

EDITION 1 2016

RED

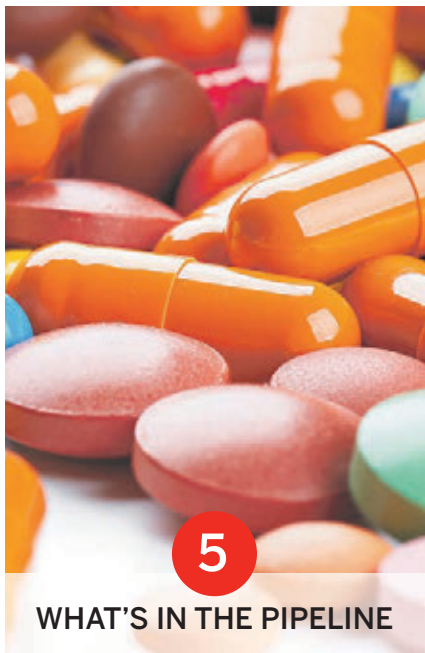
*Cystic Fibrosis WA
40th Anniversary*



In This Issue
Our Community



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RED

CEO Message

THE THEME OF THIS EDITION OF RED MAGAZINE IS OUR COMMUNITY



NIGEL BARKER, CEO

We often talk about the cystic fibrosis (CF) community as a clearly defined group of individuals that share a common cause and belief and act together to achieve some remarkable outcomes. The reality is however, that we are all individuals, often with our own agendas and diverse interests. We sometimes find ourselves competing against each other as we pursue these.

Having worked at CFWA now for eight

years, I have come to appreciate how hard it is to align everyone and get the CF community to focus. When this happens however, we can and do, achieve some remarkable results. Clearly, together we are more powerful than the sum of our parts.

Often it is a crisis that draws people together or a challenge like the listing of Kalydeco™ or advocating for access to new treatments.

In 2016, we will be providing training and orientation to existing and new volunteers and a team of advocates who will play a vital role in arguing for access to the new therapies like the combination drug Orkambi™, speaking with one voice across the whole of Australia.

We will focus on raising money for research and service delivery in what promises to be a tough market as the economy struggles with the downturn in commodity prices. We will be innovative in our fundraising; I am particularly looking forward to the Halloween Run in October and our workplace giving campaign, but even here we need to act together as a community to reach our full potential.

I would encourage you to think about how you may be able to contribute in 2016. This may be limited to a donation of time or money or encouraging your friends to get involved in an outrageous community fundraiser. If you are short of ideas then please download a copy of our community fundraisers hand book from our website or call the office on 08 9346 7333.

2016 is CFWA's 40th Anniversary and whilst we will be celebrating this throughout the year, the festivities will culminate at our Annual Awards night on Friday 25 November 2016. We had over 100 people present in 2015 and we look forward to seeing you there so, although it may seem a long way off, put it in your diary now to lock away the date.

Finally I'd also like to take this opportunity to formally welcome CF Consultant Dr Anna Tai who has recently joined the team at Sir Charles Gairdner Hospital as Assoc Prof Siobhain Mulrennan steps up into recently retired Dr Jerry Ryan's role. There's a special introduction to Anna in this edition and we can't wait to start working with her in the years ahead.

DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our winter issue, please contact us before April 1, 2016

DO WE HAVE YOUR CORRECT DETAILS?

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

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Community Newspaper Group

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ON THE COVER

Cystic Fibrosis WA Home Care Workers and Community Nurse Sharon.

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CFA Update

THE NORTH AMERICAN CONFERENCE

In October this year, I attended the North American Cystic Fibrosis Conference in Phoenix, Arizona.

Before I left Australian shores I set up a full schedule of meetings with my US and UK counterparts. Over the four days I managed to meet with more than 20 people with key roles in a myriad of areas in the cystic fibrosis space.

We really do have a global CF community and there are amazing things happening around the world. Our offshore colleagues are keen for Australia to play a key role in this community.

As new drugs are developed, there are opportunities for Australia to become involved in more trials as our clinicians and researchers are highly regarded around the world.

The Cystic Fibrosis Foundation mentioned specifically Australia's involvement in the Orkambi™ trials and the AREST-CF Early Surveillance Program. Internationally, AREST-CF is seen as a valuable resource for understanding early lung disease and CFA is committed to supporting this program well into the future.

A good deal of work is also being done across the globe in further development of the effectiveness

and flexibility of data registries and peer review processes. CFA plans to collaborate internationally to ensure that our quality improvement programs are world's best practice and truly deliver positive outcomes for people with cystic fibrosis.

As projects develop and progress is made, I will provide updates – and in many instances CFA will be looking to the CF community for feedback and inspiration.

Nettie Burke
CEO, CFA



Official Notice of 2016 AGM



CYSTIC FIBROSIS WESTERN AUSTRALIA (INC)

Wednesday 6 April 2016 7.30pm

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

Corner of Aberdare Road & Hospital Avenue.

Guest Speaker Professor Jonathan Carapetis,
Director of the Telethon Kids Institute in
Perth, Western Australia.

Jonathan holds separate qualifications as a medical practitioner (MBBS), specialist paediatrician (FRACP Paediatrics), specialist infectious diseases physician (FRACP Infect Dis), and specialist public health physician (FAFPHM), as well as a PhD.

RSVP for catering please Friday, 1 April to

08 9346 7333

Refreshments served following the AGM



What's in the Pipeline?

THIS YEAR SAW THE LISTING OF KALYDECO™ (IVACAFTOR) ON THE PHARMACEUTICAL BENEFIT SCHEME (PBS) IN AUSTRALIA. THE DRUG WAS DEVELOPED BY VERTEX PHARMACEUTICALS WITH SIGNIFICANT SUPPORT FROM THE CYSTIC FIBROSIS FOUNDATION (CFF) IN THE USA. CFF SUBSEQUENTLY SOLD THE ROYALTY RIGHTS FOR KALYDECO™ BACK TO VERTEX FOR US\$3.3BN (AUD\$4.7BN) AND IS NOW USING THAT MONEY TO SUPPORT FURTHER RESEARCH INTO CYSTIC FIBROSIS. THIS VENTURE PHILANTHROPY MODEL HAS CAUSED QUITE A STIR IN THE CF COMMUNITY AND FUNDRAISING CIRCLES AND MAY PROVE TO BE A PARADIGM SHIFT IN THE WAY THAT MEDICAL RESEARCH IS FUNDED IN THE FUTURE.

Whilst Kalydeco™ initially targeted the G551D mutation, its use has now been expanded to include other mutations: G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P, G1349D and R117H.

In Australia, these mutations affect just over 7% of the CF population. Kalydeco™ was the very first drug to attack the underlying cause of CF and caused a huge stir of interest as it progressed through clinical trials to market.

Whilst the listing of Kalydeco™ has been warmly received, the CF community in Australia and around the world is now abuzz with the hope that other Cystic Fibrosis Transmembrane Regulators (CFTR modulators) currently in the drug development pipeline will bring relief to people carrying the more common CF mutations.

Orkambi™ also known as Lumacaftor/ Ivacaftor is a combination of a "corrector" designed to move the defective CFTR protein to the proper place in the airway cell membrane and a "potentiator" that improves function of CFTR as a chloride channel. It's the next cab off the rank.

The US Food and Drug Administration (FDA) has approved the use of Orkambi™ for people who have two copies of the F508del CFTR mutation and are 12 years and older. A phase III trial is being conducted in children aged 6-11 who have two copies of the F508del CFTR mutation.

In Australia in November 2015, Vertex submitted Orkambi™ to the Therapeutic

Goods Administration (TGA) and Pharmaceutical Benefits Advisory Committee (PBAC).

In late 2015, CFA sent out over 250 letters to politicians and decision makers. Consumer letters were prepared for distribution over December and January.

The PBAC meeting and Orkambi™ presentation will take place between 6 - 11 March and we anticipate PBAC notification by approximately 23 April 2016.

The Politicians Contact List is available on the national website whilst the Department of Health will meet in early 2016 to discuss Orkambi™ reimbursement strategies.

Orkambi™ has had mixed trial results for people with two copies of the F508del mutations. Importantly however, many people on the drug saw a decrease in exacerbations, hospitalisations and lung damage and furthermore, reported improvements in their quality of life.

Whilst results may be mixed for Orkambi™, there are other CFTR modulators in the pipeline such as Ataluren, which completed a phase III trial in 2011. This showed patients had a lower decline in lung function and a lower rate of pulmonary exacerbations, compared with those who took a placebo. A new phase III trial is currently underway.

The combination drug VX-661 and Ivacaftor completed phase II trials for

people with CF who have two copies of the F508del mutation in January 2015. Several phase III trials were completed in 2015 in people who have one or two copies of the F508del CFTR mutation.

Other modulators in phase II trials include Riociguat and a new potentiator, QBW251, similar to Kalydeco™.

In The Netherlands, Galapagos NV reported in October 2015 that their corrector, GLPG2665, combined with the other two compounds, showed up to six-fold greater chloride transport than Orkambi™ in vitro. The triple combination therapy of C2 with GLPG2222 and GLPG1837 is expected to address 80% of mutations in the CF population. This is due to enter Phase I trials in mid-2016.

If you would like to keep abreast of where new drugs and therapies are in the development pipeline please visit the Drug Development Pipeline at www.tools.cff.org/research/drugdevelopmentpipeline/

Getting these drugs to market is a huge effort involving years of trials and lobbying of government especially when the cost is so high. CF Australia has recently established CF CAN, a CF Community Advocacy Network to help lobby for access to Orkambi™ and other drugs as they become available and also on issues affecting people living with CF and their families. Members from every state around Australia are currently undergoing training so that the CF community can speak with one voice.

Looking Back on 2015

CONVICTS FOR A CAUSE
LOCK 'EM UP AND THROW AWAY THE KEY!

Saturday 7 November saw large numbers of people “locked up” for charity at Convicts for a Cause, Perth’s greatest annual costume party, organised by CFWA and the Rotary Clubs of Perth and Mt Lawley. This year, we were proud to also have Diabetes Research WA on board. As always, it was an evening of charity, fun and mischief! We were pleased to have 6PR’s Steve Mills as our master of ceremonies with live entertainment provided by the internationally acclaimed Ellandar Productions and music by Dirtwater Bloom.

The event netted nearly \$60,000. We are indebted to our major sponsors; Veritas Check, Two Moons Consulting, as well as Capel Vale, Gage Roads Brewing Co, A-Team Printing, Abacus Rent It, Localise, and many others who supported Convicts for a Cause 2015. Planning is already underway for next year’s event.

Great Strides

A beautiful sunny day saw hundreds of families, friends and supporters take part in our Great Strides sponsored walk and family fun day out. Participants, mascot races, live entertainment from Radio Lollipop and a sausage sizzle helped net over \$21,000 for the Community Newspaper Group-sponsored event.

Fortunately, the forecasted rain held off until all the entertainment was finished and the bouncy castle was packed away.

The highest individual fundraiser was Michelle Webber who raised \$4,428. The highest team fundraiser was Sharon Crocker’s team “For Grace” raising \$2,306. Last but not least was the CF Spirit Award presented to Peter Valentine who ran the whole 8km distance pushing his daughter in her pram!

The ladies’ 8km race was won by Sarah Anderson whilst Charlie Mudd took out the 8km event for the men. Matthew

Jones took out the men’s 4km course whilst Lynette Collis was first across the line for the ladies 4km run.

This year we’ll be launching the Halloween Run. Brought to you by Great Strides, there’ll be prizes galore for the scariest costume and most gruesome grinch, the horriblist horror and much more! So tune up your broomsticks, sharpen your witches hats and put the date in your diary now for some seriously scary monster fun!

The Halloween Run will be on 23 October at Perry Lakes. Watch out for more details nearer the date. Proudly sponsored by Community Newspaper Group.

CFWA Christmas Party & Awards Night

Over 100 people attended our Christmas Party and Awards Night in November last year where four awards were presented to some remarkable individuals.

The volunteer of the year award was presented to the Gillard family. Each and every member and their close friends were recognised for their individual contribution from the youngest to eldest.

The Gillards have supported the Golf Classic for the last six years taking a leading role in the organisation and execution whilst the youngest member Lyla, was recognised as the face of CF in WA, appearing on merchandise boxes,



THE OLD FREMANTLE PRISON WAS FILLED WITH FAMOUS CONVICTS



PERRY LAKES RESERVE WAS PAINTED RED WITH RUNNERS SUPPORTING CYSTIC FIBROSIS.

featuring in CFWA's tax appeal (which raised over \$40,000) and starring in My First Admission DVD.

Hayley Gillard's acceptance speech brought tears of joy and applause as she motivated the crowd to take on bigger and better challenges.

The fundraiser of the year was awarded to a remarkable young man, Hunter Jackson, who took up the annual 65 Roses Challenge.

Hunter decided to run an uber marathon of 65 kilometres, solo from Two Rocks to Cottesloe!

His sister, Ella, who lives with cystic fibrosis, was his inspiration and true to the spirit of the 65 Roses Challenge he set a fundraising target of \$6,500. Even though he'd never run a marathon before, a gruelling eight week training program saw him progress from 5km to 35km.

Hunter set off from Two Rocks at 4am with his dad, David, driving ahead of him the whole way.

He was joined at the half-way point, three hours into the run, by five friends on bicycles, and another friend who ran beside him for 30km, all keeping his spirits high.

In an extraordinary time of just 6 hours and 41 minutes to cheers and jubilation, led by his mum, Judith, Jackson sprinted the final leg, running through the finish tape and dived straight into the ocean.

Hunter had set his target at \$6,500, a multiple around the theme of the 65 Roses Challenge, but like everything he does in life, he over achieved and raised \$15,754!

The long service award recognises outstanding support of CFWA over a period of at least 10 years and was presented to one of the country's top law firms, Herbert Smith Freehills, who over the past 14 years, have provided pro

bono professional guidance and advice to CFWA.

In accepting the award, Ante Golem, a partner based here in Perth, said that it had been a privilege to serve and also to meet such remarkable supporters on the night. He looked forward to providing another 14 years' of support as CFWA continues to grow.

The final award, for supporter of the year, was made to Adam D'Aloia, a remarkable individual whose passion and drive made a significant difference not only to CFWA and the services we can deliver, but also to the lives of many adults and children living with CF who will attend the QEII Medical Centre at either Charlies or the new Perth Children's Hospital. Adam was

the driving force behind establishing free WiFi for in-patients on Ward G54; he's raised nearly \$6,000 from his 'Serve It Up For CF' dinners; and working closely with CFWA, has through direct negotiation with the Minister for Health, secured a cap for parking fees at the QEII site for CF patients.

Adam and his family and friends continue to support CFWA and we can't wait to see what he gets up to next!

The night was a great success and also launched the workplace giving program where people were encouraged to donate a regular amount from their fortnightly salary. For more details please contact Ric at our offices on 08 9346 7333.



ADAM, OUR SUPPORTER OF THE YEAR RECIPIENT, WAS JOINED BY FAMILY AND FRIENDS TO CONGRATULATE HIM ON HIS AWARD.



FELICE & VANYA ENJOYING THE PHOTO BOOTH.

Meet the Supporter: Ruth Thomas

CYSTIC FIBROSIS WA HAS BEEN VERY FORTUNATE TO HAVE RUTH THOMAS WORK AS A VOLUNTEER AT MANY OF OUR FUNDRAISING EVENTS OVER THE PAST FOUR YEARS. RED HAD A CHAT WITH RUTH TO FIND OUT MORE ABOUT THIS LADY WHO GENEROUSLY GIVES UP HER TIME TO PICK UP RUBBISH, SERVE FOOD AND DRINKS AND WASH DISHES.

RED: Can you please tell us a bit more about yourself Ruth?

I have a husband, two grown-up children and four grandchildren. I trained as a nurse at Charlies (Sir Charles Gairdner Hospital) in 1975 and I left in 1978 to have my first child. I then worked in Port Hedland Hospital for about five years as a nurse in the Emergency Department. When I came back to Perth, I worked on the Respiratory Ward at Charlies. I worked there for 25 years. I then retired from nursing and now work in our business doing the accounts.

Our business is Aerodrome Management Services* (AMS) and we work on airports around Australia, such as Halls Creek, Paraburdoo and Broome in WA, as well as Weipa in Queensland. My husband was already running the business while I was nursing. We started it off in our lounge room but now it has grown and we have 100 plus employees including family members. AMS sponsors Cystic Fibrosis WA's (CFWA) Golf Classic and some employees attend that event as a staff day out.

RED: What led to you volunteer for CFWA?

I had just left nursing at the time and one of my friends told me to watch the TV to see Ingrid Laing, now an adult, who was being interviewed about being the Telethon* child. At the same time, I was also reading the newspaper and saw an advertisement asking for volunteers with CFWA for the Great Strides walkathon. I saw all this as a sign so I gave CFWA a call and got involved. I worked at the

Great Strides walkathon picking up rubbish and I have volunteered at most of the fundraising events since, doing anything and everything. I enjoy all of the events, they are all different. The Art Exhibition ends up being the most expensive one for me though because either my husband or I decide to buy some artwork!

RED: Why do you volunteer for CFWA?

