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RED

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RED CEO MESSAGE


NIGEL BARKER, CEO

One of the things that has always been at the forefront of minds of people living with cystic fibrosis (CF) has been the fact that not a lot of people know about it. It's a rare disease and carers particularly, often express the frustration they feel at having to explain to everyone the nature of the disease and why, for example, it's important for other parents not to send their kids to school if they have a cold.

Raising awareness is one of the primary reasons for 65 Roses Month. And this year we have done exactly that.

I was thrilled at the participation of over 245 volunteers to help wrap and sell roses right across the state, the wonderfully spectacular lighting up in red light of some of Perth's and Mandurah's iconic landmarks, and the huge number of community groups who got together to make a difference.

The free media coverage we received thanks to individuals working with their local media and our own PR company achieved over $1.3m in public relations value. This included TV interviews with Channels 7 and 9 and Network 10, several radio stations including 882 6PR, Sonshine FM, Curtin and others, spreading the word far and wide.

The importance of print media cannot be underestimated with many families volunteering to be the face of CF in their local community which resulted in a large number of articles in the community newspapers, the West Australian and Sunday Times.

Of particular note this year has been the continued growth in social media. This has caused us to look at the whole of our communications strategy and the need to seamlessly integrate this into our PR, education and support materials. This includes RED magazine of course, fact sheets, website and our fortnightly RED e-news. If you don't get the fortnightly e-news, please call the office and ask to be put on the e-mail list. It's a great way to keep in touch and you can forward it to friends and family who can, in turn, also subscribe free of charge. To respond to these challenges, we have appointed our long serving Matt Casey to the position of Communications Manager and he and his team are providing an across-the-organisation service to fundraising and services.

Of course, raising awareness is not the only aim of 65 Roses Month. It's a major fundraiser for our association. This year we set an ambitious target of selling 15,000 roses on 65 Roses Day. Just a few days out from the day itself, thanks to advance orders received from offices and individuals, we had to increase the order to a record breaking 16,500! Many, many thanks to everyone that was involved.

Finally, as we go to press, we are awaiting to hear if Vertex Pharmaceuticals has been successful in getting the label extension for Orkambi® for 2-5 year olds. We are confident of success and enormously grateful for the lobbying work of CFA and all of the families concerned.

We are also waiting to hear of their success in getting a new triple combination therapy across the line with the FDA in the USA, which promises to bring relief to over 90% of people living with CF.

Keep in touch with the breaking news by signing up to RED e-news today. Get advance notice of special events such as the hugely successful Golf Day planned for November 1 this year.

Together we will reach our vision of a world where Lives are truly Unaffected by CF.

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our next edition for 2019, please contact us before 18 October.

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
Sisters Isobel and Ruby shared their story for our Tax Appeal this year.

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Hitting the Books

Cystic Fibrosis Australia (CFA) recently attended an environmental summit at the George Institute for Health. Professor Donna Green gave a breakdown of climate change as an imminent and exponential threat to global civilisation.

Her seminar was at once scientifically sober and extremely stirring. A lively Q&A followed. There were calls for action on various grounds: technical, political and humanitarian.

But CFA was there to get the angle on cystic fibrosis (CF). People with CF are at a heightened risk from the atmospheric chaos that man-made climate change is threatening.

Dr Green and the CARCRE team at UNSW helped bring this into clear focus, bringing together a research summary on climate change and CF.

The two main risk factors here are air pollution and shifting temperature.

A study by the ACBAL group reported "ambient temperature is associated with prevalence of P. aeruginosa and lung function in four independent samples of CF patients from two continents."

Similarly, a study conducted across multiple university campuses in Northern Ireland and Queensland found that "the environment may also play an important role in the acquisition of Gram negative organisms other than P. aeruginosa... climatic and environmental factors are likely to impact on the risk of infection with NTM and fungi in people which are found extensively throughout the natural environment."

Particulate pollution may be an even bigger risk than climate. BMC Pulmonary Medicine recently published a medium-term study concluding that "fine particulate matter is an independent risk factor for initial MRSA acquisition in young children with CF". The study goes on to draw a direct link between increases in ambient air pollution and increased CF morbidity.

Two independent studies by the Imperial College London and the University Hospital Gasthuisberg also emphasise the connection between the presence of particulate pollution and CF morbidity.

A further study by Dr Sylvia Farhat in São Paulo (Brazil) looked at the exacerbating effects of atmospheric ozone, finding that this form of pollution caused significant aggravation of existing throat and lung inflammations from CF.

So, what can we do with all this bad news? We can certainly support action on climate change at the national and global level. However, at CFA, we have been looking in to more individual strategies and responses to the daunting spectre of pollution/ climate change.

Know where you stand. 'Pollution traps' occur when particulate matter is unable to disperse into the wider area because of surrounding landmass and infrastructure. The western suburbs of Sydney network are an example of this phenomenon at work. Pollution traps can also occur in high emissions areas like CBD precincts during winter because the cold air keeps smog close to the ground. Make sure to drive through these areas in a sealed vehicle and try to rely on air conditioning at work when possible.

Your own state government can provide crucial resources if you know what to look for. Sourcing the heat maps, barometrics and topography of your local area will help you get a picture of what role the atmosphere might be playing in your CF experience. Every little bit helps.

If you cannot help living or working in pollution zones, consider a fine particle filtration mask for the colder months. It may seem like an extreme measure, but the stakes are indeed very high. Dr Norman Edelman from the American Lung Association famously described the health effects of smog as like "a sunburn inside your lungs." We have a duty to protect Australians with CF from that risk.

This link **https://www.cysticfibrosis.org.au/about-cf/facts,-figures-and-publications**

will take you to some key documents on CF and climate change and air pollution.

Thanks again to Professor Donna Green and CARCRE for their amazing knowledge and generosity.

Kind regards

Nettie Burke

CEO

Cystic Fibrosis Australia

WA Painted with Roses!

65 Roses Day continues to grow with 2019 being another fantastic awareness and fundraising event in the community! This is all thanks to the support of our dedicated volunteers and partners!


Maddi amongst all the roses ready for sale in Mandurah


Stephen, who has CF, with his sister Thalia, selling roses at their school

30+ media appearances

245+ volunteers

40+ Perth metro locations

12 regional WA locations

A Wrap on 65 Roses Day!

The team at Cystic Fibrosis WA (CFWA) would like to say an enormous THANK YOU to the entire community for their help in making 65 Roses Day 2019 a big success! With all the amazing support from our volunteers, supporters and partners, 65 Roses Day grew to a massive 16,500 roses and over $85,000 raised!

Roses Far and Wide!

We expanded our reach this year with over 40 metro locations including shopping centres, schools, community groups and organisations. This growth is due to the support provided by the community and our event partners. Thank you to WAFEX and their rose growers for supplying the 16,500 roses; Telstra for putting together a volunteer team to wrap roses in their office and sell them at their own stalls; and South Metropolitan TAFE for once again including this event in their learning curriculum and providing committed and knowledgeable event student volunteers to lead our shopping centre stalls.

Our regional families have been on the 65 Roses Day journey with us for several years now, working hard to bring the event to their communities. We love


Roxanne, who has CF, and mum Kate visiting the premier, the Honourable Mark McGowan MLA


The staff at Western Power with their roses ready to sell


The team of volunteers from Albany who championed 65 Roses Day in their community

seeing our roses make it to regional locations such as Albany, Bunbury, Denham, Geraldton, Pingrup, Tom Price, Witchcliffe, and many places in between. Thank you to our regional supporters for going the extra mile to further spread awareness for CF, and to our regional transport supporters who delivered our roses free of charge, including: Great Southern Express, South West Express, Geraldton Freightliners, Kalbarri Carriers, Western Independent Food and Centurion.

