

EDITION ONE 2015

RED

magazine

CYSTIC
FIBROSIS
Western Australia

Community
newspaper group



IN THIS ISSUE
YOUR HEALTH
MORE THAN JUST
YOUR LUNGS



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

RED

CEO MESSAGE

Welcome to the first edition of RED for 2015

Your health: more than just your lungs

DEADLINE FOR NEXT ISSUE

If you would like to contribute to our next issue, please contact us before Friday, 3 April.

DO WE HAVE YOUR CORRECT DETAILS?

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

DISCLAIMER

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DESIGN BY

Function Creative
W. functioncreative.com.au
P. 08 6363 5820

PRINTED BY

Picasso Print
W. picassoprint.com.au
P. 08 9443 9911

CONTACT DETAILS

Cystic Fibrosis
Western Australia
PO Box 959
Nedlands WA 6909
08 9346 7333
info@cysticfibrosiswa.org
www.cysticfibrosis.org.au/wa/

Subscribe to our e-newsletter online
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ON THE COVER

Great Strides 2014

I recently had the privilege of meeting Kurt Fearnley, the three-time Paralympic Gold Medalist whom you may recall crawled the Kokoda track recently on his hands and knees.

Kurt and I were talking about cystic fibrosis and the challenges that people with a chronic disease or disability faced in their daily lives and I was reminded about a series of conversations that I have had with many of our younger members.

In these conversations it was not uncommon for some of them to frame their lives within their disease. Kurt felt that a person doing this was really restricting their own potential. This was also reflected by Nathan Charles who has been keen to say on many occasions that he controls his CF and doesn't let it control him. For these guys, it's all about attitude.

That's all well and good for elite athletes like Kurt and Nathan but is that really relevant to the majority of our members living with CF? Is there anything that we can learn from these outstanding individuals?

The theme of this edition of RED is 'more than just lungs'. Our vision of the future is Lives Unaffected



Nigel Barker, CEO

by CF and we hope that in the future everyone living with CF will be able to reach their full potential unencumbered by the disease.

Whilst we may not all be able to become professional athletes (or want to, for that matter) we can shift our term of reference and help ourselves and other people see us not just as the lungs or pancreas in bed four, but as people with ambitions and hope for the future. It's about an attitude and never has there been greater hope for the future than now.



NOTICE OF ANNUAL GENERAL MEETING

WEDNESDAY 1ST APRIL 2015 7.30PM

The Niche Conference Room
11 Aberdare Road, Nedlands WA 6009
(corner of Aberdare Road & Hospital Avenue)

RSVP Friday 21st March 2015 to 08 9346 7333
Refreshments served following the AGM

SPECIAL GUEST SPEAKER:

Hon Dr Kim Hames
MB BS JP MLA

Deputy Premier; Minister for Health and Tourism

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CFA 2014 in Review

Last year was an exciting year for Cystic Fibrosis Australia. There were many major accomplishments which we would like to share with you. Here are some of the highlights:



Advocacy

Most notably, CFA welcomed the news that Kalydeco® was listed for subsidy on the PBS for all Australians with the G551D mutation.

Medical experts consider Kalydeco® the most important development in the treatment of the disease since

the medical discovery of the gene in 1989. The campaign to make Kalydeco® available in Australia commenced almost two years ago and has involved countless people in the CF community and various government departments in addition to Cystic Fibrosis Australia.

65 Roses

65 Roses is the national CF fundraising and awareness campaign that runs throughout May. In 2013, CFA introduced the concept of the 65 Roses Challenge, which was wholeheartedly embraced by the community. This concept was re-engaged successfully in May 2014 with community supporters hosting an array of challenges including taking 65 photos, running 65 kms, swimming 6.5km, and selling scones for \$6.50 each.

Big W generously supported Cystic Fibrosis Australia with the sale of 65 Roses merchandise through all stores nationally for the month of May.

Event - Great Escape

The Cystic Fibrosis Great Escape is a 10-day car rally travelling through unique and iconic locations within Australia. Last year, 48 cars rallied from Shepparton, Victoria, over the Bass Strait into Smithton before touring around Tasmania and crossing the finishing line in Hobart. Over the course of the rally, the cars created awareness in regional areas, visited schools and raised much-needed funds for CF.

The Track Boss mapped out a track consisting of tar and dirt roads designed to challenge the participants, most of whom had never been to Tasmania. This year, the rally raised over \$400,000.

Track plans for 2015 are well underway. The rallytives will be departing from Kiama on 7th September, heading over the Great Dividing Range to the Back O'Bourke before finishing in picturesque Byron Bay on 17th September. If you have an adventurous spirit and want to raise funds for a great cause, we'd love for you to join us!

Event - Murray CODD The Return

CFA secured a grant from the Organ and Tissue Authority (OTA) as part of their Community Awareness Grant Program. This grant funded the successful Murray CODD - The Return event hosted during Donate Life Week 2014.

Coen Ashton, a 16-year old double lung transplant recipient jet skied 2,000 kilometres along the mighty Murray River. A grueling

7-day trek visiting remote regional towns in SA, VIC and NSW raising awareness for CF and organ donation. In 2011, Coen had jet skied the same challenging route in reverse, taking an exhausting seven weeks to complete.

CFA received unprecedented media coverage for the event with a staggering audience reach of 13,708,000. Television and on-line presence were the strongest media support areas.

Corporate Partners - LJ Hooker

Beyond the financial contributions, LJ Hooker offices nationally are instrumental in raising awareness of cystic fibrosis within their local communities. Fundraising activities including golf days, gala dinners, sausage sizzles, fashion parades, walking events and the sale of 65 Roses merchandise continue to support Cystic Fibrosis Australia.

Quality Improvement and Plans for 2015

In 2015, we are excited to be presenting the 11th Australasian Cystic Fibrosis Conference in Sydney. In addition to this, we will continue to develop our core initiatives such as the management of the CF Quality Improvement Program which covers Standards of CF Care Guidelines, overseeing the Infection Control Guidelines, Peer Review of CF Centres, managing the Australian CF Data Registry and Australian Cystic Fibrosis Research Trust (ACFRT).

Managing Your Digestive Health

Often people with CF get constipated, but don't worry too much, there is plenty you can do.

Toilet talk is common when you have young children. Many people feel awkward talking about bowel problems but all health professionals understand that CF has an impact on how the bowels work so don't be afraid to raise the issue.

Constipation causes your stools to be unusually hard and lumpy. Some triggers that cause constipation are: change in diet,

lack of fluids, pregnancy, lack of exercise, ignoring the urge to open the bowels.

