EDITION 4 2019

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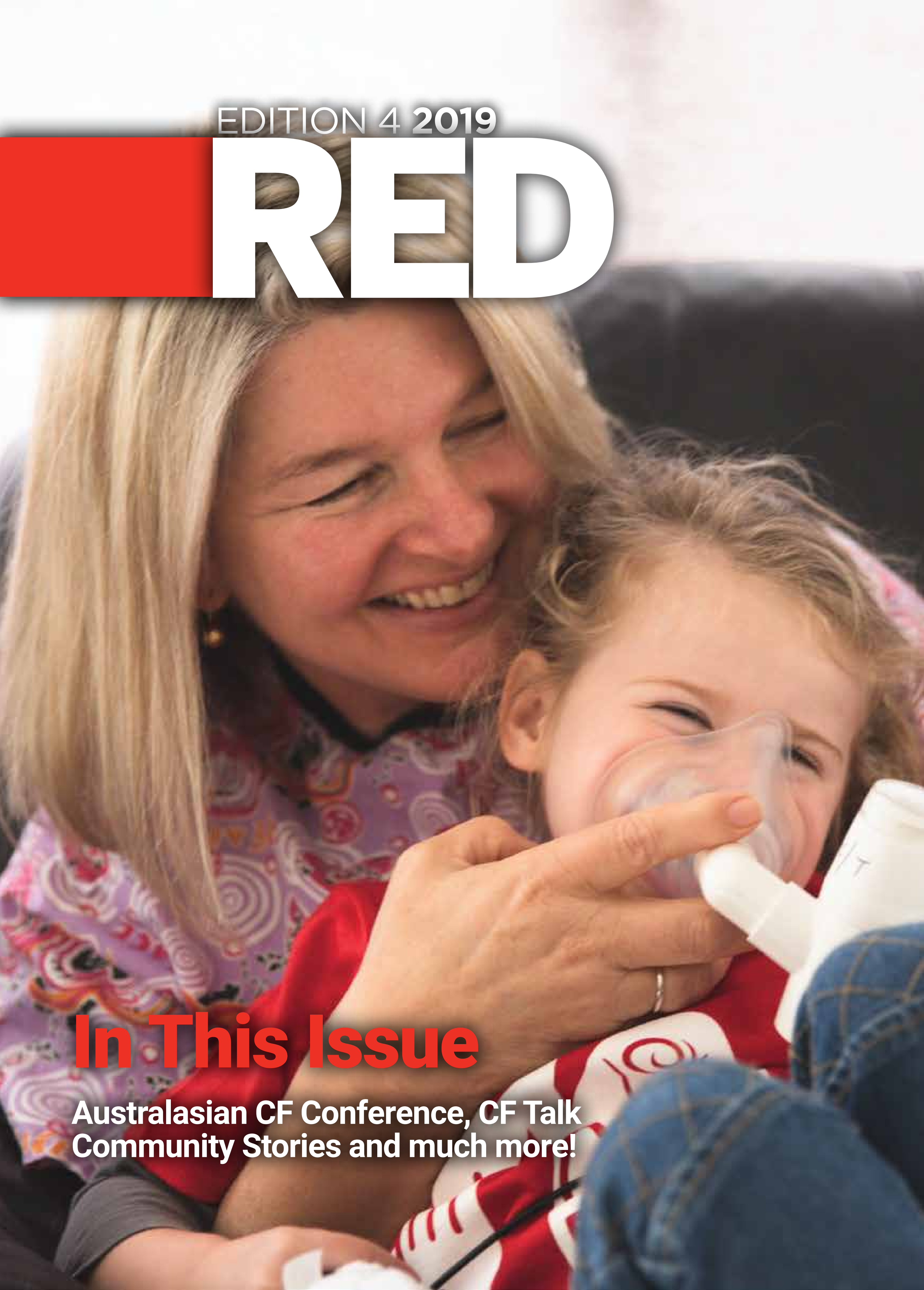

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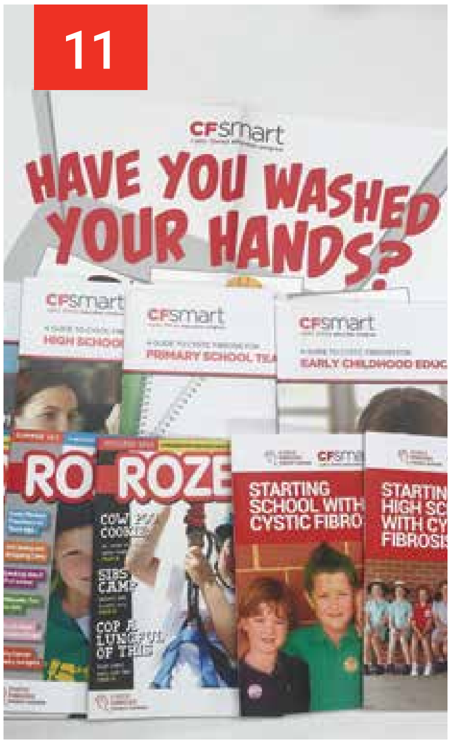

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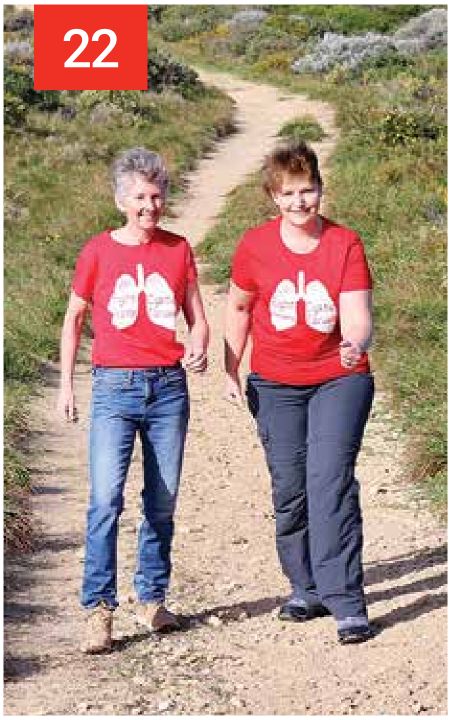

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RED CEO MESSAGE

NIGEL BARKER, CEO

In August this year, Perth was host to the 13th Australasian CF Conference (ACFC) at Crown Perth in Burswood.

The conference was a huge success, with nearly 20% more delegates across both the lay and medical sessions than has ever been achieved in the past. Despite being deep mid-winter, Perth turned on the sunshine and visitors from overseas took the opportunity to visit some of the state's iconic locations.

Special thanks should go to CFA, the Lay Conference Organising Committee and the Medical Conference Organising Committee for a splendid job; well done.

From a membership perspective, I think that it is fair to say that engagement with our members was superb, thanks in part to conference subsidies made available through CFWA, CFA and Lotterywest. Of particular note was the often-unpublished data presented in the poster sessions by researchers at the beginning of their careers. Bright young people pushing the boundaries of our knowledge of CF, many of whom are beneficiaries of the research funding we provide.

Of course, there were lessons to be learnt and applied to the 14th Biennial CF Conference in Hobart, Tasmania, and we are grateful for all the positive and constructive feedback received. The 14th ACFC promises to be a spectacular success.

Nigel Barker

CEO

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our first edition for 2020, please contact us before 18 January 2020.

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

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ON THE COVER
CFWA home care worker Jo, with Charlotte. Read more on page 20.

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Here We Go Again

The 13th Australasian Cystic Fibrosis Conference (ACFC) seems like an eon ago, but in reality, the past few months since we were all in Perth have flown by.

Plans are well underway for the 14th Australasian Cystic Fibrosis Conference in Hobart from 7-10 August 2021.

SAVE THAT DATE!

Assoc. Professor Phil Robinson has agreed to chair the 14th ACFC. He has long and strong ties with Tasmania and undertook his medical training at the University of Tasmania between 1977 and 1982.

Phil has been involved in paediatric respiratory research for more than 25 years including many innovative drug trials as well as individually designed and led projects involving aspects of cystic fibrosis lung disease.

A/Prof Robinson is currently the Head of Respiratory at the Royal Children's Hospital in Melbourne and we are thrilled to have him in place to lead us to another successful and informative conference.

By all reports both the 2019 Lay and Medical Conferences were well received and the few 'niggles' identified have been duly noted.

Perth was an outstanding destination and impressed our overseas and local visitors. I would like to thank the CF community in WA for making us all feel so welcome in your truly beautiful city.

Over the next few months we will be recruiting the Lay and Medical Committees and if you are interested in getting involved please contact Nickim@cfa.org.au. Being part of the conference development is a very rewarding experience and it does not take up a huge amount of time.

If you are time-poor then email Nicki any topics you would like considered in either of the Conference Programs. I can't guarantee anything, but we welcome your input.

We always like to see a few familiar faces return to Committees as continuity and learnings are so important.

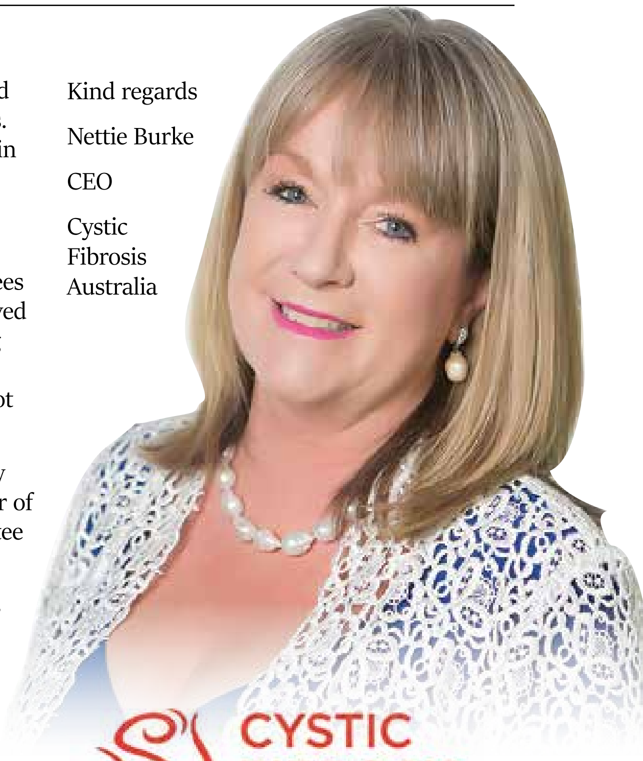
I hope you will join us in Hobart in August 2021 for the 14th Australasian Cystic Fibrosis Conference. It promises to be a great opportunity to network, learn, share, collaborate and celebrate the amazing work being done in the CF arena.

Kind regards

Nettie Burke

CEO

Cystic
Fibrosis
Australia



CF Talk Community Stories

Research indicates that sharing people's stories or "lived experiences" contributes to an improved sense of hope, empowerment and social inclusion. Underpinning this lived experience is a shared understanding of how a diagnosis such as cystic fibrosis (CF) changes life perspective; sometimes through a common experience of loss, however, also healing, humour and strength.

Here is part two of our CF Talk series, where we hear excerpts of interviews from Bianca and Amanda.

When did you feel that you wanted to hear other people's stories of caring for someone with CF?

Bianca: I have CF in my family, so I didn't feel the need to go out to the community or be in a group when Willow was born. We had to do IVF, so it was a 1 in 4 chance of having a baby with CF and when Willow was diagnosed, I had my cousin with CF and my aunty to speak to.