65 Roses in the Media!

We had many amazing stories in the media this year with over 30 appearances of our ambassadors and community representatives, including clips on Channels 7 and 9 and Network 10. This is thanks to our dedicated and generous community members for sharing their stories, our long-term media partner, Devahasdin, for facilitating the media opportunities and the media outlets for sharing our message.

65 Roses Day 2020

As we pack away our buckets and secateurs for another year, we know it won't be long before preparation begins for 65 Roses Day 2020! We look forward to seeing familiar faces and many new ones, too, for 65 Roses Day 2020: Friday 22 May!

If you'd like to get involved in selling roses or volunteering next year, like and follow our Facebook page and sign up to our e-newsletter to stay in touch. Or contact our team at **events@cfwa.org.au** or **08 6457 7333** to discuss your plans for next year.

65 Roses Day Continued

Keep your eye out later in this edition for more 65 Roses Day articles where we thank more of our volunteers, supporters and fundraisers.


Marc, who has CF, came to see the stadium lit in red for CF

TKI provided tours of their new laboratories

Sophie Longton and partner Ryan Worthington

Nick Joannides, Barry Marshall and Nigel Barker

Evening with CF Scientists

Kicking off 65 Roses Month in May, an informative array of presenters spoke at the Perth Children's Hospital auditorium.

The annual collaboration between the Telethon Kids Institute's (TKI) AREST-CF team and CFWA provided the opportunity for our cystic fibrosis (CF) community to hear the latest news from researchers and tour the new TKI laboratories.

It was great for our attendees to be able to listen to CF researchers and CFWA's Services Manager, Kathryn Pekin, along with CF adult Sophie Longton. Sophie presented a powerful speech on her journey with CF.

Attendees had the opportunity following presentations to speak with researchers and others who came to the event.

Topics and presenters included:

- An adaptive platform trial to improve outcomes in CF – André Schultz
- Emotional Wellbeing: A Community Approach – Kathryn Pekin
- Potential of antisense oligonucleotides as a therapy for people with CF – Kelly Martinovich
- Combating anti-microbial resistance - think outside the square!! – Dr Barry Clements
- Should we treat fungal infections in early CF? – Luke Garratt
- Living life to the full with CF – Sophie Longton
- Telethon Kids Respiratory Research Centre – Prof Steve Stick

All presentations were recorded and will be available on the CFWA website soon.

CF Talk Community Stories

Lotterywest has provided funding for four short films featuring local carers of people with cystic fibrosis (CF).

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 CF changes life perspective; sometimes through a common experience of loss, however, also healing, humour and strength.

We are interviewing a number of carers, and their stories will be available for future reference on our website and as a prelude to our short carer films. Here are our first series of interviews.

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

Julie: Initially I was focused solely on Anthony, trying to deal with the diagnosis and the feelings that came along with that. My circle was very small and that's how I wanted it to be. My prior-CF knowledge was limited; I knew some people with CF required postural drainage and that the condition was life shortening but refused to 'Google' it. Instead, I followed the advice of the team at PCH. When Anthony was around 5-years old, I began to want to know more about how others managed challenges with CF. I began to engage with the CF community, e.g. how to cope with the new stages my child was going through and dealing with temper tantrums during physio. Advice from those who are living through similar circumstances was great and extremely useful and in hindsight I wish I had reached out earlier. On the flip side, I am now more confident to provide insight to others. At a recent workshop I attended, I initially thought I wouldn't have much to offer but ended up contributing quite a lot to the meeting and surprised myself at how much we have grown on our CF journey!

Kris: I don't think there's ever been a particular time that I sought out people's stories about living with CF, mainly because we were getting used to being parents and I didn't have any other way of knowing what raising a child was like. The very fact that there were hospital appointments, percussions, nebulisers and tests, you could almost trick yourself into thinking that was a normal way to raise a child. The first time I became aware of the wider CF community was when we went to the CFWA starting school workshop. There were a lot of new parents there and it was interesting to hear how they were talking about CF with their kids. And it occurred to us that we hadn't actually talked to Mary about CF. It wasn't deliberate, it just all felt normal having CF and it was just the way it was.

Sarah: When Charlotte was first diagnosed in-utero at 20 weeks, that's when I knew I wanted to hear other people's stories. I contacted CFWA straightaway because at that point in time, it was likely she had CF and I knew that it was important to be connected. I also requested to speak to someone living with CF as 'Dr Google' was no help and was terrifying, so the genetics counsellor put me in contact with Adam. We spoke on the phone for over an hour, and after I got off the phone to him, I said to my husband, "Everything is going to be ok, we can do this". It was the turning point of our journey, of the diagnosis. We were posed the question if we'd like to terminate the pregnancy and go through a panel. Having that and Charlotte kicking the bejeebies out of me at 20 weeks, it was a very difficult situation. So, I felt as though the moment I finished the call with Adam, it was like a weight had been lifted and it's going to be ok, it's going to be manageable. He had the very strong notion that nothing can stop him. His mother ingrained in him, "Pity isn't an option and 'can't' doesn't exist". Right from a very young age she had instilled resilience in him; doesn't matter about your CF – you get on with it, you do your treatment, you get on with life. That stuck with me like glue.

I ran up to him after he presented at the Conquer CF Ball because we'd never met, and I said to him, "Did you by any chance speak to someone 3-years ago? She was pregnant and had just the CF diagnosis". And he said yes, and I requoted his quote and we said it at the same time. It was quite a powerful and emotional moment.

Rachel: Looking back, it took me quite a while to engage with the CF community. Having a child who is pancreatic sufficient with minimal symptoms seemed to be at odds with other's experiences. I think on reflection, perhaps I just wasn't ready to connect with those experiences as it meant

Julie and her son Anthony

Rachel and her daughter Mary

Sarah and her family

confronting the uncertainties that come with CF. The thing that changed all this was the need to advocate for improved hand hygiene resources at our school to reduce the risk of infection. CFWA put me in touch with another CF parent who had a positive outcome with her school, and through this connection, I joined the WA Parents and Carers of CF Facebook group. This reasoned pathway was probably the best way for me to become involved with the community because I felt I needed a purpose to somehow compensate for having a child with minimal symptoms. The Facebook page is a great space to listen and engage with other parents and carers. It's great to see many families supporting each other in this way; it's an evolving space and I hope new members feel welcome.

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

Julie: It's great to connect with others knowing you are speaking to people who get it, who get how you feel and get the challenges you face. The one thing you do have to remember, though, is that everyone's CF journey is different, so try not to focus on what happens to someone else as it might not happen to you. Now that my son is a teenager, it has really helped me to hear how others have navigated these tricky years. It makes me relax more knowing I'm not the only one going through it and has been a huge benefit. I really enjoy the CFWA events, the Parents Retreat in particular; it's a great way to network, educate and build fellowships within the community. Talking to others is now really important for me. You do sometimes get exposed to stuff you don't necessarily want to hear but again, you have to realise that everyone is on a personal journey and their journey is not yours.

Sarah: It offers resilience, being connected with others alike; knowing that you're not alone in the situation is a powerful thing. It gives you peace of mind, stops your mind from going crazy when you're experiencing that first illness or that first resistance of medication. You speak with others who speak your language because no one else in the community outside of CF can really fully understand the double-barrelled-ostomy, and why are you talking about poos all the time. It increases your confidence and your positive feelings. When you're feeling a bit down, it helps to bring you back up. When I've been in a really big lull and really upset, I have reached out to Kathryn from CFWA numerous times. And I thank you for that Kathryn; and as I've told others, I've always felt so much better after that phone call, just to let the tears out.

Rachel: Everyone is in a different place, looking after people with CF at different ages and stages, and connecting with others in an informal context allows for discussion that you wouldn't otherwise have. It's great to be part of a community that 'get it' and you can feel normal among them even though you might not have met in the traditional sense. It's great to see everyone supporting each other and being able to offer reassurance to another parent/carer because you know yourself that some days are extra hard.

