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RED

Cystic Fibrosis WA 40th Anniversary

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Celebrating 40 Years of Cystic Fibrosis WA

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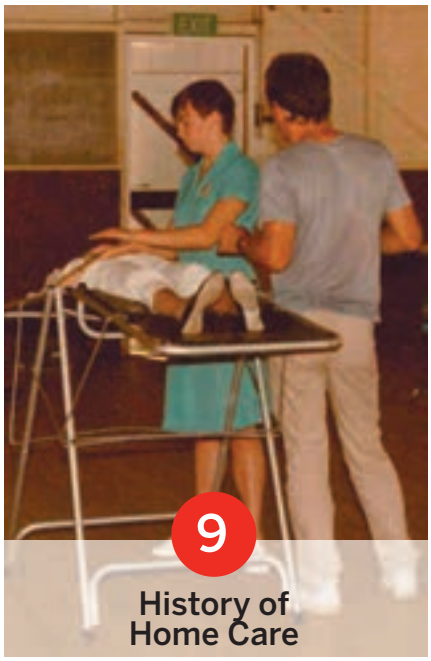

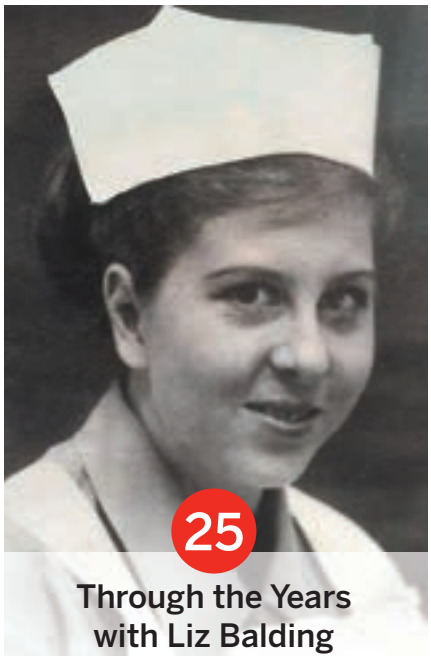

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Features

RED

CEO Message

CELEBRATING 40 YEARS OF CYSTIC FIBROSIS WA

NIGEL BARKER, CEO

In this edition of RED Magazine, we celebrate Cystic Fibrosis WA's 40th anniversary. We take a look back at the last 40 years and how far we've come. We look at how we got here and the shoulders of the giants we stood upon to do so. We dare to glimpse at where we might be in another 40 years' time. A time of personalised medicine and a time when we will have achieved our vision of Lives Unaffected by CF and be focussing on cures for CF and other genetic diseases.

In looking back, we have trawled through the boxes of archives and both laughed and cried and stood in silent contemplation as we saw faces of those who are no longer with us. We were shocked at some of the practices, both medical and social, which we no longer consider appropriate and wondered what treatments we might be doing today which would be judged so harshly in retrospect in 2056. We celebrated the birthdays of people like Mitch Messer and Caz Boyd's new lungs.

In some ways, it seemed a backward step to abandon our CF kid's camps. People often say a problem shared is a problem halved, but once we became aware of the dangers of cross infection, we had no choice in the matter. Social isolation of people with rare genetic conditions has been eased with the introduction of the internet and social media but at the time it was a devastating blow to those young people living with CF to be told that they could no longer socialise together face to face with their friends.

CFWA's 40th anniversary will be formally celebrated at our offices here at The Niche on the evening of Friday 2nd December. We hope to put up a lot of pictures celebrating the last 40 years and if you have any special images that you'd like to share, then please let us know so we can include these as well.

In this edition CFWA also celebrates the winning of the prestigious Telstra Business Award WA charity category. A fitting tribute for our 40th birthday. CFWA has grown over the past 40 years from a small self-help group into a professionally run and highly respected service provider. In doing so we now deliver a broader range of services than ever before and fund more research than the rest of Australia put together. Hopefully we still maintain the personalised approach so valued by our clients.

Thank you for joining us on our journey. We are looking forward to the next 40 years together.

Nigel Barker, CEO

DEADLINE FOR THE NEXT ISSUE
If you would like to contribute to our winter issue, please contact us before 15th January, 2017

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

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

info@cfwa.org.au
www.cysticfibrosis.org.au/wa/

Subscribe to our e-newsletter online
www.cysticfibrosis.org.au/wa

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ON THE COVER
Justin Russel. Read Justin's story on page 13.

Our Founding Members

THANK YOU TO OUR EARLY FOUNDING MEMBERS WHO WORKED SO HARD TO ESTABLISH OUR ASSOCIATION

Some of the early members were: Bob and Gail Laing, Chris Cousins, George and Marcia Messer, Bob and Helen Pearce, Barbara Hancock, Leslie Gargett, Richard and Muriel Reid, Mrs Sheminent, Dr Peter and Elizabeth Pratten, Yossi Goldburg, Bev Watterson, Bill and Shirley Fox, and Mavis King.

Bob Laing was the inaugural President; Marcia Messer took over the job when Bob and Gail left to work in the Pilbara. Shortly after they got started, there were a number of families who joined in because Princess Margaret Hospital (PMH) let people know that the association had been set up to support families. At this time there were other CF associations in the other States.

The first couple of meetings were set up by the Perth Chapter of Jaycees who met at the Perth club in Howard Street in the city. Association members then met at Chris Cousins home in Belmont. There were only a few present at the first meeting or two including Chris, Barbara Hancock, Bob and Helen Pearce and the Laings, maybe one or two more.

It is a testament to the hard work and dedication of these founding members that Cystic Fibrosis WA still exists today.

We have made an effort in this edition of RED to ensure that names, dates and places have been captured accurately. We apologise for anyone we've failed to acknowledge through this process.

BOB AND GAIL LAING


BOB AND HELEN PEARCE


INGRID LAING HAS CF AND NOW WORKS AT THE TELETHON KIDS INSTITUTE


THE PRATTEN FAMILY


GAVIN PEARCE AND HIS SIBLINGS

Marcia's Story

MARCIA AND HER HUSBAND GEORGE ARE FOUNDATION MEMBERS OF CFWA. THIS IS MARCIA'S STORY.

I am a founding member of the WA CF association and am very proud of what has been achieved over the last 40 years to make life with cystic fibrosis (CF) a little easier.

My family moved to Perth in 1974 when our son Mitch, was almost 14 and Stephen was almost 11. We had, at that stage, never met another family with a CF child. After we had been here about a year we got a phone call from a lady called Chris Cousins asking if we would be interested in forming a group. We of course agreed and had our first meeting at Chris' place with another six families and two gentlemen from Perth Jaycees who volunteered to help us develop an association.

At first we held Friday night meetings at Chris' place along with fish and chips and a beer for those who wanted one. We spent many hours with Keith Hayes from Jaycees drawing up a constitution. Keith is a wonderful man; he is blind but has never let that get in his way. He is an inspiration and his help was invaluable. We duly elected a President, Vice President and Secretary and took turns in the different roles. Our records and files were kept in a cupboard at the home of the person of the day.

With Keith's help we graduated to The Perth Club, and later to Shenton Park. We held our meetings monthly and began fund-raising; holding car raffles, cake stalls, quiz nights, hamburger stalls at the Kojonup annual show, etc. All of this with the help of family and friends. We had camps for the kids aided by physiotherapists and nurses from PMH, and parents. Of course, now we know this is a big no-no.

We joined the national CF association with Bob Laing and I becoming delegates for WA. Queensland, New South Wales and Victoria already had associations and we were the new kids on the block.

We sourced a video tape explaining what CF was, which was paid for by Peter Pratten, also a founding member. We started to increase awareness about CF through radio and newspapers as most people had never heard of CF.

We knew we needed to expand but were always nervous about spending charity money. When our son, Mitch, became President, he was young and fearless and on his encouragement the association employed our first paid part-time worker, Robyn Loughrey. A survey was done to find out what people felt they needed and the rest is history as things really started happening. We always hoped we could have an office one day - WOW! look what we have now.

I would like to tell you about our own personal journey; not to complain but to let you know how fortunate we are now. I was accused at a meeting once of being jealous because we never had the things available today. I can tell you nothing is further from the truth. I dared to say things are better now and I really appreciate the advances that have been made; don't forget I still have a child with CF, albeit he is 56 years old.

We lived in Albany and first discovered CF in 1960. There we were, not long married and expecting our first child, what could go wrong?? Mitch was born at 9:05 on 15th August weighing 9lb 5oz. We were in hospital for a week due to a difficult birth - he was always nosey and decided to come out face first. I had my 21st birthday a couple of weeks later and he tells me he is the gift that keeps on giving (how true). We went home to find having babies wasn't what we thought it would be - there was crying, feeding was difficult, sometimes it went down but often it came straight back up. What was left went straight through and we were constantly at the doctor's. The doctor later told my mother he thought I was just a silly young mum not knowing much. He admitted later he was very wrong and I was smarter than he thought. You do know when something is wrong with your baby.

I used to track along to the Infant health clinic as you did back then with some other young mums and thought their babies were a bit on the fat side, not as nice as mine. Mitch was only 11lb at three months; lucky he was a large baby at birth. Our doctor then agreed something must

MITCH MESSER AS A YOUNG MAN

be wrong, perhaps he had celiac disease and recommended we try those gluten-free jars of baby food that have just become available. No that didn't help, so off we went to Perth to PMH, where he was diagnosed with Fibrocystic disease of the pancreas, later to be called Cystic Fibrosis.

They were far from encouraging and told us he probably wouldn't finish school. WRONG!!! They then explained that it was a genetic disease and we were both carriers and the odds were 1 in 4 of having a child affected. Being young and knowing nothing about genetics, as most average people didn't, we presumed our chances of normal children was still an option.

Both our mothers were in denial and said that we couldn't possibly have an inherited gene. It was difficult for all, not only us but for the grandparents.

Things were very hard, especially living in the country, but in some ways that was a plus because Albany was a small town then. Our GP was a caring man and he tried to learn as much as he could about CF. The local pharmacist, along with our local Member of Parliament, assisted us in getting enzymes on the National Health Scheme. The pancreatic powder we used was 18 pound a tin and George's wages were 18 pound a week after rent. We were able to pay this off at £5 a week. That's another story. It was foul and had to be mixed with hot water; it smelled a little like blood and bone.

In October 1963, our second son Stephen was born and showed no signs of CF. He did all the things babies are supposed to do like eat, sleep and grow. In October 1964 I gave birth to our third son Kelvin (what was this pill people were talking about?) Anyway, all the signs of our first born were there and off we go again to PMH and sadly yes he had CF. He was admitted to PMH when he was 8 weeks old, got pneumonia and passed away at 10 weeks. I mentioned at this time to my sister-in-law, who was a nurse, that Stephen seemed unwell and she suggested when everything is settled it wouldn't hurt to ask to have him tested.

So after returning home I visited my GP and he said he didn't know if it could be, so he took a book off the shelf and found the page that said yes it can be diagnosed late, so off to PMH for more bad news. We made regular visits to Perth for checks and to collect the then cheap drugs and enzymes. Mitch had only had one hospital admission and Stephen none at that stage.

They led fairly normal lives, managed school well and were involved in sport. My GP who delivered my two younger sons had decided to move to Perth so we needed to get a new GP. A humorous thing happened when I took Stephen to the new doctor who asked me what I thought, and what I thought he should give him, which I duly answered and we left, prescription in hand. When we got outside Stephen said, "You know Mum, he should be paying us". Both our sons have always had a good sense of humour and boy does that help at times.

This is why we thought we should move to Perth where someone maybe could help, and it was then we were told about physiotherapy. "Oh weren't you told," they said. I was also told it wasn't up to me to say what should be done and I answered that is fine by me, but I never had a choice before. I was only too pleased to hand over the responsibility to the professionals. I must say the physio department were a godsend and were always there to help us. Unfortunately, things got worse for Stephen and he passed away just after his 14th birthday, but we knew he had the best that was available at that time. We had more love from him in those 14 years than some people receive in a lifetime, his life was worthwhile. All of this was before IV antibiotics and other superior drugs and treatments.

We still have our much loved Mitch and he turned 56 in August, and I am proud to say he has spent a lot of his life trying to make things better for families affected by CF, here and around the world. With all that happens no one can ever be really sure how things will turn out. I am so happy with the support we all receive from our association and the wonderful staff and the things that are happening with research, things can only get better.

Although life has been hard for my children I still feel blessed that I had them and have met some wonderful people on this journey.

Now with the Guthrie test, treatment starts early with IV drugs, and with new drugs such as Kalydeco® things are looking much better.