Amanda: It was about three or four months after Amelia was born. I typed a CF related question into Google, and it popped up with a CF support group. It was an international group, so there were people from all around the world with different experiences and perspectives. I hesitantly joined it as I wasn't sure what I would find there, however they were so supportive, welcoming, and lovely. There were a few other Australian mums on there too, mainly over east I think, and hearing their experiences made me a little bit less scared because they were all so positive, open and non-judgmental. I just felt like I could ask questions there that I might have felt silly bothering the doctors about or discuss things I wouldn't feel comfortable talking about with someone who doesn't have a child with CF because they just wouldn't understand.

What are the benefits of connecting with other carers and hearing their stories?

Bianca: My husband Jim and I met another mum, Justine, and we've all become really good friends. I'm a

hairdresser so I do her hair, and she cuts our dog's hair because she's a dog groomer. It's very hard because our kids can't be together, but we have a connection through CF and friends. We go on the Cystic Fibrosis WA (CFWA) Parent's Retreats where we meet a lot of other parents, and also the high tea that the girls put on at CFWA. And that's really nice too, because then I get to meet other people that are in the same boat as us. Then you happen to bump into them at clinic or on the wards when you're admitted.

The first retreat was two years ago. That was quite a big thing for me because you can stay a bit closed in, I think, when you're a CF parent. If you've got a bit of a support, like I've got Justine, you can bounce off each other. She encouraged me to go, and it was her first one as well, and we loved it. Then we started going to the high teas as well. You meet the grandparents of the CF kids as well, and my mum normally comes along. Things like that have been really lovely to do. And I find the girls at CFWA are amazing; you know they are always there as well.

Amanda: For me, I found just knowing that there are others in a similar situation who are there to listen and support me if I need to be invaluable. Connecting with other carers has allowed me to share the highs and lows of this journey. Hearing about other people's experiences has better helped me to understand the disease so I can better support my daughter and family. Being able to ask questions openly and learning as you go with likeminded people helps build your confidence and grow your knowledge as a carer and your child's advocate.

We're here to support each other, and I find just hearing other people's stories has made me feel more optimistic, I suppose because I'm hearing more and more positive stories. We're all connected by this awful invisible illness, but we are moving in the same direction towards a cure and it is very uplifting.

Do you have much contact with other carers and if so, how do you manage these contacts?

Bianca: I know some people are on a Facebook support group, but I stay away from that and it's my personal choice because I don't want to hear the negative side of things, or the gossip, which I find some of those forums are. But if there's an event I will attend it, and it's really nice to catch up.

Amanda: The Ladies High Tea is the one event that I have participated in every year since Amelia's diagnosis, and meeting so many strong women through that has been amazing. They are all such passionate, lovely, normal people, leading extraordinary lives despite CF. It's been a really unexpected place for friendships to flourish, and meeting mums with children the same age as Amelia has made it easier to relate and share experiences since we are all at the same life stage. I think talking to other carers, especially other mums for me, really does help. Dinners and coffee dates are also a great way to catch up, although it can be hard to coordinate since our little ones can't come along.

It takes a community to raise a child, with many others also taking on a caring role throughout this journey. What has it been like sharing this role and how has that helped?

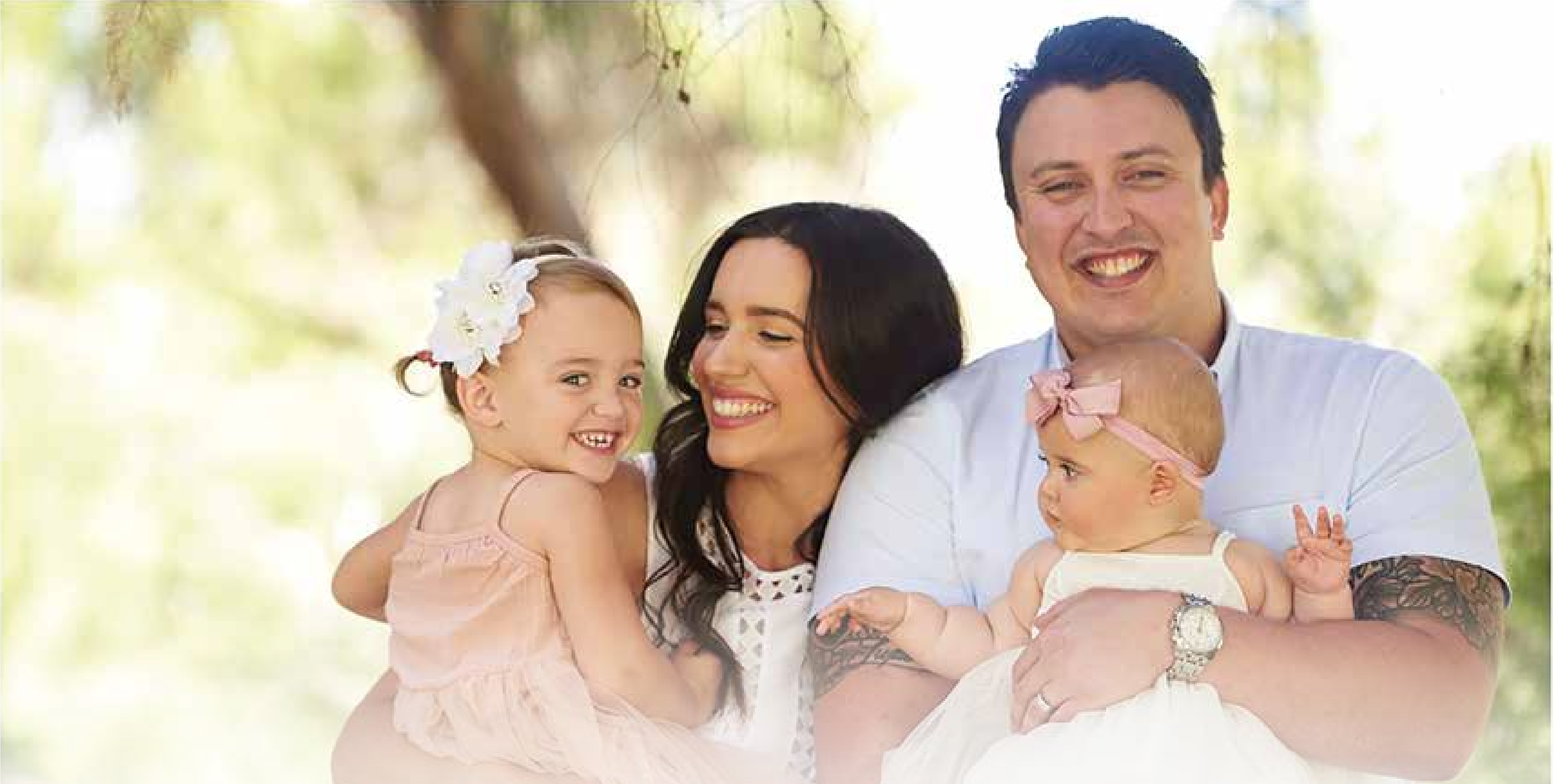
Bianca: We have a lot of support for everything with family and schooling, even the wider school community are all on board with it. They actually have another child with CF at school as well now. The mum joined the school and then heard about Willow and approached me for advice as we have been there since kindy. So, we connected, and I helped her along and put her in touch with CFWA to come out and do some school education.

CFWA coming out to the school is a big help, because they explain it so well when I don't know what to say. And they're always there for you if you need them. When we first went into kindy and spoke with them about hand hygiene, the school re-did all the toilets and put hand sanitisers through all the classrooms. And now they have hand dryers as well as paper towels. The school have been really helpful and got on board with it all and have always said anything that needs to be changed just let us know.

Willow has amazing friends at school as well. They say, "Willow have you had your tablets?" Always. So, she's got a lot of people supporting her which helps us. We do try and get on with it just like everyone else.

Amanda: I have been really lucky to have an amazing support network with family and friends who will drop everything and bend over backwards to help if I need it. My husband works really hard to support our family and it has allowed me to be home with our daughters. My mother-in-law helps me regularly each week with swimming, dancing lessons, and appointments which I couldn't do without her. My mum lives in Albany and is always fundraising for CFWA and trying to help by raising awareness about CF. I am very close with my sister and she is my sounding board and voice of reason if I ever feel overwhelmed or upset by the obstacles CF can throw at us.

I utilised CFWA's support for the first time recently after Amelia's first ever hospital admission. It helped having people I knew



had Amelia's best interests at heart along with the expertise and resources she needed. I think Amelia's recent admission has taught me to accept help more when it's offered. I have always had the mindset that if I wanted something done properly to just do it myself and felt asking for help was a sign of failing, but I am getting better at letting go and I now know the help is there for a reason and to utilise it when I need it.

What would you hope that these short films with achieve?

Bianca: I think everyone can relate to somebody and then that can lead to getting in contact with people to help you, especially if you've got no family back up or have no idea when your baby is first diagnosed.

So, I think every step of the way; schooling, coming into hospital (that's a huge thing as well) etc. if there's someone there to talk about that on the film, that would help. School is one of the hardest things to get your head around because you know there's heaps of kids there, and there's sickness, so if you've got someone that can talk you through it, and back you up and put you in the right direction, I think that really does help. If you've got a place where you can go to look and think, oh they've gone through that as well, it just really helps.

Amanda: I would hope that these films help remind carers that no matter your individual circumstances, there are others out there who understand, who care, and who are here to support you if you need it. It is important to create unity amongst carers, and for them to know that their contribution is making a difference to not only the individual they are caring for with CF, but to the wider community.

I think we as humans can often be extremely hard on ourselves and just to be told you are doing a great job can mean the world and be the encouragement needed to pull yourself together and keep fighting. I hope they help carers realise they are not alone and to not to be afraid to ask for help if they need it. I'm sure these films will also be a great way to help people share their experiences, their challenges, their achievements, their concerns and their hope. Also, that life doesn't have to be put on hold or drastically different because of CF, it's just a different version of normal.

I think they will remind people of the importance of supporting each other and taking time to care for themselves too, since you can't give all of yourself if you are running on empty. I would hope that it helps carers realise that they are enough, because I think often you question yourself just as a parent in general, let alone caring for someone with extra needs. I guess in saying that, I still struggle to think of myself as a carer. I just think of myself as a mum who is doing whatever I need to do to keep my kids happy and healthy. I would hope other carers take away from it that they're doing a great job, and every experience is going to be different so keep doing what you are doing, you've got this!

Is there any advice you think would help other carers?

Bianca: I have people I can talk to, and I think that really helps. Having something like short stories from other carers for people that don't have anyone to talk to or have no idea, would be really helpful.