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

Julie: I found it much easier to build contacts within the CF community once my son went to school. The internet and social media have helped to reduce isolation and I think it has been a benefit to the community. There are two or three people that I have regular contact with – other mums generally – but I enjoy the CF events and to see the familiar friendly faces. It makes me feel like I am not alone.

Sarah: Very much connected. On the Facebook WA Parents and Carers of CF page, I'm quite active on there. Also, I meet with a group of mums for dinner once a year; it's an open invitation and there's usually about five or six mums that attend. I catch up with others at the Evening with CF Scientists, CFWA's Ladies' High Tea, Parent's Retreat; we've gone yearly since Charlotte was born. I catch up with one particular mum on a regular basis with our non-CF children, and the Conquer CF Ball and the Casino Royale evening at the Left Bank. We've gone there every year, so connected that way. I've had two ladies sent my way as a point of connection and introduction; they were very anxious and new to the situation. And both ladies have said thank you for that offer of support, and that they're really appreciative of having been given that hope and reassurance.

Rachel: Although I've always known there are several organised events through the year, I'm really quite new to the social side of our community. Having said that, this year I attended both the High Tea event and the Conquer CF Ball and had an amazing time! My recent practicum placement at CFWA also means I have been able to meet with even more of our local parents and carers, and it's lovely that names and faces are becoming more familiar. What is really shining through is the value of connection, whether that's in person or reaching out on the Facebook page. Our community is full of amazing people who each have their own unique experience with CF but within that, there is a wealth of shared knowledge and understanding.

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

Julie: As a new mum, my world was very small; it was contained, and I didn't want to share my baby with anybody. I had good support from grandparents and good friends within my church community. As Anthony got older and I returned to work, I needed to rely more on others and at one point, my mother-in-law moved in which was a huge help to me. Support is needed in many ways, not just with Anthony, but also emotional support for yourself. I am now finding time to enjoy things outside of the home and this is a really important thing to do for yourself. Finding a good local supportive GP is extremely helpful, too; one who is happy to share the CF journey with you as a family.

Kris: I am astounded by the services and how much help and support there is from agencies and people for CF. When we were first diagnosed, I was under the impression that it was a little-known disease, but what I am constantly surprised by is that it is getting a lot more exposure, and there are a lot of services and people to help. I think we felt guilty asking for that help and support but despite that guilt, we still asked, and we still get that help and that support. And it's invaluable. When we were struggling with physio at the beginning, we had Sam from CFWA come and reassure us that the physio didn't have to be exactly perfect, it just had to be done, and that we would get better and we would gain more confidence. Having that permission to make mistakes gave us more confidence and support while we were learning about the care Mary needed. Having Jo, our home care worker who comes through for an hour each week, gives us a small break by having someone take care of Mary's physio for the morning. She's a great person to chat with and have in your home. I take comfort from the clinicians, doctors, medical staff, the volunteers, the services and CFWA; they help me feel supported and part of a bigger community because you can see that people are giving their time and their expertise and that means more to me than anything else. The staff at the hospital are also very supportive, and I'm still stunned that Ali and Liz knew our names from the beginning even though we were only there four times a year. The recent Conquer CF Ball was just stunning; that there are volunteers who can achieve so much on an annual basis is humbling.

Sarah: My mum is the strongest anchor in our family. I'm fortunate that she's a young mum and she was willing to take on that role. She learned Charlotte's routine and her treatment and just follows it to a tee. I can send Charlotte to my mum's house for a night, even for a weekend. She's had her for a couple of nights and she's done everything. My mother-in-law, she's learned her percussions so she will do that for me. Close friends have dropped in when we've had admissions. It's really a beautiful community that I'm in touch with. It was very hard for me to initially accept help. I'm not one to ask for help and I'm certainly a bit proud in that sense. And your pride takes a hit when you can't manage any more. But once I did finally accept help and assistance, it was like a weight had been lifted and I haven't looked back. Reaching out and asking CFWA for help, that was difficult, but even allowing my mum to learn the routine and take on that role was very difficult for me to let go. It's a pride thing; you sort of feel, why am I not able to cope with it? But once you let go of that pride, you realise that it's ok, and everyone needs help every now and then; you feel better afterward. If the shoe were on the other foot, I'd feel a sense of needing to help in some way, so to put yourself in your friends' and families' shoes, and know it's ok, that they don't resent you for it and you're not a burden to them. It is really important; it is good for them as well.


Kris with his daughter Mary.

Rachel: Aside from the continuity of care at the hospital which has been great, we have had support from CFWA over the years. Last year, physio had become very stressful and, among other things, we were just worn down. It was after a call to CFWA that we had Jo, our home care worker, come to help us out of the physio rut and get us back on track. She has been an amazing support, and her kind and caring manner really helped turn things around. We are very lucky to have her. I recently attended the CF High Tea and Conquer CF Ball and was amazed at how many people are involved and working so hard to help the CF community. Now I'm connecting with more parents and carers; I'm amazed by the strength, resilience and drive of our local community.

What do you hope the short films will achieve?

Julie: Fabulous idea for different stages; some families are not diagnosed until a later age (my son was two and a half). And they might also be good for those who are pancreatic sufficient as we are often forgotten, and the guidelines don't always apply to us. Information such as newly diagnosed, CF with toddlers, starting school, adolescents, what to expect on an admission, and adulthood might also be helpful. Also, information about cross-infection as some people are more visual and might understand better than a written document. CF isn't just one stage suits all, we've had different challenges at different times. Thankfully, being pre-warned means I feel armed for where we are at with the non-compliance stage.

Kris: I think being made aware of the support and services and not to feel guilty reaching out because it's there for a reason. Sometimes you don't realise you need help until you get it.

Sarah: I would like others who aren't currently connected to reach out or to communicate to a loved one or a family member that they are struggling, and they need help. Or even go on the Facebook page and put it out there and say look, this is really tough. And the moment they are connected I think would lessen the burden, the guilt, anxiety and even feelings of depression. Because you can have some real big lulls, especially if your kid isn't doing too well. Or if you're projecting too far into the future of the unknown, that it's really important to bring you back to the present. People who aren't connected are the ones who are slipping through the gaps, and they can't be the best that they can be for their child if their mental status isn't where it needs to be. So, I would really really like for them to get the peer support that I so greatly benefit from.

Rachel: I hope these stories help connect our community, especially parents and carers who are not quite ready to step into the wider world of CF. I think the nature of the videos may be a gentler way to learn about others in your community at your own pace and from the comfort of your own home.

Ladies' 'Crafternoon' at Our Annual High Tea

Held in May, the Ladies' High Tea is an afternoon event for women from our community who are caring for someone with cystic fibrosis (CF).

Our Ladies' High Tea turned crafty this year, with Cabernet and Canvas joining our soirée to guide us through a custom rose painting, created especially for Cystic Fibrosis WA to celebrate 65 Roses Day. The relaxed afternoon also included a scrumptious afternoon spread, raffle and, of course, a glass or two of bubbly!

This important event provides a chance for our female carers to come together for an afternoon of respite and networking. We know how important it is to create supportive relationships within the CF community and all of our support events offer a chance for our caring community to come together.

"This event is a great opportunity to connect with ladies in a similar position to me. It is very uplifting and rare to be able to speak to people who actually understand what we go through daily; the good, the bad, and the ugly. Hearing others speak, sharing experiences, and offering or receiving advice and support to one another is invaluable" – feedback from attendee.

A big thank you to our amazing volunteers who helped make the afternoon a huge success:

- Natasha O'Sullivan and Estee, who organised and prepared our wonderful afternoon spread
- Bianca Elford, star of our CF Talk videos
- Kerry LoPresti, Perth Children's Hospital teacher

Bianca and Kerry were kept very busy all afternoon selling raffle tickets and helped with the running of the afternoon.