It is important to prevent constipation in CF because you do not want to increase abdominal pressure and strain the pelvic ligaments if you can avoid it. These structures are already under pressure from the coughing you do. Increasing pressure on pelvic ligaments can increase the risk for rectal prolapse and stress urinary incontinence.

PREVENTION:

- Eating more high - fibre foods can prevent constipation. High fibre cereals, fruit, vegetables
- Drink plenty of water, ie 1.5 – 2 litres / day (6 – 8 glasses); Add prune juice
- Increase exercise as this helps increase muscle contractions in the gut, helping stools transit along the bowel
- Talk to the CF team, a continence nurse, or physio about the problem
- Do not delay the urge to empty your bowels... go straight away if possible
- When sitting on the toilet use the correct position for opening your bowels:
 - Knees higher than hips
 - Lean forward
 - Put elbows on knees
 - Have feet on floor or on foot stool
 - Bulge your tummy muscles forward as you take a deep breath in and then 'brace' your tummy to prevent it from bulging further forwards. **Do not tighten your tummy.** Straighten the spine
 - Relax, take your time
 - Only try this for a maximum of 3 times. If it does not work, get up from the toilet and walk around. It may help to try having a warm/hot drink.

New Study Recommends Changes to Cystic Fibrosis Monitoring in Young Children

When Telethon Kids Institute researcher Dr Kathryn Ramsey started analysing study results into the long term impact of early respiratory infection in children with cystic fibrosis, she knew she was onto something significant.



Dr Kathryn Ramsey

The study, which brought together top researchers from around Australia as part of the AREST-CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis) program, aimed to find out what impact lung infections in the very young with CF would have later in life.

Published in the *American Journal of Respiratory and Critical Care Medicine*, the results have been described as having “profound clinical implications”.

So what does this mean for those, particularly the very young, living with CF? To understand the outcomes, let's take a closer look at the research.

The study was the first of its kind to follow a large group of children with CF from birth through to early school age, who were

diagnosed following newborn screening.

Data collected over ten years was used to investigate the progression of the disease and to see what impact bacterial infections in the first few years of life had on their lung health as they headed to school age and beyond.

The group of children studied were all enrolled in the AREST-CF program between 2002 and 2007 and had undergone annual clinical assessment from diagnosis until the age of 6.

This included the collection of bronchoalveolar lavage fluid (BAL) to look at lower respiratory tract infections and inflammation, as well as CT scans to assess structural lung disease.

The group also completed infant lung function testing in the first 2 years of life, followed up by further spirometry testing between the age of 4 and 8.

“With such a wealth of good quality data over such a long timeframe we were able to have a really good look at what clinical disease outcomes in the early years were associated with impaired lung function by school age,” said Dr Ramsey.

“We found that respiratory infections in infancy were associated with significant impairments to lung function later on.”

“We believe this research clearly shows the need for early surveillance to better target these infections and improve the long term outcomes for children with CF.”

According to Dr Ramsey most centres screen for, and treat, the most common type of bacteria found in CF patients called *Pseudomonas aeruginosa* or PSA but that this latest research now suggests there is a need to test for and target additional pathogens that can cause lung problems for children with CF.



The journal agreed and even went so far as to suggest the findings “strongly support early and aggressive management of airway infection and inflammation in the first 2 years of life.”

The study conducted by Dr Ramsey and team has not only been well received by the publishing journal but also created quite an impact in the wider science fraternity.

The paper was awarded the ‘European Respiratory Society Grant for Best Abstract in Cystic Fibrosis’ at the European Respiratory Society International Congress in Spain. Dr Ramsey was also the recipient of best publication by an early career researcher at the Telethon Kids Dr Louisa Alessandri Memorial Fund Award for Scientific Publication in 2014.

Her work in CF research has also earned her an NHMRC (National Health and Medical Research Council) CJ Martin Early Career Fellowship which will see her continue her important work into cystic fibrosis lung disease in the USA and Australia.

Dr Ramsey will spend the next two years working at the CF Research and Treatment Centre at the University of North Carolina before returning to Australia to continue her work with AREST-CF.

Rectal Prolapse and Cystic Fibrosis

What is a rectal prolapse?

Rectal prolapse is a condition in which the rectum (lower end of the colon) just above the anus becomes stretched and protrudes outside the anus. To start with, the protrusion may only occur after a bowel movement and disappears when the person stands up. Sometimes the anal sphincter is also weak, which results in mucous or stool leakage / incontinence. Symptoms are similar to haemorrhoids but a rectal prolapse occurs higher in the body than haemorrhoids; it may be difficult to control bowel movements.

Having cystic fibrosis (CF) increases the risk for rectal prolapse occurring. Recent research by El-Chammas K, 2015 in USA suggests the incidence of this condition is much less than reported about 20-years ago. They studied a group of children with CF between 2000 – 2010 to look at factors associated with rectal prolapse to see if any aspect of treatment could be improved to reduce the condition. In this study 3.5% of children with CF had rectal prolapse. Rectal prolapse was more common in the past, occurring in approximately 20% of patients (Ornstein, 2005).

It is thought early diagnosis and treatment associated with the introduction of newborn screening and better pancreatic enzyme replacement therapy (PERT) resulting in less diarrhoea and constipation has contributed to the reduction in incidences.

Causes

Increases in the pressure inside the abdomen and stretching of the ligaments inside during chronic coughing are thought to be significant factors contributing to rectal prolapse. Constipation was the most frequently reported (52.1%) complaint found in those with rectal prolapse; this also increases abdominal pressure when it is difficult to pass a stool leading to strain on ligaments. Diarrhoea was also associated with the condition in 12% of those in the study.

Treatment

Ensuring the correct dosage of pancreatic enzymes is important in preventing constipation and diarrhoea. Sometimes an increase in pancreatic enzymes may be required if a prolapse occurs. Usually the prolapse can be reduced by gentle finger pressure on the lump / swelling. Medical review should be sought and consultation with the dietician will be required.

These days rectal prolapse is an uncommon condition, nevertheless it is distressing when it occurs. Initially, it is usually easily treated and the person needs to be reassured to remain calm. It is important to prevent and treat constipation early in order keep intra-abdominal pressure constant and prevent ligament strain to reduce the risk of rectal prolapse.

REFERENCES

- El-Chammas K, R. N. (2015). Rectal Prolapse and Cystic Fibrosis. *Journal of Pediatric Gastroenterology and Nutrition*, 110-112.
- Ornstein, D. R. (2005). *Cystic Fibrosis Medical Care*. Philadelphia: Lippincott Williams Wilkins.

