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RED

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COLLABORATION



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RED CEO MESSAGE

The theme of this edition of RED is collaboration.



NIGEL BARKER, CEO

Working towards our vision of 'Lives Unaffected by CF' is a team effort. As a person living with cystic fibrosis (CF) or as a carer, it's important to understand that you are not alone. Collaboration requires everyone to pull in the same direction. We've been pretty good at doing that in the past and it's been pivotal to our success.

Collaboration was the key to discovering the CF gene back in 1989. It's been the focus of our Little Lungs Big Futures CF research project. This project brings together a team of CF scientists from around the world, led out of the Telethon Kids Institute, and has already raised \$2.5m.

In August 2019, Cystic Fibrosis WA (CFWA) will be collaborating with Cystic Fibrosis Australia (CFA) to host the 13th Australasian CF Conference right here in Perth. Planning has already commenced and in this edition, CFA is calling for members to join a lay committee to help plan the lay program.

At a service delivery level, the collaboration between the multidisciplinary team at Princess Margaret Hospital (PMH), Sir Charles Gairdner Hospital and our services team, including our homecare workers, their clients and families, is a unique one. It is found nowhere else in Australia. This collaboration, trust and support enables the link towards better health outcomes.

In the school community, research has shown that children have better academic and social outcomes when their parents and teachers work together. Our CFSmart and school education programs are a feature article in this edition of RED.

The wider community continues to collaborate in fundraising to provide the financial resources to deliver these fantastic outcomes. Recent activities include the Rotary Club of Busselton Geographe Bay Golf Day and the Colour Run, to name just two.

And finally, who would have thought that the AFL would be collaborating with CFWA? Local boy Sam Powell-Pepper has become our latest ambassador. He is already having a big impact in providing a role model to children with CF at PMH.

All we need to do now is get him to give up his Port Adelaide shirt for a Dockers shirt and we'll be sweet!

Nigel Barker
CEO

DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our summer issue, please contact us before Monday 5 March 2018

DO WE HAVE YOUR CORRECT DETAILS?

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

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Catherine Fisher
The Pixelfish Designs

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ON THE COVER

CFWA home care worker Ishbel having fun with her client Lillie

CONTACT US

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

info@cfwa.org.au
www.cysticfibrosis.org.au/wa/

Subscribe to our e-newsletter online
www.cysticfibrosis.org.au/wa

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2019 AUSTRALIAN CYSTIC FIBROSIS CONFERENCE LAY COMMITTEE

Can you believe Cystic Fibrosis Australia (CFA) are already planning for 2019? In 20 months' time, CFA will be holding the 13th Australasian Cystic Fibrosis Conference (ACFC) in Perth and are now looking for volunteers to be part of the lay committee.

The ACFC lay program will be designed to meet the needs of the community, provide answers to the questions that trouble people with cystic fibrosis (CF) and their families, and deliver up to the minute national and global intelligence on CF drugs and treatments.

The Conference is also a great time to meet fellow CF travellers and share stories. Over the years, in all our Conference analyses, the peer-to-peer networking and support have been seen as most valuable.

As a lay committee member, you'll be expected to attend (as many as possible) teleconference meetings, held approximately once a month. As we get closer to the Conference opening, these meetings may become slightly more regular. Your remit will be to help identify topics for presentations, and where possible, suggest presenters from both the medical and lay communities.

André Shultz, Centre Director at the Princess Margaret Hospital for Children in Perth, is the Chair of the 2019

conference. He will be on hand to provide strategic direction and assistance in finding the best and brightest presenters. The medical committee, will be supporting him to develop outstanding content from Australia and around the world. The lay committee chaired by local CEO Nigel Barker, will have access to these speakers as well.

The ACFC details are:

Date: 3 and 4 August 2018

Venue: Crown Towers, Perth

If you would like to receive a lay committee application form please email

lizk@cfa.org.au. In addition, if you want to know more about your role, just email or phone Liz at CFA.

**Nettie Burke CFA
CEO**



CYSTIC FIBROSIS WA OFFICE UPDATE

As a result of information presented at the recent Cystic Fibrosis (CF) Conference in Melbourne, we have made some changes here at Cystic Fibrosis WA to protect you when you come to visit us.

You may notice a new sign at the door asking everyone to use hand gel before entering and a 'Staff Only' sign, restricting access to the general office area. We would

urge all visitors to avoid our office when unwell.

We have made a few other changes and hope they are seen to be a positive step

forward for our CF community. If you have any questions or would like to talk about these changes, please contact us on **08 6457 7333**.



Transplant Support Dinner

We will be hosting our annual Transplant Support Dinner on Friday 23 February. This event is open to all members who are post-transplant and their plus one.

It is a great opportunity to meet up with others who have been through their own transplant journey and share stories and experiences with one another, as well as chat with our staff.

When: Friday 23 February 2018 from 7pm

Where: Steves, 30 The Avenue Nedlands

RSVP: To Kathryn by Friday 16 February on servicesmanager@cfwa.org.au or phone 08 6457 7333



SELF-MANAGEMENT AND COLLABORATIVE CARE: IMPROVING PATIENT OUTCOMES

Cystic fibrosis (CF) is a time consuming and, at times, complex disease to manage, requiring a high level of collaboration between patients, families and health care professionals.

Self-management is a process whereby patients feel that they are empowered to be in charge of their physical and mental health. Collaboration is the process of two or more people working together to achieve something successfully. The management of CF requires a combination of both of these processes.

Successful self-management requires the following attributes:

1. Knowledge of CF and how it specifically impacts you

This is also referred to as health literacy, or the capacity to obtain, process and understand basic health information and services to make appropriate health decisions. Research indicates that 60% of Australians have low health literacy which correlates to poorer health outcomes. To improve your health literacy:

- Ask questions and/or encourage your child to ask questions. This may be difficult at first, however, it becomes easier and health professionals like to see that you're engaged.
- Write useful information down and prepare questions beforehand.
- Repeat information back to your health professional to clarify.
- Be honest. If you're not going to do a specific treatment, then say so and they will adjust your treatment plan.
- Have another adult with you if you need extra support or just someone to remember what questions to ask.

2. Ability to follow a treatment or care plan

There are a number of issues including motivation, low mood and busyness that

affect your ability to stay on track with treatment plans. If you're struggling, talk to your CF care team about setting some goals. Our home care worker service can be a great program to assist with motivation and staying on track with treatment.

3. Actively collaborate and share in the decision-making process with your care team

Be confident to say how much you can manage and if you need extra help.

4. Manage and monitor signs and symptoms

Know your own body, speak to someone if you're not sure, and track and adjust treatment as necessary.

5. Manage the impact of CF on your physical, emotional and social life

Research indicates that people with CF and their caregivers have 2-3 times greater levels of anxiety, particularly at times of exacerbations or when undergoing medical procedures. Anxiety at these times is normal, however if issues persist you could start by speaking with someone in your respiratory team, your GP or someone here at Cystic Fibrosis WA (CFWA).

