

EDITION 2 2018

RED



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RED CEO MESSAGE



NIGEL BARKER, CEO

As we get stuck into 2018, we have embarked upon a new journey outlined in our 2017-20 strategic plan. This plan has been developed with input from a broad range of stake-holders and members.

In developing this plan, we realised the value of our last strategic plan; achieving around 90% of what we set out to do. The models we employed to deliver services and raise funds did a great job. They enabled us to become one of the most successful cystic fibrosis (CF) associations in Australia. These

models were however, a product of their time. As our environment and the wants and needs of our members changed, it became clear that these models had had their day and were not going to be capable of supporting our continued growth.

Our new perspective is 'profit for purpose' and we are developing new fundraising strategies to reflect that, whilst leveraging technology to re-design service delivery models which will deliver an even bigger range of services with greater efficiency.

We have retained our vision of Lives Unaffected by CF, as this accurately portrays our vision of the future; a world where a person can achieve their full potential unencumbered by the disease.

We have re-focused our mission to identify CFWA as "a social enterprise that funds critical research and essential support services to improve the lives of children and adults affected by CF". Our stretch goals for the next three years are aligned to this mission.

Our value proposition is that; when you are supporting CFWA you are investing in 'lives unaffected by CF'.

The plan identifies 5 goals:

1. Improved quality of life for people

affected by CF. In 2017, 42% of people affected by CF in WA were classified as 'thriving' vs 62% in the Australian general public. CFWA will work towards closing this gap.

2. \$1m contribution towards CF research per annum to develop and deliver clinical benefits for people with CF.

3. New drugs are approved in line with global standards.

4. Member support to be maintained at high levels (CFWA Value Index Score > 80).

5. CFWA is financially sustainable.

We are working towards having 12 months of operational reserves in the form of cash reserves and securities.

Our 2017-2020 plan makes explicit a clear strategy to achieve these goals and meet the needs and expectations of the wider CF community. A copy of the plan is available on our new website www.cfwf.org.au/about-us/annual-reports-policies.

We are grateful to Lotterywest for providing funding, to CATALYSE for guiding the organisation through the decision-making process, and you the members, for your valued input.

Nigel Barker

DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our third edition, please contact us before Tuesday 5 June 2018

DO WE HAVE YOUR CORRECT DETAILS?

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

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ON THE COVER

Ashleigh in training for her 65 Roses Challenge

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LOOKING AHEAD AT A BUSY 2018

At Cystic Fibrosis Australia (CFA), our diaries are already brimming with events, and challenges!

We are meeting with our pharmaceutical and corporate partners, writing grant applications, designing development work for the next 12 months and looking at new initiatives. Shortly, together with members of the cystic fibrosis (CF) community, we will be evaluating the Innovation Grant applications. This is always a fascinating exercise to see what the brightest research minds in CF have planned for our future. We are told the Christmas Card campaign, directed at Vertex and the Minister for Health, was effective, and still, letters from the community continue to roll in. CFA will make sure every piece of correspondence gets to its destination. We are even producing a hard cover book for Vertex and the Minister to ensure that our message is not forgotten.

So, do you want to see yourself in print? There is still time to have your say and share your story and concerns. Simply email your message to vanessak@cfa.org.au. Over 80% of letters received were from parents, relatives and friends of people with CF. We would love more stories from people whose lives are in any way affected every day by the debilitating effects of this disease.

In 2018, think about joining CF CAN, our Consumer Advocacy Network. There will

be training across the country to meet the demand. We have many activities where we need compelling advocates, so it's a wonderful way for you to make a compelling statement for everyone's benefit. As I mentioned before Christmas, there are many ways to get involved in CFA's projects and add great value and expertise. Here's just a few...

1. New quality improvement programs will need committee members.
2. The Australian Cystic Fibrosis Research Trust 'Think Tank' needs participants.
3. Our new mental health initiative will need champions.
4. Consumer Connect needs presenters and group discussion facilitators.
5. Research grant reviewers are always required, and no medical or scientific knowledge is needed, and
6. Finally, Ministerial and Government body stakeholder meetings are another way CF CAN advocates can further our cause and add considerable weight to our arguments and protestations.

If you do want to get involved simply email Liz at Lizk@cfa.org.au and we will find you a task that is both enjoyable and worthwhile.

Yours sincerely

Nettie Burke, CFA CEO



JOIN THE CHILD AND ADOLESCENT CYSTIC FIBROSIS CONSUMER REFERENCE GROUP

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

They are looking for additional members to join this dynamic group which is a formalised group of parents and patients with cystic fibrosis (CF), brought together to:

- Support the development of partnerships between consumers, researchers, research

organisations and clinical staff.

- Provide a consumer perspective to both clinical and research aspects of CF.
- Advise about research and clinical priorities, practice and policies.
- Enhance the quality and relevance of research and clinical activities through consumer participation.

If you would like further information about

this role please contact Kaye Winfield by email on Kaye.Winfield@telethonkids.org.au or phone 08 9489 7818.





65 ROSES DAY 2018

May is the national month of awareness for cystic fibrosis (CF) and the last Friday in May is 65 Roses Day.

What is 65 Roses Day?

On 65 Roses Day we paint the state with roses to raise awareness and funds for children and adults living with CF. Every year on 65 Roses Day, many generous supporters and organisations around WA get involved by selling colourful fresh roses in their workplaces, schools and local community groups.

The funds we raise from this event will enable us to continue to provide support services and research funding for families living with CF in WA.

How to make a difference

Take roses to sell in your workplace or school

Take a bucket of 25 or 50 individually wrapped roses to your workplace, school or community centre (no pre-payment required). Sell them to your friends and colleagues for \$5 each and deposit the funds you raise to Cystic Fibrosis WA (CFWA). We can even deliver them to your home or workplace!

Treat someone special to a posy or bouquet

Help spread awareness of CF and 65

Roses Day by surprising a friend or loved one with a florist-arranged \$30 posy or \$50 bouquet. Order online to have it delivered to their home or workplace on 65 Roses Day, Friday 25 May.

