EDITION 2 2016

RED

Cystic Fibrosis WA
40th Anniversary

In This Issue

Taking the Challenge

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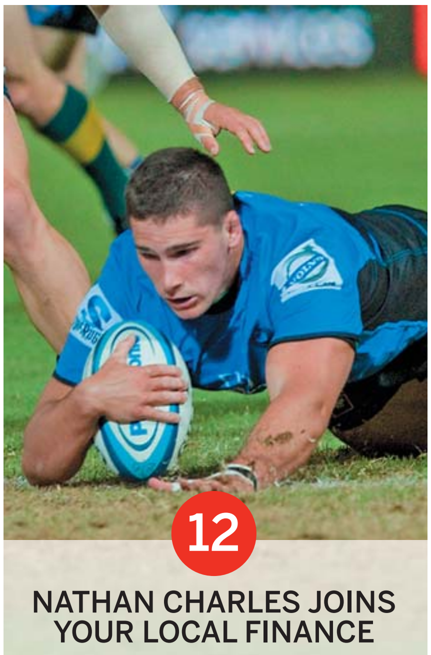

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Features

RED

CEO Message

THE THEME OF THIS EDITION OF RED MAGAZINE IS OUR COMMUNITY


NIGEL BARKER, CEO

In this edition of Red magazine we look at the importance of motivation, goal setting and compliance.

For most people, setting a goal is not a problem but sticking to it is. It's like a boat travelling on autopilot. You can grab the wheel and change course but after a while, it will drift back to assume its previous course unless the autopilot is disengaged.

So how do you disengage your autopilot and achieve lasting change? Short, medium and long term goals certainly help and if these involve being kind to yourself as well, then you are half way to succeeding. There are some great ideas inside this edition that you can use.

We also look at CF and pregnancy. It's wonderful to see more and more people living with CF start families and move inexorably closer to our vision of Lives Unaffected by CF.

Shortly after this edition goes to print we should know if our lobbying has been successful in getting Orkambi® listed. Please check our website for an update. In the meantime, check out the work that has been done nationally, here.

On the 29th April we'll be holding the 2016 George Jones Family Foundation Cystic Fibrosis Golf Classic at Lake Karrinyup day whilst also in this edition we foreshadow 65 Roses month and the fantastic evening with CF Scientists which will be held on Wednesday 4th May at the Telethon Kids Institute.

In May, we'll be holding our Regional Respiratory Training Program for health and allied health professionals helping to ensure relevant services across the state for people living with respiratory disease.

Of course, 65 Roses Day is on 27 May when hundreds of volunteers will be hitting the streets to sell 10,000 roses! Will you be one of them or will you be taking a bucket of roses to your workplace? Will you be doing something special for the 65 Roses Challenge? If you are looking for inspiration as an individual, a business or a school, why not visit our website for some cracking ideas?

Also in this edition we profile an innovative development in Rockingham where CFWA has been chosen to benefit from the sale of one of the units on the 18th June. We also highlight an arrangement with Your Local Finance and Nathan Charles as he sets his own goals for his career beyond rugby.

Finally, we look back at the 2015 Red Tie Dinner Dance at Fremantle Sailing Club and get excited about the event in 2016. Thank you for your support and being part of this journey.

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our winter issue, please contact us before July 1, 2016

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
Kirsty Ballantyne and her family: read her story on page 07.

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

FAREWELL TO ANNE MAREE

It is with a heavy heart that I report the passing on 2 March of one of our most loved employees at CFA, Ann Maree Bosch. Many members of the State and Territory CF Associations across Australia would not have known Ann Maree, but they would have benefitted from her work. Ann Maree was in many ways the backbone of CFA, providing superb organisational skills to organise the Australasian CF Conferences, manage the Australian Cystic Fibrosis Data Registry and Research Trust. She will be sorely missed.

CFA has established a scholarship in Ann Maree's name. Donations can be received at **everydayhero.com.au/event/annmareescholarship** The scholarship will fund a bright young researcher in the CF field.

The loss of Ann Maree is a sad blow but she would be furious with us if we did not continue our work and so it is that we have continued our advocacy training program, centred initially around the listing of Orkambi®, and sought ways to reduce costs and increase revenues. This has included a successful application to Vertex Phamaceuticals to part fund the data registry for three years and support from the Pharmacy Students of Australia.

Finally, if you are travelling down the Mitchell Freeway you might glance up at the new Woodside HQ and see a red platform with the CF rose painted on it. This is Tilly's platform and thanks to Preston hire its helping raise awareness for CF right in the middle of Perth.

Nettie Burke
CEO CFA

Orkambi® TGA Approval

THE TGA HAS APPROVED ORKAMBI® FOR PEOPLE 12 AND OLDER. THE NEXT CHALLENGE IS PBAC REIMBURSEMENT

The month of March was very positive for the cystic fibrosis community with respect to the drug Orkambi® for people ages 12 and older. Orkambi® is the first medicine to treat the underlying cause of cystic fibrosis (CF) for people with two copies of the F508del gene mutation.

In early March, we received news that the Therapeutic Goods Administration (TGA) of Australia had approved Orkambi® (lumacaftor 200mg and ivacaftor 125mg). The TGA approval is based on previously announced data from two 24-week global phase III studies and additional interim 24-week data from the subsequent extension study.

More than 1,100 patients across the world were involved in the phase III studies and those treated with the combination of lumacaftor and ivacaftor experienced significant improvements in lung function. Importantly, pulmonary exacerbations were reduced by 39% and hospitalizations were reduced by 61%.

Patients also experienced improvements in body mass index (BMI) and the use of antibiotic was reduced by 56%. Interim data from the extension study showed that these improvements were sustained through 48 total weeks of treatment.

In Australia, more than half (51 percent) of people with CF have two copies of the most common CFTR mutation, known as F508del. Approximately 1,000 Australians with CF will benefit from Orkambi®.

The Orkambi reimbursement process is already underway in Australia. To help secure a community hearing with the PBAC, an online petition was launched which attracted over 15,000 signatures and here in Western Australia we received media coverage on radio 6PR as well as an article in The West Australian.

As a result of our lobbying a hearing was granted and CFA and two members of the CF community met with the PBAC on 8 March in Canberra. Our advocates discussed Orkambi's® remarkable value and what life was like without it. We shared stories about what a difference Orkambi has made to many Australians on the trial.

Orkambi® has the ability to change health and life outcomes for some people with two copies of the F508del gene mutation and we are passionate about the fact that eligible Australians should have access. We expect a decision by the PBAC regarding reimbursement in the third week of April 2016 and we'll make sure the community is aware of any progress.

10,000 Roses Challenge for CF this May

WAFEX
Australia's leading flower exporter

HERE ARE 3 WAYS TO GET INVOLVED IN THE BIGGEST AND BEST 65 ROSES DAY EVER!

May is cystic fibrosis awareness month and Friday 27 May is 65 Roses Day, our national day of awareness. Every year, community supporters and businesses join us to raise funds for Cystic Fibrosis WA.

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

1. Help us wrap 10,000 roses on Thursday 26 May

This year we are aiming to sell an incredible 10,000 roses around Western Australia, but we need your help! Get a group together for a great team-building day at our office and help us package roses for sale on Friday 27 May, 65 Roses Day. To join us wrapping roses please contact **events@cysticfibrosiswa.org** or 08 9346 7339.

2. Sell Roses on 65 Roses Day, Friday 27 May

This year we are challenging ourselves to sell 10,000 roses all around the state with the help of our generous rose sponsors ,WAFEX. Take a bucket to sell in your office or workplace for $5 a rose.

We're also offering beautiful rose displays, perfect for your office reception or to surprise that special someone on 65 Roses Day.

Visit **www.65roses.org.au** to place your order. Roses can be purchased outright or taken on consignment. Please place your orders by Friday 20 May.

If you can't sell roses in your workplace, join us at one of our locations on the streets of Perth, Subiaco, Fremantle, or at one of your local shopping centres. There are spaces available throughout the day in locations all around Perth. To lend a hand, please contact **events@cysticfibrosiswa.org** or 08 9346 7339.

3. Take the 65 Roses Challenge

Choose your challenge this May, whatever that might be, and set yourself a fundraising target for the month. It could be a physical test to walk/run/swim/ride 65kms in the month or you could organise a garage sale or cocktail party to raise some funds. No idea is wrong, as long as you challenge yourself!

Visit the website **www.65roses.org.au** for some challenge ideas to get started. What are you waiting for? Challenge accepted!