I volunteer for CFWA because it keeps me linked in with an area that I worked with for so long. CFWA are very good at expressing their thanks for my time so I feel appreciated. It's a great cause and I want to help towards finding a cure for CF.

It's also good fun; I get to enjoy wine, food, and great company.

RED: What other organisations do you volunteer for?

I have been a member of the Zonta

Club of Swan Hills* for 16 years. Zonta is an international service organisation that women working in professions and businesses are involved with and they provide support for advancing the status of women in less fortunate circumstances both locally and internationally.

I have also been part of a knitting group, Ravelry, for about ten years and I mostly knit beanies and scarves for either the Street Doctor* or St Barts*. For the last six years our knitting group has also raised money for the "Relay for Life" event for the Cancer Council*. We call our group the "Knitters for a Cure" or "KFAC" and we fundraise throughout the year. In the past six years our knitting group has raised about \$30,000.

RED: If you have any spare time, what else do you like to do?

I do a bit in the garden and enjoy spending time with my grandbabies and friends. I read but am not well read.



RUTH (RIGHT) WITH ANOTHER VOLUNTEER, FAITH AT THE 2015 CFWA CHRISTMAS PARTY

Meet the Supporter: Kim Henley

KIM HENLEY HAS WORKED AS A NURSE AT PRINCESS MARGARET HOSPITAL (PMH) FOR SEVEN YEARS. HER PASSION FOR CYSTIC FIBROSIS (CF) EXTENDS BEYOND WARD 7TEEN WHERE SHE IS BASED. KIM HAS GONE ABOVE AND BEYOND HER WORK AT PMH AND HAS ORGANISED SEVERAL QUIZ NIGHTS TO RAISE MONEY FOR CFWA SINCE 2011.

RED: Hi Kim, tell us a bit about yourself.

I started out as an enrolled nurse at PMH and then I did my conversion to be a registered nurse. I have worked on Ward 7Teen at PMH for about six and a half years.

I enjoy listening to music, attending music events or festivals, watching my favourite TV shows and socialising with family and friends. I adore my two nieces, Makenzie who is almost three, and Piper who is 18 months old. I spend a lot of my spare time hanging out with them and my sister.

I have also found a real love for travel and in 2016 I am excited about heading back to the USA and the UK.

RED: How long have you organised the quiz nights to raise funds for CFWA?

I started out organising the quiz nights because back in 2011, we lost a few of our patients to CF. The nurses at PMH and I believed that there was not enough public

awareness about CF, such as how many people are affected by the condition, and how much it affects people and their families. We wanted to do something to change this and to help those people with CF and their families living in WA.

Since 2011, we have organised four quiz nights raising approximately \$42,000 in total. The quiz nights have been a great success but I would not have been able to hold them without the support of the other nurses at PMH, my friends and my family.

RED: Tell us about Ward 7Teen and what it is like working there.

On Ward 7Teen we care for adolescent patients with surgical, medical, mental health and other adolescent issues. Our CF patients are one of our most common type of patients who we care for so we get to build a strong rapport with many of them and their families.

I love working on Ward 7Teen. The things I love are the opportunity to build rapport with adolescent patients, the wide variety of different conditions that we treat, the twelve hour shifts and most of all I love the strong and supportive team I work with.

I do not think I would still be working on the same ward without such an amazing team. We have been through so many tough times and endless fun times. I just couldn't imagine working on Ward 7Teen without any of my fellow nursing, medical and allied health staff.



Become an Advocate for Cystic Fibrosis

Cystic Fibrosis Australia (CFA) are seeking to train 20 advocates. The objectives of the training are to learn advocacy skills which can be used to raise the profile of cystic fibrosis (CF) nationally on key messages to government, business and the health and community sectors. This includes key issues such as drug affordability and availability, infection control, gene testing and access to the best medical and allied

health services. This informed team of advocates will have an active voice on agreed advocacy topics that will provide a flow of valuable information to media, government and the community.

Who: Parents, adults with CF, young people (16 plus), grandparents, siblings, spouses or anyone interested.

When: Tuesday, 1 March 2016

Time: 11.00am – 5.00pm

Where: The Niche Building,
11 Aberdare Rd, Nedlands WA

If you would like to RSVP or learn more about this training and the role of the advocate, please contact

**Kathryn on 08 9346 7333 or
servicesmanager@cysticfibrosiswa.org**

The Benefits of Volunteering

THERE ARE MANY BENEFITS OF VOLUNTEERING. IT HELPS CONNECT COMMUNITIES AND BUILDS SOCIAL COHESION AND NETWORKS. IT ALSO CONTRIBUTES TO PHYSICAL AND PSYCHOLOGICAL WELLBEING AND IN SOME CASE CAREER OPPORTUNITIES.

The Australian Bureau of Statistics estimated that in 2006-07, there were 4.6 million volunteers who supported community organisations. They contributed 623 million hours, equating to 317,200 full-time equivalents. The economic value of these hours was estimated to be \$14.6 billion.

Volunteers also act as advocates and consultants, informing policy development.

The word volunteer was first recorded during the 1630s. The first recorded nationwide volunteering effort occurred out of need during the Second World War; thousands of volunteers assisted in collecting supplies and caring for the injured, amongst other duties. After the war there was a shift of focus to assisting the poor and disabled, both locally and overseas. The Peace Corps® was developed in the US in 1960 and President Lyndon B Johnson declared a War on Poverty in 1964; volunteer opportunities started to expand and continued into the next few decades.

The Salvation Army® is one of the oldest and largest organisations working for disadvantaged people, organising a number of volunteering programs since its inception. Following this, a number of other volunteer organisations were founded such as Rotary® and Lions Clubs® International.

Types of Volunteering:

Traditional volunteering:

Project work with organisations like CFWA which may involve volunteering for a one off project or on a more regular basis such as campaigns, advocacy work or committees.

Skill enhancement/student placements:

Career development and skill enhancement. This is specific voluntary work to aid in future employment. The volunteer is advised to call organisations first to ensure that it's an appropriate



VOLUNTEERS HELPING SELL ROSES ON 65 ROSES DAY

'fit' between the organisation and the volunteer.

Voluntourism:

Combining voluntary work with tourism. This type of voluntary work is becoming more popular, providing a unique travel experience through living in local communities and experiencing local life. Lonely Planet™ or Trip Advisor™ can connect you to other travellers.

Online volunteering:

Assistance with social media, mentoring, written articles via websites or online.

Micro-volunteering:

This seeks to address specific social problems, such as 'Have a Go Heroes' (aimed at improving support for carers and those cared for), 'Spots of Time' (bitesize, creative ways for people to volunteer) and the Orange 'Do Some Good' app (a collection of micro-volunteering activities that you can complete on your mobile and on the move).

"Volunteers don't get paid, not because they're worthless, but because they're priceless" - Sherry Anderson

"No one is more cherished in this work than someone who lightens the burden of another. Thank you" - Author unknown

Volunteering at CFWA:

CFWA is heavily reliant upon volunteers for the success of its events and operations. Volunteers are engaged by the organisation for a range of roles where a

need is identified and their contribution is greatly valued.

We have various opportunities for people to contribute to the cystic fibrosis (CF) community, including:

- Public speaking and awareness raising
- Participation in activities and events, e.g. Great Strides, Spring Rose Art Exhibition, 65 Roses Day
- Administrative support
- Delivery & pick up of items, e.g. money tins, merchandise boxes
- Participation on sub-committees, e.g. Golf Classic
- Participation on CFWA board
- Community fundraising
- Lobbying and advocacy

To learn more about volunteer opportunities at CFWA, please contact Shelley on events@cysticfibrosiswa.org or 08 9346 7333

References:

<http://www.theguardian.com/voluntary-sector-network/2011/jul/06/micro-volunteering-charities-people>

<https://en.wikipedia.org/wiki/Volunteering>

<https://volunteeringwa.org.au/>

<http://www.quoteagarden.com/volunteer-apprec.html>

Higher Events

LIFTING THE PROFILE OF CYSTIC FIBROSIS WA EVENTS. RED SPEAKS TO MEGAN BRIERS, OWNER.



Higher Events has been a great supporter of Cystic Fibrosis WA for many years now. How did you first get involved with the cause?

I became involved with supporting cystic fibrosis when I volunteered to be part of the Cystic Fibrosis Grand Ball, something that I feel truly proud to be a part of. When I started Higher Events I was able to extend my support not only to the Ball but to events that Cystic Fibrosis WA runs: including: the Spring Rose Art Exhibition, Celebration of Life Ceremony and most recently, the CFWA Christmas Party and Awards Night.

You have helped us out with furniture and

decorations for a wide range of events. Does Higher Events have a speciality, or do you cater for all types of events?

Higher Events is a hire company that caters for all types of events, from corporate events, weddings and the very popular back yard Aussie party. We specialise in an exciting range of party hire furniture; some of our collections are only available for hire in Perth from Higher Events.

Do you have a connection to cystic fibrosis?

Initially my connection to cystic fibrosis was through my very good friends who have a son with CF, but I have since met many families through the Grand Ball and

CFWA events who live with cystic fibrosis every day.

We're always impressed how you can transform a venue. What's your favourite item or tip to add a touch of spice to a room?

Colour and light. Add a little colour to your next event; it doesn't have to be a lot, just a little. A piece of coloured furniture with a little additional ambient lighting can make all the difference.

How can our members get in touch?

Our web site is www.higherevents.com.au and all our hire products and pricing can be found online. Our office number is 08 9259 4242.



HIGHER EVENTS CATERS FOR ALL TYPES OF EVENTS, VISIT WWW.HIGHEREVENTS.COM.AU FOR SOME MORE INSPIRATION! IMAGES: 1-5



New Body Composition Scales at Charlies

THANKS TO A SUCCESSFUL FUNDING APPLICATION THROUGH THE SIR CHARLES GAIRDNER HOSPITAL (SCGH) AUXILIARY, SCGH'S RESPIRATORY AND CYSTIC FIBROSIS DIETITIAN, PAUL O'NEILL, WAS ABLE TO PURCHASE A SET OF STATE-OF-THE-ART BODY COMPOSITION ANALYSIS (BCA) SCALES.



The scales provide detailed information about a patient's body composition such as fat-free mass, muscle mass, fat mass, percentage fat mass and fluid status including intracellular and extracellular water levels.

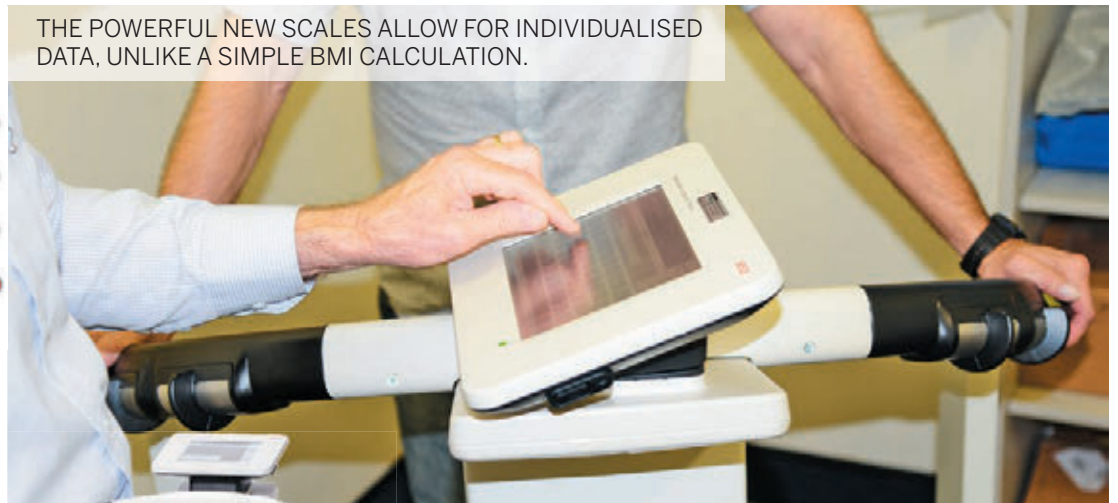
Paul says the scales use the latest technology to perform bioelectric impedance vector analysis and are validated to compare with gold standard measurements of body composition.

"A patient's body composition analysis can be completed in about 20 seconds. The patient is then provided with a visual, and easily understood printout such as the example pictured," he said.

"The Body Mass Index (BMI) is commonly used as a measure of body weight relative to height. However, BMI has some limitations, for example it doesn't provide information about a patient's body composition, such as fat or muscle. Individuals such as athletes may be classified as overweight despite having a large component of muscle."

Paul says there is a strong interrelationship between nutrition and lung health in

THE POWERFUL NEW SCALES ALLOW FOR INDIVIDUALISED DATA, UNLIKE A SIMPLE BMI CALCULATION.



ANDREW TRYING OUT THE NEW SCALES ON HIS CLINIC VISIT



cystic fibrosis (CF). Populations with a higher BMI have better lung function until they are overweight, after which the benefits plateau. The really exciting thing about this equipment is that we are now able to assess the amount of fat, muscle and fluid that comprises body weight. This information can provide insight into body composition that enables individualised and specific direction for an individual's

nutrition and exercise goals.

So far, CF patients have shown a lot of interest in the visual information provided, with comments such as 'that is really interesting', 'very cool' and 'I am going to work on that and see if I can improve', Paul said.

Paul wished to thank SCGH Auxilliary for their work and generous support in contributing to patient care.

Psychological Services at Princess Margaret Hospital (PMH)

INTERVIEW WITH ANDREA BARRETT, SNR PSYCHOLOGIST, PAEDIATRIC CONSULTATION LIAISON PROGRAM AT PMH

The psychology and social work services teams at PMH work closely and collaboratively with one another to support children and families. Most families initially meet the cystic fibrosis (CF) social worker, Heather Hugo, and CF liaison nurses, Elizabeth Balding and Alison Stone. If specific psychology services are required then a referral, with the consent of the family, is made.

Psychology support can be of a short-term nature, or longer as required. Confidentiality is discussed with the family and issues which may pose a risk for the child or directly affect their management are discussed with the rest of the respiratory team.

Common requests for psychology support are:

Procedural anxiety – most children and parents experience a level of anxiety around needles and other invasive procedures, e.g. PICC line or bronchoscopy, however, for some it can become extremely traumatic. The psychologist can develop a treatment plan and strategies with the child, family and the medical team to manage anxiety around procedures.

Mood disorders – young people sometimes experience low mood or mood disorders. Having a chronic illness can compound regular issues of childhood and adolescence. The strategies will vary depending on the situation.

Food aversion – there can be a lot of anxiety around appropriate weight and eating. Some children develop food



aversion for a number of reasons causing a lot of stress for all family members. Collaborative strategies can be used to assist in this area.

When should someone seek support?

If a parent is concerned about their child's psychological wellbeing, or if there is notable change in the child or young person's functioning which cannot be explained by a medical cause, families should discuss these issues with the social worker or liaison nurses and if required,

a referral can be made to the Paediatric Consultation Liaison Program (PCLP) at PMH. Once a referral is made to PCLP, the child or young person will be allocated to either a clinical psychologist or a child and adolescent psychiatrist, depending on the nature of the presenting problem.

If there are any concerns regarding a child or adolescent's safety in terms of self-harm or risk of suicide, then emergency services should be sought through the PMH Acute Response Team on 1800 048 636. This is a 24-hour 7-day-a-week service.

\$33,750 PhD Top Up Scholarship

APPLICATIONS OPEN NOW FOR PHD TOP UP SCHOLARSHIP.

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

Today, as a result of improvements in early diagnosis, intervention, treatment and better pharmaceuticals, most children affected by CF are now surviving well into adulthood. As a result, for the first time ever, there are now more adults living with CF than children.

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

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

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

This scholarship is administered through the Australian Cystic Fibrosis Research Trust on behalf of CFWA. The Scholarship is for \$11,250 per annum for a maximum of three years. Conditions apply.

Applications open Monday 18 January 2016 and close on Friday 12 February 2016 at 5pm EST.

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

Application forms are available from:

The Australian Cystic Fibrosis Research Trust

PO Box 268

North Ryde NSW 1670



Cystic Fibrosis WA Home Care Workers in the Community

CFWA HOME CARE WORKERS (HCW) PROVIDE SUPPORT FOR FAMILIES AND ADULTS AFFECTED BY CF. THEY ARE SPECIAL PEOPLE THAT ADD A POSITIVE DIMENSION TO THE MANY TREATMENTS OF CF.

This in-house service has been delivered by CFWA for over 20 years. It has now grown to meet the needs of 107 children and 24 adults currently receiving the service. Our HCWs have a comprehensive knowledge of CF, attending an annual study day and monthly training sessions and are under the direction of the CFWA senior physiotherapist and community nurse.

Referrals are received from Princess Margaret Hospital (PMH), Sir Charles Gairdner Hospital (SCGH) and by self-referral. Support ranges from supervision

of airway clearance, supervision and/or participation in exercise programs, to occasional respite.

With a smile and expertise in distraction and motivation, our HCWs work their magic. CFWA provides a service to children and adults from Mandurah to Helena Valley to Yanchep.