Spoil your mum with a Mother's Day bouquet

Give your mum a gift that makes a difference this Mother's Day with a florist-arranged bouquet in support of CFWA. Order online and receive a certificate to present to your mum on Mother's Day to let her know her bouquet will be hand delivered to her home or workplace on 65 Roses Day, Friday 25 May.

More Information

We can support your 65 Roses fundraising efforts by providing you with a free resource kit full of goodies such as posters, balloons and stickers.

Visit www.cfw.org.au/65roses to order your roses or contact Marnie on events@cfwa.org.au or 08 6457 7333 for more information.



One of the 65 Roses bouquets you can order



The WAFEX team selling roses in our stall in the city



65 ROSES DAY VOLUNTEERING

Last year, with the help of hundreds of volunteers, we wrapped and sold 12,600 fresh, colourful roses around metro and regional WA.

We need your help again this year to spread further awareness and raise much needed funds for children and adults living with cystic fibrosis (CF) in WA.

Join our volunteer team and help paint WA with roses this 65 Roses Day!

How you can help

Join us to wrap roses on Wrapping Day

Get a group of family, friends or colleagues together for a fun day of wrapping and packing thousands of fresh, colourful roses ready to sell on 65 Roses Day. No experience is required, and we'll show you how to prepare, wrap and pack the roses when you arrive.

Date: Thursday 24 May 2018

Time: Arrive at 8:30am – finish around 1pm

Venue: Cystic Fibrosis WA, The Niche, 11 Aberdare Road, Nedlands

Help us at a stall on 65 Roses Day

Join us at the Perth city stall or one of our shopping centre locations around metro WA and help sell fresh, colourful roses to raise much needed awareness and funds in the community.

Date: Friday 25 May 2018

Time: Morning shift (9am-1pm), afternoon (1pm-5pm) or all day (9am-5pm)

If you'd like to join the 65 Roses Day

volunteer team visit www.cfwa.org.au/65roses to sign up or contact Marnie on events@cfwa.org.au or **08 6457 7333**.

Regional 65 Roses

In 2017, we had 65 Roses Day stalls and fundraisers spread far and wide from Broome to Albany and everywhere in between! If you live regionally and would like to be involved in 65 Roses Day, please get in touch with Marnie on events@cfwa.org.au or **08 6457 7333**.

We'll let you know what might be happening in your area and can give you more information on hosting your own 65 Roses awareness and fundraising activity in your community.

65 ROSES DAY STALLS

Find your closest stall to visit on 65 Roses Day



Drop in to one of our shopping centre stalls on 65 Roses Day, Friday 25 May 2018, and buy a \$5 rose in support of children and adults living with cystic fibrosis in WA.

We're working to add more stall locations to this list, including stalls in regional areas. To stay up to date with new locations as they are added, visit the website www.cfwa.org.au/65roses or like and follow Cystic Fibrosis WA on Facebook.

Here are our current stall locations:

- Perth City
- Westfield Carousel
- Bull Creek Stockland
- Waterford Plaza
- Westfield Whitford City
- Belmont Forum
- Yanchep Central
- Wanneroo Central
- Alton Park Shopping Centre
- Ocean Keys Shopping Centre
- Karrinyup Shopping Centre
- Winthrop Village

- Albany Plaza

Unable to visit a 65 Roses Stall?

You can take roses into your workplace or school to sell for \$5 each and deposit the funds raised to Cystic Fibrosis WA after the day. Visit www.cfwa.org.au/65roses to make an order of 25 or 50 individually wrapped fresh roses (with no up-front cost to you) and we'll send you a free 65 Roses Day resource kit to help with your awareness and fundraising efforts.



PERTH CHILDREN'S HOSPITAL UPDATE

The new children's hospital is on track to commence taking its first patients in May 2018, with the final move of all patients by June 2018. For a comprehensive update, information can be found on their website.

www.perthchildrens-hospitalproject.health.wa.gov.au



MEET ONE OF OUR 65 ROSES AMBASSADORS, ALEX

We spoke to Alex, a young woman living with cystic fibrosis (CF), about her motivation for being an ambassador both online and in her community.



Alex sharing a picture of her makeup skills and her PICC line



Alex shares a bit about her daily treatments with her Instagram followers

RED: What inspires and motivates you to be an ambassador for CF?

ALEX: As a CF patient, you have to stay positive. CF is life consuming and you can't let it get the better of you. Therefore, I motivate other people living with CF to stay positive by doing what they love; whether it be a hobby, passion or their actual job. That way we are driven and motivated to keep going and stay strong. Working towards goals one-by-one is the best way to go. Without positivity, passion and motivation, there can really be nothing but gloomy hospital visits, CF symptoms and nasty chest infections.

RED: What do you do as an ambassador for Cystic Fibrosis WA (CFWA)?

ALEX: Keeping my own hobbies, passions and interests, I aim to inspire those with any illness that no matter what, you can do what you want to do to the best of your

ability. I include my daily CF routines and warrior wounds, like my PICC (peripherally inserted central catheter) line, in photos and show them off to the world!

RED: How do you help to raise awareness for CF?

ALEX: I include my CF in my social media posts. My hobby, passion and part-time work is MAKEUP. Yes, I am a makeup artist and I love to show off my true beauty. And my beauty includes CF. Unfortunate as it is, it is what it is, and what better way to raise awareness through one of social media's biggest influence topics, "BEAUTY".

RED: Do you have a message you'd like to share with other people living with CF?

ALEX: Us CF'ers, we are who we are, we have this illness we cannot fix, but we can maintain it. Therefore, stay positive, motivated and driven. Don't give up on

what makes you happy. Yes, we can dream, but not all dreams come true. So, eliminate the negative and surround yourself with happy and loving people. Without our health, we are nothing. Stay as healthy as you can. With a positive mind and setting yourself goals, you can do anything! Work smarter, not harder and be good to yourself.

Take a look at Alex's Instagram **Instagram.com/alexbrwynmua** and Facebook **Facebook.com/alexbrwynmua** to stay up-to-date with her awareness raising.