A History of Cystic Fibrosis Australia

The Australian Cystic Fibrosis Association was formed in March 1971 by the Queensland and NSW associations with the objective of conducting international liaison, nurturing new state organisations and providing a central body that would promote cystic fibrosis (CF) at a federal level. It was an important first step on a quest to alleviate the suffering of children afflicted with CF and search for better ways to cope with what was then a largely uncharted disease.

The association's first President was Professor J Beveridge. He was supported by Vice President, Mrs J Robertson and the Hon Sec/Treasurer, Mr I Beatty. A medical and scientific advisory panel was also formed and the first convenor of this group was Dr J Brown.

In 1983, the six state and territory organisations formed a national body called the Australian Cystic Fibrosis Associations Federation Incorporated. In 1998 it was renamed Cystic Fibrosis Australia Incorporated (CFA). CFA was established to facilitate and promote the provision of optimal care to all people affected by cystic fibrosis and ensure they have the best possible quality of life. At the end of April 2003, CFA became a company limited by guarantee.

The national organisation assists the member organisations achieve common objectives in advocacy, funding and collaboration. CFA develops and manages national clinical improvement programs, consumer engagement initiatives and conducts CF research throughout Australia into the cause, treatments and an eventual cure for CF. The Australian Cystic Fibrosis Research Trust (ACFRT), operating within the CFA corporate structure, has supported more than 30 projects valued at more that $3,000,000.

In 1996 work began on developing the Australian Cystic Fibrosis Data Registry (ACFDR) and the working model was released in 1998. CFA is responsible for the funding and data custodianship of the ACFDR and on 1st September 2016 the Monash Data Registry Centre became the new management company. The future of the ACFDR is in great hands and the move will enable new digital and clinical development to be undertaken.

In 1988 the first International Cystic Fibrosis Conference in the southern hemisphere was held in Sydney and in 1994 CFA organised the inaugural Australasian Cystic Fibrosis Conference (ACFC). This allowed medical, scientific, allied health and lay communities to come together for knowledge gathering, information sharing and understanding of new trends from overseas. The 12th ACFC will be held in Melbourne from 5th to 8th August 2017 and the 2019 conference will be held in Perth.

Systemic advocacy and promoting the rights of people with CF is key and in the past 18 months, CFA has established a number of programs to do this. They include CF CAN (Consumer Advocacy Network), a clinical trials information portal; Consumer Connect a drug development pipeline and online forum for the CF Community and the Governor General's Patrons Awards. CFA is also funding the development of transition guidelines and Standards of Care plus centre director forums that are held twice a year.

As CF drug and treatment development continues at a rapid pace, CFA is compelled to work towards establishing equitable funding and access for all people with CF. CFA proactively offers innovative solutions to the federal government and relevant health bodies to ensure CF remains at the top of the health agenda.

CFA does not receive any government funding so negotiating and securing sponsorships and partnerships are a vital part of their work as they enable us to continue our work for people with CF and their support networks. 40 plus years on, from small first steps we have made enormous strides. But the journey and its challenges, continue.

CYSTIC FIBROSIS Australia

SUNDAY 6TH NOVEMBER @ THE NICHE

Join us for a day of kayaking, massage, yoga, mindfulness & beauty treatments!

Email servicesmanager@cfwa.org.au for more information

Thanks to ConnectGroups for supporting this event

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History of the Comprehensive Home Care Service

CYSTIC FIBROSIS WA IS VERY UNIQUE IN THE SERVICES WE PROVIDE TO OUR MEMBERS WITH CYSTIC FIBROSIS (CF). OUR HOME CARE SERVICE HAS EXISTED IN VARIOUS FORMS OVER THE YEARS AND WAS DEVELOPED AFTER A SURVEY CONDUCTED IN 1983 IDENTIFIED SUPPORT IN THE HOME AS A KEY PRIORITY FOR OUR MEMBERS.

This remains a priority today, as indicated by our members needs analysis which is conducted every three years. Our current home care service is known as Comprehensive Home Care, a state government funded program that provides a broad range of services to children and adults with CF around Western Australia.

Over the past 12 months under the Comprehensive Home Care contract, our home care workers have:

7500
WORKED 7500 HOURS IN THE HOME COMMUNITY

110,000
TRAVELLED OVER 110,000 KILOMETRES

250
RECEIVED OVER 250 HOURS OF EDUCATION AND TRAINING

CFWA has also:

35
EDUCATED 35 HEALTH PROFESSIONALS IN THE REGIONS

600
DISTRIBUTED OVER 600 EDUCATIONAL REROURCES

480
EDUCATED OVER 480 CHILDREN AND ADULTS ABOUT CF IN SCHOOLS

REGIONAL RESPITORY TRAINING PROGRAM

23
23 REGIONAL NURSES AND PHYSIOTHERAPISTS TRAINED

140/157
DISTRIBUTED HEALTH COACHING AND CLEANING EQUIPMENT

371
PROVIDED 371 COUNSELLING SESSIONS

90
LOANED OR GIFTED 90 ITEMS OF EQUIPMENT

100
OVER 100 REGIONAL VISITS FOR CLEANING AND RESPITE

OUR LONGEST SERVING STAFF MEMBER LAPPA PERFORMING PHYSIO AT AN OLD CF CAMP.

The earliest written record of a home visiting service came from a CFWA newsletter in 1984, describing a program called the Family Support Scheme which provided physiotherapy, practical help, emotional support and educational resources to adults and children with CF. This program was initially funded by a federal government grant that employed our first home care workers, including Lappa, who is still employed at CFWA 32 years later.

With lots of hard work and initiative from CFWA founding members, grants from Telethon, the state government and the Lotteries Commission, as well as fundraising efforts from members, the service was able to continue under a new name: the Home Support Service. The Home Support Service involved regular visits by a CFWA home care worker to provide respite for carers and assistance with percussion to promote independent living for adults with CF. A registered nurse and community physiotherapist were also employed.

In August 1996, the Comprehensive Home Care program commenced with only 10 clients as a government funded early intervention and early discharge service, providing daily physiotherapy and nursing visits. It was designed to provide clinical treatment and assistance in the home for people with CF to reduce the incidence of hospitalisation. Comprehensive Home Care nurses would take IV antibiotics to people from the hospital, give doses of medication, take bloods for antibiotic levels and provide information to clinic about each client's progress. The physiotherapist would support airway clearance, exercise programs and oversee airway clearance programs being provided by homecare workers. Comprehensive Home Care was only available by referral from the CF clinic doctor and offered support in the home on a 2-week short-term basis whereas the Home Support Service provided long term or ongoing support. The Home Support Service was clearly different as it was not a clinical service but a support service. Over time the two programs were combined and expanded under our existing WA Department of Health funded Comprehensive Home Care contract.

In 2016, the Comprehensive Home Care service exists as a truly comprehensive program, combining the Home Support Service and previous Comprehensive Home Care services to deliver a wide range of outcomes. Anyone with CF who is a member of CFWA can access our homecare worker, nursing, physiotherapy, education and social worker services without a referral.

If you would like more information about how you can access these services, please call us on 08 6457 7333.

Sue Morey: Changes in Adult Cystic Fibrosis Care

WITH OVER 40 YEARS OF WORKING IN RESPIRATORY MEDICINE, SUE MOREY, A NURSE PRACTITIONER AT SIR CHARLES GAIRDNER HOSPITAL (SCGH), HAS SEEN DRAMATIC CHANGES WITH CYSTIC FIBROSIS (CF) TREATMENT AND THE IMPACT THAT IT HAS HAD ON HER PATIENTS.

I began my career at SCGH as a staff nurse in 1972 in respiratory medicine. I became second in charge, then charge nurse of the CF Ward of Respiratory Medicine, and then I became a Clinical Nurse Specialist in 1988.

In 1972 there were only about six patients with CF and they were under the care of Dr Janet Elder who took a special interest; also Dr Des Gurry worked with patients with CF. Each year more patients with CF were transferred across from Princess Margaret Hospital (PMH) and by 1981, Dr Gerry Ryan formalised the CF adult clinic, so that outpatients came on specific days. The clinic became more systematic in taking bloods and doing lung function tests. In the 1980s Prof. Lou Landau came to work at PMH from the eastern states and he formalised the management of the paediatric patients with CF. As the care for paediatrics was better managed, more and more young people were living longer and the number of patients attending the CF clinic at SCGH continued to increase.

SUE HAS BEEN INVOLVED WITH CYSTIC FIBROSIS WA FOR MANY YEARS.

In B Block, where the CF and respiratory Clinic is currently located,there used to be a general ward for respiratory inpatients. There were three wards there, two of which were upstairs with 56 beds. I organised for a high dependency unit to be set up so that the sickest respiratory patients could be placed there under closer observation by the nursing staff, especially at night. The respiratory ward moved to G54 in 2000 where there are currently 28 beds.

In the 1980s a bronchoscopy suite was set up in Ward B12. Initially, bronchoscopies were performed once a week on a Friday, but by 1981, there was capacity to do them every day. When this suite was closed down, it moved to Ward G75 and bronchoscopies are now performed Tuesdays and Thursdays. We have access to a theatre on Wednesdays for more complex procedures (such asstenting and laser).

The first CT scans, which were introduced in the late 1970s, revolutionised treatment and I have seen great changes in the health of respiratory patients because of the improved assessment of patients and better availability of drugs.

When I first started in respiratory medicine, tuberculosis (TB) was a big problem, but that became better managed. Then I was working with patients with mesothelioma from exposure to asbestos as a result of the Wittenoom disaster - we had the highest rate of people affected by this in the world. Asthma also changed as a disease when inhaled steroids were introduced, so we see people with asthma more as outpatients than as inpatients.

I worked with patients who required lung transplants and originally needed to go to Melbourne or Sydney to receive them, until 2007, when they were able to do lung transplants here - initially at Royal Perth Hospital and now at Fiona Stanley Hospital. In the ten years that I did this role, I worked with 100 patients (some of whom had CF) who received lung transplants.

I actually saw my first lung transplant performed in 1986 in London. They started doing lung transplants in Melbourne and Sydney in 1989, so Australia wasn't that far behind.

The changes I have seen for patients with CF include access to intravenous antibiotics, which improved their treatment, as before this inhaled antibiotics and chest physio (postural drainage) were the main treatments for lung infections. When Pulmozyme® was first introduced, we thought that was the biggest thing, but then when Kaledecyo® became available that seems to be the most significant pharmaceuticalprogress for CF so far. Access to positive airway pressure (CPAP and BiPAP) for long or short term use has also improved treatment options available for adults with CF.

Currently there are 187 adults who attend the outpatient CF clinic. I have noticed that our adult patients, due to the fact that they have a better quality of health, are able to access further education, work and have families of their own. So one of the biggest areas where we have had to increase our knowledge and expertise is in the area of fertility. I have also noticed that over the years, our adult patients are more positive and also more responsible in their outlook on life.

The way that Dr Ryan ran the clinic was not to be prescriptive but to give the patients a choice as to how they wanted to handle their treatment. We like to be on the same page as our patients and if they are honest about where they are at, we can treat their condition accordingly. We also put the ownership of treatment back on the patient.

AREST-CF, the program run by Dr Stephen Stick, which aggressively treats lung damage in very young children is one of the biggest things impacting the health of people with CF in WA. The AREST-CF program means that children will be in better health when they come to us as adults.

I have enjoyed all the challenges and changes I have seen throughout my career at SCGH in respiratory medicine and it is very rewarding to see adults with CF doing much better for longer and having a significantly improved quality of life than was previously possible. It is great to see that adults with CF are able to live a mainstream life, as opposed to being labelled as very sickly patients as they were back in the 1970s and earlier.

At the CF clinic we have a good team - the right sort of people have gravitated towards respiratory medicine. You can't do it on your own, so I feel lucky that we have such a good team and I have also had great support from the physicians, which has reinforced my commitment to the speciality of respiratory medicine. I feel it is my responsibility to maintain the momentum of the dedication that Dr Elder, Dr Ryan and others I have worked with throughout the years, have initiated.

I hasten to add that this is not a retirement article and I hope to be able to continue to contribute for some time yet.

Born in 2000!

INTERVIEW WITH JUSTIN RUSSELL AND SARA LINDQUIST. IN NOVEMBER 2000, JUSTIN, A BEAUTIFUL BOY WEIGHING 9LBS 4OZ, WAS BORN. A COUPLE OF WEEKS LATER, HIS MUM, SARA RECEIVED A PHONE CALL THAT WOULD CHANGE LIFE AS THEY KNEW IT FOREVER. JUSTIN HAD BEEN DIAGNOSED WITH CYSTIC FIBROSIS ON HIS NEWBORN SCREENING TEST, ONE OF THE FIRST BABIES IN WESTERN AUSTRALIA TO BE DIAGNOSED THIS WAY.

