EDITION 1 2019

RED

In This Issue

Education and Awareness

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RED CEO MESSAGE

NIGEL BARKER, CEO

It was with a heavy heart that we learned of the passing late last year of one of the greatest philanthropists in Western Australia Stan Perron AO.

Stan was a remarkable man with a passion for Western Australia that is rarely equalled. This passion was reflected in his work, in business ethics and through his lifelong commitment to Rotary. His family trust supported many, many charities here in WA, particularly our charity Cystic Fibrosis WA and the CF research we sponsor. Recently Stan donated $1.5m to our research program Little Lungs: Big Futures. And whilst Stan will be sorely missed, his legacy will live on, safe in the hands of the trustees, as will our long and trusted relationship. Vale Stan Perron AO!

There is a special feature in this edition of our other wonderful sponsors and volunteers who were recognised in our 2018 Awards night.

Looking ahead, 2019 promises great hope for the future including the commencement of phase III clinical trials for the new triple combination therapy Symdeko. If successful, this will be the third drug to be developed to treat the underlying cause of the disease rather than the symptoms.

We are also very excited to report that Perth will host the 13th Australasian CF Conference with guest speakers attending from around the world. CFWA is offering some subsidies to allow parents and carers to attend from both metro and country areas. We are also planning to have our parent's weekend run around the same time to allow people to do both.

There is a focus on research in this edition and getting the word out to members on some of the cutting-edge work that is being done.

We are also really proud to launch our CF Talk videos as part of our mental health program to support young people living with CF.

Finally, we are making a big effort in our fundraising to better engage with the corporate world, so if you would like some information about how your workplace can get involved, please give us a call. There are lots of options and it's a lot of fun to be part of a winning team.

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our second edition for 2019, please contact us before 5 April 2019.

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
Sera, of the six adults in our new CF Talk videos

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Australasian Cystic Fibrosis Conference Update

The Australasian Cystic Fibrosis Conference (ACFC) is being held in Perth this August and plans are well underway. The Lay Conference is being held on Saturday 3 and Sunday 4 August and the Medical Conference begins on Sunday 4 August and concludes on Tuesday 6 August 2019.

Dr Andre Shultz is the Conference Chair and he has set the tone with his inspirational concept of 'Celebrating Partnerships'.

Both the Medical and Lay Conference programs are complete and all set to 'celebrate partnerships' in informative and inspirational ways.

12 international cystic fibrosis (CF) luminaries are taking the podium at the 13th ACFC and topics from infection to infertility are on the agenda.

Jane Davies, Stuart Elborn, Lisa Saiman and Felix Ratjen are just a few of the overseas speakers and the full list including impressive biographies can be found here.

www.cysticfibrosis.org.au/what-we-do/cystic-fibrosis-conferences/speakers

Over 30 Australasian CF specialists have also been invited to present in Perth and all medical and allied health disciplines will be well represented.

Early Bird registrations are now open and this will not only save you money but possibly secure a $150 Travel Grant for those traveling by plane to WA, if you get in quick.

The $150 Travel Grant is on a first come first served basis so don't delay. You don't need to provide travel details immediately but we will be allocating Travel Grant funds in February 2019.

CFA is excited about the Perth CF Conference and the Crown Towers venue is the perfect setting for 'Celebrating Partnerships' both lay and medical sharing information and appraising innovation.

Go to **www.cysticfibrosis.org.au/acfc** to read more about the 13th ACFC or contact CFA directly.

Nettie Burke

CEO

Cystic Fibrosis Australia

2019 Australasian Cystic Fibrosis Conference in Perth

We're very excited that the 13th Australasian Cystic Fibrosis (CF) Conference is heading to Perth in 2019!

Cystic Fibrosis WA are really excited about the Australasian CF Conference coming to Perth!

This biannual event brings together members from the global CF community including scientists, clinicians and allied health professionals. The conference presents the latest advances in CF research, care and drug development as well as also providing a forum to discuss new ideas and visions for the future.

Information about the event can be found on the Cystic Fibrosis Australia website

www.cysticfibrosis.org.au/acfc

Cystic Fibrosis WA (CFWA) is excited to be able offer conference subsidies to our members. Please see the CFWA website for more details.

www.cfwa.org.au/what-we-offer/subsidies-equipment

Please contact **Paula** on **services@cfwa.org.au** if you would like more information about this event.

CFWA Personal Training, Gym and Activity Subsidies

There is a strong correlation between an active lifestyle and good emotional and physical wellbeing.

Cystic Fibrosis WA (CFWA) is now providing subsidies for people with CF across the whole of Western Australia. These subsidies are specifically designed so that you can access your choice of activity closer to home.

These benefits include:

Emotional wellness

- Promotion of feel-good chemicals in your brain such as endorphins and serotonin
- Improves brain function and circulation
- Helps you sleep better and relax more
- Improves self-esteem and body image
- Gives you a sense of accomplishment
- Increases your energy

Physical wellness

- Improves appetite
- Improves exercise tolerance
- Assists with airway clearance
- Improves ability to perform daily activities such as shopping and cleaning
- Increases bone density
- Improves muscle strength and function
- Slows the rate of decline in lung function
- Increases body mass and strength

Exercise Subsidies for Adults with CF

Physical activity subsidies are available for adults with CF up to $40 per week or $160 per month, for a maximum of 12 weeks. This subsidy is available for adults across the whole of Western Australia.

Prior to commencing new activities, we highly recommend:

- Reading the three CF Fit booklets **www.cfwa.org.au/what-we-offer/resources**
- Seeking advice and an exercise plan from CF hospital physio
- Locate fully qualified gym or qualified class instructor/personal trainer who understands CF or is open to learning about CF. The CF Fit for Personal Trainers booklet is a good place to start. CFWA is also available to provide education

To be eligible for the subsidy, you must:

- Ensure the enterprise you choose is a registered business or sole proprietor with a legitimate ABN. You can check the ABN by visiting ABN Lookup at **abr.business.gov.au**
- Provide a tax invoice / receipt (showing ABN and full payment details) to be uploaded onto our online Subsidy Request Form
- Complete a pre- and post-questionnaire about your fitness levels and exercise habits. This program will be continuously reviewed and availability will be dependent on funding. Please contact Kathryn to discuss funding availability prior to applying

Note: The budget for these subsidies will be reviewed every three months starting at the end of March. Ongoing funding will be assessed at this time.

For further information, please contact Kathryn at **servicesmanager@cfwa.org.au** or on **08 6457 7333.**

Exercise Subsidies for Children with CF

There is also a CFWA activity subsidy available for children with CF, however, you are now required to see if you are eligible for financial assistance from Kidsport before accessing the activity subsidy.