Holly Ralph Talks Tough Issues and CF

Holly is a very active, vibrant woman with CF. She currently works as a social worker in mental health and has a keen interest in sexuality and disability.

RED: Could you tell our readers a little about why sexuality and disability is an area that has so caught your interest?

I have had a “lived” experience of disability, something that impacts out of the normal, impairment and disability. I see lots of women who have been sexually abused as children and find a way out of the cycle of sexual abuse, having to learn how to create healthy relationships when damaged so much. Sexuality and love are such important facets of life for us all. Girls learn to survive often having no say in what happens to them as children. I find that working in women’s health is a good fit as it taps into similar issues I face having CF which for me is a hidden “illness”.

RED: What are some of the BIG issues that you feel people with CF often want to discuss but perhaps find it difficult to broach with their clinician or with friends and/or partners?

Emotional issues: fear loneliness, sadness of being a burden, not being good enough. CF is less hidden as the disease changes. It’s a privilege to be private about health and how we look, however, with disease progression it’s harder to hide.

Pointing out to someone with a chronic illness that you look “bad” is like pointing out to someone with cerebral palsy that they “walk funny”.

The whole beauty myth about the perfect body and look is very challenging to our vanity, particularly when unwell.

RED: Are there some ways that discussing potentially embarrassing topics could be discussed in an easier way?

Embarrassing topics should be named and discussions should be led by clinicians as part of the review process. I would recommend mental health screening of all people with CF and presume that ALL patients are affected through having a chronic illness. Each hospitalisation creates trauma. There is a flight/fight response of what will be the outcome of this test, such as; is my health

declining, will this procedure be painful, can I get my lung function up? There is always another test, e.g., CF-related diabetes, blood sugar levels, kidneys, etc. There is always an element of “danger, danger” which I think needs to be recognised and discussed.

There is little preparation for serious declines in health and generally a poor response to mental health issues. Cultural attitudes of hospital staff generally only look at the physical manifestation of CF, not the emotional consequences which greatly affect the way we manage our treatment and view ourselves.

RED: Do you have any tips in discussing embarrassing topics with new partners?

Go into partnerships slowly, talk about stuff as friends first. I feel it’s important to tell people about what it’s like to have CF when the relationship is not so loaded, so you can test the water so to speak. I’m usually very candid about some of the difficulties I face so there are no surprises. It’s different with friends because the expectations are different and we’re not tied up in the myth of the “happy ever after”.

RED: How do you discuss having CF with children?

It’s important to promote diversity and inclusion, have discussions about the issues and values. Having CF can be challenging to your vanity; sometimes I look sickly, grey or hunchy. Sometimes I look bad when feeling bad, so I might dress up more or sometimes I might just stay at home.

RED: Do you have some tips to help balance CF and a good life?

Each time I’m unwell all the negatives come up again, e.g., allergies to a few drugs. If I have a decline in my health it also affects my mental health; I sometimes feel flat and unmotivated. That’s where it’s really important to fall back on discipline; this trumps motivation every time and



then eventually the motivation comes back. The endorphins from exercise also help my mood. It's important to enlist friends to help; I ask people to pick me up and take me to the gym, doing anything is better than nothing.

Don't use fear as a motivation; capitalise on your natural rhythms and use your energy well when you have it. I also recommend that you get away from stress as your will power is finite, so don't misuse it, do the hard stuff first, e.g., physio. Build resilience through positive self talk, managing stress and enjoying yourself.

RED: Thanks for your time Holly, we appreciate it!



The Value of Support – with Fiona Jackson

Interview with mum, Fiona Jackson, who has a husband, Stuart, and three lovely daughters, two of whom have cystic fibrosis.

RED: What are some of the things that were difficult to talk about when you had your first child with CF?

It was an initial shock to start with. Three-day intensive training at PMH and then when we came home it felt very isolating and we didn't know anyone in a similar situation. It would have been great to have known someone just ahead of us to provide some initial support. Since my first child was born there are now a lot more people at CFWA to provide support for all sorts of different things.

RED: What were some of the difficult things to come to terms with?

The truth of the diagnosis: “are you sure? Could you have mixed it up, she looks so healthy, lots of doubt about the diagnosis”. I wanted it to go away, then I felt really angry - “why us” - there was a whole grieving process. It would have been good for someone to say “it's normal to feel like this and you will get through it”. To also know that anger is a normal part of this grieving process.

RED: Let's talk about the Parent Support Group that you facilitate.

This group came about initially from a CFWA Newly Diagnosed support group meeting held four years ago. A number of fairly new parents came along and exchanged

contact numbers. I have since become a primary contact and event organiser. Events are usually weekend coffee meetings at King's Park or an evening dinner, with groups catching up every three months. There is also ongoing Facebook dialogue between parents. It's great to talk to other parents who are in the same boat, you realise there are NO silly questions and ALL questions have probably been asked before.

Everybody is different some people would like face-to-face support around 3-6 months, other people prefer to have remote support via Facebook or blogs, some prefer to do it by themselves.

RED: What are some of the 'should have known's'?

There are different things for different developmental stages. One of the first shocks I had was with bath toys with holes in them. The water gets into them and they can be a breeding ground for bacteria. There are lots of other cross-infection issues that are really hard to get your head around like shell sand pits, mulch and swimming pools. It was hard enough just to get on board with physio routines etc, let alone all of these other things, but now I feel more comfortable with it all. It's important not to feel guilty we can only do our best and sometimes you just can't do physio every day of the week or get the completely right dose of Creon and that's OK.

RED: You are a little different in that you have two children with CF. How does that work for you?

It was really different in that my first child is pancreatic sufficient and the second child is pancreatic insufficient. We did not feel so overwhelmed about having another child with CF, however, I went through a whole new phase of grieving in having to learn about enzymes. I was pretty stressed about this and then a beautiful mum said, "at least they will have each other" and my whole perspective of the situation changed and everything was alright. I also knew I had to cope as we don't have any other family here. I have three children and it's the one without CF that often gets sicker picking up all the bugs at school. I think that this is because the two children with CF are so thorough with hand washing and hygiene and also because of their extra vitamins and antibiotics. The difficulty is keeping the children apart when they have colds, etc.

RED: Other difficult questions that some of the parents have brought up in the support group?

Extended families don't always understand. We have discussed how to tell people not to come around when they have a cold. Most people are good. Some of the older generation still think they will outgrow it because they look so well. This is very frustrating.