The early years:

Confirmation of Justin's diagnosis followed with a positive result on his sweat test. In WA, CF had only been added to the newborn screening test, or Guthrie test, three months prior. Had it not been for newborn screening, Justin may not have received a diagnosis for years and would not have been able to access the treatment he needed as early as he did. This would have had a detrimental impact on Justin's health.

Naturally, Justin's family were in shock on receiving the news but mum, Sara and dad, Tony, quickly realised that they had to learn all they could about CF to best look after their little boy; and so began the journey.

Mum reports that Justin was a calm baby;, he responded well to touch and was easy to settle. He took to percussion straight away and actually enjoyed it, often falling asleep. Justin was breastfed for eight months, solids being introduced at three months and taking enzymes was just a natural process as this is all he had known. He always had a good appetite and since the age of ten or eleven, Sara says she can't feed him enough!!!

Annual bronchoscopies and lung function were performed and Justin didn't have too many admissions when he was young. He had three admissions in 2012 and then annual admissions up until this year.

The challenges:

When Justin started high school he was diagnosed with diabetes. At first the family thought it was just the stress of the new school and all that high school brings, but with the obvious signs of a thirst that couldn't be satisfied and increased visits to the toilet, he soon had a diagnosis of diabetes. Justin's diabetes is more like Type I diabetes though, so he has the added challenges of managing insulin injections four times a day and needs to be very aware of when and what he is eating. Having the diagnosis presented even greater obstacles and Justin is still working hard on overcoming his needle phobia.

With increased time spent in hospital this year, Justin has had the challenge of keeping up with school work. Kerry, the school teacher liaison for PMH, has been wonderful in setting up a plan for Justin, arranging to have work forwarded by his school teachers and assisting Justin to get back on track.

There are day-to-day challenges for Justin and Sara too such as finding the time they need to set aside for treatment. Justin says, "I have quite a lot of treatments I need to fit into my day and sometimes I struggle to do all the things I want to do when I am feeling unwell."

Justin's dreams:

Justin dreams of becoming a famous soccer player with Manchester United, as their goal keeper. They have started the process toward applying for a scholarship to play soccer with one of the colleges in America. This is through NSR Australia. He has attended the initial try outs and has been conditionally accepted, as long as he gets a 'C' average for his school subjects. He is currently in year 10 and his favourite subjects at school are sport, maths and science. If he can achieve B's or A's this will increase his options and improve his chances for a soccer scholarship.

Justin is very aware however, to have a contingency plan and is also interested in becoming an auto mechanic. This way he will have a trade to support him as he gets older.

Justin's highlights:

When asked to talk about the highlights in his life so far, Justin's face lit up and he talked enthusiastically about his Starlight Wish, arranged by PMH and the Starlight Children's Foundation.

He had his wish in 2015 when he met with the Socceroos! He was invited to one of their closed training sessions, one day before a big game, at NIB Stadium in Perth. He met with the players and was presented with a book and poster hand signed by all the team. Sadly, his hero, "Matty" Ryan, wasn't there as he was recovering from knee surgery. "He is my favourite as he is the goal keeper and this is the position I play. It was a very special day!"

Justin enjoys playing sport and this has helped keep him as healthy as possible.

He is obviously a very talented sportsman as he has received many achievement awards for both athletics and soccer, including an award for sportsmanship and courage. He currently plays for Belmont Villa Soccer Club under 18s as their goal keeper.

Another highlight for Justin was being our Great Strides ambassador and winning a signed West Coast Eagles jersey and a cricket bat signed by Australian cricket captain Michael Clarke.

Justin's brother Nat is also mentioned as a highlight in Justin's life and even though he now lives in the wheatbelt town of Cunderdin, he visits as often as he can.

We wish you well in the future, Justin, and look forward to hearing all about achievements in the years to come.

Turning Lives Around!

THE ADVANCE LUNG DISEASE PROGRAM WAS ESTABLISHED AT ROYAL PERTH HOSPITAL (RPH) IN WA IN 2005. THE PROGRAM, NOW IN OPERATION AT FIONA STANLEY HOSPITAL (FSH), IS ONE OF FOUR AUSTRALIAN TRANSPLANT CENTRES KNOWN FOR HAVING THE HIGHEST TRANSPLANT SURVIVAL RATES IN THE WORLD.

More than 2,500 lung transplants are performed each year worldwide. Lung transplantation is a generally accepted therapy for a wide range of severe lung disorders with evidence supporting the primary goal, improved quality of life and survival. Studies have shown significant benefit in certain conditions, one of which is cystic fibrosis (CF), however, it remains a non-curative procedure.

The screening and 'workup' for transplant is extremely thorough and extensive. All body systems are screened and there is optimisation of lung function, nutrition and psychosocial status. Listing involves a complex discussion of patient information with the transplant team which includes surgeons, lung transplant physician, nurses, physios, OT, social worker, dietitian and more. Not all individuals benefit from transplantation.

It is all about the "window of opportunity", with the aim to transplant when the benefit outweighs the risk. The guidelines for consideration of lung transplant in CF are an FEV1 < 30% predicted or a rapid decline, especially in females; exacerbation requiring ICU; increasing requirements for antibiotics; pneumothorax or haemoptysis not controlled by embolisation; and a significant decline in quality of life.

The relative contraindications for lung transplant in the CF community are: a multi-resistant bacteria infection, severe liver or renal disease, nutritional failure or a history of non-adherence or an inability to complete the post-operative regime.

Once a decision is made to add someone to the list, the patient must agree to relocate to Perth and be contactable 24/7. They must also agree to participate in pulmonary rehabilitation, which is mandatory, and be compliant with all health appointments and treatments.

Matching donors and recipients is imperative. This involves matching blood group, lung size and recipient must not have any antibodies against the donor lung otherwise rejection will occur.

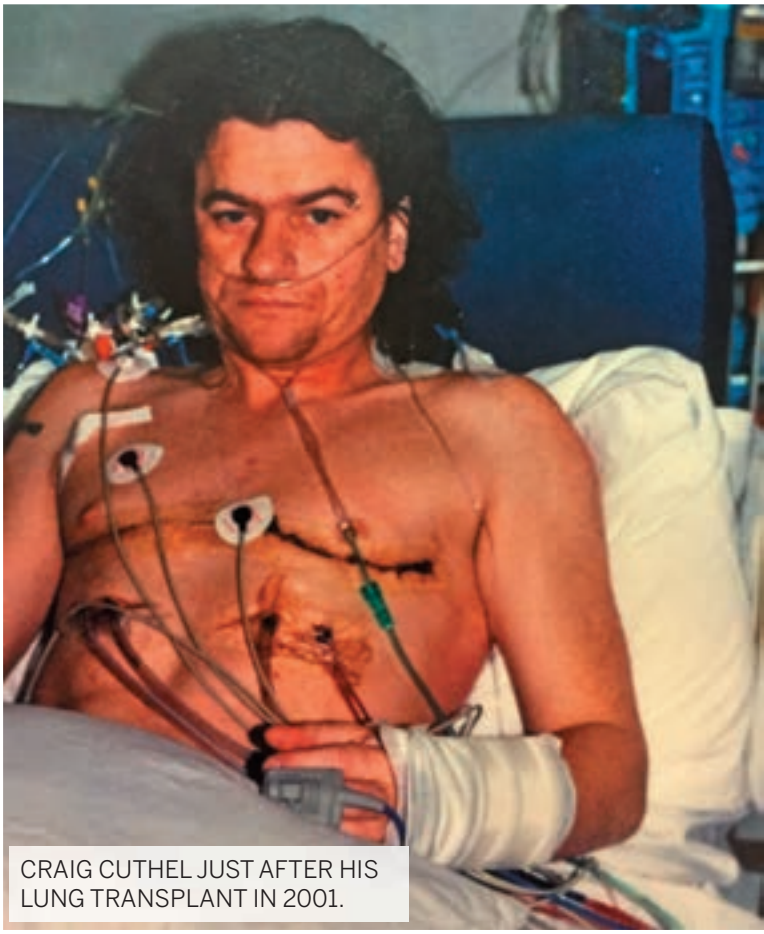
The long term management of lung transplant involves rejection prevention, achieved by lifelong immunosuppression drugs and infection prevention by the use of prophylactic antibiotics and early detection procedures. There is routine pulmonary function surveillance by biopsy, FEV1 monitoring and regular sputum sampling.

Transplantation improves quality of life and survival in selected patients through careful selection and a complex ongoing management plan involving lifelong immunosuppression and infection prevention and control. FSH continues to perform successful lung transplantation for our CF community bringing a brighter outlook and improved quality of life for many of our members.

Reference:

Lung Transplantation (PowerPoint Presentation 2016)
Sharon Lawrence
Advanced Lung Disease CNC
Fiona Stanley Hospital

Lung Transplantation in Cystic Fibrosis (PowerPoint Presentation 2016)
Jamie Wood
Senior Physiotherapist Cystic Fibrosis
Sir Charles Gairdner Hospital



CRAIG CUTHEL JUST AFTER HIS LUNG TRANSPLANT IN 2001.

CRAIG IS HAPPY AND HEALTHY AFTER 15 YEARS WITH HIS NEW LUNGS. READ MORE ABOUT CRAIG'S STORY IN OUR UPCOMING "POSITIVE PROFILES" TRANSPLANT BOOKLET.

Caz Boyd: Transplant Positive Profiles

WE ARE PRODUCING A TRANSPLANT POSITIVE PROFILES BOOKLET THAT WILL BE LAUNCHED IN DECEMBER 2016. THIS WILL INCLUDE 15 INSPIRATIONAL STORIES FROM PEOPLE WHO HAVE UNDERGONE LUNG TRANSPLANTATION, BOTH HERE IN PERTH AND OVER EAST. THIS IS ONE OF THE STORIES.

Caz is a vibrant and iconic woman in the world of CF; having spent several years on the CFWA board up until 2010, and once again as a current and active member. She has been involved in several campaigns such as Kalydeco®, travelling to Canberra to meet with politicians. She has also presented numerous very moving speeches to continue to raise awareness about CF to our broader community. She has a true sense of the glamorous, often with a touch of the colour red, a wicked sense of humour and tons of resilience. If you can't find Caz in Perth, guaranteed you will find her in her beloved Bali with her loving partner, Chris, sipping cocktails and enjoying a massage.

At what age did you get your transplant?

I was 27 years old. I got my transplant 22 years ago in 1994.

What sorts of things did they assess you for to get onto the waitlist for transplant?

I had to go to St Vincent's in Sydney as lung transplants were not being performed here. However, they started the assessment here at SCGH when the Sydney team visited. They advised me that if I didn't have the transplant I would be dead within two years. When I arrived in Sydney I had to undergo the same assessment which was a bit stressful. I believe I am the longest surviving female lung recipient in WA.

What was the decision making process around getting a transplant?

I was in hospital for a tune up when my specialist mentioned to me that the Sydney transplant team were coming over and that I should see them. I didn't think I was that unwell to need a transplant. I was working albeit part time and had a great social life. My FVC was 0.8; I am not sure what that is in percentage.

I knew of people who had gone to Melbourne and not survived because transplant was still fairly new back then. It was such a different time; success rates were not so good and I didn't really have any mentors. I only knew of one person who had a successful transplant.

I guess I was in denial so I spoke to a friend who helped me to decide. She said to me "if I were given a second chance I would take it" Retrospectively, it would have been better to have gone across a lot sooner, before getting so sick. Recovery is so much better if you are healthier.

What happened when you were on the list for transplant? E.g., did you have to work really hard to go to physio and attend appointments?

I went over to Sydney in October 1993; the transplant was in November 1994. I was given a pager as mobile phones were relatively new and the size of a brick. I had to attend both Royal Prince Alfred for the CF clinic and St Vincent's for my transplant. I had to attend the gym twice a week at St Vincent's which I really enjoyed as it was very social.

Did you have to wait long when you were listed for transplant?

I was listed for nearly 18 months before I got my transplant. The 3 - 4 months were the hardest. I was on oxygen 24/7; so much seemed impossible. Ten days prior to my transplant I was admitted to RPA with palpitations, shortness of breath and haemoptysis. My body was shutting down. I was given IV antibiotics but was not responding to these. I couldn't shower myself without the help of my mother. I couldn't even make it to the toilet without soiling my pants. Here I was, 27 years old, and all my dignity was being viciously stripped from me. Even the simple task of brushing my teeth would render me breathless. I barely had the energy to breathe. I would simply sleep all day scared that this time I wouldn't wake up. I suffered excruciating headaches as my carbon dioxide level was getting dangerously high day by day.