KidSport enables eligible Western Australian children aged 5 to 18 years to participate in community sport and recreation by offering them financial assistance of up to $150 per calendar year towards club fees.

Who is eligible for KidSport?

All Western Australian children aged 5 to 18 with a valid Health Care Card or Pensioner Concession Card are eligible for KidSport.

How does KidSport work?

You can apply for KidSport online or by using a hard copy application form.

KidSport applications are assessed by the local government in which the child resides or by the KidSport team at Sport and Recreation (WA). If an application is approved, the KidSport team will email you a voucher code (unique to the child). The code needs to be provided to the club when registering so that the approved amount can be deducted from the registration or membership fees.

KidSport Application

For more information and to register visit the Kidsport website.

www.dsr.wa.gov.au/funding/individuals/kidsport

CF Talk Short Film Series Coming Soon

These six short films, featuring real stories from people with CF, will be released on our website very soon!

Our newly developed CF Talk short films are specifically targeted towards young people with cystic fibrosis (CF), however, many of the topics may also be relevant for parents, siblings, other family members and even friends. Each film shows real people from our CF community talking about the impact of CF on their life, covering topics such as motivation, relationships and school experiences.

The will be available to view on our website very soon. To check them out visit **www.cfwa.org.au**

In future, we would like to develop more short films, including some involving parents, carers, siblings, spouses and grandparents. If you would like to be part of any future projects, please contact Kathryn at **servicesmanager@cfwa.org.au** or on **08 6457 7333**.

Toby, one of our stars, chatting with Bruce from Gingerbeard Media

Bianca shared some of her personal experiences with us for the CF Talk video series.

65 Roses Day 2019: Save the Date!

We need your help to paint WA with roses to raise awareness and funds for people living with CF this 65 Roses Day.

Gift a florist-arranged bunch of roses to that special someone this 65 Roses Day.

Some of the team from WAFEX joined us at our Perth 65 Roses Day stall.

Vault Fitness and Exchange Tower hosted a huge 65 Roses Spin Challenge in the foyer of their building.

May is cystic fibrosis (CF) awareness month and Friday 24 May is our national day of CF awareness. Every year, on 65 Roses Day, we paint Western Australia (WA) with beautiful, fresh roses to raise funds and awareness for people living with CF.

Funds raised from these fundraising events support our vital service programs and research funding for children and adults with CF in WA.

Here's how you can get involved.

Take 65 Roses to Your Workplace or School

Your workplace or school is the perfect place to help raise awareness and funds for CF this 65 Roses Day.

Pre-order your roses (no pre-payment required) on our website and we'll deliver them to you on 65 Roses Day; sell them for $5 a rose and deposit the funds raised to us after the event. It's that easy!

If you can't sell roses in your community, you can still support CF with a beautiful florist-arranged bouquet, delivered to a friend or loved one on 65 Roses Day, Friday 24 May.

Order your roses today at **www.cfwa.org.au** or get in touch with the team at **events@cfwa.org.au** or on **08 6457 7333.**

Volunteer With Us

To paint WA with beautiful roses this 65 Roses Day, we need an army of volunteers to help us!

Join our volunteer team and lend a hand for a couple of hours on Thursday 23 May to wrap roses, or Friday 24 May to sell them on the streets of Perth and surrounding suburbs.

To join our volunteer team, visit **www.cfwa.org.au/get-involved/volunteer**

Host a fundraiser in May

Community members and organisations host all sorts of fundraisers during May, all supporting people living with CF.

Take the 65 Roses Challenge and host a morning tea, free dress day or undertake a physical challenge during May. The sky's the limit as long as you're challenging yourself and raising funds for CF!

For some inspirational stories of people who have taken on their own 65 Roses Challenge, visit **www.cfwa.org.au/news**

Become a 65 Roses Corporate Partner

65 Roses Day is made possible with the generous support of our 65 Roses partner organisations.

Special thanks to our long-term 65 roses partners WAFEX, South Metropolitan TAFE and Telstra for your continued support.

We welcome the opportunity to work with your organisation to increase awareness and raise funds for CF. For more information or to discuss corporate support opportunities contact
Karen at **marketing@cfwa.org.au** or on **08 6457 7333.**

WAFEX Australia's leading flower exporters

Government of Western Australia

TAFE WA South Metropolitan

Share Your Ideas: 65 Roses Catch-up

Do you have an idea about how we could improve 65 Roses Day or do something differently? Join us for a morning or evening 65 Roses catch-up for an informal chat with us to share your ideas.

65 Roses Catch-up

Date: Wednesday 6 March

Time: 10:00am and 6:00pm (2 sessions)

For more information or to register your interest, get in touch with Marnie at **events@cfwa.org.au** or on **08 6457 7333.**

CF Talk
Interactive Magazine

We are excited to bring you a new online interactive magazine, focusing on young people with CF and their siblings.

The first edition of our exciting new interactive magazine, CF Talk, is set to be released very soon. This magazine has stories from people with CF about landing your dream job, taking your medications in front of others at high school, and so much more!

CF Talk will be a future space to share your insights, so if you have a story you would like to share, we would love to hear from you.

As we said, this magazine is focused on young people with CF. We want to keep you informed of new, relevant information and when the next edition is coming out. So, get in touch with us and give us your best contact information so we can keep you updated.

For more information or to join the mailing list contact Maggie at **education@cfwa.org.au** or on **08 6457 7333**.

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Cystic Fibrosis WA Annual General Meeting

Official notice of 2019 AGM Cystic Fibrosis WA (INC)

Date: Wednesday 17 April 2019 | **Time:** 7:00pm

Venue: The Niche Conference Room, 11 Aberdare Rd Nedlands WA 6009,
corner Hospital Ave and Aberdare Rd
Guest speaker TBA. Refreshments will be served following the meeting.
Please RSVP by Friday 12 April 2019 to
Ric at **admin@cfwa.org.au** or **08 6457 7333.**

Introducing Maggie!

We'd like to welcome to our new Resource Development and Training Officer, Maggie, to the CFWA team

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Hello everyone, my name is Maggie and I am the new Resource Development and Training Officer. I am originally from the United States, growing up in Washington state, but I have also lived in Missouri, Oregon, and Texas before settling in Australia.

Within my role at Cystic Fibrosis WA (CFWA) I have had the opportunity to visit schools and provide education sessions on cystic fibrosis (CF). These sessions are targeted towards school staff and cover general CF information as well as specific information about the child with CF.