OUR BEAUTIFUL ROSES ARE DELIVERED FRESH FROM WAFEX.

JOIN US ON THURSDAY 26 MAY TO HELP US WRAP 10,000 ROSES!

CHOOSE YOUR CHALLENGE THIS MAY. GET STARTED AT WWW.65ROSES.ORG.AU

65 Roses at Your School

Cystic Fibrosis WA invites you to join Tammy, Todd and Rosie as they learn how to be CF Smart and celebrate the 65 Roses Challenge during the month of May.

The month of May is the national month of awareness for Cystic Fibrosis (CF) and a fantastic opportunity for teachers and students alike to raise money for a great cause, by joining in the 65 Roses Challenge to take part in some fun educational activities and make a difference!

Plus, the school that raises the most per capita will win $500 worth of sports equipment!*

Getting involved is easy:

1. **Pick your date** – Either during May, 65 Roses month, or another time of year that suits your school.
2. **Choose your fundraising idea** – e.g. wear red and students bring in a gold coin to take part.
3. **Get in touch with Cystic Fibrosis WA at 08 9346 7339 or events@cysticfibrosiswa.org** – We'll design a fundraising kit to meet your needs with planning tips, balloons, posters, stickers, educational activities and an online fundraising page if needed. You'll also have the opportunity for one of our staff to visit your school for a CF Smart education session.

We have a 65 at School booklet available packed full of informational worksheets and fundraising ideas.

**Funds raised must be deposited prior to 30 June 2016 in order to be eligible for this competition. The top fundraising school will be calculated on a per capita basis for the student population of the school. The winning school will be announced in the first week of July 2016.*

The Challenge of Pregnancy with Cystic Fibrosis

WORKING AT CYSTIC FIBROSIS WA (CFWA) MEANS THAT WE FREQUENTLY MEET PEOPLE IN THE CF COMMUNITY WHO ARE TRULY AMAZING AND INSPIRING AS THEY DEAL WITH THE CHALLENGES THAT LIVING WITH CF CAN BRING. KIRSTY BALLANTYNE, A 35-YEAR OLD WHO HAS CF, IS CERTAINLY AN EXAMPLE OF AN INSPIRING AND LOVELY PERSON, WHO KINDLY SHARED HER PREGNANCY EXPERIENCES WITH RED AND THE CHALLENGES SHE HAS FACED BEING A MOTHER OF TWO LITTLE GIRLS

RED: Hi Kirsty. Tell us about yourself, your family and your experiences of pregnancy.

I was diagnosed with CF two weeks after birth and my sister who also has CF, was diagnosed at 18 months. My husband, Peter, and I are both from New Zealand and we met through my best friend's brother, who was Peter's best friend. We came over to Western Australia seven years ago for work, before we had any children.

I was told from a young age that it would be unlikely that I would be able to have children due to having CF, even with IVF. For some reason I didn't agree with the doctors. I thought, "That's not me, I'm going to have a child, and I'm meant to be a parent." I think being raised by a really positive mum has influenced me to be a positive person, too.

Peter and I decided to try and start a family while we were working in Karratha but we had a plan B if I was unsuccessful in getting pregnant which was to travel lots and see the world. We had been trying for about three years to get pregnant and I was just about to book a holiday to Rome as we thought we would need to put our plan B into action. We were also organising our wedding; I had chosen a dress, and we had even bought ourselves a dog. But then I had to call my family and say that Peter and I weren't going to be getting married and at first my family were shocked and thought we were breaking up. Luckily, I had great news to tell them - I was pregnant! I didn't believe it at first, so I did four tests and then had a blood test with the doctor. It took ages for the test to come back, but it confirmed that yes, at the age of 30, I was pregnant.

While I was pregnant I was working about 50 hours a week – still up in Karratha. I had to take lots of salt and electrolytes while I was there. By 30 weeks, I finished working as I wanted to focus on my health. I did three nebs a day to keep myself well, and in preparation for the labour I did lots of yoga and swimming. I had trouble gaining weight during my pregnancy. Paul, the dietician from Charlie's, had lots of advice on how to add calories, and although I did try my best, I could only gain seven kilos. I had

to go to King Edward (KEMH) to see an obstetrician as my pregnancy was classed as high risk. I found my obstetrician, Janet, to be great and very vigilant. She liaised with the CF clinic at Charlies. I did have double the appointments though, as I had to go to both King Edward and Charlies. I had ultrasounds every four weeks and clinic at Charlies every four weeks too.

I did get gestational diabetes and so had to watch my sugar intake and I ate lots of red meat - I doubled up on chops. My lung function went down to the 60s towards the end of my pregnancy, but it went right back up after the birth. I had my baby, Chelsea at 38 weeks and she was 6 pounds 11. I was in labour for about seven hours. They monitored my oxygen saturation during the birth and I didn't need extra oxygen. I also had an epidural. I spent two nights in the hospital with Chelsea before I could come home.

I breast fed Chelsea for three months, but I was losing too much weight, despite the fact that I had lots of snacks stashed everywhere around the house to eat while I was breast feeding. Chelsea was a good feeder so it was a shame, but I had to focus on not losing too much weight. I had the support of Fran, a home care worker from CFWA, who came to look after Chelsea so I could go and exercise.

Chelsea is now four years old, attending kindy and doing very well. So a couple of years after I had Chelsea, I spoke to the CF team about trying again for another child. They thought my health was good and my lung function was over 60%. We were trying casually to get pregnant and it took about a year. With my second pregnancy I needed a three to four day admission at Charlies for intravenous antibiotics. I had gestational diabetes again but my lung function was good towards the end of this pregnancy.

Chelsea came to my appointments and I would pack a bag of supplies to keep her occupied; she is used to coming to appointments with me, so she was good. I was in labour for three days with Ariah and had an epidural for this birth too. I spent one night in the hospital before I could come home with my baby girl, who was born at 37 weeks and weighed 7 pounds 14. After two births, my pelvic floor is also not too bad!! I breast fed Ariah for two months but again, I was losing too much weight so I had to give her formula.

While I was pregnant with Ariah, I made lots of food that I froze, so I didn't have to do too much cooking once I came home. During my second pregnancy I also had private yoga lessons as well as going to group sessions. I found the private ones were really helpful in teaching me to breathe in and out and I also had a routine I did at home. I saw the yoga lady once a week, and it was a bit expensive but it really helped with my lung function and also with my pregnancy.

I found the first few months after I had Ariah very hard. I was so tired but luckily I had my mum there for the first couple of weeks, cooking all sorts of amazing food, without which I would have wasted away. But after she left I found it very difficult. We had some other stressful things going on too so my health failed a bit and I just couldn't find the time to exercise. We had to head back to New Zealand when Ariah was six months to help our family out. My lung function dropped and I haven't been able to get it back this time.

Now though, I have got myself back into a good exercise and physio routine. We have worked hard to get both the girls into a good sleep routine too. We followed a book called "The Baby Whisperer" very closely and I dug my heels in about the girls sleeping well. They sleep from 7pm. to 7am. and Ariah has a 1-2 hour nap each day.

I never miss a day of doing my nebs, except if we are flying to New Zealand and it's too difficult. In order to do my exercise I will put on a movie for Chelsea and go on the exercise bike while Ariah is having a nap. I have found that walking on soft sand at the beach is a really good form of exercise too.

I set my alarm each day for 6am and do my airway clearance for 30 minutes. At night I do a saline neb, once the girls are in bed. I look forward to this as I have made it my time. I watch something I enjoy on Netflix and can zone out for 45 minutes as I have to lie down while I am doing the treatment. I know that if I look after myself then I am looking after my children. Pete is a hands-on, amazing dad so that also helps a lot and he reminds me to do my treatment too. He is a fabulous husband to have, I don't know what I would do without him.

I am now finding having two children is easier than I thought it would be but the hardest thing is when I have to go to hospital. I recently had to go for an admission and Pete brought the girls in each day, but I found it very hard not being with them.

We are moving back to New Zealand soon to a house with lots of land as Ariah loves running around outside. We will have great family support, and I will be closer to my sister who also has a three year old child. We are really looking forward to moving back home.

RED: We will miss Kirsty and her family but we wish them all the best as they settle back into life in New Zealand.