A few days later I was put on a respirator. My physician spoke to mum, unbeknownst to me and said that "we've pulled out all the stops for Carolyn, there's not much more

we can do. I just want you to know that she probably won't make it to transplant."

Finally, just 12 hours prior to my predicted demise, I received the call. I was in the theatre at RPA waiting for the anaethetist to put a PICC line in me as my port had decided it had had enough. The nurse and I were chatting and she asked me what I was having the line for. I told her I was waiting for a lung transplant and that I needed to have it before the end of November so I could go home and be bridesmaid for my best friend, when the phone rang. The nurse said "Yes, yes, OMG yes!" She then turned to me and said "we've got some lungs for you". I was then taken by ambulance to St Vincent's for the operation. I was so weary by this stage my CO2 levels were dangerously high; I had the worst headache. They only just managed to get this all under control to operate. A few days after the transplant, I saw the anaesthetist who was present during my transplant,and he said to me, "wow, look at you! And to think I thought you would be a waste of organs".

What sorts of changes happened to your body after transplant?

The usual puffy face; I already had chubby cheeks, but after the transplant I looked like Burt Newman's love child. Taste was different. I think mostly because I had such a long history of coughing and wariness about regurgitation and just wanted easy food. Oh! I love food now. So much more energy, that was amazing. I had an extra two hours a day – no physio!!!

My first breath was amazing, too, I had pink nails, pink lips, I could feel my toes. I still have a phobia about blue lips; I always like to wear a little lipstick.

My best experience was when I took my first shower. I asked the nurse if I could close the door and shower in private. I was able to inhale steam without coughing; it was so good even though I was still very weak. Before this, I always had to shower with the door and windows open because any steam made me cough.

I also got constipated, which strangely enough also felt great because it was something I had never experienced before. You have the love the CF bowel.

Pre-transplant my energy requirements were so high everything just went straight through me. I took a lot of drink supplements.

Some people report weird dreams or other strange experiences e.g. suddenly liking beer did anything like this happen to you?

I think that has a lot to do with, and the fact that when you feel healthy, you're more willing to try different foods. I had highs and lows, mentally, from prednisolone.

There is some evidence that people experience some trauma after coming out of ICU after the transplant; do you remember anything about this?

I recall being moved from recovery to ICU after the transplant and spitting out the tracheal tube. I was woken up pretty soon after the operation to the nurses scrubbing me to take all the betadine off. I thought 'geez, give a girl some rest I have had a major operation'. During my first bronchoscopy, they discovered I also had some fluid on my new lungs, so they had to drain 4 litres of fluid, but I still felt good, there wasn't too much pain. The pain was more when I got home, a bit like muscle pain after a full-on gym session.

Where are you now in terms of your health and outlook on life?

I have very good health and, yes I need to get back to the gym. I have a lot of sinus issues, but my lungs are great. I get check-ups as needed at SCGH.

My outlook is very good; I have lots of normal plans such as travel and retirement, normal getting old stuff. I didn't really make plans when I was young for things such as superannuation, life and health insurance.

What words of wisdom can you offer other people considering transplant?

Don't think your immortal, don't wait until your too weak and unwell, don't leave it until it's too late. Life is truly amazing after transplant; you have so much more energy. Listen to your body, pace yourself if necessary. Take advantage of your medical team, ask questions and listen to them. Make plans and set goals for after transplant. Most of all, remember you have been given a second chance; take it and enjoy your new-found life.

Celebrating Forty (One) Years with Cindy

CINDY IS A DYNAMIC 41-YEAR-OLD LADY WITH CYSTIC FIBROSIS WHO IS A SUCCESSFUL CHEF, LIVING AND MANAGING HER VERY OWN CAFÉ IN BORANUP, NEAR AUGUSTA. SHE IS ALSO HAPPILY MARRIED AND HAS A COOL DOG.

What age were you when you were diagnosed?

I was diagnosed at birth. Dr Williams kissed me, tasted salt and sent me straight to Princess Margaret Hospital (PMH). I also had meconium ileus and he had a previous patient in Donnybrook, so he saw the similarity.

Did you and your parents go to hospital for education and management of CF after you were diagnosed?

Due to distance and work, my dad did not have CF education. Mum went to PMH for education, but she was told that I probably wouldn't make it so to go home and prepare for a funeral. After two bowel blockages and regulating salt intake, things settled down and obviously I was OK.

Did you spend much time in hospital when you were young or was this something that happened more as you go older?

I went back into hospital when I was five months with a bowel blockage. There were enzymes then, but they caused a bit of a rash and I couldn't take breast milk so had to have "pre-digested" milk.

My parents took me monthly for check-ups until I was about six months old and then it was every three months. I kept pretty well as a child until I got whooping cough when I was twelve, despite immunisations, ending back in PMH.

I have had a few issues with sinus, having between 14-24 sinus operations, the last one was when I was 24 years.

Keeping well was mostly due to my parents; they kept me really physically fit. We lived on a dairy farm and there was salty air from the sea in Augusta. They were very serious about physiotherapy; all our friends were trained in percussion so they could do it, too. I always took my full course of antibiotics. We didn't have TV and I did lots of sports and general fitness and still do. I don't really identify seriously as having CF; we're all really different. Don't compare; know your own body. CF has never been the centre of my life, however, I have taken good care of myself so that it doesn't have to be.

Having CF, was it something that impacted your life choices about education, career and relationships?

I went on a lot of camps with other children with CF. My mum was one of the founding members so organised a lot of things. I first heard about cross infection when I was around 10 years old and knew some kids that died, that really affected me and I never really planned more than five years ahead and lived by the mantra: only live once, so do it all now as I thought I wouldn't be around. I still tried hard at school etc., because I liked the challenge, but the future was always more of a fantasy than a reality.

I had lots of different jobs, tried lots of different things. I tried to pack as much into life as I could, but settled into cooking because I love it and it can take me to different places. It can be physically demanding and that's why I went into business rather than working for someone

else. I did a mature age apprenticeship as a chef when I was living in Broome. This took three years. I was cooking for years before this, but it was getting harder to get jobs without the ticket. It was hard to stick to as I had not really done any future planning before, but my husband really supported me through this and kept me on track.

Relationships: well I needed an understanding man. The whole town where I live know that I have CF; I'm very open about it. It's easier now that there is so much more public awareness about it. I have been with Jim now for thirteen years. When we first me I told him that I had CF. He knew someone with whom he went to school with that had CF and used to help with physio. I look quite healthy so people don't really think it's too much of an issue.

What do you think are the most significant changes to the way people are treated with CF?

Physio has changed, it's more breathing-based than coughing. More about exercising the lungs. Home IVs have made the most significant difference, it gave us flexibility to go home, to work, etc. At the end of the day you just want to be normal. Hospital is not so much appointment-based, it's more tailored to our lifestyle and we can have as much input now into what happens with our treatment. I have a spiro PD which has really helped me track my

health and feed this back to the team at Charlies.I don't mind the three monthly check-ups, I get to see everyone that I need to and visit friends in Perth and do shopping. There are no shops in Augusta.

What do you think the future holds for people with CF?

I don't think a cure is too far away. It won't fix it for us older ones, but if you are born with CF now you should be OK. Keep focused and do your physio every day, exercise lots, wash your hands and tell your friends not to come around if they're sick, but to give you a call instead.

Take care of yourself and put your health first. Be straight up about what you need and keep a good balance in your life.

PARENTS DINNER

JOIN US FOR A SOCIAL
GET-TOGETHER,
ALL PARENTS WELCOME!

Where: Metro Bar & Bistro, Mounts Bay Road, Perth
When: Saturday, October 22nd

Thanks to our supporters, Carer's WA and Lotterywest, we can provide overnight accommodation for up to 5 sets of regional parents and a highly subsidised meal for all parents at $35 per ticket, so book your babysitter and register your interest now! *recreation@cfwa.org.au*

lotterywest supported

Carers WA AUSTRALIA

Capel Vale Red Tie Dinner Dance

THE POWER SECTION OF THE FREMANTLE SAILING CLUB (FSC) HOSTED THE SECOND RED TIE DINNER DANCE ON 27 AUGUST THIS YEAR, RAISING A RECORD NET $23,000 FOR CYSTIC FIBROSIS WA.

The sell-out crowd of 300 guests bid furiously on items ranging from a luxury cruise on the Queen Mary II to a beautiful south sea pearl pendant, grown and donated by one of CFWA's members, David Jackson at Elizabeth Bay in Arnhem Land, David and Judi's daughter, Ella, lives with CF and so this pearl was extra special. World-renowned jeweller Don Mazzucchelli set the pearl in an 18ct gold and diamond mount.

One lucky patron took away the beautiful "Spirit of the Sea" statement ring (pictured) most generously donated by Keiko Uno Jewellery. This incredibly generous gift raised over $4,000 in the raffle on the night!

This year, Capel Vale, who support a number of our events, were the naming rights sponsor for the evening and supplied sparkling, reds and whites. Beers were supplied by a new brewery, the ABC; no, not the Broadcasting Corporation but the Albany Brewing Company. Everyone commented on the superb quality of the wine and beer and complimented the galley and Michael and his team on the superb food. They are already talking about coming back for more in 2017.

If you thought that the theming of the room could not get any better than last year, you were wrong! Darren Heath's Stage and Studio Productions really out did themselves this year, donating a significant amount of time and expertise in the two days it took to set up. Complementing, the theme were stunning displays of roses donated by CFWA supporter, WAFEX, who also bought an entire table at the event and then drew employees names from a hat

to see who would attend! You'll need two tables next year boys!

The FSC chipped in as well with free room hire, and publicity and promotion which ensured that there was a waiting list for tickets months before the highly anticipated event took place. Special thanks to Margie and the team at FSC reception who managed all the bookings so professionally and Jayllee for design and printing.

FSC Commodore Burbidge gave a rousing speech at the start of the evening and Prof. Stick made sure that everyone in the room knew what they were there for.

Back by popular demand was Tod Johnson's band. Tod kindly donated MC services for the evening and international auctioneer John Garland was better than Black Beard in extracting the last dollar from the sailors and land lubbers.

The evening would not have been possible without the tireless work of Wendy Barker who chaired the Power Boat Section organising committee, the hunter gatherers who sourced a fantastic range of auction items and the major sponsors: Capel Vale, Albany Brewing Company, Catalano Trucks, Robinson Insurance Brokers, Tail Lift Transport and WAFEX.

Plans for next year have already commenced! If you would like to be involved as a hunter gatherer, please call Wendy on 0408 940 851. Advance tickets for the 2017 event will be made available to previous attendees later this year with general tickets going on sale in the new year.

Looking Forward with Amanda

AMANDA IS NEARLY 47 YEARS OF AGE AND CONSIDERS GETTING OLDER AN ACHIEVEMENT. SHE IS A VIBRANT, INSIGHTFUL AND INSPIRING WOMAN WHO IS ABLE TO SHARE WITH YOU SOME OF THE CHANGES TO TREATMENT OVER HER LIFETIME.

What age were you when you were diagnosed?

I was nearly three years old (1972) when I was diagnosed mainly due to failure to thrive. No one could diagnose me; my mother was accused of being neurotic. It was a relief to my parents when I was finally diagnosed. I was started on a NO fat diet and pancreatic enzyme powder that had to be mixed with apple sauce so obviously my compliance was minimal. Physio was all the rage and I absolutely hated it! It was a constant battle for my parents with much crying and fighting. Unfortunately for my parents, there wasn't much education on CF back then but they were told not to expect too much as kids didn't generally reach adulthood.

Did you and your parents go to hospital for education and management of CF after you were diagnosed?

There wasn't much education back then but there were good support systems with CF NSW and other families with CF that formed close networks. We didn't worry about cross infections in those days and great friendships were formed. Much of the bases of treatments were the same as now but obviously then less advanced. One medication I recall was mucomyst which was a foul tasting and smelling drug that was nebulised and mixed with coke for gut aches, which I reckon could also unblock drains.

Did you spend much time in hospital when you were young or was this something that happened more as you go older?