As each session is tailored to the considerations specific to a school or a child, there is an opportunity to address and provide solutions to any concerns a parent, child, or staff member may have. If you or your child have a new school, day-care, teacher, workplace, sporting club, or any other new experience where you would like their CF noted, please contact me to book in an education session.

What I enjoy most about training is the interaction with diverse groups of people and assisting in their development. My favourite training sessions are interactive and engaging as the audience will take away more from an experience than facilitation. The most rewarding outcome of training is receiving feedback that I have helped someone understand something they previously felt was challenging.

Training is something that I sincerely enjoy and it's going to be an exciting challenge to learn more about cystic fibrosis and continue to organise educational resources that will suit various audiences. I genuinely look forward to the opportunity to meet everyone within the CF community and I hope to hear from you soon!

To organise an education session at your school, workplace or in your community, get in touch with Maggie at **education@cfwa.org.au** or on **08 6457 7333.**

Starting School with CF

Take a look at our new "Starting School with Cystic Fibrosis" and "Starting High School with Cystic Fibrosis" booklets, packed with great tips and resources.

These handy little booklets have been designed with parents of children living with CF in mind and contains information on things such as collaborating with the school, managing CF needs in a learning environment and preparing for the first day.

These booklets will soon be available on the CFWA and CFSmart websites soon, otherwise to receive a hard copy, please contact **education@cfwa.org.au** or **08 6457 7333.**

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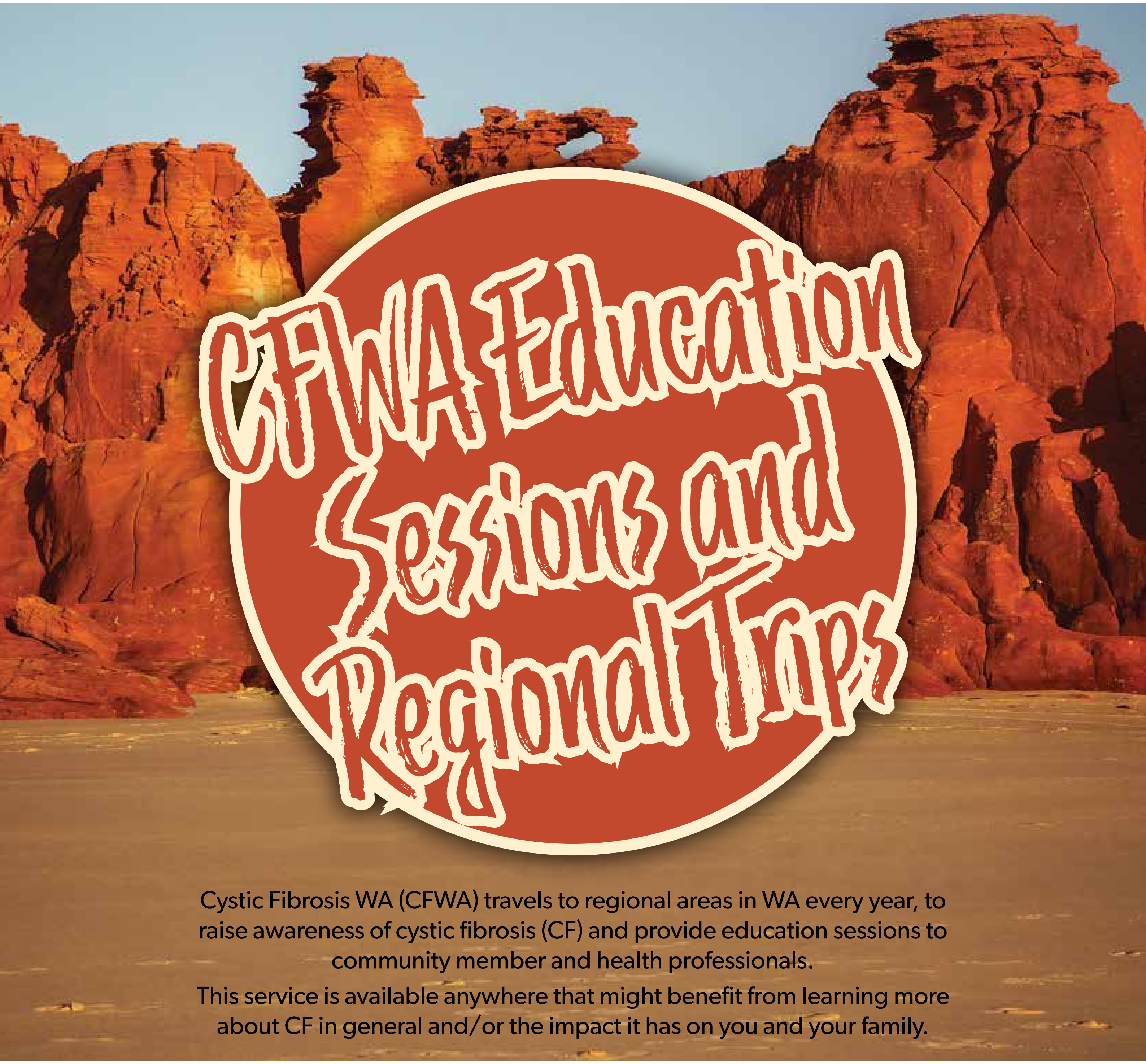
CYSTIC FIBROSIS
Western Australia

CELEBRATING 50 YEARS
telethon 7



CFWA Education Sessions and Regional Trips

Cystic Fibrosis WA (CFWA) travels to regional areas in WA every year, to raise awareness of cystic fibrosis (CF) and provide education sessions to community member and health professionals.

This service is available anywhere that might benefit from learning more about CF in general and/or the impact it has on you and your family.

We can provide education at:

- Day Care
- Schools
- Community Groups
- Sporting Clubs/Youth Groups
- Your Place of Work
- Health Professional Workplaces

For more information or to book an education session please contact Maggie on **education@cfwa.org.au** or **08 6457 7333.**

Regional trips and support events are proudly supported by Telethon.

ORKAMBI® Roll-out at Perth Children's Hospital and Sir Charles Gairdner Hospital

On 1 October 2018, Orkambi® (a combination of lumacaftor and ivacaftor) was placed on the Pharmaceutical Benefits Scheme (PBS) for patients living with cystic fibrosis (CF), aged six years and over, that have two copies of the F508del mutation in the CFTR gene.

This announcement brought much excitement and eagerness for eligible patients to gain access. So where are we now?