How can you help?

Visit the CFWA Facebook and Instagram and like, follow and share! Don't forget to tag us and hashtag **#CysticFibrosisWA** **#65Roses** when posting.

facebook.com/CysticFibrosisWA
instagram.com/cysticfibrosiswa

ASHLEIGH'S 65 ROSES CHALLENGE

Ashleigh is a young inspirational adult who has taken the 65 Roses Challenge of cycling 65 kilometres (kms)

Ashleigh spent much of her childhood growing up in the North West, specifically Port Hedland and Broome, which she loved. She moved to Perth last year and has taken full use of her opportunities, recently becoming part of the state netball league. She is currently doing year 12 and although she misses country life, she loves being able to see more of her extended family and go to the beach.

RED: How did you get the idea of doing this challenge?

ASHLEIGH: I read an article on someone doing a bike challenge and that inspired me. I bought myself a good mountain bike to take the challenge. I have always wanted to help out and give back to the cystic fibrosis (CF) community. People living with CF face many challenges on a daily basis, so I have decided to challenge myself by riding 65kms in one day.

I'm doing this for my brother Jordan, who has CF. We don't see each other as often as we used to but we're still close. He's currently studying geology at university which he's enjoying, something he first became interested in whilst living in Port Hedland.

RED: What are you hoping to achieve through this challenge?

ASHLEIGH: Help raise awareness and help younger children's lives. I have told my school and the gym I attend regularly about my bike challenge, so I'm getting supporters and they will help promote

this through their newsletter. My friends have seen this on my Facebook page and are interested in making donations. Some have already donated, so that's also good. My brother and my family are my main support crew. Jordan will be driving alongside me and giving me water, food and support as I ride.

RED: What are you doing for training?

ASHLEIGH: I ride each day, the furthest I've ridden so far is 25km. I'm expecting it to take me about 5-6 hours. I also do a lot of training for netball 3-4 times a week, so I'm keeping fit.

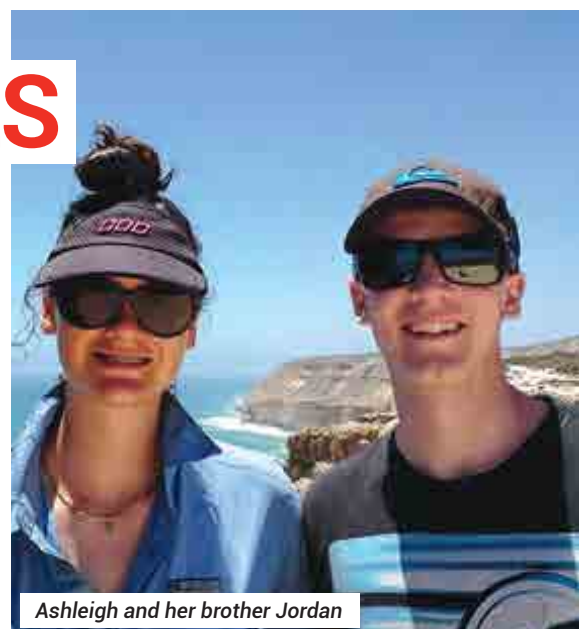
RED: What date are you planning to do your ride and what are your future plans?

ASHLEIGH: It will be on a Sunday in May, after I have worked out my netball schedule. Next year I'm thinking of going to university, maybe studying teaching or something around sport, not too sure yet.

To read more about Ashleigh's 65 Roses Challenge or to support her fundraising efforts visit 65roseschallenge.everydayhero.com/au/cystic-fibrosis-65-roses-65km-bike-ride-challenge

Take the 65 Roses Challenge

If you're inspired by Ashleigh and would like to get started on your own 65 Roses Challenge, visit www.everydayhero.com.au/event/65roseschallenge or contact Marnie on events@cfwa.org.au or 08 6457 7333.



Ashleigh and her brother Jordan



65 ROSES CHALLENGE
FOR CYSTIC FIBROSIS

 **CYSTIC FIBROSIS**
Western Australia





RESPIRATORY EDUCATION FOR REGIONAL NURSES AND PHYSIOTHERAPISTS

Each year Cystic Fibrosis WA (CFWA) facilitates a five-day training program for regional nurses and physiotherapists, which is fully funded by the Department of Health WA

The aim of the Regional Respiratory Training Program (RRTP) is to increase knowledge, skills and networks amongst regional nurses and physiotherapists, to provide them with the confidence and competence to support and care for patients with respiratory conditions in the regions. It also facilitates improved communication between regional health professionals and the respiratory experts in the metropolitan tertiary centres.

The RRTP is a collaborative project supported by Princess Margaret Hospital,

Sir Charles Gardiner Hospital, Royal Perth Hospital, Fiona Stanley Hospital, Silver Chain, Black Swan Healthcare and the Asthma Foundation of WA.

It is an extremely popular program which fills very quickly. We already have a full quota of twenty regional nurses and physiotherapists registered to attend the 2018 program. The registered participants are from all over WA including Kununurra, Port Hedland, Broome, Newman, Northampton, Exmouth, Geraldton, Bunbury, Pemberton, Albany and Esperance.

The RRTP has been running since 2010 and the feedback received continues to be positive with participants eagerly encouraging their regional colleagues and networks to register for the next program.

If you would like more information, please contact Kathryn Pekin on **08 6457 7333** or servicesmanger@cfwa.org.au



Government of Western Australia
Department of Health

CYSTIC FIBROSIS

WA ANNUAL

GENERAL MEETING

Official Notice of 2018 AGM

CYSTIC FIBROSIS WESTERN AUSTRALIA (INC)

Wednesday 18 April 2018 7.00pm

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

Corner of Aberdare Road and Hospital Avenue.