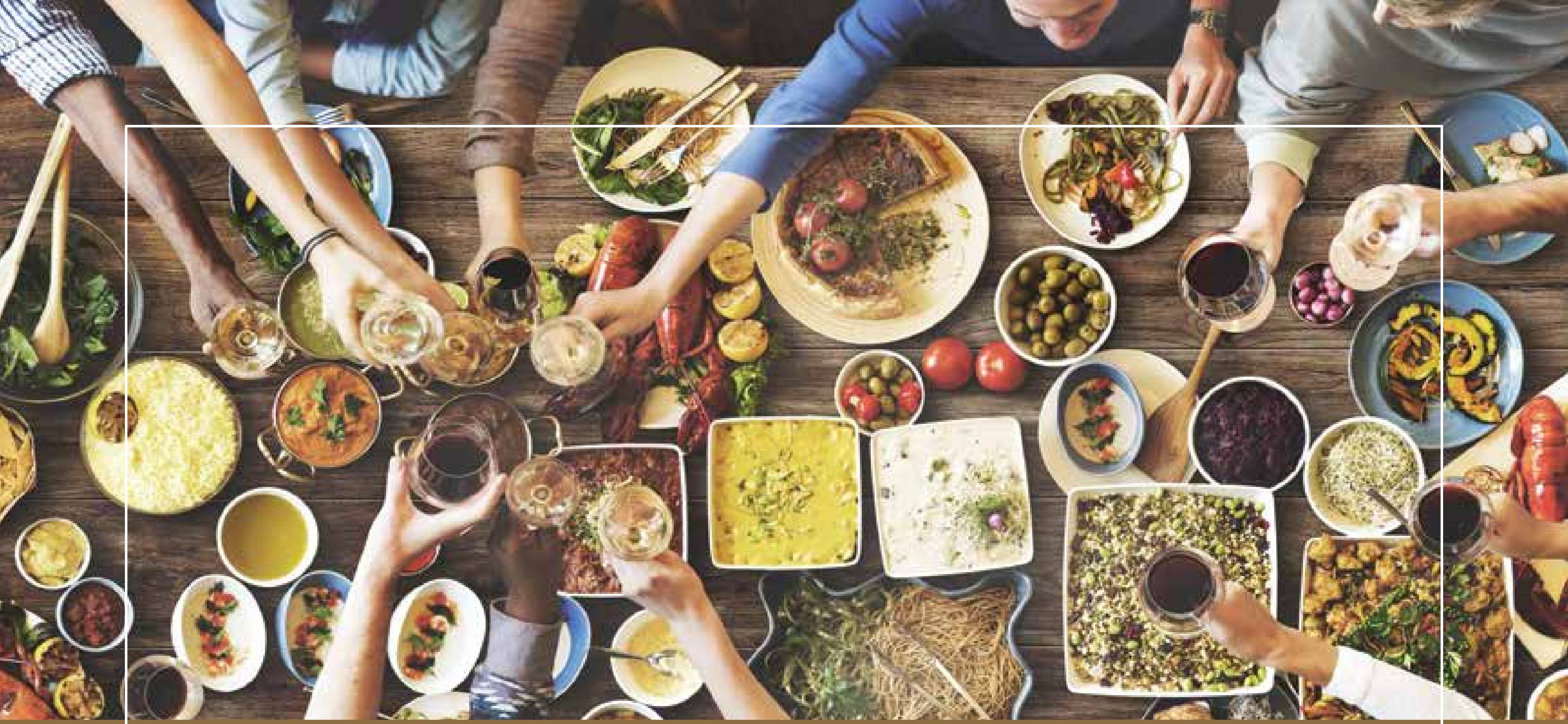
Having a family member with CF has meant that Willow, at nine, has gone through seeing people have transplants and seeing what happens when it hasn't worked. We've had support through the hospital clinical psych to help Willow get through that side of things as well. Because she's very young and knows that she's got CF herself, we find we have to be honest with how it is. Someone else might be going through that as well.

When my cousin was born, they didn't have the antibiotics and stuff that they have as babies now, whereas when Willow was born, they were straight onto that. All the medications have come such a long way and that's why they are so much healthier these days.

Amanda: To take one day at a time, create a routine that works for your family, and to make treatments as fun as possible. I think despite being told not to, all parents with a CF diagnosis go and do a Google search, which returns some terrifying results. A lot of the information out there is out-dated and won't be applicable to our kids. It is so easy to scare yourself, and then exert that anxiety and your fears onto your child, which again is not in their best interests and is not fair on them. Just know that not everything is applicable to your child, and no two cases of CF are the same.

Be in the moment and be as present as you can be, enjoying your child for who they are in that season of their life. But in saying that, I think it's also really important to make sure you are making plans for the future and setting goals along the way, as there is going to be a future, and it's looking brighter every day for our little warriors. Everyone is really positive in the CF community which helps you to stay encouraged and motivated, and hopeful that the cure's right around the corner. I can't help but feel really positive for each individual.

I am so beyond grateful for the generation before us who paved the way with research, fundraising, awareness, and clinical trials so our CF kiddies don't have to endure what they have. They should be really proud of themselves, and everything they've accomplished, and the legacy they will leave behind.



PARENTS' RETREAT 2020

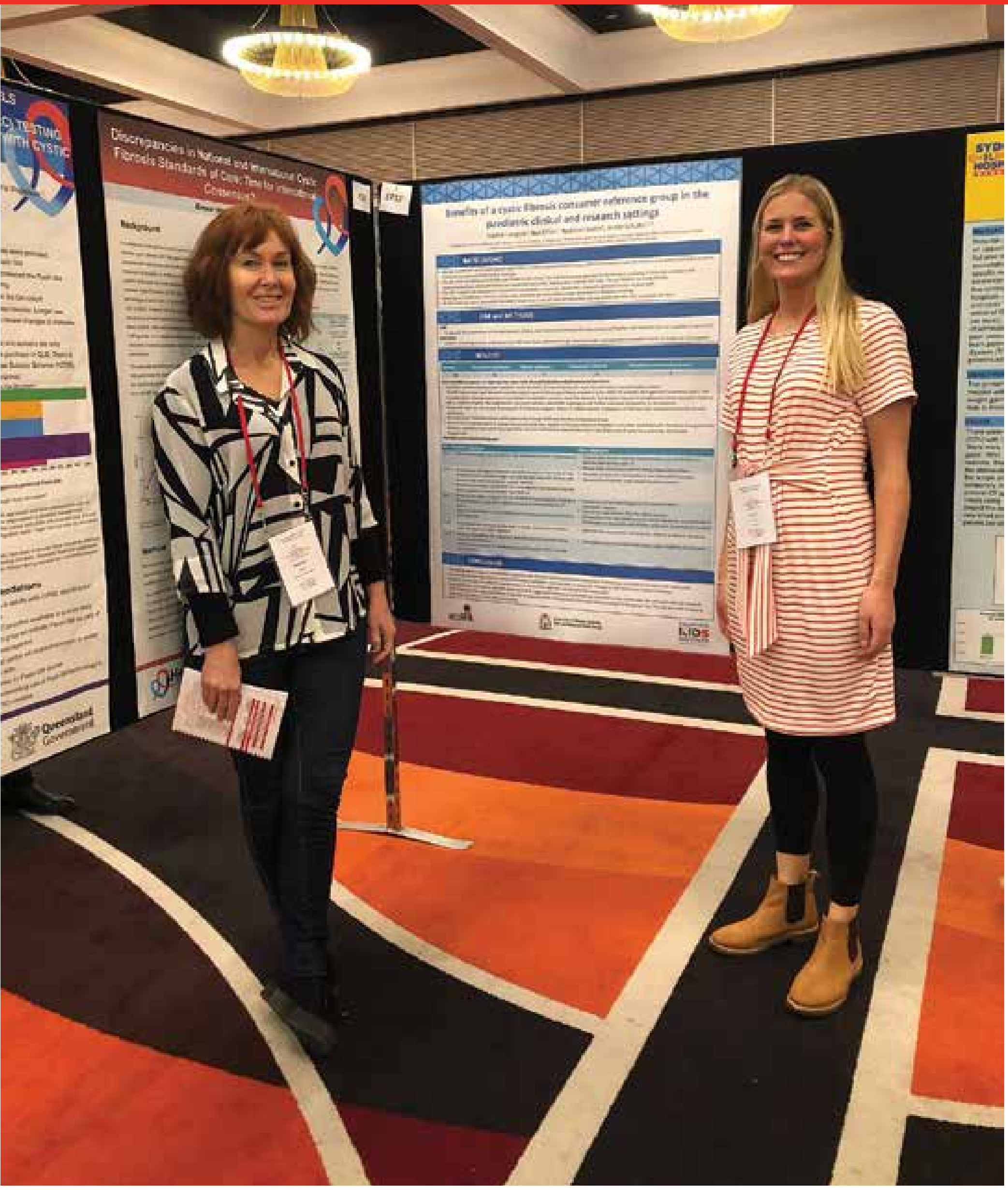
GET EXCITED PARENTS; WE HAVE BOOKED IN THE 2020 PARENTS' RETREAT!

When: 6-8 March 2020
Where: Discovery Parks, Swan Valley
(www.discoveryholidayparks.com.au)

More information to come later in the year, but be sure to add this exciting event to your diaries now.

Celebrating Partnerships at the 13th Cystic Fibrosis Australasian Conference

After a 16-year hiatus, the biennial conference returned to the west and with 'Celebrating Partnerships' as the underlying theme, our local community members and health professionals got the chance to come together and learn about the latest developments in cystic fibrosis research, treatment and care from over 140 national and international speakers.



Some of the presentations at the lay conference included: Maximising Your Medications, All Things Exercise, A Fat Lot of Good and Infection Control in the Real World. There was also a lay dinner with over 100 people in attendance. In fact, record numbers saw a twenty percent increase in attendance at both the lay and medical conference, making this conference the biggest one yet!

A few of the highlights of the medical conference included sessions with international speakers on the future of exercise testing, gene therapy, and an entertaining lunchtime debate on infection control entitled 'We Are Not Doing Enough vs Have We Lost Perspective?'

Thanks to Lotterywest and Telethon, Cystic Fibrosis WA (CFWA) was able to combine our annual Parents' Retreat with the conference and provided generous subsidies to help our members attend the weekend event. We are proud of the partnership we have with our local CF community and appreciate your kind words and feedback.

"I thought the conference was fantastic! A massive thank you to CFWA for providing the subsidies and for all their hard work at the conference"

"Thank you for facilitating our attendance at the conference, it would not have been accessible without subsidies and the flexibility from the organisers."

"The conference was amazing! Thank you for providing the subsidy and accommodation. We learned so much and met other people whose lives are affected by CF. I am already looking forward to the next conference. We are so lucky to have the opportunity to hear from such experienced and knowledgeable practitioners!! I really appreciate the support from CFWA."

Congratulations to Nettie Burke and her team at Cystic Fibrosis Australia for a great event and we look forward to rugging up and heading down to Tasmania for the next CF Conference in 2021!

lotterywest supported

telethon 7

Our Conference Experience

Katya is mother to Jordan, 17 years, who has cystic fibrosis (CF). She attended the Perth lay conference back in August with her husband, Craige, and shared a bit about their experience at the conference.

What enticed you to attend the conference in Perth?

We've been to a number of conferences and they are always great with lots to learn and people to share with. To have a conference in Perth, and with the subsidies being offered by Cystic Fibrosis WA (CFWA), I was looking forward to meeting a lot of WA parents as well as hearing from world leaders in CF management. I was also looking forward to a night away at a beautiful venue.

Can you tell us a bit about your experience at the conference?

I thought it was one of the best venues I've been to for the conferences. It was well run with lots of choices of speakers to select from. It was fabulous to hear that other sessions were being filmed so we could catch up on them later. It was also great to hear that people with CF could tune in from the comfort of their homes; it always makes me sad that they miss out on hearing everything that is so relevant to them due to infection control.

At the conference it was great to see "old" friends and meet new ones. The CF community is like extended family, but this family truly do understand what you are going through. We enjoyed listening to the speakers, especially the ones from the UK. It's great to hear how we benchmark and how much we are progressing with treatments, medications and research.