Perth Children's Hospital Roll-out

Since the announcement, Perth Children's Hospital (PCH) has been working hard aiming to have all eligible children commence treatment within 3-6 months. The PBS approval requires specific criteria to be met prior to commencing Orkambi® and to provide ongoing prescriptions. You and your child will be required to attend an Orkambi® Initiation Clinic. This first appointment will take approximately 2-3 hours. Your CF team will go through the criteria required for the initial application. All the information regarding administration, use and potential side effects of Orkambi® will be discussed. Your child will have lung function testing – if it has not been done within the last month – and a liver function test if not completed in the last 12 months.

Families will only have extra reviews if PCH

think there are issues but most of these can be resolved over the phone. An appointment will be arranged if required. Your child will have a repeat liver function at 3 months.

For those in rural areas, PCH will endeavour to initiate the process via video/teleconference or at a Rural Clinic.

Please contact your PCH CF team if you have any questions about access or ongoing use of Orkambi®.

Sir Charles Gairdner Hospital Roll-out

Some patients attending the Adult CF Clinic at Sir Charles Gairdner Hospital (SCGH) have been receiving Orkambi® on a special access program. This program is no longer continuing and these patients have now been transferred to the new scheme. SCGH had approximately 35 adults to transfer and they were a priority to ensure continuation of the medication. The initial focus was to meet the needs of these patients and this process was completed in October 2018.

The next step is to initiate the remaining patients who meet the criteria as per the PBS. This involves completion of baseline clinical tests and questionnaires which would allow the clinicians to gauge the outcomes of this new drug in adult patients. The requirements for these patients, in addition to their usual clinic/hospital attendance, is as follows:

- Consultation with their CF specialist to discuss suitability of Orkambi® and if agreed, to go forward.
- An appointment with the pharmacist for educational purposes and a medication review. This takes about one and a half hours on a Thursday or Friday morning. During this appointment, the dietician will meet you and assess your body composition and answer any queries you may have.
- Baseline clinical assessments including formal lung function testing, General Respiratory Function (GRF), low dose Chest CT scan and a fasting blood test. Participation in ongoing research projects will also be discussed.
- Once your application has been processed and approved (approximately a week), an appointment for initiation of the drug will be arranged. An allocation of four hours is needed for this appointment to observe tolerance of the drug and any reaction that occurs. Spirometry will be done prior to and during the 4-hour period. The initiation appointments will be held predominantly on a Wednesday or Thursday commencing in the morning.
- A follow-up appointment for spirometry and possibly repeat blood tests will be necessary ranging from a week to a month after initiation but the timing will be dependent upon the individual patient's situation.

For all patients, regardless of transferring from the special access program or initiating Orkambi®, there will be a periodic review incorporated with your usual clinic visits. However, every six months, you may need a short appointment at the clinic to fulfil the requirements to reapply for renewal of prescriptions.

Staff at the Adult CF Clinic at SCGH are mindful that patients have commitments of work and study and some patients live in regional areas. Wherever possible, they will aim to keep attendance at clinic and hospital to a minimum and will make every effort to expedite these appointments. For those who live in country areas, teleconferencing may be used where suitable.

If you have any queries in relation to this new treatment, please feel free to contact a member of your SCGH Adult CF Team.

CF Research News – Effect of Orkambi® on Blood Sugars

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 August 2018

‘Continuous glucose monitoring in youth with cystic fibrosis treated with lumacaftor-ivacaftor’

Authors: Angel Li, Tim Vigers, Laura Pyle, Edith Zemanick, Kristen Nadeau, Scott D. Sagel, Christine L. Chan

What was your research question?

Do blood sugars in patients with cystic fibrosis, measured by continuous glucose monitoring, improve after starting lumacaftor/ivacaftor?

Why is this important?

Previously, a small study found improvements in insulin secretion and diabetes for patients with CF and G551D mutations after starting ivacaftor treatment. The effects of lumacaftor/ivacaftor (Orkambi®) on blood sugars in patients with F508del mutations are unknown. As newer CFTR modulators are developed for different mutations, it is important to perform ongoing assessments of the effects of these medications on blood sugars and CF-related diabetes.

What did you do?

Nine individuals, ages 11-15 years, with homozygous F508del mutations, wore a continuous glucose monitor (CGM) before and after Orkambi® treatment. One had CF-related diabetes, 5 had abnormal glucose tolerance tests, and 3 had normal glucose tolerance tests prior to Orkambi®. CGM data was collected and compared roughly a median of 26 weeks before and 29 weeks after Orkambi® initiation.

What did you find?

There were no significant differences in blood sugars measured by continuous glucose monitoring before vs after Orkambi® treatment in this small group of people. In fact, one individual with normal glucose tolerance before Orkambi® developed diabetes after Orkambi® start.

What does this mean and reasons for caution?

Blood sugar abnormalities in the F508del population may be harder to correct with Orkambi® than in the G551D population treated with ivacaftor. However, in this study, insulin secretion problems, which are the underlying cause of blood sugar abnormalities in diabetes, were not directly measured.

What’s next?

Future studies measuring both insulin secretion and blood sugar changes, before and after the start of newer CFTR modulator drugs, are needed to better understand the impacts of these medications on blood sugars, risk for diabetes, and diabetes progression.

Original manuscript citation in PubMed:

www.ncbi.nlm.nih.gov/pubmed

Triple Combination Therapy Drug Looks Promising

New small molecules like Kalydeco®, Orkambi® and Symdeko®, developed by Vertex Pharmaceuticals with funding from the US CF Foundation, are the first of a new family of drugs to treat the underlying cause of cystic fibrosis (CF). They have given great hope for the future and achieving our vision of Lives Unaffected by CF.

The latest drug in the development pipeline has now completed phase II clinical trials and is entering phase III. The results so far are very encouraging.

According to the New England Journal of Medicine "VX-445 is a next-generation cystic fibrosis transmembrane conductance regulator (CFTR) corrector designed to restore Phe508del CFTR protein function in patients with cystic fibrosis when administered with tezacaftor and ivacaftor". We're calling this a triple combination therapy until Vertex come up with a more unpronounceable brand name.

A randomized, placebo-controlled, double-blind, dose-ranging, phase II trial was conducted to evaluate this oral triple combination therapy in patients who were F508d homozygous and F508d heterozygous.

The phase II trials found that the triple combination therapy had an acceptable safety and side-effect profile, describing most side effects as mild or moderate coupled with very significant increases in lung function (11-13.8 points), decrease in sweat chloride concentrations and an improvement in the respiratory domain score on the Cystic Fibrosis Questionnaire–Revised. (The respiratory domain score is a measure of respiratory symptoms relevant to patients with CF such as cough, sputum production and difficulty breathing)

These results mean that this triple combination therapy if successfully brought to market, has the potential to treat the underlying cause of cystic fibrosis in approximately 90% of patients. But as my grandma used to tell me, "there is many a slip between spoon and lip."