Not so much when I was younger but increased as I got older. My first admission was when I was nine years old. My parents were told that I had staphylococcus and Methicilllin-resistant staphylococcus aureus (MRSA) so I was isolated. Obviously, this was extremely scary as I'd never been in hospital before and then I was put into this huge room where no one came near me and when they did, everyone had to gown up and a wear mask to see me. Funny thing is, my main nurse ended up having TB! When I was 13 years old, I started going to hospital approx. every 1-2 years. I remember I was a guinea pig for any new treatments and young doctors to practice their cannulations skills on. I was the third person in Australia to get a Percutanous endoscopic gastrostomy (PEG). At 13, I got an infusaport (port) which as a teenager I found extremely invasive. In my older teenage years, I generally had yearly admissions.

My mental health suffered being a teenager and generally having to deal with having CF. I really struggled about having a PEG and infusaport plus I was much shorter than everyone else. Generally, I just felt really different. Up until my 30s, I tried to keep having CF on a 'need-to-know basis' as I felt embarrassed and wanted to be 'normal.' Let's face it, often we (with CF) don't look obviously any different and it's a silent disease. I'm now much more open about it and really, no one really cares or judges me and if they do it's their problem.

Generally, I have encountered very little discrimination. When I was in my 20s I worked for a bank and a credit union and didn't receive much support. I received a lot of pressure about taking time off work so I resigned. I decided to shift my career to something I enjoyed and started work in the HIV, where I receive much better support. I then went on to do registered nursing but once done, my graduate year moved onto non-acute patients in community health which is more flexible; less chance of being exposed to people with bugs. Recently, I had to drop down to three days a week due to health which was a tough but necessary decision.

Having CF, was it something that impacted your life choices about education, career and relationships?

Absolutely, I missed a lot of high school as it was easier to be at home than being at school 'feeling different' to everybody else, so university wasn't an option at that stage. I tried different careers including chef work as I had a passion for cooking but found this industry too physically tiring. As mentioned, my experience in working in the banking industry was tough due to discrimination (this was in the 80s and 90s) & it was boring. I then went into welfare as I wanted to help people. I had finally found my niche and later in life studied nursing. Obviously, general nursing put me at risk of bugs and was physically challenging so I adjusted my nursing career to specialise in women's and sexual health/public health which required extra study.

Relationships yes, especially when I didn't tell people I had CF, but when I did later no one cared. I only had one incident where I was "dumped" because of CF. I now have a really supportive man in my life and we've been together over ten years.

What do think are the most significant changes to the way people are treated with CF?

Generally, people are seen as having a full and productive life; it's not a death sentence now. CF is part of their life, but not their life, and it doesn't define the person. I started Kalydeco® three years ago and feel like my health was where it was ten years ago. I have more energy, can keep working, can exercise and generally lead a normal life within limits.

What do you think the future holds for people with CF?

I think they can do whatever they want to. New treatment can start before damage is done. There are more and more treatments and a lot more money is going into research. Most people are living relatively normal lives.

I believe mental attitude is a huge component and has a big impact on health. Get out there and live life, have friends, work, hobbies, sport, career, even if it's part time or voluntary it's important to stay involved. We all need something to get up for and a purpose in life.

Bunbury Outreach

telethon 7

Sam Wallace, our physio, and Sharon Dewar, our community nurse, made a trip down to Bunbury on Friday 9th of September to have a morning tea catch up with some of the lovely families who live in the south west region. Our home care worker Sue Williams, who works with the families in the South West was also there. The catch up gave everyone the chance to discuss issues they face, share stories and network with other families living with cystic fibrosis in their local area.

Celebration of Life

TODAY DIAGNOSIS OF CYSTIC FIBROSIS IS A "MANAGEABLE DISEASE", HOWEVER, MANY ADULTS HAVE EXPERIENCED THE LOSS OF PEOPLE AND FRIENDS WITH CF THAT DIDN'T MAKE IT.

Grief and loss are present for many people in our community. Grief is often felt and expressed differently, there is no set pattern. Some people grieve for weeks or months, for some it's ongoing and unresolved. Grief can sometimes come at unexpected moments such as an anniversary or a particular milestone that you would have liked to share.

Grief is a normal reaction to loss. It can leave you feeling sad, shocked, angry, relieved, regretful, overwhelmed, numb. It can affect your emotions, physical health, beliefs, thoughts, sense of self, identity, your relationships, your work and direction. It can also affect your ability to concentrate, make decisions and your sleeping patterns, which can lead to headaches, pains and nausea.

For most people, grief is something that takes a while to work through. It's important to try and talk with someone about how you feel. It's OK to grieve in your own way, honour your feelings and take one step at a time.

If you would like to talk someone please contact Kathryn on 6457 7348 servicesmanager@cfwa.org.au

Bequests Pave the Way to a Brighter Future for CF

In 2008, Edith Chandler left a significant bequest of $443,566 to CFWA to help fund research that would one day find a cure for CF. That money was quarantined whilst we searched the globe for a project that would deliver clinical outcomes within a five-year period.

Following a global search, Edith's bequest was invested in a project designed to raise money for research that would reduce structural lung damage in infants by 50% within 5 years and add 20 years to life expectancy. Edith's bequest has now been responsible for generating total research funds which will exceed $2.3m in 2016. The researchers, based in Australia, USA and Netherlands, are on track to reach their audacious goals and recently presented their progress at the Telethon Kids Institute. This progress was reported upon in the last edition of RED magazine.

Late in 2016, we also received a smaller bequest from the Orner estate which will help deliver services which will keep young lungs healthy and change the trajectory of the disease, reducing the rate of decline in lung function and delaying the onset of structural lung damage.

This research and service delivery are fundamental in reaching our vision of Lives Unaffected by CF.

Bequests are generally large unexpected donations which allow small organisations like ours to make step changes in advancing our knowledge, understanding and treatment of disease.

If you would like to know more about leaving a specific bequest, or residuary bequest to CFWA, please contact Nigel Barker CEO on 08 6457 7333 for a confidential discussion or email ceo@cfwa.org.au to request the correct form of wording for your will. Of course we'd love to know about any provision you'd care to make and talk with you about how best we can apply those funds with yourself.

Through the Years with Liz Balding at Princess Margaret Hospital (PMH)

LIZ COMMENCED WORKING AT PMH IN JULY 1987 AS A LIAISON NURSE. PRIOR TO THIS SHE WORKED IN VARIOUS REGIONAL CENTRES INCLUDING PORT HEDLAND.

Liz received her nursing training on site within hospitals, however, went back to further her education and skills, graduating with a nursing degree in the 1990s. Part of this training was around "models of nursing" which set a framework for the future development of a multi-disciplinary team (MDT) which included doctors, nursing, physiotherapy, dietetics and social work. It was around this time that she interviewed for her current position of clinical nurse consultant (CNC).

When Liz started Prof Lou Landau, Prof Peter Le Souff and Prof Des Gurry.were already working there.Professor Stephen Stick started in 1989. The MDT evolved under their leadership. The team has continued to grow in strength with Liz remaining a consistent coordinator of the team.

The introduction of Tobramycin® nebulisers made a very significant impact whereby parents were able to treat their children at home. Prior to this, children were hospitalised regularly and for long periods. Peripherally inserted central catheters (PICC) were also introduced around this time which also made a significant difference to treatment times.

In 1989, the discovery of the CF gene radically changed the science around CF. There was so much hype, it opened up a Pandora's box of possibilities and new developments in research.

On the 1 June 2000, the Newborn Screening Program (NSP) was introduced. Up until this time, children were often getting a late diagnosis and were much sicker and older when they first came to hospital. Expectations were also much lower with many children having very little schooling as many parents were told that their children wouldn't make it to adulthood, so schooling wasn't seen as important.

Big Sibs Get Together

Date: Friday 28 October 2016

Venue: Pot Black 106 James St Northbridge

Time: from 6:30pm

Food and non-alcoholic beverages provided

RSVP: servicesmanager@cfwa.org.au or 08 6457 7333

CAN

Life After High School with Marina

AT 18, MARINA IS VERY LEVEL HEADED AND PRAGMATIC. IT IS SO INSPIRING TO ALSO MEET A PERSON WHO IS HAPPY WITH HER LIFE AND WHO WORKS SO HARD TO ACHIEVE HER GOALS DESPITE HAVING THE EXTRA BURDEN OF DOING TIME-CONSUMING TREATMENT FOR CYSTIC FIBROSIS.

I am studying a law and arts degree at the University of Notre Dame, majoring in politics and international relations. I found the criminal law unit I did last semester very interesting and I also really like learning about international law. I am enjoying going to uni; there's lots of freedom which is a good and bad thing. I have purposely selected some 8:30 am sessions for a few of my units so I get things done during the day, instead of sleeping in.

I found it very difficult fitting everything in during my final years at high school in terms of doing my physio, plus study, playing sport, going to church and the gym and having a bit of a social life. I felt like because I was playing netball and going to the gym, I could get away with not doing my physio as much, but I knew it wasn't clearing the mucus as well as physio does. My parents were always asking me when was the last time I did my physio as they were concerned I wasn't doing it regularly enough, and one day I had a bit of a meltdown. I had an English test to study for and I am one for leaving things a bit too late, so I had lots of study to do and my parents were asking me about my physio and I just snapped!! But my parents said they understood and they backed off a bit.

Growing up, I played water polo, netball and I did dancing and little athletics. I play netball at a district level for Fremantle. I started going to the gym towards the end of year 11 with a friend who goes and she often forces me to go to classes with her, so that's good.

I am currently trying to look for part-time work which is proving to be very tricky. They want you to have experience but I have spent the last few years studying hard to get into uni, so I haven't had any part-time jobs. I should have got a job at 14, so I had something to put on my resumè.

I'm not sure yet, if later on, I want a career as a lawyer. I am looking at the students in my course who are loud and outgoing and are leaders, where as I am more of a follower. There's lots of options so I will see what happens. I may even do a teaching degree so I can teach law and politics.

It's a big thing for my age group to party. My friends go out every weekend and if you want to keep your friends and see them you kind of have to go out. I do like going to parties but I feel like it's a bit of a waste of money at times. I live near the Raffles and I know lots of girls who go there every week, and I don't know how they have the time or money to do that. It's fun from time-to-time but not all the time.

I do really enjoy spending time with my friends, but I enjoy going out for dinner or sharing a pizza at home. Clubbing is fun but it takes a lot of effort and it can be tiring. Lots of people will meet up for drinks or "pre's" as we call them, where they BYO their drinks and because I don't want to drink too much I don't bring any and as drinks are so expensive, that stops me from buying too many. It's kind of gross seeing people so drunk and you feel crappy when you have things to do the next day. I find it's more fun if I'm in control and can also remember the night.

I went to an all girl's school where they drilled it into us about staying together as a group, and this has been good for safety when we go out.

I went to Busselton with a group of friends and it was the first time we were staying away with no adults telling us what to do. It was a bit daunting and strange and I was worried it was going to be a drunken brawl, but I had a really good time and felt really safe. It was run by volunteers from the Red Frog organisation. My friends and I stuck together when we went out and there were lots of things to do which were organised by Red Frog.

Having CF doesn't restrict me. I still play sport fine and I don't feel weird taking my medication. All my high school friends know I take medication. Though it has been a bit difficult at uni taking my enzymes in front of new friends. Sometimes I don't want to have to answer questions about why I am taking Creon, so I have taken them a bit later on, to avoid annoying questions. But 90% of the time I don't have an issue.

When I was about ten, I thought to myself that I still had 20 years to go, which seemed like ages. I also thought it was so unfair that it was me who had CF and not my brother. It was when I was admitted to hospital and so it all seemed more real.

During the time I was in high school I felt frustrated about having CF, when I wanted to be an exchange student at a school in France. The school was concerned that it would be too difficult for a host family to have me because of my CF and that if I were unwell, they would have to take me to hospital. I felt like my CF was holding me back from something I really wanted to do.

But now I accept it, it's something I've got, I've just got to live with it. I can control it with physio (if I did it more often) – I'm a big procrastinator. I know if I do it, I would feel clearer and healthier.

I did have a boyfriend for about ten months. I can't really remember how I told him about having CF, but I know I took my medication in front of him so he would ask me about it. He did ask me about the life expectancy and that freaked him out. I told him it's just a statistic. But I can understand where he was coming from. I guess I think if the person really loves you it doesn't matter how long you live for.

In terms of boyfriends, I think if they don't accept that you have CF, there's no point dating them. They are not worth it, as CF is a big part of my life. I don't think people should be ashamed of having CF, it's no one's fault. It makes interesting conversation!

In the future I would like to travel to America, Europe and to South Africa to go on a safari tour.

Now I am also thinking about a career and family and will I see my grandchildren or experience old age? But I feel very lucky to live this life. Being Christian also really helps. I am having a happy life. I don't feel the need to go sky diving and to tick off things on a bucket list, I am satisfied with all the things I have done and can do now.