**Special Guest Speaker: Dr Robert LARBALSTIER,
Director WA Heart Lung Transplant Unit and Head of
Cardiothoracic Surgery and Transplantation, Fiona
Stanley Hospital.**

Refreshments served following the AGM

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

KATE'S REASON FOR RUNNING

Kate is running in the HBF Run for a Reason this year and has already raised over \$1,700! We asked her to share her story and motivation for raising awareness and funds for Cystic Fibrosis WA (CFWA).



Kate and Roxie: photo courtesy of Kerry Bardot Photography



In June 2016, my daughter Roxie was born with cystic fibrosis (CF).

I had no knowledge of this disease or family history of this genetic disorder.

While she may live longer than children born with CF in previous generations, I am not satisfied with the average life expectancy for my beautiful, dynamic, cheeky, sweet baby girl.

The community of CF researchers here in WA and around the world are currently investigating and trialling new medications which can extend the life of her lungs, which deteriorate every single day.

There are medications being developed

now that may stop her from needing regular hospital admissions, or from being on oxygen or needing a lung transplant. I want her to be able to play and enjoy her childhood and not worry about those things for her future. There is even hope of a cure one day. I want to tell my daughter I helped raise funds for that and played a part in supporting research.

Her life matters, especially to me.

After 14 months of not exercising due to a nerve injury from her birth, this 4km run is going to be a challenge. But every day is a challenge for my daughter with two physiotherapy treatments per day and

multiple medications every few hours to help her digest food, absorb vitamins, protect her from bacterial infections, and replace the salt lost from her body to avoid dehydration.

I'm running for you Roxie, I hope you will outrun my lifetime, that's for sure.

If you would like to help make a difference and support children living with CF like Roxie, you can join the CFWA team in the HBF Run by registering at www.hbfrun.com.au and nominate CFWA as your chosen charity, or donate to Kate and Roxie's fundraising page at hbfrun2018.everydayhero.com/au/cystic-fibrosis-roxies-angels

FUN IN FREO FOR OUR 2018 PARENTS' RETREAT

Held from the 16 to 18 March at the Gallery Suite Apartments in Fremantle, we had a full house at this year's Parents' Retreat, with 39 attendees.

Parents enjoyed a range of activities including a quiz night, a fun afternoon at The Escape Hunt with the mission to 'escape the room' in 60 minutes, a rejuvenating yoga session, group dinner at a local Italian restaurant and plenty of time to relax and enjoy some alone time or chat with others.

This important event provides parents with the opportunity to take a break from the caring role, spend one-on-one time with their partners and connect with other parents of children with cystic fibrosis (CF).

A big thank you to Lotterywest for their generous support in enabling us to run this event, which is so greatly looked forward to by our members each year.





CYSTIC FIBROSIS GOLF CLASSIC 2018

Cystic Fibrosis WA (CFWA) invites you to be a part of the annual George Jones Family Foundation Cystic Fibrosis Golf Classic, held at the prestigious **Lake Karrinyup Country Club** on **Friday 26 October 2018**.

Register a team of family, friends or colleagues 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.

If you're unable to attend you can still support the event through the donation of goods or services to use in our raffle, silent and live auctions. We'd be delighted to accept donations of any nature, including; holiday packages, experience vouchers, wine and spirits.

For more information or to register a team, visit www.cfwa.org.au/golf or contact Marnie at events@cfwa.org.au or on 08 6457 7333.



HOW CAN OUR HOMECARE WORKERS HELP YOU?

Cystic Fibrosis WA (CFWA) are contracted by the Department of Health WA to provide home services to our members and their families. These services are delivered by our Homecare Workers (HCWs) in consultation with the cystic fibrosis (CF) teams at Princess Margaret Hospital, Sir Charles Gairdner Hospital and Fiona Stanley Hospital.



HCWs are supported by the CFWA services team including our services manager and social worker Kathryn, community nurse Sharon and physiotherapist Sam. Home visits occur each week and may include assistance with airway clearance and exercise, nebuliser support, light home duties and occasional respite.

Each month our team of HCWs meet at CFWA to receive education and training on key competencies to ensure they are delivering treatment in accordance with best practice. Some of the topics covered over the past 12 months include cystic fibrosis related diabetes, professional

boundaries, CF medications and infection prevention and control.

In February this year we held our Annual Study Day where our HCWs attended a full day of training to complete annual certifications, including CPR and hand hygiene and receive more in-depth training on airway clearance techniques and devices. These sessions include both theoretical and practical components to enable the HCWs to understand how the various treatments work, assemble equipment and troubleshoot when equipment isn't working.

Our HCW service is unique and provides

much needed assistance to people with CF and their families. At CFWA we are constantly reviewing the quality of the service we provide. We are currently in the process of developing a new series of e-Learning modules for our HCWs to ensure they have immediate access to the training they need to allow them to continue to deliver a high-quality service to our members.

If you would like more information about how our HCW service could help you and your family, please contact Kathryn on servicesmanager@cfwa.org.au or **08 6457 7333**.

CyFi SPACE STUDY

Parents, if you have a child with cystic fibrosis (CF) aged between 12 and 17 years of age, with access to either a smartphone or a tablet, the Telethon Kids Institute (TKI) would love to hear from you.

TKI has developed a smartphone app, CyFi Space, designed to improve social contact and wellbeing in young people with CF and they want to know what young people think about it.

If your child is happy to test the app and complete an online survey, go to www.telethonkidsinstitute.org.au/CyFiSpaceStudy or call **Dr Jacinta Francis** or **Rebecca Nguyen** on **08 9489 7931** or email CyFiSpaceStudy@telethonkids.org.au to find out more.

Participants of the study will receive \$15 for completing the survey and \$15 for the online interview.



FUNDRAISING NEWS

We have hit the ground running in 2018 with a rugby team 65 Roses Challenge, the return of the Corporate Battle of the Bands and a swimmer in the Rottnest Channel Swim.



The CF Cougars wearing their 65 Roses jerseys



CF Cougars in action!