6. Adopt lifestyles that promote health

Easier said than done! Try and stay active as much as possible (join a gym, sports team or join in activities you enjoy, such as hiking), stay connected to family and friends, eat well for your body, find hobbies and do things that make you happy. Here are some websites with useful information:

- CFFit- exercise resources <https://www.cfwa.org.au/what-we-offer/resources/>
- CFFood- nutrition resources <https://www.cfwa.org.au/what-we-offer/>

resources/

- CF Fitness by the UK Trust have some video demonstrations on exercises beneficial to people with CF <https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/cystic-fibrosis-care/staying-active/cf-fitness-space>

- Act Belong Commit <https://www.actbelongcommit.org.au/>

7. Have confidence, access and the ability to use support services

We have a range of support services for both those with CF and their families. These include home and hospital support, financial subsidies, equipment loan and support, advocacy, education, regional support, member events, counselling and a range of information resources. Visit www.cfwa.org.au for more information on our services.

Other support organisations can also be found on our website here: www.cfwa.org.au/what-we-offer/counselling-support/

References:

Clancy, C (2010). Improving Your Health Literacy. Sourced from <https://archive.ahrq.gov/news/columns/navigating-the-health-care-system/090710.html>

Quittner et al., Thorax. 2014;69 (12): 1090-7
Slatore C, Kulkarni H, Corn J & Sockrider M (2016). Improving Health Literacy. The New American Thoracic Society Guidelines for Patient Education Materials. 13(8).

The Flinders Chronic Condition Management Program. Flinders University (2017). Sourced from <http://flindersprogram.com/wp-content/uploads/Flinders-Program-Information-Paper.pdf>

A SPECIAL KIND OF PARTNERSHIP!

The relationships between our home care worker (HCW) and their client and family is a unique one. This collaboration, trust and support enables the link towards better health outcomes.

Due to the nature of chronic health conditions such as cystic fibrosis (CF), management and treatments are adjusted according to the individuals' symptoms and progression of the condition over time. A client-centred approach with the clients driving and contributing to the management of their health, facilitates individuals to have a more positive outlook. This self-management model starts from diagnosis and requires the support and guidance of all members of the tertiary and community CF team to manage the many challenges that people living with CF face.

At Cystic Fibrosis WA (CFWA) our HCWs, in collaboration with the CFWA physiotherapist and community nurse and the treating tertiary CF teams, encourage self-management and the approach is targeted to the specific stages and the individual client.

Recently, RED interviewed our HCW Ishbel, about her role and how she helps support her clients and families on the road to self-management:

Stage 1. 0-3 years (Emotional adjustment/parenting/child care/positive reassurance)

RED: How do you, as a HCW, collaborate with your families to provide support in the early years?

ISHBEL: With my initial meeting with the family, I focus most of my attention on the parent and their child's experiences so far. Collaborating with the parents to establish or maintain a solid routine is important and it pays off in the long term.

I provide information about the support services CFWA offer such as equipment loans or subsidy information and availability of education sessions at day care centres, kindy and/or with extended family. I also keep the families informed about CFWA support events such as the Parents Retreat and the Ladies High Tea, which are events where parents have an opportunity to chat with other parents in a relaxed atmosphere and establish some new friendships.

RED: How do you keep the child interested and co-operative?

ISHBEL: I give lots of positive reinforcement, clapping, smiling and having fun. Playing afterwards shows that I am here for fun too. Using the TV or iPad to watch cartoons during percussion is a great distraction. I always ensure the parent is happy with what I am doing - usually they are happy to have some time to themselves!

Stage 2. 4-9 years (Move to primary school/participation in own treatment)

RED: This is a time for increasing independence. How do you help the child develop new skills, stay engaged, actively participate and continue to support the family?

ISHBEL: I like to make contracts with the kids who are learning to read and write. I encourage their input and I get them to sign their contract to signify that they agree and have made a commitment to their treatments. I find this a very positive step towards them gaining some control.

At this age the kids begin to ask questions about why they have to do their physio. It is important to check in with parents to see what they know or what they want their child to know. I always listen and try my best to answer their questions as honestly as possible.

Getting kids involved with building and washing their neb equipment is good too. Mum or dad have usually been doing this day-in and day-out for years. It is good for the kids to realise they are responsible for their equipment. I make it fun and we always finish washing up with a bubbly hand 'jacuzzi'! All these strategies assist in building a firm foundation in developing self-management routines and skills.

Stage 3. 10-13 years (Primary to high school/more formally introduce independent health care behaviours)

RED: How do you manage adherence at this age?



Ishbel having fun with her client Lillee

ISHBEL: When daily physio has been a part of your life for 10 plus years, I think the kids find it tough and really isolating. As they should, they want to be more independent and they start socialising more with friends and noticing the things they have to do that their friends don't. I think it is important that friends see the physio side of things, so that they can gain some understanding about living with CF and have the opportunity to offer encouragement. I always try to remember their friends' names and get to know them too because they are probably the most important people to them at this age.

Even if the child has had a good routine from the get-go, they still question why they need to adhere to daily treatments. I find calling a challenge is a helpful motivator! For example, 'can you do physio every day for a whole month?'

Making them tick off charts made for their bedroom walls or filling in a personalised journal shows them what they have achieved, and providing small incentives helps too. Kids don't really see the health benefits of daily physio and want short-term gratification, which is usually a fancy donut!

I like to ask about after-school activities and sports and what they like to do and

tell them about famous people, or just instafamous people with CF, so they feel less alone. A lot of kids are on Snapchat, Instagram and Musical.ly so that is a way to keep everything current and fun.

RED: How do you bring CF education into your sessions?

ISHBEL: Again, checking in with parents to see how much they are happy for me to explain to their child is very important, as well as keeping it all relevant to the individual child. Education is ongoing and is generally driven by the child's inquiring mind. I answer in language that the kids understand and am honest but always guided by the parents.

I have asked kids to explain to me what their tablets are for. This way, they gain an understanding of why they have to take them and a little about how they work. YouTube is really helpful with this too.

Stage 4. 14-15 years (Starting to think about life goals/risky behaviours/moving towards independence)

RED: How do you manage building independence? How do you encourage ongoing health literacy – managing medications, cleaning of equipment etc?

ISHBEL: Working closely with the services team at CFWA is essential as they communicate regularly with the CF team at Princess Margaret Hospital and the CFWA services team support my role by providing updates on current treatments and treatment goals. At this age, teens can omit important details and changes made at their recent clinic appointments or just not know! Having input from CFWA prompts me to inquire about their clinic visits. For example, I would ask what they thought about their current lung function and reinforce the rationale for their treatments and continue to encourage routine, independence and self-management.

Being honest and frank about the consequences of regularly not taking medications and frequently missing physio is sometimes necessary, as they can experiment with “hmmm let's see how I feel if I don't take this tablet.”

Being equipped with the tools and skills learned at our HCW training sessions and meetings, I like to take the opportunity, when it arises, to spend extra time chatting with my teens about the unfairness of life and the hand they have been dealt. Having someone to talk to that is not a

parent, a family member, friend or health professional, can be helpful. Having someone that you have learned to trust just to talk to about how you are feeling, and your challenges, can assist in the transition to adulthood and in becoming an independent, self-motivated and self-managed individual.

With the future looking brighter for most people living with CF, I talk to them about plans for employment, enrolling in university, or plans to apply for an apprenticeship. I regularly reinforce their health literacy, with chats about current medications and treatments, encouraging equipment cleaning and promoting responsibility for their own care.

