EDITION 3 2018

RED

IN THIS ISSUE

WHAT'S NEW IN CF?

CONTENTS

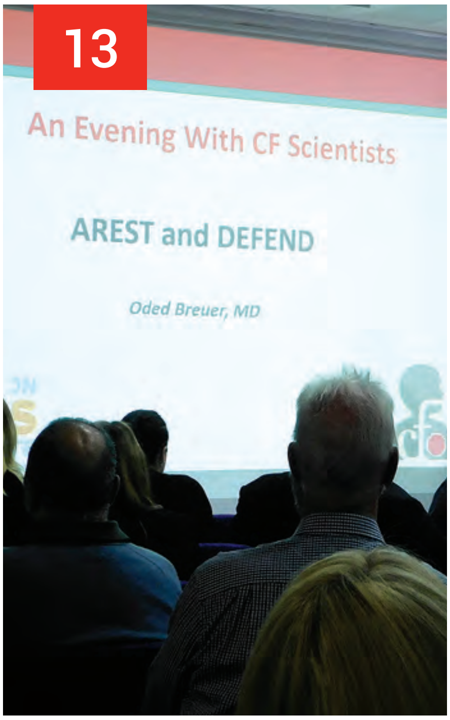
05

15,000 Roses for Cystic Fibrosis

06

A Little Excitement with this Admission

13



An Evening with CF Scientists

21

May Month Fundraising Champions

FEATURES

Like us on Facebook
/cysticfibrosiswa

Stay Informed
/cysticfibrosiswa

Follow us on Instagram
/cysticfibrosiswa

Find us on Linkedin
/Company/Cystic-Fibrosis-Western-Australia

RED CEO MESSAGE

NIGEL BARKER, CEO

The month of May was of course 65 Roses month. It's a time when we pull out all the stops around the nation to raise awareness of cystic fibrosis (CF) and funds for service delivery and research. 2018 was massive.

Thanks to literally hundreds of volunteers and sponsors like Telstra, Iris Residential, WAFEX, Vault Fitness, South Metropolitan TAFE and far too many to mention here, we literally turned the state red! This included lighting up the new Perth Stadium, Bell Tower, and thanks to Haydee Carman, the new traffic bridge in Mandurah in red lights.

We also sold record numbers of roses and obtained over a million dollars of free publicity on TV, radio print and social media.

A feature article appears in this edition of RED magazine, together with articles on just a few of the hundreds of events that took place in May.

The month was officially launched at the increasingly popular Evening with CF Scientists, where some of the country's top researchers show and tell what they have been up to over the past year.

In this edition, we also welcome Charlotte Burr as the new Clinical Nurse Specialist for the Department of Respiratory Medicine at Perth Children's Hospital, who has taken over from Liz Balding, and celebrate success in winning a grant from Lotterywest to enhance our CFSmart educational resource, which is now being used right around the world.

Talking of education, we had a record level of participation by health and allied health professionals in our Regional Respiratory Training Program, spreading expertise in CF across the state.

Don't miss out on the beautiful interview with a lucky lung transplant recipient and how its changed her life and take a sneak preview of what the new Children's Hospital is like through the eyes of Kiah and her mum Trilby, one of the first CF patients to be admitted.

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our fourth edition, please contact us before Friday 24 August 2018.

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

DESIGN BY
Catherine Fisher
The Pixelfish Designs

PRINTED BY Picton Press

ON THE COVER
65 Roses Junior Ambassador, Lyla Gillard.

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

info@cfwa.org.au
www.cfwa.org.au

Subscribe to our e-newsletter online
www.cfwa.org.au

CFA UPDATE COMMUNITY POWER IN FULL FORCE

A sea of red balloons, flags, placards and T-shirts crossed Sydney's iconic Harbour Bridge on 30 April and wound its way to Vertex's Head Office at St Leonards to let the company know that people with cystic fibrosis (CF) need access to Orkambi®, and we need it now.

It was an emotional and strenuous 6.5km march for more than 100 CF community members, that began outside Channel 7's 'Sunrise' studio in Martin Place in Sydney's CBD. For over two hours the 'Sunrise' windows were awash with friendly but enthusiastically committed protestors, and hosts Kochie, Nat and Monique spoke of the plight of people with CF waiting for drugs that cost $250,000 per year.

Vertex Country Manager Eilis Quinn met with protestors and assured the crowd that Vertex was doing everything possible to get Pharmaceutical Benefits Advisory Committee (PBAC) reimbursement approval. The crowd had a chance to ask questions, and while the mood was hopeful that the result from the PBAC meeting in July would be positive, there was definitely a feeling of frustration that the two-and-a-half-year waiting game continues.

Most concerning is the fear that if Vertex does not get PBAC approval this time around – after three previous attempts – they will no longer run clinical trials in Australia.

Cystic Fibrosis Australia (CFA) is keen to point out to Vertex, and the government, that they should not confuse 'what a life is worth' with 'what a life costs'. The protest march demonstrated that it is at their peril they equate the fact that CF affects a small number of people and consequently, and tragically, regarding this as being an insignificant cohort.

We generated some great media coverage and I am thrilled to be able to share this with you all. Congratulations to Cystic Fibrosis South Australia for an outstanding march in Adelaide.

There are many things we can do to ensure both Vertex and the government appreciate the ripple effect throughout our community from the suffering of one to the financial, tangible, emotional and psychological effects of so many. Your support plays a major factor in any successes we achieve.

Kind regards,
Nettie Burke, CFA CEO

2018 SIBLING AND OFFSPRING CAMP

This year we are super excited as our Sibling and Offspring Camp will be held over 2 nights and in an all NEW location!

WHEN: Tuesday 2 to Thursday 4 October 2018.
WHERE: Camp Kulin, 3 hours east of Perth.
A bus will be arranged to take kids to the camp, departing from both north and south locations.

WHO: All kids aged 8-16 years with a sibling or parent with cystic fibrosis.

Registration packs with more detailed information about the camp, including the program, will be sent out closer to the event. For more information please contact Paula on **services@cfwa.org.au** or phone **08 6457 7333.**

You can find out more about Camp Kulin at **www.campkulin.com.au**

Thank you to the Mazda Foundation for supporting this important event.

CFSIBS' Mazda FOUNDATION

Over 100 volunteers filled up our conference room to help wrap roses for 65 Roses Day

15,000 ROSES FOR CYSTIC FIBROSIS!

65 Roses Day 2018, our national day of cystic fibrosis (CF) awareness, was our biggest and best EVER thanks to hundreds of dedicated volunteers.

We'd like to give a huge THANK YOU to everyone who gave their time and efforts to help us paint WA with roses for CF this May. From our dedicated rose wrapping and stall volunteers to our corporate partners; and of course, everyone who bought a rose on 65 Roses Day - you have all made a valuable contribution.

We have been absolutely blown away by the generosity of our volunteers this year. Your dedication and generosity has enabled us to grow 65 Roses Day to an incredible 15,000 roses!

210 volunteers gave their time over the huge rose wrapping day on Thursday 24 May and 65 Roses Day on Friday 25 May. This amounted to over 1,000 hours of volunteer service over the two days; incredible!

There are too many people to thank individually but we want you to know that your time and efforts are greatly appreciated, and we couldn't do it without you. Thank you!

Read through the rest of this edition of RED Magazine for more 65 Roses stories.

The wet weather didn't stop our volunteers from selling roses!

