarrassed or ashamed of their bodies. They embrace their bodies, scars and all, to inspire women everywhere to do the same.

The following is Cynthia's story:

"Growing up, I would lie to everyone about my disease, as if I could ignore it away. Scars from two ports, an embarrassing feeding tube incision, and numerous PICC lines made me stand out, and in return I became a very reserved person. The constant coughing and bright red face was always a head turner. When kids didn't understand, I became a target for ridicule. Being a teenager is awkward and hard enough on its own, but when you're the "diseased kid" it can tear you down mentally. I'm short, skinny, barrel chested, pale as a ghost, my fingers are clubbed, and my posture is atrocious. I didn't fit the mould and became ashamed of my body. People always assume because I'm small, that I must be secure with my body, but that couldn't be further from the truth.

Salty Girls has changed the way I see myself. I do have a disease; I have CF and I am still beautiful. My body is different than most and that's okay. My body may be marked up from years of medication and procedures, it may fail me on most days, but its brought me this far and for that I'm grateful. I have fought like hell to keep my body going my entire life and I'm proud of that fact. This is me, take it or leave it.

"I'm so far from perfect, so far its been worth it", is tattooed on my arm to remind me of my many imperfections, but also to remember that my struggles got me here. Everything I've been through in my life, whether it be hospital stays, embarrassing side effects from medications, or causing a scene during a public coughing attack, has made for some awkward moments (and amusing stories), but it has also made me who I am. Those experiences have led me to this moment and in this moment, I am proud to be in my flawed body. I am proud to show it off. I am proud to be a Salty Girl".

Cynthia

Photograph by Ian Ross Pettigrew

Other products from The CF Project include:

Just Breathe- A collection of portraits of adults living with CF

The Salty Life- A quarterly magazine

For more information or to purchase a copy, go to The CF Project **http://thecfproject.bigcartel.com/**

USEFUL APPS FOR RELAXATION, MINDFULNESS AND MEDITATION

Mindfulness-based programs have been found to be effective for reducing stress, anxiety, and depression. There are thousands of apps available, so we've done some research to find the ten most popular and trusted mindfulness and meditation apps currently available.

- Headspace (FREE)(iOS and Android): A great app for people just starting out, with 10 newbie-focused 10-minute meditation exercises, known as Take 10. It's designed to help you quickly understand what the practice is all about.
- Smiling Mind (FREE)(iOS and Android): This app helps with anxiety and stress. The meditation content is sectioned in different age groups. Children as young as 7 can use the app as well as adults of any age.
- MyCalmBeat (FREE)(iOS and Android): Brain exercises that help improve your ability to manage stress through slow breathing.
- IMindfulness ($2.99)(iOS and Android): Guided meditations as well as a silent meditation timer, ability to set reminders and track your meditation practices. For beginners through to advanced.
- Mindfulness Daily ($2.99)(iOS): This app supports quick, effective guided practices to reduce stress and anxiety and improve performance.
- Calm (FREE)(iOS and Android): With Calm, you can choose from an assortment of guided meditation experiences. 16 guided meditations from 3 to 30 minutes.
- Worry Box (FREE)(Android): Self-help for worry and anxiety. Use the worry cognitive diary to help you determine how to cope with worry.
- Insight Timer (FREE) (iOS and Android): This app features more than 4,000 guided meditations from over 1,000 teachers, on topics like self-compassion, nature, and stress, plus talks and podcasts.
- The Mindfulness App (FREE) (iOS and Android): This app comes packed with features, including a five-day guided meditation practice, meditation reminders, personalised meditation offers, and timers for keeping you on track.
- Relax Melodies (FREE) (iOS and Android): This app is useful for those with busy minds who struggle to get a good night's sleep. Play with 52 free melodies and nature notes to create a soothing mix. By incorporating a customisable soundtrack, users are guided on to a sleeping path that works.

THE 12TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

The 12th Australasian Cystic Fibrosis Conference (ACFC) –'Optimism, Opportunities, Outcomes', will take place at the Crown Promenade Hotel, Melbourne, from 5-8 August 2017.

The ACFC provides a collaborative and educational forum for cystic fibrosis (CF) professionals to help advance CF research and care. This bi-annual meeting brings together scientists, clinicians and caregivers from around the world to discuss and share ideas on the latest advances in CF research, care and drug development and to exchange ideas about ways to improve the health and quality of life for people with CF.

Cystic Fibrosis Victoria (CFV) have brought together an assemblage of CF specialists from a variety of backgrounds to support the vibrant agenda which will celebrate both Australasian and international breakthroughs, innovative treatments and research.

Over the four days, lay and medical sessions will be held, illuminating the very latest CF research and innovation in treatment and care.

Lay Conference: Saturday 5 and Sunday 6 August

Medical Conference: Sunday 6 to Tuesday 8 August

To view the program, go to the CF Lives Matters website: **http://cflivesmatters.org.au/conference**

To look up discounted hotel rates: **http://cflivesmatters.org.au/conference/Accommodation**

FUNDRAISING NEWS

Alongside our 65 Roses fundraisers, we had some incredible people in our community raising funds and awareness for cystic fibrosis (CF) in the most creative ways! Take a look at some of the amazing things they achieved in April and May.