A Positive Challenge! Pregnancy in Cystic Fibrosis

MANY WOMEN WITH CF ARE WELL ENOUGH TO CONSIDER PREGNANCY AND WITH THE SUPPORT OF THEIR CF AND OBSTETRICS TEAM, GO ON TO HAVE HEALTHY BABIES. BUT HOW DOES PREGNANCY IMPACT THEIR HEALTH AND HOW WILL THEY BE AFFECTED AFTER THE BIRTH?

One of the most important questions for women with CF is whether pregnancy will have a detrimental effect on their long-term health. The consensus now is that pregnancy does not significantly shorten survival. In a large study published by Gross et al, 680 women with CF who became pregnant were compared with women with CF who did not. It was found that the 10-year survival rate was higher for the women who became pregnant.

However, caution regarding pregnancy is advisable as individual women respond differently. Some women do experience a deterioration in their health during and after pregnancy and the long term prognosis needs consideration.

Women with good pre-pregnancy lung function (FEV1 >70% predicted) tolerated pregnancy very well and had the most successful outcomes and lowest maternal mortality. As lung function declines, the risk of poor pregnancy outcome increases, as does maternal mortality.

Pulmonary hypertension and corpulmonale (the abnormal enlargement of the right side of the heart associated with lung or pulmonary blood vessel disease) are considered absolute contraindications to pregnancy. There are also reports of poor pregnancy outcomes and increased maternal mortality associated with the presence of maternal infection with the organism B. cepacia.

It has also been suggested that women with CF who become pregnant have less severe disease and superior nutritional status than women who do not.

Pregnancy Counselling

Accurate and unbiased advice and counselling is essential for women with CF who are contemplating pregnancy. A thorough assessment of the severity and rate of progression of the disease is crucial to obtain accurate information about the likely outcome of pregnancy and its effect on maternal health. Thorough discussion about the many challenges of parenthood when coping with a life-limiting disease is imperative. The possibility of maternal death and a partner being left alone to bring up a child is a difficult topic to discuss but should be considered.

CF and Your Baby

If you have CF, your baby will be a carrier of the CF gene. As part of the genetic screening process you will be offered counselling to help understand the results and make the right choice for you and your partner. As an adult with CF, your partner should be tested to see if they carry the CF gene. If they do, there is a 50% chance your child would have CF.

Things to check with your CF centre:

- Talk to your CF specialist about a medication review to make sure they are safe for your baby; some may need changing.
- Ensure weight and lung function are the best they can be to help your baby grow.
- Check your blood sugar levels.
- Seek advice regarding a fertility specialist

referral if you are having difficulties falling pregnant. It is important to do all your treatments to make sure your baby grows and your lungs keep as healthy as possible to reduce the risk of pre-term birth and complications. You need to maintain a regular routine of airway clearance, exercise and inhaled medications to reduce respiratory exacerbations during pregnancy. Your airway clearance and exercise regimes may need to be adjusted during pregnancy. Regular check-ups with your specialist physiotherapist to make sure you are on track with treatment are very important. Some women may require intravenous (IV) antibiotics prior to conception and expected delivery date to ensure optimal health.

- A pre pregnancy anoral glucose tolerance test should be performed to look for evidence of CF related diabetes (CFRD) or impaired glucose tolerance. Women with diabetes should be referred to a specialist in CFRD before conception.

Diabetes during pregnancy is more common with CF. Untreated diabetes may lead to weight loss, fatigue and decline in lung function. High blood sugars can harm your baby; it is, therefore, necessary to monitor your blood glucose levels during your pregnancy. Testing for diabetes is also important, as the incidence of gestational diabetes is higher in CF and failure to diagnose and treat it may be associated with poorer pregnancy outcomes. An oral glucose tolerance test is recommended in the first trimester and at 24-28 weeks of gestation in all women who have normal glucose tolerance prior to pregnancy.Optimising glucose stability will reduce the risks of congenital malformation and pregnancy complications.

A first trimester ultrasound, for accurate dating of the pregnancy, and a second trimester anomaly scan are recommended. Women with pre-existing diabetes may also be offered a foetal echocardiogram. Regular ultrasound assessment of foetal growth and wellbeing in the third trimester is essential.

Nutritional Considerations in Pregnancy

Good nutrition is vital for your health and to store nutrients to help your baby grow. Focus on eating nutrient rich foods and make every mouthful count. The increase in energy requirements while pregnant can make gaining weight a challenge, however, weight gain is essential for baby's growth and development and those who gain adequate weight during pregnancy have better outcomes and bigger, healthier babies. If you have CF and are pregnant, you will need to eat a range of foods from the five food groups in three meals and many snacks daily to meet your nutritional needs and those of your baby. Talk to your dietician for advice on increasing energy intake for your pregnancy.

Vitamins and Pregnancy

Taking your vitamins is important to build your stores to have adequate levels for your baby. Your CF team will advise you on additional vitamins needed in pregnancy. Folate and iron are important for all women planning a pregnancy.

Folate (folic acid) is a B-group vitamin essential for the healthy development of the foetus in early pregnancy, in particular their neural tube. It is recommended you take folate supplements 3 months pre pregnancy to reduce the risk of neural tube defects, e.g. spina bifida.

Calcium and vitamin D are important for baby's bone growth. Pregnant women with CF need more than this because calcium is not always absorbed in the gut. It is important dairy products are stored safely to avoid contamination with bacteria including listeria (a bacteria that can cause infection and serious illness in pregnant women). You need to take your vitamins A, B, D, E and K to build up your stores.

Pregnancy Concerns

Alcohol: No amount of alcohol is safe in pregnancy and, therefore, should be avoided.

Gastro Intestinal Issues: Hormonal changes and the enlarging uterus often give rise to troublesome gastrointestinal issues in pregnancy. Discuss issues such as morning sickness, reflux and constipation with your CF team as there may be different solutions for each person.

Continence: Pregnancy may weaken the pelvic floor muscles due to the weight of the growing baby and pregnancy hormones which soften the ligaments in the body and the support structures in the pelvic floor. If you have poor bladder control and have urine leakage with coughing, airway clearance, laughing or exercise, you will benefit from seeing a women's health physiotherapist or contacting the National Continence Helpline on 1800 33 00 66.

Delivery

An individual delivery management plan should be made with gestational age, disease severity and foetal wellbeing all being taken into account. Elective pre-term delivery may be required if maternal health and lung function is declining or if there is evidence of restricted foetal growth. Elective pre-term delivery is usually by caesarean section. In the majority of cases, if maternal health is well maintained and the baby is growing normally, vaginal delivery can be anticipated at term. Lung function should be optimised prior to delivery and this may require admission to hospital in the third trimester for intensive physiotherapy and antibiotics prior to induction or caesarean section.

The outlook for people with CF has improved dramatically in recent years. The long-term prognosis in the majority of women is unaffected by pregnancy and, if lung function is maintained, it can be undertaken safely. Women with poor lung function have an increased risk of pregnancy complications and maternal death. Pre pregnancy counselling and the input from the multidisciplinary team during pregnancy is essential to optimise the outcome for mother and baby

Breastfeeding

Breastfeeding is exhausting and uses up calories so women with CF may find it difficult to breastfeed exclusively. If

Nathan Charles' Plea to Give Back

CYSTIC FIBROSIS WA IS DELIGHTED TO ANNOUNCE A NEW AGREEMENT WITH FINANCE SOLUTIONS PROVIDER, YOUR LOCAL FINANCE (YLF)

CF ambassador Nathan Charles, recently joined YLF as part of his long-term plan to transition from professional sport to a lifetime career. "It's prudent to plan for my future and I'm really pleased to have joined the team at YLF and to continue to support the CF community at the same time. Alex and the team at YLF can save you money and offer you a truly independent approach with access to over 28 lenders."

ACTION: Call TODAY if you haven't reviewed your home loan in the last 12 months. You will almost certainly save thousands of dollars over the life of the loan, or be able to pay the loan off much sooner. Call Alex Stajka, Finance Executive on 0450 020 552 for your free quote.

Make sure you mention Cystic Fibrosis WA when you start your stress-free and seamless financing application.

This is a win-win situation in every respect. You save money on your home loan and Cystic Fibrosis WA receives a commission for every deal so that we can help SAVE LIVES!!

YOUR
LOCAL
FINANCE

2016 Parents' Retreat

OVERLOOKING THE BEAUTIFUL INDIAN OCEAN, HILLARYS HARBOUR RESORT HOSTED OUR ANNUAL PARENTS' RETREAT FROM 11 – 13 MARCH

PARENTS RETREAT HILLARYS HARBOUR RESORT

A fantastic turnout this year saw 34 parents - our biggest group ever - attending a weekend getaway at the marina resort. To provide opportunities to socialise and network, the group were treated to a visit to AQWA, a Saturday matinée and a delicious three-course Italian meal at Mia Cucina. The weekend also included plenty of down time for our wonderful parents to relax and recharge.