For more information in regards to the support services provided by CFWA, contact the services team on

Phone: 08 9346 7333

Email: info@cysticfibrosiswa.org

Web: www.cysticfibrosis.org.au/wa



CYSTIC FIBROSIS WA IN HOME CARERS ATTEND REGULAR TRAINING TO ENSURE PATIENTS RECEIVE THE MOST UP-TO-DATE CARE.

Welcome to Dr Anna Tai

IN LATE 2015, DR ANNA TAI JOINED THE TEAM AT SIR CHARLES GAIRDNER HOSPITAL AS A CF CLINICIAN FOLLOWING AN OUTSTANDING CAREER IN NEW ZEALAND AND QUEENSLAND.

Anna trained as a respiratory physician with a subspecialty interest in CF. She graduated from the School of Medicine, University of Auckland, in 2001. Following this, she undertook advanced clinical training in respiratory medicine before embarking upon the role of clinical and research fellow in CF at The Prince Charles Hospital in Brisbane in 2008.

Anna continued to work as a respiratory physician at the adult CF centre in Brisbane and in 2011, commenced a

full time PhD study in CF with a view to identifying methods to individualize antibiotic treatment for patients with CF.

Anna visited the CFWA offices in December to meet the staff. We are delighted at Anna's appointment and can't wait to work with her in the near future.



Fundraising News

THANK YOU TO EVERYONE THAT HAS BEEN PART OF OUR FUNDRAISING ADVENTURES IN 2015!

We are proud to say that we have a wonderful group of supporters. The funds you have raised will go towards providing services to people and their families that are living with CF and also fund vital research projects.

We are so grateful to have such strong supporters. Thank you!

Striding for Life

To everyone that participated in Great Strides on Sunday 25 October 2015 – thanks so much!

Whether you helped as a course marshal, cooked sausages, registered runners, cleaned tables, parked cars, handed out water, ran in the challenge or raised funds, we couldn't have done it without you. Thank you for your support, we think you are pretty amazing!

We are pleased to say the combined fundraising efforts reached over \$21,000.

Thank you!

Team Vicki Liddle	\$558.75
Cure for Cruze	\$1707
Wade Croome	\$100
For Grace	\$2,305.75
Jaclyn Gerritzen	\$35
Just Breathe Carly and Tina	\$1,804.52
Lisa Rae	\$10.50
Michelle Webber	\$4,428.25
Mitch Messer	\$1,049
The Walsh Corbetts	\$1,558
Sarah MacArthur	\$504
Sarah Potts	\$745
Sharon Roberts	\$525.25
Team Marvel	\$5

Schools do it again!

Once again the school community has impressed us with their ingenuity and entrepreneurial efforts when it comes to

raising money for cystic fibrosis.

Thank you to the teachers that taught and encouraged the students along the way. And thank you to each of the students for your time, effort, hard work and brilliant fundraising ideas.

The Year 6 students at Perth College raised a very nice sum of \$2,647.36 by selling goods and services through their newly



ADAM "SERVING IT UP" FOR CF.



developed entrepreneurial program. Well done and thank you for such a great effort!

Wesley College students cooked sausages, rattled donations tins and sold Christmas cards, raising an impressive, \$714.30. Thanks so much!

Cannington Community College set their sights on holding a free dress day. The day's result came to a total of \$439.80. Thank you to everyone who participated.

Small Business Making a Difference

Every month a small number of businesses from the corporate community make an effort to help improve the quality of life of people living with CF. Thank you for your consistency, effort and faithful commitment. We are so very grateful for your ongoing support!

The Good Guys Malaga raised \$1,185 through their ongoing fundraising efforts. Thanks so much!

Thank you to Gia and Jade and the team from Amcal Inglewood for raising a very impressive \$4,337.75. Such an amazing effort!

Thanks to Emma Pridda and the team from Rowdy Promotions for raising \$27.27 and thanks also to the Xpresso Code for raising \$120.85.

Catherine North and the organizers of the York Pharmacy Health Expo raised \$90.91. Thanks team!

A Quiz for a Cause

On Friday 13 November, a fabulous team of PMH nurses, led by Kim Henley, hosted the BIG Quiz at the South Perth Community Centre. The evening was packed full with prizes, raffles, games, live and silent auctions. The final result was a very healthy \$8000 for Cystic Fibrosis WA.



GUESTS HAVING FUN IN THE PHOTO BOOTH AT THE RED TIE DINNER DANCE



LUKE IS RAISING MONEY BY HOLDING EVENTS AT HIS SCHOOL AND SELLING HIS CUSTOM PILL BOXES, ALL FOR HIS BROTHER WITH CF.

Thanks to Kim and the team for running such a fabulous night, and of course for the funds you raised for CF.

Adam Serves it Up

On Saturday 24 October, Adam D'Aloia Served it Up for CF!

This isn't the first time Adam has held a Serve it Up dinner, having held one in 2014. Adam has built a reputation for hosting a sumptuous feast while raising funds for CF.

Adam has managed to secure a small team of generous suppliers and supporters for his Serve it Up dinners and managed to raise, \$2,811.25.

Thank you Adam, and thank you to your team for what you have done to help to improve the lives of people living with CF.

Jumping for Cash

Sarah and Gavin Haddow and their two sons, Ricardo and Casey, who are living with cystic fibrosis, wanted to give something back to CFWA for the support their family has received over the years. But much to our amazement their choice of fundraiser surpassed reason when Gavin and Casey decided to jump out of a perfectly good working plane at 15,000 feet!

We are pleased to say that all went well and both Gavin and Casey have achieved something noteworthy for their bucket list, and managed to raise \$4,797!

Thank you for making such an impressive effort, for sharing your joy and for helping others that are living with CF.

Congratulations on a job well done!

Want to do More?

Are you feeling inspired by some of these fundraising stories?

Whatever your idea is, big or small, low key or full production, we'll support you

along the way. And if you aren't sure what you want to do, we can help you out with some ideas, too.

Contact Shelley today at CFWA on events@cysticfibrosiswa.org or 08 9346 7333 - let's make your fundraising aspirations a reality!

The Good News is In

The Red Tie Dinner Dance is on again!

Yes, the Red Tie Dinner Dance will be back for 2016. Tickets sold out very early for the 2015 inaugural event, and it is expected they will sell even quicker second time around. So mark the date in your diary and book your table early to avoid disappointment.

The Red Tie Dinner Dance will be held on Saturday 27 August 2016 at the Fremantle Sailing Club. To book a table or make a sponsorship enquiry, please contact Wendy Barker on 0408 940 851.



GAVIN & CASEY HADDOW TOOK A 15,000 FOOT JUMP FOR CF.



TOD JOHNSON ENSURED EVERYONE HIT THE DANCE FLOOR AT THE RED TIE DINNER DANCE.



Changes to Cystic Fibrosis WA's Subsidies in 2016

CFWA HAVE TWO SUBSIDIES THAT MAY BE ABLE TO ASSIST YOU AND YOUR FAMILY.

Patient Support Subsidy:

Up to \$300 annually to help towards items/costs such as exercise equipment, nebulisers and physiotherapy devices, sporting club fees/uniforms, sporting classes etc.

This new subsidy has now replaced the previous Equipment Subsidy, Activity Subsidy and Driving Licence Subsidy. We hope that this new amalgamated subsidy is a more flexible approach to our members' changing needs.

Country Patient Assistance Subsidy:

This subsidy is available for adults with CF or parents of children with CF living in regional areas where the person with CF requires a clinic appointment or admission to hospital in the Perth metropolitan area.

Patients who are also eligible for the Patient Assistant Travel Scheme (PATS), may be eligible for between \$100-\$200 per visit, depending upon length

of stay and distance travelled. A subsidy of \$50 is provided for families not eligible for PATS but residing in the Mandurah-Peel or Northam/York regions.

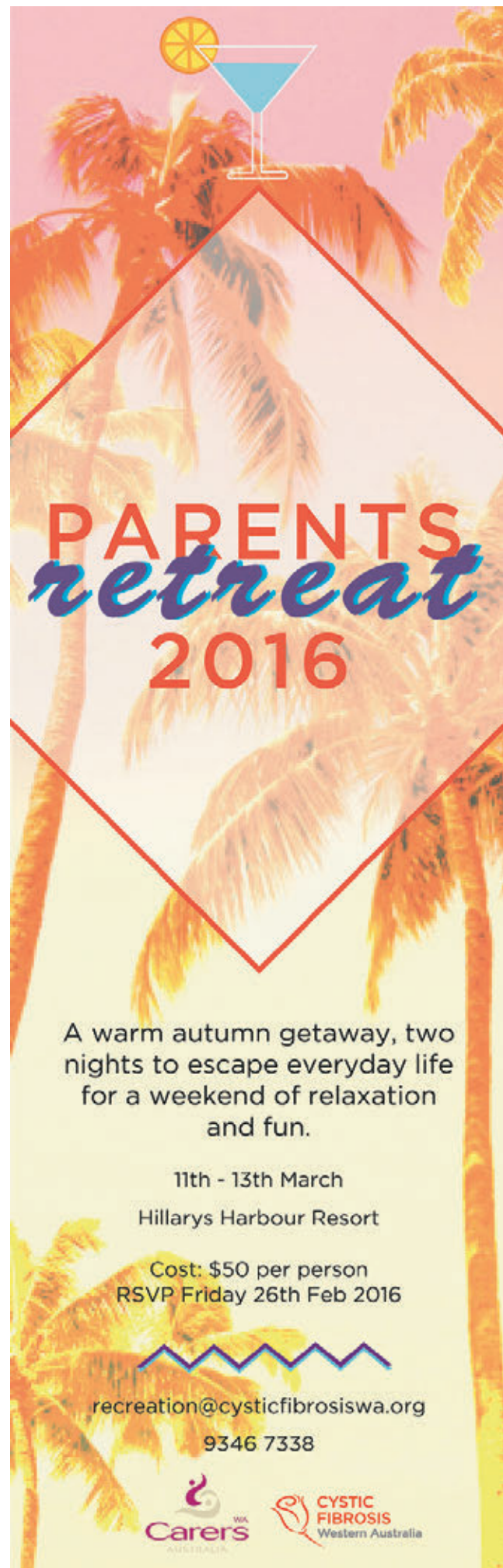
If two siblings are attending clinic at the same time, a reduced rate will apply to the second child. Applications must be submitted within 30 days of your visit; back payments cannot be made.

More information about PATS can be found here:

<http://www.wacountry.health.wa.gov.au/index.php?id=pats>

Applications must include a tax invoice as proof of payment. You can apply for the subsidies online here: <http://tinyurl.com/q4ccbpn>

For more information about our subsidies, contact Kathryn on servicesmanager@cysticfibrosiswa.org or 08 9346 7333.

A vertical poster for the 'Parents retreat 2016'. The background is a warm, orange-toned image of palm trees. At the top, there is a graphic of a martini glass with a blue liquid and a yellow citrus slice. The title 'PARENTS retreat 2016' is centered, with 'PARENTS' in a bold, sans-serif font, 'retreat' in a stylized, cursive script, and '2016' in a bold, sans-serif font. Below the title, the text 'A warm autumn getaway, two nights to escape everyday life for a weekend of relaxation and fun.' is written in a clean, sans-serif font. The dates '11th - 13th March' and the location 'Hillarys Harbour Resort' are listed. The cost 'Cost: \$50 per person' and the RSVP date 'RSVP Friday 26th Feb 2016' are also included. A wavy line separates the text from the contact information: 'recreation@cysticfibrosiswa.org' and '9346 7338'. At the bottom, there are two logos: 'Carers WA AUSTRALIA' and 'CYSTIC FIBROSIS Western Australia'.

Golf Classic in Full Swing

REGISTRATIONS ARE NOW OPEN FOR THE 2016 GEORGE JONES FAMILY FOUNDATION CYSTIC FIBROSIS GOLF CLASSIC

The George Jones Family Foundation Cystic Fibrosis Golf Classic is set to tee off for the sixth successive year at the prestigious Lake Karrinyup Country Club on Friday 29 April.

Register a team now for this wonderful day out, with a professional golf demonstration and friendly Ambrose competition, followed by an elegant three-course meal at the club house.

Don't miss the opportunity to treat yourself and your clients to an amazing day whilst at the same time making a difference to the lives of all

people living with cystic fibrosis.

For more information about the event please visit www.cysticfibrosis.org.au/wa/golfclassic or contact Brad Coutts, committee chairman on 0417 946 729 or on golf@cysticfibrosiswa.org

If you are unable to participate and can donate goods or service for our auction, please contact Shelley on 08 9346 7333 or at events@cysticfibrosiswa.org



WILDCATS LEGEND ANDREW VLAHOV TEES OFF FOR CF



GET INVOLVED...

with fundraising and become a CF Superhero

TAKE ACTION TODAY AND HELP FIND A CURE

Whether it's a celebration, a challenge, at your school, a bake sale or a bingo night, individuals, families and community groups play an important role in raising funds for cystic fibrosis.

You could be surprised at how simple it can be!

To find out how you can fundraise and become a CF Superhero, contact Shelley, events@cysticfibrosiswa.org or 9346 7333

cysticfibrosis.org.au/wa facebook.com/CysticFibrosisWA



CYSTIC FIBROSIS
Western Australia

65km Solo Run by 17-Year Old for CF

INSPIRED BY HIS SISTER ELLA, HUNTER JACKSON SET OUT TO RUN 65KM ON SATURDAY 18 JULY AT 4AM, TO RAISE MONEY FOR CYSTIC FIBROSIS.

Hunter completed his first ever major run - an uber marathon of 65 kilometres by running solo from Two Rocks to Cottesloe Beach all in the name of raising awareness and funds for a cause very close to his family's heart, cystic fibrosis (CF).

Growing up beside his older sister, Ella, who has CF, Hunter has suffered vicariously the pain of this disease. It is this first-hand experience and the inspiration of his sister's strength and tenacious attitude to life that led him to enter the '65 Roses Challenge' - to run 65km.

"In order to raise a large amount of money, so as to have the greatest impact possible, I decided to complete a challenge that would push me to my physical and mental limits, just as cystic fibrosis does for my sister every day," said Hunter

Having never run more than 20km before, this very fit and committed 17-year old found time in the midst of his final year at Christchurch Grammar School to undertake the necessary preparation for such a monumental challenge for his sister.

Hunter's rigorous training regime started just eight weeks prior, building up from a 5km run to a maximum 35kms run. At 4am in Two Rocks on a dark and rainy morning, he commenced his 65km solo challenge.

His father, David, who drove ahead of him the whole way providing sustenance and support remarked, "I have often joked that nothing exceeds like excess, but this exceeded everything I thought possible - to witness this charity run first hand from 0400 until the finish line leaves me in awe of my son and daughter".

Joining Hunter at the half-way point, three hours into the run, were five friends on bicycle and another friend who ran beside him for 30km, all keeping his spirits high.

The finishing line support crew lead by his mother, were stationed at Cottesloe Beach, preparing for Hunter to arrive around midday. Plans were thrown into chaos when they awoke to the news that he was making faster time than anticipated and was set to arrive around 10am.

In an extraordinary time of just 6 hours and 41 minutes to cheers and jubilation, Hunter sprinted the final leg, running through the finish tape and diving straight into the ocean.

"At 3am on Saturday morning I was doubting I could make it, but thanks to everyone's amazing support I was able to finish my 65km for 65 Roses run," said Hunter.

"I felt great at the start but had to push through the middle section. Having a team of cyclists and a runner beside me, knowing that a fantastic crowd of supporters would be there at the end, a

having beautiful view of our coastline along the route and even a whale swim by, all made a really big difference".

Awaiting Hunter on the grass near the Beach was Ella, 23, who has the G511D mutation. It was an emotional scene when he ran straight out of the ocean to throw his arms around his sister before heading off to eat one of her specially baked homemade cakes!

By running 65km Hunter raised a remarkable \$15,754, a result that also saw him win the highest fundraiser of the year award for Cystic Fibrosis WA.

"My sister is a fierce spirit and above all has admirable qualities of tenacity persistence. Having been beside her for most of her journey with cystic fibrosis, I am so grateful to finally be able to make a difference, albeit a small one".



HUNTER JACKSON RAN 65KMS IN JUST 6 HOURS 41 MINUTES IN SUPPORT OF HIS SISTER WITH CF.

Looking to Make a Difference?

HERE ARE SOME EASY WAYS TO GET INVOLVED WITH CYSTIC FIBROSIS WA THIS YEAR!

Do you want to make a difference in the lives of people living with CF? Then you have come to the right place!

CFWA is a small organisation doing big things for people living with CF. This year we've delivered services to over 200 people and their families, been at the forefront of promoting critical research projects and recently taken part in the successful drive to have Kalydeco™ listed on the PBAS, and much more.

But none of this would have been possible if it wasn't for the labour of love and funds that have been raised by you, the community, the people who help us each and every day in our efforts to improve the lives of people living with CF. Working together, as we work towards our aspirational goal of 'Lives Unaffected by Cystic Fibrosis'!

With one in every 25 people, often unknowingly, carrying the CF gene, there is still much to do and you can help! You can make a difference by simply holding a humble cupcake or garage sale. The choice is yours. These days fundraising includes everything from morning teas to shaving your head. Anyone can fundraise!