What were your biggest take home messages or moments of impact?

Wellness is so important for people with CF and their families. With all the new drugs in the pipeline, it's crucial to maintain good health now. The biggest take home message for me was around nutrition. In the past, our understanding was to have maximum fat and salt intake regardless of source, however, at the conference, we learnt the importance of eating good, healthy wholesome food for the body and mind. Gut health seems to be the buzz. I also learnt new strategies for relating to teens.

I think we all were impacted with the speaker who told us about how they have trained dogs to sniff out pseudomonas – there was a lot of chat about that over lunch.

Would you attend another conference again?

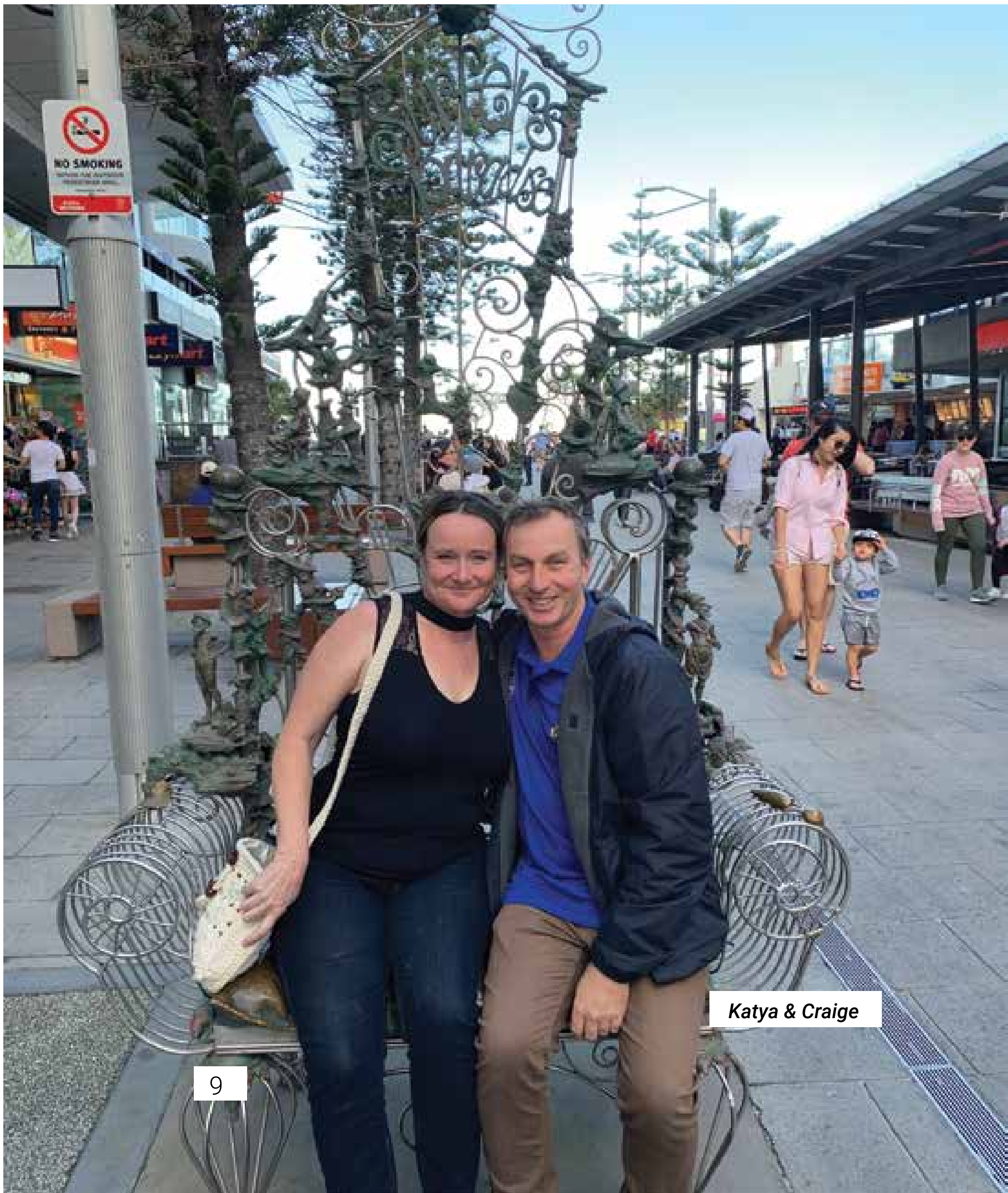
Absolutely. It's an opportunity to take a break from the outside world and focus on what's really important. Hearing different ideas, talking to those with similar journeys, and learning from the world's best reenergises, strengthens and encourages me. Most of all, hearing all the new developments gives me great hope for the future.

Did you enjoy attending the lay dinner and chatting with other members?

Very much so. Spending time with others in similar situations is beneficial. I always pick up tips and ideas, and it's great to share experiences with people who understand. Being part of this community is very rewarding. It's always fabulous to catch up with the CFWA team also!

Was the weekend a good break from the caring role?

Definitely. It's always great to have a break, and what a fabulous venue to spend that break. I came away feeling refreshed, encouraged and motivated. Thank you CFWA for facilitating.



Katya & Craige

A Quick Study on Stephanie

Stephanie Ball is the Education Coordinator for the Ronald McDonald Learning Program in Western Australia. In this issue, we have taken the time to get to know her a little bit better.

Hi Stephanie. Thanks for having a chat with us. Tell us a little bit about yourself.

Well, I'm a local girl, born and raised in Perth WA, and was an early childhood teacher at a couple of metropolitan schools before I stepped into my role at the Ronald McDonald Learning Program. I have a background in health science and teaching and I also have a keen interest in cognitive functioning in young learners. I enjoy being active and spending lots of time with family and friends, love my trips down south to enjoy all that our beautiful South West has to offer, and love enjoying good food, great wine, and even better company!

As you've mentioned, you currently work at Ronald McDonald House Charities Western Australia (RMHC WA); what do you do there are how long have you been there?

Yes! I have the privilege of working at RMHC WA and have been there for just shy of four years now! I am lucky enough to be based at the Nedlands House where regional Western Australian families can seek accommodation when their child must come to Perth for medical treatment. The House provides a home-away-from-home and is a truly special place where we try to create an extraordinary environment and extraordinary experiences for families staying with us.

My role, coordinating the Ronald McDonald Learning Program (RMLP), is quite unique. The Learning Program is just one of the many services that RMHC Australia offers and is something that both metropolitan-based AND regional families have access to. The program offers support to school-aged children with a wide range of chronic health issues, from things such as type 1 diabetes, juvenile arthritis, acquired brain injury, and cystic fibrosis.

What services can a family access from you and how do they go about accessing those services?

Through the Ronald McDonald Learning Program, eligible students can receive the following services:

1. A psychometric assessment with an Educational Psychologist
2. Speech Therapy and Occupational Therapy
3. Up to 40 hours of private, one-to-one tuition with a registered teacher

Schools or health professionals can refer families to the program, and families are also welcome to self-refer their child through our website. Each child's case is assessed on an individual basis, so people are also welcome to contact me directly for more information.

What does a typical day look like for you at RMHC?

Each day in my role at RMHC WA is different, which I love! My responsibilities can range from liaising with families who are on the program, to managing our team of over 170 tutors! I communicate with schools and health care professionals who are also caring for our families; I meet with other not-for-profit organisations with similar missions, such as Cystic Fibrosis WA, in order to make sure the community is aware about our fabulous service; I often meet with hospital school services and our long-term families here from the House who are ready to transition back home to their local school; and make sure teachers are supported in knowing how to effectively welcome a child back to the classroom after significant time off!

I also have lots of opportunities to communicate with our incredible team of volunteers at the House and at Perth Children's Hospital, without whom our organisation would not be possible! We have a beautiful team of staff who are all very passionate about our local mission, to create extraordinary experiences to help our families thrive. As you can imagine, it is a very motivating and rewarding place to work.

Is there anything else you can think of that might be important for families to know?

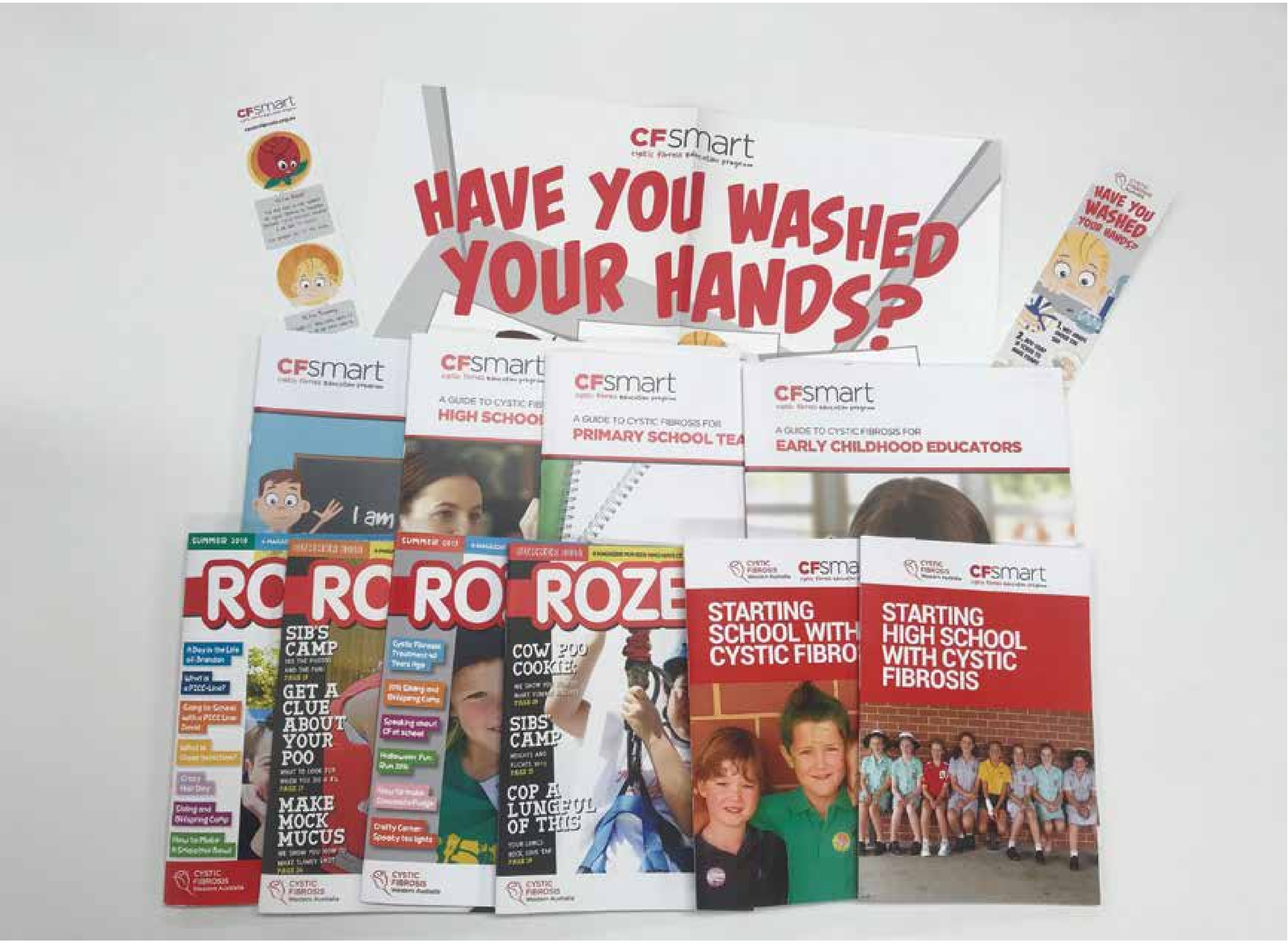
The RMLP also provides a professional development opportunity to schools and universities to help prepare teachers in better catering for sick kids in the classroom. 'EDMed' is a free PD and is available both through a face-to-face presentation and an online module! We also have a Ronald McDonald Family Retreat in which eligible families have access to up to seven nights of free accommodation at one of our retreats. The retreats provide an opportunity for families to reconnect and to have some respite and a much-needed break from the pressures of everyday life with a chronic illness. There are five spread across the country and two down in the South West!