Lindsay crosses the finish line at Rottnest Island



Lindsay swimming solo in the Rottnest Channel Swim

Cystic Fibrosis Cougars

The Casuarina Cougars, a Darwin based Rugby club, raised awareness for cystic fibrosis (CF) at this year's international Hottest 7's event held in late January. They named themselves the 'Cystic Fibrosis Cougars', organised special 65 Roses Challenge jerseys for the competition and held a special dinner which raised \$5,360.20 for Cystic Fibrosis WA (CFWA).

The club has several connections to CF, including one of the organisers, who is the uncle of a child living with CF in WA. In

addition to this, the guest speaker for the evening was Mark Cummins, who has two children with CF. Mark captivated the guests with personal stories about the challenges of being the father of children who have CF.

Thank you to the organisers Dwight and Shane, the team and the supporters for raising much needed awareness and funds for CF in the community!

Rottnest Channel Swim

Lindsay Livingstone set herself the challenge to participate in the 2018 Rottnest Channel Swim to raise funds and awareness for

children living with CF, like her son Murray who was diagnosed with CF at five weeks old.

She finished the 19.7km swim from Cottesloe Beach to Rottnest Island in an incredible five hours and 16 minutes and raised \$4,489 for CFWA. What an amazing effort!

A massive thank you to Lindsay for all her support and a special thanks to her support crew who wore red CF shirts and flew a CF flag off the boat, so everyone could see who she was swimming for!

CORPORATE BATTLE OF THE BANDS

Five local bands hit the stage at The Charles Hotel on Saturday 10 February to fundraise for CFWA and Youth Focus. Over \$12,000 was raised for the two charities through band sponsorships, ticket sales, raffles and auctions!

Critical Incident won over the crowd and was voted 'People's Choice' on the night and, after much deliberation from the judging panel, the winner of the 2018 Corporate Battle of the Bands was CoveFefe!

Thank you to Phillip Russo, Roger Blow and Tamara Blow

for organising another incredible event; your time and effort is greatly appreciated.

We would also like to thank the MC for the night James Lush, special guest judges John Carey and Patrick Carre, CFWA speaker Caz Boyd, photographer Livia Carre and volunteers Kandace Boyd, Sonya Phillips and Naomi Thomson.

Visit and follow the event Facebook page www.facebook.com/corporatebotb to see live footage and photos from the night.



CFWA Vice President Caz Boyd and Fiona Kalaf, CEO of Youth Focus



2018 winners CoveFefe live on stage



People's Choice winners Critical Incident

.....

Please join us at our

Annual Ladies High Tea

.....

Female cares are invited to join us for an afternoon of high tea, champagne, games and lots of laughter at our Ladies High Tea!

When: Saturday 19 May 2018,
from 3-6pm

Where: The Niche Building,
11 Aberdare Road, Nedlands

Cost: \$20 per person

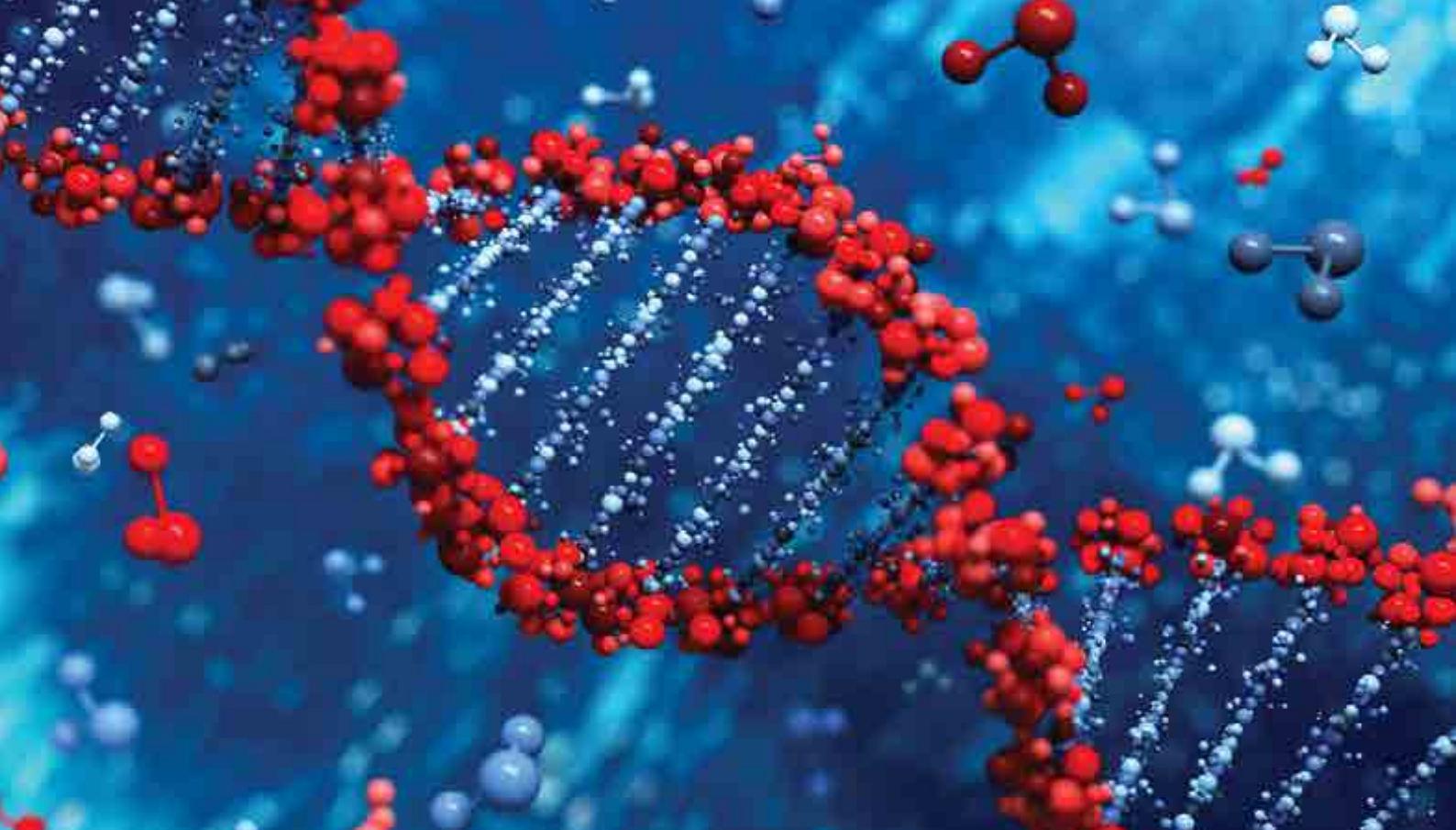
RSVP: <http://tinyurl.com/h3qlrxn>
by Friday 4 May

Guest Speakers:

CFWA member Carolyn Boyd talking about life with CF, and motivational presentation from Australian Diamond netballer, Natalie Medhurst.