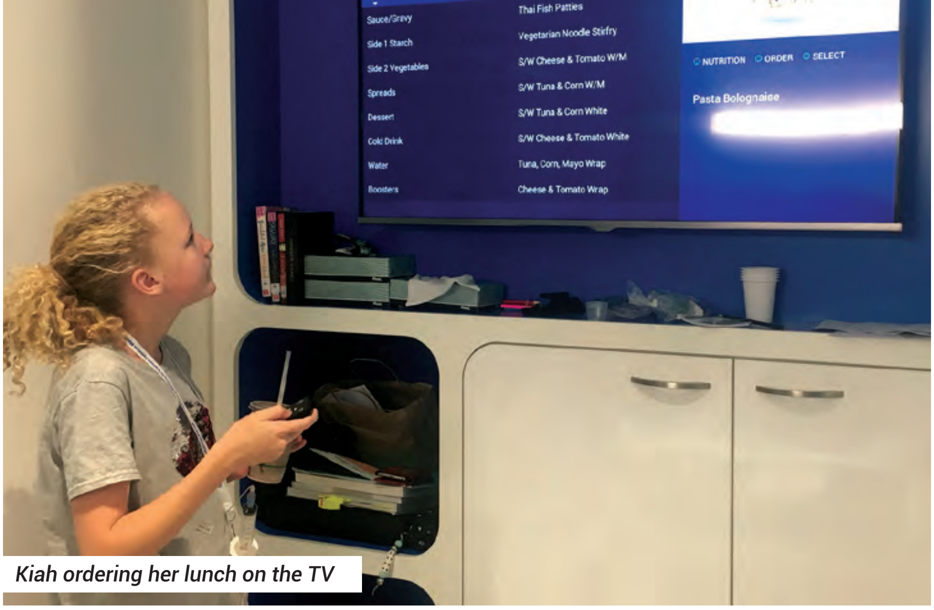
A special group of volunteers helped Fel, our florist, to prepared over 150 beautiful rose posies and bouquets

Hon. John Carey MLA stopped in to buy a rose at Mt Hawthorn Primary School from Ella, one of our junior 65 Roses ambassadors

Hon. Rita Saffioti MLA received a rose bouquet from her colleagues on 65 Roses Day. The Public Transport Authority also took roses to sell in their offices on the day

Some of the ANZ Mandurah team had a quick snap at our rose wall as they picked up their roses to sell

A huge number of volunteers joined us on 65 Roses Day at our Perth CBD stall



Kiah ordering her lunch on the TV

Trilby on the parents bed/lounge

A LITTLE EXCITIMENT WITH THIS ADMISSION!

Perth Children's Hospital (PCH) has officially opened its doors and Cystic Fibrosis WA staff made their first round of weekly patient visits on 14 June. We were able to have a chat with Kiah and her mum Trilby. Kiah was one of the first cystic fibrosis (CF) patients to be admitted.

RED: How has your first admission at PCH been?

Kiah: Good. It's a lot prettier. I think everyone seems a lot happier.

Trilby: It has been great. Everyone here really does seem so much happier.

RED: What can you tell us about the facilities?

Kiah: There are so many cool things around the place. Like the sensory lights on level 4 that change colour when you move. There's also a massive interactive screen on the ground floor and lots of wooden climbing sculptures around- I love the whale shark the best.

The gym is massive and has beautiful views. There is also Livewire and a library where you can actually loan books.

Trilby: It's lovely. There are so many open spaces and big windows and there are plenty of outdoor areas. There are also lots of cafes with great food options. There is a mini cinema and apparently, they are partnering with Event Cinemas, and soon they will be able to show new release movies in there. They also have Wi-Fi now which is great.

RED: What's some of the major differences from Princess Margaret Hospital to PCH?

Kiah: The food is better and there are so many more options for your meals. You actually order all your meals on the TV.

Trilby: It is a lot more comfortable. No more blue recliners! The bed for the parents is much more comfortable, and it also doubles as a couch during the day. There is also a curtain around the 'parents area' so you can have some privacy.

RED: What would you say to kids/ families who will be coming to PCH for their first admission?

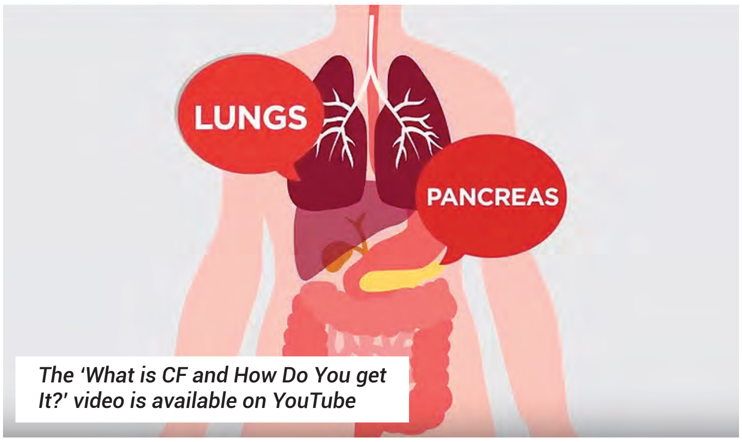
Kiah: It's amazing! It's a happier place to be.

Trilby: It is a much happier place to come. There is lots of beautiful artwork and it's bright and less daunting for new families.

Perth
Children's
Hospital

LOTTERYWEST SUPPORTS CFSMART FOR NEW RESOURCES

We are so excited to share the news that Lotterywest has approved our grant application for developing additional resources for the CFSmart Education Program in 2018.



The 'What is CF and How Do You get It?' video is available on YouTube

Our new poster is available to download from the CFSmart website

There will be a range of new and exciting resources coming soon in late 2018 and early 2019, targeting primary and high school aged children with cystic fibrosis (CF) and their parents and teachers. These include:

Primary School Aged

- 'Starting Primary School with Cystic Fibrosis' booklet with information and tips about sending your child to kindergarten or pre-primary.
- 'Understanding CF' activity booklet for children with CF aged three to six years to assist parents in explaining and answering questions about CF.
- Enzyme stickers and fridge magnets for use at school and home.
- Lesson plans for primary school teachers to teach students about CF.
- Poster encouraging students to cough and sneeze into their elbow.

High School Aged

- 'Starting High School with Cystic Fibrosis' booklet with information and tips about your child transitioning to high school.
- Online interactive magazine for young people with CF aged 13 to 17 years.
- Short videos for young people with CF including:
    - How to take medication discreetly.
    - How to talk to friends/ girlfriend/ boyfriend about CF.
    - How to talk to teachers about CF needs.
    - Coping with CF-related issues that might be embarrassing.

We have already developed the hand hygiene poster and short animation explaining CF.

Hard copies of the poster will be available very soon and are also online at **www.cfsmart.org/teachers/teacher-information-resources/primary-school.**

The short film is available on YouTube, simply search "What is cystic fibrosis and how do you get it?" or the link is **www.youtube.com/watch?v=wx-97TdcgEM**

If you or your child would like to be involved in the development of any of these resources, or would like more information, please contact **education@cfwa.org.au.**

To keep up to date with new CF resources find our CFSmart Facebook page or visit **www.cfsmart.org.**

lotterywest supported

CFsmart
cystic fibrosis education program


Ella visited the volunteers at Telstra on wrapping day and took home 5 big buckets of roses to sell at her primary school


Jayton and brother Patrick came down to check out the new Perth Stadium, lit up red for CF on 65 Roses week!


Jordan shared her story with the Weekend Courier – photo courtesy of Community News

Toby & Melissa spoke to the Hills Gazette – photo courtesy of Community News

CYSTIC FIBROSIS COMMUNITY MEMBERS HELP TO SPREAD AWARENESS THIS MAY

We had tremendous support from our community this 65 Roses month, sharing their stories to raise significant awareness for cystic fibrosis (CF).

We would like to thank the record number of community members who were involved in raising awareness this May month on social media, in newspapers, on the radio and on TV.

The involvement from many different members of our community, ranging from children to adults and siblings to parents, will help the wider community to understand the unique journeys CF families go on and the challenges that they face.

A huge thank you to Lyla and Sam, our 65 Roses Day Junior Ambassadors for 2018. Their smiling faces featured in our media for the month and helped to raise awareness for both CF and 65 Roses Day.


Lyla, one of our junior 65 Roses ambassadors, helped us spread awareness of cystic fibrosis in the lead-up to 65 Roses Day


Sam, one of our junior 65 Roses ambassadors, used his toothy grin to help sell our rose bouquets!


Willow volunteered with mum Bianca at Oceans Keys Shopping Centre – photo courtesy of Community News


Sarah and Fiona spoke with the Western Suburbs Weekly – photo courtesy of Community News

CFWA President Caz Boyd and Australian Netball Diamond Natalie Medhurst

DELIGHTFUL AFTERNOON AT OUR LADIES HIGH TEA

Our Ladies High Tea was held on Saturday 19 May as a way to celebrate and pamper our wonderful community of female carers. We had 52 women including mums, grandmothers, aunties and supportive friends attend the event.

Guests were treated to a lovely afternoon high tea with champagne, games and lots of chatter and laughter filling the room. This important event allows carers to make new support networks and enjoy a fun afternoon of respite.

Thanks to the support of Telstra, we were lucky enough to have special guest and Australian Netball Diamond, Natalie Medhurst, attend the event and address the ladies with a motivating and uplifting presentation.

Cystic Fibrosis WA member and newly appointed president, Caz Boyd, also shared some of her stories growing up with cystic fibrosis and how the times have changed!

More photos from the event can be found on our Facebook page, Cystic Fibrosis WA.

This event was partially supported by Bankwest Easy Grants.

WELCOME CHARLOTTE!