Thanks to Carers WA and Lotterywest for recognising the value of our carers and providing funding to make this significant respite event possible.

lotterywest supported

Carers SA AUSTRALIA
Supporting Family Carers

Join Our Champagne High Tea...

All female carers of people with CF are invited to frock up for a fabulous afternoon of champagne and high tea.

Venue
Hyatt Regency Perth

Time
3pm - 5.30pm

Cost
$20 per person

Date
Sat 14 May

RSVP by Friday the 29 April
at tinyurl.com/h3qlrxn

CYSTIC FIBROSIS
Western Australia

More information contact 9346 7333
or recreation@cysticfibrosiswa.org

An Evening with CF Scientists

TO LAUNCH 65 ROSES MONTH, THE AREST-CF TEAM WILL ONCE AGAIN BE PROVIDING AN UPDATE ON THE VERY LATEST CF RESEARCH

Researchers from the Telethon Kids Institute, Princess Margaret Hospital and Sir Charles Gairdner Hospital will be sharing their views on early childhood, adolescent and adult CF reserach. The evening will also include laboratory tours, presentations and an informal poster session with an opportunity to chat to the researchers followed by light refreshments.

This year, Capel Vale will be providing their beautiful wines and WAFEX will be helping launch the month by donating to every participant a very special rose.

Date: Wednesday 4 May

Time: 6pm for a 6:30 start

Venue: Telethon Kids Institute, 100 Roberts Road, Subiaco

Space is limited to just 80 people so RSVPs are essential. Please RSVP to **http://aneveningwithcfscientists.splashtaht.com**

TELETHON
KIDS
INSTITUTE
Discover. Prevent. Cure.

Advocating for CF

IN EARLY MARCH 2016, NETTIE BURKE THE CEO OF CFA, VISITED CFWA TO PROVIDE A COMPREHENSIVE DAY'S TRAINING TO POTENTIAL ADVOCATES FOR CF. THIS TRAINING HAS NOW BEEN PROVIDED TO POTENTIAL ADVOCATES IN ALL STATE AND TERRITORY CF ASSOCIATIONS

Here in WA, nine people attended the training and now form a core of people which CFWA and CFA can draw upon to fight for our cause. Of course, advocacy skills is not restricted to national issues like pharmaceuticals but can also be applied locally.

The need for advocates to speak with one voice across Australia was highlighted during the Kalydeco® campaign. We discovered the importance of working collaboratively with the Department of Health and Ageing, the Pharmaceutical Benefits Advisory Committee, Vertex Pharmaceuticals, the Minister for Health and Federal and State MPs. Ironically, we also discovered the dangers of acting unilaterally and the double edged sword that is social media which although well intentioned, actually threatened to delay the listing of this drug. Formal advocacy training is designed to minimise the potential for harm and maximise the opportunity for success.

CFA provides a national co-ordinating role for all the CF associations and their advocacy training has proved to be critical in our latest advocacy campaign which seeks to get Orkambi® listed on the Pharmaceutical Benefits Scheme as the next small molecule to address the underlying cause of CF.

For more information on Orkambi® and the latest research make sure you RSVP to your invitation to attend an evening with CF Scientists at the Telethon Kids Institute on 4 May.

Staying Motivated

CYSTIC FIBROSIS (CF) HAS A HIGH BURDEN OF CARE AND BIG EXPECTATIONS TO REMAIN MOTIVATED IN THE TREATMENT REGIME. FOR MANY PEOPLE WITH CF IT'S VERY DIFFICULT TO MAINTAIN WHAT SOMETIMES SEEMS RELENTLESS TREATMENT.

Adult comment:

"At around age 16, I really started to resent the constant pressure to eat and constant monitoring at hospital visits. I think at that point some of the pleasure of eating disappeared." (female, 31)

As children, a lot of motivation comes from our parents, however, at some stage it's important to self-motivate; owning our own goals and desire to make things happen.

Here are some effective motivation strategies which can help us remain motivated, even when we are just "over it" and find it really difficult to stay on track.

Set goals that are important to you. Sometimes things can feel too big or just overwhelming. Setting goals will help break things down into manageable parts and assist in making things happen.

Start with a list of five things you enjoy. Identifying some of your key strengths will help you achieve your goals. Similarly, make a list of 5 things that you don't want, turning them around to become goals e.g. "I don't want to spend my days at home, not working" into "I want a good job that is flexible and that I enjoy" or if work is difficult at the moment "I want to do things that make me feel good about myself, such as….."

The goal needs to be:

- Realistic e.g.know your own body, its strengths and limits. Speak to your medical team if unsure and develop a plan
- Specific e.g. "I aim to be my ideal weight which is…"
- Time frame and have an end point e.g. "each day/week I will do… and at 3 months I will reach my goal"

Set sub goals if it's a larger goal such as saving money and staying healthy enough to travel, it's important to break it up, having a plan of action to achieve the ultimate goal. Celebrate small successes.

Make a plan of action

- Write down your sub goals and keep them in a place where you can see them
- Include a time frame for each small goal, including a deadline to prevent putting things off or forgetting your goal
- Choose goals that interest you. Positive motivation is easier to work for when you genuinely want to achieve something
- Reframe goals that don't interest you and find a goal within something that does interest you. e.g. physio is really boring and time consuming, but it keeps me healthy and I need to be healthy to go on that great trip overseas
- Tell your friends, make your goals public. Then you've made a public promise to do something. You may also get support to achieve your goals
- Track your progress. You can use a visual chart, diary, bank statement or something similar to help motivate you to achieve yourgoals
- Break up your goals. It's easier to start small and build up to bigger challenges. This also helps build your confidence for bigger tasks. e.g. if your big goal was to achieve a run you would definitely start small with a well thought out exercise plan
- Reward yourself. Each small win should be celebrated
- Get support. Get your friends and family involved, join a class, use apps, use a CFWA home care worker, talk to your CF care team and make a plan.

Learn to problem solve. You have great goals but you're not sure how to get there. Similarly to setting goals it's useful to use a few strategies:

- What's the problem? Separate out the issues. Sometimes everything gets lumped together and seems overwhelming. By doing this you can focus on each issue separately and develop small steps or goals that are manageable to resolve an issue
- Brainstorm lots of different solutions. Be creative and come up with as many solutions as you can think of and then rule out any options that aren't useful
- Use a pro/con list. Identifying all the benefits and negatives for each option, then choose the best options and make a plan
- Review and be flexible.All good plans can sometimes need adjusting.

Adult comment:

"I planned to do a 12km run and worked really hard to get fit, but got sick just before it, so I readjusted my plan and walked the 12kms instead. I still felt really proud that I was able to achieve this" (Female, 26)

Be kind to yourself. Having CF can be tiring and can sometimes get you down. Try not to compare yourself to others and set your goals around what's important to you. Planning things and setting goals not only enhances motivation it has also been proven to improve mood. When you are really struggling a plan can also help get you back into good routines. The routine will help you get back your motivation.

If you are really struggling to get motivated or feel that your mood is getting in the way, Cystic Fibrosis WA can help with health coaching and motivation. **Call Kathryn for further information servicesmanager@cysticfibrosiswa.org or 08 9346 7348.**

REFERENCES:

Didsbury&Thackray, 2010
cfbodyimage@gmail.com

http://au.reachout.com/

Welcome Karen

Are you looking for ways to get involved with Cystic Fibrosis WA this year? Our new Business Development Manager, Karen De Lore, welcomes your contact to discuss fundraising, events, and partnerships that will help Cystic Fibrosis WA achieve our vision of "Lives unaffected by CF".

Karen was most recently working with the Spirit of the Streets Choir, and has a background in community fundraising, and information management in the oil & gas sector. Just in time for our busy events calendar, you will have an opportunity to meet with Karen at our CF Scientists Evening, our upcoming Golf Classic or as part of the 65 Roses campaign.

Karen is looking forward to being an integral part of our upcoming events, and can be **contacted on 08 9346 7336 or via email marketing@cysticfibrosiswa.org.**

Plan Your Fitness Events for CF This Year

IT'S TIME TO PLAN YOUR FUN-RUN FOR CF THIS YEAR. WE'VE PUT TOGETHER A LIST TO MAKE IT EASY TO CHOOSE. PICK YOUR FAVOURITE, OR BETTER YET, DO THE LOT!