So how long will we have to wait?

Recruitment for phase III clinical trials are underway and usually involving between 1,000 and 3,000 patients around the world. Typically, they'll take three years to complete.

After the completion of the phase III trials, Vertex will analyse all the data and if found to be safe and effective, they will file a New Drug Application with the FDA in the USA which can take up to two and a half years to approve.

Typically, once approved and in use in the USA, Australia plays catch up. In the case of Kalydeco®, we had to wait two years and in the case of Orkambi®, the wait was an agonizing three years.

We're hopeful that future approvals will be fast tracked but even so, it may be anything up to eight years before Australians can benefit from this triple combination therapy. And that's assuming everything goes to plan in the phase III trials, FDA approval, lodgement with the Pharmaceutical Benefits Advisory Council (PBAC) and a recommendation for its listing on the PBS.

Importantly, while the research steams ahead, we need to do everything we can to keep lungs as healthy as possible so that they benefit to the maximum effect once these new small molecules become available. Then we look to you to support our advocacy efforts to fast track approval.

This triple combination therapy is just one shot on goal. As the former President and CEO of CFF was fond of saying, "CFF's strategy is many shots on goal" and there are another 11 small molecules in the pipeline.

Clinical trials are conducted around the world including here in Australia. If you are interested in participating in a clinical trial, please speak with your physician.

The above information is based on a paper published in the new England Journal of Medicine on 18 October 2018 and relates to a new triple combination drug.

Original manuscript citation

www.nejm.org/doi/full/10.1056/NEJMoa1807120

Bringing CF Research to the Regions!

Dr Oded Breuer presenting at the 2018 Albany Evening with CF Scientists.

Due to the unwavering support of Telethon, our regional families continue to receive first class education about new cystic fibrosis (CF) care, research and drug developments.

The annual Evening with CF Scientists, a collaborative event between Cystic Fibrosis WA (CFWA) and Telethon Kids Institute (TKI), has been held in Perth for over 5 years. This event showcases the latest information from WA CF researchers.

Thanks to the generous support of Telethon and TKI, CFWA visited Bunbury and Albany in 2017 and 2018 to host a mini Evening with CF Scientists event. Dr Luke Garratt, Dr Oded Breuer and Prof Steve Stick, from the AREST CF team, have presented to our regional families and provided members with the opportunity to discuss CF research with the experts.

Due to the ongoing support from Telethon, we're able to continue providing education to our regional families and are excited to be able to offer a generous subsidy to regional parents and carers to travel to Perth and attend the 13th Australasian Cystic Fibrosis Conference, to be held at Crown Towers on 3-4 August 2019. The biannual conference allows medical, scientific, allied health and lay communities from around the world to come together to discuss and share ideas on the latest advances in CF care, research and drug development. The conference schedule is packed with information from CF experts both locally and internationally.

The 'Telethon CF Conference Parents and Carers Package' is a generous subsidy to help towards the cost of conference registration, attendance at the Lay Community Dinner and overnight accommodation. If you live regionally and haven't received information about this fantastic subsidy, please contact Paula on **services@cfwa.org.au** or telephone **08 6457 7333.**

CFWA are also providing a subsidy package for our metro parents and carers. Please visit our website for further information.

www.cfwa.org.au/what-we-offer/subsidies-equipment

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

CELEBRATING 50 YEARS
telethon 7

Health Professional Education to Reach New Heights

2018 was a busy year, with our services team visiting many country health services to provide cystic fibrosis (CF) education. However, our face-to-face presentations are soon to be supported by online health professional education and resources for quick and easy access in both the metro and country settings.

Every year, the Cystic Fibrosis WA (CFWA) team drives many kilometres so that nurses, doctors and allied health professionals have access to CF education. In 2018, both country and metropolitan centres received CF education, stretching from Albany to Darwin, by face-to-face or by video conferencing presentations. Rural and remote centre nurses and physiotherapists also accessed comprehensive respiratory education by attending the annual CFWA Regional Respiratory Training Program.

A total of 161 health professionals were provided with an overview of CF based on the current best practice guidelines. This is a great number, but 2019 will bring a new dimension. Health professionals, not only in Western Australian but globally, will have access to current CF information and related resources on a new online platform currently being developed by CFWA. We are hoping to launch this new concept on our website **cfwa.org.au** in the first half of this year, so watch this space!

Catching Up with Caz

In this issue, we jumped at the opportunity to have a chat with Caz Boyd who has adopted many roles within the cystic fibrosis (CF) community.

Caz is a post-transplant adult living with CF. She wears many hats; CFWA President, member of the Adult Advocacy Group, contributor to the CF Talk Facebook page, professional in the health industry, ray of sunshine in the lives of many, and so much more.

You are one of the stars of the new CF Talk videos. What do you hope will be the impact of these films?

I really hope these videos will have a positive impact on the community, but I hope they will especially impact young people with CF. I hope young people with CF see the variety of age groups - Mitch and I are the older end and the others are on the younger end - and they realise we all have gone through the same type of things. If they are sitting at home or watching these videos online, they know that they are not the only ones out there experiencing whatever they are going through.

What do you think you specifically brought from your experiences that will help people who watch the CF Talk videos?

Motivation. For me, something that was important to get across was that career-wise – what I am doing now – wasn't what I initially wanted to do. I wanted to be a policewoman, or a hairdresser, but I was told that someone with CF couldn't chase a criminal or that the chemicals would be detrimental to my lungs. But I am now in a job that I love. If you get knocked back once and then knocked back twice, just keep at it. Keep going.

What was it like for you, reflecting on being a young person?

It brought up a lot of emotions, actually. It was good because I am very much an open book and if I can help someone, I am more than happy to tell them my life story. I don't hide a thing. It provided a lot of insights for me. CF now is nothing like it was in the 70s and 80s.

In the films, you discuss your achievement of becoming CFWA President. What inspired you to take on a role like this?

Simply being on the board initially was a great achievement for me. I believe having someone on the board with CF gives a different perspective. Currently we have a mix of people who don't have a connection with CF; we have parents who have children with CF; and then there is me. The board, as a whole, has a great dynamic. Being voted Vice President I thought, "this is great". Being nominated and then voted in as President was like winning an Academy Award to me. I was so honoured. If I can make a difference to one person with CF, I am happy with what I have done. If I can inspire or empower 100 people with CF, then that's a great achievement to me.