I think it's important for families to know that this service is available and that we are passionate about advocating and supporting families who are living with 'invisible illnesses' such as cystic fibrosis. I encourage anyone reading this to reach out for a chat! The Ronald McDonald Learning Program is available nationally, for children from kindy to year 12, for both regional and local families.

Thank you so much for letting us get to know you Stephanie!

For more information about the RMHC learning program:

www.rmhc.org.au/ronald-mcdonald-learning-program



Back to School

It's already time to start thinking about the start of the school year!

The start of the school year can be an exciting and daunting time, particularly when your child has cystic fibrosis (CF). Partnering with your school, especially in the early stages, can help ensure your child's education and school experience is not limited by CF.

There are a range of resources on CFSmart and the Cystic Fibrosis WA website to help guide conversations with your school. Check out the new and improved CFSmart resources library to make it easier to find what you are looking for! Go to **www.cfsmart.org**

In addition to these resources, our Education Coordinator, Maggie, is on hand to facilitate a discussion with you and your school on a range of topics such as medications, environmental concerns, school absences and much, much more!

Contact Maggie at **education@cfwa.org.au** or phone **08 6457 7333** for more information or to request an education session at your school.

Great Success for Our First Ever Grandparents' Morning Tea

As they say, it takes a village to raise a child, and grandparents are often one of the greatest supports a parent can have. Having a child with cystic fibrosis (CF) has extra pressures and grandparents are often able to take on a greater supportive role; be it helping with physio, hospital appointments or simply being a listening ear.

It is important that grandparents feel supported and connected, so in September we held our first ever Grandparents' Morning Tea. The event was a huge success with 14 grandparents in attendance. We had a wonderful morning catching up with some familiar faces and welcoming some of our newer members.

The event included a CF educational component as well as meeting the services team and learning about all our services.

Everyone loved their special surprise: a video recording from their grandchildren to thank them for all their love and support. There wasn't a dry eye in the room!

We look forward to hosting more grandparent support events next year.

Staying Connected

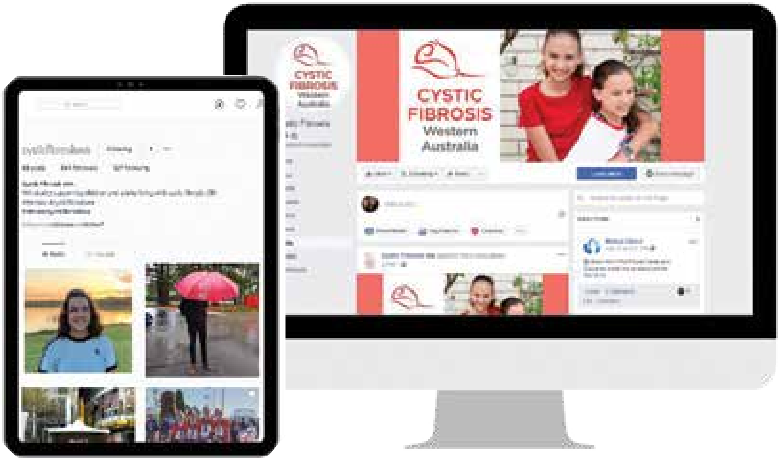
There are lots of ways that you can keep up-to-date with CFWA and our wonderful community!

Did you know that CFWA has a Facebook page, Instagram, LinkedIn and Twitter? We love to share stories from the community, research updates, event invites, volunteer opportunities and so much more!

Just search for Cystic Fibrosis Western Australia on social media and like and follow our page to start seeing our posts in your feed.

We also love to hear from our community on social media. If you're sharing something about cystic fibrosis or CFWA, please tag us and use our hashtags #CFWA, #65ROSES and #cysticfibrosiswa so we can see it too.

If you have a story you would like us to post to our page, please contact Matt at **communications@cfwa.org.au** or **08 6457 7333.**



Early Learning Night

Learn how we can help you prepare for the start of school

RSVP or for more information:

Contact:
Maggie Cunnington
08 6457-7337
or
education@cfwa.org.au

November
13th
2019
6pm

Volunteer Spotlight

We had a chat with volunteer Amy Robinson, who has been supporting the marketing and fundraising team at Cystic Fibrosis WA (CFWA) this year

Amy (middle) selling roses with Gemma (left) and Louise (right) on 65 Roses Day

How did you start volunteering with CFWA?

I met Marnie, the Events and Community Fundraising Coordinator, at the beginning of the year during a pitch session for a university project. I went and spoke to her after the pitches and found out that Marnie had also completed an Events Management Degree. We discussed coming in to the office to gain some work experience under Marnie's mentorship and the rest is history.

What kinds of things have you been helping with at CFWA?

I assist the Fundraising and Communications teams. I have created marketing collateral, worked on data reporting and helped with the volunteer program. I also provided a lot of assistance with this year's 65 Roses Day, helping Marnie with the operations of that event and of course, selling a few roses. Which was a blast! I'm currently working on putting together the Volunteer Training and Awareness Evening for the beginning of next year which I'm super excited for!

What has been your favourite thing about volunteering?

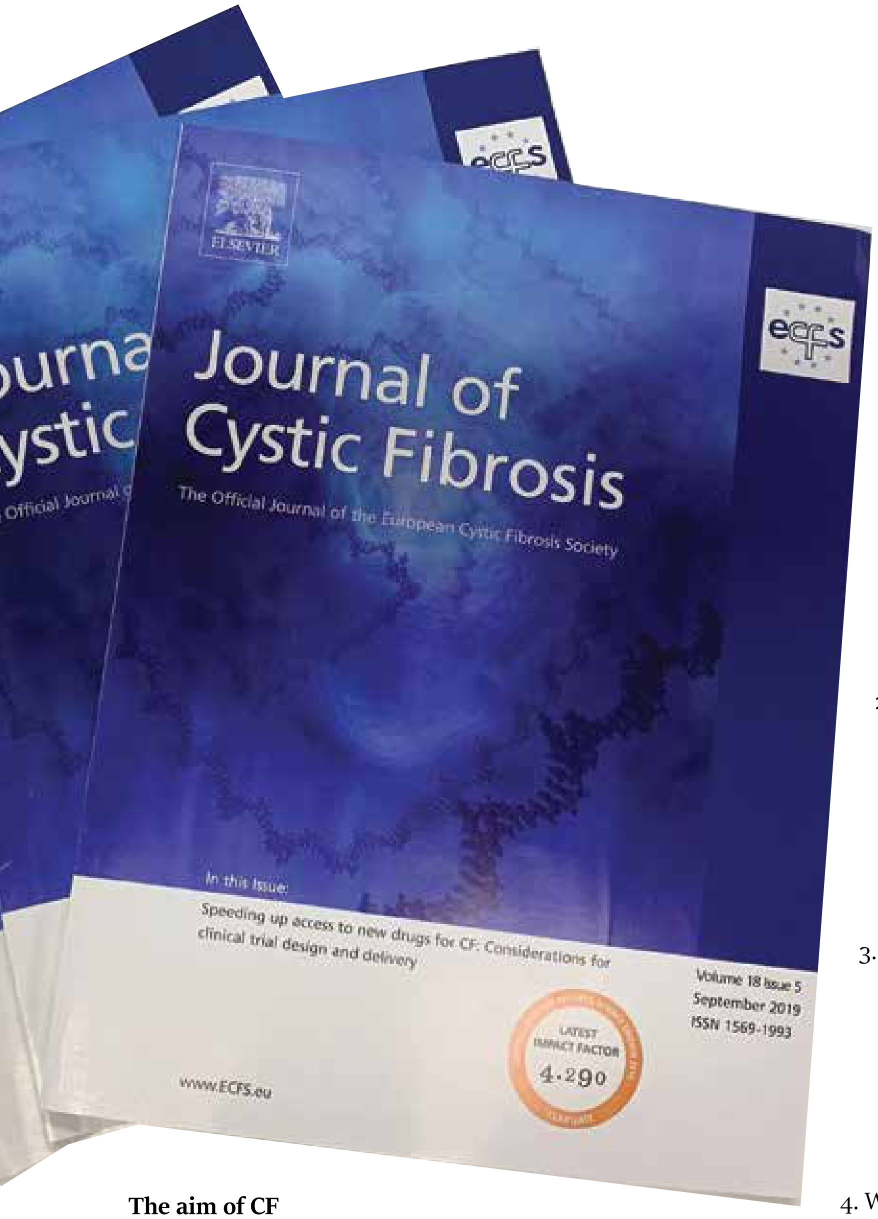
Definitely working with all the staff here at CFWA. It has been amazing for me – even coming in one day a week – to feel so welcomed and appreciated. Everyone is so fantastic and full of joy it truly makes every day that I spend in the office a lot of fun. Also, just knowing that I'm contributing to an environment that actively tries to improve the quality of life for its members makes me elated!

Inspired by Amy and want to lend a hand?

We have a few opportunities to lend a hand before the end of the year, including helping to raise awareness at Consulate Court Christmas Lights, assisting with gift wrapping in the CBD and handing out CFWA flyers around your neighbourhood. Visit **www.cfwa.org.au/get-involved/volunteer** or phone Marnie on **08 6457 7333** for more details and to sign up.

CF Research News

Do clinical trials in CF match the priorities of patients and clinicians?



The aim of CF Research News is to bridge the gap between people with cystic fibrosis (CF) and the researchers investigating CF, providing access to patients, parents, relatives, friends and caregivers to all scientific work published in the Journal of Cystic Fibrosis (JCF). The following article was published in June 2019.

'Do current clinical trials in cystic fibrosis match the priorities of patients and clinicians? A systematic review.

Authors: Izabella S Kalaitzis, Nicola J Rowbotham, Sherie J Smith, Alan R Smyth

What was your research question?

Do current CF clinical trials reflect the research priorities set by the larger CF community?

Why is this important?

Recently, the first James Lind Alliance Priority Setting Partnership in CF (or @questionCF as it was known on Twitter!) was completed, bringing together people with CF, their family, their friends, and health care professionals, to identify the top 10 priorities for CF research.

These top 10 priorities were:

1. What are the effective ways of simplifying the treatment burden of people with CF?
2. How can we relieve gastro-intestinal symptoms, such as stomach pain, bloating and nausea?
3. What is the best treatment for non-tuberculous mycobacterium (including when to start and what medication)?
4. Which therapies are effective in delaying or preventing progression of lung disease in early life?
5. Is there a way of preventing CF-related diabetes?
6. What effective ways of motivation, support and technologies help people with CF improve and sustain adherence to treatment?
7. Can exercise replace chest physiotherapy?
8. Which antibiotic combinations and dosing plans should be used for CF exacerbations and should antibiotic combinations be rotated?
9. Is there a way of reducing the negative effects of antibiotics e.g. resistance risk and adverse symptoms in people with CF?
10. What is the best way of eradicating Pseudomonas aeruginosa?