Cystic Fibrosis WA would like to welcome Charlotte Burr as the new Clinical Nurse Specialist for the Department of Respiratory Medicine at Perth Children's Hospital (PCH), who will be taking over the role from Liz Balding.

Recently our Community Nurse, Sharon, sat down with Charlotte to find out a little about who she is and about her new role. Charlotte's passion and energy was inspirational and contagious.

RED: Please tell us about your background in nursing. Where did you train and in which areas have you worked?

I am a Perth local and completed my nursing training at Edith Cowan University. I have worked at Princess Margaret Hospital (PMH) for over 20 years but have also worked in several international and national paediatric tertiary hospitals. The majority of my clinical career has been in paediatric intensive care and in recent years paediatric palliative care. I have been working in the Respiratory Department at PMH over the last few years looking after the complex needs of children with tracheostomies and those that require invasive ventilation to assist them to breathe.

RED: Charlotte, can you tell us a little about you 'the person'.

I am a mum of two beautiful children, one in primary school and one in high school. I am married with a husband who works fly in/fly out on an offshore oil rig and have a scruffy dog called Ted who is spoilt rotten! Between my work, my family and catching up with friends, my life is very full, happy and enriched.

RED: What are your aspirations in your new role as CNS of the Department of Respiratory Medicine?

I feel absolutely privileged to be working in respiratory medicine with such a fabulous and dedicated team of multi-disciplinary health professionals looking after the beautiful children and their families who live with cystic fibrosis (CF). It is such an exciting time to be working in this specialty and I look forward to assisting you as much as I can to live well with CF.

I look forward to working with the amazing team of professionals dedicated to improving the lives of those with CF, getting to know the beautiful children and amazing families and moving to our new home at PCH.

I am really excited to be here. I am passionate and enthusiastic, and I look forward to meeting you soon.

As a reminder, the new PCH Respiratory Department contact details for Charlotte and Ali are:

Email: **PCH.CF@health.wa.gov.au**

Phone: **08 6456 0217**

NEW LUNGS, NEW LIFE!

12 months ago, Fiona's life was very different, but that was before she received 'the call' and was gifted her new lungs. We are fortunate to have met Fiona and her beautiful family and to be able to share the story of her journey with its many challenges, and now, her new chapter!

Life Pre-Double Lung Transplant

RED: How old were you when you were diagnosed with cystic fibrosis (CF)?

I wasn't diagnosed until I was 12 years old. I was initially diagnosed with asthma and was considered one of 'those sickly kids'. When I was 12 I had a severe attack of cholecystitis - gall stones and a badly diseased gall bladder. My chest was also presenting quite badly. So, with my sister having CF, it was finally decided I should be tested further. It turns out I had bronchiectasis and pseudomonas. It was around this same time the CF gene was discovered and gene mapping started, so that's how I was diagnosed.

RED: How was life as a teenager and as a young adult?

From when I was diagnosed I was in hospital at least twice a year. It was pretty tough being diagnosed as a 12-year-old. I really didn't like all the treatment; the physio, the nebulisers and the tablets (although I was very aware of them because of my sister). The household was chaotic in the mornings, fitting treatment

Fiona, husband Joe and son Theo

Fiona and Theo

in for both of us plus the usual business of family life.

I had a lot of infections in Year 11 and Year 12. I was in and out of hospital five or six times each year. This was a difficult time, but fortunately, I went to Perth Modern School, just across from Princess Margaret Hospital, so I could still get to some lessons.

RED: When did your health really start to decline?

I managed fairly well after my rough patch as a teenager. My partner and I always had our own business, so I was able to fit in admissions and intravenous (IV) antibiotics quite well. I was on IV antibiotics two to four times a year. I started to get sicker around 2013 when I was about 35 years old. It was during this time that we had just entered into a surrogacy agreement and we were pregnant! In some ways this was a positive because if I had been sicker earlier we wouldn't have considered surrogacy at all. However, it was difficult getting sicker with a new baby.

RED: When was the prospect of a lung transplant first discussed and what was your reaction?

During the time we were 'pregnant' (through surrogacy) was when I first met the transplant team - although it was an early referral. I knew then it was just a matter of time. I knew lots of people that had had lung transplants, including my sister, who was transplanted 12 years earlier. I felt I was fairly knowledgeable about the process, but it was also really scary knowing how much sicker I would have to get before I was listed.

RED: For how long were you listed before you received 'the call'?

The path to finally getting listed was a long one. I was living in Geraldton and we needed to sell our business and our house and move to Perth before I could be listed. It was all a very stressful process, especially when I was so sick. When I did move to Perth, I was listed for three months before I got the call!

Life Post-Double Lung Transplant

RED: What were your initial thoughts when you woke up after your surgery?

I was pretty high on pain medication, but I definitely wanted that breathing tube out!!! Apart from that I remember thinking, "thank goodness that's over and that now my three-year-old son, Theo, won't remember me being sick all the time". The other thing I thought of immediately was the donor and their family. They were possibly sitting here in the Intensive Care Unit just a couple of days ago and now they've saved my life. It's hard to get your head around.

RED: Was life very different from the start or did it take some time to feel the benefits of your new lungs?

I had a lot of complications post-transplant. The recovery was gradual and very difficult, but the big difference was, once I got better this time that was it, it was for good!! I wasn't going to get better and then get sick again a few weeks later. My new lungs were pretty good after a few setbacks - the rest of my body was more of a challenge and took its time to catch up.

RED: What are some of the things you can do now that you weren't able to do 12 months ago?

EVERYTHING!!

The biggest benefit is I am back in my own home. We had to move back in with my parents - I was just too sick to look after a household and my family. I couldn't even read a full book to my little boy. Now I can play with him and do the school drop-offs and pick-ups. Every single thing was so difficult before and now I just do things with ease.

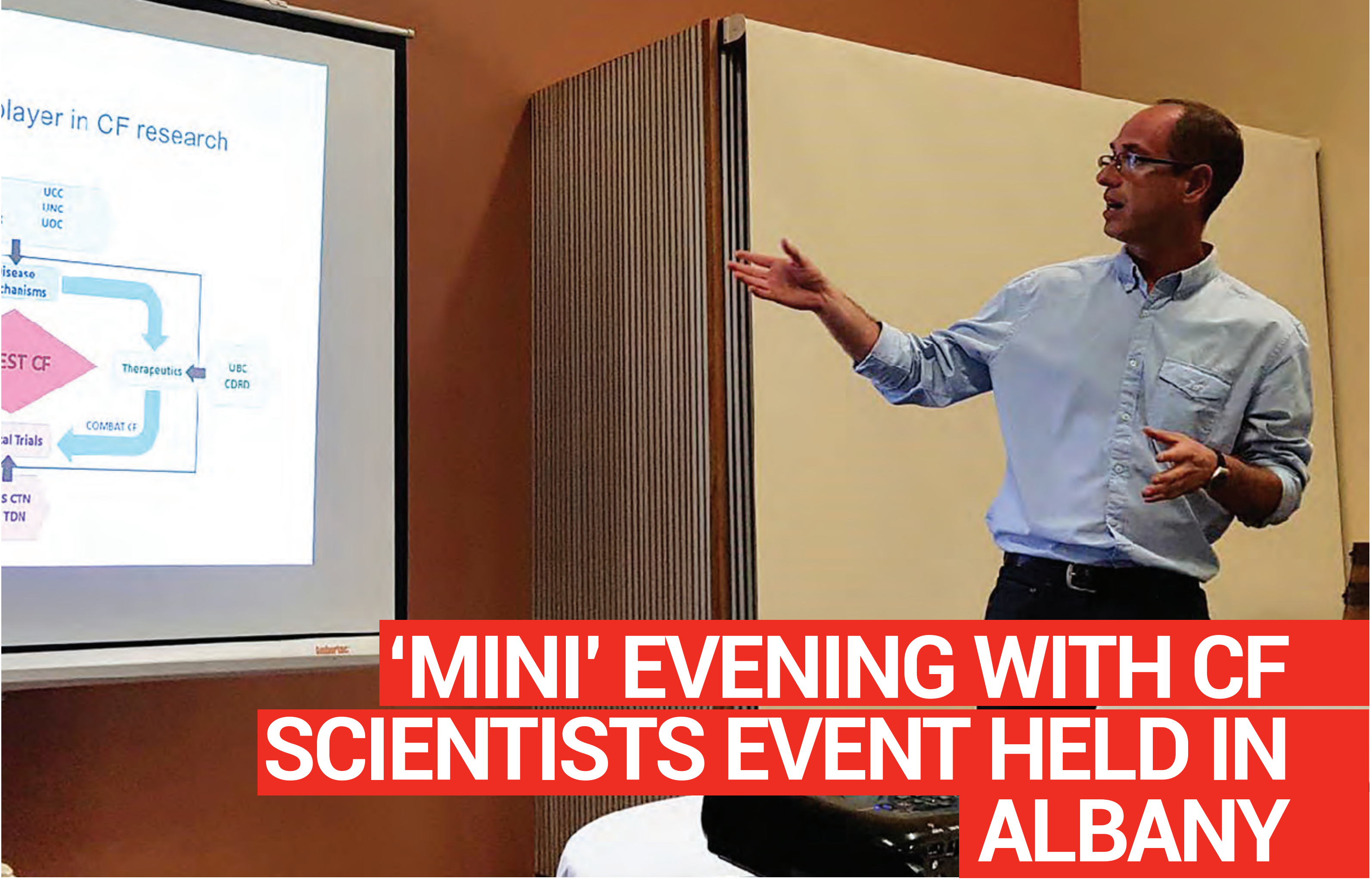
RED: How would you describe your life now?