What do you wish to achieve in this role?

I wouldn't go as far to say "Lives Unaffected by CF" which is part of our [Cystic Fibrosis WA's] strategic plan as I think we are still a long way off from that. I would like to help with the little things. One of my focuses is to recognise the adult population with CF and all the new challenges that come with the aging CF population.

You are in the Adult Advocacy Group. What are the objectives of the group and how do you see your role?

Advocating for adults. We are going through menopause; we are going through andropause; we are breaking bones; we are aging in new ways. We are getting older and there are things like financial assistance, such as having a financial advisor speak to the community, that could be beneficial. I took out my superannuation when I went to Sydney for my transplant. A lot of people with CF who are my age have very little super because we didn't think we would need it. That's something we can advocate for.

We have talked about your involvement in various roles. You are also a significant contributor to the CF Talk Facebook page. You give lots of advice and share your story to other adults with CF. What would be your advice for others who want to be involved, like you, in CF-related activities?

We do have some unique challenges because of cross-infection but try and get on the board! Get involved on Facebook, volunteer, ring up CFWA and see what you can do, make yourself available and known for campaigns. CF Talk on Facebook is a great forum; we are all very open. This morning I posted about forgetting to take Creon® and how I am suffering today and people understand that. Get active on social media; it's a great place where we are all involved.

To join our CF Talk closed Facebook group, open to all adults with CF, visit **www.facebook.com/groups/cftalkadults**

CFWA Sponsors and Volunteers Evening

On Friday 7 December 2018, we gathered to celebrate the end of another big year of awareness raising and fundraising, and to acknowledge the efforts of many people from our committed and generous community.

South Metro TAFE educator Kylie-Anne (left) and Long-Service award recipienct Michael from Comprac (far right) with CFWA staff and supporters.

Volunteer of the year Kandy receiving her award.

Every year, our organisation is supported by hundreds of volunteers, partners and sponsors from right around WA. We can't thank these people enough for the time and energy they put into helping us raise awareness and funds for families affected by cystic fibrosis (CF).

Our sponsors and volunteers 'thank you' evening is our way of being able to turn the tables and give something back to all these wonderful people and bestow some special awards to five individuals or groups who have made a big impact for the year.

The 2018 Cystic Fibrosis WA (CFWA) award recipients were:

Volunteer of the Year: Kandace Boyd

Kandace has given her time and shared her expertise to support CFWA in many ways since signing up as a volunteer, including hosting her own fundraiser at her workplace and helping to implement a charity program within her organisation. Kandace is also a regular volunteer at other community fundraisers and 65 Roses Day. Her efforts have helped us to extend our reach further into the community and create new partnerships with local organisations.

Supporter of the Year: South Metropolitan TAFE Bentley

SM TAFE Bentley has been partnering with CFWA for over three years, supporting 65 Roses Day by organising committed and reliable volunteers to manage the stalls and assist in selling thousands of roses while raising important awareness in the community. Our partnership with SM TAFE Bentley demonstrates how working together with organisations in our wider community extends our reach and contributes hugely to both CF awareness and fundraising.

Fundraiser of the Year: CF Goldfields

This year the CF Goldfields team, made up of long-time supporters and members of CFWA, took on a big 65 Roses Challenge and raised over $15,000. They took on the 135km Cape-to-Cape track in relay style with Peggy and Wilf walking it first and then Jennifer and Rick walking it after. The team was supported through their fantastic families, friends and community. Well done and thankyou to the CF Goldfields team!

Long Service Award: Michael Mansell

Michael and his business, Computer Practitioners, has been supporting CFWA for over 20 years as a service provider and donor. Michael has worked with CFWA to transition our IT infrastructure from the days of a very small organisation on Hampden Road to the large organisation it is today.

Lappa 65 Roses Spirit Award: Brooke Murphy

The 65 Roses Award was introduced two years ago to recognise an inspirational role model who exemplifies our vision of 'Lives Unaffected by CF'. In 2018, we re-named the award in honour of a very inspirational role model who has been a part of our community for a long time: Wojciech Lappa.

Brooke Murphy, an adult living with CF and mum to Brodie, who also has CF, hosted a big fundraiser in her small regional town. Brooke gathered the community to raise significant awareness and over $7,940 in fundraising for CFWA during 65 Roses month.

Shari and Matthew on their amazing Nepal Trek for CF.

Fundraising News

Here's just a small taste of the dedicated community fundraisers who've recently held fundraising activities for Cystic Fibrosis WA.

Busselton Golf

We'd like to thank the Rotary Club of Busselton Geographe Bay and Busselton Golf Course for their support of Cystic Fibrosis WA (CFWA) at their second annual Golf Day for cystic fibrosis (CF). Players were spoilt with a beautiful sunny day out on the course, followed by a sausage sizzle and presentation of prizes in the clubhouse.

Thanks to their hard work and the support of the local community, they raised a whopping $7,000 which will go towards important support services and CF research funding.

We would like to make special mention of all the Rotarians, club members and players for helping to make the event such a success and continuing to spread awareness of CF in regional WA.

Trekking Nepal for CF

In October 2018, siblings Shari Douglas and Mathew O'Brien completed a six-day trek in Nepal to raise awareness and over $11,700 for CF.

Their inspiration for the challenge is a childhood friend who has CF. Shari spoke to the Albany Advertiser before the trek and said, "Growing up we have learnt and witnessed the difficulties he [their friend] has had to go through so this is very important to us".

Shari has been a long-time supporter of CFWA and this is the second trek she and her brother, Matt, have completed. They also did a Kokoda trek in 2016 with their sister, Nicole Forgione, which also raised significant funds and awareness for CF.

Thank you to Shari, Matt and all their supporters!

65roseschallenge.everydayhero.com/au/nepal-trek-cystic-fibrosis

The volunteer organisers of the Busselton Golf Day for CF

Charitable Acts

A big shout out to the crew at Heaps Cool Music for making CFWA a beneficiary of their first Charitable Acts gig late last year. They wanted to combine their love of music with helping a good cause and came up with the brilliant idea of 'Charitable Acts', a show that brings together feel-good music and feel-good vibes of supporting the community.

Hosted at the Aardvark on Saturday 2 December, the gig brought together local talents Butter, Montana Wildhack, Platform 2, Maeve from Maeve & Sara and Sean from Lakesider.

Thank you to the Aardvark, all the performers and the crew at Heaps Cool Music for your support and help in raising awareness for families affected by CF in the community.