Physio: how do you fit it in? My best advice has been "do what you can in manageable bits". Some days it really is just too hard; mix it up and get them to do some extra trampolining. Be honest about it. I spoke to the physio and advised her that it was really difficult and she helped me out with a routine that has made it a lot easier.

Food battles are another issue; you're always worried about growth, what's normal. The same thing, try and become confident as a parent and talk to your dietician or another parent. I am



Fiona and Stuart Jackson

much more assertive now in asking questions. Vitamins are another issue before they can swallow them, they stain clothes, and we have had lots on discussions on firstly how to get them vitamins into the children as they taste horrible but secondly, how to get the stains out of the clothes.

It's important to develop confidence in your role as a parent. You know your child best, you know what's normal or not. Learn to trust your judgement. Remember there are NEVER any stupid questions as someone would have had to have asked it before.

Fiona is happy for parents to contact her directly via email to discuss joining her parent support group fionannjackson@gmail.com

If you have any questions regarding cross infection or any other issues contact your PMH respiratory team or Kathryn servicesmanager@cysticfibrosiswa.org CFWA for further information.

Home Care Worker Study Day

CFWA held our annual Home Care Worker study day on 4th February.



Topics covered included correct puffer and spacer technique, nebuliser education, infection control education and practices presented by the CFWA Nurse Educator, airway clearance and exercise presented by CFWA physiotherapist Sam. Thanks so much to Yvonne from the Asthma Foundation, Libby from Pulmomed Technipro and Pam from PMH Physiotherapy Department for their time and support.

This full day of training is a vital part of ongoing professional development for our carers to ensure they have the most up to date training and education.

Nats' Back!

Fresh from maternity leave, the CF community will be excited to know that our resident educator, Natalie Amos, is back in the hot seat! It's fantastic to have Nat re-join us and we know our members will be excited, too.

Although new daughter, Emily, misses her mum it is only for a couple of days a week. Natalie is available for school visits and community CF education sessions Mondays and Tuesdays 9.30am to 5.30pm. Her contact details are 08 9346 7337 or email education@cysticfibrosiswa.org

Gillian, our Recreation and Health Promotions Officer will be available for school visits on Thursdays. Her contact details are: 08 9346 7338 or via email recreation@cysticfibrosiswa.org



Nat, Emily and husband Richard

Q&A

RED answers some common questions posed by our readers.

I'm lucky to have a healthy CF child. At what stage does someone with CF need to go for tune up? What symptoms do they feel / show?

It is always different for each child. Your CF team will let you know. Usually, your child will be coughing more than usual and will produce more sputum which may be a different colour; they may be off their food and not gaining weight. Your child may be more tired or moody, or more short of breath than usual and their lung function tests will be declining. There may be an increase in the growth of bacteria from a sputum/bronchoscopy sample. They may have a fever. If home management such as nebulised antibiotics and increased airway clearance sessions, does not improve your child's symptoms, your CF team may recommend an admission.

Should I be boiling the physio equipment regularly to sterilise it, or does washing it with soap and water suffice? If so, how often?

It is recommended that you should take your nebuliser apart completely and wash it with warm, soapy water after every use.

In the home, nebulisers and accessories (not the tubing) should only be disinfected by boiling or using a steam disinfectant. There is no recommendation for chemical disinfectants in this situation.

Because rinsing only cleans the nebuliser, microorganisms are only eliminated if the nebuliser is disinfected by boiling. Please read the instructions for use on this subject.

Cleaning and sterilisation:

- After each use, take your equipment apart, wash with warm soapy water, rinse with tap water and leave it apart to air dry on a lint free towel.
- Sterilise your equipment for ten minutes in boiling water every one-two weeks.

Are air purifiers or air filters recommended for people with cystic fibrosis?

According to a study published in Chest in 2013 which looked at the impact of air pollution on pulmonary exacerbations in cystic

fibrosis, the risk of having an exacerbation increased significantly on days with higher air pollution. An exacerbation was defined as the need for additional antibiotic treatment.

There is no research into the usage of air purifiers or air filters in cystic fibrosis and the impact on exacerbations or the associated risks or benefits of use. There is some discussion to say that people with cystic fibrosis who suffer from allergies may benefit from using a HEPA filter (High Efficiency Particulate Air filter). These filters are reported to help remove or reduce the amounts of certain contaminants from the air, such as mould and dust. This may reduce exposure to some air pollution but only in the area in which the filter is being used. Whether or not this would have a significant impact on overall exposure and reduce exacerbations is unknown.

If you are considering purchasing an air filter or purifier, please discuss with your medical team.



Welcome CFWA Community Nurse – Sharon Dewar

Sharon advised that she feels very privileged to be the new Community Nurse for CFWA. She is passionate about being part of our vision 'Lives Unaffected by CF'.



Sharon has nursed for many years, originally at RPH in Burns and Plastics then moving on to Surgical Nursing. She worked as a Continence Advisor and in Acting Management roles at Kalamunda and Bentley Health Services. Between 2007 – 2009, she worked for WA Country Health and in her spare time, worked as an aerobics instructor.

In 2010, she took a break from nursing and became a first aid trainer. She then decided to return to bedside nursing for a

short time. Some of you already know Sharon as she worked for the past 18 months as a Home Care Worker (HCW) for CFWA.

As a HCW she has seen first-hand what you and your families are required to do each day to stay healthy. Sharon wants to be your advocate alongside our great team in pursuing best possible practice in the services that we deliver. Being blessed with a wealth of life experiences with a blended family of six children and now, two grandchildren, support, motivation, compromise and guidance are skills that she has grown very familiar with. It is with these skills that she looks forward to the future, working together towards our great vision, 'Lives Unaffected by CF'.

Don't forget to say "hi" to Sharon if you see her on the wards.

CF Scientist Night

4th March 6:30pm - 8:30pm,

Telethon Kids Institute, Roberts Road, Subicao

Join the AREST-CF team for an informative presentation on all things cystic fibrosis.

For further information visit:

[HTTP://ANEVENINGWITHCFSCIENTISTS.SPLASHTHAT.COM](http://ANEVENINGWITHCFSCIENTISTS.SPLASHTHAT.COM)



Regional Respiratory Training Program

3rd - 8th May

CFWA is hosting their 6th annual training program for Allied Health and nursing professionals from regional WA. This program is funded by the Department of Health WA to deliver comprehensive training on a range of respiratory issues including an overview of cystic fibrosis, CF-related diabetes, psychosocial issues related to having a chronic illness, dietary and nutrition issues, PICCs and Ports, physiotherapy techniques, presentations and much more.