Stage 5. 16-17 years (Peer influence/ risky behaviours/acceptance of CF/semi-independence)

RED: This is somewhat of a daunting time for this age group, especially with the thoughts of leaving the safety network you have become so familiar and comfortable with at the paediatric hospital. How do you support your older teens?

ISHBEL: I am lucky in the sense that the teens I see seem to have got off on the right foot with groups of friends and know that they don't want to go down the wrong path. Being that I am young(ish) and can share stories from my late teens (that don't feel too far away!), I'd like them to feel like I am a relatable adult that comes around a couple of times a week to hang out while they do physio and other treatments. I make sure I ask the teen straight out about aspects of their condition and how their days have been when I haven't seen them, but respect times of silence if that's the vibe. I also tell them funny stories about myself so they know I am a human being and usually we end up having a good laugh.

I have had teens ask me questions about things that have made my eyes widen in horror, but I think it's good they can trust me. I'd rather they asked me and be informed rather than isolate themselves from peers. Keeping them motivated for their future and offering practical support for things happening after high school, holidays, learning to drive etc. I really hope they feel like I am a person they can collaborate with into adulthood.

I am lucky to be a part of a really strong team within CFWA that provides practical answers for just about anything that CF will throw at families. I feel like I am not usually



Toby doing his physio with his physio plan on the wall



Ishbel put together this plan to help Toby understand his physio treatment routine

lost for options when I am faced with a family with questions or issues and while we are not perfect, I think we all do a pretty good job!

For information about CFWA HCW support services, please contact our CFWA Services Manager, Kathryn Pekin, on **(08) 6457 7333** or servicesmanger@cfwa.org.au

References:

Consensus document from paediatric clinicians of the Tasmanian Cystic Fibrosis Service (2012). Reviewed 2016.

Quality Self-Management Assessment Framework. Government of Western Australia, Department of Health/Curtin University of Technology (2009).



Sarah and Sam - marking practice (byo ladder!)



Sam and Sarah with Sarah's parents Carmel and Tim



Jayton and Sam hanging out

FROM AFL TO CFWA

AFL Rookie Sam Powell-Pepper caused a sensation in AFL circles at the start of the 2017 AFL season, but footy followers back in North Perth had been watching Sam for many years.

When Port Adelaide AFL player Sam Powell-Pepper was home in WA following his first AFL season, a coffee with his manager Andrew McDougall, and Cystic Fibrosis WA's (CFWA) Karen De Lore started the ball rolling for a new volunteer role as an ambassador with CFWA.

Growing up in North Perth, Sam's AFL journey started at the Mt Hawthorn Cardinals Junior Football Club (Cardies). Spending a lot of time with fellow Cardies family the De Lores, Sam first learned a little about cystic fibrosis (CF). Alongside, Cardies coaching coordinator Tim Kerr, dad of Sarah who has CF, keenly watched Sam's development from junior footy to AFL.

Sam first volunteered with CFWA during 2016, helping on 65 Roses Day, the Halloween Fun Run and Convicts for a Cause. Keen to continue his association with CFWA, Sam saw the opportunity to be involved during his post-season break and caught up with a couple of young people

with CF.

A visit with Jayton at Princess Margaret Hospital (PMH) included a walk to the park and playing basketball. Jayton spent some time talking to Sam about his CF, explaining the function of his port, his medication and physical regime. Sam explained his AFL training program, and the highs and lows of his first AFL season.

The local park in North Perth was a great place to catch up with Sarah, for a kick of the footy and a bit of marking practice! Sam and Sarah spent some time talking about Sarah's CF, including her double lung transplant in 2014 and her journey back to full health.

As passionate Geelong supporters, the Kerr family found their traditional club allegiances a little difficult in 2017. Tim tells us that they found themselves watching as many Port Adelaide games as his beloved Cats. Having watched Sam as a junior at

our local club, to see him on the AFL stage is an amazing journey. They joined a big 'Sam' support contingent at the round 16 Port Adelaide v West Coast Eagles game.

Sam aims to lend his support to CF fundraising and awareness, especially with young groups in the community, both when he is home in WA or in Adelaide getting ready for season 2018! Although Sam's time in Perth will be limited, we aim to have Sam catch up with more of the young people in our CF community through the year and hopefully spend some time with junior players at the Cardies.

Please let us know if your child would be keen to catch up with Sam at a park for a kick of the ball, or some exercise and we will look to work it into the future. Meanwhile, keep an eye on the footy field during the 2018 season for those big 'don't argue' fend offs that have become Sam's trademark.

TOBY'S BUZZY BEE AND THE KKIND PROGRAM

Toby is a bright, industrious and curious little boy with cystic fibrosis (CF) who is now 7-years old. He has also had some issues around needle phobia and procedural trauma. Toby's mum, Melissa, shares his story and how they are working with KKind (Keeping Kids in No Distress) to manage his anxiety.



MELISSA: "Toby was first in Princess Margaret Hospital (PMH) at two days old for a double hernia operation. We then found out about CF when he was one month old. His first tune up was from 7-9 weeks old. He needed a pre-med before surgery and he didn't like the taste, so he spat it out. Nurses had to hold him down and forced it into his mouth. They held his nose shut so he would swallow.

When he was 16-months old he needed his second tune up. He was held down again for the pre-med as he vomited up the first dose. Then when he went through to theatre he needed to be held down with the mask on to get him to sleep.

Toby had many experiences like this. When nurses needed to do Tobramycin levels they tried pricking his toes whilst he was asleep. He would wake screaming and be difficult to settle. This led to many phobias.

It was difficult to manage his phobias for many years, and during this time, he was in and out of hospital. Many tears were shed by both Toby and myself. Then he had two and a half years without an admission.

He recently required an admission to get

rid of a stubborn cough. We met the KKind team and they have been amazing!! They introduced both Toby and myself to many options to help with scary procedures. When Toby had his Tobramycin levels taken they gave him a buzzy bee to hold. This vibrating device sends signals to the brain, confusing it, which lessens the pain felt. Amazing!! They also help give control back to Toby. This admission has been the least stressful so far. Toby now feels a lot less fear around needles and feels like he was listened to.

Toby is very independent when it comes to his treatment. We encourage him to take control and follow his routine. This is important because he knows that he must have physiotherapy to clear his lungs. He understands that if he didn't do physio he would be sick a lot more often and that the damage done is irreversible. Our Cystic Fibrosis WA (CFWA) home care worker has been instrumental in encouraging his independence. She is patient with him and I appreciate the break I get on the days

she visits.

We want to thank CFWA for their support. Also, we want everyone to know about KKind and realise what is available to help our kids and avoid negative experiences in hospital. It's as easy as asking your nurse to contact KKind and they come to you. Anything that makes hospital easier on our kids is a blessing".

More information about the KKind program can be found here: <http://www.cahs.health.wa.gov.au/services/kkind/>



Toby during his latest hospital admission

FAREWELL TO LAPPA AND FRAN

In 2017, we farewelled two of our much loved, longest serving home care workers (HCWs), Lappa and Fran.