My life now is so full. Before I was just existing. Now I have a future, I have plans, even if it's just to go down to the shops for the afternoon. I just can't wait to experience each day of my life.

RED: What would you say to someone who is currently indecisive about the prospect of a double lung transplant if it was offered to them?

Without a transplant I would have died. My life was so difficult, there really wasn't any choice. I wanted the chance to be here for my son, my husband and my family. Without pain there is no gain. I had a huge amount of pain, but the gain is a million times greater. To experience life like this after so many years like that.... it's AMAZING!

You just have to be prepared, ready to work hard, do what the team expect of you (even if you think you don't need to) and try and have a positive attitude. It's worth it!



‘MINI’ EVENING WITH CF SCIENTISTS EVENT HELD IN ALBANY

In April, Cystic Fibrosis WA (CFWA) facilitated our second annual ‘mini’ Evening with CF Scientists event with the Telethon Kids Institute (TKI).

Our first ‘mini’ Evening with CF Scientists was held in Bunbury back in July last year, and the event was such a success we decided to host another one. The evening included an overview of research being undertaken at TKI, a rundown of CFWA services, a sit-down dinner and the opportunity to catch up with other regional families and CFWA staff.

Our guest speaker was Oded Breuer, who is a Paediatric Respiratory Physician at the Hadassah Hebrew University Medical Centre in Jerusalem, Israel, and is currently working out of TKI. Oded arrived in Perth as an honorary research fellow supported by a Lowy Foundation Paediatric Fellowship arranged by AUSiMED (Australia/Israel Medical Research), in order to establish and lead the DEFEND CF study.

Oded’s main research interests are early lung infections and strategies to improve lung function decline in patients with cystic fibrosis (CF), as well as research in general paediatric respiratory medicine.

During his presentation, Oded focussed on these three areas:

- Personalised medicine: Updates from global clinical trials and emerging pharmaceuticals including Tezacaftor®, a new triple-combination therapy.
- AREST CF (Australian Respiratory Early Surveillance Team for Cystic Fibrosis): Understanding disease origin, predicting long term outcomes.
- DEFEND CF: Study initiation for children and young teens investigating why, despite the delayed onset of lung function decline, the rate of lung function decline remains the same.

The audience were rivetted and obviously enjoyed the opportunity to hear about all the positive developments in local and global research. It is wonderful to be able to bring more events like this to our regional members, thanks to funding from Telethon.

Here is some feedback from those who attended:

- “It met and exceeded my expectation. Thoroughly enjoyable and informative presentation”.
- “I would definitely like more of these types of events as it allows us to keep more up-to-date and informed of where CF research is at”.
- “We found Oded and the evening very informative”.
- “Every bit of information to share and spread to the community is going to be helpful for CF sufferers”.
- “Presentation by Oded was interesting and most informative. His presentation and slide show explained the whole spectrum and various degrees of CF very clearly”.
- “From a volunteer and grandparent perspective, I thoroughly enjoyed the whole evenings event and thought everyone from the foundation spoke really well. It gives families, carers and people living with CF hope”.

For more information about trials available at TKI, please contact Kaye Winfield on **Kaye.Winfiled@telethonkids.org.au** or **08 9489 7818.**

AN EVENING WITH CF SCIENTISTS

Thanks to some very special people like the Stan Perron Charitable Trust, our very own patron, John Rothwell, the Allingame and McCusker families, Conquer Cystic Fibrosis, the Australian Cystic Fibrosis Research Trust (ACFRT) and the Cystic Fibrosis WA (CFWA) Golf Committee and other donors, CFWA have been able to invest heavily in cystic fibrosis (CF) research over the years.

Medical research is often referred to as a marathon not a sprint. This might explain why often monies raised by charities for medical research can seem to disappear down a bottomless pit and one's left wondering what has been achieved. It's not that scientists are wasting time and money but let's face it, many researchers are not very good when it comes to "show and tell" to the general public.

This makes an Evening with CF Scientists all the more important. It's the time when the best minds in WA present their results to members and bring hope and excitement to the CF community. Such has been the popularity of our Evening with CF Scientists, that it was taken on a road show to Bunbury last year and Albany this year. There is also a plan to repeat this in the Southwest later in 2018.

At the Perth event held at TKI in May, sponsored in part by WAFEX and Capel Vale, we had over 100 people attend. That's a record turn-out of parents and carers, and they were not disappointed.

Presenters on the evening included:

Oded Breuer, a Paediatric Respiratory Physician from Israel who leads the DEFEND-CF study focussed on reducing the rate of lung function decline.

CFWA Hardie Foundation Top-Up Scholar Samuel Montgomery, who talked about how airways responded to hypoxia and viral infection and the mechanisms that result in inflammation.

Dr Jacinta Francis who talked about her work on the social and emotional health of young people and their families and the CyFi Space Study: An Innovative Smartphone Application to Support Social Connectedness and Wellbeing in Young People Living with CF.

Elise Orange, a participant in the innovative CF Consumer Reference Group, who talked on the importance of ensuring a strong linkage between consumers and research.

CFWA Golf Classic Top-up Scholar Clara Mok who talked about her research which aims to characterise an important feature on chest CT scans of children with CF, known as 'trapped air,' using specialist image analysis techniques.

CFWA's very own Services Manager, Kathryn Pekin, who presented a section on health literacy and demonstrated the world-wide reach of CFWA's educational resources.

The evening was wrapped up by Professor Stephen Stick, the lead clinician in the AREST CF team. Steve explained that this group of researchers were responsible for a paradigm shift from an approach based on amelioration of respiratory disease, to one focussed on prevention of bronchiectasis, the major cause of morbidity and mortality in CF.

Importantly, much of the research being undertaken by the AREST CF team is directly translatable into the clinic. Utilising the Telethon Kids Institute's (TKI) new adaptive platform trial starting early next year, will mean the very best treatments for people living with CF will be fast tracked from the laboratory to the patients.

According to the latest impact report from TKI, Dr André Schultz believes that the adaptive platform trial will revolutionise the treatment of CF by comparing multiple treatments against each other at the same time. This is a very different approach to the traditional randomised controlled clinical trials which would take decades to provide the same information.

TKI researcher Anthony, CFWA CEO Nigel Barker and Professor Stephen Stick

TKI researchers Kim and Kelly

CFWA members Justin, Sharon and Kat with Lisa Bennett (centre right) from TKI

Dr Schultz' trial is attracting world-wide attention and the relatively modest seed funding provided by one of CFWA's generous donors, has been used to win $3.4m over five years from the Government of Australia's Medical Research Future Fund.

There is little doubt that Perth is well and truly on the international stage when it comes to CF research and in August next year we will be hosting the 13th International Australasian CF Conference at Crown. Unlike many medial conferences which restrict participation to health professionals, there will be a huge two day lay program where the same international speakers from the medical program will present to a lay audience in advance of the more technical presentations to their peers.

Of course, you're all invited.

WHY I'M PART OF THE CHILD AND ADOLESCENT CF CONSUMER REFERENCE GROUP OF WA

Elise Orange is a clinical psychologist, a mum of two young girls and has an older sister with cystic fibrosis (CF). Elise has been involved in the CF community for many years, supporting her sister. During the Evening with CF Scientists event, Elise provided an amazing, heart-warming and informative presentation about her involvement with the Consumer Reference Group of WA and why it's a worthwhile group to be part of.