We encourage all our carers to access our resources, attend events and seek support; it's what we're here for! Go to **www.cfwa.org.au** or speak to Kathryn on **08 6457 7333** for more information and how we can help.

Reloved for Research

Inspired by Marie Kondo, Japanese tidying guru, Rachael has begun a new project raising funds for Cystic Fibrosis WA called 'Reloved for Research'.

Marie teaches that if something doesn't 'spark joy' or isn't useful, you don't need that item in your life. Rachael took this advice and listed all her spare things for sale online with all the proceeds going to CFWA.

A bit overzealous, Rachael even made husband Craig and son James bring home a 1930s sofa from the local verge collection, selling it to a set designer working on the remake of the Icelandic comedy movie, Rams, being shot in WA, starring Sam Neill and Michael Caton.

So far, her efforts have raised $1,800 for CFWA!

Having cleared out her house, Rachael is looking for more good quality items to sell. Best sellers have included: chinaware (tea sets, teapots and tea cup trios), musical instruments, silverware (trays), glassware (crystal, cut glass or etched) and vintage or mid-century homewares.

If you have any household items that no longer 'spark joy', drop them in to CFWA's office for Rachael to sell. Items should be in good, clean condition with no chips, cracks or discolouration. Please, no clothes, handbags or large items that won't fit in the boot of a small car. If you're unsure about an item, give Rachael a call on **0409 102 514** before bringing it in.

If you want to drop something off to the office, please phone ahead on **08 6457 7333.**

Rachael tidying up a new treasure to sell

CF Research News

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 February 2019.

‘Social Support is Associated with Fewer Reported Symptoms and Decreased Treatment Burden in Adults with Cystic Fibrosis’

Authors: Kassie Flewelling, Deborah Sellers, Gregory Sawicki, Walter Robinson, Edward Dill

What was your research question?

The current study was conducted to determine if social support was related to health outcomes in adults with cystic fibrosis (CF). Based on previous research and theory, it was hypothesized that those with more social support would have better mental health, physical health, quality of life, and treatment activity.

Why is this important?

Social support is the degree to which an individual reports tangible support (having help in accomplishing tasks), appraisal (having someone to talk to), belonging (having someone to do activities with, and self-esteem (feeling you positively compare to others). In adults with and without chronic illness, social support has been related to a variety of positive health outcomes. Despite this, social support is rarely studied in adults with CF who may face unique challenges to obtaining social support, including frequent hospitalisations, time-consuming treatments, and infection prevention and control procedures that limit contact between patients. Medical care teams are aware of the potential for isolation, but may not encourage social support during clinic visits because they are focused on other issues and because no research is available to demonstrate the importance of social support in adults with CF.

What did you do?

Surveys about social support, mental and physical health symptoms, quality of life, and treatment activity were administered to 250 adults with CF. The participants were also part of a larger longitudinal study on adult care in CF. Participants ranged in age from 20 to 65 and were 61% female.

What did you find?

Those with more social support had fewer mental and physical health symptoms. They also reported functioning better emotionally, socially, and in their societal roles. Those with more social support experienced less burden from their treatments and had improved vitality, body image, and health perceptions. Those with more support also had fewer eating disturbances and digestive symptoms. Having more social support was not related to problems gaining weight, respiratory symptoms, or how individuals were functioning physically. Social support was not related to beliefs or behaviours regarding treatment adherence.

What does this mean and reasons for caution?

In this study, higher levels of social support were related to fewer mental and physical health symptoms, better quality of life in a variety of areas, and less treatment burden. As with any study, there are limitations. First, participants in this study had significant disease-severity, making results less generalisable to healthier adults with CF. Second, the measures of treatment activity used focused on beliefs about treatment and airway clearance treatments completed the previous day. A more thorough measures of treatment adherence is needed.

What’s next?

Members of the medical team are encouraged to discuss social support with their patients and patients are encouraged to get involved in virtual events with other adults with CF and seek support opportunities with healthy peers. The CF community would also benefit from social support screenings and interventions.

Original manuscript citation in PubMed:

https://www.ncbi.nlm.nih.gov/pubmed/?term=Social+Support+is+Associated+with+Fewer+Reported+Symptoms+and+Decreased+Treatment+Burden+in+Adults+with+Cystic+Fibrosis

Justin Talks About His Role in the CF Consumer Reference Group of WA

Justin and his wife, Sharon, have two children Jessica, 6 years, and Grace, 4 years. Grace has cystic fibrosis (CF). She is also very independent, outgoing and currently enjoying her first year in kindergarten. Justin became part of the CF Consumer Reference Group over 12 months ago.

Why did you decide to join this group?

I saw a letter regarding the mask requirement during clinic visits which was an initiative implemented after consultation with the CF Consumer Reference Group. It got me thinking about who and what the group is. I spoke to Ali at clinic and Lisa at Telethon Kids Institute and they explained more about the group and that they were looking for dads.

What are the benefits of being part of this group?

As a parent, it's knowing that you have input in to proposed trials and being able to discuss the various positives and negatives that may not have been considered by the researchers. The researchers are passionate about what they do, but the input from parents helps inform a collective, practical response that can help engage children when they do the research. Also, ongoing improvement in regard to parent/hospital relationships. We feel listened to and there is a genuine desire to make things better in clinic and with research.

The group meets every three months; what are the meetings like?

Very structured and professional, however, also very relaxed. It's also very punctual. Sophie, the chairperson, has CF and she keeps things on time which is great as we know we're going to leave by 9.00pm. There are also a couple of presentations from researchers; they discuss potential protocols and how they can best work with parents and children. There is also a question and answer session at the end with André and Ali from the respiratory team at Perth Children's Hospital, so we can save up some questions for them.

Is there much of a commitment to do things outside of the meetings?

Not really. It's just listening to the presentations, giving feedback, and suggestions and queries are answered in the meetings.

What would you say to other parents considering joining this group?

If you've got the time, definitely consider it. It's very informative and you can have input into what affects your child and other children with CF. It's nice to meet people who are involved in the research. A lot more is going on than most of us are aware. It's really inspiring to hear about this research into best treatment or potentially a cure. The group is primarily mums so it would be great to have some more dads along.

Join the CF Consumer Reference Group WA

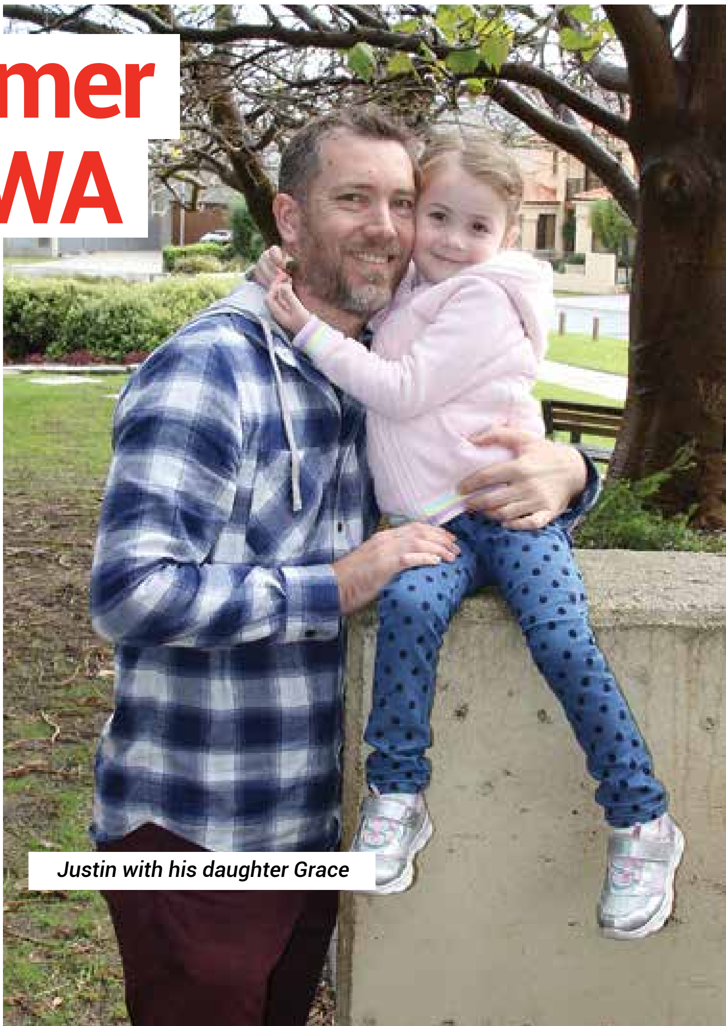
Expressions of interest are being invited for the Child and Adolescent Cystic Fibrosis Consumer Reference Group (CRG) of WA.