HBF Run for a Reason

Sunday 22 May

Perth's favourite fun run is coming soon! There's a 4km, 12km and half marathon course, so this event has something for everyone. Join the Rose Runners and help us reach our $30K target.

Visit www.hbfrun.com.au for more information and to sign up.

Swan River Run

Sunday 24 July

The Swan River Run course takes you along the banks of the river and through King's Park with your choice of a 5km or 15km run.

Visit www.swanriverrun.com.au for more information and to sign up.

City to Surf

Sunday 28 August

One of Perth's oldest fun runs, with a range of distances from 4km to a full marathon. There are also City to Surf events in Karratha, Albany, Geraldton and Busselton.

Visit www.perthcitytosurf.com for more information and to sign up.

Halloween Run: A Great Strides Event

Sunday 23 October

The Perth Great Strides event is getting a spooky makeover as the Halloween Run. We'll give you more details closer to the event, but make sure you save the date!

If you have questions about any of these events, please get in touch at events@cysticfibrosiswa.org or 08 9347 7339.

2016 Transplant Dinner

THE PAGODA RESORT & SPA HOSTED OUR ANNUAL TRANSPLANT DINNER

A great turnout this year saw some of our lung transplant recipient's and their invited guest enjoy a delicious three course meal at the Pagoda in Como. As well as using the time for networking and support, the group were also asked to brainstorm ideas to be included in our Transplant Support Day, scheduled in November. If you have any ideas that you would like to be considered **please contact Paula on recreation@cysticfibrosiswa.org.**

Thanks to Connect Groups and (Live it Forward Together Program) for their support with this program.

Outreach Adventures

CYSTIC FIBROSIS WESTERN AUSTRALIA (CFWA) PROVIDES SUPPORT FOR OUR MEMBERS AND EDUCATION TO HEALTH PROFESSIONALS, SCHOOLS AND OTHER COMMUNITY GROUPS IN REGIONAL AREAS OF WESTERN AUSTRALIA.THIS IS ONE OF THE SERVICES TEAM'S HIGHLIGHTS OF THE YEAR.

February of this year found us on our travels again heading to Kalgoorlie and Esperance. As usual, we were met with much enthusiasm by our wonderful families and the local hospitals.

As Jan Howie, our nurse educator, headed to Kalgoorlie Hospital to upskill the nursing staff on cystic fibrosis, Sharon Dewar, our community nurse, set out to a family day care to offer support and education there. In both instances there was a captive audience and a lot of questions and queries were answered.

That evening some of our Kalgoorlie members joined Jan and Sharon for a tasty dinner at a local Tapas Restaurant. This was a great opportunity for the families to meet and to swap stories and build special friendships and support networks. There were lots of laughs and 'Yes, I know how you feel' moments.

Once the sun had started to rise the following day, Jan and Sharon were back on the road for the trip to Esperance. Meeting families there, another chance to offer support, to listen, to educate and to be inspired by our members.

Esperance Hospital were ready and eager with a full room of enthusiastic nurses. They were ready to learn more about CF and how best to deliver care and support to those affected.

We are now planning our next trip down south to Albany. So let us know if you would like us to arrange an education session at your local school or day care centre while we're there. We look forward to catching up with you all.

JAN AND SHARON HIT THE ROAD TO EDUCATE REGIONAL HOSPITAL STAFF AND CONNECT WITH LOCAL CFWA MEMBERS.

Taking the Fundraising Challenge: Red Tie Dinner Dance

WENDY BARKER TALKS ABOUT THE CHALLENGES AND REWARDS OF ORGANISING THE RED TIE DINNER DANCE

How did you first get involved in the organisation of the Red Tie Dinner Dance?

My husband Nigel, the CEO of CFWA, was talking to Bill Rawlings of the power section at Fremantle Sailing Club (FSC) where we are members. Bill said the power section would love to organise an event to support CFWA at which point Nigel immediately volunteered me! So I really had no say in the matter. Since getting involved however, I have loved it and the club has been fantastic in freely offering its support. FSC is a large business in Fremantle but is also part of the community. The club recognises its corporate social responsibilities and the Red Tie Dinner Dance filled a gap where it could support children and young adults living with CF. This support has been right across the board from Commodore Terry Baker to Michael Deleanu and his staff who organised all the catering. The FSC staff gave freely of their time and of course, all the committee members who have been great sponsorsand hunter gatherers for our auction items.

What motivates you to fundraise for Cystic Fibrosis WA?

Nigel and I don't have a family connection with CF but as a nurse, I understand the impact that diseases like CF have

on families and individuals and I see the passion that drives Nigel every day – it's quite infectious and I was happy to combine my work as a volunteer duty officer and committee member at FSC with something that is making a real difference to the lives of children and young adults living with CF. I know how hard it is to raise funds (and how careful CFWA is in spending them) and with some organisations pulling back on their donations this year, it was clearly time to step in.

What part of organising the event was the most challenging?

As a new event on FSC's calendar it was an unknown quantity so it was a really steep learning curve for my committee. Sourcing donations for the live and silent auctions was the most challenging aspect. This year will be the second year and so things are a bit easier. I was worried last year that we wouldn't sell enough tickets but of course I needn't have been. This year, people have been quick to pay for 12 of the 30 tables available (the club doesn't take reservations without payment) and that's even before we have started advertising. Our philosophy is that we want to price the tickets so that everyone can afford to go. At only $99 a head for a three course meal, entertainment and beautiful Capel Vale Wines, it really does represent exceptional value for money. I think that next year it will be invitation only!

What support from did you find most useful from Cystic Fibrosis WA?

Everyone at CFWA were fantastic all volunteering on the night. I realise that this is a FSC event but we could not have done it without their support and advice. Shelley gave us so much valuable advice and support and Matt did a lot of the design work which is now being done free of charge by FSC. Thanks go to Margie and the administration staff at the club who were brilliant in co-ordinating the ticket sales and Terri in accounts who managed the finances.

GUESTS DRESSED TO IMPRESS WITH RED FLOURISHES.

What piece of advice would you give to someone wanting to host their own fundraising event?

Give yourself time to plan the event well in advance. CFWA produce a great guide for anyone that would like to do a fundraiser but doesn't know quite where to start. Talking to Matt and Shelley has been invaluable as both are highly experienced fundraisers and of course, knowing the boss may have helped just a little bit.

Planning is already well underway for this year's Red Tie Dinner Dance. How can our members get tickets?

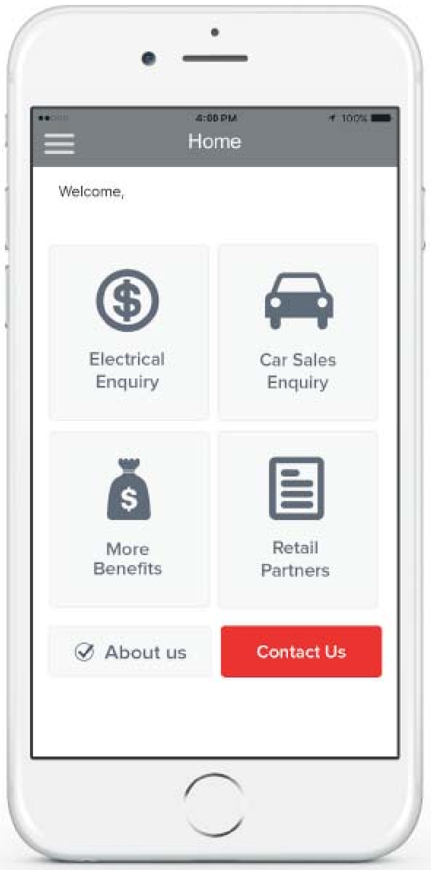
As a club event most of the promotion has been to FSC members but this year I want to throw it open to people that have a connection to CFWA. Unfortunately, the venue restricts the number of seats we can sell so inevitably people will miss out but if you are quick you can call the club on 08 9435 8800 and buy your tickets over the phone. This year's Red Tie Dinner Dance will be held on Saturday 27August. Importantly if you have any items you'd like to donate to the silent auction, then please let me or CFWA know I am on the lookout!

The stress-free way to buy electrical appliances, motor vehicles & much more!

The Trades and Labor Council of Western Australia officially launched ShopRite in August 1996, making this year their 20th Anniversary. ShopRite is a professional service, which focuses on enhancing organisation memberships by providing a discount buying service to members.