For further information contact Kathryn:
servicesmanager@cysticfibrosiswa.org



Collie and Albany Outreach

9th & 10th March

The services team will be travelling to Collie and Albany on 9th and 10th March to provide education to any schools, day care or regional hospital staff. They will also be available for individual consultation and an evening get together.

For further information contact Kathryn: servicesmanager@cysticfibrosiswa.org



Government of Western Australia
Department of Health



RED Resources

The Upside of Down: A Memoir

Susan Biggar

‘A rare combination of laugh-out-loud humour and an intensely honest exploration of difficult issues ... It’s like Eat, Pray, Love but with children, a husband and health issues along for the ride! Anyone who has ever experienced illness in their family or considered an expatriate life will want to read this book.’

— ANDREA J. MILLER, Shares in Life Foundation, NZ

Susan Biggar fell in love with a New Zealander. Maybe as an American, she saw Darryl as a ticket to an exhilarating, global life. When her first son arrived, he came with fierce blue eyes, a curly toe and cystic fibrosis. The doctors said he would be lucky to reach the age of thirty.

A job offer in Paris snatched the family from New Zealand, depositing them in the City of Lights, romance—and a whole new medical world. When Susan’s second baby was also born with cystic fibrosis, the insignificant worries of her old life slipped away, shifting her from ‘normal mum’ to ‘gotta-figure-out-how-to-keep-the-kids-alive-mum.’

This—and all that followed—was not what she expected.

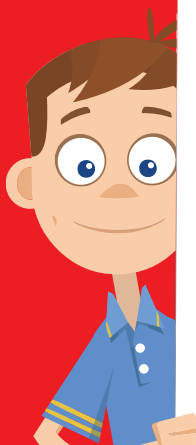
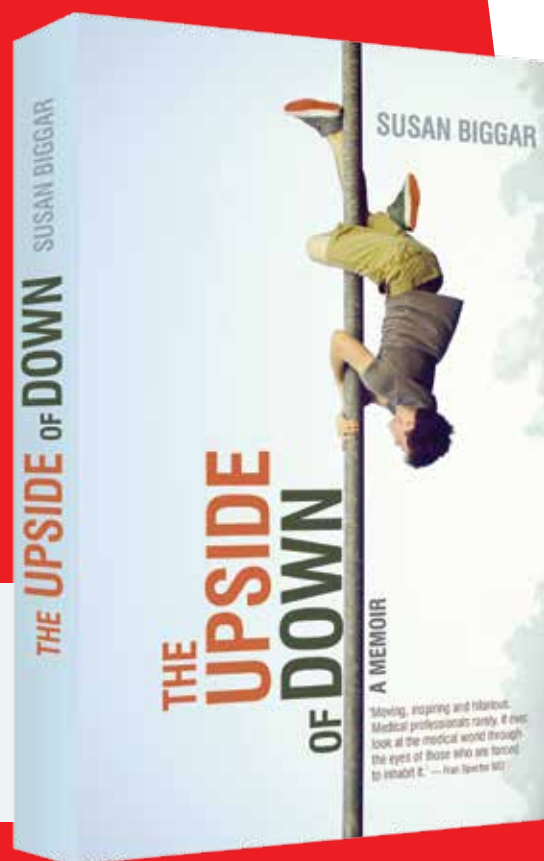
Set across the globe—in California, New Zealand, France and Australia—The Upside of Down is a story of belief, of learning that sometimes joy is a decision.

Susan Biggar was raised in the San Francisco Bay Area, but lived in Europe and New Zealand for a decade before settling in Melbourne, Australia. She holds degrees in Politics and International Policy from Duke and Stanford universities (BA/MA). She has written for many publications, including The Age, Good Weekend and The Big Issue. She now works in consumer health, encouraging a more patient centred health system with a greater role for those who rely on it.

**The Upside of Down:
A Memoir**
Susan Biggar

RRP \$29.95

Release date:
Available now



School Education Sessions

We are now taking bookings for the 2015 school year. If you would like to book in an education session for your child’s new teacher/s or class mates, please contact Natalie on 08 9346 7337 or email education@cysticfibrosiswa.org

Cystic Fibrosis Treatment Reminder

CF MedCare is a FREE App designed to help Cystic Fibrosis (CF) patients with their therapeutic regime. Many CF patients have a complex and time-consuming regimen, which can lead to non-compliance, due to simple forgetfulness.

More specifically, CF MedCare:

- Allows users to create their own Treatment Profile (or multiple profiles for family members and carers) adding all their medications, schedules and instructions
- Alerts when it's time to take a medicine and asks users to insert their feedback (e.g. I Already Took, Take Now, Skip, Postpone, etc)
- Captures the user's compliance so that it is easy to track and remember which doses were taken on time, delayed and which were skipped
- Provides ability to share user's compliance records via email with their healthcare professional or individual of choice
- Reminds users when it's time to renew their medication(s)

<http://www.cfmedcare.eu/about.php>



Parents' Retreat

The 2015 Parents' Retreat will be held on the weekend of the 27th to 29th March in Preston Beach. Join us for a warm autumn getaway at Footprints Resort situated on Preston Beach and neighboured by the scenic Yalgorup National Park. Activities include a quiz night, bus tour to local winery for lunch and enjoying the resort facilities and surrounds.

The Parents' Retreat costs \$50 per person which is required prior to the event to secure your spot.*

RSVP is due by Friday the 13th of March.

For more information about the event please contact Gillian on recreation@cysticfibrosiswa.org or 08 9346 7338.

***Travel subsidies may be available for regional members. Contact CFWA for more information.**

Richard Simons – Thrifty

RED chats to CFWA President, Richard Simons, about his role leading our organisation and well-known vehicle rental company, Thrifty.

RED: Most of our readers will know you as President of CFWA but not how you became involved as a board member. Can you tell us a little about how it came about?

In early 2009, I was walking down the street minding my own business when I bumped into the then outgoing CFWA Treasurer Martin Langridge. Martin was my boss when I first started work as a fresh-faced young accountant in 1989. I made the mistake of saying “hello” and the next thing I knew, I was press ganged into becoming Martin’s replacement as Treasurer. I still have only a very vague recollection of how it all happened!!

I have no shame in admitting that I was a bit daunted by the responsibility that I would be taking on in becoming an office bearer for CFWA. However, when I discussed it with my wife Sarah, we both decided that it was the least that we could do given that we were blessed to have a healthy daughter, Gracie, who was 14-months old at that time.