They are looking for additional members to join the Child and Adolescent Cystic Fibrosis CRG of WA. It is a formalised group of parents and patients with cystic fibrosis (CF) brought together to:

- support the development of partnerships between consumers, researchers, research organisations and clinical staff.
- provide a consumer perspective to both clinical and research aspects of CF.
- advise about research and clinical priorities, practice and policies.
- enhance the quality and relevance of research and clinical activities through consumer participation.

If you would like further information about this role, please contact Nadzirah Bashir by email on **ARESTCF@telethonkids.org.au** or phone **08 6319 1000.**

If you are interested in joining the group, please get in touch with the AREST-CF team at **ARESTCF@telethonkids.org.au**



Justin with his daughter Grace

May Month Volunteer Legends!

We are very lucky and thankful to have an expanding team of skilled and kind-hearted community members behind us throughout the year and during 65 Roses Month. We couldn't have achieved such success on 65 Roses Day without your help. Thank you!

CBD volunteers brightening the streets of Perth with fresh colourful roses

Spreading awareness for CF in the CBD

Volunteers selling roses in Fremantle

The Telethon Kids Institute wrapping team getting stuck into rose wrapping

Rose Selling Team

Selling roses can be a tricky task at times, but that doesn't stop our volunteers from putting themselves out there and doing their best to spread awareness and raise funds for the CF community. Well done and thank you to all our fantastic volunteers who sold roses and represented our cause in the community.

Wrapping Day

Every year we get fantastic support from organisations and individuals who spend hours preparing, wrapping and packing thousands of roses. Thank you to our corporate volunteer teams including Telstra, Telethon Kids Institute, Suncorp, BT, Assetivity, QBE, Teachers Mutual Bank and UWA Guild for their support as well as all the individual volunteers who came to lend a hand.

Floristry Team

Our amazing posies and bouquets were made possible through the support of Fel, a volunteer florist, who returned for her third year of sharing her expert floristry skills to design the arrangements. Well done as well to Naomi and Kandy for stepping up and leading the volunteer floristry team to create over 130 beautifully crafted bouquets and posies.

Delivery Drivers

Our champion volunteer delivery team doubled this year to keep up with the huge number of rose orders we received. These volunteers had a fun time spreading joy by delivering fresh, colourful roses around the Perth metro area. Thank you to all our drivers who donated their time and their vehicles to help us deliver hundreds of orders over two big days of deliveries.

'Can Do' Crew

A special mention to the collective volunteers who went above and beyond during May to support the CFWA office team with all odd jobs and special volunteer tasks that popped up throughout the month. A massive thank you to Amy, Gemma, Liam, Chris, Clare and many more who made up our 'Can Do' crew.

We asked some of our volunteers what they thought of 65 Roses Day this year and here's what they said:

What did you learn by volunteering for 65 Roses Day?

"Many people are involved in making something like this happen; it's not just one day of work. It's a huge team of volunteers across months of planning and days of wrapping and preparation."

"Cystic fibrosis is a really good cause to raise money for; so many people are affected by this lung disease."

What was your favourite part of volunteering?

"The best part was seeing the look on people's faces when you delivered the roses and knowing how much it means to them."

"The pleasure of talking to people about this important cause and seeing the joy they got in buying roses."

CITY TO SURF THIS AUGUST!

SUPPORT THE CYSTIC FIBROSIS COMMUNITY BY RUNNING IN THE CITY TO SURF!

Join as an individual runner or gather your running buddies and register as a team to run in the City to Surf on **11 August** (Karratha) or **25 August** (Perth).

Visit **http://perthcitytosurf.com** for more information or contact our team on **events@cfwa.org.au** to find out how you can get involved and raise funds and awareness for the CF community.

Introducing Haylee

Hi everyone!

My name is Haylee. I am the new social worker at Cystic Fibrosis Western Australia (CFWA). My background is working with young people and their families at Starship Children's Health in New Zealand. I have had the privilege of working with lots of families through chronic illness, trauma and liver transplantation. I moved to Perth a few years ago with my young family and we now call WA home (although I will always be a supporter of the All Blacks!). I will be working two days a week at CFWA, and I am really looking forward to meeting all our members over the coming months.

As a social worker, I can provide counselling and emotional support, advocacy, practical support (i.e. information on subsidies), Centrelink and TAFE applications. I can work with young people around goal setting, career planning and transitioning into independence. If you would like to meet up for a chat, please get in touch at **socialworker@cfwa.org.au** or **08 6457 7333.**

First Aid Training for Mental Health

Research suggests 1 in 5 Australians aged 16-85 experience some form of common mental health illness in any year. This is just one of the statistics our team learned at a recent training course on Mental Health First Aid.

In July, eleven members of our team undertook a two-day training course with Amanda Lambros, trainer for not-for-profit organisation Mental Health First Aid Australia (MHFAA). They learnt the skills for providing initial help to a person who is experiencing a mental health problem or experiencing a mental health crisis.

MHFAA has a range of courses educating in mental health that are available for members of the community, including carers, friends, families and colleagues of someone who is experiencing a mental health problem.

Visit their website **www.mhfa.com.au** to see their range of courses.

2019 Regional Respiratory Training Program: That's a Wrap for Another Year.

This year we welcomed a record number of nurses and physiotherapists from regional WA to our annual Regional Respiratory Training Program (RRTP).

The RRTP is a collaborative project supported by Perth Children's Hospital, Sir Charles Gardiner Hospital, Royal Perth Hospital, Fiona Stanley Hospital, Silver Chain and Asthma WA. It would not be possible without the continued funding by the Department of Health WA. We are also thankful for sponsorship by Vertex, and ongoing support by Technipro Pulmomed and Fisher and Paykel.

This program, endorsed by the Australian College of Nursing, aims to improve regional hospital outcomes for cystic fibrosis (CF) patients through improved awareness, knowledge and connection to our metropolitan counterparts.

Sixteen regional nurses and eleven regional physios attended from throughout WA, including Albany, Busselton, Collie, Esperance, Exmouth, Kalgoorlie, Kununurra, Norseman, Pemberton and Port Hedland. The RRTP is instrumental in facilitating professional development and providing a forum for networking with experts and peers to enhance practice.

The presenters give generously of their time and share knowledge in their area of expertise. Participants attend sessions that provide an overview of a number of chronic health conditions including CF, bronchiectasis, asthma, diabetes and chronic obstructive pulmonary disease. There are opportunities for practical, hands-on learning in non-invasive ventilation, oxygen therapy and lung function testing. Other topics covered include pharmaceuticals, lung transplant and psychosocial aspects of chronic health conditions. One of the most meaningful sessions every year is a presentation from a regional parent of a child with CF. This session provides valuable insight into the 'lived experience' of families dealing with CF in country WA.

The regional physiotherapy participants engaged in an intense day and a half with two of Perth's senior respiratory physiotherapists, updating knowledge and skills on current methods of airway clearance for chronic lung disease, with both a paediatric and adult patient focus.