Kate Serves It Up

Kate held a Serve It Up for CF fundraiser for family and friends in May and raised an incredible **$2,826.39!** We'd like to extend a massive thank you to Kate and her family for hosting such a wonderful fundraiser. Also, thank you to Kate's generous guests who donated and helped her reach her target; your support is greatly appreciated.

Solomon Mine Run for a Reason

The team at Gym Kangi on Solomon Mine site put on their own HBF Run for a Reason to help raise funds and awarness for cystic fibrosis (CF). Workers at the site donated to participate in the run and attended a 65 Roses quiz night fundraiser as well. Together they raised **$1,160** for Cystic Fibrosis WA (CFWA) – thanks Solomon Mine and Gym Kangi!

Shellabears competition is a winner!

Shellabears Real Estate have come up with an innovative way of raising funds for CF. In May, they held a colouring contest and announced that the winning design would feature on their real estate signs during June and July. Eight-year-old Kaely's winning design painted the Shellabears logo in a rainbow of colours – well done Kaely! During June and July, Shellabears will donate $1,000 to CFWA every time one of their signs with the new logo are put up. Thank you Shellabears Real Estate, we can't wait to see the signs popping up all over the neighbourhood! Check out their fundraising page to see how they're going: **give.everydayhero.com/au/help-us-help-cystic-fibrosis**

So far they have raised **$1,337.50**, which is awesome!

Kalgoorlie 65 Roses Day

One of CFWA's members and mother of a child who has who has CF, Peggy, worked with a team of friends and family to raise awareness and funds for CFWA in her local community of Kalgoorlie. The team crafted felt, paper and soap roses to give out on 65 Roses Day attached to an information card about CF. We love this idea – what a great way to share information and spread awareness!

They also came up with something slightly more out of the norm for their fundraising efforts this year. With the help of local artist, Em Anders from Hippocrocaduck, a CF themed "Brave Art Night" was held. 28 lucky locals were guided through the unfamiliar art realm to produce some incredible beauty and the beast's enchanted rose artworks. They raised over **$1,000** with their unique fundraising – well done goldfields team!

Grass Patch Patchers Raffle

The Grass Patch Patchers 65 Roses Quilt raffle was drawn at the end of May and the proud winners are:

1st – Russ Rogan
2nd – Jan O'Connell
3rd – Elsie Casey

Well done! Enjoy your beautiful handcrafted prizes!

Thank you to those who purchased tickets. The Grass Patchers sold all of the 2,000 tickets and raised **$3,512** which has been donated to CFWA. Thank you to the Grass Patch Patchers and the Esperance community where the majority of the tickets were sold. That is an incredible result!

Schools and Child Care Centres

Thanks to the schools and child care centres that held a fundraising or awareness event for CFWA recently. See how they went:

Sawyer's Valley Primary School	**$234.50**
Boyare Primary School	**$231.50**
Lake Grace District High School	**$132.00**
Play's Kool Child Care	**$54.40**

FIRST PRIZE OF THE GRASS PATCH PATCHERS RAFFLE

CF GOLDFIELDS HOSTS AN ARTISTIC FUNDRAISER

IS YOUR SCHOOL CFSMART?

Over the past year Cystic Fibrosis WA (CFWA) has been working with Cystic Fibrosis Victoria (CFV) on giving the CFSmart website a facelift. Generous funding from the Ian Potter Foundation made this possible.

If you haven't seen it before, the CFSmart website includes educational resources for teachers, parents, students and health professionals.

The most exciting and important addition to the website is a free online teacher training resource, consisting of four separate professional development modules. The modules contain key information about cystic fibrosis (CF) delivered through videos, images and text. Our hope is that teachers around Australia will use this resource as a go-to source of information about how to best support their students with CF.

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

Let's all promote this wonderful resource to schools and teachers. Make sure they know that it's there and accessible for all interested staff. Visit **www.cfsmart.org** to check it out!

Additionally, please feel free to contact our Education Officer, Natalie, on **education@cfwa.org.au** if you would like CFWA to speak directly to your child's school.

The Ian Potter Foundation

'Starting School with CF'

WORKSHOP FOR PARENTS

If your child is starting school in 2018 and you would like to know some hints and tips for ensuring the school is educated about cystic fibrosis, and that your child's specific needs are catered for, then come along to our workshop.

We will have a range of CFSmart education resources available, as well as drinks and nibbles.

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WHEN: Tuesday 5 September 2017 7:00 – 8.30pm

WHERE: CFWA office, The Niche Building,
11 Aberdare Road, Nedlands

RSVP: Natalie Amos (Education Officer) by 5pm, Monday 4 September
E: education@cfwa.org.au
T: 08 6457 7333

CFsmart
cystic fibrosis education program

12th

AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

OPTIMISM • OPPORTUNITIES • OUTCOMES

5–8 August, 2017

Crown Promenade Hotel, Melbourne

The 12th Australasian Cystic Fibrosis Conference consists of two streamlined programs for the cystic fibrosis community.

The ***Lay Conference*** will see an assemblage of CF specialists from a variety of backgrounds share and celebrate international breakthroughs, innovative treatments and research.

Our ***CF Medical conference*** promises to be a highly informative and stimulating event for the CF clinicians, scientists, allied health, practitioners, nurses and researchers.

This biennial conference also offers endless networking and social opportunities for attendees.

Early bird tickets now on sale.

CYSTIC FIBROSIS Australia

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