CFWA Wins Prestigious Telstra Business Award

IT WAS 9.00PM ON FRIDAY 8 JULY 2016. THE MANAGEMENT TEAM AND BOARD MEMBERS OF CFWA COLLECTIVELY HELD THEIR BREATH AS THEY SAT AROUND THE TABLE AT THE TELSTRA BUSINESS AWARDS GALA DINNER AT CROWN.

CFWA had been nominated in the charity category of the prestigious Telstra Business Awards and had progressed through the gruelling application and interview stages to be listed as just one of four state finalists in WA from around 200 nominees.

The competition was stiff. All of the state finalists were worthy winners. The Telethon Adventurers, the Motor Neuron Disease Association of WA and Midwest Charity Begins at Home Inc., but this wasn't about profile or monies raised so much as it was about overall business strategy, risk management, growth and sustainability.

Cameron Syme from the Great Southern Distilling Company in WA, an Award winner from 2015, took to the stage and announced "The 2016 Telstra Western Australian Charity Award goes to: Cystic Fibrosis Western Australia!"

This was the first time that Telstra had included charities in the Award's 24-year history. To be the inaugural WA winner means a lot to CFWA and our members and has opened the door to discussions with a number of larger corporates who are keen to support our cause.

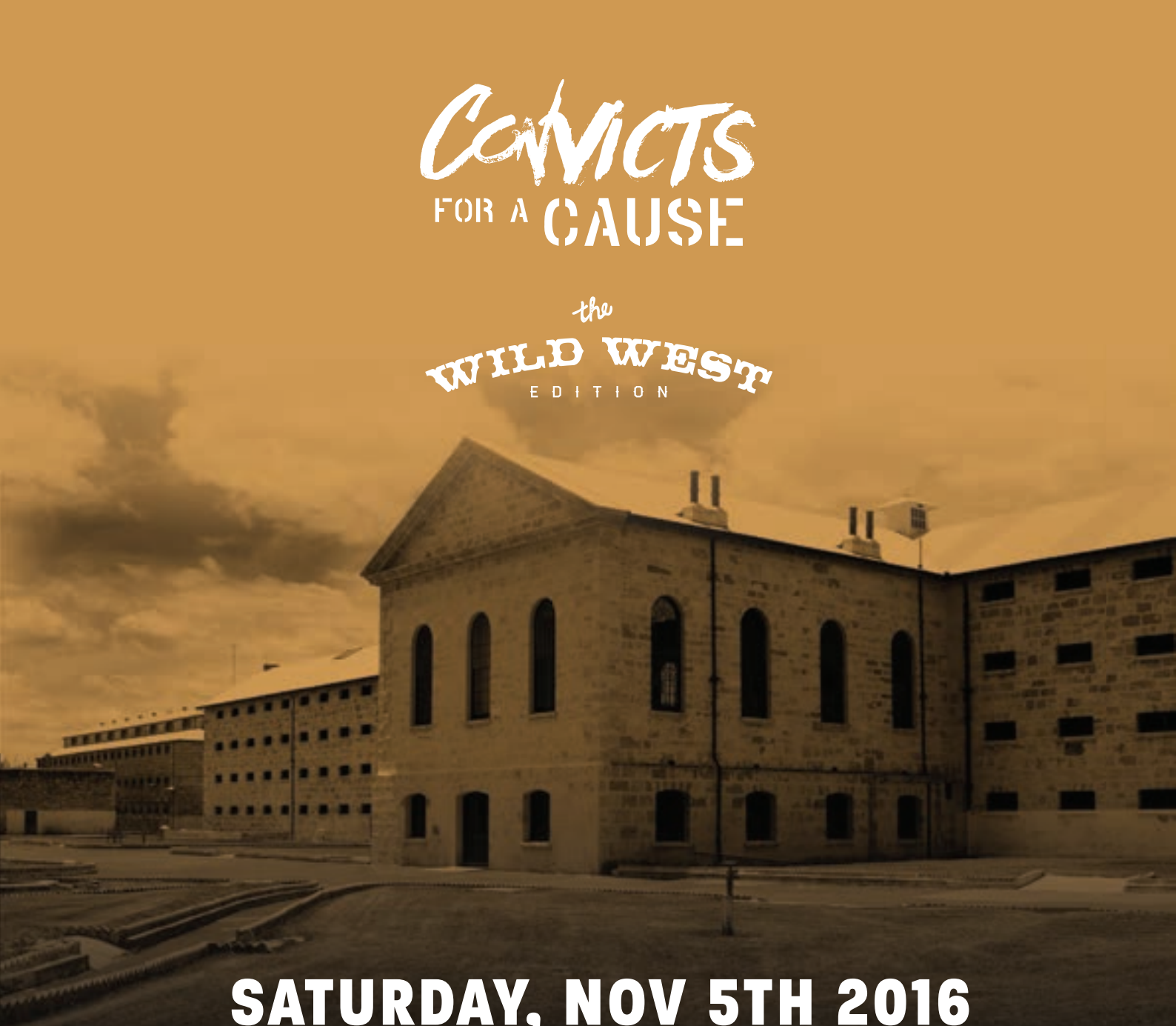
In accepting the Award, CEO Nigel Barker, insisted that all the team get up on stage as this was a superb team effort. He said that "To be successful and sustainable, CFWA needed to employ the very best and latest business tools. Good governance, good planning, transparency and accountability were the foundations for this success.

We are constantly trying to position ourselves where the ball is going to land rather than find ourselves chasing after it."

In the next few months, we will be embarking on our 2017 - 2020 strategic planning process, so look out for an opportunity to have your say about your future needs as we strive ever closer to our vision of Lives Unaffected by CF.

CONVICTS FOR A CAUSE

the WILD WEST EDITION



SATURDAY, NOV 5TH 2016
FREMANTLE PRISON
7 - 11PM

Experience a night of charity, fun and mischief in the historic Fremantle Prison.

www.convictsforacause.org.au

CYSTIC FIBROSIS Western Australia

Diabetes Research Western Australia

Rotary

REFLECTIONS THROUGH REALITY

Fundraising News

THANK YOU TO ALL OUR COMMUNITY FUNDRAISERS FOR 2016. YOUR CONTINUED SUPPORT IS ALWAYS GREATLY APPRECIATED BY CYSTIC FIBROSIS WA AND THE GREATER CF COMMUNITY. 2016 WAS A YEAR OF CRAZY HAIR, TOPPED UP TINS AND CREATIVE CAMPAIGNS THAT TOGETHER, HAVE RAISED A FANTASTIC AMOUNT OF MONEY TO GO TOWARDS SUPPORT, EDUCATION AND RESEARCH FOR CYSTIC FIBROSIS.

Community Events

Chevron City to Surf 2016

Over 30,000 participants pounded the pavement again for this year's Chevron City to Surf for Activ Perth. Nine of these represented CFWA in their efforts and raised some much appreciated funds. Congratulations and thank you to everyone who participated, you've raised over $1900 together!

Top Cystic Fibrosis Fundraisers for City to Surf

1. Ben Cooper	$667.50
2. Kelly and Abbey Barker	$436.00
3. Mary Smith	$413.75
4. Chelsea Wilkie	$218.50
5. Luke Garratt	$193.50

Out and About

Donation Tin Success

Chris, who volunteers for CFWA, has been out and about collecting, replacing and dropping off collection tins at businesses across Perth. Since July, these tins have raised over $2,000 to go towards services and research. A big thank you to all the businesses out there and a massive thank you to Chris for his continued support.

Top Tins July

1. Liquor Baron Crawley	$53.40
2. Liquor Baron Belmont	$30.45
3. House Homewares	$20.00
4. Floreat Vet Centre	$6.95

Top Tins August

1. Amcal Forrestfield	$201.40
2. Oliver Coco	$164.55
3. Xpresso Code	$151.85
4. Mt Hawthorn Pharmacy	$142.60

Top Tins September

1. Lucky Charm	$123.80
2. Scarborough 7 Day Chemist	$111.75
3. Best Drop Tavern	$104.70
4. Anaconda	$67.60

OAKLEY, CASSIUS AND BRODII RAISED $515 THROUGH A "HERO DAY" AT THEIR SCHOOL.

Community Fundraisers

From crazy sock fundraisers to Hero days, our community fundraisers continue to impress. The schools, community groups and individual supporters who've fundraised for CFWA in July, August and September have collectively raised just shy of $5000! It is amazing how every little bit of effort can make a big difference.

Satterley Property Group

Satterley Property Group has raised funds for CF by holding a Crazy Hair Day in August. They raised $246.05 from their efforts and say they had a great time doing so. Thank you Satterley Property Group!

St Vincent's Hero Day

On August 12th Cassius, Brodii and Oakley Goncalves from St Vincent's Catholic Primary School helped raise money for CF by holding a Hero Day. They raised a neat profit of $515 by gathering donations from peers, families and the community. What a heroic effort!

Crazy Sock Day

Brighton Catholic Primary School has raised

PAUL IS MAKING GREAT TIME ON HIS CROSS-CONTINENT 65 ROSES CHALLENGE.

a fantastic $450 by hosting a Crazy Sock Day. Children wore crazy and funky socks to school for a gold coin donation. What a creative and easy way to get involved and make a difference. Well done Brighton Catholic Primary School.

Jayton at the Cunderdin Markets

A big thank you to Jayton Carter for manning a stall for CFWA at the Cunderdin Markets on Sunday 14th August. He raised $120 from the stall and plans to do it again for September and October. Thank you for your support Jayton, you've done a fantastic job.

Derrick Ernst Neighbourhood Centre

Thank you to Derrick Ernst Neighbourhood Centre who raised $63.85 by hosting a Crazy Hair Day for CF on 29 July. Every bit counts, and judging by the photos, you look like you've had a blast.

Nails Are a Wrap

Kathleen Grinfelds, an independent consultant for Jamberry Nails, has recently held a fundraiser where she raised over $160 for CF by donating part-proceeds from her sales in July. Thank you Kathleen for your creative fundraising and generosity.

Upcoming Community Fundraisers

We have a number of exciting community fundraisers in the works for the rest of 2016 which we hope you'll get behind and support. If you would like to host your own fundraising event or have an idea, contact Marnie on events@cfwa.org.au or 08 6457 7333.

Hip Hope for Roses

Sera Taylor, a CFWA member who has CF, is hosting a hip hop fundraising event with live music, raffles, prizes and more. With support from a number of Perth hip hop artists, photographers, DJs and more, Sera's event is sure to be a success.

24 Hour Walk for CF

Luke Ioppolo, a PE teacher from Cunderdin, will be attempting a 24-hour non-stop walk for CF on 29 and 30 September. Inspired by one of his students Jayton, who has CF, Luke is attempting to raise $3,000 to build awareness and raise much-needed funds for CFWA. So far he has raised $777.50 and this number is continuing to rise. Good luck Luke!

Paul Hits 1,000km

In the last RED edition, we introduced Paul Fowler, a member of the CF community who has CF, who was challenging himself to ride a bike across Europe. Paul set off on his trip in August and since then has achieved a number of milestones, come across some challenging situations and gathered a massive amount of supporters. While at times he's said it has been a humbling experience, he has managed to reach a total of 1,000km in less than a month, ridden a 100km day and seen some amazing sights.

Paul has been blogging about his amazing experience and the things he is learning on his travels. If you'd like to check it out, go to **paulmichaelcycle.com** or go to **65roseswa2016.everydayhero.com/au/paulmichael** if you'd like to donate and support his cause. So far he has raised almost $19,000 and is so close to reaching his goal of $20,000.

I'm sure Paul's adventure is an inspiration to a lot of people in the CF and wider communities. We couldn't be more excited to be supporting him and his campaign to raise awareness and inspire. Stay safe and healthy Paul, we can't wait to hear what you discover next.

LOVE THE SHIRT BRODI!!!


THE DERRICK ERNST NEIGHBORHOOD CENTRE HELD A CRAZY HAIR DAY IN JULY.

Irulan's Life as a Teen with Cystic Fibrosis

WE ASKED IRULAN, WHO IS 14 AND LIVES IN JARRAHDALE WITH HER PARENTS AND TWO SISTERS, ABOUT HER LIFE AS A YOUNG PERSON LIVING WITH CYSTIC FIBROSIS. DESPITE EXPERIENCING SOME EXTRA OBSTACLES ON TOP OF HAVING CF, IRULAN'S STRENGTH, MATURITY AND BUBBLY PERSONALITY ALLOWS HER TO DEAL WITH DAY TO DAY CHALLENGES AND STILLBE A TYPICAL TEENAGER WHO ENJOYS HANGING OUT WITH HER FRIENDS.