"Thanks for having me here tonight. It is exciting to see all the different opportunities and advances currently being pursued in the research and treatment of CF. I am representing the Consumer Group tonight and I am looking forward to talking about who we are, what we do and why we do it.

Who is in the consumer group?

The group is made up of people who are quite different but who have one thing in common; their lives are impacted by CF. Many members of the group are parents of children with CF, but we also have an adult who lives with CF and I attend because I have an adult sister who has CF. One of the really important and useful features of the group is that it is also attended by Ali Stone (CF Clinical Nurse) and Dr André Schultz, who provide treatment through Perth Children's Hospital (PCH). We are also fortunate that Kathryn Pekin from Cystic Fibrosis WA attends, and she supports us in reaching the wider CF community, as well as talking through what has worked in the past and what is currently available to support families in the CF community.

The group wouldn't be possible without TKI, who not only conduct the research, they host and provide all the important logistics and administrative infrastructure to support community groups like this to move from a talk fest to actual action and outcomes, so thanks Kaye Winfield (research coordinator at TKI).

What do they do?

Our group meets four times a year for two hours. It doesn't sound like much, but we jam a lot of content into those meetings. Sometimes we have to finish without finalising everything we planned to talk about, but what we do get through is important. We hear about, and then provide feedback, on a wide variety of issues and opportunities. Most of the projects here are presented to the group first and we try and consider the impact of the research planned and how it can be undertaken in ways that are going to have the most positive impact on families and individuals in the CF community.

Elise (left) and her sister Ingrid

Members have enjoyed hearing about a wide variety of projects across the spectrum of research, from surfing to airway epithelia. When asked, members recall participation in the Circle of Care and the Beat CF projects as highlights, but really, we have been so fortunate to hear about a broad range of important projects.

If you are a medico or a researcher here tonight, I want to pause and tell you that you are our super heroes. You get up in the morning and you put your undies on under your tights, but don't doubt that the work you do has changed the world.

As well as getting a sneak peek into what is in the future for the treatment of CF, we also discuss current clinical issues for families accessing clinics and inpatients through PCH. We hear from the hospital about issues like infection control and programs like KKind (Keeping Kids in No Distress) which support the psychological health of children. We talk about the day-to-day living stuff. We talk about important medical concerns and about what is hard in accessing supports and treatment when you are family, or an individual impacted by CF. This is information only we have.

Why we do it?

And this is why we do what we do. My sister is older than me, so I don't have any memories of life without CF. My sister's health and treatment share the patchwork of childhood memories alongside family celebrations, dentist appointments, school assemblies and TV ad jingles. Although I am sure most of you are probably really excited about moving from Princess Margaret Hospital (PMH) over to PCH, I will admit to a bit of nostalgia. I visited this hospital every three months of my childhood for my sister's clinic visits. I came here more often than the homes of some of my country cousins, and Dr Des Gurry was as much a part of my family's story as my Uncle Gerrard who lives in Victoria and was once on the Wheel of Fortune. Des is gone now but his name lives on in my memory. As an adult I understand that he and his colleagues kept my sister alive and well but as a child he was just the kind man who we visited at the hospital.

This is the lived experience of families with CF. We hold special knowledge that professionals in the field can't share. We live the day in day out, knowing what loss of lung function looks, sounds and feels like. Not just a change in cough, but the tiredness, the lack of motivation, the fear, the worry; is it bad enough to call the clinic? We know how powerless it feels to hand the care of a loved one to someone else. Someone who doesn't know that the smell of eggs is enough to make her dry retch, but she will eat smelly soft cheese and pâté under water.

As families, we know that while treatment regimes can look straight forward on paper, in practice they don't consider that no three-year-old ever wants to do anything they are told. Ever. They don't consider that teenagers are aliens who inhabit the bodies of living humans and turn them into unknowable mysteries. As families we know that hospitals and staff care for health, but that being well is not just about lung function and weight gain. It is about feeling safe on the first day of school and having a part in the school play and going for sleep overs and dealing with boyfriend angst and finding a group of friends at uni and getting a job you can keep even if you have to have time off to go to hospital. I recall that when she was well my teenage sister could yell "don't touch my stuff" very loudly! She wasn't much quieter even when unwell.

Hospitals care for our health, but families heal us, and that healing comes from a knowing that a medical professional cannot share.

We are enormously privileged to have a world class hospital that works alongside a world class research facility to provide world class health care for families. The people who work in clinical care and research around CF in Perth know so much and they are learning more every day.

But they don't know what we know. So, we, at the TKI CF Consumer Reference Group meet with them. And we tell them. We ask questions about their research and we ask the questions they have never thought of and that drives their research.

That is why the Consumer Group exists. It is a privilege and a responsibility. It takes time and energy, but research can change the world and we can help.

When my sister was born, my parents were told that she would be short of stature and of lifespan. She is now a little under six feet and a little over forty and going strong. Research changed the world she was born into.

If you are wondering about my sister, she works here at TKI. She is one of the superheros. Her name is published around the world and she is changing the world. She still gets annoyed if I touch her stuff without asking and unless she is dressing up to play with my girls she usually wears her undies under her tights. But don't ever doubt she is a super hero and together we are changing the world".

For more information about the TKI Consumer Group, you can contact Kaye Winfield at **Kaye.Winfiled@telethonkids.org.au** or **08 9489 7818**. The group is particularly keen to have some dads involved.

65 ROSES PARTNERSHIPS BLOOMING

We'd like to thank our generous 65 Roses 2018 partners, who helped us paint WA with roses for people with cystic fibrosis (CF) this May.

65 Roses Day is a huge undertaking that wouldn't be possible without the help of our generous supporters. This year, we partnered with four special organisations to help us improve the event and borrow some of their expertise! This invaluable support helped us grow 65 Roses Day to a whopping 15,000 roses around WA.

Thank you. Your generous support has enabled us to continue to spread vital awareness and essential funds for WA families living with CF.

WAFEX

There would be no 65 Roses Day without roses! Thank you to WAFEX, our long-term supporter who supplied the thousands of fresh, colourful roses and joined us throughout the day on the streets of Perth to sell them. They ensured the roses were sourced and delivered nice and fresh on Thursday morning for our wrapping volunteers, coordinated with couriers for our regional locations and a couple of the staff even hopped on the spin bikes for the Vault Fitness 65 Roses Challenge on the day!

www.wafex.com.au

South Metropolitan (SM) TAFE

The SM TAFE Bentley Campus have partnered with us for many years now to help run our shopping centre and Perth CBD stalls. They also supported our busy rose wrapping day, helping with event logistics.

This crucial volunteer work completed by the students gave them valuable real-world event experience and helped us spread our 65 Roses stalls to 35 locations around Perth in 2018; the perfect partnership!

www.southmetrotafe.wa.edu.au

Telstra

Joining us as a major event partner again in 2018, Telstra volunteers wrapped thousands of roses in their state office and sold them from Telstra stores around WA on the day. This amazing support extended the reach and awareness of CF around the Perth metro area, with 18 Telstra stores selling roses with the help of their volunteers.

www.telstra.com.au

Iris Residential

We welcomed Iris Residential as a major supporter in 2018. Their generous support this year helped us extend our valuable awareness and fundraising. In addition to financial support, they placed a beautiful rose and iris display in their Amara City Gardens Development showroom to spread awareness of CF.

www.irisresidential.com.au

If your organisation is interested in partnering with us for 65 Roses Day or one of our services programs, please get in touch with Karen at **marketing@cfwa.org.au** or on **08 6457 7333.**


WAFEX team at the CBD stall


Telstra team


TAFE students at the CBD Stall


TAFE students on wrapping day

65 ROSES DAY IN THE REGIONS

Community spirit was blooming in the regions in support of 65 Roses Day

Albany volunteers ready for rose wrapping!

65 Roses Day in the regions has an added challenge. Roses can't be shipped by the bucket, neatly in sleeves and ready to sell. Roll out our fabulous regional volunteers and supporters, who take responsibility of our roses from the moment WAFEX drops them to our wonderful transport supporters.

Thanks to Great Southern Express, South West Express, Kalbarri Carriers, Freightlines Group Geraldton and Western Independent Foods, roses were dropped to Albany, Bunbury, Geraldton, Denham, Manjimup and Augusta. These trucking companies come on board each year, providing complimentary delivery of our roses. In Albany, this included door-to-door service with John from Great Southern Express pulling up to the Albany Bowls Club with his prime mover to drop 1,500 roses to our fantastic community volunteers, where they were wrapped and prepared for sale.