One of our top fundraising ideas is to host an event at your workplace or school, or if you want to keep things simple, just tap into one of the CFWA fundraising opportunities listed.

Serve It Up

Throw a dinner party, morning tea, lunch, BBQ or after-work drinks and Serve It Up! Ask your guests to donate what they would have spent going out - <http://www.serveitupforcf.org/event/serveitupforcf>

My Celebration

In times of great celebration and joy, it is always appreciated when people choose to help others in need and contribute to the future of their community. For your next celebration event, ask your friends and family to make a donation instead of receiving gifts. Just set up your My Celebration for CF donation page and share with your friends and family - <https://everydayhero.com.au/event/celebrationsforcf>

65 Roses Challenge

Get on board with the 65 Roses Challenge by holding a fundraiser themed around the number '65'. While the month of May is cystic fibrosis awareness month, we encourage you to fundraise anytime throughout the year – whenever suits you!

65roseswa.org.au/event/65roseswa2015

Hallowe'en Run

The Hallowe'en Run, presented by Great Strides, will be held on Sunday 23 October at Perry Lakes Reserve. Sign up, dress up, and raise funds through your own Hallowe'en Run donation page. (CF Hallowe'en page launch to be advised)

Choose a Challenge

Signing up to take part in an organised challenge event, such as City to Surf, HBF Run for a Reason or similar, can be a great way to keep active and also raise funds for CF.

Create Your Own

But if these ideas don't appeal to you, or you have your own fundraising idea. Simply contact the team at CFWA and we will show you how to get started. You can make it big or small, simple or festive, grand or elaborate - you decide! By yourself or in a

team - the sky's the limit! So think bake sale, bingo night, morning tea, gala dinner, dance-a-thon, karaoke night, long table lunch or sausage sizzle. We will support you every step of the way and we will provide you with the assistance and tools you need to make it a success!

Fundraising can be a fun and exciting experience and you could be surprised at how easy it can be. **So contact Shelley at CFWA to find out more: events@cysticfibrosiswa.org or 08 9346 7333.**

We're calling on you to have a go and make a difference to the lives of people with CF. So take action today and help to find a cure!



FUNDRAISING IDEAS COME IN ALL SHAPES AND SIZES.



How Does a Diagnosis of Cystic Fibrosis Affect the Family?

CINDY BRANCH-SMITH, PHD CANDIDATE AT THE TELETHON KIDS INSTITUTE®, IS PART OF A RESEARCH TEAM LOOKING AT THE LEVELS OF STRESS, DEPRESSION AND FAMILY AND RELATIONSHIP FUNCTIONING AMONG FAMILIES OF YOUNG CHILDREN WITH CYSTIC FIBROSIS, AND RELATING THESE TO HEALTH IN THE CHILD.

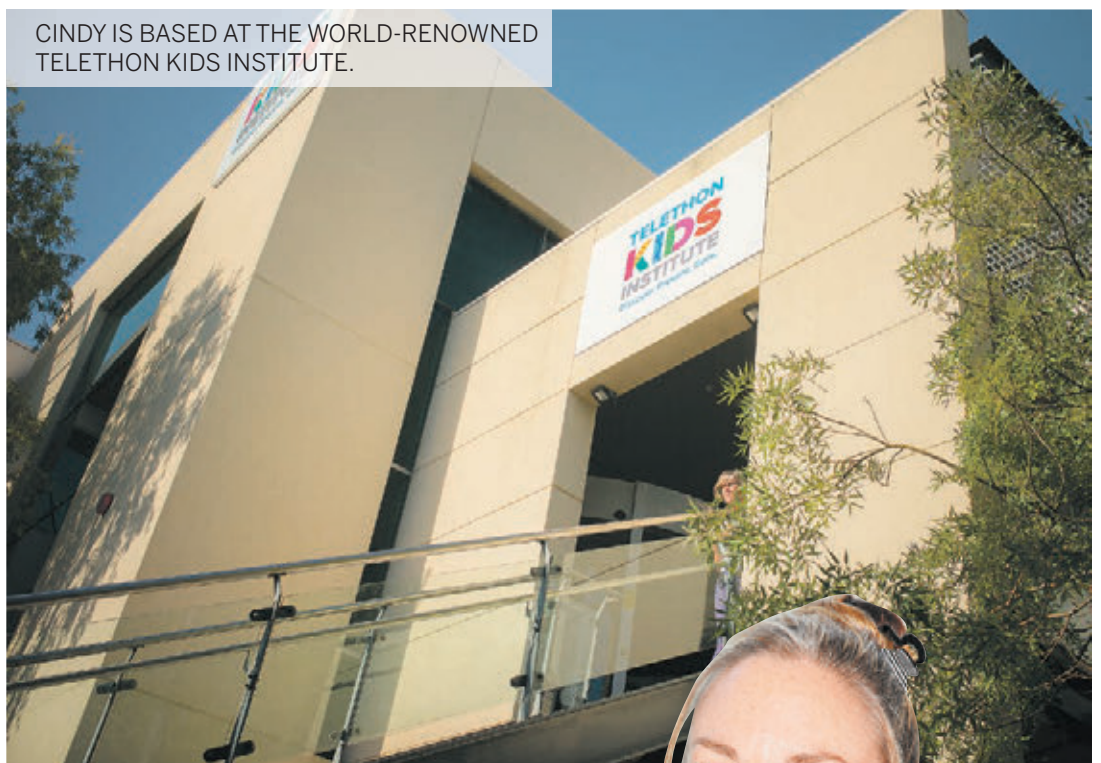
How can parents minimise the effects of chronic illness and hospital admissions on the family unit?

Establishing and maintaining family routines is important for families to be able to stick together through difficult times such as cystic fibrosis (CF) exacerbations and hospital admissions. Though it is not always possible, getting help from extended family members with routines can be an important resource for families. Support from family, friends and other CF parents can also help with some of the psychological burden associated with challenging times; just sharing your burden can help to lighten the load.

How can families, especially mothers, have a work-life balance with a child who has a chronic illness? What are the most common parental concerns and how can they deal with them?

It is difficult for mothers to return to work and to keep a work-life balance. Job-sharing can be an option, working part-time or volunteering a small amount of time with an advocacy group can help mums to have a life outside of being a parent. Research shows that mums who work at least part-time develop coping mechanisms from their work life that help to cope with their family life.

CINDY IS BASED AT THE WORLD-RENOUNDED TELETHON KIDS INSTITUTE.



What effect does a chronic illness like CF have on relationships within the extended family, including grandparents?

A CF diagnosis is difficult for families to accept because most times, due to the recessive genetic nature of CF, parents have no idea that CF is even a possibility. Speaking with your genetic counsellor and getting extra counselling may help parents to develop strategies in order to have important discussions with extended family members. A cohesive family is the best support for those managing CF, therefore, support from extended family members and friends really helps parents to manage day-to-day family life.

**TELETHON
KIDS
INSTITUTE**
Discover. Prevent. Cure.



Relationships Make a Community

ALL RELATIONSHIPS ARE VIEWED WITH CERTAIN EXPECTATIONS; MANY OF THESE UNCONSCIOUS, BASED ON OUR UPBRINGING, CULTURE, VALUES AND PEOPLE THAT ARE IMPORTANT TO US. PERSONALITY AND OUR COMMITMENT TO WORKING TOWARDS COMMON GOALS ALSO AFFECT OUR RELATIONSHIPS.

Relationships involve negotiation, which at times may involve conflict which is normal. However, how you manage conflict is what's important. Firstly, it may be useful to consider your own values and expectations and if in a couple, your partner's values too.

Workshop values:

My mother's values:

1.....
2.....
3.....
4.....

My father's values:

1.....
2.....
3.....
4.....

Society's values:

1.....
2.....
3.....
4.....

The values I actually live by:

1.....
2.....
3.....
4.....

The values I would like to live by:

1.....
2.....
3.....
4.....

When you understand where each other is coming from it's easier to work through issues, however, here are some useful tips to help navigate through potential arguments.

Fair fighting rules:

1. No put down or degrading language

Criticising or putting down your partner's character shows disrespect, it also says "you're not safe with me"; potentially forcing the other person to protect themselves, upping the ante, and doing whatever it takes to win.

2. No blaming

Focus on solving the problem, not blaming the person. Blaming creates defensiveness and escalates the problem.

3. No shouting

If you need to shout then it may be useful to take time out or discuss the issue when there is not so much heat in it. Yelling escalates arguments creating more issues for resentment.

4. No use of force

Feeling safe in a relationship is essential for proper intimacy and good communication. This includes no physical or threatening behaviour.

5. No talk of divorce or separation

Using this as a threat quickly dissolves your partner's trust in your commitment to work through the current issue.

6. Define yourself not your spouse

You are only an expert of your own feelings, needs and wants, not your partner's. Try and use words that describe how you feel, what you need and want and what happens for you when your partner does something that upsets you. For instance, if you feel your partner is not doing their fair share of the cooking you may interpret this as them being inconsiderate. Perhaps this is how their parents did things in the household or perhaps they feel you always like to cook. It's important to ask them how they feel about things.

7. Stay in the present

You can only change the present and the future, not the past. Bringing up past resentments gets things off track and can escalate issues without resolution. Agree to keep things on track and try to discuss issues as they arise.

8. Take turns speaking

Learn to listen with full attentiveness. Let each of you speak one person at a time without interruption or talking over each other.

9. Use time outs if necessary

This is ok, particularly if you feel you might say or do something you might regret. Have a signal and agree that it's ok to take a short break and make a commitment to get together soon when more calm to resolve the issue. This should only be about half an hour, not several days.

10. Keep the relationship alive

Do things for yourself that bring fun and happiness into the relationship such as exercise, a hobby or seeing friends.

11. Relationship counselling

Many relationships can benefit from an outside perspective at times. There are numerous counsellors available.

Useful resources:

<http://www.healthymarriageinfo.org/find-resources/index.aspx#topic=4&subtopic=5&year=all>

<http://relationships911.org/cgi-bin/links/jump.cgi?ID=5935>



Join the Fight Against Antibiotic Resistance

ANTIBIOTICS ARE “MIRACLE MEDICINES” BUT MUST BE USED WITH CARE.

What is antimicrobial resistance?

Antimicrobial resistance (AMR) happens when bacteria stops an antibiotic from working effectively. This has resulted in standard medical treatments not working as effectively as in previous times and sometimes there may not be an available treatment for the infection, e.g. ebola. Multi-resistant superbugs are a strain of bacteria that has mutated (changed) after coming into contact with an antibiotic. The bacteria then becomes resistant to the antibiotic which means the antibiotic cannot kill the bacteria or stop them from multiplying.

Antibiotics save lives every day and are especially important in complex care situations e.g. chronic disease including CF, transplant, immunosuppression, ICU

But..... antibiotics are a limited resource.

Over the last three years it has been recognised more widely that antimicrobial

resistance is a public health crisis requiring global action. AMR infections require more investigations, complex and expensive treatments and longer hospital stays. Australia contributes to a global action plan to fight AMR. You can play a part in the fight against antibiotic resistance.

Pseudomonas aeruginosa is an example of a bacteria that develops resistance. Current strategies to manage this include the use of different types of antibiotics and use of inhaled antibiotics using a nebuliser or inhaler.

Things you can do to reduce antibiotic resistance:

Take the pledge to reduce antibiotic resistance

- I will wash hands frequently to reduce spread of infection
- I will prevent spread of resistance by coughing into my sleeve

- I will maintain immunity by getting vaccinated
- I will use antibiotics appropriately -I will only take antibiotics exactly as prescribed even if I feel I no longer need to take them– correct dose for the length of time the doctor prescribes
- I will not miss doses of antibiotics and I will take them on time, no long gaps between doses
- I understand that it is possible to pass on antibiotic resistant bacteria to others
- I will travel safely avoid raw food, cooked food is safer
- I will not share antibiotics

Useful resources

Understanding Bugs, Infections in CF

<https://www.youtube.com/watch?v=94m8aWa6vKg>

<https://www.cff.org/PDF-Archive/Bacteria-and-Antibiotic-Resistance-in-People-With-CF/>

Connect With CF Around the World

CYSTIC FIBROSIS (CF) AFFECTS 70,000 PEOPLE WORLDWIDE AND OVER 3,200 CHILDREN AND ADULTS IN AUSTRALIA. THE GLOBAL NETWORK OF CF ORGANISATIONS IS EXTENSIVE AND CAN HELP YOU WITH RESOURCES ON MANAGING THE PRACTICAL ASPECTS OF CF LIKE SCHOOL, WORK AND TRAVEL AS WELL AS IN KEEPING IN TOUCH WITH THE LATEST TREATMENTS AND RESEARCH.

CF global community:

Worldwide, the CF organisations are united in attempting to find a cure for CF. Internationally, the CF community is driven by a dedicated group of scientists, carers, donors, volunteers and people with CF and their families.

CF resources:

Not for profit CF organisations committed to finding a cure for CF include:

- Cystic Fibrosis Australia
<http://www.cysticfibrosis.org.au/>
- Cystic Fibrosis Canada
<http://www.cysticfibrosis.ca/>
- Cystic Fibrosis Foundation (US)
<https://www.cff.org/>
- Cystic Fibrosis Trust (UK)
<http://www.cysticfibrosis.org.uk/>
- European Cystic Fibrosis Society
<https://www.ecfs.eu/>
- Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF): a team of over 60 doctors and researchers dedicated to the improvement of respiratory health and outcomes in children with CF. A collaboration of specialist paediatric CF centres in Perth and Melbourne who want to better understand which factors predict lung damage early so that CF can be treated early and CF lung disease reduced

<http://www.arestcf.org/our-research/arest-cf-early-surveillance-program/>

Where can I find reliable scientific information on CF?

- e- cystic fibrosis review: electronic newsletter from Johns Hopkins University of Medicine featuring the latest evidence for CF care management.

<http://www.ecysticfibrosisreview.org/s>

- Journal of Cystic Fibrosis: original scientific research based information on CF, edited by Australian Scott Bell from Brisbane. Articles published are freely available after two years. Visit Science Direct and navigate to previous years.

<http://www.sciencedirect.com/>

- Cochrane CF & genetic disorders group: an international network, based in the UK, of healthcare professionals, researchers and consumers preparing, maintaining, and disseminating systematic reviews of randomised control trials for treating CF and other genetic disorders

<http://cfdg.cochrane.org/>

NEWLY DIAGNOSED MEET & GREET

All parents with newly diagnosed babies or small children are invited to attend

Thursday 31st of March 2016
The Niche Bldg, 11 Aberdere Rd Nedlands
From 6:30pm onwards

For more information & RSVP:
recreation@cysticfibrosiswa.org
08 9346 7338 / 0419 926 277

CYSTIC FIBROSIS
Western Australia

RED Resources

Fact sheets

We have a range of new fact sheets available on the CFWA website; www.cysticfibrosis.org.au/wa under the 'resources' tab. The fact sheets cover a range of topics such as:

- exercise
- PICCs and PEGs
- pill swallowing
- reproductive information for males and females
- siblings
- sweat testing
- carers
- salt and fluid replacement

There are new fact sheets that will be added early in 2016, with topics including: starting school with CF, procedural anxiety, travel, nutrition, cystic fibrosis-related diabetes (CFRD) and more currently in the works.

School visits 2016 CFWA education support

If you would like your child's school to learn more about CF, we have a range of resources to assist. Our education officer, Natalie Amos, is available to provide education sessions with teachers, other parents and students, and can also post you or your child's school information materials if needed.

Contact Natalie at education@cysticfibrosiswa.org or phone 08 9346 7333

Check out our website www.cfsmart.org to see the range of support materials available and also our CF Smart Facebook page: <https://www.facebook.com/cfsmarteducation/?fref=ts>

Princess Margaret Hospital (PMH) CF seminar for school teachers

Aim: to broaden the teachers' knowledge of CF and the implications for management for both primary and secondary students in the school

environment and support their education through periods of hospitalisation. Participants will gain an insight into the mental health implications for the student and family, arising from living with CF.

Date: 1 April 2016

Registration closing date: 30 March

From: 12.45pm to 3.45pm

Cost: Free

Venue: PMH, Admin Building, McDonald Lecture Theatre, Roberts Road, Subiaco
<http://goo.gl/maps/5AgYB>

Presenters: PMH respiratory team and liaison teachers

Book online: Institute for Professional Learning <http://det.wa.edu.au/professionallearning/detcms/portal/>

Course Enquiries: Kerry Lo Presti
08 9340 8529

CFsmart
cystic fibrosis education program

Celebration of Life Ceremony

Please join us for a twilight ceremony in Kings Park

Friday 26 February 2016

6:00pm - 9:00pm

Place of Reflection, Kings Park

Please come and join us in commemorating the lives of those that have been lost to cystic fibrosis. Drinks and nibbles provided. If you wish to participate please contact Kathryn on 9346 7348 or servicesmanager@cysticfibrosiswa.org

Corporate Supporters – We Need You

MORE AND MORE WESTERN AUSTRALIAN BUSINESSES ARE RECOGNISING THE IMPORTANCE OF WORKING WITH CHARITIES LIKE CYSTIC FIBROSIS WA. SUPPORTING OUR CAUSE WILL HELP MOTIVATE STAFF AND DEMONSTRATE YOUR COMMITMENT TO HELPING MAKE OUR WORLD A BETTER PLACE. BELOW ARE A FEW OF THE WAYS YOUR ORGANISATION CAN HELP.