Lappa started with Cystic Fibrosis WA (CFWA) in 1983 as one of the first HCWs, and is the organisation's longest serving employee. Having dedicated over 30 years to the service and care of people with cystic fibrosis (CF), Lappa is known for his love of exercise, enthusiasm for life, sense of humour and ability to tell a great story! He is an avid tennis player who always encouraged his families to be more active and live life to the full. CFWA would like to thank Lappa for his dedication and loyalty

and wish him all the best for the new adventures ahead.

Fran joined CFWA in 2001 and over the past 17 years has been one of our busiest and most hard working HCWs. Fran has worked with many young children who have benefited from her firm but kind approach to airway clearance and is much loved by her families. Fran is known for her can-do approach to her work; nothing was ever too much trouble for her and she often went over

and above the call of duty to help a family in need. CFWA staff and families will definitely miss Fran and hope she enjoys being able to spend more time with her family.





CAREGIVER BURDEN OF PARENTS OF YOUNG CHILDREN WITH CYSTIC FIBROSIS

Researchers in Ireland looked at how the care provided by both mothers and fathers of young children with cystic fibrosis (CF) impact on their lives. Here they provide a lay summary of their findings.

Why is this important?

Informal caregivers provide an important economic and social service in society, which is likely to increase due to pressures on healthcare services. The number of sometimes complicated treatment schedules needed by children with CF and adherence to these schedules means a large burden of care is placed on their parents or caregivers. They also have to cope with uncertainty about the progression of their child's condition, financial strain due to costs linked to caring for their child, as well as frequent clinic visits and hospitalisation. There is very little research that has examined how this burden of care impacts on the lives of parents and caregivers of young children with CF.

What did you do?

We used the Carer Quality of Life (QoL) questionnaire, which has not yet been tested specifically in carers of people with CF, although it has been used for other long-term conditions. The questionnaire is made up of two parts; the first part (the CarerQoL-7D) describes the care situation in terms of the negative (problems with relationships, mental and physical health) and positive (a feeling of fulfilment or support) effects of caregiving and the second part measures happiness on a scale from 0 (completely unhappy) to 10 (completely happy). Both parts are used to calculate a utility score (US) and a higher US indicates a reduced burden of care. A total of 213 families whose child had been diagnosed with CF were invited to complete the Carer QoL questionnaire and at least one parent from 195 families completed the questionnaire (130 mother-father pairs

189 mothers and 137 fathers).

What did you find?

Fathers had a significantly lower caregiver burden (higher US score) compared to mothers, most of whom described themselves as the primary care-giver. We also found that the caregiver burden increased with the child's age and was linked to the child testing positive for *Pseudomonas* (Pa). Most parents did not report any relationship problems with their child. Many parents reported problems with their own mental health (these problems were more common in mothers than fathers). Very few parents reported a lack of fulfilment when carrying out care tasks, the majority of parents reported good support when they needed it to carry out care tasks.

What does this mean and reasons for caution?

This study found that the Carer QoL was a brief questionnaire easily completed by parents of children with CF. This was the first time this questionnaire has been used for CF caregivers. The questionnaire was effective in identifying parents of children that were positive for Pa as having higher caregiver burden (it was anticipated that this group of parents would have a higher burden due to the increased treatment burden for Pa), increasing age of the child and being a mother were also found to be associated with high burden. CF is considered a life limiting condition and the burden of care on parents of children with CF can be significant so we anticipated that this would be reflected in the results however caregiver burden and happiness scores were rather higher than

anticipated for a condition that carries a daily care burden for parents. It is possible that the results may reflect parents' attitudes that what they face is a challenge rather than a burden. Higher caregiver burden in mothers may be because they are the primary caregivers not because they are mothers.

What's next?

Findings from this study highlight the importance of assessing the psychological wellbeing of parents of young children with CF and advising parents of the importance of seeking support or counselling if needed. The Carer QoL is a generic tool that enables comparisons of the impact of caring between different groups of patients and caregivers, however, there is a need for a dedicated well validated tool, using items generated by parents of children with CF which could be used in this specific population.

The results from this study are generally quite positive for parents (high median US) although many parents do report problems with their own mental health. It is unclear what specific problems they are experiencing as the questionnaire asks if they have problems with their own mental health (stress fear gloominess depression or concern about the future) it could be that they are concerned about the future given the life-limiting condition their child has been diagnosed with. Further research is needed as it is unclear why parents are reporting these problems.

Research by Catherine Marie Fitzgerald, Sherly George, Barry Linnane, Rebecca Somerville & Patricia Fitzpatrick



NEWBORN NUTRITION PILOT PROJECT

In 2017, Cystic Fibrosis WA (CFWA) and the Dietetics Department at Princess Margaret Hospital (PMH), worked together on a new initiative to provide nutrition support for families and their newly diagnosed babies.

In early 2017, the cystic fibrosis (CF) dietitian at PMH, Christine Kowalski, realised there was a need for greater nutritional guidance and support for parents of a baby newly diagnosed with CF. From this vision, and in collaboration with CFWA, and input from the senior CF nurses at PMH, a new program was established. The program includes a Nutrition Diary as well as a cooler bag with all the essential tools for administering enzymes, including apple puree, baby spoon and enzyme containers. The diary tracks your baby's feeds along with the administered doses of pancreatic enzyme replacement therapy, Creon and doses of salt and VitABDECK

supplements. It also offers advice as to how to administer these medications. A record of your baby's bowel motions is recorded too. The Nutrition Diary will be given to all new parents with babies diagnosed with CF by the CF dietitian at PMH and will be regularly reviewed and updated. This ensures you are kept informed and gives you the opportunity to provide input and discuss any changes made. If you have a diary already, please always take your diary to each appointment. If you would like a diary, please speak to the CF dietitian. The Nutrition Diary is a beneficial tool for all as it provides valuable information for the dietitian and the CF team

for future nutritional and treatment recommendations.

The pilot program was launched towards the end of 2017 and the evaluation and feedback process will be ongoing. With this collaborative process and funding by CFWA, this simple but extremely worthwhile initiative provides support and education for new families and assists to achieve positive outcomes for the future.

If you would like more information about CFWA support services visit our website www.cfwa.org.au or contact our office on 08 6457 7333.

COFFEE MORNING IN ROCKINGHAM

WE WILL BE HOSTING A COFFEE MORNING FOR MEMBERS IN ROCKINGHAM AND SURROUNDING AREAS. OUR COFFEE MORNINGS ARE AN INFORMAL EVENT THAT PROVIDE THE CHANCE FOR MEMBERS TO CONNECT UP WITH OTHER CYSTIC FIBROSIS (CF) FAMILIES IN THEIR LOCAL AREA AND CHAT WITH CYSTIC FIBROSIS WA STAFF ABOUT SUPPORT AND SERVICES.

WHEN: THURSDAY 8 FEBRUARY 2018, 10AM- 12 NOON
WHERE: DOME CAFÉ, 2/15 KENT STREET ROCKINGHAM
RSVP: BY TUESDAY 6 FEBRUARY TO GILLIAN ON
HEALTHPROMOTIONS@CFWA.ORG.AU OR
PHONE 08 6457 7333

*CROSS-INFECTION POLICY APPLIES. PLEASE SEE WWW.CFWA.ORG.AU FOR
LINK TO OUR POLICY.