Headed up by cystic fibrosis (CF) grandmother Lorraine, CF mums Zoe and Simone and local volunteer Anne, the team set about preparing the roses for delivery of pre orders and to supply shopping centre stalls at Albany Plaza and Chester Pass Mall.

The Albany team achieved record rose sales and saw prepared roses travelling as far as Gnowangerup. At the time, Albany and surrounds was gripped by some of the worst bush fires ever to affect the region and our volunteers' efforts are a testament to their commitment and energy.

In Bunbury, for the second year, the office of the Hon. Adele Farina MLC coordinated staff to wrap and sell hundreds of roses around their town. They sold their roses to local organisations and at Bunbury Forum on 65 Roses Day.

The North and Chitty families in Northam and York ferry their roses direct from rose

Hon. Adele Farina MLC at the Bunbury Forum stall

The Norrish team from York

wrapping day at the Niche. Once their stock is wrapped, they head east ready for selling on Friday at various supporting organisations such as Westpac York, York Quality Butchers and Northam Boulevarde.

CF adult and mum, Brooke Murphy hosted a 65 Shades of Purple fundraiser in Manjimup, along with wrapping and selling roses for 65 Roses Day. With the support of family and friends, Brooke's fundraising totalled $7,940 for Cystic Fibrosis WA (CFWA).

This year's new regional location for rose sales has a nautical edge. South West Express' final delivery was to the Leeuwin Lighthouse where local, Cynthia, wrapped and sold some of the roses, and delivered the rest to Café Boranup and Jewel Cave Café to sell.

Geraldton family, the laria's, are regulars for rose deliveries. In addition, one of the local basketball teams, the Geraldton Buccaneers, sported our red CF lungs shirts for their warm up. Thanks also to Sadleirs for the priority delivery of these very special shirts in support of this fundraiser.

Our most complicated delivery heads to Denham. The Oakleys, another long-term supporter of 65 Roses Day, collect their roses from the Shark Bay IGA on the morning of 65 Roses Day, following the tag team delivery by Kalbarri Transport and Western Independent Foods. The local Shark Bay Youth group supported 65 Roses Day in Denham by hosting a cycle challenge and selling yummy cupcakes, raising over $380 to add to the areas fundraising efforts.

For all our regional communities, the opportunity to raise awareness about CF is vitally important and 65 Roses Day provides a wonderful way to engage with local businesses and families. All our fundraisers have told us how supportive their local community has been in participating in 65 Roses Day 2018. At CFWA we extend our thanks to our fundraising families, and their local communities.


After the golf, supporters and guests enjoy an elegant 3-course meal and entertainment at the clubhouse.


Heath and Hayley Gillard. Heath is the chairman of the 2018 Cystic Fibrosis Golf Classic


Corporate teams enjoy a friendly game of golf at the prestigious Lake Karrinyup Country Club on the day


Lyla Gillard (centre) with George Jones (centre left), naming rights sponsors for the Cystic Fibrosis Golf Classic

CYSTIC FIBROSIS GOLF CLASSIC

The Gillard family have been an important part of the volunteer organising committee for the Cystic Fibrosis Golf Classic for many years. We had a chat to Hayley Gillard about this year's event.

RED: How did you first get involved in the organisation of the Cystic Fibrosis Golf Classic?

Brad Coutts, former chair of the Golf Classic, put a message in Cystic Fibrosis WA's (CFWA) E-newsletter and asked if there was anyone that had any connections with golf clubs that were interested in starting up a golf fundraiser.

My husband and his family had been members of Lake Karrinyup Country Club for over 30 years. So, I spoke to my mother in Law, Di, and mentioned it. Straight away she said, "yes let's get on to this!". It was a no brainer, it all seemed like it was meant to happen.

RED: What part of organising the event do you find the most challenging?

The challenges have changed over the past eight years. At first, getting corporate sponsors was really a struggle. Trying to get across that this was going to be an awesome event is hard when you have no back history. But after the first couple of years we had started to get sponsors that wanted to come back, as it is such a premium, well-organised event.

Now one of our most challenging parts is getting donations for our live and silent auctions for the evening. We have some very generous people donate some amazing auction items; from luxury holidays, diamond rings, paintings, bikes, sporting memorabilia, the list is endless. But this takes hard work to get and we are only a small team and we often are asking the same people.

We are just one of many organisations asking for donations and often I think cystic fibrosis (CF) is not given the same level of importance compared to other charities that are household names.

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

You just need to have a vision of what you are trying to achieve, it doesn't have to be on a grand scale. As parents of a daughter with CF, a cure is out of our control, but raising money and awareness is not. We need to do this for our children, no matter how big or small, every effort helps.

RED: How can people in the CF community help you make this event a success?

If you have your own business or are in a business that you think might be interested in bringing a corporate team to our events, just contact us and we can provide all the information.

We are also looking for any donations of goods or services for use in our live and silent auctions. Again, it doesn't matter how big or small, we appreciate everything. We are doing this for all our children.

RED: What have the funds raised from the Golf Classic achieved?

We are very proud that funds raised from the Cystic Fibrosis Golf Classic have funded two PhD Top Up Scholarships looking at psycho-social research and gene therapy, and contributed over $500,000 to CF research and services for people living with CF.

All research programs are fully assessed by an independent scientific advisory committee to make sure we get the very best bang for our buck. A lot of this research is currently being undertaken right here in WA by the AREST CF team at Telethon Kids Institute. This research forms part of the CF Federation's Little Lungs Big Futures fundraising campaign, a campaign which originated here in WA and has already raised a staggering $2.6m.

Golf Classic Event Details

Date: 2 November 2018

Location: Lake Karrinyup Country Club

Registrations are now open for the 2018 George Jones Family Foundation Golf Classic supporting Cystic Fibrosis WA.

Register a team now for a wonderful day out with a professional golf demonstration and a friendly game of Ambrose golf on the beautiful course, followed by an elegant three-course dinner at the club house.

The volunteer organising committee appreciate any donations of goods or services that would be suitable to use in the auctions or as raffle prizes on the night.

For more information and to register visit **www.cfwa.org.au/golf** or get in touch with Marnie at **events@cfwa.org.au** or on **08 6457 7333.**

SANDIE'S LIFE IS EASIER WITH TELEHEALTH

Sandie Smith's life is constantly interrupted with medical issues and specialist appointments, because she lives with cystic fibrosis (CF).

SCGH clinic staff Jamie Wood and Dr Siobhain Mulrennan with CF patient Sandie

Since her diagnosis 12 years ago, the Albany mum has had constant trips to Perth to see medical specialists, but in recent years her life has become easier thanks to the availability of telehealth.

Healthcare delivered closer to home is under the spotlight this week as part of Telehealth Awareness Week, 25–29 June. The week has been organised by the WA Country Health Service and its service partners to highlight that healthcare appointments delivered by telehealth are now widely available to country patients, without the stress and cost of travel.

In years gone by, Sandie would regularly have to take several days off work and spend days organising paperwork in order to see her specialist team in Perth – but now she uses her lunch break to pop into Albany Health Campus where she holds a videoconference with the Adult Cystic Fibrosis Service at Sir Charles Gairdner Hospital (SCGH).

“Having constant medical appointments in Perth just cripples your life. Using telehealth really allows you to get on with your life. Now I can do my lung test at Albany Health Campus and the specialist team in Perth have my results by the time I have my telehealth appointment,” she said.

SCGH senior physiotherapist Jamie Wood said the CF clinic started using telehealth because patients were so tired of traveling that they simply didn’t attend clinics the four times a year that is required to keep on top of their condition.

Jamie said people with CF lived with a life-long condition and it was essential they attended regular appointments with their specialist team, to maintain their health. He said not attending appointments could impact on their clinical outcomes, as well as their productivity.

“With telehealth, we can offer more patient-centred care, and can actually meet the clinical and the social needs of our patients. Luckily WA has great telehealth infrastructure and we have been able to connect with our patients without making them travel away from work and family.”

Telehealth Awareness Week includes the launch of a 1300 number for telehealth inquiries, a state-wide regional advertising and social media campaign, new information materials for patients and healthcare professionals, and displays in hospitals and health centres across the state.

People can enquire about having an appointment by telehealth by asking their health professional or calling **1300 367 166**.