I can say hand on heart that I have not regretted for one second bumping into Martin on that fateful day. Having the opportunity to work with the CF community in WA has been one of the best things that has happened in our lives.

RED: How have you found the first twelve months in the role and what do you see as the changes in the next year?

My first 12 months as President has been a huge learning curve. I thought that I was pretty well versed in most of the matters with which CFWA is involved. There was, however, a significant part of what CFWA does that I didn’t know much about and that was the

role that the organisation plays in shaping the national agenda.

We might only have some 10% of the national CF population in WA, but through the outstanding leadership of Nigel Barker and the experience of Mitch Messer and Feliciano Sanchez, CFWA takes a lead role in developing national policies and fundraising initiatives – not the least of which is a major project to be launched soon, which was born in WA.

We are very fortunate to have an incredibly talented and dedicated team at CFWA, a relationship with the State Government and Health Department which is the envy of other CF organisations, and a number of outstanding world-class researchers, clinicians and health care professionals. CFWA leverages all of these advantages to take a lead role in advancing the CF cause on a national basis for the benefit of all those with CF and their families.

RED: Telethon is a major beneficiary of a donation from Thrifty each year and CFWA appreciates the wonderful contribution we receive from that organisation. How is the Thrifty donation achieved?

Thrifty’s association with Telethon dates back over 10 years. During this time we have donated a portion of every rental to supporting our Telethon donation. For the last few years, this has amounted to \$100,000 each year. That is a big sum of money for what is a family-owned business in Western Australia, however, we feel that as a Western Australian business that derives all of its income in this state, we have a duty to support Western Australian kids and families that need help.

Thrifty is a fantastic supporter of CFWA offering assistance with the access to vans and trucks used for events such as the George Jones Cystic Fibrosis Golf Classic, 65 Roses Day and Spring Rose Art Show.

RED: Thrifty has saturated radio with a catchy jingle and voiceovers featuring strong Scottish accents. Was this your brainchild or should we be thanking someone else?

Alas I can't take the credit for what must be the most annoying advertisement on TV and radio today. My friends and family never miss an opportunity to complain about the adverts whenever they see me. I'm just glad that people remember them !!

RED: If you could lead one change that makes a lasting impact on the lives of members with CF in the next 12 months, what would that be?

The big project I mentioned earlier has the potential to offer life-changing opportunities to current and future generations of those with CF. Being a part of this project, even in a small way, is an incredibly important and valuable activity.

RED: When not driving great value for Thrifty customers, what do you like to do in your spare time?

Spare time? What's that?

Gracie is now 7 and has a raft of after school activities that ranges from reading and maths classes through to swimming, tennis and most recently, golf. So spare time doesn't accrue very often. I hope one day that she will become the next Michelle Wie and keep me in the manner to which I wish to become accustomed.

When time permits, I like to tinker with old cars but that doesn't happen too often these days.

RED: Thanks for your time Richard. We appreciate you're very busy in and out of work!



Richard, Sarah and daughter Grace

www.bigbounce.org.au/wa

The Big Bounce for CF



2014 was a big year for fundraising right around this big country of ours with many new campaigns springing to life.

Sister organisation, Cystic Fibrosis Victoria, found themselves jumping for joy in July with the first ever Big Bounce for CF with fundraising topping \$6,000. With the assistance of a trampolining centre and enthusiastic participants, the campaign proved very successful.



Not only did the initiative raise funds but it also created awareness of cystic fibrosis via mass media eager to capitalise on a unique news item.

First things first: you need to decide how you're going to bounce. Don't worry if you don't have access to a trampoline – you could team up with a friend who has one, get your school, community club or sports club involved, go to a trampolining centre, such as BOUNCEinc.

If you would like assistance to set up a fundraising page or require further information call 08 9346 7339 or email fundraiser@cysticfibrosiswa.org

Get ready to bounce your way through March as Cystic Fibrosis WA joins the national Big Bounce for CF!

There are some great reasons to get behind the Big Bounce.

- Raise money for an important cause
- Trampolining is great for people with cystic fibrosis
- It's a brilliant way to exercise - 10 minutes on a trampoline is equivalent to a 30 minute run!
- Trampolining boosts your energy levels
- It's fun!

How to get involved

- Host a Big Bounce party for your friends and family using your own trampoline or at BOUNCEinc
- Get your class bouncing
- Design your own Big Bounce Challenge. Why not get a team together to bounce for 65 minutes? Or get a team of 65 people bouncing? Or you could commit to bouncing for 30 minutes a day in March? The possibilities are endless...

65 Roses Blooming Fantastic!

The Challenge

Over the past two years \$34,198 has been raised by many wonderful supporters who have taken on the 65 Roses Challenge. From riding 65km to baking 65 cakes for a morning tea there have been many putting themselves to the test.

Every day people living with cystic fibrosis are put to the test, taking medication, undergoing physio treatment, clinic visits and more just to stay healthy. So the concept of challenging yourself to reach a goal, sustain an effort and make a difference fits well with the month of May and the concept of the 65 Roses Challenge.

There is no shortage of challenge ideas; you can make your challenge anything that is relevant to you. However if you need some inspiration the team at Cystic Fibrosis WA can help you to find a niche. Call on 08 9346 7339 or email fundraiser@cysticfibrosiswa.org

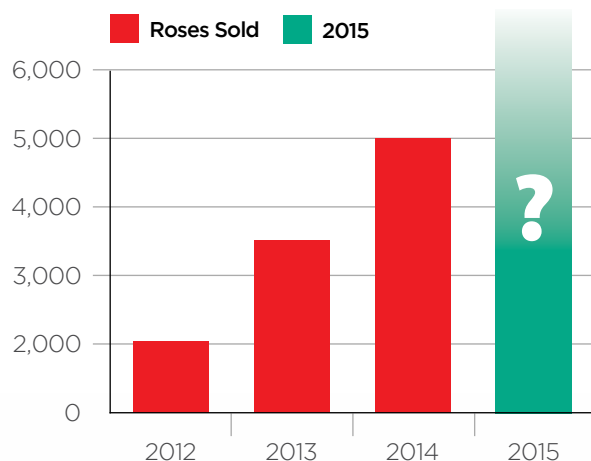
Rose Wrap

Our beautiful rose logo has become a meaningful symbol of hope for lives unaffected by cystic fibrosis. With its origins embedded in a story that has warmed hearts and ignited emotions, the simple misinterpretation by young Richard Weiss in the 1950s of "cystic fibrosis" and "65 Roses" has left a lasting legacy.