.....

Event also includes raffles and door prizes.
For more information, contact Paula
at services@cfwa.org.au or phone 08 6457 7333.



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. The following article was published in January 2018.

'Hypertonic saline has a prolonged effect on mucociliary clearance in adults with cystic fibrosis'

Authors: Aaron T Trimble and colleagues; A Whitney Brownb; Beth L Laubec; Noah Lechtzind; Kirby L Zemane; Jihong Wue; Agathe Ceppea; David Waltzf; William D Bennette; Scott H Donaldson

What was your research question?

CF causes mucus to become more difficult to clear from the lung. Hypertonic saline (HS) inhalation helps rehydrate airway mucus and speed up its clearance. We wanted to know if the effect of HS on mucus clearance lasted for at least four hours in adults with CF.

Why is this important?

Studies showing the health improvements (e.g. improved lung function) of HS treatment in CF patients have typically been performed on teens and adults. In another study, no clinical benefits were found after HS treatment in CF children who were younger than 6 years. These observations led us to question whether the duration of

HS's effect on mucus clearance determines whether or not it improves health outcomes in the patient being treated.

We hypothesised that mucus clearance would generally be accelerated for at least four hours in adults with CF compared to healthy volunteers where HS only has a transient effect.

What did you do?

We measured the rate of mucus clearance in 13 adults with CF at baseline (without any HS), 15 minutes after a dose of HS, and four hours after a dose of HS.

What did you find?

We found that, overall, HS inhalation increased mucus clearance for at least four hours. Even though individual responses varied, the rate of mucus clearance measured in an individual four hours after HS inhalation was about the same as the rate measured 15 minutes after a dose of HS.

What does this mean and reasons for caution?

These results suggest that HS is a longer-acting drug in CF adults than was previously realised.

The results also demonstrate that while not all patients respond to HS, the immediate effect strongly predicts the sustained effect. While these results suggest that a personalised approach to HS use in CF might be possible, we do not yet have proof that the mucus clearance response to HS predicts clinical improvements.

What's next?

Future studies should be aimed at finding ways to determine if a given individual is likely to benefit from HS. It should also be determined whether children with CF, who seem to benefit less from HS, have a shorter duration response to HS.

Original manuscript citation in PubMed:

<https://www.ncbi.nlm.nih.gov/pubmed/?term=HYPERTONIC+SALINE+HAS+A+PROLONGED+EFFECT+ON+MUCOCILIARY+CLEARANCE+IN+ADULTS+WITH+CYSTIC+FIBROSIS>

OUTREACH VENTURES

Providing support to our members and education to health professionals, schools and community groups in regional WA is always a highlight for the services team at Cystic Fibrosis WA (CFWA).



School Education Session



Education at Esperance Hospital



In February, Sharon our community nurse, and Kathryn our services manager, took the early flight to Kalgoorlie to start their busy outreach adventure.

Their first stop was to the Kalgoorlie Hospital to provide an overview of cystic fibrosis (CF) to the emergency department (ED) nurses. Despite the ED being busy, the staff were very interested and grateful for the update on CF, made even more relevant with the news of a few families in town.

That afternoon they provided more education, this time to the children's ward where again, they were met by paediatric

nurses keen to improve their knowledge and skills in caring for someone with CF.

From here it was a quick drive to one of the local primary schools to deliver CF education to a room full of vibrant and engaged teachers, with the drive to implement and learn all they could to achieve the best outcomes for their student. The day ended with a relaxed dinner with one of our local members. Good food, great conversation and many laughs.

The next day they hit the road for Esperance. Here they provided education to staff at a local community centre, held an

education session at the Esperance Hospital and educated 24 teachers and support staff at one of the local primary schools. All the staff were very welcoming and appreciative.

The outreach trip ended with a lovely catch up with one of our Esperance families. It is during these times that the importance and value of our regional visits is clear.

The team at CFWA are currently planning future outreach trips to Bunbury and Albany. We will keep you posted in E-news and in our next edition of RED as to our plans for the rest of the year.

EXERCISE PROGRAM FOR KIDS WITH CYSTIC FIBROSIS

Curtin University have offered up their innovative new physical activity program, PAEDS (Participate Achieve Encourage Develop Succeed), to children with cystic fibrosis (CF) aged five to 15 years.

The program pairs each child with their very own university Student Mentor studying Exercise, Sport and Rehabilitation Science, Physiotherapy, Exercise Physiology or Occupational Therapy for one-on-one sessions that are targeted towards helping your child achieve their sporting goals, whatever they may be.

The Student Mentors are passionate about helping kids get active and achieve their goals, and the Curtin campus has world-class sport

and gym facilities.