Our nursing participants' experience included a guided tour of the SCGH respiratory ward with time for hands-on learning with NIV equipment, high flow oxygen and intercostal drainage systems.

Comments from Participants:

- "Absolutely amazing, well organised and structured course that has allowed me to feel empowered to ensure better healthcare with evidence-based practice for our regional patients"
- "I would recommend this to everyone who works in health. A fantastic course"
- "Thank you. This program is a priceless tool of current research for all of us who choose to live and work regionally. This course has proven to be of huge benefit in not only upskilling me clinically but in increasing my confidence to apply this work in my area of practice"
- "Awesome week – outstanding education opportunity for me. Going home with a new passion. Thanks"

If you are a regional member, our CFWA nurse is available to provide CF health professional education at your local hospital, with your general practitioner (GP) or other health provider. There may also be a regional health professional in your area who has attended our RRTP course and may be able to assist you. For further information, please contact Sharon on **08 6457 7333** or **nurse@cfwa.org.au**

Cystic Fibrosis WA $37,500 PhD Top Up Scholarships

Cystic Fibrosis Western Australia (CFWA) is a charitable not-for-profit association incorporated in WA whose vision is of a world where Lives are Unaffected by Cystic Fibrosis.

Today, due to improvements in early diagnosis, intervention, treatment and better pharmaceuticals, most children affected by cystic fibrosis (CF) are now surviving well into adulthood. As a result, there are now more adults living with CF than children.

The ageing of the CF population is seen as a great success story in which CFWA has played a role, however, this is placing increasing demands on CF services here in Western Australia and particularly adult services.

Domestically, and indeed internationally, there appears to be a shortage of specialists in this field who will meet these future demands as the population ages. So, after extensive consultation with a broad range of stakeholders, CFWA has offered a limited number of PhD Top Up Scholarships to encourage and support PhD students here in WA who are undertaking research in areas related to CF. This year there are two scholarships available to a PhD student working in this field, however, applications from researchers working in an area of CF which has specific implications for adults living with CF are particularly encouraged.

CFWA hope that these scholarships will stimulate a lifelong interest in this exciting area of research and thus increase the pool of talent in WA from which to draw in the future.

This scholarship is administered through the Australian Cystic Fibrosis Research Trust (ACFRT) on behalf of CFWA. The scholarship is for $12,500 per annum for a maximum of three years. Conditions apply.

Applications open Tuesday 19 August 2019 and close on Friday 20 September 2019 at 5pm AEST.

Emailed applications will be accepted but copies with academic records and a signed declaration must follow by mail. A funding agreement will need to be entered into with ACFRT.

Application forms are available from:

The Australian Cystic Fibrosis Research Trust

PO Box 268

North Ryde NSW 1670

nickim@cfa.org.au

For further information please contact

the ACFRT on **02 9889 5171**

Painting the CBD Red

65 Roses Day was bigger than ever in the city this year and we couldn't have done it without so many businesses helping us.

65 Roses Taking over the city!

Traditionally, CBD rose sales have focussed on our Murray Street Mall flagship stall with volunteers selling roses around the city centre. This year, building managers and tenants in office towers joined forces and organised or hosted rose stalls in their buildings as a show of support for the cystic fibrosis (CF) community.

It was great to have new buildings involved and see our awareness messaging carried on lift and digital display screens. Thanks to the following incredible supporters for your generous involvement.

Mia Yellagonga – Woodside's new home – continued past support with employee and CF dad Tim Kerr and his team selling 400 roses in record time.

Exchange Tower sold roses through their reception and through tenant Moore Stephens, continuing many years of support.

Kings Square shone red for CF on the eve of 65 Roses Day. The Equiem/Dexus team were on board early in the morning supporting our volunteers and joining them to sell roses. Together with **240 St Georges Tce**, the Equiem/Dexus stalls proved a huge hit with office workers resulting in combined sales of over 900 roses.

108 St Georges Tce hosted a stall through collaboration between Telstra and Brookfield Properties with tenant, Woods Bagot, also ordering roses to sell.

Brookfield Precinct launched a collaborative stall with Telstra which included a beautiful display wrap of our junior ambassador, Ella. This stall kept the Telstra volunteer team busy well into the

B&C Finance volunteers selling roses in Enex100 afternoon with rose sales. Several organisations in buildings in the precinct also bought buckets of roses for their teams through this Brookfield hub.

Enex100, through building manager JLL, tenant Plan Australia and CFWA supporter B&C Finance, made sure their office workers didn't miss out on their roses.

225 St Georges Tce tenant Marsh organised their stall with building manager Charterhall. Quick initial sales saw them calling for backup supplies to make sure everyone could buy a rose. Building tenant and CFWA supporters Iris Residential continued their support buying beautiful bunches of roses.

QV1, with the support of CBRE and Herbert Smith Freehills, grew their previous years' support with the CBRE team bringing new buildings **140 William St** and **Cloisters Square** on as new stall hosts and volunteering for rose sales.

65 Roses Day 2020

Securing stalls in buildings and in office precincts allows CFWA to grow CBD sales each year. If your business is keen to be involved in hosting a stall to sell roses or volunteering next year, sign up to our e-newsletter to stay in touch or contact our team at **events@cfwa.org.au** or **08 6457 7333** to discuss how you can help next year.


Kings Square – lit up red for CF

Team Telstra at the 108 St Georges Tce Stall


The team from Marsh blitzing 225 St Georges Tce rose sales

Top Runners at the HBF Run

Top ranking teams, individuals who smashed their targets, and crowds of red lung shirts in a sea of blue – this year's HBF Run for a Reason was an absolute winner!

We were very lucky to have a big team of participants who made cystic fibrosis (CF) their reason to run this year in the 2019 HBF Run for a Reason, and we are blown away by the support the community provided them.

Thanks to the efforts of more than 30 participants and the support of hundreds of generous donors; **over $34,451** was raised for children and adults living with CF in WA.

In addition to the fantastic fundraising, there was a significant amount of awareness raised in the lead up to the event and on the day. Thank you to everyone who actively shared their experiences and stories of living with CF, or knowing somebody who does.

We had so many success stories from our runners this year, with many of them exceeding their original fundraising target and others smashing their personal best times on-the-day. One of our teams, 'For Norah', **raised over $20,000,** making them the second biggest fundraising team for the whole of WA!

Thank you to everyone who took steps this year to help make a difference to the CF community – your efforts are greatly appreciated!

Team Achievements

For Norah	$20,186
TFG Team Ruby	$3,351
Ladies with Attitude	$1,074
Team Tander	$401
The Brunch Club	$184

Individual Achievements

Lillian Petchell	$4,796
Natalie Ryder	$1,322
James Harold	$981
Jemma Bergin	$643
Nikita Kukadia	$552

Empowering Our Volunteers

Here at Cystic Fibrosis WA, we like to think of our volunteers as the life force of our awareness and fundraising events. Which is why we are very excited to announce that we've been given funding to support the empowerment of our volunteer team!

Some volunteers in the City on 65 Roses Day

This year 65 Roses Day luckily landed on National Volunteer Week, an annual celebration to acknowledge the generous contribution of volunteers across Australia. Thanks to the generous support of Volunteering WA, we were able to thank our volunteers on 65 Roses wrapping day with a scrumptious brunch, games and prizes throughout the day, a jam-packed goody bag for volunteer delivery drivers and a beautiful fresh rose for each volunteer to take home and enjoy.

We are also excited to announce that we've also been given a Volunteer Grant through generous support from the Community Grants Hub on behalf of the Department of Social Services. This funding is provided to build equipment kits to support our enormous volunteer crew with useful equipment for their fundraising and awareness activities. We have a selection of small tables, chairs and display equipment that can be loaned for your next event.