UNDERSTANDING THE 2015 CYSTIC FIBROSIS DATA REGISTRY RESULTS

One of the critical activities that the Cystic Fibrosis Federation funds is the production of the Australian Cystic Fibrosis Data Registry (ACFDR), which includes data from all the cystic fibrosis (CF) centres across Australia.

This is important as it shows us how we are travelling. It also allows us to identify trends in the CF population and see how our clinics compare against each other in Australia and around the world.

Recently, the contract to collate and report on the data has been awarded to Monash University. The latest results are out now from December 2015.

So, what does CF look like in Western Australia?

At 31 December 2015, the ACFDR held records of 3,379 people living with CF in Australia, 52% of whom were adults.

In WA, there were 384 people with CF, 47.9% of whom were adults.

The average age of the Western Australian registry population was 20.4 years; 21.2 for males and 19.5 for females.

Within the WA Registry population, the median age was 18.4 years. The median age for males was 18.7 and 18.1 for females. The number of new diagnoses of CF notified to the registry for 2015 was ten (four males and six females). The number of deaths reported to the registry was one.

We are often asked about life expectancy for someone living with CF.

It is misleading to suggest that there is an ‘average life expectancy’ that can be applied to everyone with CF. Life expectancy is likely to be different for people of different ages; and this is before taking into account the fact that CF also affects people differently.

For example, average life expectancy at birth is lower than it is when you reach the age of 18, having survived all of the challenges of growing up that everyone faces. For this reason, misunderstanding of this statistic in the media the difficulty in calculating average life expectancy at any given age, CFWA have decided to phase out its use of average life expectancy at birth in favour of more easily understood statistics which

measures Median Age at Death (MAAD) and in the future, will be looking to use the Estimated Median Age of Survival (EMAOS).

Interestingly, the CF data registries in the USA, Canada and the UK and the Australian Bureau of Statistics (ABS) all now record MAAD. So not only can we compare CF stats to the rest of the world, we can also compare Australia’s CF population to the population of Australia.

Median is a different statistical measure from the mean (also called the average) with which it is sometimes confused. Median is measured by taking all the ages of people who died, ranking them and finding the middle value. This helps to negate the influence of extreme highs and lows. For example, in the series of numbers below, 31.6 is the middle value and is the median.

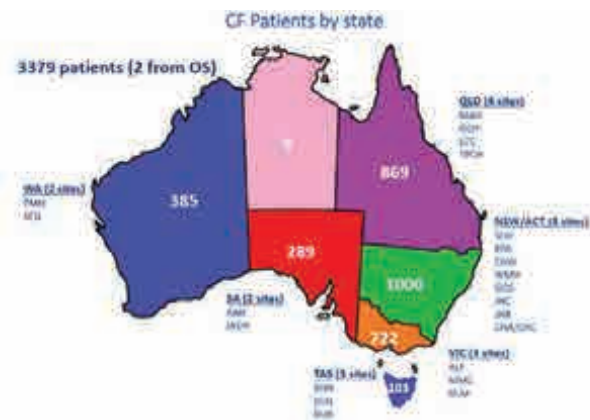
18.5	21.6	27	27	31.6
33.4	50.4	50.4	67	

If there were an even number of values, then the two middle numbers would be added together and averaged out to find the median value.

If you wanted to find the mean (average) of the above numbers, then you would add them up (326.9) and divide by nine. That would give you an average of 36.3 years.

The MAAD for people living with CF in Australia in 2015 was 31.6 years. This was an increase up from a median of 27.7 years in 2014.

A rising trend from 1998, when MAAD was approximately 17 years of age, appears to have stabilised or even reversed a decline from 2006 when the MAAD was 35 years. Whilst the 2015 figure may signal the return of an upward trend, the change should be interpreted conservatively because of the



relatively small number of deaths in 2015 – just 17 across Australia.

How does Australia rank globally?

In the UK, the MAAD for people living with CF was 31 years in 2016, 32 years in Canada in 2014, and 30 years in the USA in 2015. So, we appear to be holding our own in the overall scheme of things.

The EMAOS is the estimated age to which 50% of the CF population would be expected to survive, assuming current treatments, therapies and mortality rates remain constant.

The EMAOS figures were not available from the ACFDR at the time of going to print, however in Canada the EMAOS was 53.3 years and in the UK 47 years. We hope to bring you the EMAOS for Australia in late 2018.

How do CF population figures compare to the Australian population as a whole?

Well in Australia, the ABS report that the MAAD for Australia was 81.65 years in 2014. So clearly, we have some catching up to do. But this is a gap that we are closing. New drugs coming on to the market and the advances in gene therapies will continue to close that gap and move us ever closer to our vision of Lives Unaffected by CF.

To view the full state report, visit <https://www.cfwf.org.au/what-we-offer/resources/>

COLLABORATING WITH SCHOOLS: A PARENT'S PERSPECTIVE

Research has shown that children have better academic and social outcomes when their parents and teachers work together. A positive parent-teacher relationship can result in a child doing better academically, emotionally and socially, being happier at school and attending school more regularly.



Establishing a good collaborative relationship with a child's school community is even more imperative when you have a child with a condition such as cystic fibrosis (CF). Evidence suggests that due to the great length of time that children and young people spend in school, 'teachers play a key role in supporting pupils with long-term conditions to manage symptoms, integrate with peers and achieve their academic potential' (Strawhacker & Wellendorf, 2004). In order to promote optimal health and academic achievement for the child who has CF, parents and school staff need to work together to establish trust

and maintain relationships.

The benefits of developing a strong collaborative partnership with your child's teacher and school community include:

- Relieving some parental stress, particularly around your child's health. It is not about the school taking responsibility away from the parents, it's about creating the best environment for the child.
- Feeling confident or trusting that you can approach the teacher or school about the issues relating to your child.

So, how do you go about establishing

a collaborative relationship with your child's teacher and school to ensure your child's health, social and academic needs are being met and understood?

- Initially, make an appointment with the principal to discuss how your child is affected by CF and what it means for them in a school context. Take documentation with you e.g. information about CF and the latest reports from your child's multidisciplinary team at Princess Margaret Hospital, which can be kept on file.
- Make a list of issues or concerns you have which you can share with the principal

and/or teacher at the initial meeting.

- Once you and the teacher have agreed on planned actions and desired outcomes, the actions should be reviewed during the school year.
- Take a support person with you if needed. Our education officer at Cystic Fibrosis WA can provide support and CF education for these initial meetings.
- Provide feedback to school staff about things that are going well and when things are not working.
- If you are unhappy with something it is best to speak to the class teacher first and then the principal.

(Department of Education, 2018)

To gain a further insight into ways in which parents collaborate with a school community, RED spoke with Helen, who has a son with CF in primary school. Helen shared her perspective on the ways in which she has built a relationship with her son's school

community, and how the school has catered for his needs.

HELEN: My son is now in year one, however, when he started kindy I set up an initial meeting with the principal. Every year I have an individual meeting with the class teacher and if possible, with the other teaching staff, such as the music, art, and phys ed teachers. I give the teachers a list of the main things I want them to consider regarding my son's health needs, and a little background about him. The meeting with the teaching staff takes about 30 minutes. I break it up into what happens before, during and after school. But my main aim is to not make them feel overwhelmed. I want them to feel confident and comfortable with the information I provide them. The teachers have been very receptive to these meetings.