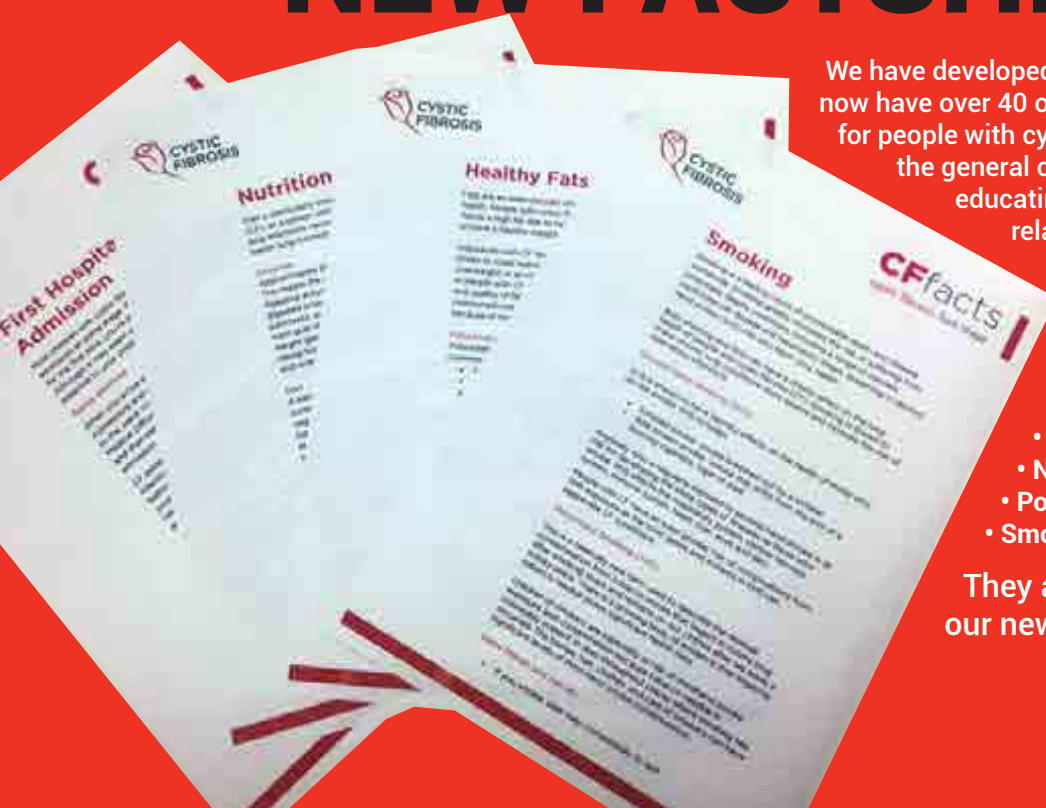
The program runs four times a year to run alongside university terms. Term 2 commences on 30 April and runs for 6 weeks on Mondays and Thursdays 4:30-5:30pm.

Total cost of the program is \$219.50 for the term. KidSport funding of \$150 is available for eligible participants or the CFWA Patient Support Subsidy can be used for those ineligible for KidSport.

To apply, please contact Kathryn on servicesmanager@cfwa.org.au or phone 08 6457 7333.



NEW FACTSHEETS



We have developed a range of new factsheets and now have over 40 on our website. They are designed for people with cystic fibrosis (CF), their families and the general community, so are a great tool for educating those around you on specific CF-related topics.

New topics include:

- Healthy Fats
- Infection Control in Schools
- My First Hospital Admission
- Nutrition for Babies
- Nutrition for Children
- Nutrition for Adults
- Ports
- Smoking

They are all available to download on our new website www.cfwa.org.au.

GRAND BALL GLAMOUR TO SUPPORT VITAL RESEARCH



Arrabella Lawrance will officially open this year's Capel Vale Conquer Cystic Fibrosis Grand Ball at the Crown Grand Ballroom on 12 May. The Margaret River girl with cystic fibrosis (CF) is excited to dress up and represent the CF community in front of an expected crowd of 600 guests.

Conquer Cystic Fibrosis (CCF) is a volunteer-run WA charity which has raised more than \$2.8 million for CF research over the past 15 years. Some of the discoveries made as a result of these funds are used in clinical care today.

CCF hosts events across the state throughout the year, culminating in its Grand Ball.

Arrabella aspires to be a doctor when she grows up to help other people with CF and jumped at the chance to be a part of this year's event.

"I hope we can raise lots and lots of money

that will help me and all the others who have CF," she said. "CF makes me special, but it can also make people very sick, so we need more medicines to make people better."

Last year the charity raised \$509,000 since its previous ball; \$120,000 of which was raised in that one evening.

The funds were distributed to the Australian Cystic Fibrosis Research Trust, Telethon Kids Institute, Cystic Fibrosis WA and the Institute for Respiratory Health.

CCF has a \$1 million commitment over five years to the Institute for Respiratory Health at QEII. The Institute is undertaking several promising CF research projects which also



support the delivery of clinical care to adults through Sir Charles Gairdner Hospital.

Tickets to the CCF Grand Ball will be released on 26 March. For more information, go to www.conquercysticfibrosis.com.



AN EVENING WITH CF SCIENTISTS



You are invited to attend the 2018 cystic fibrosis (CF) research update hosted by the Telethon Kids Institute (TKI). Join us for an annual CF research update from researchers at the TKI. The evening includes laboratory tours, presentations, and an opportunity to chat with researchers and other members of the community. We'll also provide an update on the services and programs provided by Cystic Fibrosis WA (CFWA).

If you have CF, please be aware that there may be other people with CF at this event. We request that you follow standard cross infection guidelines. For further information visit www.cfwf.org.au/about-us/annual-reports-policies

Date: Wednesday 9 May | Time: 6:00pm - 8:30pm, for 6:30pm start

Venue: Telethon Kids Institute, 100 Roberts Rd Subiaco

Drinks and nibbles provided. Please note, RSVP is essential for catering purposes.

To RSVP please visit cfscientists2018.splashthat.com or contact Kaye Winfield at

Kaye.Winfield@telethonkids.org.au or **08 9489 7818**.

MIDWIVES KEEN TO LEARN

King Edward Memorial Hospital (KEMH) is the centre of excellence in Perth that manages and cares for women with complicated pregnancies. They are often the preferred carer for pregnant women with cystic fibrosis (CF), as well as women who are pregnant with an infant with CF.

With advances in CF treatment and management, long-term relationships and pregnancy have become an exciting reality for many women with CF. KEMH work closely with the CF centre at Sir Charles Gairdner Hospital (SCGH) to provide the care required for the unique challenges that are faced.