Participating organisations advertise to their members the benefits of directing enquiries to a central point where the information is distributed to specific traders, who in turn relish in the increase in turnover. The traders are happy to discount their usual pricing in return for an increase in sales.

To date, ShopRite has saved members hundreds of thousands of dollars. One simple request could save you a lot of time and money. Register today if you haven't already and start to see the benefits you are entitled to as a Cystic Fibrosis WA member.



As a Cystic Fibrosis WA member you can now register and download the new ShopRite iOS or Android App. No more pen and paper when you’re looking for savings on appliances, motor vehicle or many other trades & services. Just grab your phone, open the app, provide ShopRite with the best price you have found and let them do their magic. Alternatively, call them on 08 9300 1221.

Visit: www.shoprite.com.au/apps

ShopRite Pty Ltd aims to benefit organisations by enhancing their members’ affiliation through genuine everyday savings. The business aims to be an integral part of an organisation’s marketing strategy and provide a service that reflects the professionalism of the organisation.

Fundraising News

THANK YOU TO OUR FAITHFUL SUPPORTERS FOR RAISING THE FUNDS WE NEED TO MAKE A DIFFERENCE IN THE LIVES OF PEOPLE LIVING WITH CF. WE THINK YOU ARE PRETTY AMAZING!

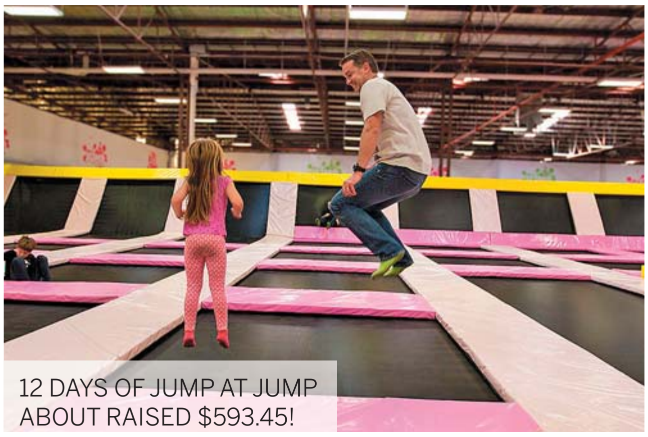
Bethany Flatt and her team of hardworking supporters held a motorcycle challenge and raised $2,800. Thank you so much!

Thanks to Peta Hofer and the team for hosting a Serve it Up BBQ dinner and raising $300. Thanks also to Ron York for coming up with the very clever idea of loaning out his bicycle for donations to CF and raising $26

AynurAtak raised funds through recycled clothing which came to the total of $1,085.25 and Frances Stone hosted a 'Belly Dance Soiree,' raising a very nice sum of $365. Thanks so much!

Megan Stuart, Rueban Campbell and the team from Jump About Trampoline Park held 'Twelve Days of Jump' and raised, $593.45. Thank you!

The year six art students from South Bunbury Primary School raised an impressive $1,286. The students showed -off their creative talents by holding an up-cycling, paint and auction of roadside furniture. A great fundraising idea and a great result! Congratulations on a job well done and thanks so much!



12 DAYS OF JUMP AT JUMP ABOUT RAISED $593.45!

SWIMMING TO ROTTNEST

Ten years ago, Gary Semini promised his body he would never complete another Rottnest Channel Swim. However, Gary's mind overruled his body and on Saturday 27 February 2016, Gary jumped into the Indian Ocean to compete in the Rottnest Channel Swim to raise money for CF.

Thank you Gary for your amazing effort and raising $1,406.25 for helping to improve the lives of people living with CF!

THANKS TO MOUSSE

Shae Clarkson and Mousse raised a remarkable $4,500 by selling their "Twelve Month of Mousse" calendar. The docile, lovable Labrador, who featured throughout the calendar sported an array of colourful and quirky costumes to raise funds for CF.

Thanks for creating such a delightful calendar, for the time and effort you have given, and of course for the funds you raised for CF.

LOOSE CHANGE MAKING A BIG DIFFERENCE

Thank you to the small and some not-so-small businesses who have placed collection tins in their workplace. Your loose change is making a big difference!

Thanks to Sir Charles Gairdner Hospital for the amount of $152.55, Stay Healthy for raising $97.75 and Liquor

SHAE AND MOUSSE RAISED $4,500 WITH A "12 MONTHS OF MOUSSE" CALENDAR.

OUR SUPERSTAR VOLUNTEER CHRIS HAS BEEN PLACING COLLECTION TINS IN LOCATIONS ALL OVER PERTH.

Baron for the amount of $32.15.

My Health Food Store also placed a CF collection tin and raised $15.85 as well as Floreat Vet Centre who raised $46.50, not to mention Xpresso Code for raising $215.45. The Corfield Tavern also hosted one of your collection tins and raised $422. Thank you!

Thanks also to Amcal Chemist for raising $130.55 and Jewell Mend Jewellers for the amount of $232.10

Placing a collection tin is one of the simplest ways to raise funds, so if you would like to place a collection tin at your workplace, contact Shelley events@cysticfibrosiswa.org

TAKE THE 65 ROSES CHALLENGE

Feeling inspired by some of these fundraising stories? Then do to the 65 Roses Challenge!

The month of May is when we shout a little louder for cystic fibrosis. Set a challenge around the number 65 or simply take on the challenge of raising money for cystic fibrosis **www.65 roses.org.au**

If you aren't sure what you want to do, we can help you out with some ideas. We have plenty!

Stackit Development

THANKS TO STACKIT WA PTY LTD. AND HARVEY NORMAN, CYSTIC FIBROSIS WA IS SET TO BENEFIT FROM THE SALE OF A BRAND NEW APARTMENT IN ROCKINGHAM ON 18 JUNE.

The development known as Coast Apartments is a mix of modern, well-appointed 1, 2, and 3 bedroom apartments centrally located within the newly formed Waterfront Village Precinct on the corner of Wanliss Street and Attwood Way.

Many cafes, restaurants and wine bars abound in close proximity and Rockingham's award winning safe swimming beach is just a casual 5 minute stroll away.

The Coast Apartments development has caused quite stir, not just because of its stunning architectural design and car stacking technology, which allow 8 cars to be stored in the space normally occupied by two but because of its innovative building technologies. These give the very best available acoustic and thermal values and the highest sustainability ratings. Of course it may have caused a stir because the profits from the sale of one of the units is being donated to CFWA.

The development uses a new modular construction technique which prefabricates stand alone, single or multi-story buildings and delivers them to site fully kitted out with mechanical, electrical and plumbing, fixtures and interior finishes. This saves both time and money and reduces environmental impact at the site. Typically around 80% of the building construction activity is removed from the site location, significantly reducing site disruption, vehicular traffic and improving overall safety and security.

Ian Duperouzel from Stackit who first approached member Teresa Carlson at Harvey Norman with the idea of donating proceeds to CFWA, said that "structurally, modular buildings are generally stronger

than conventional construction because each module is engineered to independently withstand the rigors of transportation and craning onto foundations. Once together and sealed, the modules become one integrated wall, floor and roof assembly.

The factory-controlled process generates less waste, creates fewer site disturbances and allows for tighter construction. Traditionally, projects can be completed in half the time of traditional builds. This is because the construction of the modules can occur at the same time as the site works. In addition, by building the modules inside a factory they don't have to worry about weather delays."

According to Ian, because the modular structure is substantially completed in a factory-controlled setting using dry materials, the potential for high levels of moisture being trapped in the new construction is also eliminated.

Stackit claim that the Coast Apartment development meets or exceeds the same building codes and standards as site-built structures, and the same architect-specified materials used in conventionally constructed buildings are used in the modular construction projects – wood, concrete and steel. Once assembled, they are virtually indistinguishable from their site-built counterparts.

The CFWA apartment has been fully furnished by Harvey Norman and is ready to move into or would make a fantastic secure investment property. The auction will be held on 18th June on site. For details about the units or if you would like to view these before the auction date please call **Ian Duperouzel 0417 649 905 or Email Ian@stackit.net.au**

THE UNIQUE CONSTRUCTION TECHNIQUE EMPLOYED BY STACKIT ALLOWS BUILDING TO BE COMPLETED IN A MUCH SHORTER TIME FRAME.