Looking for a tax break?

Cystic Fibrosis WA has deductible gift recipient (DGR) status meaning all donations above \$2 are tax deductible.

Volunteer

Volunteer a team to help out at one of our major events this year.

Workplace & matched giving

Setting up a workplace giving program allows employees to regularly donate to Cystic Fibrosis WA in a simple and effective way.

Businesses can enhance staff donations and fundraising efforts by matching their efforts and donations dollar-for-dollar up to a pre-determined level.

For businesses without an established workplace giving program, consider using an existing purpose-built platform like Good2Give.

Join or run an event

Create your own office event or support one of ours.

George Jones Family Foundation Cystic Fibrosis Golf Classic

Organise a team for 18 holes of golf followed by dinner at Lake Karrinyup Country Club on Friday 29 April 2016.

Convicts for a Cause

Throw your boss in jail, set bail and help fundraise to set him/her free.
convictsforacause.org.au

Physical challenges

Join the HBF Run for a Reason, Chevron City to Surf or Swan River Run and you can fundraise online.

Support a campaign

May is all about raising awareness for CF and it's a great time to hold a fundraiser.

65 Roses Day

The national cystic fibrosis day of awareness is on Friday 27 May 2016. Talk to us about getting involved.
65roses.org.au

65 Roses Challenge

Organise a fundraiser themed around the number '65'.

Go RED for CF

All kinds of fundraisers can draw on this colourful theme.

everydayhero.com.au/event/goredforcf

Serve it up for CF

Ask your social club to host a function and ask guests to donate what they would have spent on a night out.

serveitupforcf.org/event/serveitupforcf

Sponsor

Cystic Fibrosis WA has a range of major events such as an art exhibition and a fun run, patient and respite care programs, education and training programs needing sponsors.

Through your support, we are able to deliver essential services to some 400 people living with CF in WA.

Want to know more?

To discuss how your organisation can get involved in helping the CF community in 2016, contact our fundraising & marketing manager today on 08 9346 7336 or email marketing@cysticfibrosiswa.org.

Visit us online at <http://www.cysticfibrosis.org.au/wa/>



Save the Dates: 2016 Events

CYSTIC FIBROSIS WA'S 2016 CALENDAR IS FAST FILLING UP, SO MARK YOUR DIARIES NOW. THERE ARE EVENTS FOR EVERYONE, WHETHER YOU ARE LOOKING FOR OPPORTUNITIES FOR FURTHER EDUCATION, VOLUNTEERING, FUNDRAISING OR TO COME ALONG AND MEET OTHER MEMBERS AND ENJOY SOME RESPIRE.

February

- 18 Volunteer Training
- 19 Coffee Morning Baldivis
- 26 Celebration of Life

March

- 1 Advocacy Training
- 11 - 13 Parents' Retreat
- 31 Newly Diagnosed Meet and Greet

April

- 1 Transplant Support Dinner
- 6 AGM
- 29 Golf Classic

May

- 1 - 6 Regional Respiratory Training Program (for health professionals)
- 14 Ladies' High Tea
- 27 65 Roses Day

June

- 24 Coffee Morning Mandurah

August

- 1 Starting School with CF Information Seminar
- 27 Red Tie Dinner Dance

September

- 12 Art Exhibition Opening Night
- 16 Coffee Morning Bunbury

October

- 6 and 7 Sibling & Offspring Camp
- 14 Parents' Dinner
- 21 CFWA Expo
- 23 Hallowe'en Run: a Great Strides event

November

- 6 Post-Transplant Support Day
- 25 Christmas and Awards Party

More information about each event will be made available closer to the time.
Please note dates may be subject to change.



How Can I Find Out if I'm a Cystic Fibrosis Carrier?

KNOWING YOUR CARRIER STATUS CAN HELP INFORM THE LIFE CHOICES YOU MAKE FOR YOURSELF AND YOUR FAMILY.

Approximately 1 in 25 Australians of Caucasian ancestry are carriers of the CF gene changes that cause CF. Being a carrier does not mean you have CF but that you have the gene that can cause CF. Both parents need to be carriers in order for a child to be born with CF. Over 95% of children born with CF have parents who were unaware that they were carriers of the CF gene.

So how can you find out?

In Western Australia you can self-refer to the Genetic Services of Western Australia at King Edward Memorial Hospital or

your doctor or specialist can refer you. Eligibility for free screening depends on how close your relatives affected by CF are to you and your partner.

Your initial consultation with the genetic counsellor will discuss any of your concerns and answer your questions. Your family history will be reviewed and choices of early detection will be discussed.

For more information contact your doctor or:

Genetic Services of Western Australia*

King Edward Memorial Hospital

374 Bagot Road

Subiaco WA 6008

Phone: 08 9340 1525

Fax: 08 9340 1678

Email: gswa@health.wa.gov.au

References: http://www.kemh.health.wa.gov.au/services/genetics/brochures/genetics_services_wa.pdf

<http://www.cysticfibrosis.org.au/vic/info-resources-kit>

Beat the Heat!

LIVING IN PERTH, WESTERN AUSTRALIA BRINGS AN ABUNDANCE OF SUN, SAND AND SEA BUT HOW DOES THIS IMPACT THOSE LIVING WITH CYSTIC FIBROSIS?

In the warmer months, managing the heat can be of concern in people with CF. Increased heat, with or without increased humidity, impacts greatly on your daily management.

The CF genetic defect causes changes inside the sweat gland. Since chloride is not taken up by the body, more chloride and sodium (salt) is lost in the sweat. People with CF lose 3-4 times more salt through their sweat glands than those without CF, so the daily need for this essential mineral is high. Salt loss leads to a higher risk of dehydration in people with CF as they also tend to have a lower thirst drive.

The more you sweat the more salt you lose, so in the summer months, during exercise, or both, this can add up to a large excess of salt lost in sweat. If the sodium in the blood is too low this can lead to:

- loss of appetite
- tiredness
- impaired performance
- nausea
- difficulty concentrating
- weakness
- dizziness
- muscle cramps
- headaches and dehydration

Dehydration can cause mucus to be thicker, making airway clearance more difficult, thereby increasing the likelihood of infection; and increasing the risk of severe constipation and Distal Intestinal Obstruction Syndrome (DIOS) in people with CF.

All these things can be prevented or reduced by ensuring enough salt and fluid is taken in. It is important to remember that it is a combination of salt and fluid that

prevents salt loss and dehydration in people with CF.

How much fluid do I need?

The healthy population loses 0.5–2 litres of fluid per hour and, as we know that people with CF sweat even more during exercise, they are likely to lose more than this. The amount of fluid lost every 24 hours must be replaced. The average guide for fluid requirement is 35-45 ml/kg/day which in adults, approximates to somewhere between 2–3 litres/day minimum. This need increases with activity, heat and humidity.

Children with CF are known to drink less during exercise which correlates with the lower thirst drive, so will likely need constant reminding.

How much salt do I need?

- Approximately 500-1,000mg per day for infants
- Approximately 4,000mg per day for children over the age of one
- Approximately 6,000mg per day for adults
- Salt requirements may exceed 6000mg/day with extreme heat and/or humidity or with excessive exercise. This is at least 2–3 times the amount recommended for adults in the healthy population.

There is however, large differences between individuals depending on physical activity levels and climate conditions. It is best to be guided by the individual's CF care team.

How much sodium is in Glucolyte® and salt tablets?

- 1 sachet Glucolyte® = 360mg sodium
- 1 salt tablet = 240mg sodium
- 1 teaspoon salt = 1600mg sodium
- 1 café style sachet salt = 400mg sodium

Salt and fluid TOGETHER!

Research has shown high salt drinks containing 460mg/litre helped prevent dehydration in people with CF exercising in a hot climate and also helped to accelerate the thirst drive.

This equates to:

- 1 sachet Glucolyte® in 600ml water
- 2 salt tablets with 2 glasses of water
- ¼ tsp salt (1 café-style sachet) in 1 litre of cordial

How do I fit enough salt and fluid into my day?

- Add salt to all foods in cooking and at the table
- Include foods high in salt, e.g. salted nuts, cheese, vegemite, pretzels, chips, processed meats, etc.
- Instead of drinking just water, use a high sodium chloride drink such as Glucolyte® (1 sachet in 600ml water), Gatorade®, Powerade®, or try a homemade sports drink (¼ to ½ tsp salt in 1 litre cordial),



- Use salt tablets and take with a glass of water or cordial
- If you have a gastrostomy button or feed via a nasogastric tube, try flushing your tube with salty water or adding ¼ to ½ tsp salt to feeds.

We must also be reminded to be Sun Smart

Skin cancer is the most commonly diagnosed cancer in Australia and is largely preventable by being sun smart. When the UV level is 3 or above, protect yourself against damage and skin cancer by using a combination of these five steps endorsed by the Cancer Council Australia:

1. Slip on sun protective clothing – clothing that covers as much skin as possible and is made of close weave fabrics such as cotton, polyester/cotton and linen. If swimming, materials such as lycra which stays sun protective when wet.
2. Slop on SPF 30+ sunscreen – make sure your sunscreen is broad spectrum and water-resistant. Apply sunscreen liberally to clean, dry skin at least 20 minutes before you go outside and reapply every 2 hours.
3. Slap on a hat – a broad-brimmed, legionnaire or bucket-style hat provides good protection. Caps and visors do not provide sufficient protection for your whole face. Also wear sunglasses and sunscreen.
4. Seek shade – staying in the shade is an effective way to reduce exposure to the sun. Use trees or built shade structures or bring your own! Also use other protection to avoid reflective UV radiation from nearby surfaces, such as:

clothing, hats, sunglasses and sunscreen.

5. Slide on your sunglasses – sunglasses and a broad-brimmed hat worn together can reduce UV radiation exposure to the eyes by up to 98%. Sunglasses should be worn outside during the daylight hours. Choose close-fitting wrap-around sunglasses that meet the Australian Standard AS 1067. Sunglasses are just as important for children as they are for adults.

Be UV alert

Be extra cautious in the middle of the day when the UV levels are most intense.

Check your skin regularly and see a doctor if you notice any unusual skin changes. If you have a skin lesion that doesn't heal, or a mole that suddenly appears, changes in size, shape, thickness, colour or has started to bleed, see your doctor immediately.

For further information in regards to being Sun Smart contact the Cancer Council on 13 11 20.

Being aware, planning and taking extra precautions can ensure a fun-filled summer!

References:

- Cystic Fibrosis Australia salt and fluid replacement fact sheet.: https://www.cysticfibrosis.org.au/media/wysiwyg/CF-Australia/Fact_Sheets/CF_Aust_Fact_Sheet_Salt_Fluid_Replacement.pdf
- Cancer Council Australia: <http://www.cancer.org.au/preventing-cancer/reduce-your-risk/be-sunsmart.html>

Proudly Supporting



George Jones Family Foundation Cystic Fibrosis Golf Classic

Friday 29 April 2016
Lake Karrinyup Country Club



Register before 29 February for your chance to win a round of golf for four!

Cystic Fibrosis WA is proud to present the sixth annual Cystic Fibrosis Golf Classic, to be held on Friday 29 April 2016 at the exclusive Lake Karrinyup Country Club.

Enjoy a professional golf demonstration followed by lunch, a friendly game of Ambrose golf, pre-dinner drinks, a three-course meal with live entertainment and plenty of auctions and prizes.

Registrations are now open with packages starting at \$500 per person up to \$4000 for Gold Sponsorship including 4 players and an extra 4 dinner guests.

For more information please contact Brad Coutts at golf@cysticfibrosiswa.org or on 0417 946 729.

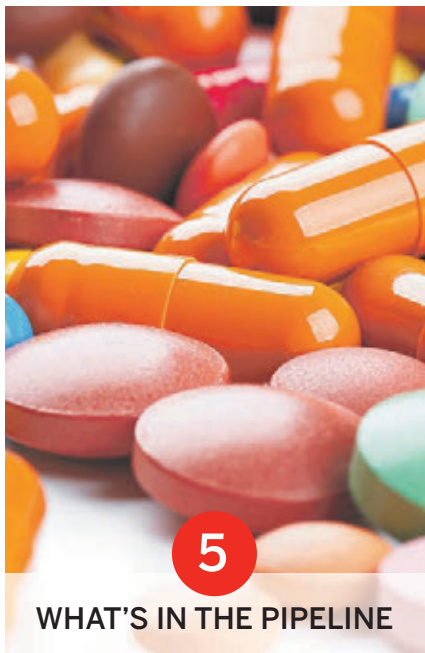
All proceeds from this event will be donated to cystic fibrosis research and services.



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RED

CEO Message

THE THEME OF THIS EDITION OF RED MAGAZINE IS OUR COMMUNITY



NIGEL BARKER, CEO

We often talk about the cystic fibrosis (CF) community as a clearly defined group of individuals that share a common cause and belief and act together to achieve some remarkable outcomes. The reality is however, that we are all individuals, often with our own agendas and diverse interests. We sometimes find ourselves competing against each other as we pursue these.

Having worked at CFWA now for eight

years, I have come to appreciate how hard it is to align everyone and get the CF community to focus. When this happens however, we can and do, achieve some remarkable results. Clearly, together we are more powerful than the sum of our parts.

Often it is a crisis that draws people together or a challenge like the listing of Kalydeco™ or advocating for access to new treatments.

In 2016, we will be providing training and orientation to existing and new volunteers and a team of advocates who will play a vital role in arguing for access to the new therapies like the combination drug Orkambi™, speaking with one voice across the whole of Australia.

We will focus on raising money for research and service delivery in what promises to be a tough market as the economy struggles with the downturn in commodity prices. We will be innovative in our fundraising; I am particularly looking forward to the Halloween Run in October and our workplace giving campaign, but even here we need to act together as a community to reach our full potential.

I would encourage you to think about how you may be able to contribute in 2016. This may be limited to a donation of time or money or encouraging your friends to get involved in an outrageous community fundraiser. If you are short of ideas then please download a copy of our community fundraisers hand book from our website or call the office on 08 9346 7333.

2016 is CFWA's 40th Anniversary and whilst we will be celebrating this throughout the year, the festivities will culminate at our Annual Awards night on Friday 25 November 2016. We had over 100 people present in 2015 and we look forward to seeing you there so, although it may seem a long way off, put it in your diary now to lock away the date.

Finally I'd also like to take this opportunity to formally welcome CF Consultant Dr Anna Tai who has recently joined the team at Sir Charles Gairdner Hospital as Assoc Prof Siobhain Mulrennan steps up into recently retired Dr Jerry Ryan's role. There's a special introduction to Anna in this edition and we can't wait to start working with her in the years ahead.

DEADLINE FOR THE NEXT ISSUE

If you would like to contribute to our winter issue, please contact us before April 1, 2016

DO WE HAVE YOUR CORRECT DETAILS?

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

DESIGN BY

Catherine Fisher
Community Newspaper Group

SPONSORED BY

Community Newspaper Group

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www.cysticfibrosis.org.au/wa/

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ON THE COVER

Cystic Fibrosis WA Home Care Workers and Community Nurse Sharon.

DISCLAIMER

This magazine is edited and produced for Cystic Fibrosis Western Australia. Articles or advertisements in this publication do not necessarily reflect the views of the editor or those of Cystic Fibrosis WA.

CFA Update

THE NORTH AMERICAN CONFERENCE

In October this year, I attended the North American Cystic Fibrosis Conference in Phoenix, Arizona.

Before I left Australian shores I set up a full schedule of meetings with my US and UK counterparts. Over the four days I managed to meet with more than 20 people with key roles in a myriad of areas in the cystic fibrosis space.

We really do have a global CF community and there are amazing things happening around the world. Our offshore colleagues are keen for Australia to play a key role in this community.

As new drugs are developed, there are opportunities for Australia to become involved in more trials as our clinicians and researchers are highly regarded around the world.

The Cystic Fibrosis Foundation mentioned specifically Australia's involvement in the Orkambi™ trials and the AREST-CF Early Surveillance Program. Internationally, AREST-CF is seen as a valuable resource for understanding early lung disease and CFA is committed to supporting this program well into the future.

A good deal of work is also being done across the globe in further development of the effectiveness

and flexibility of data registries and peer review processes. CFA plans to collaborate internationally to ensure that our quality improvement programs are world's best practice and truly deliver positive outcomes for people with cystic fibrosis.

As projects develop and progress is made, I will provide updates – and in many instances CFA will be looking to the CF community for feedback and inspiration.

Nettie Burke
CEO, CFA



Official Notice of 2016 AGM



CYSTIC FIBROSIS WESTERN AUSTRALIA (INC)

Wednesday 6 April 2016 7.30pm

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

Corner of Aberdare Road & Hospital Avenue.

Guest Speaker Professor Jonathan Carapetis,
Director of the Telethon Kids Institute in
Perth, Western Australia.