We wanted to see how well what was going on in clinical trials around this time matched with what the CF community wanted. We hope that by increasing awareness of the top 10 priorities, it will fuel future research into areas that are important to the CF community.

What did you do?

We searched all the trial databases and online medical publication databases that we could to look for active trials in CF. We included all trials that were looking at an intervention in CF care and were registered or published between 1 January 2016 to 11 September 2017. We then checked to see if these active trials could be matched against one or more of the top 10 research priorities.

What did you find?

We found 259 trials with 193 of these fitting the inclusion criteria described above. Only 63 (33%) of the trials that we found matched one or more of the 10 research priority areas.

What does this mean and reasons for caution?

This shows that current clinical trials poorly reflect the top 10 research priorities selected by the CF community. This study covers the time period when the PSP was being carried out, so it is not saying that the priorities of CF community have been ignored, just that there was a mismatch at that time.

What's next?

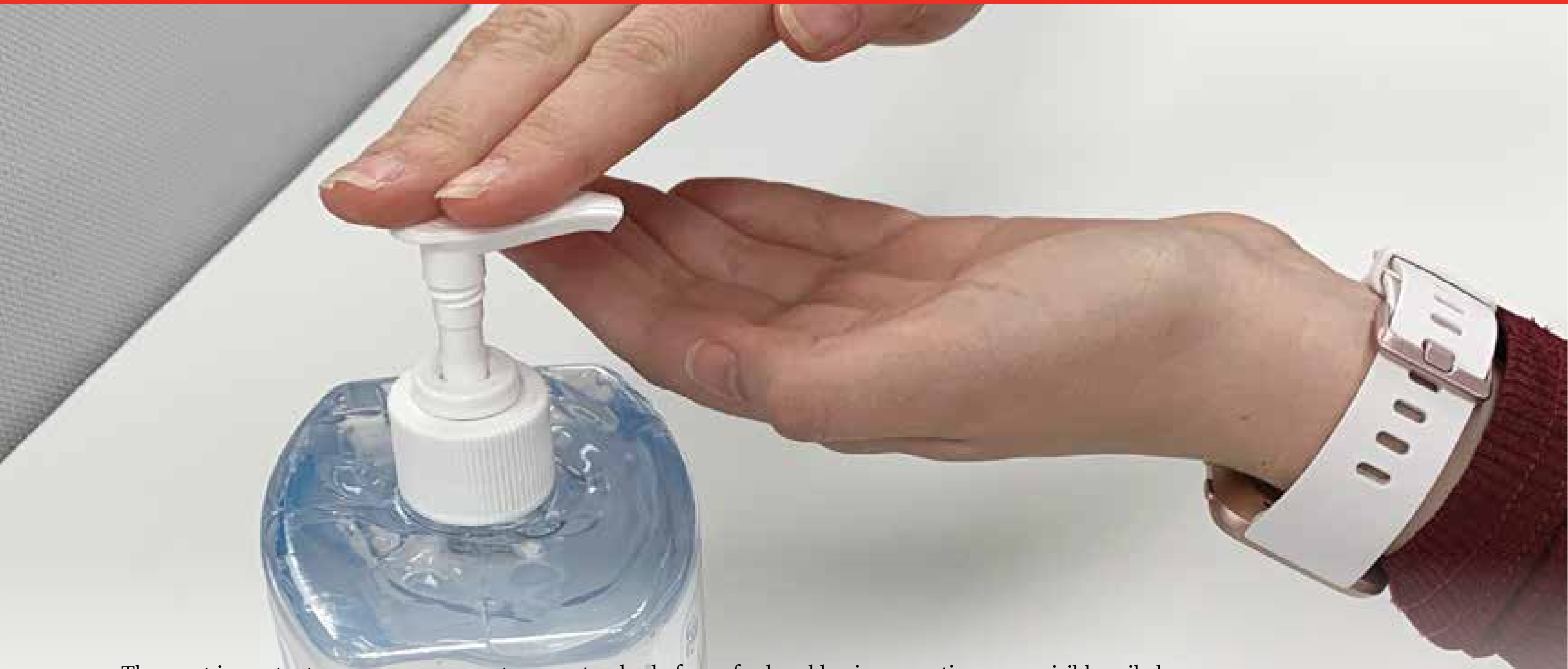
We hope that by increasing awareness around the top 10 research priorities that this will fuel future research in areas important to the CF community. We hope to get a much greater percentage of matches when we repeat this exercise in five years' time.

Original manuscript citation in PubMed:

www.ncbi.nlm.nih.gov/pubmed

The Hand Sanitiser Quandary

What should I be looking for in a hand sanitiser?



The most important way we can prevent the spread of infection is by effective hand hygiene. Using a hand sanitiser is convenient, less time-consuming and less irritating than washing our hands constantly with soap and water. We are all wanting to do our very best to prevent and control the spread of infection, and most of us would feel confident that the hand sanitiser we are using is doing the job we intend it to do; but is it?

What is a hand sanitiser?

A hand sanitiser is a disinfectant agent applied to the hands for the purpose of removing common germs. Various ingredients can be used in a hand sanitiser, but formulations of the alcohol-based type are preferable. Alcohol-free hand sanitisers have been found to be less effective at killing germs and contain a variety of antiseptic ingredients. (**www.ncbi.nlm.nih.gov/pubmed/30777389**).

Things to consider when buying a hand sanitiser

Alcohol is the most important active ingredient in a hand sanitiser and the alcohol content must have a concentration of 60-95% to be effective against germs, however, not all alcohol is effective. Your hand sanitiser should include either ethyl, isopropanol or ethanol alcohol. The Centres for Disease Control and Prevention (CDC) and the World Health Organisation (WHO) promote the use of alcohol-based hand sanitisers containing 60-95% alcohol as the standard of care for hand hygiene practice in health care settings when hands are not visibly soiled (Boyce, Pittet 2002/WHO guidelines, 2009).

Hand sanitisers are available in gels, liquids and foams. While the choice of format usually comes down to personal preference, it is worth noting that foams are usually more expensive. Liquid hand sanitisers are equally as effective but can spill or leak easily, whereas gels can be more practical.

Most superior hand sanitisers are odourless. It is best to avoid fragranced products as this non-essential ingredient may cause skin irritation.

Effectiveness

How effective your hand sanitiser is depends on multiple factors including:

- the quantity used
- the exposure time
- the frequency of use

Generally, alcohol-based hand sanitisers, if rubbed thoroughly over all hand surfaces and fingers for a period of 30 seconds and allowed to completely air dry, can effectively reduce the number of bacteria, fungi and some viruses, such as Influenza A.

Points to remember

- Use a hand sanitiser which contains 60-95% ethyl, isopropanol or ethanol alcohol
- Wash with soap and water if hands are visibly soiled or greasy
- It is recommended to wash hands with soap and water after using your hand sanitiser 4-5 times as the build-up will decrease the effectiveness
- Always use enough hand sanitiser to cover all surfaces of your hands and fingers for 30 seconds and allow to air dry
- For effective hand hygiene, limit the amount of jewellery you wear
- Hand washing with soap and water is preferable against preventing the spread of infections such as Clostridium difficile and norovirus. This means, if there is a gastrointestinal bug around, wash your hands carefully with soap and water!
- Hand sanitisers are not effective in removing or inactivating harmful chemicals. If hands are in contact with harmful chemicals, wash thoroughly with soap and water or as directed by your local Poisons Information Centre

Useful links

www.britannica.com/topic/hand-sanitizer

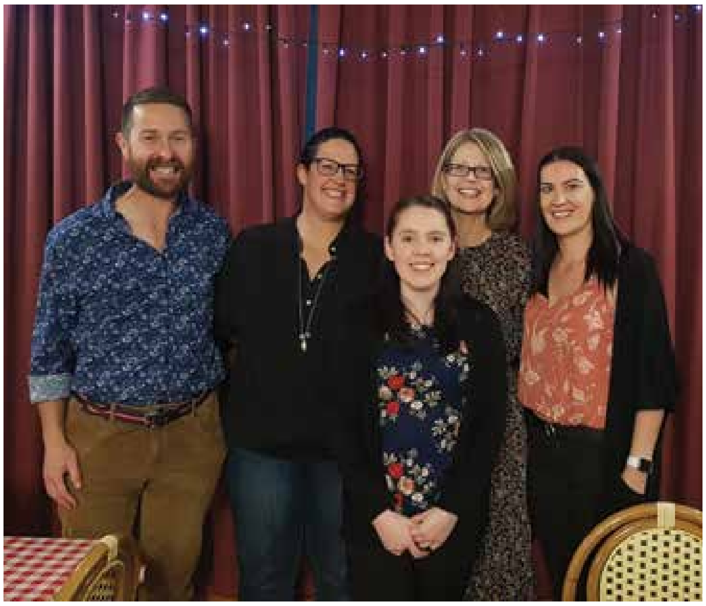
www.cdc.gov/handwashing/show-me-the-science-hand-sanitizer.html

www.hha.org.au

www.ncbi.nlm.nih.gov/pubmed/30777389

On the Road Again

2019 continues to be a busy year with recent trips to Geraldton and Kalgoorlie, visiting our members and raising awareness as we go.



In July, we were invited to present 'An Overview of Cystic Fibrosis' to nurses and nursing students at Geraldton Regional Hospital. We were fortunate to have Mullewa Hospital join us via video conferencing. The education session was well attended with an attentive and enquiring audience eager to learn more about cystic fibrosis (CF).