Every 65 Roses Day, corporate supporters, schools, retailers, community organisations, staff and volunteers band together to raise awareness and funds to advance our vision of Lives Unaffected by Cystic Fibrosis.

With the assistance of our generous partner, WAFEX, the target this May will be our biggest yet. However, we need a larger team of volunteers than we have ever had before, so if you can assist please contact us on 08 9346 7336 or email marketing@cysticfibrosiswa.org

Involvement is key to continuing the 65 Roses Day success enjoyed in recent years. So if you can't volunteer but your workplace, school, community group or even your friends would like to purchase a rose, watch our social media and e-news updates for how you can place your orders!



Fundraising News

The spirit of Christmas giving has been kind to Cystic Fibrosis WA since our last edition of RED. There have been some great fundraisers, so a big thanks to everyone whose made it their mission to improve the lives of people with CF!



Belinda Kemp and
Riverside Signs
raised over \$4000

Glenn Robson and the CrossFit team at Energize Performance Training got behind Cystic Fibrosis WA with a "Cindy for CF" competition. They raised a whopping \$2697.15 - thank you!

Jewel-Mend put out a collection tin to raise \$369.75. Not a bad effort at all!

Zoe Marie Cummings and her sister **Hayley** took on a 65 Roses Challenge to fast for 65 hours. They raised \$957.45 and must have wolfed down their Christmas lunch!

The crew at **Amcal Max Tuart Hill** gave Cystic Fibrosis WA some great support by raising \$938 with a team in the Colour Run.

Alan Cooper took part in seven fun runs around Australia to raise funds for Cystic Fibrosis WA and Cystic Fibrosis Qld. By the end of his challenge he ran over 100kms, flew 20,064kms, visited Perth, Hobart, Brisbane, Sydney, Canberra, Adelaide, and Melbourne, and raised a whopping \$6,110!

The ladies at the **Melville Glades Golf Club** raised \$11,388.85 via a range of events throughout 2014.



The Melville Glades
Ladies Club raised
\$11,388.85 in 2014

What a wonderful result, we very much appreciate it!

Hayley Norrish and Cathy North were invited to hold a stall at the York Pharmacy Health Expo and raised \$600.

Belinda Kemp and the team at Riverside Signs held an auction fundraiser to raise \$4,357.95. Thanks to all those in the local community who supported the event.

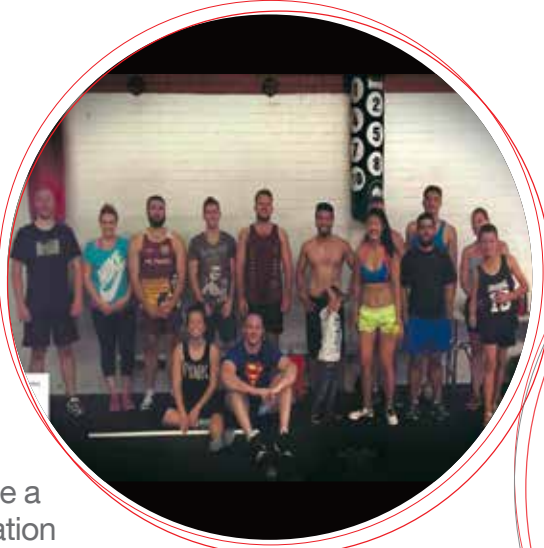
The Glengarry Private Hospital Volunteer Group donated \$3,462.95 raised throughout 2014. Thank you!

Thank you to **Lisa Redmond, Kate McGillivray, Ashleigh Grostate and Nicole Lawrence** who created a giving page in memory of an amazing young woman who was lost to CF. The page raised over \$1000, and Cystic Fibrosis WA would like to thank all those who contributed. Our thoughts are with you.

God's Kitchen have been donating part proceeds from the sale of their delicious fetta, with \$1,588.30 raised in 2014.



Alan Cooper ran
seven races around
Australia



The Borden Bowling Club made a very generous donation when they raised \$5,000!

The City of Perth Staff Social Club donated \$250 raised through their Christmas Raffle.

Kingston Primary School have been great supporters of CFWA, fundraising throughout the year to raise \$785.50!

The Scrivener Family and Caitlin Jones fundraised online and through a car wash to raise \$5,319!

Fiona Campbell placed a collection tin at Lamint in Henderson and has raised \$41.90.

Tim Rankin, Marianela Pereira and Mark Marron have raised over \$550 with a great range of fundraisers held at ECU throughout 2014. Thanks for helping to spread awareness on campus.

Kearnan College held a Crazy Hair Day and raised \$243.50. What a great result!

Landgate have been great supporters of CF again, donating \$488 raised through free dress days.

Georgiou Group have been very active supporting Cystic Fibrosis WA in 2014. They've contributed nearly \$7,500 since August, raised through donations, chocolate sales and a sausage sizzle.

Sealanes have raised \$775 by holding staff free-dress days. A great way to make a difference!

The team at **The Good Guys Malaga** have continued their fantastic support of CFWA to donate over \$6,000 raised through their in-store local giving program in 2014.

The band 383 & Emma C raised some great awareness for CF by releasing a song. The band and their supporters have donated \$300!

Glen Robson and the team at Energize Performance Training raised \$2697.15



The Glengarry Private Hospital Volunteer Group present Cystic Fibrosis WA with \$3462.95

The State Solicitor's Office took on a Cystic Fibrosis WA collection tin and raised \$429.50.

Amanda de Vos put collection tins out in businesses around Collie and raised over \$100.

The students, parents, and teachers of Hardey House, Wesley College, have made another generous contribution by donating over \$1,500 from their fundraising.

Cadoux Primary School held a Crazy Hair Day and raised \$40.

The Fat Boys Drinking Club have kept up their support of CF with a collection tin at the club and donated \$96.30.

Blue Illusion in Claremont Quarter have donated \$47.45 from a fundraiser they held.

Community Newspaper Group placed a collection tin at a local café to raise \$84.55.

Steve and Sue Williams have donated \$200 raised on their caravanning adventures.

Lauren Ramsden and Get Motivated Now Geraldton held a raffle to raise \$350.

Graham Hyland took on the 2015 Dubai Marathon in support of the Cooper Family, and raised funds for Cystic Fibrosis WA and Cystic Fibrosis Qld. He smashed his target to raise \$1,300!

SERVE IT UP FOR CF

Thanks to everyone who got behind Serve It Up for CF last September! The campaign raised almost \$6,000 in its first year, so it'll be exciting to see where it goes in 2015. If you can't wait until September 2015 to get started, you can host your event whenever suits. Visit www.serveitupforcf.org to check it out.