Our community nurse was more than happy to accept an invitation to provide an

update on CF to 45 midwives and nurses at KEMH during their Genetics and Rare Diseases Study Day. The presentation included the pathophysiology, diagnosis, clinical manifestations, treatment and management of CF.

Feedback from participants showed they found the session informative and interesting, and provided them with

the knowledge, resources and networks required to enhance their nursing practice in caring for this special group of women.

If you are pregnant or thinking of becoming pregnant, we have a range of factsheets under the resources section of our website (www.cfwa.org.au), covering topics including pregnancy, fertility and carrier screening.





\$3.4 MILLION FOR CF RESEARCH!

We're excited to announce that researchers at the Telethon Kid's Institute (TKI) have won a competitive grant from the Australian Government's Medical Research Future Fund (MRFF) of \$3.4m over five years.



Dr Tom Snelling

Dr Tom Snelling, the lead investigator from the Wesfarmers Centre of Vaccines and Infectious Diseases at TKI, said that this type of clinical trial is the best way to determine which treatments work, and which ones don't.

"We are pioneering a new approach to clinical trials, called an adaptive platform trial. This adaptive trial is a type of 'learning health care' model, in which we aim to learn as quickly as possible which treatments are best, which treatments aren't, and in whom".

Dr André Schultz a member of the research

team, said that the grant will be used to support the BEAT CF ('Bayesian Evidence-Adaptive Trial to optimise management of Cystic Fibrosis') trial, which was seed funded by one of Cystic Fibrosis WA's generous philanthropists through the ACFRT (Australian Cystic Fibrosis Research Trust).

"BEAT CF aims to not only directly improve the care of those who take part in the trial – but hopes to provide lasting benefits to CF patients in the future."

The seed funding provided helped the team at TKI to make progress in developing the

platform that they will use as a patient/physician interface for data collection.

For more information about this exciting project, go to [www.telethonkids.org.au/news--events/news-and-events-nav/2018/january/\\$3.4mill-to-improve-treatment-management-of-cf/](http://www.telethonkids.org.au/news--events/news-and-events-nav/2018/january/$3.4mill-to-improve-treatment-management-of-cf/)





CYSTIC FIBROSIS EDUCATION IN WA AND BEYOND

In 2017, our services team were able to provide cystic fibrosis (CF) education, resources and information to a greater audience, due to the updated CFSmart website and our new online eLearning modules.

The website was completed in April 2017, and since the launch, the number of teachers around Australia, and the world, accessing the site has continued to increase throughout 2018. The eLearning modules, designed for early childhood, primary and high school teachers, provide an easy-to-access forum to learn more about the needs of their student with CF.

We worked in collaboration with Cystic Fibrosis Community Care (formerly CFVictoria) who were awarded a grant from the Ian Potter Foundation to further develop the CFSmart website from its basic form.

In 2017, the requests for

CFWA to provide face-to-face education for teachers and students also increased substantially.

In 2017, we provided education to:

- 534 adults
- 205 children
- 57 school education sessions

For further information about the CFSmart program or about our school education sessions please contact our education officer, Natalie via email education@cfwa.org.au or visit the CFSmart website, www.cfsmart.org.

In 2017, our CFSmart stats were:



2,876 visits to the new CFSmart website



Clocked 4,500 YouTube viewings (2014-2017) for the 'Good Clean Hands' video

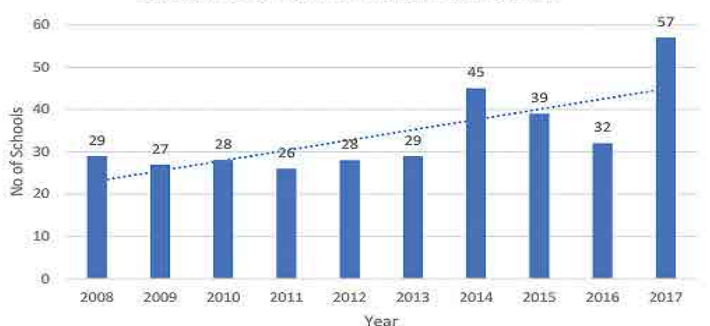


300 eLearning modules completed by 176 people



1,098 followers on the CFSmart Facebook Page

Number of School Visits from 2008-2017



CFsmart
cystic fibrosis education program



event calendar 2018

MARK YOUR DIARIES FOR THESE 2018 EVENTS

APRIL

5 — REGIONAL EVENING WITH CF

SCIENTISTS

5-6 - GREAT SOUTHERN OUTREACH

18 - ANNUAL GENERAL MEETING (AGM)

MAY

9 — AN EVENING WITH THE CF SCIENTISTS

7-11 — REGIONAL RESPIRATORY

TRAINING PROGRAM

19 — LADIES HIGH TEA

24 — ROSE WRAPPING DAY

25 — 65 ROSES DAY

27 — HBF RUN FOR A REASON

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

26 — PERTH CITY TO SURF

OCTOBER

2-4 — SIBLING AND OFFSPRING CAMP

19 — PARENTS' DINNER

26 — CF GOLF CLASSIC

NOVEMBER

10 — MEN'S SUPPORT EVENT


DECEMBER

7 - SPONSORS AND VOLUNTEERS

AWARDS NIGHT

*PLEASE NOTE, DATES MAY CHANGE IF
CONFLICTS ARISE.

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/](http://WWW.CFWA.ORG.AU/GET-INVOLVED/UPCOMING-EVENTS/) OR
CONTACT MARNIE ON [EVENTS@CFWA.
ORG.AU](mailto:EVENTS@CFWA.ORG.AU) OR ON 08 6457 7333.



Spoil your mum with a Mother's Day bouquet

Give your mum a gift that makes a difference this Mother's Day
with a florist-arranged bouquet in support of Cystic Fibrosis WA.

Order online and receive a certificate to present to your mum for Mother's Day.
Her bouquet will be hand delivered to her on 65 Roses Day, Friday 25 May 2018!

www.cfwa.org.au/shop