We were also lucky enough to receive funding through Lotterywest to develop our volunteer program and create more resources for people wanting to give their time and expertise to help our organisation. We're working on some handy informational videos, guidelines and volunteer kits (including new volunteer polos) to support our committed and generous volunteers in their efforts.

If you would like to join our volunteer team, or know someone who is looking to offer their skills or expertise pro-bono to a not-for-profit, please visit our website **www.cfwa.org.au/get-involved/volunteer** or contact our Events & Community Fundraising Coordinator on **events@cfwa.org.au** and have a chat!

Having brunch on Wrapping Day thanks to our volunteer grant

Volunteers with their roses to take home

I'm Healthier Than I Have Ever Been in My Life

Michael, who is turning 40 later this year, is a family man who has seen life-changing results thanks to his new lifestyle and exercise regime. Michael was one of the first participants to take up our Personal Trainer, Gym and Activity Subsidy, with incredible results. He spoke to us recently about the benefits of exercise and how the subsidy can help you.

We know physical fitness is important to you. How did you first get motivated to exercise?

Back in 2017, I had two episodes of haemoptysis (coughing up blood). It was very scary and a big wake up call.

Straight out of hospital, I decided to focus solely on my health. I started a new exercise regime and quit my full-time job.

I was already going to Jetts gym in Ellenbrook when I decided I needed some more guidance in reaching my fitness goals, so I approached Danny from Sustain Health and Performance to provide me with personal coaching and support. I started having personal training sessions with him four times a week and continued to do so for over a year.

What changes have you noticed in your health since increasing your exercise habits?

My health stabilised. My lung function plateaued (no more declines), and I had no more lung infections. I was feeling really good. Almost a year later, I went on to a drug trial. The triple combination therapy, combined with my new exercise routine, saw my health improve dramatically.

My lung function increased by 20%, my energy levels skyrocketed, my strength increased – so much I can now carry my 10-year-old daughter up to bed. I haven't had a hospital admission since 2017 and my check-ups have gone from once a month to three-monthly.

I'm now back at work part-time, which is great as it means I'm able to be more involved in my daughter's life; doing school pickups and taking her to extracurricular activities.

I am committed to my new lifestyle. It's a routine and I make exercise and nutrition a priority.

What other changes have you made?

I have dropped down to one personal training session a week and then the other three sessions I work out on my own with the program Danny has written me.

My diet has also changed a lot. Danny has taught me a great deal about nutrition and fuelling my body. I'm currently eating over 3,200 calories a day in order to build muscle mass but still maintain a low body fat percentage. I haven't had a can of Coke or junk food in months and instead, aim for healthy fats and high-protein foods.

My wife, Natalie, has joined the gym, too, and our eating habits at home have changed a lot. We generally follow the 80/20 rule, so allow ourselves to enjoy ice cream for dessert. It's all about balance.

Has the subsidy helped you?

It has been a huge financial help. It just helped take the edge off the costs as having a personal coach isn't cheap, particularly when I wasn't working.

I used the subsidy to take part in a 12-week challenge with Danny at Sustain Health and Performance. We had to track calories and be within 90% of our target, as well as submit a photo update every 4 weeks (you can see my results in the image). I ended up winning the challenge and a $1,500 cash prize!

I have developed such a passion for fitness; I have decided to put that money towards getting my Certificate III in Fitness.

How did you find the process for claiming the subsidy?

It was really easy. I read about the subsidy in Cystic Fibrosis WA's (CFWA) e-news and sent off an e-mail to check they still had subsidies available; from there, it was all online. I paid the gym and provided proof to CFWA and they reimbursed me.

What would you say to someone thinking of applying for a PT, Gym and Activity Subsidy?

GO FOR IT! Definitely. Do something you enjoy that is sustainable. I have made so many friends at the gym. I think going to a group fitness class or having a personal trainer are great options because they can offer support and advice.

I want to say thank you to CFWA as the support has allowed me to take my fitness to the next level with a whole new life-changing experience. I will continue training hard as I have never been this healthy in my nearly 40 years of life.

Personal Training, Gym and Activity Subsidy

Recognising the need to increase assistance to our adult CF population, CFWA introduced a new subsidy late last year.

The PT, Gym and Activity Subsidy can provide up to $480 per quarter to assist with costs associated with physical exercise, such as personal training sessions, gym memberships and other physical activity fees.

Knowing the huge benefits – both mental and physical – that exercise can offer, we encourage all adults with CF who are able to do so, to engage with this program.

The PT, Gym and Activity Subsidy, like all our subsidies, is dependent on funds. You will need to confirm availability with CFWA prior submitting your application. It is claimed retrospectively, which means you have to pay up front with your exercise provider and then we can reimburse you upon receipt of your proof of payment. For more information, please visit **www.cfwa.org.au/subsidies** or phone **08 6457 7333.**

For support with exercise, you can also check out our CFFit resources at **www.cfwa.org.au/what-we-offer/resources/#cf-fit**

Creative Challenges for May Month!

Let's hear it for our creative and incredible community members who have been very busy raising awareness and funds for cystic fibrosis (CF) during May, our national month of awareness for CF.

Some of the Vault Fitness team with the CF spinners at the Spin Challenge in May.

Kandy (in red) and her team of supporters

Kate and Paul with their dinner guests

"Serve It Up" at the Spaapen House

Each Saturday night in May, Paul and Kate, parents of David who lives with cystic fibrosis (CF), hosted a three-course dinner party for friends and family to raise funds and awareness for CF.

Kate created the menu and cooked the delicious food while Paul was in charge of looking after the guests (topping up their glasses!) and hosting a quiz for entertainment, with some CF questions thrown in for awareness raising.

Kate says, "The night is usually full of laughs with brief periods of silence whilst everyone is eating. Over the 5 years we've been doing this, we get the frequent flyers/guests coming back for the delicious food and fun night out."

This year they raised over $2,566, bringing their grand total over 5 years to over $10,000! Well done and thank you to Paul, Kate and David for serving it up for CF.

Team Cooper and the Vault Fitness Spin Challenge

Todd and his amazing crew from Vault Fitness were back with their Spin Challenge in May, proudly supporting Cystic Fibrosis WA (CFWA) and the Steve Waugh Foundation. Hosted in Exchange Tower and supported by Primewest, this three-day cycle challenge involved tenants from Exchange Tower and surrounding CBD buildings registering to ride in teams.

This year the Cooper family were back, taking on all three days of the Spin Challenge. Alan, Karen, Dylan and Ben organised a CFWA team for each day and were supported by other CF families and CFWA partners, including WAFEX's Kerryn Musson. Dylan, who has CF, set a blistering pace for the team and kept everybody motivated throughout the ride.

Thank you to everyone who was involved in organising the event, the teams who participated, and the generous supporters and donors to the challenge for making it another successful year. A total of $23,500 was raised for the two charities, with CFWA receiving $11,750 – an amazing effort!

Kandy's Just Breath Yoga

Last year's CFWA Volunteer of the Year Award winner, Kandy, held a Just Breathe Yoga event to raise funds and awareness CF in May. Thank you to Yab Yum Yoga who generously offered their studio, and Louise Lawrence from Kosha Connections who shared her expertise and lead the session. Together, Kandy and her supporters raised $975!

But Wait, There's More!

There were so many great awareness and fundraising initiatives undertaken in the community that deserve recognition. Visit **www.cfwa.org.au/news** to read about Aaron's Crack a Cure challenge, Madisyn's Hair Today Gone Tomorrow story and more from our other fundraising legends from May.

Playdough for a Purpose

Nido Early School in Beeliar recently invited Cystic Fibrosis WA (CFWA) to be part of their giving back initiative, 'Playdough for a Purpose', which aims to bring a smile to little faces fighting big health battles.

The educators at Nido Beeliar Village will lead small groups of children in making up and packaging fresh batches of playdough to be donated to CFWA. As child experts, the educators at Nido understand how beneficial and educational exploring and creating with playdough is, and Playdough for a Purpose allows the children the opportunity to give back to the community and learn about the importance of kindness.