Adam D'Aloia Served It Up for CF to raise \$2050!

Paul and Kate Spaapen hosted Cystic Fibrosis WA's first ever Serve It Up for CF event with two dinners earlier in the year and raised \$1,255.50!

Adam D'Aloia took out the top fundraising prize and won a voucher donated by The Byrneleigh Hotel when he contributed \$2,050 by hosting a spit-roast dinner! Thank you to all the local businesses that donated products to his event.

Kirsty Fairclough Served It Up for CF with a delicious six-course meal. She and her guests raised \$961!



Sarah Brown and her friends Served It Up for CF to raise \$407.50.

Debbie Scott Served It Up for CF and raised \$90 with a dinner at Joondalup Tafe.

Liam and Bernadette Finestone teamed up with **Stuart and Lana Chitty** to host a dinner where guests came dressed as something beginning as either the letter 'C' or 'F'. They raised \$750!

Nena Johnston and the Central Institute of Technology, Perth, got behind Serve It Up for CF by raising \$357 with a morning tea.

Sarah Brown, CFWA's Event and Community Fundraising Coordinator, held a Serve It Up for CF picnic with her friends and raised \$407.50. Thank you to The Voluptuous Cupcake Company for donating some beautiful rose-themed cupcakes!

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

Fundraise and Run for FREE!

Fancy raising funds for a great cause and being rewarded for your effort? This year we've partnered with two of Perth's major fun runs to give you the opportunity to run for free! Charity runners will start ahead of the pack, enjoy free gifts, plus you'll receive one-on-one fundraising support to help you reach your minimum target.

HBF Run for a Reason - Sunday 24th May 2015

Swan River Run - Sunday 26th July 2015

Places are limited so get in quick at www.cysticfibrosis.org.au/wa/our-events or email events@cysticfibrosiswa.org for more info.



Run for CF and receive a free shirt!

Get Crazy Hair and Go RED at School!

Give the kids at your child's school the opportunity to learn about CF while letting their hair down and having some fun. Crazy Hair Day and Go RED for CF are educational fundraisers where students bring in a gold coin to take part. Schools have access to activities, stickers, balloons, and much more.



Getting involved is easy:

- 1) Pick your date – May 29th is 65 Roses Day, or any other time that suits
- 2) Pick your theme – Crazy Hair Day or Go RED for CF
- 3) Contact Cystic Fibrosis WA at events@cysticfibrosiswa.org or 08 9346 7339

Farewell Sarah

Many of our members will know Sarah Brown as our Community Fundraiser & Events co-ordinator over the past 3 years.

Having recently left CFWA, Sarah has made a fantastic contribution to the CF community, our fundraising efforts and events.

On behalf of the CFWA community, RED wishes Sarah every success as she takes on new challenges, and we hope to see her around in the future!



Incredible Strides

With a revamped national logo and leafy new venue, Great Strides has launched to Incredible Strides!

Although the morning of Great Strides was a little cooler than experienced in recent years, plenty of shade was available when the sun burst through the clouds at the picturesque Perry Lakes venue.

With a steady stream of registrations, the excitement built as the 8km participants gathered under the CF start arch. There were just as many 4km runners and walkers striding out thirty minutes after the first wave; a great sight to see hundreds of CF red shirts at the start line embracing the spirit of Great Strides.

Amongst the throng a handful of serious runners really set an amazing pace. Providing inspiration to those following, these guys were leading more than just the event. They represent the first of what it is hoped will be hundreds more runners in future years all striding for lives unaffected by CF.

At the finish line, all the fun of the carnival embraced participants. Pony rides, craft activities, Johnny Young Talent School, hot dogs, giveaways and more ensured there were plenty of activities to enjoy.

Collectively, everyone who walked, ran or rode a bike achieved an amazing result. With donations from family, friends, work mates and others, an incredible \$50,000 was raised to assist in the delivery of services and research! Thank you to everyone who raised funds or made a donation; the total couldn't have been realised without you!!!

Of course Great Strides is not possible without our wonderful sponsors and supporters. We have included the logos below just to remind you exactly who they are and to say thanks to them all one more time. We know many of them have already committed to Great Strides 2015!

Special thanks to Chris and Andy from Spirit Events; they provide guidance and expertise to support the CFWA staff in coordinating the event and ensuring its professionalism.

Great Strides 2015 will be held on Sunday 25th October, book a place in your diary and help make this the most successful yet!



Post Work Out Quesadilla

Ingredients

Wraps, choose highest carb value
 1/3 cup Mexican blend shredded cheese
 2 Tbs full fat sour cream
 2 Tbs salsa
 1 chopped chicken breast (cooked BBQ is easy)
 1/2 pat butter (about 1 tsp)

Information

High in protein, 300 calories
 Minutes to Cook: 15
 Number of Servings: 1

Method

1. Take 1 wrap butter generously
2. Place butter side down in frypan
3. Add chopped chicken and cheese evenly, covering most of wrap (leave about 1/4 inch at edge).
4. Cover and watch for cheese to be mostly melted.
5. Close the quesadilla by folding in half.
6. Cook until browned and crispy.
7. Flip over and cook other side until browned and crispy
8. Cut in 3 wedges and serve with sour cream and salsa.



RECIPES
SPONSORED BY
MENU
MAGAZINE

CF Diary

FEBRUARY

27 > Coffee Morning Dome
Café Baldivis

MARCH

01-31 > Big Bounce
 04 > Research Seminar
 04 > CF Scientist Night
 9-10 > Albany Outreach
 20 > Coffee Morning Dome
Café Joondalup
 27-29 > Parents' Retreat

APRIL

1 > AGM

MAY

1 > Golf Classic
 29 > 65 Roses Day

Other coffee mornings to be held in Armadale, Midland, Mandurah and Scarborough later in the year.



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

George Jones Family Foundation

Cystic Fibrosis Golf Classic

Friday 1st May 2015
Lake Karrinyup Country Club



Register before February 28th for your chance to win a round of golf for four!

Cystic Fibrosis WA is proud to present the 5th Annual CF Golf Classic to be held on Friday, 1st May 2015 at the exclusive Lake Karrinyup Country Club

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

Registrations are now open with packages starting at \$500 per person up to \$4,000 for Gold Sponsorship including 4 players and an extra 4 dinner guests.

For more information please contact

Brad Coutts on 0417 946 729 or golf@cysticfibrosiswa.org

All proceeds from this event will be donated to Cystic Fibrosis research and services.