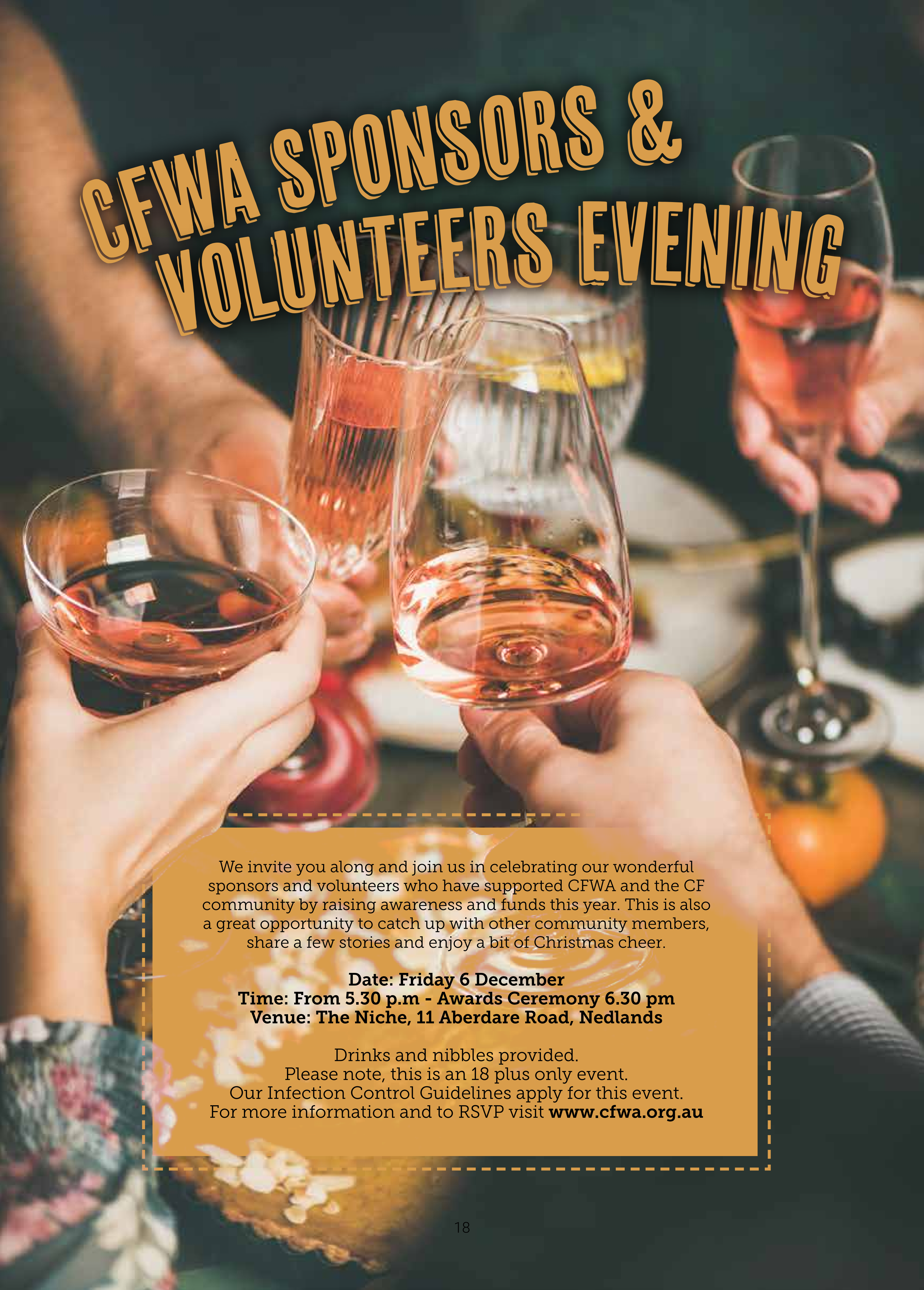
During our visit to Geraldton we met with our members which, as always, is the highlight of our trips. Meeting on home ground allows for good conversation and opportunities to connect and offer appropriate support.

Energised and full of enthusiasm from the Cystic Fibrosis Australasian Conference held in Perth in August this year, we headed to Kalgoorlie. Kalgoorlie Regional Hospital welcomes us back every year to educate their staff about CF and the latest developments. An education session was held on the children's ward for paediatric nurses and midwives.

School education was also on our agenda for our Kalgoorlie trip, attending two schools and educating 12 teachers. School education is an important role for Cystic Fibrosis WA, providing staff with the knowledge and tools to support young people living with CF at school.

We enjoyed a warm Kalgoorlie evening catching up with a couple of our Kalgoorlie families over a delicious Italian meal. Lots of laughs amongst lots of meaningful conversation.

Our outreach trips are invaluable. We gain insight into the challenges our members are facing. This insight helps drive our programs, keeping us focused and responsive to the needs in the community. Many thanks to Telethon for their continued commitment to this program.



CFWA SPONSORS & VOLUNTEERS EVENING

We invite you along and join us in celebrating our wonderful sponsors and volunteers who have supported CFWA and the CF community by raising awareness and funds this year. This is also a great opportunity to catch up with other community members, share a few stories and enjoy a bit of Christmas cheer.

Date: Friday 6 December
Time: From 5.30 p.m - Awards Ceremony 6.30 pm
Venue: The Niche, 11 Aberdare Road, Nedlands

Drinks and nibbles provided.
Please note, this is an 18 plus only event.
Our Infection Control Guidelines apply for this event.
For more information and to RSVP visit **www.cfwa.org.au**

2019 Sibs Camp a Hit!

Our annual Sibling and Offspring Camp was held during the October school holidays and was a huge success. This camp allows young carers to take a break, meet other kids whose families are affected by cystic fibrosis (CF) and have fun – a whole lot of fun!

This year, the camp was held at Ern Halliday Recreation Centre in Hillarys. The weather held off until the very last day enabling us to get out and about and try things like caving, lost pilot and the good old flying fox which remains a firm favourite with our returning campers. We also spent a morning at Aloha Surfhouse in Joondalup where our budding surfers got to use an indoor wave machine as well as 'rock' climbing some fantastic vertical obstacle courses.

The camp provides a great opportunity for our siblings and offspring to try something new and this year included three older siblings who returned as camp leaders and six new young campers who are all keen to come back again next year.

Here are some responses to the question asked to our campers this year:

What would you say to someone who was thinking of coming to camp?

"It's an enjoyable and fun packed adventure fit for anyone from the smallest of tots to the largest of giants"

"It is really fun, and you meet new people and share your stories. You should absolutely go"

"Camp is a fun place where you stay at camp for 3 days and everything is different each day"

"I think that you should go, everything is so fun!"

"It's fun, you can make lots of friends"

'It's amazing and you should definitely go"

"Sibs Camp is the best camp ever"

Thanks to Mazda Foundation and Lotterywest for their support of this important event.

Parents Dinner for Carers Week

City of Nedlands

Carers Australia WA

lotterywest supported

To celebrate Carers Week, we hosted our annual Parents and Carers Dinner on 19 October.

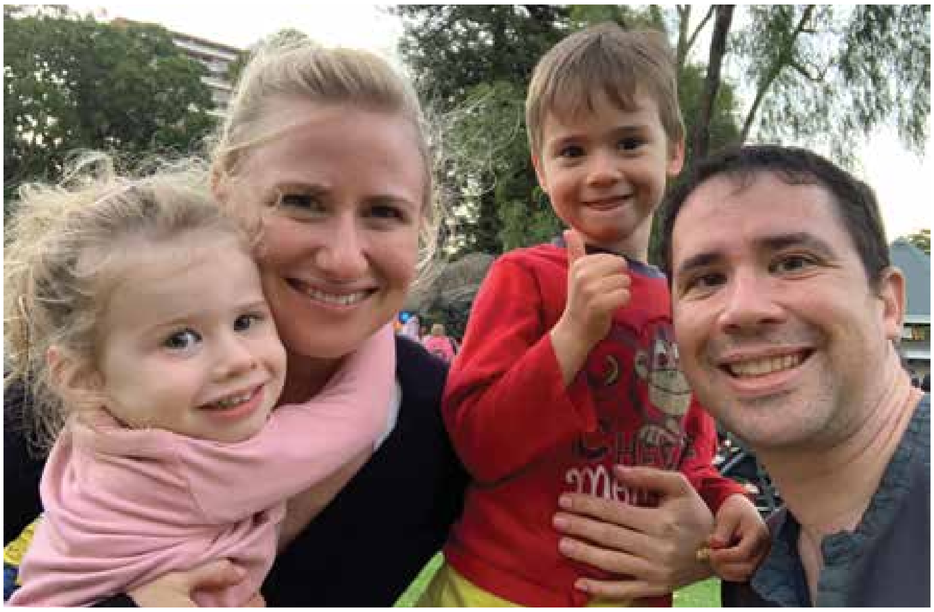
This important event allows parents caring for someone with cystic fibrosis (CF) to enjoy a night out sharing experiences and making connections with other parents who can relate to the unique experiences that come with having a child with CF.

Held at Little Way Restaurant in Nedlands, our parents enjoyed a night off from their caring role, met CFWA staff and learnt about services available to their family.

This event is possible thanks to support from Carers WA, Lotterywest and the City of Nedlands.

CFWA Members Spreading awareness this Christmas

Thank you to our board President, Caz Boyd, and the Potts family for sharing your stories for our 2019 Christmas Appeal.



2019 is a very special year for Cystic Fibrosis WA's board President. Caz Boyd, who lives with CF, will be celebrating 25 years with her new lungs this November! She has also had the benefit of witnessing some of the incredible advances in CF treatment and care that have been developed during this time.

That's why we've asked Caz to share her incredible story with us for our 2019 Christmas Appeal.

The Potts family (pictured) have also been incredibly generous in sharing their story for this campaign, including details of the support they've received from CFWA over the years.

Four-year-old Charlotte, who lives with CF, is one of the new generations who has benefitted – and will benefit – from the services and stunning research that people in the CF community have funded.

Your gift this Christmas time will help us continue to provide our vital services and research funding for people like Caz and Charlotte living with CF.

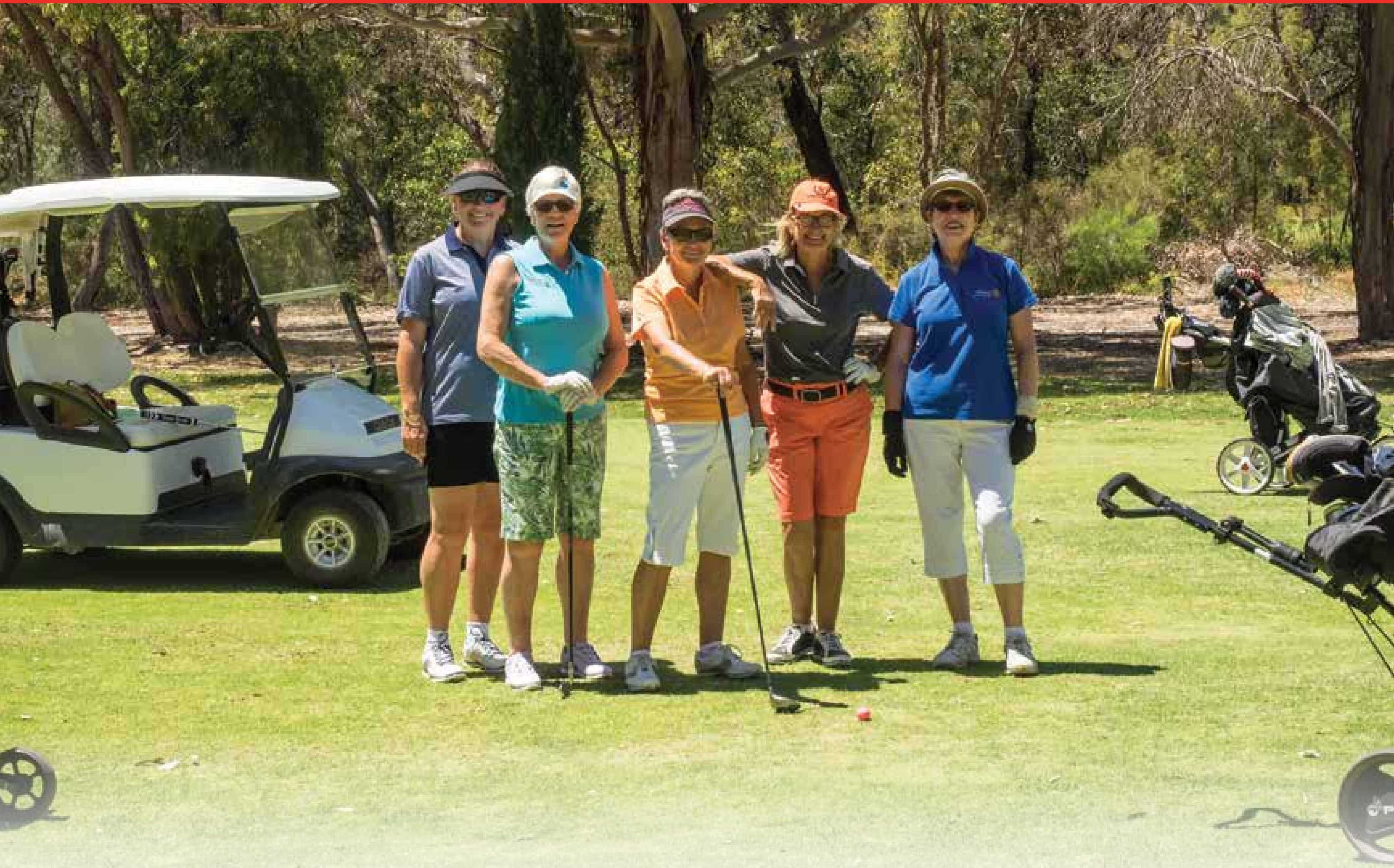
Visit our website at **www.cfwa.org.au/news** to read more on their stories.