Jonathan holds separate qualifications as a medical practitioner (MBBS), specialist paediatrician (FRACP Paediatrics), specialist infectious diseases physician (FRACP Infect Dis), and specialist public health physician (FAFPHM), as well as a PhD.

RSVP for catering please Friday, 1 April to

08 9346 7333

Refreshments served following the AGM



What's in the Pipeline?

THIS YEAR SAW THE LISTING OF KALYDECO™ (IVACAFTOR) ON THE PHARMACEUTICAL BENEFIT SCHEME (PBS) IN AUSTRALIA. THE DRUG WAS DEVELOPED BY VERTEX PHARMACEUTICALS WITH SIGNIFICANT SUPPORT FROM THE CYSTIC FIBROSIS FOUNDATION (CFF) IN THE USA. CFF SUBSEQUENTLY SOLD THE ROYALTY RIGHTS FOR KALYDECO™ BACK TO VERTEX FOR US\$3.3BN (AUD\$4.7BN) AND IS NOW USING THAT MONEY TO SUPPORT FURTHER RESEARCH INTO CYSTIC FIBROSIS. THIS VENTURE PHILANTHROPY MODEL HAS CAUSED QUITE A STIR IN THE CF COMMUNITY AND FUNDRAISING CIRCLES AND MAY PROVE TO BE A PARADIGM SHIFT IN THE WAY THAT MEDICAL RESEARCH IS FUNDED IN THE FUTURE.

Whilst Kalydeco™ initially targeted the G551D mutation, its use has now been expanded to include other mutations: G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P, G1349D and R117H.

In Australia, these mutations affect just over 7% of the CF population. Kalydeco™ was the very first drug to attack the underlying cause of CF and caused a huge stir of interest as it progressed through clinical trials to market.

Whilst the listing of Kalydeco™ has been warmly received, the CF community in Australia and around the world is now abuzz with the hope that other Cystic Fibrosis Transmembrane Regulators (CFTR modulators) currently in the drug development pipeline will bring relief to people carrying the more common CF mutations.

Orkambi™ also known as Lumacaftor/ Ivacaftor is a combination of a "corrector" designed to move the defective CFTR protein to the proper place in the airway cell membrane and a "potentiator" that improves function of CFTR as a chloride channel. It's the next cab off the rank.

The US Food and Drug Administration (FDA) has approved the use of Orkambi™ for people who have two copies of the F508del CFTR mutation and are 12 years and older. A phase III trial is being conducted in children aged 6-11 who have two copies of the F508del CFTR mutation.

In Australia in November 2015, Vertex submitted Orkambi™ to the Therapeutic

Goods Administration (TGA) and Pharmaceutical Benefits Advisory Committee (PBAC).

In late 2015, CFA sent out over 250 letters to politicians and decision makers. Consumer letters were prepared for distribution over December and January.

The PBAC meeting and Orkambi™ presentation will take place between 6 - 11 March and we anticipate PBAC notification by approximately 23 April 2016.

The Politicians Contact List is available on the national website whilst the Department of Health will meet in early 2016 to discuss Orkambi™ reimbursement strategies.

Orkambi™ has had mixed trial results for people with two copies of the F508del mutations. Importantly however, many people on the drug saw a decrease in exacerbations, hospitalisations and lung damage and furthermore, reported improvements in their quality of life.

Whilst results may be mixed for Orkambi™, there are other CFTR modulators in the pipeline such as Ataluren, which completed a phase III trial in 2011. This showed patients had a lower decline in lung function and a lower rate of pulmonary exacerbations, compared with those who took a placebo. A new phase III trial is currently underway.

The combination drug VX-661 and Ivacaftor completed phase II trials for

people with CF who have two copies of the F508del mutation in January 2015. Several phase III trials were completed in 2015 in people who have one or two copies of the F508del CFTR mutation.

Other modulators in phase II trials include Riociguat and a new potentiator, QBW251, similar to Kalydeco™.

In The Netherlands, Galapagos NV reported in October 2015 that their corrector, GLPG2665, combined with the other two compounds, showed up to six-fold greater chloride transport than Orkambi™ in vitro. The triple combination therapy of C2 with GLPG2222 and GLPG1837 is expected to address 80% of mutations in the CF population. This is due to enter Phase I trials in mid-2016.

If you would like to keep abreast of where new drugs and therapies are in the development pipeline please visit the Drug Development Pipeline at www.tools.cff.org/research/drugdevelopmentpipeline/

Getting these drugs to market is a huge effort involving years of trials and lobbying of government especially when the cost is so high. CF Australia has recently established CF CAN, a CF Community Advocacy Network to help lobby for access to Orkambi™ and other drugs as they become available and also on issues affecting people living with CF and their families. Members from every state around Australia are currently undergoing training so that the CF community can speak with one voice.

Looking Back on 2015

CONVICTS FOR A CAUSE
LOCK 'EM UP AND THROW AWAY THE KEY!

Saturday 7 November saw large numbers of people “locked up” for charity at Convicts for a Cause, Perth’s greatest annual costume party, organised by CFWA and the Rotary Clubs of Perth and Mt Lawley. This year, we were proud to also have Diabetes Research WA on board. As always, it was an evening of charity, fun and mischief! We were pleased to have 6PR’s Steve Mills as our master of ceremonies with live entertainment provided by the internationally acclaimed Ellandar Productions and music by Dirtwater Bloom.

The event netted nearly \$60,000. We are indebted to our major sponsors; Veritas Check, Two Moons Consulting, as well as Capel Vale, Gage Roads Brewing Co, A-Team Printing, Abacus Rent It, Localise, and many others who supported Convicts for a Cause 2015. Planning is already underway for next year’s event.

Great Strides

A beautiful sunny day saw hundreds of families, friends and supporters take part in our Great Strides sponsored walk and family fun day out. Participants, mascot races, live entertainment from Radio Lollipop and a sausage sizzle helped net over \$21,000 for the Community Newspaper Group-sponsored event.

Fortunately, the forecasted rain held off until all the entertainment was finished and the bouncy castle was packed away.

The highest individual fundraiser was Michelle Webber who raised \$4,428. The highest team fundraiser was Sharon Crocker’s team “For Grace” raising \$2,306. Last but not least was the CF Spirit Award presented to Peter Valentine who ran the whole 8km distance pushing his daughter in her pram!

The ladies’ 8km race was won by Sarah Anderson whilst Charlie Mudd took out the 8km event for the men. Matthew

Jones took out the men’s 4km course whilst Lynette Collis was first across the line for the ladies 4km run.

This year we’ll be launching the Halloween Run. Brought to you by Great Strides, there’ll be prizes galore for the scariest costume and most gruesome grinch, the horriblist horror and much more! So tune up your broomsticks, sharpen your witches hats and put the date in your diary now for some seriously scary monster fun!

The Halloween Run will be on 23 October at Perry Lakes. Watch out for more details nearer the date. Proudly sponsored by Community Newspaper Group.

CFWA Christmas Party & Awards Night

Over 100 people attended our Christmas Party and Awards Night in November last year where four awards were presented to some remarkable individuals.

The volunteer of the year award was presented to the Gillard family. Each and every member and their close friends were recognised for their individual contribution from the youngest to eldest.

The Gillards have supported the Golf Classic for the last six years taking a leading role in the organisation and execution whilst the youngest member Lyla, was recognised as the face of CF in WA, appearing on merchandise boxes,



THE OLD FREMANTLE PRISON WAS FILLED WITH FAMOUS CONVICTS



PERRY LAKES RESERVE WAS PAINTED RED WITH RUNNERS SUPPORTING CYSTIC FIBROSIS.

featuring in CFWA's tax appeal (which raised over \$40,000) and starring in My First Admission DVD.

Hayley Gillard's acceptance speech brought tears of joy and applause as she motivated the crowd to take on bigger and better challenges.

The fundraiser of the year was awarded to a remarkable young man, Hunter Jackson, who took up the annual 65 Roses Challenge.

Hunter decided to run an uber marathon of 65 kilometres, solo from Two Rocks to Cottesloe!

His sister, Ella, who lives with cystic fibrosis, was his inspiration and true to the spirit of the 65 Roses Challenge he set a fundraising target of \$6,500. Even though he'd never run a marathon before, a gruelling eight week training program saw him progress from 5km to 35km.

Hunter set off from Two Rocks at 4am with his dad, David, driving ahead of him the whole way.

He was joined at the half-way point, three hours into the run, by five friends on bicycles, and another friend who ran beside him for 30km, all keeping his spirits high.

In an extraordinary time of just 6 hours and 41 minutes to cheers and jubilation, led by his mum, Judith, Jackson sprinted the final leg, running through the finish tape and dived straight into the ocean.

Hunter had set his target at \$6,500, a multiple around the theme of the 65 Roses Challenge, but like everything he does in life, he over achieved and raised \$15,754!

The long service award recognises outstanding support of CFWA over a period of at least 10 years and was presented to one of the country's top law firms, Herbert Smith Freehills, who over the past 14 years, have provided pro

bono professional guidance and advice to CFWA.

In accepting the award, Ante Golem, a partner based here in Perth, said that it had been a privilege to serve and also to meet such remarkable supporters on the night. He looked forward to providing another 14 years' of support as CFWA continues to grow.

The final award, for supporter of the year, was made to Adam D'Aloia, a remarkable individual whose passion and drive made a significant difference not only to CFWA and the services we can deliver, but also to the lives of many adults and children living with CF who will attend the QEII Medical Centre at either Charlies or the new Perth Children's Hospital. Adam was

the driving force behind establishing free WiFi for in-patients on Ward G54; he's raised nearly \$6,000 from his 'Serve It Up For CF' dinners; and working closely with CFWA, has through direct negotiation with the Minister for Health, secured a cap for parking fees at the QEII site for CF patients.

Adam and his family and friends continue to support CFWA and we can't wait to see what he gets up to next!

The night was a great success and also launched the workplace giving program where people were encouraged to donate a regular amount from their fortnightly salary. For more details please contact Ric at our offices on 08 9346 7333.



ADAM, OUR SUPPORTER OF THE YEAR RECIPIENT, WAS JOINED BY FAMILY AND FRIENDS TO CONGRATULATE HIM ON HIS AWARD.



FELICE & VANYA ENJOYING THE PHOTO BOOTH.

Meet the Supporter: Ruth Thomas

CYSTIC FIBROSIS WA HAS BEEN VERY FORTUNATE TO HAVE RUTH THOMAS WORK AS A VOLUNTEER AT MANY OF OUR FUNDRAISING EVENTS OVER THE PAST FOUR YEARS. RED HAD A CHAT WITH RUTH TO FIND OUT MORE ABOUT THIS LADY WHO GENEROUSLY GIVES UP HER TIME TO PICK UP RUBBISH, SERVE FOOD AND DRINKS AND WASH DISHES.

RED: Can you please tell us a bit more about yourself Ruth?

I have a husband, two grown-up children and four grandchildren. I trained as a nurse at Charlies (Sir Charles Gairdner Hospital) in 1975 and I left in 1978 to have my first child. I then worked in Port Hedland Hospital for about five years as a nurse in the Emergency Department. When I came back to Perth, I worked on the Respiratory Ward at Charlies. I worked there for 25 years. I then retired from nursing and now work in our business doing the accounts.

Our business is Aerodrome Management Services* (AMS) and we work on airports around Australia, such as Halls Creek, Paraburdoo and Broome in WA, as well as Weipa in Queensland. My husband was already running the business while I was nursing. We started it off in our lounge room but now it has grown and we have 100 plus employees including family members. AMS sponsors Cystic Fibrosis WA's (CFWA) Golf Classic and some employees attend that event as a staff day out.

RED: What led to you volunteer for CFWA?

I had just left nursing at the time and one of my friends told me to watch the TV to see Ingrid Laing, now an adult, who was being interviewed about being the Telethon* child. At the same time, I was also reading the newspaper and saw an advertisement asking for volunteers with CFWA for the Great Strides walkathon. I saw all this as a sign so I gave CFWA a call and got involved. I worked at the

Great Strides walkathon picking up rubbish and I have volunteered at most of the fundraising events since, doing anything and everything. I enjoy all of the events, they are all different. The Art Exhibition ends up being the most expensive one for me though because either my husband or I decide to buy some artwork!

RED: Why do you volunteer for CFWA?

I volunteer for CFWA because it keeps me linked in with an area that I worked with for so long. CFWA are very good at expressing their thanks for my time so I feel appreciated. It's a great cause and I want to help towards finding a cure for CF.

It's also good fun; I get to enjoy wine, food, and great company.

RED: What other organisations do you volunteer for?

I have been a member of the Zonta

Club of Swan Hills* for 16 years. Zonta is an international service organisation that women working in professions and businesses are involved with and they provide support for advancing the status of women in less fortunate circumstances both locally and internationally.

I have also been part of a knitting group, Ravelry, for about ten years and I mostly knit beanies and scarves for either the Street Doctor* or St Barts*. For the last six years our knitting group has also raised money for the "Relay for Life" event for the Cancer Council*. We call our group the "Knitters for a Cure" or "KFAC" and we fundraise throughout the year. In the past six years our knitting group has raised about \$30,000.

RED: If you have any spare time, what else do you like to do?

I do a bit in the garden and enjoy spending time with my grandbabies and friends. I read but am not well read.



RUTH (RIGHT) WITH ANOTHER VOLUNTEER, FAITH AT THE 2015 CFWA CHRISTMAS PARTY

The Benefits of Volunteering

THERE ARE MANY BENEFITS OF VOLUNTEERING. IT HELPS CONNECT COMMUNITIES AND BUILDS SOCIAL COHESION AND NETWORKS. IT ALSO CONTRIBUTES TO PHYSICAL AND PSYCHOLOGICAL WELLBEING AND IN SOME CASE CAREER OPPORTUNITIES.

The Australian Bureau of Statistics estimated that in 2006-07, there were 4.6 million volunteers who supported community organisations. They contributed 623 million hours, equating to 317,200 full-time equivalents. The economic value of these hours was estimated to be \$14.6 billion.

Volunteers also act as advocates and consultants, informing policy development.

The word volunteer was first recorded during the 1630s. The first recorded nationwide volunteering effort occurred out of need during the Second World War; thousands of volunteers assisted in collecting supplies and caring for the injured, amongst other duties. After the war there was a shift of focus to assisting the poor and disabled, both locally and overseas. The Peace Corps® was developed in the US in 1960 and President Lyndon B Johnson declared a War on Poverty in 1964; volunteer opportunities started to expand and continued into the next few decades.

The Salvation Army® is one of the oldest and largest organisations working for disadvantaged people, organising a number of volunteering programs since its inception. Following this, a number of other volunteer organisations were founded such as Rotary® and Lions Clubs® International.

Types of Volunteering:

Traditional volunteering:

Project work with organisations like CFWA which may involve volunteering for a one off project or on a more regular basis such as campaigns, advocacy work or committees.

Skill enhancement/student placements:

Career development and skill enhancement. This is specific voluntary work to aid in future employment. The volunteer is advised to call organisations first to ensure that it's an appropriate



VOLUNTEERS HELPING SELL ROSES ON 65 ROSES DAY

'fit' between the organisation and the volunteer.

Voluntourism:

Combining voluntary work with tourism. This type of voluntary work is becoming more popular, providing a unique travel experience through living in local communities and experiencing local life. Lonely Planet™ or Trip Advisor™ can connect you to other travellers.

Online volunteering:

Assistance with social media, mentoring, written articles via websites or online.

Micro-volunteering:

This seeks to address specific social problems, such as 'Have a Go Heroes' (aimed at improving support for carers and those cared for), 'Spots of Time' (bitesize, creative ways for people to volunteer) and the Orange 'Do Some Good' app (a collection of micro-volunteering activities that you can complete on your mobile and on the move).

"Volunteers don't get paid, not because they're worthless, but because they're priceless" - Sherry Anderson

"No one is more cherished in this work than someone who lightens the burden of another. Thank you" - Author unknown

Volunteering at CFWA:

CFWA is heavily reliant upon volunteers for the success of its events and operations. Volunteers are engaged by the organisation for a range of roles where a

need is identified and their contribution is greatly valued.

We have various opportunities for people to contribute to the cystic fibrosis (CF) community, including:

- Public speaking and awareness raising
- Participation in activities and events, e.g. Great Strides, Spring Rose Art Exhibition, 65 Roses Day
- Administrative support
- Delivery & pick up of items, e.g. money tins, merchandise boxes
- Participation on sub-committees, e.g. Golf Classic
- Participation on CFWA board
- Community fundraising
- Lobbying and advocacy

To learn more about volunteer opportunities at CFWA, please contact Shelley on events@cysticfibrosiswa.org or 08 9346 7333

References:

<http://www.theguardian.com/voluntary-sector-network/2011/jul/06/micro-volunteering-charities-people>

<https://en.wikipedia.org/wiki/Volunteering>

<https://volunteeringwa.org.au/>

<http://www.quoteagarden.com/volunteer-apprec.html>

Higher Events

LIFTING THE PROFILE OF CYSTIC FIBROSIS WA EVENTS. RED SPEAKS TO MEGAN BRIERS, OWNER.



Higher Events has been a great supporter of Cystic Fibrosis WA for many years now. How did you first get involved with the cause?