The Challenge of Setting up a Daily Treatment Routine

MANAGING THE DAILY DEMANDS OF CYSTIC FIBROSIS CAN BE VERY CHALLENGING NO MATTER WHAT AGE, SO WHAT IS THE BEST WAY TO GET INTO A GOOD ROUTINE WITH YOUR TREATMENT?

Routines are an essential part of life, they help us get things done and be more productive and organised. Routines make actions automatic as they remove the need to deliberate over decisions.

Following a routine helps to create habits which then set up the expectation that certain things will be done. It is important to create good, positive routines from diagnosis so children grow up knowing what is expected of them. For example, positive routines around physio might include a special game with mum or dad, their favourite rug, favourite DVD or book so children look forward to their physio time.

If you establish good routines with children then it's easier to continue these into adulthood. Adults and children who are in good routines are more compliant with their treatments which will have a positive impact on their health.

How do you set up a routine? First, make a list of all the things you need to do in your day including physio, exercise, medications and nebulisations. List all the things you want to accomplish, including some down time for yourself, and create a timetable to fit it all in. Think about the times of day that you are most productive or have the most energy and schedule more challenging tasks in then.

Give your routine a test run and be ready to adjust if needed. It's important to allow some flexibility within your routine for things that come up, like parties and other special events. It is ok to miss things in your routine every now and then as long as missing treatments doesn't become your routine!

Cystic Fibrosis WA have home care workers who are available to help you with your treatment routine. If you are interested in accessing this service please contact us on 08 9346 7333.

A Sprinkle of Sparkle

GUEST COLUMNIST EMMA PUGSLEY: STUDIES SHOW THAT HAPPINESS LEADS TO SUCCESS IN ALL THE AREAS OF OUR LIFE, FROM RELATIONSHIPS, HEALTH, WORK PERFORMANCE, INCOME AND LONGEVITY.

Myall wellbeing

You've heard the saying "happy wife, happy life," however, this concept applies to all of us!

There is nothing more important than happiness because it allows the "sparkle" of the mind to touch the heart of others.

"Sparkle" is a quality found more so in children and can be very infectious (in a good way!) if we allow it.

One would even go so far as to say "a sprinkle of sparkle" each day not only helps keep the doctor away (perhaps even more so than an apple a day), it allows us to flourish, which is something worth striving for!

So besides spending some quality time with the children in our lives, how do we cultivate our own little bit of "sparkle"?

At Myall Wellbeing, we believe that "sparkle" starts with a smile, and is further enhanced with the feeling of ease that comes from practising mindfulness, joyfully moving our bodies and eating delicious healthy food.

Another scientifically proven way is to adopt an attitude of gratitude. So in keeping with the theme of this edition of RED "Taking the Challenge" how about taking the 365-day gratitude challenge.

Every morning when you first wake up, smile! Then take five minutes to think of five things in your life that you are grateful for.

The act of writing down what you are grateful for helps you to focus on the good in your life, rather than what you don't have, which makes life brighter and more fulfilling.

And what a great way to start your day, with positivity!

So what are you grateful for?

MY PERSONAL BIG 5

1.______________________________________

2.______________________________________

3.______________________________________

4._____________________________________

5.____________________________________

Do You Know Your CF Facts?

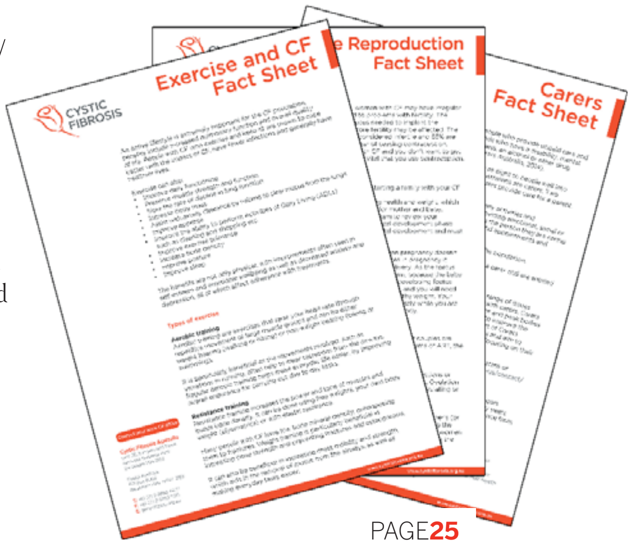
OUR FACT SHEETS PROVIDE USEFUL INFORMATION FOR FAMILIES, CARERS AND THOSE WITH CF

Fertility and family planning can all be confusing, exciting and scary times in your life. You can find out more about these topics on the CFWA website. You can read more about whichever topic relates to you and talk to your CF team about any questions you have.

http://www.cysticfibrosis.org.au/wa/fact_sheets

CF facts:

- **Female reproduction fact sheet.** This fact sheet offers information on fertility in women with CF, assisted reproductive technologies, IVF and lists some useful support resources available online. **https://www.cysticfibrosis.org.au/media/wysiwyg/CF-Australia/Fact_Sheets/CF_Aust_Fact_Sheet_Female_Reproduction.pdf**
- **Male reproduction fact sheet.** Offers information on male infertilityand assisted reproductive technologies commonly used to assist couples experiencing conceptions difficulties. **https://www.cysticfibrosis.org.au/media/wysiwyg/CF-Australia/Fact_Sheets/CF_Aust_Fact_Sheet_Male_Reproduction.pdf**



CYSTIC FIBROSIS

Exercise and CF Fact Sheet

Reproduction Fact Sheet

Carers Fact Sheet

Funding Secured for Transplant Support Program

THANKS TO CONNECT GROUPS, CYSTIC FIBROSIS WA HAS SECURED FUNDING TO BETTER SUPPORT CYSTIC FIBROSIS PATIENTS BOTH PRE AND POST-TRANSPLANT.

The program will include:

- A support dinner for post-transplant recipients and their partner/primary carer. Was held on Friday the 1st of April.
- A post-transplant wellbeing day with meditation, yoga and information followed by lunch. To be held on Sunday 6th of November.
- Development of a Personal Profiles Booklet outlining transplant recipient experiences for those in the lead up to transplant and post-transplant (if you are a transplant recipient and would like to share your story in this resource, please contact Kathryn on the details below).

These supports will complement current services we can offer this group, including:

- A home care worker to assist with airway clearance and exercise routines
- Clinical support (physiotherapy consultation, community nursing, counselling and general support)
- Patient Support Subsidy (annual subsidy up to $300 to help towards costs of equipment and/or exercise)
- Education and information
- Post-Transplant Support Pack which is delivered to the individual during their hospital admission post-transplant.

For more information about the program and services available for pre and post-transplant recipients, please contact **Kathryn on 08 9346 7333** or **servicesmanager@cysticfibrosiswa.org**

Training for Regional Nurses and Physiotherapists May 2016

THE REGIONAL RESPIRATORY TRAINING PROGRAM IS A FIVE DAY INTENSIVE TRAINING PROGRAM FACILITATED BY CFWA AND FUNDED BY THE DEPARTMENT OF HEALTH WA.

This is a collaborative program supported by Asthma Foundation WA, Diabetes WA, Princess Margaret Hospital, Sir Charles Gairdner Hospital, Lung & Heart Transplant Department at Fiona Stanley Hospital and Silver Chain.

The program has been running since 2010 and has grown in popularity over the past six years. In 2016, we have twenty regional nurses and physiotherapists attending from all over the state including Kununurra, Broome, Derby, Kalgoorlie, Esperance, Narrogin and Bridgetown.

The aim of the program is to increase knowledge of respiratory conditions and facilitate better communication between health professionals in the regions and the metropolitan area. Feedback from previous attendees has been overwhelmingly positive and places for this program fill very quickly. If you would like more information or you are interested in attending in 2017, please contact **Kathryn Pekin on 9346 7333** or **servicesmanager@cysticfibrosiswa.org.**

Telethon Kids Institute CF Research Projects Update

DEVELOPING AN ONLINE INTERVENTION TO SUPPORT SCHOOLING FOR CHILDREN AND YOUNG PEOPLE WITH CYSTIC FIBROSIS - CINDY BRANCH-SMITH

Having CF can be stressful for young people in school. Sometimes things can happen at school that make young people feel lonely, affect their grades and make them feel stressed or sad. It is not known if there is anything that will make school more enjoyable. Knowing how young people with CF can be better-supported at school is important so they can enjoy school more and do their best. This is very important for us to know how we can improve education for young people with CF. By involving young people in our research as co-researchers and not just participants, we think we can help schools to create a supportive environment for young people living with CF who attend school.