More information about telehealth is available at **www.healthywa.wa.gov.au/telehealth**

Do you have a good telehealth story? Share it on your favourite social media channel with the hashtag **#telehealthwa** or on **www.patientopinion.org.au.**

Fact File

- Telehealth saved WA country patients from travelling 27.3 million kilometres in 2017 – that’s about 12,500 return trips across the Nullarbor, or 35 trips to the moon and back.
- About 350 outpatient appointments are delivered every week by telehealth at more than 150 telehealth-enabled sites across WA.
- In 2017, there were more than 18,000 outpatient consultations by telehealth across country WA, a one-third increase on 2016.
- More than 30 outpatient specialties delivered via telehealth are now available closer to home for country people. The top five in 2017 were plastic surgery, respiratory medicine, haematology, orthopaedics and gastroenterology.
- Health services delivered by telehealth include emergency care, cancer treatment, palliative care, mental health, stroke emergency treatment and rehabilitation, surgical follow-up and education for chronic conditions such as diabetes and asthma.

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 two articles on eradication of Pseudomonas and effectiveness of Ivacaftor, were published in April 2018.

ERADICATION OF EARLY P. AERUGINOSA INFECTION IN CHILDREN

Authors: Felix Ratjena, Alexander Moellerb, Martha L. McKinneyc, Irina Asherovad, Nipa Alone, Robert Maykutf, Gerhild Angyalosig, EARLY study group[†]

What was your research question?

How effective is inhaled tobramycin solution (TOBI) in treating lung infections due to Pseudomonas aeruginosa (Pa) in young children, between the ages of three months and seven years.

Why is this important?

Pa is a bacterium, which is known to cause significant lung damage in individuals with CF. Various antibiotic treatment regimens are used in an attempt to eradicate infection early on and avoid chronic colonisation. While inhaled antibiotics are used, it is unclear as to how effective they are in treating early infections in children at this young age.

What did you do?

In a clinical study we have enrolled children between the ages of three months and up to seven years of age with a positive culture for Pa. Patients received either TOBI or placebo for the first 28-days. Following the 28 days, patients who still cultured Pa received TOBI. Patients who did not have a positive culture for Pa at Day 28 could choose whether they wanted to receive study medication for an additional 28-Days or not. Patients who cleared the infection were followed for 12 months after the study to track their cultures. If another positive culture was reported, the patients received an additional 28-days of TOBI.

What did you find?

Patients with an early PA infection that is treated shortly after the bacterium is detected, had more positive outcomes using TOBI, than the patients whose treatment was postponed for a few weeks.

What does this mean and reasons for caution?

Our study has shown that early treatment of patients with Pa infection with TOBI can be effective in clearing the infection. The study has further found that earlier treatment might be better than delaying inhaled antibiotic therapy. However, the study was completed within a small number of patients (n=51) and the study design was complicated.

What's next?

We hope that this new information will be useful for physicians as they decide how to treat early Pa infections, leading to more success in treating young children with CF.

Original manuscript citation in PubMed:

www.sciencedirect.com/science/article/pii/S1569199318300870

EFFECTIVENESS OF IVACAFTOR IN CYSTIC FIBROSIS PATIENTS WITH NON-G551D GATING MUTATIONS

Authors: Jennifer Guimbellot, George M. Solomon, Arthur Baines, Sonya L. Heltshe, Jill VanDalfsen, Elizabeth Joseloff, Scott D. Sagel, Steven M. Rowe, On behalf of the GOALe Investigators

What was your research question?

Is the cystic fibrosis (CF) drug Ivacaftor helpful in adults and children with CF, who have a gating mutation similar to the most common gating mutation G551D?

Why is this important?

We know that Ivacaftor is very effective for adults and children who have the CFTR mutation G551D. People with mutations that are similar to G551D, called "gating" mutations, should also respond well to this drug. As there are fewer patients with non-G551D gating mutations, clinical trials to study whether the drug is safe and effective in these patients are difficult to do. More clinical studies to observe these patients over time will help us to be sure the drug is effective.

What did you do?

People (n=21) over six years of age, who had one of these rare non-G551D gating mutations (e.g. S549N, G178R, S1251N) and were already taking Ivacaftor were enrolled in an observational trial. During this trial we monitored them to see if they had improvements in lung function, growth, sweat chloride, quality of life, isolation of Pseudomonas aeruginosa (Pa), and rates of hospitalisation while taking Ivacaftor.

What did you find?

We found that the children and adults with CF enrolled in this study over six months had significant improvements in lung function (as measured by spirometry), sweat chloride, weight, and quality of life with Ivacaftor use. We also found a trend toward lower rates of hospitalisation and isolation of Pa; however, these effects, while important, were not statistically significant (i.e. we could not tell if these were really due to the treatment or just a random variation).

What does this mean and reasons for caution?

Ivacaftor should continue to be used in children and adults over age six years who have a non-G551D gating mutation. Our study was limited because of how few patients were enrolled, due to the rare mutations studied. In addition, this was not a randomised controlled trial, so there was no comparison to patients who did not take Ivacaftor, and it was not "blinded", meaning that all patients we studied knew they were taking the drug, which could influence the subjective reports of improvement, especially in improvement of symptoms. These limitations may influence our findings.

What's next?

We will continue to study Ivacaftor in this population, as well as younger children and people with other types of mutations, to be sure that Ivacaftor continues to be the best and most effective drug for these particular patients.

Original manuscript citation in PubMed:

www.ncbi.nlm.nih.gov/pubmed/?term=Effectiveness+of+ivacaftor+in+cystic+fibrosis+Patients+with+non-G551D+gating+mutations

MAY MONTH FUNDRAISING CHAMPIONS!

We had so many people participate in awareness and fundraising during May and would like to thank everyone who hosted a community awareness and fundraising event this 65 Roses month!

Brooke, an adult living with cystic fibrosis (CF), organised a big event in her regional community of Manjimup on 65 Roses Day and raised $7,940. The event, hosted at the Deanmill Workers Club, attracted over 100 people and included raffles, auctions, marron races, rose sales and a live performance from Velvet Edge. Thank you to Brooke and the generous Manjimup community for your support!

Kate, the mum of a young boy with CF, raised over $4,256 by hosting several 'Serve It Up' dinner parties during May. She invited guests to a lovely meal at home and asked them to donate what they would have paid for a night out. Thanks Kate!

We also had a lot of schools get involved in awareness raising during May month, including Wembley PS, Hale PS, St Mary's PS, Mt Hawthorn PS, Swan Christian College, Quintilian PS and more! With the help of one of our CF community members, Narelle and her family, Swanbourne Primary School took on 65 Roses Day and ordered 22 posies, 22 bouquets and hundreds of individual roses, raising over $2,690!

Brothers Ben (front left) and Dylan (front right) and mum Karen (far right) joining in on the 65 Roses Spin Challenge.

65 ROSES SPIN CHALLENGE

For Vault Fitness and Exchange Tower management and tenants, the fourth 65 Roses Spin Challenge for cystic fibrosis (CF) was the biggest yet.

Running over two days in 2018, the team took their challenge to a new level. The team from Vault and Exchange Tower, enlisted 320 riders, mostly tenants of the building, for the challenge.

The strong Vault Fitness health, wellness and community focus resulted in new teams from other office towers taking on the 2018 challenge. For the first time we had a Cystic Fibrosis WA (CFWA) team including staff member Karen, some of the WAFEX crew and CFWA members, the Coopers, join the spin for a session on 65 Roses Day.

Event organiser, Todd Guthridge, put in a gruelling eight-hour stint on both days, clocking up 412.7kms. And, as if this wasn't enough, he was coach and champion for the ride for every team as they rode their session. Glen Mesch and Perpetual Services sponsored Todd for his ride with a generous $1,500 donation, and Glen also rode alongside Todd for most of the time on the bike.

Clayton, from Vault Fitness, was the task master, starting each session and keeping the stats on team achievement, told us "What an amazing two days it was. We had so much fun and the feedback from those that rode has been amazing and they are all looking forward to the next one."

Engagement in Exchange Tower was a team effort. Special thanks to Filipa and Chris for working with the Vault team to get as many tenants on board as possible. Fundraising included a spin challenge fundraising page, Little Angel coffee donations, rose sales and donations through collection tins and a pay-wave machine.

The event finale was a presentation of awards, with Chris Whincop, representing building owners, AMP and Prime West, announcing a sensational matched giving amount of $10,000. The final figure was a fantastic result with over $22,000 raised to support people living with CF in WA.

CFWA and the event organisers would like to thank; Lalla Rookh, Andaluz Bar and Tapas, Sentinel Bar, Little Angel, Old Bridge Cellars and Westwinds Gin who all donated towards the prizes for winning teams.

Special mentions also for Patersons Securities, Built Pty Ltd and Knight Frank Australia Pty Ltd who all donated on behalf of their staff. Tom and Dan Bahen, Andrew Mckenzie of Euroz Securities Limited and Katana Asset Management Ltd who also made generous donations.