I have also realised that you need to collaborate with the school receptionist and registrar, as well as the deputy. They need to know about my son in terms of whether he needs me to pick him up or not if he is unwell, or if he is ok and whether the school

should call me or not. This can be a difficult thing for schools to always know so it is helpful for me as a parent to give them specific details about my son and his symptoms of being unwell.

At the start of kindy and pre-primary, the school distributed a letter that I wrote for the other parents, explaining CF and how it impacts my son, and what would be helpful from them in terms of my son's needs. I realise, however, that just because this is my issue it is not the other parents issue. They have other things going on, so my concerns will not be a priority to them. I have had to realise that the world doesn't stop because of my family's concerns.

The response to the letters I have sent to the parents has been varied, and parents will ask questions which is good, and overall, they have been supportive. I have found I do need to have patience and be diplomatic to establish good relationships and understanding of my son's needs. I do believe it is a bit of give and take when collaborating with the school community.

The school has also sent out a standard letter each year about minimising spreading of germs in school and keeping unwell children at home.

This year I became a class rep, as I wanted to get to know the other parents and not just have the focus on things only being about CF. I haven't wanted my son to stand out, but we have accepted that, in some ways, he is different, and we are not ashamed of this.

We are very vigilant about not seeing people who are sick, and we have found that our son's classmates have been supportive of this. There have been times when they might say something like "I can't hug you today, I'm a bit snotty".

We have encouraged play dates but when my son first started kindy, it was half way through the year at the current school he is at, so we didn't have many to start with. But as time went on we have found like-minded parents and some who are keen to hear about CF and what it means.

When our son has gone on new playdates, we have given the parents a list of things e.g. the CFSmart enzyme bookmark with amounts of enzymes required for common snack foods. I have said to the parents not to panic if our son doesn't take them when he eats. I have thought about what





Helen with her son Archie and husband Matt

are the worst things that could happen on a playdate and concluded that nothing is that bad in comparison to the benefits my son will have socialising and making friends. I have been up front with parents and tried to pre-empt any issues.

We have also educated and encouraged our son to look after his health while at school, such as knowing how to wash his hands properly and not sitting close to others who have colds. As he is getting older, I am finding I'm able to let go a little bit.

Something amazing that the school has done is to provide hand sanitiser dispensers in all the classrooms. It first began when I saw a Dettol campaign on television, which was set in a school, and I asked the principal if it was possible to gain funding from Dettol to then be able to install hand sanitisers in the classrooms. I stressed that this would be good for everyone, not just for the benefit of my son. The principal at the time was very open to this idea and must have done some investigating. She didn't get funding from Dettol but instead used money from the school's budget to pay for the dispensers and sanitiser (the Department of Education provides funding to schools through the school grant). The dispensers arrived but sat there for a while due to a change in principals. I reintroduced myself and asked the new principal about what would happen with the dispensers. In the end he installed them all himself. There

is even one in the library. In some classes, adjustments needed to be made to cater for students who may not be able to cope with the dispensers being in an easily accessible place.

The teachers have also put up notes or posters around their classrooms reminding students to wash their hands and to use the hand sanitiser.

My main overall tip for other parents when collaborating with the school community would be to try to see things from other perspectives; think what you would be like if your child didn't have CF, but at the same time it is very important to advocate for your child's needs and collaborate with the school community.

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2017 SPONSORS AND VOLUNTEERS AWARDS NIGHT

Our cystic fibrosis (CF) community came together on Friday 8 December for the annual Sponsors and Volunteers Awards Night. This event is designed to acknowledge and celebrate individuals and organisations who have supported Cystic Fibrosis WA (CFWA) throughout the year.

CFWA CEO Nigel Barker opened proceedings with the announcement of our new PhD Top Up Scholars. Kelly Martinovich was the recipient of the CFWA Golf Classic Scholarship and Samuel Montgomery was awarded The Hardie Foundation Scholarship. We will be sharing more information about these exciting research projects in the coming months.

During the evening, we presented five awards and made the most of the balmy evening to enjoy nibbles from our very elegantly dressed grazing table and drinks courtesy of Capel Vale in the courtyard of our office at The Niche.

The 2017 award recipients were:

Volunteer of the Year Award: Denise Sharpe

Denise has been volunteering for CFWA for over 18 months and comes into the office every Thursday morning to help our Services team. Look out for a feature article on Denise in this edition of RED.

Supporter of the Year: Telstra WA

As well as providing gifts and prizes for various events throughout the year, Telstra WA have provided phenomenal support for our 65 Roses Day campaign. Hosting a rose wrapping day event at their offices, staff wrapped over 3,000 roses and then helped to sell those roses through 17 stores on 65 Roses Day. We look forward to working with Telstra again in 2018.

Fundraiser of the Year: Exchange Tower and Vault Fitness

A combined effort by two organisations that worked together to create a dynamic spin cycle fundraising event as part of our 65 Roses campaign. The vibe, camaraderie and interest in our cause was amazing and the event demonstrated incredible community commitment and fundraising. The team is already working on their spin challenge for 2018.

65 Roses Award: Ron Bragg

Our 65 Roses Award recognises an exemplary person who has gone above and

beyond the call of duty, and that describes our award winner, Ron Bragg. Ron has managed The Niche building in a volunteer capacity for over 13 years. Ron's initial drive to be involved was partly due to his personal connection to CF. However, it quickly became apparent that he had a wealth of skills that could be utilised not only to assist CFWA, but the whole of The Niche building.

We wish Ron all the best in his well-earned retirement.

Long Service Award: Liz Balding

Awarded to Liz Balding who began her association with CF as the first CF liaison nurse for Princess Margaret Hospital back in 1987. Through her dedication and commitment to families, Liz has played a crucial role in supporting WA families and young people with CF.

Thank you for all those that attended, and we look forward to working with our award recipients and all our wonderful sponsors and volunteers in 2018!



Brett from WAFEX with CFWA staff



Liz Balding with Kathryn and PMH colleague Ali



PhD top-up scholarship recipients Kelly and Samuel



Aaron from Telstra WA with Karen

A GREAT NIGHT AT THE CARER'S SUPPORT DINNER

On 21 October 2017, we held our annual Carers Dinner at Steves in Nedlands. Held during Carers Week, this allowed us to acknowledge and support those caring for someone living with cystic fibrosis (CF).



The event attracted 17 carers, including both parents and grandparents. It was a wonderful opportunity to share stories, make new connections and have a rare night out.

Thank you to Carers WA, Lotterywest and the City of Nedlands for providing funding to help us run this important event.

Our 2018 dinner will again be held in October to coincide with Carers Week.



VOLUNTEER OF THE YEAR 2017

Meet Denise Sharpe, our latest Volunteer of the Year Award recipient, and find out her thoughts on her role within our organisation.

Denise Sharpe is our Volunteer of the Year for 2017 and has been working with Cystic Fibrosis WA (CFWA) since June 2016. We wanted to know what motivates Denise to volunteer and what she thinks of CFWA as an organisation.

RED: Thank you, Denise, for taking the time to talk to us about your volunteering experience with CFWA. Can you tell us how you came to volunteer for CFWA?