When I'm at school I sometimes forget about having CF until lunch time, when I have to take my Creon. During the holidays I know it's there because I've got my parents nagging me to do my treatment. It gives me a headache doing all the stuff. CF does impact on my life to some extent because I am private about having it, so it's hard going to parties or to sleepovers if I have to do my treatment there. But I am going to Canberra next year with the school for a week and it will be my first time away so I will have to do my treatment, possibly in front of others. My sister went on the same trip last year and it sounds great. I am really looking forward to it.

The hardest thing about having CF is trying to keep track of everything. All the medications and physio are difficult to fit in along with homework and getting ready for school. Trying to remember the names of all the medications is hard too. Most of them though I can say, but there are a few I have to think about. The names of the medications are on my medical alert card so that helps. I have a medication box where you can put two weeks' worth of medication in there. I make it up myself and then my mum checks it.

Sometimes I try to argue myself out of doing my physio when I'm at home but if I don't do it I feel slightly guilty. I take my Creon at school at the drink fountain. My friends don't really know anything much about it, they don't know what it is. As I said before, I keep it private.

The check-ups at the CF clinic are changing now that I'm a bit older. I go in first, then mum comes in a little while later with me. They are trying to do it so that when I'm older I will be used to going to appointments on my own. Occasionally I like it but sometimes it is hard as I feel like I will forget what they say.

Apart from my CF, I also have epilepsy. Two years ago I had a seizure at school. Luckily my mum was actually already on the way to my school to take me to a CF appointment. I don't really remember much except I woke up on the floor and there was my mum. I spent a week and a half at PMH as I was having continuous seizures and they were trying to get them under control. They were able to get the seizures under control but I still needed to stay in hospital for another couple of weeks so they could check I was OK. The epilepsy was brought on by adolescence. About eight weeks later I had to go into PMH again for a tune-up, which was my first admission for CF. I was there for another three weeks. It was a tough few months for me and my family. My seizures are under control now. I just have some more medication to add to my CF medications.

A lot of people say I'm good with little kids, so I am thinking of being a primary school teacher when I am older. I already do some babysitting which I enjoy. At high school I like media, sport and cooking, although I do have my own style of cooking which the teacher isn't too keen on. I also really like Anime - which is a Japanese style of animation - and I like playing netball, too.

I don't want to think about the future in terms of CF; I live with the now. If I think too much about it, I can't sleep at night as I get really curious about things. So if I just think about the present, that makes it easier for me.

Halloween Fun Run for Cystic Fibrosis

Sunday 23 October 2016
Perry Lakes Reserve Floreat
Check in from 8.00am

Sign up now

www.halloweenrun.com.au

CYSTIC FIBROSIS Western Australia

Proudly supported by: Community newspaper group

Do You Plan on Using the RED Room to Pass the Time at PMH Clinic?

A FEW WORDS ON OUR INFECTION PREVENTION AND CONTROL POLICY

Cystic Fibrosis WA (CFWA) is committed to ensuring the health and safety of all members and visitors to the CFWA environment and to provide a safe working environment for all staff and volunteers. This commitment includes the adoption of an infection control policy that minimises risks of members acquiring healthcare associated infections.

The "RED Room" is available for all members of the CFWA community, including members with CF and family members without CF. It is available as a space for members to use as respite during hospitalisation and as an area to spend time awaiting clinic appointments or test results.

In using this area there is a risk that you may be exposed to pathogens (disease-causing organisms) that may harm you (or your children's) health.

There is no reliable way to completely eliminate the risk of cross infection. However, we wish to minimise the risk of cross infection and have made the following recommendations as a guide.

1. **Use alcohol hand rub prior to entering the RED Room**
2. **Anyone who has signs of cold, flu, respiratory or gastrointestinal illness is asked not to use the RED Room or to leave if they develop any signs or symptoms.**
3. **Anyone who believes they may have an infection that could be harmful to other people is asked not to use the RED Room.**
4. **Only one person with CF should use the room at a time. You should phone ahead to book the room if you would like to use it or to check to see if it is free.**
5. **Everyone should practice good public health hygiene. Always cover your mouth and nose with your elbow when coughing or sneezing and dispose of used tissues in a covered container.**
6. **Always wash and dry your hands or use alcohol hand sanitiser after coughing, sneezing, touching your mouth or nose and before eating.**
7. **All items usedwhilst in the room are to be placed in the "Used Items" receptacle.**
8. Use alcohol hand rub prior to leaving the RED Room.

FRIDAY OCTOBER 21st
9am to 2.30pm

REGISTER ONLINE
http://tinyurl.com/j7uucub

Any questions contact -
Natalie Amos
education@cfwa.org.au
6457 7333

CYSTIC FIBROSIS & REPRODUCTIVE CHOICES SEMINAR

An information day for people with CF, their partners and parents of children with CF

Institute for Respitory Health,
Harry Perkins Research Institute,
QEII campus, 6 Verdun St, Nedlands

09.00 - 9.25	Registration Tea and coffee
09.25	Welcome & introduction
09.30 - 10.00	Reproductive options for males, male infertility, semen analysis
10.00 - 10.20	IVF and stages of IVF
10.20 - 10.45	Pre implantation and genetic diagnosis in WA
10.45 - 11.00	Morning tea
11.00 - 11.45	Managing pregnancy with CF
11.45 - 12.30	Legal aspects of surrogacy
12.30 - 1.00	LUNCH
1.00 - 1.30	Insight into surrogacy consumer perspective
1.30 - 2.30	Panel discussion of personal experiences

CYSTIC FIBROSIS
Western Australia

Save the Dates: 2016 Events

CYSTIC FIBROSIS WA'S 2016 CALENDAR IS JAM-PACKED, SO MAKE SURE YOU 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 RESPITE

October

6 and 7 Sibling and Offspring Camp

14 Parents' Dinner

21 CFWA Expo: Fertility and CF**23** Halloween Run: a Great Strides Event

November

5 Convicts for a Cause

6 Post-Transplant Support Day

December

2 CFWA 40th Anniversary and Christmas Party

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

Our Partners are Sharing our Journey

FORTY YEARS OF CYSTIC FIBROSIS WA HAS SEEN INCREDIBLE SUPPORT AND COMMITMENT FROM OUR COMMUNITY. EVENTS AND COMMUNITY FUNDRAISERS PLAY AN IMPORTANT ROLE IN FUNDRAISING AND AWARENESS, AND ALSO CONTRIBUTE TO THE FORGING OF STRONG BONDS WITHIN THE CF COMMUNITY. CYSTIC FIBROSIS WA IS PROUD OF THE COMMITMENT SHOWN BY OUR INCREDIBLE GROUP OF SUPPORTERS. IN 2016 CFWA WAS THE RECIPIENT OF THE WA TELSTRA BUSINESS AWARD IN THE INAUGURAL CHARITY CATEGORY AND WE ACKNOWLEDGE THE ROLE THAT OUR PARTNERS HAVE PLAYED IN OUR ACHIEVEMENT.

Lotterywest

Lotterywest continues to be committed to the cystic fibrosis journey. Support has taken many shapes since the inception of CFWA. As our first non-government partner Lotterywest(formerly the Lotteries Commission) made a very generous donation in 1990 specifically for the purpose of developing Donor Management software and computer hardware. Lotterywest have continued their generous support of a number of programs and projects and, in 2002, in collaboration with the Department of Health, the Niche Building was completed. Since this time, CFWA has received ongoing tenancy with a number of other not-for-profits within this building.

Capel Vale

Capel Vale wines have been proud supporters since the first years of CFWA. Peter Pratten is a Past President and past board member, and the support of Peter, Elizabeth and Simon over the years has been unstinting. Capel Vale has supported fundraising and program events as our major wine sponsor, and the significant support that this has provided for our services, education programs and research means the name 'Capel Vale' has become synonymous with CFWA over time.

THE COMMBANK TEAM HELP US WRAP THOUSANDS OF ROSES FOR 65 ROSES DAY, SUPPLIED BY OUR GENEROUS SUPPORTER WAFEX.

CAPEL VALE WESTERN AUSTRALIA

WAFEX

Community newspaper group

telethon 7

lotterywest supported

TELETHON HAVE BEEN BIG SUPPORTERS OF CFWA FOR MANY YEARS.

Community Newspaper Group

Creating awareness within the community can be challenging for small not for profit organisations. The continued support and creative assistance from the team at Community Newspaper Group continues to spread our message through our member communities. With coverage of all our events, and graphics and production support for our RED Magazine, the Community News team also get involved in many of our events. In 2016, Community Newspaper Group is the major sponsor of our Halloween Fun Run, and our community fundraiser 'Crack-a-cure' saw the Community Newspaper team throw caution to the wind and be at the end of lots of eggs!

WAFEX

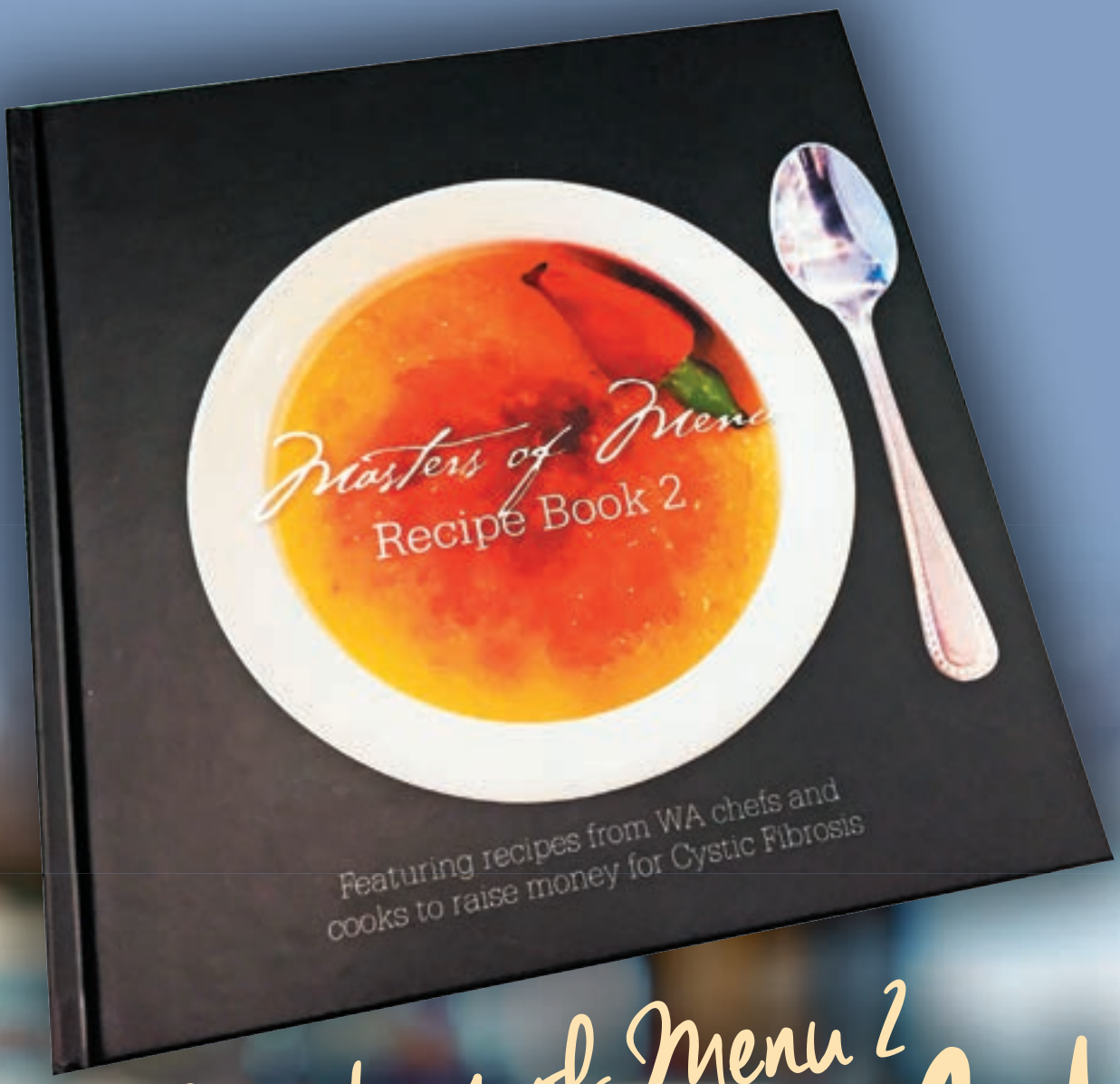
65 Roses Day is our signature fundraising event. Flower importer and exporter WAFEX has been part of our efforts since 2009. Their support not only includes the supply of our beautiful flowers but also involves the WAFEX team volunteering on the day to sell roses around Perth. The committed team continue to expand their support for events like the Golf Classic, Red Tie Dinner Dance, Art Exhibition and our CF Scientist evening. We look forward to 65 Roses Day growing in its community presence with the ongoing support of WAFEX.