We are excited to receive our first batch of playdough shortly and to distribute them in our hospital bags to help pass the time during admissions.

*Please note: the educators will be the only ones handling the dough and hand hygiene practices will be followed.

SAVE THE DATE – SIBLINGS' AND OFFSPRING CAMP 2019

For: Children and Teens aged 8 – 18 years who have a sibling or parent with cystic fibrosis

Where: Ern Halliday Recreation Camp,
Whitfords Ave, Hillarys WA 6025
When: Wednesday 3rd October
– Friday 5th October
(school holidays)

Activities include:
- Aloha Surfhouse
- Caving
- Flying Fox
- Lost Pilot

MORE INFO WILL BE COMING SOON, BUT MAKE SURE YOU SAVE THE DATE!

It Only Takes A Minute to Donate Life

Sunday 28 July to Sunday 4 August is DonateLife Week. Held every year, DonateLife Week is a key event that highlights the benefits that organ and tissue donation has for transplant recipients and their families in Australia. Lung transplant has prolonged the lives of many people with cystic fibrosis (CF), however, a shortage of suitable donors is an issue that delays lung transplantation.

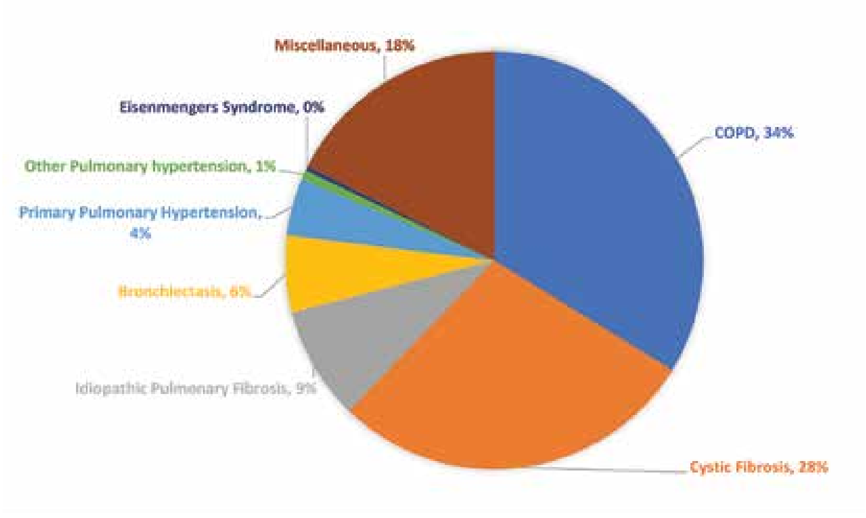
Since 1992, there have been 2,494 bilateral lung transplants performed in Australia. Of these, 781 (31%) were for people living with CF. Australia's lung transplant program is highly regarded and has an extremely good survival rate; 70% of those transplanted will live for more than 5 years. Lung transplants, while not a cure for CF, can dramatically improve an individual's quality of life.

Some people with CF will even require kidney or liver transplants due to the impact CF can have on these organs.

Unfortunately, too few people are registered as organ donors. If every registered organ and tissue donor found one person who wasn't and encouraged them to register, it would double the number of potential donors. It is quick and easy to become a registered organ and tissue donor and we encourage anyone who can, to register at **www.donatelife.gov.au**; it only takes a minute.

To read about one of the many cases of organ donation saving the life of someone with CF, head to our website to read Fiona's story **www.cfwa.org.au/news/new-lungs-new-life.**

DonateLife
28 July–4 August 2019 Week



Is School Enrolment Stressing You Out?

Starting school 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 the CFSmart and CFWA websites to help guide conversations with your school. In addition to these resources Maggie, our Education Coordinator, is on hand to facilitate a discussion with you and your potential school on topics such as medications, school absences, environmental concerns, and much, much more!

Contact Maggie at **education@cfwa.org.au**
for more information or to set up a meeting at your school.

Barbagallo Men's Health

Personal health and wellness are the passion of the team at Perth Integrated Health Clinic.

Nathan Charles and some of the team from event sponsors, Byfield Business Advisers

The Barbagallo Group in Osborne Park hosted the series with the generous support of additional sponsors Byfields Business Advisers, Belgravia Leisure, Coaching Zone, Reliance Partners Insurance Brokers, Brila, The Fathering Project and DT 38. The series covered a range of topics including heart health, the importance of fitness, and endurance in sport.

Cystic Fibrosis WA (CFWA) ambassador, Nathan Charles, believed to be one of the only people in the world to play contact sport at an international level with cystic fibrosis (CF), presented a powerful session on endurance in the elite sport of Rugby Union.

As the nominated charity beneficiary, CFWA provided weekly speakers including CEO Nigel Barker, CFWA President Caz Boyd, CFA Vice President Mitch Messer and Business Development Manager Karen De Lore to raise awareness of CF amongst attendees. Fundraising from the event achieved $1,656 in support of CFWA services and programs, including those that support fitness and wellbeing in the CF community.

Felicity Snowsill, Andrew Ng, Nigel Barker, Ian Wee (left to right)

Sharing the CF Journey

Cystic fibrosis is hard to ignore in the Donaldson household, but it doesn't define their lives.

Every year, Cystic Fibrosis WA (CFWA) runs an end of financial year appeal to support our ongoing services and programs. This year's appeal focussed on the daily attention to medication and routine in the lives of Isobel and Ruby, sisters who both live with cystic fibrosis (CF).

We are grateful to the incredible support of our generous CF donor community, with the appeal raising a net income of over $78,000 in WA. The 'You Can't Ignore CF' campaign was run in four states including Cystic Fibrosis Queensland, Cystic Fibrosis Community Care NSW and Victoria. Collaboration with our sister organisations keeps our costs down and maximises our message across Australia.

Thank you to Isobel, Ruby and their family for featuring as our 2019 appeal story. We very much appreciate the time and energy that comes with sharing personal journeys. We know that increasing awareness for CF in the community is vital in supporting the work of CFWA, so if you would like to be part of a future campaign, please contact our Business Development Manager on **marketing@cfwa.org.au** or **6457 7333** to have a chat. It's also not too late to be a part of this year's appeal, visit **www.cfwa.org.au/appeal** to read Isobel and Ruby's story and support the CF community.

EVENT CALENDAR

Save the date for these 2019 events

August

3-4 –Australasian CF Lay Conference

4-6 –Australasian CF Medical Conference

25 - Perth City to Surf

September

1-30 - Serve It Up for CF

20 - Grandparents Morning Tea

October

2-4 – Sibling and Offspring Camp

19 – Parents' Dinner

TBC – Telethon Weekend

November

1 – Cystic Fibrosis Golf Classic

22 – Sponsors and Volunteers Evening

*Please note, dates may change if conflicts arise.

For more information and to register for these events visit **www.cfwa.org.au/get-involved/upcoming-events/**

Cake Angels Making Cakes for Kids with CF

The Australian Cake Angels are a group of over 1,900 volunteer cake decorators all over Australia that make beautiful cakes for children with chronic illness or disability.

These wonderful volunteers have kindly reached out to Cystic Fibrosis WA and offered to make birthday cakes for children living with cystic fibrosis.

Check out **www.cfwa.org.au/news/cake-angels** for more information about the group, and how to book a cake for your child.

George Jones Family Foundation

Cystic Fibrosis Golf Classic

We invite you to participate in the 2019 Cystic Fibrosis Golf Classic. Join us on Friday 1 November for a round of golf at the prestigious Lake Karrinyup Country Club followed by an evening of entertainment, with proceeds supporting vital cystic fibrosis research and services.

Visit our website **www.cfwa.org.au/golf** to view the various sponsorship opportunities available and to register your involvement.