Researchers from the Telethon Kids Institute are now recruiting young people aged between 10-16 years and their parents to complete a survey that asks about school experiences, family experiences and social experiences. Surveys can be completed during clinic visits or online at home. The next phase of the study will be to invite young people online into private and secure discussion forums (called e-summits) to talk with other young people about school, family and social experiences. We want young people to help us create an online support tool. The e-summit will mean that young people can get online and add thoughts and ideas to conversations about things that are important to them. Once we create the online support tool, we will ask young people to try using the tool and to give us thoughts, concerns and ideas on improving the support tool.

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

The project team currently run a stakeholder committee meeting once every 2-3 months where consumers and other interested parties come together to give feedback and input into the way we run the study. The committee would like to invite parents onto the committee who would like to give feedback and advice make sure that we run the study in the best way possible and that we are helping young people living with CF in the best way possible. Cindy Branch-Smith leads the project at the Telethon Kids Institute. If you would like to become a member of the stakeholder committee or if you would any information about the study, please contact her on 08 9489 7822.

The Telethon Kids Institute is currently run two similar, but different, studies that are both focussing on improving mental health of young people living with CF. This study focusses specifically on young people with CF and the next study is more broadly about chronic diseases including hearing loss and diabetes. The other difference between the studies is that this study includes young people aged 10-16 years and the next study is a larger age range that includes young people aged 6-18 years.

The Wellbeing in Chronic Conditions Study

The other study, into mental health of young people, is a study called the Wellbeing in Chronic Conditions Study. This study investigates the mental health, wellbeing and school experiences of young people diagnosed with a chronic condition who attend a mainstream school in WA. It is hoped that this research will lead to the development of programs designed to better equip young people to improve their school experiences, mental wellbeing, and their quality of life.

We are looking for parents with a child aged 6-18 with CF who attends a mainstream school to participate in this research. Participation involves completing an online survey about your child's CF, their wellbeing and experiences at school. The survey should take about half an hour to complete online. If your child is aged 11 to 18, we would also like them to complete a similar survey to hear about their experiences.

If you have any questions, or would like more information about this study, please contact Rena Vithiatharan, the Wellbeing in Chronic Conditions Study Coordinator, on 9489 7807 or Rena.Vithiatharan@telethonkids.org.au. For more information and to complete the survey, please go to **www.telethonkids.org.au/wellbeing-study**

To thank you for participating, you will have the opportunity to enter a draw to win one of three $100 gift vouchers.

Identifying and Treating Parents of children with Cystic Fibrosis with Unresolved Grief

A new study at the Telethon Kids Institute is going to be looking at parents' unresolved grief from their child's diagnosis. We know that diagnosis of CF is a challenging time for parents and their families but we don't know how many parents experience grief for long periods of time well into their child's early years of life. This study will identify if parents experience extended grief and chronic sadness beyond their child's diagnosis, and try to support parents to resolve their grief. Parents will soon be sent a letter asking if they would like to take part in an intervention research project that will test whether education and psychological support can help parents to resolve grief associated with a CF diagnosis. Parents taking part in the research will be offered financial support to participate in the research.

Please contact Cindy Branch-Smith if you have any questions or concerns on 08 9489 7822.

Slow Cooked Smokey Pulled Pork

A TASTY WINTER WARMER, THIS TENDER JUICY PORK IS WELL WORTH THE WAIT

PREP: 15 MIN **COOK: 5-7 HR**
SERVES: 6

Ingredients

1 Boneless Pork Shoulder, 2.5-3Kgs
2 Cups Apple Cider Vinegar
1 Onion
6 Garlic Cloves
2 Tablespoons Smoked Paprika
2 Teaspoons Cumin Seeds
1 Tablespoon Brown Sugar
1 Teaspoon Fennel Seeds
1 Teaspoon Cardamom Pods
1 Teaspoon Ground Chilli (Optional)
1 Teaspoon Cracked Black Pepper
6 Hamburger Buns

BBQ Sauce

1 Can Crushed Tomatoes
¼ Cup Apple Cider Vinegar
2 Tablespoons Smoked Paprika
1 Teaspoon Cumin
2 Cloves Garlic
1 Teaspoon Salted Butter
1 Teaspoons Brown Sugar

1. Pre-heat oven to 170 degrees. Place oven rack in lower section of oven.
2. Dice onion and garlic and line the bottom of a deep pan. Cut shallow slits in pork skin and place in pan.
3. Mix brown sugar and spices into apple cider vinegar and pour over pork.
4. Cover pan with aluminium foil and place in oven for 2 hours. After 2 hours remove foil and check every hour, pour some vinegar from the bottom of the pan over the pork to keep it moist.
5. Cook for 3-5 hours until pork is tender. Total time varies depending on weight and cut of pork.
6. Remove pork from pan. Remove fat layer and discard. Use 2 forks to pull apart meat. Set aside to rest.

BBQ sauce

1. Add butter to small pot and sauté diced garlic cloves
2. Pour remaining liquid and onion from the pan into the pot. Add crushed tomatoes and extra spices. Bring to the boil
3. Simmer for 10 minutes.
4. Place pulled pork and BBQ sauce in serving dish and mix. Season with salt and pepper to taste.
5. Spoon pork into hamburger buns and serve.


HALLIDAY 2016
5 STAR
★★★★★
WINERY
WINE COMPANION
40 YEAR ANNIVERSARY
CAPEL VALE
Regional Series
PEMBERTON
Semillon Sauvignon Blanc
40 YEAR ANNIVERSARY
CAPEL VALE
Regional Series
MOUNT BARKER
Shiraz

Save the Dates: 2016 Events

CYSTIC FIBROSIS WA'S 2016 CALENDAR IS FAST FILLING UP, SO MARK YOUR DIARIES NOW. THERE ARE EVENTS FOR EVERYONE, WHETHER YOU ARE LOOKING FOR OPPORTUNITIES FOR FURTHER EDUCATION, VOLUNTEERING, FUNDRAISING OR TO COME ALONG AND MEET OTHER MEMBERS AND ENJOY SOME RESPITE

May

1 - 6 Regional Respiratory Training Program (for health professionals)
14 Ladies' High Tea
27 65 Roses Day

June

24 Coffee Morning Mandurah

August

1 Starting School with CF Information Seminar
27 Red Tie Dinner Dance

September

9 Coffee Morning Bunbury
12 Spring Rose Art Exhibition Opening Night

October

6 and 7 Sibling & Offspring Camp
14 Parents' Dinner
21 CFWA Expo: Fertility and CF
23 Halloween Run: a Great Strides event

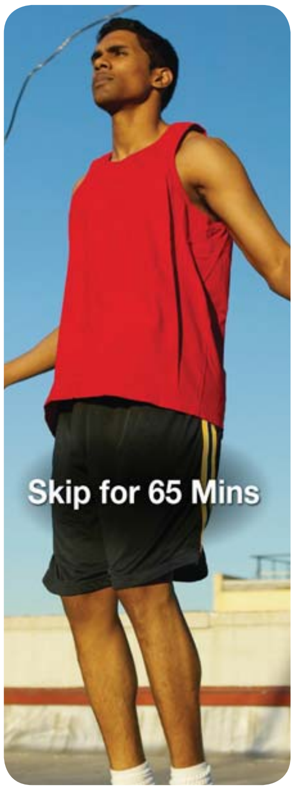
November

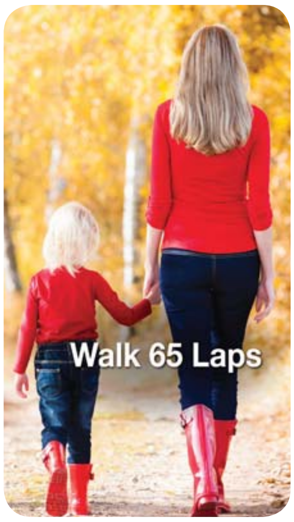
6 Post-Transplant Support Day
25 Christmas and Awards Party

More information about each event will be made available closer to the time.
Please note: dates may be subject to change.

Take the 65 ROSES CHALLENGE

FOR CYSTIC FIBROSIS





Choose Your Challenge

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

Funds raised will enable vital services and research funding for people living with cystic fibrosis in Western Australia.

What are you waiting for?

CHALLENGE YOURSELF
www.65roseswa.org.au

65 Roses
Cystic Fibrosis

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www.twitter.com/
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