Watch out for the 2019 65 Roses Spin for CF with Vault and Exchange Tower already in planning mode for another event.

CYSTIC FIBROSIS GOLDFIELDS 65 ROSES CHALLENGE

With determination, passion and the help of a generous community of supporters, the cystic fibrosis (CF) Goldfields group smashed their fundraising target four times over and raised a total of $15,000!

The CF Goldfields group have been supporters of 65 Roses month for a long time now, helping to raise significant awareness and funds in the Goldfields of Western Australia. This year they wanted to do something different and decided on attempting a big 65 Roses Challenge, walking the Cape to Cape in WA's South West.

The group, made up of friends of family who have a connection to someone living with CF, began fundraising and training in April. Members of the group, Peggy Grimm and Jennifer Thompson, said "Our original goal was to double last year's fundraising, which was a modest $600. We surpassed our first target of $1,500 within a week." They increased their target three times before hitting their final fundraising total of over $15,000 at the start of June!

Jennifer and her brother Rick Grzyb walked the Cape to Cape in a week, beginning at Cape Naturaliste and ending at Cape Leeuwin Lighthouse. Then Peggy and her father Wilf Lynch started their walk following in the same path only a week later. Together the two teams walked a combined 270km over 14 days.

Peggy and Jennifer said, "We were able to talk to other hikers and tourists along the way and tell them about the incredible services and support Cystic Fibrosis WA offer CF affected families throughout the state". Peggy also gave out handcrafted felt roses and an information card about CF to take with them, spreading awareness every step of the way.

The CF Goldfields group would like to thank their families for their support, as well as Evolution Mining Mungari Operations, Robert Grimm, Stuart Tonkin (Northern Star), Sara Young and Phil Yates (Versatile Plant Hire & Contracting) for their contribution to the challenge.

If you want to see more about their story head to their Facebook page or their fundraising page.

www.facebook.com/CFGoldfields

www.65roseschallenge.everydayhero.com/au/cf-goldfields

Peggy, with her daughter Lillian and her father Wilf

Jennifer and Rick at the start of their walk

F45 WILLETTON GETS MOVING FOR CYSTIC FIBROSIS AWARENESS MONTH

During May, F45 Willetton focused their efforts on raising awareness and funds in support of families affected by cystic fibrosis (CF).

CFWA president Caz with CFWA board President Richard

Team F45 Willetton

The team post run at the HBF Run

The team at F45 Willetton first learnt about Cystic Fibrosis WA (CFWA) through one of their members Richard, who sits on the CFWA board. Through the month they hosted several events, including a stall at the Festival of Movement and a dress red day where CFWA's President Caz Boyd spoke about her journey and experiences of living with CF.

They finished the month off by participating in the 2018 HBF Run for a Reason on Sunday 27 May. Their team of runners and supporters raised over $1,000 online and shared their success proudly on their social media.

They were among over 35 teams and individuals fundraising for CFWA through the HBF Run and together all our runners raised an incredible $22,980! This will go towards important services to help children and adults living with CF in WA and will support critical research funding.

If you're feeling inspired and are looking to participate in a fun activity this year, registrations are open for the 2018 City to Surf, which will be on Sunday 12 August. City to Surf have events in Albany, Busselton, Geraldton, Karratha and Perth, which means everyone can join in the fun. Visit **www.city2surf.com.au** for more information and to sign up now!

B&C FINANCE; HELPING YOU TO HELP CFWA

For Michael Saunders, Director of B&C Finance, a conversation with Cystic Fibrosis WA's (CFWA) Ric Reyerson made a connection that continues to grow.

B&C Finance have been CFWA supporters for nearly two years through a referral commission program. We had a chat with Michael on 65 Roses Day when he was volunteering in the CBD to sell roses.

How did you first get involved in CFWA?

I first met Ric through my business and spent some time talking with him about his role at CFWA. Ric's passion for the organisation and the great work that all at CFWA do struck a chord. From there I reached out to CFWA CEO Nigel Barker and put in place a referral program to help meet the finance needs of those connected with CFWA whilst generating an ongoing commission for CFWA. All done for FREE. So far, the program has raised over $2,000 and has great potential to generate much more into the future.

As a small business owner what does community mean to you?

I am 100% committed to helping my clients achieve their financial dreams and passionate about the community we all live in. By supporting CFWA and other sporting and community groups I am helping my community to grow and improve. Something that gives me great pleasure.

Tell us about your 65 Roses Day

I watched the buzz grow around 65 Roses Day on social media and decided to be a part of the volunteer team in the city. I spent some time with Nigel (CFWA CEO) walking the streets of Perth selling roses and visiting a business who supported the day by buying roses for their staff. Despite the weather it was great to see so many people helping the CFWA cause both through volunteering time and buying roses.

What does B&C Finance provide?

B&C Finance provide a full range of finance solutions to meet the needs of individuals, families, investors and businesses. All done for FREE to help you to help CFWA.

Visit **www.bcfin.com.au** for more information about Michael and the services he offers.

EVERY DAY IS PRECIOUS WITH CF

Celebrating every day and sharing precious moments is what mum Kate strives for.

Kate, who lives with cystic fibrosis (CF), has shared her journey with CF with us for this year's national Tax Appeal. Kate, from the Gold Coast, shared her story with Cystic Fibrosis Queensland, celebrating her lung transplant and the joy of having daughter Molly.

Following a childhood in and out of hospital, Kate's health took a serious dive in her 20s, and she was put on the list for a double lung-transplant at age 26. Eleven years ago, Kate received her transplant. Kate says "I'm forever grateful for the new lungs I've been gifted. My lung transplant saved my life. It allowed me to experience the joy of becoming a mother."

At Cystic Fibrosis WA we are grateful at this financial year end to be able to share Kate's story to raise awareness and funds that will continue to provide services and programs for WA families, and contribute to research and advocacy nationally, with the aim of finding a cure for CF.

Working together with state CF organisations to create our national Tax Appeal means we strengthen our brand and message. This collaboration also helps reduce costs of campaigns and allows us to share member stories across Australia.

Visit **www.cfwa.org.au/appeal** to read more of Kate's story or support our Tax Appeal.

MARK YOUR DIARIES FOR THESE 2018 EVENTS

JULY

22 – ALBANY CITY TO SURF

29 – BUSSELTON CITY TO SURF

AUGUST

2 – BUNBURY OUTREACH

5 – GERALDTON CITY TO SURF

12 – KARRATHA CITY TO SURF

18 – RED TIE DINNER DANCE

26 – PERTH CITY TO SURF

SEPTEMBER

13 – MERREDIN OUTREACH

OCTOBER

2-4 – SIBLING AND OFFSPRING CAMP

19 – PARENTS' DINNER

NOVEMBER

2 – CYSTIC FIBROSIS GOLF CLASSIC

4 – THE COLOUR RUN

DECEMBER

7 SPONSORS AND VOLUNTEERS AWARDS NIGHT

*PLEASE NOTE, DATES MAY CHANGE IF CONFLICTS ARISE.

TO FIND OUT MORE ABOUT THESE EVENTS OR TO GET INVOLVED, VISIT THE UPCOMING EVENTS SECTION OF OUR WEBSITE AT **WWW.CFWA.ORG.AU/GET-INVOLVED/UPCOMING-EVENTS/**

OR CONTACT MARNIE ON **EVENTS@CFWA.ORG.AU** OR ON **08 6457 7333.**

FSC POWER SECTION EVENT

RED TIE *DINNER DANCE*

$125
PER PERSON

SATURDAY 18th AUGUST 2018

All monies raised go towards Cystic Fibrosis WA


Proudly Supporting
CYSTIC FIBROSIS
Western Australia

ENJOY AN EVENING AT FREMANTLE SAILING CLUB WITH AUCTION ITEMS, RAFFLES, DOOR PRIZES, AND LIVE ENTERTAINMENT FROM TOP PERTH BAND

TOD JOHNSTON AND PEACELOVE

FUNDRAISER FOR CYSTIC FIBROSIS WA

VENUE
Wardroom
Fremantle Sailing Club

INFO
Tickets are $125 pp and include a delicious three course meal, limited beer and wine plus cash bar.
Book tickets via FSC Reception
9435 8800

DATE
Saturday
18th August 2018
7pm for 7.30pm start
Ending 1.00am

CROKER CONSTRUCTION
CIVIL ENGINEERING CONTRACTORS

stage&studio productions

OAKOVER WINES

FIORI

Robinson
Insurance Broking Services

FREMANTLE SAILING CLUB INC
POWER YACHT