I became involved with supporting cystic fibrosis when I volunteered to be part of the Cystic Fibrosis Grand Ball, something that I feel truly proud to be a part of. When I started Higher Events I was able to extend my support not only to the Ball but to events that Cystic Fibrosis WA runs: including: the Spring Rose Art Exhibition, Celebration of Life Ceremony and most recently, the CFWA Christmas Party and Awards Night.

You have helped us out with furniture and

decorations for a wide range of events. Does Higher Events have a speciality, or do you cater for all types of events?

Higher Events is a hire company that caters for all types of events, from corporate events, weddings and the very popular back yard Aussie party. We specialise in an exciting range of party hire furniture; some of our collections are only available for hire in Perth from Higher Events.

Do you have a connection to cystic fibrosis?

Initially my connection to cystic fibrosis was through my very good friends who have a son with CF, but I have since met many families through the Grand Ball and

CFWA events who live with cystic fibrosis every day.

We're always impressed how you can transform a venue. What's your favourite item or tip to add a touch of spice to a room?

Colour and light. Add a little colour to your next event; it doesn't have to be a lot, just a little. A piece of coloured furniture with a little additional ambient lighting can make all the difference.

How can our members get in touch?

Our web site is www.higherevents.com.au and all our hire products and pricing can be found online. Our office number is 08 9259 4242.



HIGHER EVENTS CATERS FOR ALL TYPES OF EVENTS, VISIT WWW.HIGHEREVENTS.COM.AU FOR SOME MORE INSPIRATION! IMAGES: 1-5



New Body Composition Scales at Charlies

THANKS TO A SUCCESSFUL FUNDING APPLICATION THROUGH THE SIR CHARLES GAIRDNER HOSPITAL (SCGH) AUXILIARY, SCGH'S RESPIRATORY AND CYSTIC FIBROSIS DIETITIAN, PAUL O'NEILL, WAS ABLE TO PURCHASE A SET OF STATE-OF-THE-ART BODY COMPOSITION ANALYSIS (BCA) SCALES.



The scales provide detailed information about a patient's body composition such as fat-free mass, muscle mass, fat mass, percentage fat mass and fluid status including intracellular and extracellular water levels.

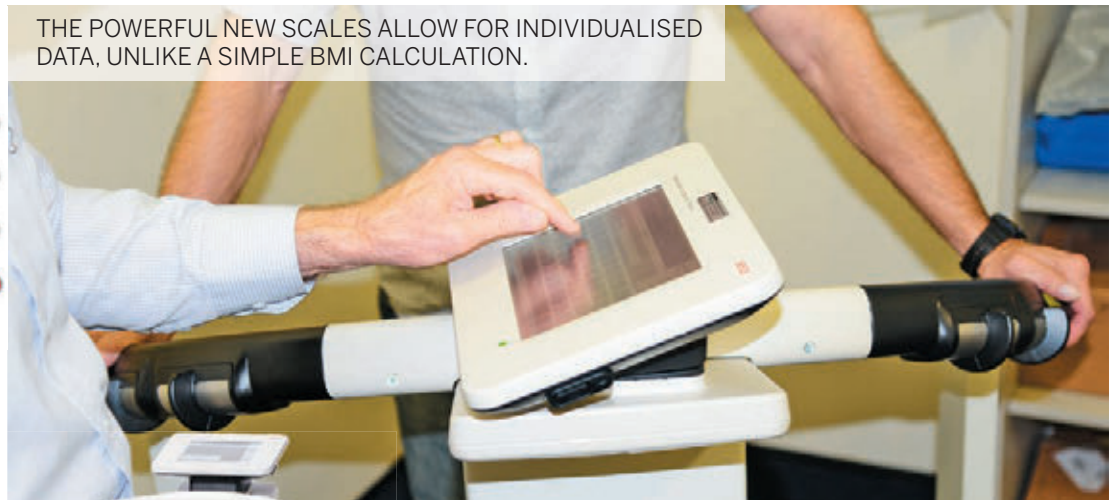
Paul says the scales use the latest technology to perform bioelectric impedance vector analysis and are validated to compare with gold standard measurements of body composition.

"A patient's body composition analysis can be completed in about 20 seconds. The patient is then provided with a visual, and easily understood printout such as the example pictured," he said.

"The Body Mass Index (BMI) is commonly used as a measure of body weight relative to height. However, BMI has some limitations, for example it doesn't provide information about a patient's body composition, such as fat or muscle. Individuals such as athletes may be classified as overweight despite having a large component of muscle."

Paul says there is a strong interrelationship between nutrition and lung health in

THE POWERFUL NEW SCALES ALLOW FOR INDIVIDUALISED DATA, UNLIKE A SIMPLE BMI CALCULATION.



ANDREW TRYING OUT THE NEW SCALES ON HIS CLINIC VISIT



cystic fibrosis (CF). Populations with a higher BMI have better lung function until they are overweight, after which the benefits plateau. The really exciting thing about this equipment is that we are now able to assess the amount of fat, muscle and fluid that comprises body weight. This information can provide insight into body composition that enables individualised and specific direction for an individual's

nutrition and exercise goals.

So far, CF patients have shown a lot of interest in the visual information provided, with comments such as 'that is really interesting', 'very cool' and 'I am going to work on that and see if I can improve', Paul said.

Paul wished to thank SCGH Auxilliary for their work and generous support in contributing to patient care.

\$33,750 PhD Top Up Scholarship

APPLICATIONS OPEN NOW FOR PHD TOP UP SCHOLARSHIP.

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

Today, as a result of improvements in early diagnosis, intervention, treatment and better pharmaceuticals, most children affected by CF are now surviving well into adulthood. As a result, for the first time ever, there are now more adults living with CF than children.

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

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

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

This scholarship is administered through the Australian Cystic Fibrosis Research Trust on behalf of CFWA. The Scholarship is for \$11,250 per annum for a maximum of three years. Conditions apply.

Applications open Monday 18 January 2016 and close on Friday 12 February 2016 at 5pm EST.

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

Application forms are available from:

The Australian Cystic Fibrosis Research Trust

PO Box 268

North Ryde NSW 1670



Cystic Fibrosis WA Home Care Workers in the Community

CFWA HOME CARE WORKERS (HCW) PROVIDE SUPPORT FOR FAMILIES AND ADULTS AFFECTED BY CF. THEY ARE SPECIAL PEOPLE THAT ADD A POSITIVE DIMENSION TO THE MANY TREATMENTS OF CF.

This in-house service has been delivered by CFWA for over 20 years. It has now grown to meet the needs of 107 children and 24 adults currently receiving the service. Our HCWs have a comprehensive knowledge of CF, attending an annual study day and monthly training sessions and are under the direction of the CFWA senior physiotherapist and community nurse.

Referrals are received from Princess Margaret Hospital (PMH), Sir Charles Gairdner Hospital (SCGH) and by self-referral. Support ranges from supervision

of airway clearance, supervision and/or participation in exercise programs, to occasional respite.

With a smile and expertise in distraction and motivation, our HCWs work their magic. CFWA provides a service to children and adults from Mandurah to Helena Valley to Yanchep.

For more information in regards to the support services provided by CFWA, contact the services team on

Phone: 08 9346 7333

Email: info@cysticfibrosiswa.org

Web: www.cysticfibrosis.org.au/wa



CYSTIC FIBROSIS WA IN HOME CARERS ATTEND REGULAR TRAINING TO ENSURE PATIENTS RECEIVE THE MOST UP-TO-DATE CARE.

Welcome to Dr Anna Tai

IN LATE 2015, DR ANNA TAI JOINED THE TEAM AT SIR CHARLES GAIRDNER HOSPITAL AS A CF CLINICIAN FOLLOWING AN OUTSTANDING CAREER IN NEW ZEALAND AND QUEENSLAND.

Anna trained as a respiratory physician with a subspecialty interest in CF. She graduated from the School of Medicine, University of Auckland, in 2001. Following this, she undertook advanced clinical training in respiratory medicine before embarking upon the role of clinical and research fellow in CF at The Prince Charles Hospital in Brisbane in 2008.

Anna continued to work as a respiratory physician at the adult CF centre in Brisbane and in 2011, commenced a

full time PhD study in CF with a view to identifying methods to individualize antibiotic treatment for patients with CF.

Anna visited the CFWA offices in December to meet the staff. We are delighted at Anna's appointment and can't wait to work with her in the near future.



Fundraising News

THANK YOU TO EVERYONE THAT HAS BEEN PART OF OUR FUNDRAISING ADVENTURES IN 2015!

We are proud to say that we have a wonderful group of supporters. The funds you have raised will go towards providing services to people and their families that are living with CF and also fund vital research projects.

We are so grateful to have such strong supporters. Thank you!

Striding for Life

To everyone that participated in Great Strides on Sunday 25 October 2015 – thanks so much!

Whether you helped as a course marshal, cooked sausages, registered runners, cleaned tables, parked cars, handed out water, ran in the challenge or raised funds, we couldn't have done it without you. Thank you for your support, we think you are pretty amazing!

We are pleased to say the combined fundraising efforts reached over \$21,000.

Thank you!

Team Vicki Liddle	\$558.75
Cure for Cruze	\$1707
Wade Croome	\$100
For Grace	\$2,305.75
Jaclyn Gerritzen	\$35
Just Breathe Carly and Tina	\$1,804.52
Lisa Rae	\$10.50
Michelle Webber	\$4,428.25
Mitch Messer	\$1,049
The Walsh Corbetts	\$1,558
Sarah MacArthur	\$504
Sarah Potts	\$745
Sharon Roberts	\$525.25
Team Marvel	\$5

Schools do it again!

Once again the school community has impressed us with their ingenuity and entrepreneurial efforts when it comes to

raising money for cystic fibrosis.

Thank you to the teachers that taught and encouraged the students along the way. And thank you to each of the students for your time, effort, hard work and brilliant fundraising ideas.

The Year 6 students at Perth College raised a very nice sum of \$2,647.36 by selling goods and services through their newly



ADAM "SERVING IT UP" FOR CF.



developed entrepreneurial program. Well done and thank you for such a great effort!

Wesley College students cooked sausages, rattled donations tins and sold Christmas cards, raising an impressive, \$714.30. Thanks so much!

Cannington Community College set their sights on holding a free dress day. The day's result came to a total of \$439.80. Thank you to everyone who participated.

Small Business Making a Difference

Every month a small number of businesses from the corporate community make an effort to help improve the quality of life of people living with CF. Thank you for your consistency, effort and faithful commitment. We are so very grateful for your ongoing support!

The Good Guys Malaga raised \$1,185 through their ongoing fundraising efforts. Thanks so much!

Thank you to Gia and Jade and the team from Amcal Inglewood for raising a very impressive \$4,337.75. Such an amazing effort!

Thanks to Emma Pridda and the team from Rowdy Promotions for raising \$27.27 and thanks also to the Xpresso Code for raising \$120.85.

Catherine North and the organizers of the York Pharmacy Health Expo raised \$90.91. Thanks team!

A Quiz for a Cause

On Friday 13 November, a fabulous team of PMH nurses, led by Kim Henley, hosted the BIG Quiz at the South Perth Community Centre. The evening was packed full with prizes, raffles, games, live and silent auctions. The final result was a very healthy \$8000 for Cystic Fibrosis WA.



GUESTS HAVING FUN IN THE PHOTO BOOTH AT THE RED TIE DINNER DANCE



LUKE IS RAISING MONEY BY HOLDING EVENTS AT HIS SCHOOL AND SELLING HIS CUSTOM PILL BOXES, ALL FOR HIS BROTHER WITH CF.

Thanks to Kim and the team for running such a fabulous night, and of course for the funds you raised for CF.

Adam Serves it Up

On Saturday 24 October, Adam D'Aloia Served it Up for CF!

This isn't the first time Adam has held a Serve it Up dinner, having held one in 2014. Adam has built a reputation for hosting a sumptuous feast while raising funds for CF.

Adam has managed to secure a small team of generous suppliers and supporters for his Serve it Up dinners and managed to raise, \$2,811.25.

Thank you Adam, and thank you to your team for what you have done to help to improve the lives of people living with CF.

Jumping for Cash

Sarah and Gavin Haddow and their two sons, Ricardo and Casey, who are living with cystic fibrosis, wanted to give something back to CFWA for the support their family has received over the years. But much to our amazement their choice of fundraiser surpassed reason when Gavin and Casey decided to jump out of a perfectly good working plane at 15,000 feet!

We are pleased to say that all went well and both Gavin and Casey have achieved something noteworthy for their bucket list, and managed to raise \$4,797!

Thank you for making such an impressive effort, for sharing your joy and for helping others that are living with CF.

Congratulations on a job well done!

Want to do More?

Are you feeling inspired by some of these fundraising stories?

Whatever your idea is, big or small, low key or full production, we'll support you

along the way. And if you aren't sure what you want to do, we can help you out with some ideas, too.

Contact Shelley today at CFWA on events@cysticfibrosiswa.org or 08 9346 7333 - let's make your fundraising aspirations a reality!

The Good News is In

The Red Tie Dinner Dance is on again!

Yes, the Red Tie Dinner Dance will be back for 2016. Tickets sold out very early for the 2015 inaugural event, and it is expected they will sell even quicker second time around. So mark the date in your diary and book your table early to avoid disappointment.

The Red Tie Dinner Dance will be held on Saturday 27 August 2016 at the Fremantle Sailing Club. To book a table or make a sponsorship enquiry, please contact Wendy Barker on 0408 940 851.



GAVIN & CASEY HADDOW TOOK A 15,000 FOOT JUMP FOR CF.



TOD JOHNSON ENSURED EVERYONE HIT THE DANCE FLOOR AT THE RED TIE DINNER DANCE.



Golf Classic in Full Swing

REGISTRATIONS ARE NOW OPEN FOR THE 2016 GEORGE JONES FAMILY FOUNDATION CYSTIC FIBROSIS GOLF CLASSIC

The George Jones Family Foundation Cystic Fibrosis Golf Classic is set to tee off for the sixth successive year at the prestigious Lake Karrinyup Country Club on Friday 29 April.

Register a team now for this wonderful day out, with a professional golf demonstration and friendly Ambrose competition, followed by an elegant three-course meal at the club house.

Don't miss the opportunity to treat yourself and your clients to an amazing day whilst at the same time making a difference to the lives of all

people living with cystic fibrosis.

For more information about the event please visit www.cysticfibrosis.org.au/wa/golfclassic or contact Brad Coutts, committee chairman on 0417 946 729 or on golf@cysticfibrosiswa.org

If you are unable to participate and can donate goods or service for our auction, please contact Shelley on 08 9346 7333 or at events@cysticfibrosiswa.org





GET INVOLVED...

with fundraising and become a CF Superhero

TAKE ACTION TODAY AND HELP FIND A CURE

Whether it's a celebration, a challenge, at your school, a bake sale or a bingo night, individuals, families and community groups play an important role in raising funds for cystic fibrosis.

You could be surprised at how simple it can be!

To find out how you can fundraise and become a CF Superhero, contact Shelley, events@cysticfibrosiswa.org or 9346 7333

cysticfibrosis.org.au/wa facebook.com/CysticFibrosisWA



CYSTIC FIBROSIS
Western Australia

How Does a Diagnosis of Cystic Fibrosis Affect the Family?

CINDY BRANCH-SMITH, PHD CANDIDATE AT THE TELETHON KIDS INSTITUTE®, IS PART OF A RESEARCH TEAM LOOKING AT THE LEVELS OF STRESS, DEPRESSION AND FAMILY AND RELATIONSHIP FUNCTIONING AMONG FAMILIES OF YOUNG CHILDREN WITH CYSTIC FIBROSIS, AND RELATING THESE TO HEALTH IN THE CHILD.

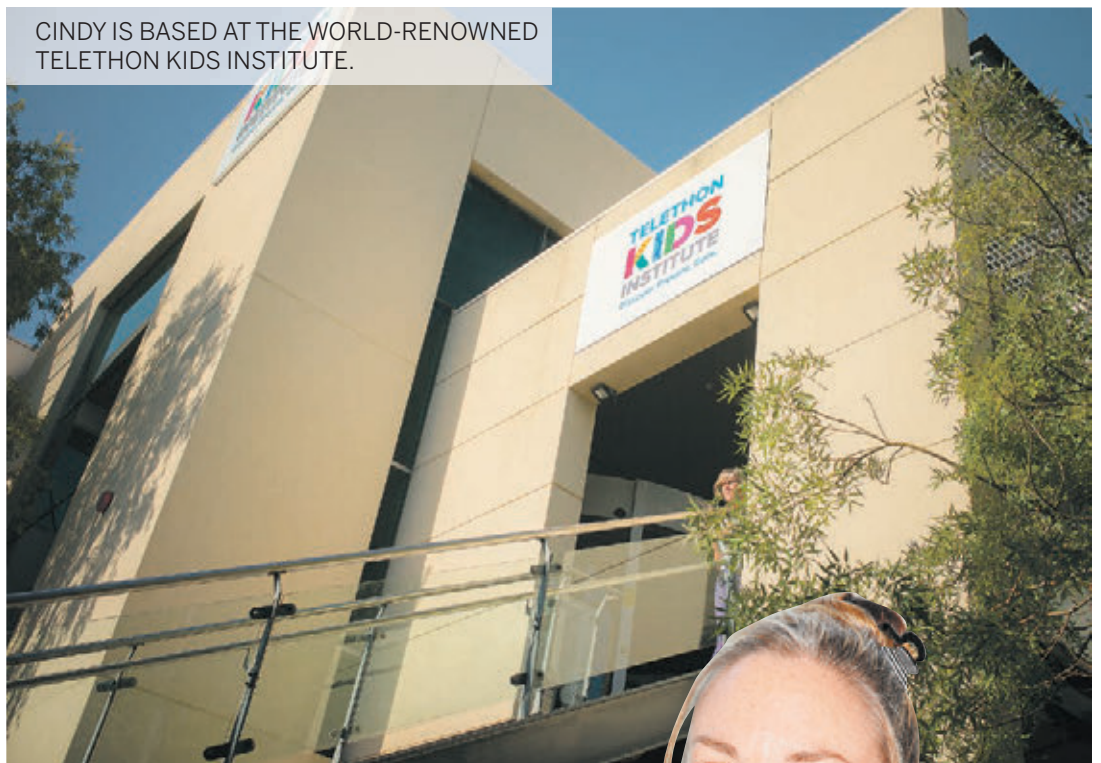
How can parents minimise the effects of chronic illness and hospital admissions on the family unit?