I came to volunteer at CFWA as a result of a conversation with my daughter. She asked me what I was going to do, now that I have some free time. I said I would like to volunteer, and she suggested CFWA.

RED: Have you found a benefit in volunteering?

The benefit I have from volunteering is knowing I am playing a small part in helping someone else. I am working in a

team with people who are doing all they can to help promote the importance of caring for those who have cystic fibrosis (CF) so that their outcome is the best health possible.

RED: Would you recommend it to others?

I would recommend volunteering to whoever has some time to spare. The benefit to the volunteer outweighs anything you could contribute.

RED: What are some of the tasks you have been given to work on?

The tasks at CFWA are varied, from shopping, wrapping gifts, writing birthday cards, cleaning and sewing.

Denise has been Paula's 2IC (second in charge), and a wonderful asset to our organisation. We so look forward to Thursdays when we know Denise will be

in to lend a hand. Thank you Denise for all that you do, and we look forward to another great year working together in 2018.

We have hundreds of wonderful people who give their energy and time through volunteering for CFWA every year. Thanks to our partnership with Volunteering WA, we will be able to better promote upcoming opportunities for volunteering in 2018. Keep an eye on our Facebook and E-newsletter for the chance to be involved as a volunteer in our awareness and fundraising events for the year.



Denise and Paula at the Sponsors and Volunteers Awards

Denise helping to clean nebulisers



This year's event will be held from the 16-18 March in Fremantle. All parents with a child with cystic fibrosis (CF) are invited along to this important event for a weekend of respite and fun.

We are busy organising lots of great activities including the Escape Hunt challenge, a relaxing yoga session, dinner at a local eatery and plenty of time to explore the vibrant Fremantle area.

Where: Gallery Suites, 185 High Street Fremantle and surrounding areas

When: 2pm Friday 16 March until 10am Sunday 18 March

Registrations with more detailed information were emailed mid-January. If you did not receive yours or need more information, please contact Paula on services@cfwa.org.au or phone 08 6457 7333.

A big thank you to Lotterywest for their support of this important event.





REGIONAL COLLABORATION

Thanks to Telethon and the Department of Health WA, Cystic Fibrosis WA will continue to provide regional support and education to both members and health professionals across Western Australia.

In February, the Services Team will be travelling to Kalgoorlie and Esperance to deliver a number of hospital and community-based education sessions. We are also looking forward to catching up with some of our families and young people with cystic fibrosis (CF).

In April, we are planning on travelling to the South West, including Collie, Narrogin and Albany, where we will provide similar

education sessions and a social member catch up over dinner.

In May, leading up to 65 Roses Day, we will collaborate with expert speakers from Princess Margaret Hospital (PMH), Sir Charles Gairdner Hospital (SCGH) and Fiona Stanley Hospital (FSH) to facilitate a 2 to 5-day intensive education program; our Regional Respiratory Training Program (RRTP). This program is designed

specifically to educate regional nurses and physiotherapists about CF to improve healthcare for our regional members.



Government of **Western Australia**
Department of **Health**



FUNDRAISING NEWS

The new year has begun and as we make plans and set our awareness and fundraising targets for 2018, we want to take a moment to recognise the community groups and individuals who raised awareness and funds for Cystic Fibrosis WA (CFWA) towards the end of 2017.

Busselton Golf Day

On 1 December, the Rotary Club of Busselton Geographe Bay hosted a fun day of golf to raise funds and awareness for cystic fibrosis (CF). Rotary member Ross organised the event with a team of generous volunteers, including locals Carolyn and Bernie, who have a son, Jackson, with CF.

The event was held at the Busselton Golf Course where the sun was shining, and the buzz of friendly competition was in the air. Players had the opportunity to purchase ‘mulligans’, ‘grenade balls’ and ‘strings’ before heading out onto the course to give them a ‘helping hand’ during the game if needed.

On completing a round of golf, the teams returned to the clubhouse for a BBQ and to tally up the fundraising total. Through the efforts and generosity of the players, volunteers and Rotary members, Jackson and Rotary President Robert presented us a cheque for an incredible \$6,000 at the end of the day. Thank you to everyone who was involved in making the day a success!

Colour Run Perth

An incredible 20,000 people flocked to the city for the Colour Run in November last year. Amongst the large crowds were a number of participants running in support of CFWA.

ANZ bank had a team of participants made up of dedicated staff from three of their Peel Region branches; Mandurah, Mandurah East and Falcon. They raised \$1,500 online and through the sale of merchandise, and helped to help raise awareness in their local communities by decorating their branches in red for CF. Thank you ANZ for your generous support!

We also had a number of individuals and teams who also raised significant funds and awareness for CFWA, including Tahnee and Dakota Richards, Tania O’Meara and the Arc Infrastructure team, home care worker Ishbel Macqueen and the Rose Runners team, who included friends and family of CFWA’s Karen De Lore.

Altogether, these colour running community fundraisers raised over \$4,800 for CFWA and helped to spread awareness for CF in the community!



Our very own home care worker Ishbel on the course!



Rose Runners Team before they were covered in colour!



Dakota and Tahnee spread their colourful wings.



Jackson and Robert present Karen from CFWA with a cheque for \$6,000



The team of dedicated golf day volunteers



CHRISTMAS APPEAL THANK YOU

On behalf of everyone at Cystic Fibrosis WA (CFWA) we would like to thank all our supporters of the 2017 Christmas Appeal.

Our 2017 appeal was created in collaboration with other state cystic fibrosis (CF) organisations, with one of our WA families sharing their CF story throughout Australia. We are very grateful to Nyssa, Cody, Norah and Cole for participating in our campaign and sharing their life with us. We hope that 2018 brings health and happiness for your beautiful family.

We are also very appreciative of the generous pro bono skills provided by Curtin University graphic design student Jade Koch who created our appeal design.

Jade recently completed her degree and is now chasing her dream job, although that didn't stop her from spending some time with us this week to lend her skills to some graphics work. We wish Jade all the best for her future career and hope that she takes her CF awareness with her wherever her journey leads.

Funds raised through our appeal came from far and wide. We wish to thank everyone who has donated. In donating, you help to broaden the reach of our services and

extend research opportunities. Our caring community in WA has raised over \$7,050 through the appeal.

Every year we collaborate with the other states to run two direct mail campaigns. Sharing our stories helps to convey a clear CF message nationally and keeps costs down. If you would like to be a part of a future campaign by sharing your family's CF story, please contact Karen De Lore at marketing@cfwa.org.au or on 08 6457 7333.

The background of the entire poster is a photograph of a natural landscape. In the foreground, there is a large, weathered log with visible wood grain and cracks. Behind the log, a grassy field stretches towards a single, large, leafy tree. The sky is a pale, hazy blue. The text is overlaid on this background in various colors and fonts.

CYSTIC FIBROSIS

WA ANNUAL

GENERAL MEETING

Official Notice of 2018 AGM

CYSTIC FIBROSIS WESTERN AUSTRALIA (INC)

Wednesday 18 April 2018 7.00pm

**The Niche Conference Room,
11 Aberdare Road Nedlands WA 6009**

Corner of Aberdare Road and Hospital Avenue.