Thank you to Ricky Longshaw for your support with the wonderful photos!

Ricky Longshaw – photographer
www.rickylongshaw.com

Busselton Corporate Golf Day

The Rotary Club of Busselton Geographe Bay is once again hosting a corporate golf day at Busselton Golf Club to raise funds for people living with cystic fibrosis (CF) in WA.



You're invited to attend the annual Corporate Golf Day generously organised by Rotary Club of Busselton Geographe Bay and hosted at the Busselton Golf Club. This wonderful event raises funds to support critical services for people living with CF in WA and life-changing CF research.

Date: Friday 29 November 2019

Venue: Busselton Golf Club

Entry: $200 per team or $50 per player (includes lunch-time snack on course)

If you would like to attend, provide sponsorship or donate an item to the raffle, please contact Chris White on **chrisrotarybsn@iinet.net.au** or **0450 152 068.**

Rotary Club of Busselton Geographe Bay

Fundraising News

JCLA Quizzing & Sizzlin' for CF

CFWA was nominated to participate in the John Curtin Leadership Academy (JCLA) program again this year and was selected by a group of bright and motivated university students who were on a mission to raise awareness and funds for cystic fibrosis in the community.

They hosted an Easter Egg hunt, a Quiz Night at the Stables Bar and ran multiple Bunnings sausage sizzles. Thank you to this fantastic team and all their supporters for helping to make a difference!

Cape to Cape

Friends Rachael and Kathryn are challenging themselves to walk the 130km Cape to Cape track over seven days in November this year in support of CFWA. Whilst the walk will be a challenge, it is nothing like the daily challenge faced by people living with CF. Rachael knows this all too well as a current board member of CFWA and having a son who lives with CF.

They have been documenting their training and fundraising journey on Facebook and have raised over $4,000 already!

Visit **www.cfwa.org.au/news** to read more and support their efforts.

Kilimanjaro Climb

In January next year, this group of legends will be climbing Mount Kilimanjaro in Tanzania in support of CFWA. Team leader Tatiana has gathered a crew of friends and family to take on the climb with her in support of her brother who lives with CF and others in the community who are also affected by CF.

They have already raised fantastic awareness and over $4,150 while training for their climb by participating in fitness events.

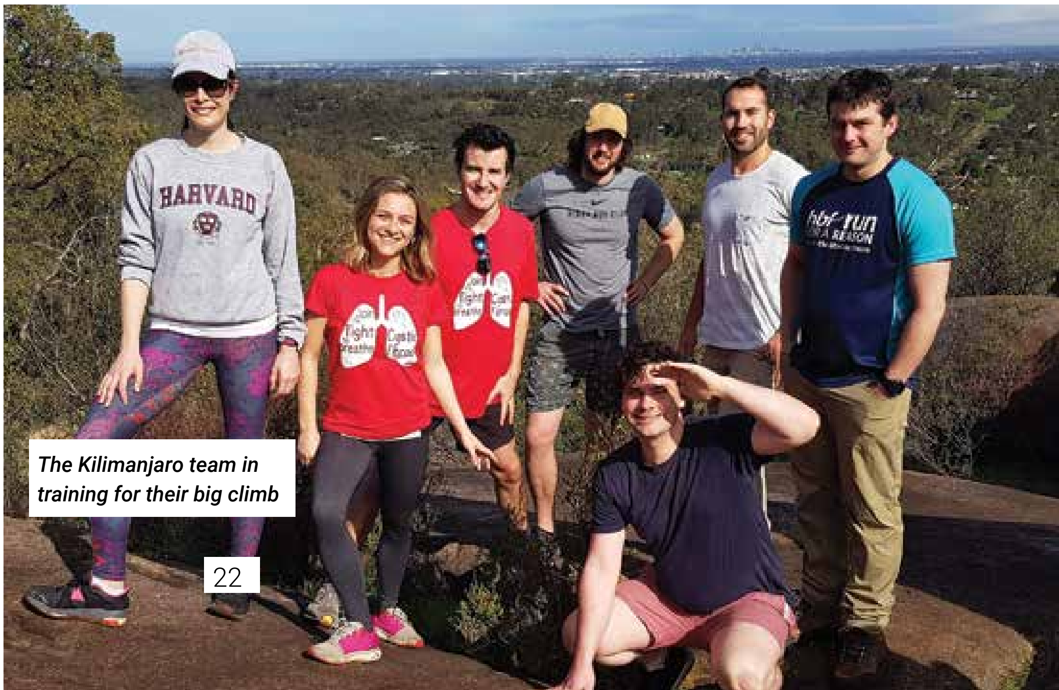
Visit the 65 Roses Challenge page for more of their story and to support their efforts. **www.everydayhero.com.au/event/65roseschallenge19**

Planning on a Fundraiser?

Are you thinking of planning your own awareness and fundraising event or challenge? We can help! We have lots of resources and goodies which we can provide to people supporting CFWA in the community. Visit our website **www.cfwa.org.au/get-involved/fundraising** for lots of ideas, tips and tricks!

Kathryn (left) and Rachael (right) training for their walk

The JCLA team at their Easter Egg Hunt



The Kilimanjaro team in training for their big climb

Tee Off for CF

The 2019 George Jones Family Foundation Cystic Fibrosis Golf Classic was a huge success, with fantastic support from the dedicated organising committee and the wider community!

QUBE

George Jones Family Foundation

GILLARD BUILDERS
(1977) PTY LTD

AMS
Aerodrome Management Services Pty Ltd

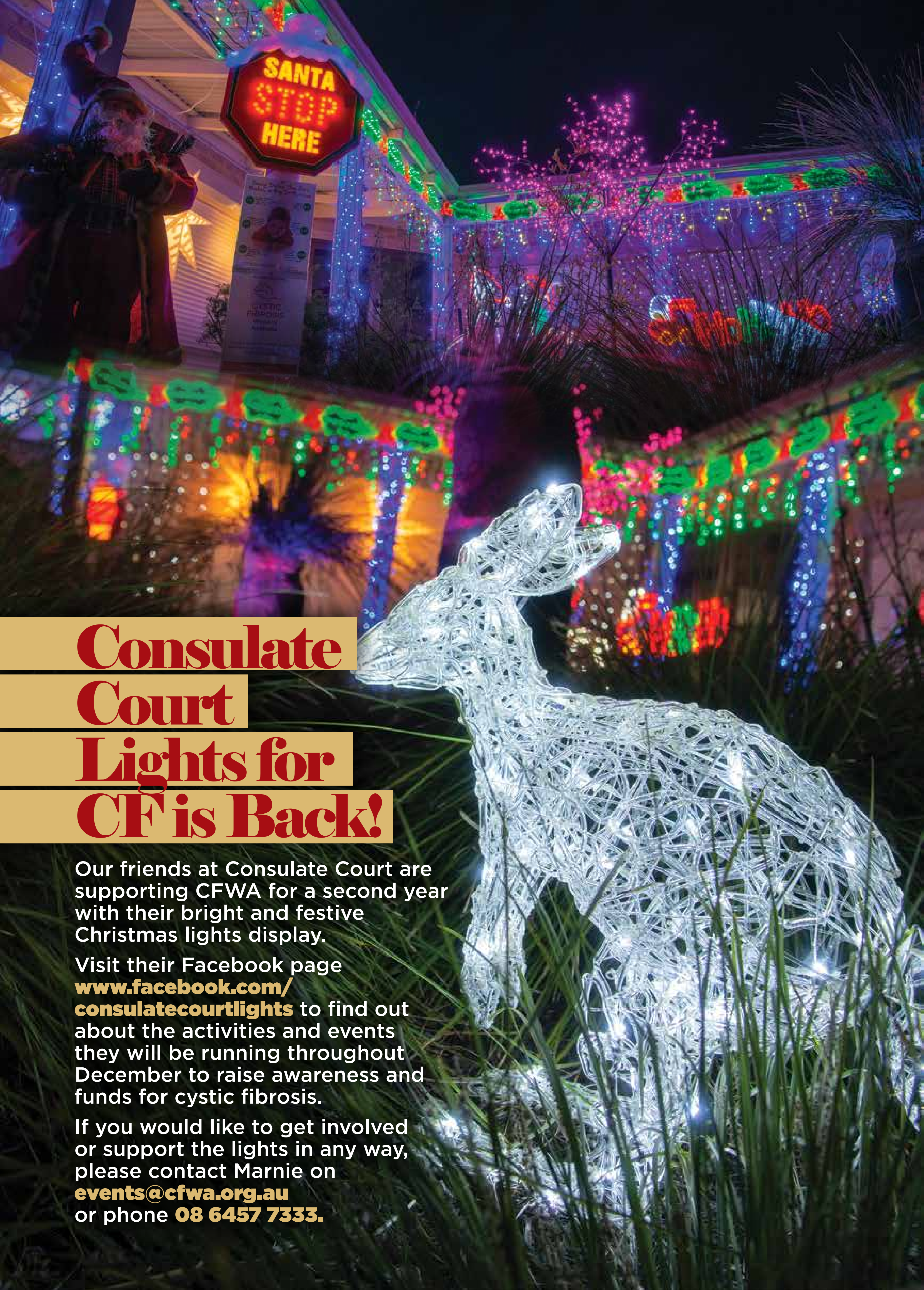
arc infrastructure

This year's Cystic Fibrosis Golf Classic at Lake Karrinyup Country Club was another fantastic day of friendly competition as well as awareness-raising and fundraising for children and adults living with cystic fibrosis (CF).

Now in its ninth year, the CF Golf Classic raises over $100,000 in support of critical CF research. In 2016 and 2017, funds raised at this event went towards two PhD Top Up Scholarships for CF researchers Clara Mok and Kelly Martinovich. We look forward to sharing the total funds raised at this year's event with you very soon!

The success of this event is possible due to the efforts of a dedicated and hardworking committee. Thank you to Heath Gillard, Hayley Gillard, Di Gillard and Emma Bacci.

Thank you also to our long-term Platinum sponsor The George Jones Family Foundation, and Gold sponsors Gillard Builders, Arc Infrastructure, AMS and Gulf Hydraulics, for making a significant contribution towards the success of the event.



Consulate Court Lights for CF is Back!

Our friends at Consulate Court are supporting CFWA for a second year with their bright and festive Christmas lights display.

Visit their Facebook page **www.facebook.com/consulatecourtlights** to find out about the activities and events they will be running throughout December to raise awareness and funds for cystic fibrosis.

If you would like to get involved or support the lights in any way, please contact Marnie on **events@cfwa.org.au** or phone **08 6457 7333.**