Telethon

Telethon was established in 1968 by Channel 7 Perth. They have, over many years, funded significant programs to support families through CFWA including the Home Support Service which operated in the early days before funding was secured from the WA Department of Health. Most significantly in the last decade, regional support services have received significant funding, including regional education to schools, day cares, regional hospitals, workplaces and extended families. This funding also includes regional travel subsidies, general support and networking opportunities via coffee mornings and dinners for regional families.

ON SITE AT THE LOTTERYWEST NICHE BUILDING WHERE OUR OFFICES NOW RESIDE.

THE CYSTIC FIBROSIS WA OFFICE WAS RECENTLY REFURBISHED THANKS TO THE SUPPORT OF LOTTERYWEST.



Masters of Menu 2 Now on Sale!

Masters of Menu 2 has now arrived!

This brand new hardback cookbook is packed full of tasty recipes from some of Perth's best restaurants and includes a special CF section!

The book is available for sale online at **www.cysticfibrosis.org.au/wa** or via phone order on **08 6457 7333**.
Pick up your copy now for just **$50** while stocks last!

40 Years of Fundraising and Fun!

Events have been a key part of CFWA's support, awareness and fundraising. Along the way events have created incredible bonds and community connections. Support from volunteers, members and memberbusinesses has helped us to continue to fund member support, services and research. In a changing world, our events have changed, too, as we continue to challenge ourselves to provide new opportunities to encourage and bring about awareness and fundraise.

Many members will remember Star Search and Models on Parade, along with the Interservices Relay. Car rallies, raffles, bingo nights and silly sock days – all have contributed to the fabric of our CF community. Our CF staff have wandered through the years of events, and although too numerous to highlight all of them the enduring theme is one of collaboration and participation. Offers of assistance are never further than a phone call away and often bring with them another piece of our history, or opportunity to do something new.

Our annual Parent's Retreat has been a feature of the CFWA calendar for many years. In 2016, 34 parents enjoyed a couple of days at the Hillarys Harbour Resort with the opportunity to network, share information, relax and recharge. Lotterywest and Carers WA provided funding to make this event possible and we look forward to continuing this event into the future.

Golf Days are scattered through our newsletter history. In 2005, our golf event raised $27,085 with a day at The Vines in November. Run annually since 2011 as the Golf Classic and sponsored by George Jones Family Foundation since 2012, the event has become a staple on the CFWA calendar. With the generous support of sponsors and donors, the event has raised over $577, 500 net profit in the past 6 years. We look forward to the Golf Classic continuing in 2017.

In 2015, a collaboration between the Telethon Kids Institute, CFWA and AREST-CF initiated the CF Scientist evening. Hosted by the Telethon Kids Institute, the event is a wonderful launch for 65 Roses Month. Continuing in 2016, the evening included laboratory tours, presentations and poster sessions, and was again supported by Capel Vale and WAFEX.

A cup of tea and a chat is a great way to relax, network and share stories. Our Ladies High Tea has been a fixture on the calendar for many years with venues from the Niche to this year's event at the Hyatt Hotel. This year we welcomed Marcia Messer, one of CFWA's founding members, to share her story.

65 Roses Day 2016 dawned chilly with a hint of rain. A huge volunteer working group had been at the Niche for most of Thursday packaging roses ready for the day, and rose boxes had been despatched to our regional centres of Broome, Shark Bay, Geraldton, Northam, Margaret River, Esperance and Albany. The day has an incredible vibe and our volunteers from all walks of life and daily jobs joined with us to sell 9,700 roses. The huge growth in 65 Roses Day over the years

Golfers strike a winner

Pictured above are four of the golfers who took part in the AMP Corporate Gold Day held at The Vines last November.

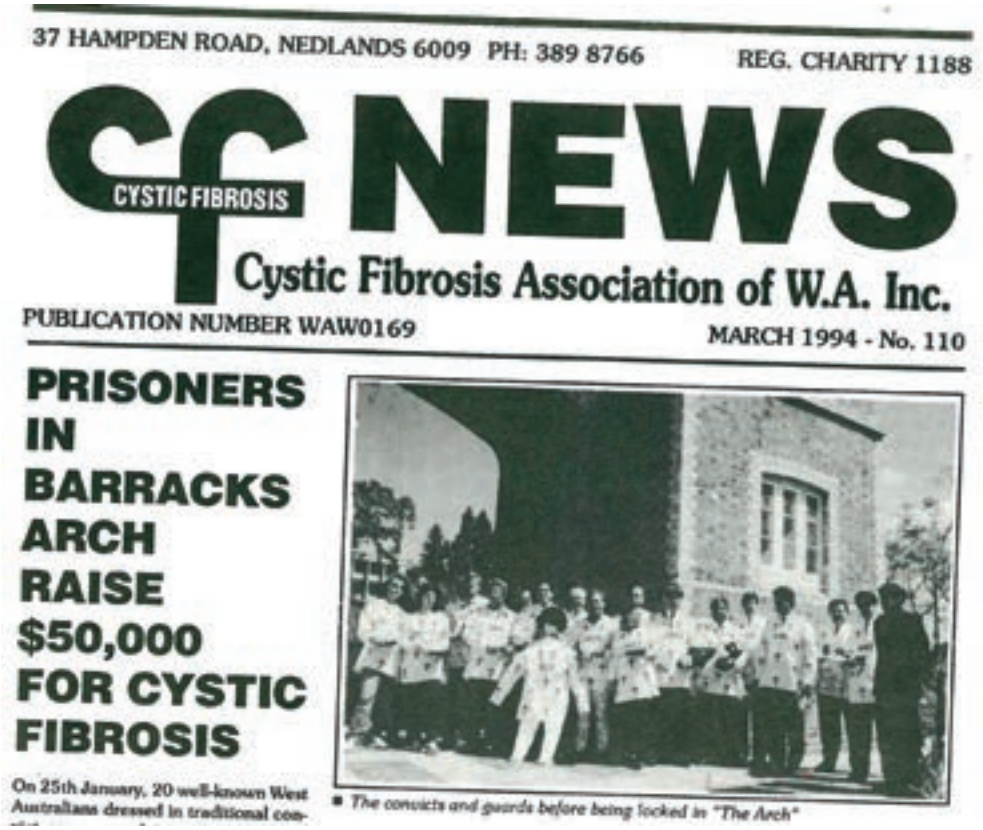
They are (l-r) Ron York, Peter Ralph, John McFaul and John Kirwan-Ward.

It was a great day for all and resulted in raising $27,085.00. Well done, everyone and thanks heaps to AMP.

THE GOLF CLASSIC IS HELD AT THE PRESTIGIOUS LAKE KARRINYUP COUNTRY CLUB

JUNIOR AMBASSADOR RUBY FOR THE 2016 CONVICTS FOR A CAUSE.

NIGEL AND PAULA RECEIVING A GENEROUS COMMBANK STAFF COMMUNITY FUND GRANT FOR THE 2016 SIBS CAMP



37 HAMPDEN ROAD, NEDLANDS 6009 PH: 389 8766 REG. CHARITY 1188

CF NEWS

CYSTIC FIBROSIS

Cystic Fibrosis Association of W.A. Inc.

PUBLICATION NUMBER WAW0169 MARCH 1994 - No. 110

PRISONERS IN BARRACKS ARCH RAISE $50,000 FOR CYSTIC FIBROSIS

On 25th January, 20 well-known West Australians dressed in traditional con-

The convicts and guards before being locked in "The Arch"

provides a great opportunity in the future to spread our message.

Our rose partner WAFEX is unwavering in their support and in 2017, together we are aiming to involve more of our great state and are looking forward to working with our members and business partners to spread out message further. Listen out for our call to secateurs and gloves!

The Spring Rose Art Exhibition is in its 9th year in 2016. Originally held in the Niche, the event has been sponsored by Deloitte since 2011 and is now held in their new office building at Brookfield Place. WA artists are invited annually and we enjoy an incredible level of commitment from our artists, many who have connections with CF. We thank them for supporting our vision, services and research. In 2017, the support of additional sponsors Capel Vale, Kott Gunning, Higher Events, Brookfield and Marathon Print made this exhibition a great success. Feature artist Di Taylor generously created seven fabulous pieces for the exhibition, of which 'Red Bathers' was donated ,resulting in 100% of the sale proceeds being received by CFWA.

Our Sibling and Offspring Camp started when cross infection risks became better understood in the CF community. Prior to these camps our young CF members got together annually to share each other's journey. Today, our CF siblings and offspring have the opportunity to spend time with other youngsters who face similar challenges in their homes. Thanks to the continuing support from the Commonwealth Bank Staff Community Fund for our 2016 camp..

This year's Great Strides event is taking on a spooky theme. We are rebranding it as the Halloween Fun Run, and with the support of Community Newspaper Group, the day will be filled with spooky costumes, entertainment and our 3km and 6km run/walks. An annual event since 2003, Great Strides has been a great day for families in our extended CF community to get together and support CFWA and our CF children.

Wanted – Wild West Convicts and posses for this year's Convicts for a Cause. In March 1994, a much younger Mitch Messer and a band of 20 well-known WA businessmen dressed up in traditional convict gear and descended on Barracks Arch and Convicts for a Cause was hatched. Our 1994 newsletter states that they only had their 'mobile phones for company.' We are guessing there wasn't much room for anything else! This event raised $50,000 and started the annual event that is now held at the Fremantle Prison in November. Now managed by the Rotary Club of Perth, it has become a collaboration between Rotary, Diabetes Research WA, Reflections Through Reality, and CFWA. Our junior ambassador, Ruby, along with convicts from our board and the Commonwealth Bank are seeking convicts to be involved or guests to be part of the event.

Dinners, Coffees and Outreach –every year our services team organises and participates in get togethers with member families and health professionals. These events are made available with support from many organisations and help to maintain awareness, identify new service needs, and allow members, CFWA staff and health professionals to network.

Thank you to all of the generous organisations and people who've supported us over the past 40 years. We look forward to working with you further to achieve our vision of Lives Unaffected by CF.

PARTICIPANTS FROM THE HIGHLY REGARDED REGIONAL RESPIRATORY PROGRAM.

CAZ BOYD PRESENTING FEATURE ARTIST DI TAYLOR WITH THE CFWA STAFF CHOICE AWARD AT THE DELOITTE SPRING ROSE ART EXHIBITION.

Doing Good with the Good Guys

Since 2012 the Good Guys in Malaga have been supporting CFWA at events, taking on community fundraisers, and donating raffle and auction items. CFWA is also the recipient of the Good Guys – Local Giving Program which sees a percentage of every transaction in-store and online donated back to local community organisations. Next time you are at the Malaga store put your doing good token into the supporting CFWA box to help fundraise. In addition our youth program was recently the recipient of donations through the Doing Good Week program. Natalie Amos and Karen De Lore collected five donations from the Good Guys Malaga team to be used for our youth program.

SERVICES RESOURCES

Over the past few years the services team have been very busy developing a wide range of resources to help educate both the CF community and the wider community about all the different aspects of CF. Go to our website to download your copy or contact us if you would like a hard copy.

www.cysticfibrosis.org.au/wa

CYSTICFIBROSISWA

40TH ANNIVERSARY PARTY

FRIDAY 2ND DECEMBER

WE'RE GOING BACK TO THE 70'S AND CELEBRATING OUR 40TH ANNIVERSARY YEAR WITH A CHRISTMAS AND AWARDS ANNIVERSARY PARTY!

OUTDOOR AREA AT CYSTIC FIBROSIS WA
THE NICHE 11 ABERDARE RD NEDLANDS

CELEBRATING ALL MEMBERS, FAMILIES AND SUPPORTERS WHO HAVE BEEN INVOLVED WITH CFWA SINCE 1976

WE'D LOVE YOU TO PULL OUT YOUR FAVOURITE 70'S OUTFIT OR WEAR SOMETHING RED AND COME AND CELEBRATE 40 FABULOUSLY FUNKY YEARS!

PUT THE DATE IN YOUR CALENDAR AND RSVP RECREATION@CFWA.ORG.AU

CYSTIC FIBROSIS Western Australia