Guest Speaker TBA

Refreshments served following the AGM

**RSVP for catering please
by Friday 13 April 2018 to
Ric at admin@cfwa.org.au or
08 6457 7333**



event calendar

2018

MARK YOUR DIARIES FOR THESE 2018 EVENTS

FEBRUARY

8 - ROCKINGHAM COFFEE MORNING
10 - CORPORATE BATTLE OF THE BANDS
19-20 - KALGOORLIE/ESPERANCE
OUTREACH
23 - TRANSPLANT SUPPORT DINNER
24 - ROTTNESST CHANNEL SWIM

MARCH

8 - VOLUNTEER AWARENESS AND TRAIN-
ING EVENING
16-18 - PARENTS' RETREAT

APRIL

5-6 - GREAT SOUTHERN OUTREACH
18 - ANNUAL GENERAL MEETING (AGM)

MAY

TBC - AN EVENING WITH THE CF
SCIENTISTS
7-11 - REGIONAL RESPIRATORY
TRAINING PROGRAM
19 - LADIES HIGH TEA
24 - ROSE WRAPPING DAY
25 - 65 ROSES DAY
27 - HBF RUN FOR A REASON

JUNE

19 - GERALDTON OUTREACH

AUGUST

2 - BUNBURY
26 - CITY TO SURF

SEPTEMBER

13 - MERREDIN OUTREACH

OCTOBER

2-4 - SIBLING AND OFFSPRING CAMP
19 - PARENTS' DINNER
26 - CF GOLF CLASSIC

NOVEMBER

10 - MEN'S SUPPORT EVENT

DECEMBER

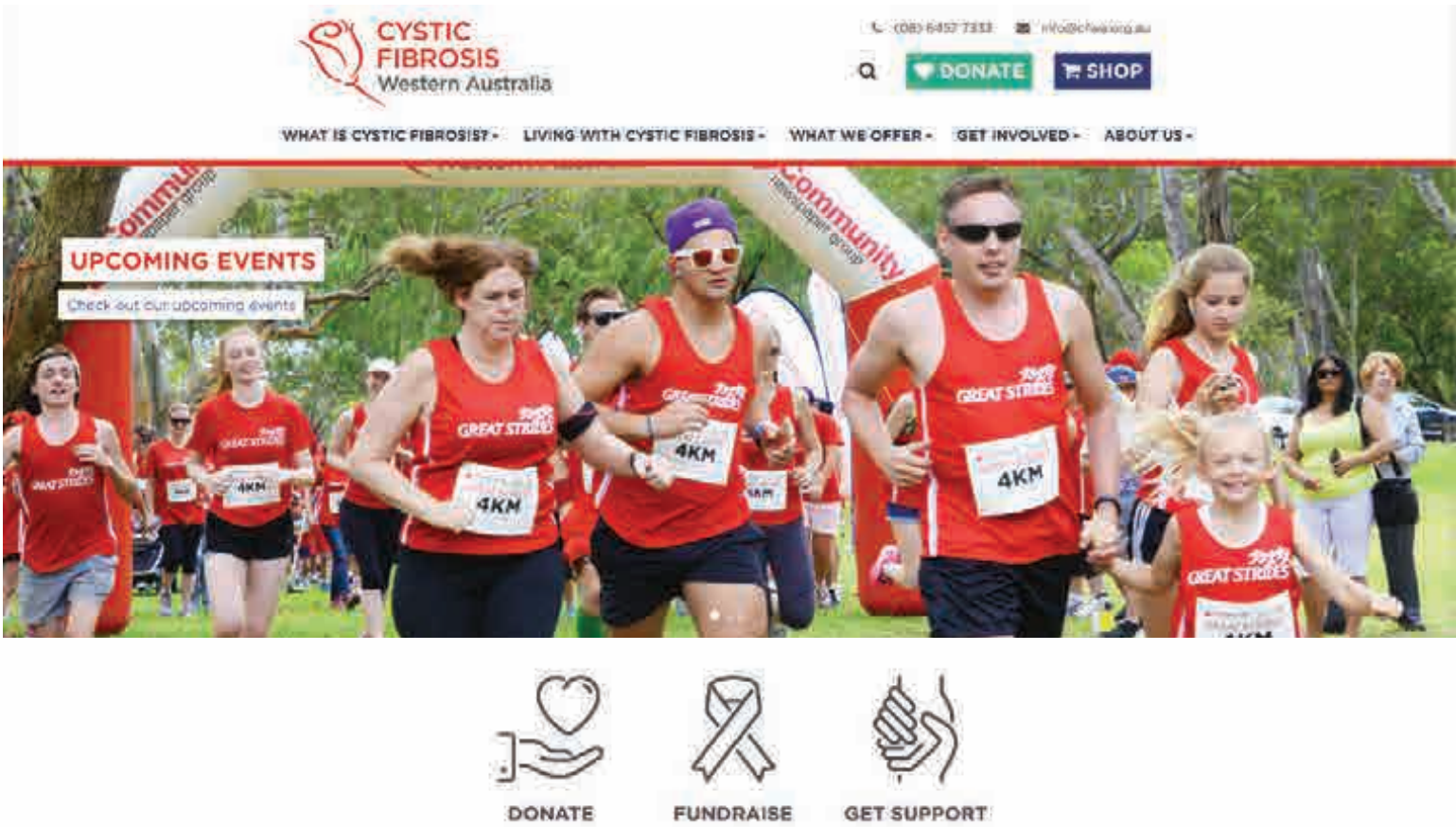
7 - SPONSORS AND VOLUNTEERS
AWARDS NIGHT

*PLEASE NOTE, DATES MAY CHANGE IF
CONFLICTS ARISE.



NEW CFWA WEBSITE

Thanks to generous support from Lotterywest, we've launched a new Cystic Fibrosis WA (CFWA) website



HomeCare Team Training

Our Homecare Workers were in the office today for their last meeting of the year, followed by a Christmas lunch.

Every month they come together for training and a catch-up to make sure they are up to date with the latest techniques.

Today we distributed new iPads, funded by a generous grant from Lotterywest, equipped with resources to help streamline our ongoing education and make our team even more efficient.

We are fortunate to have such a dedicated and passionate team of homecare workers at CFWA and know they're appreciated in the cystic fibrosis community!



We're excited to introduce our brand new CFWA website, funded through a Lotterywest grant.

The new site has been designed as a hub for members to get quick and easy access to our available services and find up-to-date information on cystic fibrosis (CF). We've streamlined and categorised the content to make it easy to find the information you're looking for.

What is CF?
Information about CF and carrier screening for the general public.

Living with CF
All the information your need about living with CF, including treatment, nutrition and exercise.

What We Offer
Get access to our range of services including our in-home care, subsidies and equipment loans.

Get Involved
Get involved with CFWA by becoming a volunteer, hosting a fundraiser or joining one of our events.

About Us
Get in touch with the team and learn about our history and vision for the future.

Visit the new website at www.cfwawest.org.au to check it out for yourself.

We look forward to expanding our range of services and resources in the future.



CORPORATE BATTLE OF THE BANDS

6PM Saturday 10th February 2018

CHARLES HOTEL, NORTH PERTH

Tickets online \$30 or available on the door \$35

FEATURING

Loud Bastards *CoveFefe* **SMASHED**

The Sweet Pavlovas *Critical Incident*



KOSMIC