Concept AV Proudly Supporting Cystic Fibrosis WA

Connect, Inform, Inspire

Geoff, owner and Managing Director of Concept AV, had heard a little about cystic fibrosis (CF) and he wanted to understand more. With no personal connection to CF, he had read and seen enough to understand the relentless nature of the condition. Geoff contacted Cystic Fibrosis WA (CFWA) Business Development Manager Karen De Lore to talk about how he could get involved.

What does Concept AV do?

Concept AV is dedicated to providing our customers with innovative audio-visual solutions that connect business, inform communities and inspire students. We build custom-designed solutions, including work on the conference facilities in The Niche building. We work with businesses, educators and government organisations and are perfectly placed to help create awareness around CF.

What drew you to CFWA?

We were supporting charities on an ad hoc basis and I decided to make a bigger difference by putting all our support behind one local charity. I have always had a real fear of not being able to breathe. What I have read about people who live with CF going through struck a chord. I felt that my organisation could be a part of helping CFWA achieve better lives for people living with CF.

How Concept AV is helping CFWA

Concept AV is now a regular donor to CFWA and is providing pro bono advice and loan equipment to help us increase our communications IT capability.

We also welcomed Geoff and his team as a sponsor for our 2018 Cystic Fibrosis Golf Classic. Geoff's team heard first hand from our speakers and guests how their support for CFWA makes a difference.

The Concept AV website **www.conceptav.com.au** carries a strong message to their business network, seeking to further involve their clients in our CFWA mission. We are grateful for their continued support of our work.

CONCEPT AV

CONNECT INFORM INSPIRE

www.conceptav.com.au

Number 12 brightly lights up the evening sky

Adam, Emma and their kids

Consulate Court De-Lights This December!

The families from Consulate Court in Thornlie lit up their street for cystic fibrosis (CF) this December, creating explosions of colour and spreading festive joy to the community.

Thanks to the hard work and commitment of these families, an incredible amount of awareness and over $9,311 was raised for CF, brightening all our lives that little bit more!

From remote control drift car showcases and appearances from famous children's characters, to carolling choirs and a visit from the big guy himself, Santa Claus, this exciting little cul-de-sac in Thornlie had it all this festive season!

Do you know what the best part of all this merry fun was? That it was all in the spirit of raising awareness and funds for families affected by cystic fibrosis in WA!

Through the efforts of everyone involved in this incredible month-long event, over $9,311 was raised, a new fundraising record for Consulate Court. This greatly received donation for Cystic Fibrosis WA (CFWA) will go towards supporting important support services and critical cystic fibrosis research.

Not only did the Consulate Court Christmas lights blow our socks off and draw in crowds from all around Perth, it also placed first in the City of Gosnells Safe City 'Best Decorated Street' competition.

This event could not have been possible without the support of several individuals and organisations generously giving their time and energy to bring magic to the street every night. Thank you to the WA Team of Charity Heroes (WATCH) for putting smiles on everyone's faces with their characters, the City of Gosnells for bringing Santa himself to visit, and the Peppermint Choir for filling the street with the sweet sounds of Christmas carols, what a treat!

A special thank you to Emma, Adam and all the residents of Consulate Court who were involved in putting on this massive month of awareness and fundraising for CF. Thank you to all the volunteers who helped throughout the month including those who were part of the CFWA volunteer team.

Kids enjoy fun and games.

The WATCH team greet Santa's firetruck as he arrives

CFWA Christmas Appeal

Thank you to Ari and his family for sharing their story this Christmas time.

Happy New Year and thank you to all our generous Christmas Appeal supporters.

Cystic Fibrosis WA (CFWA) is very grateful to Ari's family for participating in our recent appeal. Adorable Ari has had a wonderful Christmas with his family, full of laughter and fun times. As always, his cheeky little smile never fades. We wish Jamie, Jodie and their family all the best for the year ahead.

Our Christmas Appeal has raised over $8,500 which will make a difference providing essential support services and programs for CFWA families. If you missed our campaign, you can still support through our website **www.cfwa.org.au/appeal** or by contacting the CFWA office on 08 6457 7333.

Working with other state cystic fibrosis (CF) organisations, CFWA runs two annual appeals. This collaboration allows us to share resources and provide a consistent awareness campaign across Australia.

If you would like to be part of a future campaign by sharing your family's CF story, or your business can help with pro bono support, please contact Karen De Lore at **marketing@cfwa.org.au** or on **08 6457 7333.**

Sunshine for Siblings

Lisa, mum of Joshua (aged 5), held a picnic at Kings Park for young cystic fibrosis (CF) siblings.

Not quite sunshine, but the rain did hold off long enough to allow for a lovely morning at Kings Park for the recent "Sunshine for Siblings" event.

Fairy Sparkles and her sidekick, Superman, kept the children entertained and we all got to enjoy some yummy picnic food. This was a great chance for families with young siblings to come together and make new friends. Thank you to Lisa for organising this wonderful event.

If you think you might be interested in attending a similar event this year, please contact Paula on **services@cfwa.org.au** or **08 6457 7333.**

Parents and Carers Dinner

Some of our parents and carers came together to enjoy an evening out at The Captain Stirling Hotel in Nedlands.

Held during Carers Week, the evening provided a great opportunity for parents to share stories, build relationships within our community and enjoy some well- deserved R & R.Thanks to the generous support of Carers WA, Lotterywest and the City of Nedlands, we were able to provide dinner, drinks and a gift bag for all parents that attended.

For more information about the Parents Dinner and other member events we run, visit **www.cfwa.org.au/what-we-offer/events**

Carers WA Australia

City of Nedlands

lotterywest supported

Siblings Camp Goes Bush!

Thanks to the generous support of the Mazda Foundation, the Siblings and Offspring Camp 2018 travelled to regional WA for a fun-filled 3-day outback adventure!

Mazda Foundation

A three-hour bus ride east delivered us to Camp Kulin which runs a nationally-recognised camp program for young people. Team building, confidence building, and persistence were the key motivators behind all the activities we participated in, and I do mean 'we' as everyone got involved with some of the CFWA staff being the most competitive!

Giant Foosball, four-square in the air, hungry hippo and the blind maze were some of the highlights but really, everything we did was awesome and the kids that came along to camp were awesome, too.

We visited the town's local museum and tried out some of the old vintage cars and trucks and on the last night we enjoyed a quiz night 'Tanya style' which involved lip sync battles, dancing, toilet rolls and newspaper, and ended with Ric being crowned Camp Kulin King!