Establishing and maintaining family routines is important for families to be able to stick together through difficult times such as cystic fibrosis (CF) exacerbations and hospital admissions. Though it is not always possible, getting help from extended family members with routines can be an important resource for families. Support from family, friends and other CF parents can also help with some of the psychological burden associated with challenging times; just sharing your burden can help to lighten the load.

How can families, especially mothers, have a work-life balance with a child who has a chronic illness? What are the most common parental concerns and how can they deal with them?

It is difficult for mothers to return to work and to keep a work-life balance. Job-sharing can be an option, working part-time or volunteering a small amount of time with an advocacy group can help mums to have a life outside of being a parent. Research shows that mums who work at least part-time develop coping mechanisms from their work life that help to cope with their family life.

CINDY IS BASED AT THE WORLD-RENOUNDED TELETHON KIDS INSTITUTE.



What effect does a chronic illness like CF have on relationships within the extended family, including grandparents?

A CF diagnosis is difficult for families to accept because most times, due to the recessive genetic nature of CF, parents have no idea that CF is even a possibility. Speaking with your genetic counsellor and getting extra counselling may help parents to develop strategies in order to have important discussions with extended family members. A cohesive family is the best support for those managing CF, therefore, support from extended family members and friends really helps parents to manage day-to-day family life.

**TELETHON
KIDS
INSTITUTE**
Discover. Prevent. Cure.





Join the Fight Against Antibiotic Resistance

ANTIBIOTICS ARE “MIRACLE MEDICINES” BUT MUST BE USED WITH CARE.

What is antimicrobial resistance?

Antimicrobial resistance (AMR) happens when bacteria stops an antibiotic from working effectively. This has resulted in standard medical treatments not working as effectively as in previous times and sometimes there may not be an available treatment for the infection, e.g. ebola. Multi-resistant superbugs are a strain of bacteria that has mutated (changed) after coming into contact with an antibiotic. The bacteria then becomes resistant to the antibiotic which means the antibiotic cannot kill the bacteria or stop them from multiplying.

Antibiotics save lives every day and are especially important in complex care situations e.g. chronic disease including CF, transplant, immunosuppression, ICU

But..... antibiotics are a limited resource.

Over the last three years it has been recognised more widely that antimicrobial

resistance is a public health crisis requiring global action. AMR infections require more investigations, complex and expensive treatments and longer hospital stays. Australia contributes to a global action plan to fight AMR. You can play a part in the fight against antibiotic resistance.

Pseudomonas aeruginosa is an example of a bacteria that develops resistance. Current strategies to manage this include the use of different types of antibiotics and use of inhaled antibiotics using a nebuliser or inhaler.

Things you can do to reduce antibiotic resistance:

Take the pledge to reduce antibiotic resistance

- I will wash hands frequently to reduce spread of infection
- I will prevent spread of resistance by coughing into my sleeve

- I will maintain immunity by getting vaccinated
- I will use antibiotics appropriately -I will only take antibiotics exactly as prescribed even if I feel I no longer need to take them– correct dose for the length of time the doctor prescribes
- I will not miss doses of antibiotics and I will take them on time, no long gaps between doses
- I understand that it is possible to pass on antibiotic resistant bacteria to others
- I will travel safely avoid raw food, cooked food is safer
- I will not share antibiotics

Useful resources

Understanding Bugs, Infections in CF

<https://www.youtube.com/watch?v=94m8aWa6vKg>

<https://www.cff.org/PDF-Archive/Bacteria-and-Antibiotic-Resistance-in-People-With-CF/>

Connect With CF Around the World

CYSTIC FIBROSIS (CF) AFFECTS 70,000 PEOPLE WORLDWIDE AND OVER 3,200 CHILDREN AND ADULTS IN AUSTRALIA. THE GLOBAL NETWORK OF CF ORGANISATIONS IS EXTENSIVE AND CAN HELP YOU WITH RESOURCES ON MANAGING THE PRACTICAL ASPECTS OF CF LIKE SCHOOL, WORK AND TRAVEL AS WELL AS IN KEEPING IN TOUCH WITH THE LATEST TREATMENTS AND RESEARCH.

CF global community:

Worldwide, the CF organisations are united in attempting to find a cure for CF. Internationally, the CF community is driven by a dedicated group of scientists, carers, donors, volunteers and people with CF and their families.

CF resources:

Not for profit CF organisations committed to finding a cure for CF include:

- Cystic Fibrosis Australia
<http://www.cysticfibrosis.org.au/>
- Cystic Fibrosis Canada
<http://www.cysticfibrosis.ca/>
- Cystic Fibrosis Foundation (US)
<https://www.cff.org/>
- Cystic Fibrosis Trust (UK)
<http://www.cysticfibrosis.org.uk/>
- European Cystic Fibrosis Society
<https://www.ecfs.eu/>
- Australian Respiratory Early Surveillance Team for Cystic Fibrosis (AREST CF): a team of over 60 doctors and researchers dedicated to the improvement of respiratory health and outcomes in children with CF. A collaboration of specialist paediatric CF centres in Perth and Melbourne who want to better understand which factors predict lung damage early so that CF can be treated early and CF lung disease reduced

<http://www.arestcf.org/our-research/arest-cf-early-surveillance-program/>

Where can I find reliable scientific information on CF?

- e- cystic fibrosis review: electronic newsletter from Johns Hopkins University of Medicine featuring the latest evidence for CF care management.

<http://www.ecysticfibrosisreview.org/s>

- Journal of Cystic Fibrosis: original scientific research based information on CF, edited by Australian Scott Bell from Brisbane. Articles published are freely available after two years. Visit Science Direct and navigate to previous years.

<http://www.sciencedirect.com/>

- Cochrane CF & genetic disorders group: an international network, based in the UK, of healthcare professionals, researchers and consumers preparing, maintaining, and disseminating systematic reviews of randomised control trials for treating CF and other genetic disorders

<http://cfdg.cochrane.org/>

NEWLY DIAGNOSED MEET & GREET

All parents with newly diagnosed babies or small children are invited to attend

Thursday 31st of March 2016
The Niche Bldg, 11 Aberdere Rd Nedlands
From 6:30pm onwards

For more information & RSVP:
recreation@cysticfibrosiswa.org
08 9346 7338 / 0419 926 277

CYSTIC FIBROSIS
Western Australia

RED Resources

Fact sheets

We have a range of new fact sheets available on the CFWA website; www.cysticfibrosis.org.au/wa under the 'resources' tab. The fact sheets cover a range of topics such as:

- exercise
- PICCs and PEGs
- pill swallowing
- reproductive information for males and females
- siblings
- sweat testing
- carers
- salt and fluid replacement

There are new fact sheets that will be added early in 2016, with topics including: starting school with CF, procedural anxiety, travel, nutrition, cystic fibrosis-related diabetes (CFRD) and more currently in the works.

School visits 2016 CFWA education support

If you would like your child's school to learn more about CF, we have a range of resources to assist. Our education officer, Natalie Amos, is available to provide education sessions with teachers, other parents and students, and can also post you or your child's school information materials if needed.

Contact Natalie at education@cysticfibrosiswa.org or phone 08 9346 7333

Check out our website www.cfsmart.org to see the range of support materials available and also our CF Smart Facebook page: <https://www.facebook.com/cfsmarteducation/?fref=ts>

Princess Margaret Hospital (PMH) CF seminar for school teachers

Aim: to broaden the teachers' knowledge of CF and the implications for management for both primary and secondary students in the school

environment and support their education through periods of hospitalisation. Participants will gain an insight into the mental health implications for the student and family, arising from living with CF.

Date: 1 April 2016

Registration closing date: 30 March

From: 12.45pm to 3.45pm

Cost: Free

Venue: PMH, Admin Building, McDonald Lecture Theatre, Roberts Road, Subiaco
<http://goo.gl/maps/5AgYB>

Presenters: PMH respiratory team and liaison teachers

Book online: Institute for Professional Learning <http://det.wa.edu.au/professionallearning/detcms/portal/>

Course Enquiries: Kerry Lo Presti
08 9340 8529

CFsmart
cystic fibrosis education program

Celebration of Life Ceremony

Please join us for a twilight ceremony in Kings Park

Friday 26 February 2016

6:00pm - 9:00pm

Place of Reflection, Kings Park

Please come and join us in commemorating the lives of those that have been lost to cystic fibrosis. Drinks and nibbles provided. If you wish to participate please contact Kathryn on 9346 7348 or servicesmanager@cysticfibrosiswa.org

Corporate Supporters – We Need You

MORE AND MORE WESTERN AUSTRALIAN BUSINESSES ARE RECOGNISING THE IMPORTANCE OF WORKING WITH CHARITIES LIKE CYSTIC FIBROSIS WA. SUPPORTING OUR CAUSE WILL HELP MOTIVATE STAFF AND DEMONSTRATE YOUR COMMITMENT TO HELPING MAKE OUR WORLD A BETTER PLACE. BELOW ARE A FEW OF THE WAYS YOUR ORGANISATION CAN HELP.

Looking for a tax break?

Cystic Fibrosis WA has deductible gift recipient (DGR) status meaning all donations above \$2 are tax deductible.

Volunteer

Volunteer a team to help out at one of our major events this year.

Workplace & matched giving

Setting up a workplace giving program allows employees to regularly donate to Cystic Fibrosis WA in a simple and effective way.

Businesses can enhance staff donations and fundraising efforts by matching their efforts and donations dollar-for-dollar up to a pre-determined level.

For businesses without an established workplace giving program, consider using an existing purpose-built platform like Good2Give.

Join or run an event

Create your own office event or support one of ours.

George Jones Family Foundation Cystic Fibrosis Golf Classic

Organise a team for 18 holes of golf followed by dinner at Lake Karrinyup Country Club on Friday 29 April 2016.

Convicts for a Cause

Throw your boss in jail, set bail and help fundraise to set him/her free.
convictsforacause.org.au

Physical challenges

Join the HBF Run for a Reason, Chevron City to Surf or Swan River Run and you can fundraise online.

Support a campaign

May is all about raising awareness for CF and it's a great time to hold a fundraiser.

65 Roses Day

The national cystic fibrosis day of awareness is on Friday 27 May 2016. Talk to us about getting involved.
65roses.org.au

65 Roses Challenge

Organise a fundraiser themed around the number '65'.

Go RED for CF

All kinds of fundraisers can draw on this colourful theme.

everydayhero.com.au/event/goredforcf

Serve it up for CF

Ask your social club to host a function and ask guests to donate what they would have spent on a night out.

serveitupforcf.org/event/serveitupforcf

Sponsor

Cystic Fibrosis WA has a range of major events such as an art exhibition and a fun run, patient and respite care programs, education and training programs needing sponsors.

Through your support, we are able to deliver essential services to some 400 people living with CF in WA.

Want to know more?

To discuss how your organisation can get involved in helping the CF community in 2016, contact our fundraising & marketing manager today on 08 9346 7336 or email marketing@cysticfibrosiswa.org.

Visit us online at <http://www.cysticfibrosis.org.au/wa/>



How much salt do I need?

- Approximately 500-1,000mg per day for infants
- Approximately 4,000mg per day for children over the age of one
- Approximately 6,000mg per day for adults
- Salt requirements may exceed 6000mg/day with extreme heat and/or humidity or with excessive exercise. This is at least 2–3 times the amount recommended for adults in the healthy population.

There is however, large differences between individuals depending on physical activity levels and climate conditions. It is best to be guided by the individual's CF care team.

How much sodium is in Glucolyte® and salt tablets?

- 1 sachet Glucolyte® = 360mg sodium
- 1 salt tablet = 240mg sodium
- 1 teaspoon salt = 1600mg sodium
- 1 café style sachet salt = 400mg sodium

Salt and fluid TOGETHER!

Research has shown high salt drinks containing 460mg/litre helped prevent dehydration in people with CF exercising in a hot climate and also helped to accelerate the thirst drive.

This equates to:

- 1 sachet Glucolyte® in 600ml water
- 2 salt tablets with 2 glasses of water
- ¼ tsp salt (1 café-style sachet) in 1 litre of cordial

How do I fit enough salt and fluid into my day?

- Add salt to all foods in cooking and at the table
- Include foods high in salt, e.g. salted nuts, cheese, vegemite, pretzels, chips, processed meats, etc.
- Instead of drinking just water, use a high sodium chloride drink such as Glucolyte® (1 sachet in 600ml water), Gatorade®, Powerade®, or try a homemade sports drink (¼ to ½ tsp salt in 1 litre cordial),



- Use salt tablets and take with a glass of water or cordial
- If you have a gastrostomy button or feed via a nasogastric tube, try flushing your tube with salty water or adding ¼ to ½ tsp salt to feeds.

We must also be reminded to be Sun Smart

Skin cancer is the most commonly diagnosed cancer in Australia and is largely preventable by being sun smart. When the UV level is 3 or above, protect yourself against damage and skin cancer by using a combination of these five steps endorsed by the Cancer Council Australia:

1. Slip on sun protective clothing – clothing that covers as much skin as possible and is made of close weave fabrics such as cotton, polyester/cotton and linen. If swimming, materials such as lycra which stays sun protective when wet.
2. Slap on SPF 30+ sunscreen – make sure your sunscreen is broad spectrum and water-resistant. Apply sunscreen liberally to clean, dry skin at least 20 minutes before you go outside and reapply every 2 hours.
3. Slap on a hat – a broad-brimmed, legionnaire or bucket-style hat provides good protection. Caps and visors do not provide sufficient protection for your whole face. Also wear sunglasses and sunscreen.
4. Seek shade – staying in the shade is an effective way to reduce exposure to the sun. Use trees or built shade structures or bring your own! Also use other protection to avoid reflective UV radiation from nearby surfaces, such as:

clothing, hats, sunglasses and sunscreen.

5. Slide on your sunglasses – sunglasses and a broad-brimmed hat worn together can reduce UV radiation exposure to the eyes by up to 98%. Sunglasses should be worn outside during the daylight hours. Choose close-fitting wrap-around sunglasses that meet the Australian Standard AS 1067. Sunglasses are just as important for children as they are for adults.

Be UV alert

Be extra cautious in the middle of the day when the UV levels are most intense.

Check your skin regularly and see a doctor if you notice any unusual skin changes. If you have a skin lesion that doesn't heal, or a mole that suddenly appears, changes in size, shape, thickness, colour or has started to bleed, see your doctor immediately.

For further information in regards to being Sun Smart contact the Cancer Council on 13 11 20.

Being aware, planning and taking extra precautions can ensure a fun-filled summer!

References:

- Cystic Fibrosis Australia salt and fluid replacement fact sheet.: https://www.cysticfibrosis.org.au/media/wysiwyg/CF-Australia/Fact_Sheets/CF_Aust_Fact_Sheet_Salt_Fluid_Replacement.pdf
- Cancer Council Australia: <http://www.cancer.org.au/preventing-cancer/reduce-your-risk/be-sunsmart.html>

Proudly Supporting



George Jones Family Foundation Cystic Fibrosis Golf Classic

Friday 29 April 2016
Lake Karrinyup Country Club



Register before 29 February for your chance to win a round of golf for four!

Cystic Fibrosis WA is proud to present the sixth annual Cystic Fibrosis Golf Classic, to be held on Friday 29 April 2016 at the exclusive Lake Karrinyup Country Club.

Enjoy a professional golf demonstration followed by lunch, a friendly game of Ambrose golf, pre-dinner drinks, a three-course meal with live entertainment and plenty of auctions and prizes.

Registrations are now open with packages starting at \$500 per person up to \$4000 for Gold Sponsorship including 4 players and an extra 4 dinner guests.

For more information please contact Brad Coutts at golf@cysticfibrosiswa.org or on 0417 946 729.

All proceeds from this event will be donated to cystic fibrosis research and services.



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