The Sibling and Offspring Camp is for kids aged 8 to 16 with a parent or sibling with cystic fibrosis. The camp provides the opportunity to meet other kids who know what it's like to have someone with CF in their family, share stories and make new friends. If you haven't been to camp before and would like more details, contact Paula on **services@cfwa.org.au** or telephone **08 6457 7333**

A Breathless Love Affair

A review of the book *Five Feet Apart*.

Five Feet Apart is a young adult novel, soon to be released as a movie, which explores the complications of being a young person living with cystic fibrosis (CF). It is read in alternating perspectives of Stella and Will, two teens staying in the respiratory ward of Saint Claire's Hospital. Stella has forgone the chance to attend her senior class trip to Mexico in order to prepare herself for a double lung transplant. During her stay in hospital, Stella meets Will – a devastatingly handsome boy with CF. Although they initially do not attract, soon a whirlwind romance develops.

How does this book discuss cross-infection?

As the title suggests, a main factor in the developing relationship of Stella and Will is the possibility of sharing infections, commonly known as cross-infection. Although the recommendation from their treatment team is to stay six feet apart, they steal one foot back as a way to feel control over their CF.

Research has shown that people with CF can easily share germs with each other. Bacteria found naturally in the environment can thrive in the lungs of people with CF and once contracted, some of these germs are difficult to treat with antibiotics. Burkholderia cepacia (B. cepacia) is an example of a resistant bacteria.

In this story, Will is being treated for B. cepacia, an infection which currently prevents people with CF from being considered for lung transplant. However, with continued advances in medicine this may not always be the case.

Is this book relevant to Australian readers?

Although the majority of CF information is accurate and relatable to an Australian audience, the book is set in small-town America at a fictitious hospital. There are treatments that have been made up or are specific to the United States.

In terms of cross-infection, Cystic Fibrosis WA (CFWA) have adopted the Infection Prevention and Control recommendations which states that 'People with CF should be separated by a distance of at least four metres, or 13 feet'. This is obviously a lot more than the recommended six feet apart referred to in the book.

There is also prominent mention of the AffloVest as a means of daily treatment. Although current research does not support the use of the vest, this part of the book does reflect positive routines for airway clearance. Further, it is important to note that the American medical system is different to the Australian medical system. As Australians have greater access to affordable care, the outcomes and attitudes towards CF are, generally, more positive.

What are the positive themes of this book?

There are many positive themes throughout this book and both the book and movie will help to increase awareness of CF to the general public. Five Feet Apart explains the intricacies of CF as well as detailing the treatment burden undertaken by people with CF. Although the first concern most people have about this book is the distance of two teens with CF in love, there are many examples throughout the book of teens with CF interacting in a safe and appropriate manner. Many teens may feel alone in their experience with CF, however Five Feet Apart shows that the use of technology can safely connect teens to each other.

Do you recommend this book?

I recommend reading this book and using it as a tool to facilitate a discussion surrounding the challenges presented with your young person. For young people with CF, there are many confronting issues that could be found distressing, however, this book and movie will be in mainstream media and most likely to be discussed by friends, family and others in the community.

If you or someone you know find this content distressing please contact CFWA. We have a range of resources available to address your concerns.

Further support

If you read this book or watch the movie and find that you have questions, or would like some support, please contact Kathryn on **servicesmanager@cfwa.org.au** or **08 6457 7348.**

Barbagallo Men's Health Series

Health, Fitness and Wellness

The Perth Integrated Health Group has been passionate about health, fitness and wellness as part of their patient care ethos for over 30 years with many of their events and programs benefitting not for profit organisations they support.

Hot on the heels of the Maserati Women's Health Symposium that they hosted in September 2018, they have just launched The Barbagallo Men's Health Series comprising six workshops where he will bring together like-minded health professionals with the common purpose of enhancing and promoting men's health and wellness.

Barbagallo Motors are the major sponsor of this event and the series will be held at their showrooms.

Cystic Fibrosis WA (CFWA) is grateful to Perth Integrated Health Group for nominating CFWA as the charity partner for this event, with part ticket sales supporting CFWA.

Themed around their Managing Director's favourite cars the series will be run on Wednesday evenings during March and April 2019.

- **Wednesday 20 March** - Heart to Heart by Alfa Romeo
- **Wednesday 27 March** - Land Rover & The Science of Cycling
- **Wednesday 3 April** – The Importance of Fitness by Jaguar
- **Wednesday 10 April** – Endurance by Maserati
- **Wednesday 17 April** - Performance Enhancement by Ferrari
- **Wednesday 24 April** – Volvo for The Next Generation
- **Wednesday 1 May** – Coaching Zone

To register for the series or individual workshops go to **https://www.registernow.com.au/secure/Register.aspx?E=33322**

Tickets

$60 per person to attend all seven presentations OR $15 per person to attend one workshop.

EVENT CALENDAR

Save the date for these 2019 events

2019

February

16 - Corporate Battle of the Bands

22 – Charity Gig by band Sixty+

23 – Rottnest Channel Swim

March

6 – Coffee Morning for 65 Roses Day

20 – 27 Barbagallo Men's Health Session 1 - 2

TBC – Great Southern Outreach

April

3 – 24 Barbagallo Men's Health Session 3-6

4 – 65 Roses Volunteer Workshop

17 – CFWA Annual General Meeting

May

1 – Barbagallo Men's Health Session 6

1 – Evening with the CF Scientists

4 – Ladies' High Tea

5-10 – Regional Respiratory Training Program

19 – HBF Run for a Reason

23 – 65 Roses Rose Wrapping Day

24 – 65 Roses Day

August

3-4 –Australasian CF Lay Conference

4-6 –Australasian CF Medical Conference

TBC - Perth City to Surf

September

1-30 - Serve it up for CF in September

October

2-4 – Sibling and Offspring Camp

19 – Parents' Dinner

TBC – Telethon Weekend

November

1 – Cystic Fibrosis Golf Classic

10 – Men's Support Event

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/**

13TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

3-6 August, 2019 | Crown Towers Hotel, Perth

Celebrating Partnerships

CYSTIC
FIBROSIS
Australia

The 13th Australasian Cystic Fibrosis (CF) Conference is heading to Perth in 2019!

Don't miss out on a fantastic opportunity to join with fellow members of the cystic CF community and learn about the latest advancements in CF research, treatments and care. Book your registrations now!

For more information and to register visit.

www.cysticfibrosis.org.au/acfc

Cystic Fibrosis WA is excited to be able offer conference subsidies to our members. Visit our website for more details.

www.cfwa.org.au/what-we-offer/subsidies-equipment