

Annual Report **2015**



**CYSTIC
FIBROSIS**
Western
Australia

Organisation Details

Cystic Fibrosis Western Australia (Inc)
(Cystic Fibrosis WA)
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Patron

John Rothwell AO

Cystic Fibrosis WA Board of Directors

Office Bearers

President Richard Simons
Vice President Simon Martin
Treasurer Andrew Walsh

Elected Members

Carolyn Boyd
Ray Gard
Simon Martin
Jackie Ormsby
Feliciano Sanchez
Ken See
Richard Simons

Co-Opted Members

Darryl Gaunt
Rachael Hosking
Andrew Walsh

Chief Executive Officer

Nigel M Barker

Front Cover Addison Chitty at
the 2015 Great Strides Perry Lakes

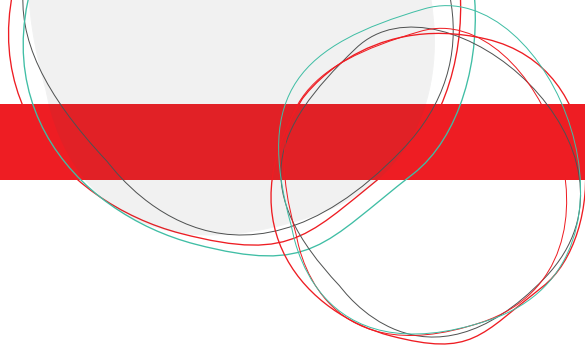
Board Meeting Attendance Register	Eligible to Attend	Attended	%
Elected Members			
Carolyn Boyd	11	9	82%
Ray Gard	11	7	64%
Simon Martin	10	10	100%
Jackie Ormsby	11	6	55%
Feliciano Sanchez	11	10	91%
Ken See	8	8	100%
Richard Simons	11	7	64%
Co-opted Members			
Darryl Gaunt	9	6	55%
Rachael Hosking	5	4	67%
Andrew Walsh	9	8	91%



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Making a
Difference



Message from the Patron

JOHN ROTHWELL AO
PATRON

The resilience of the not-for-profit sector to the economic fluctuations experienced in Australia in 2015 is epitomised at CFWA.

Faced with uncertain fundraising streams in 2015, we have not only maintained but achieved a significant growth in service delivery over the course of the past year, the details of which appear elsewhere in this report.

We have also received a significant vote of confidence from the state government when it awarded us a \$5.4m contract to deliver our core services. This contract future-proofs the organisation for the next five years and safeguards the interests and health of children and young adults living with cystic fibrosis (CF) in WA.

I have also been delighted with the progress being made in CF research at the Telethon Kids Institute. This is on track to achieve the admirable goal of reducing structural lung damage in infants with CF under 5 years of age by 50% within the next 5 years. It will also add 20 years to life expectancy, and good ones, too.

This project, led by Professor Stephen Stick, is a truly international project, originated by CFWA, adopted by the CF Federation, and is the only one of its kind in the world today. It is being closely watched by researchers around the world and will make a

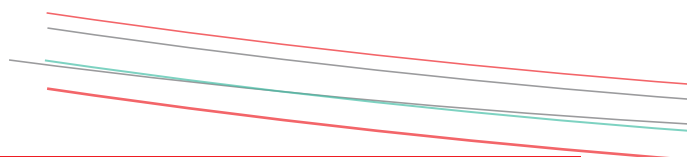
significant contribution to clinical practices globally.

My wife, Denise, and I have been privileged to be in a position to help establish Dr Daan Caudri as the inaugural Rothwell Fellow at the Institute as part of the research team. I would also like to recognise the leadership of Mr Stan Perron, the Allingame family, Conquer Cystic Fibrosis, CFWA's Golf Committee and the CF Foundation in the USA in supporting this very important initiative.

The appointment of a new CEO at CFA has strengthened the CF Federation. CFWA continues to make a most significant contribution to the Federation, branding many of the resources developed here 'CFA' to enable our sister organisations to make full use of them and indeed, our overseas cousins as well.

Similarly, other CF associations at home and abroad have shared their intellectual property to improve the lives of people living with CF.

The board and management of CFWA have positioned the organisation well to weather the current uncertainty of the economic situation we are facing. I am confident that in 2016 the organisation will continue to grow and contribute to the Federation and with your help, deliver on our vision of Lives Unaffected by Cystic Fibrosis.



President's Report

RICHARD SIMONS
PRESIDENT



Following nearly two years of negotiation, we signed a new outcomes-based contract with the Health Department of WA (HDWA) on 1 April 2015 valued at \$5.4m over five years. This was a critical milestone in our 2014-17 strategic plan securing the delivery of core services to our members and the long term financial security of our association

As one of the first not-for-profit associations in WA to enter into a contract under this new framework, there was a very steep learning curve for both ourselves, Treasury and the HDWA. I was delighted to see the close collaboration and trust between our association and the state government throughout these protracted negotiations.

The framework we developed has subsequently been used successfully by other charities in WA including the Asthma Foundation, with whom we maintain close links particularly through our Regional Respiratory Training Program.

Working collaboratively and openly with government, other charities and our sister organisations has become increasingly important as we faced the reality of changes in the economy. This has allowed us to share costs in areas like fundraising and service delivery and benefit from each other's experience and intellectual property.

We continue to brand our world class resources 'CFA' where possible to allow their use by our sister organisations and also openly share that IP with our counterparts in the UK and USA.

Whilst the economy has slowed, our service delivery has nevertheless continued to grow. This has been made possible largely by increases in efficiency and the new HDWA contract.

Our research program has also continued as we play a very active role in the national research project 'Little Lungs Big Futures' and continue to support young researchers through our highly valued PhD Top Up Scholarships.

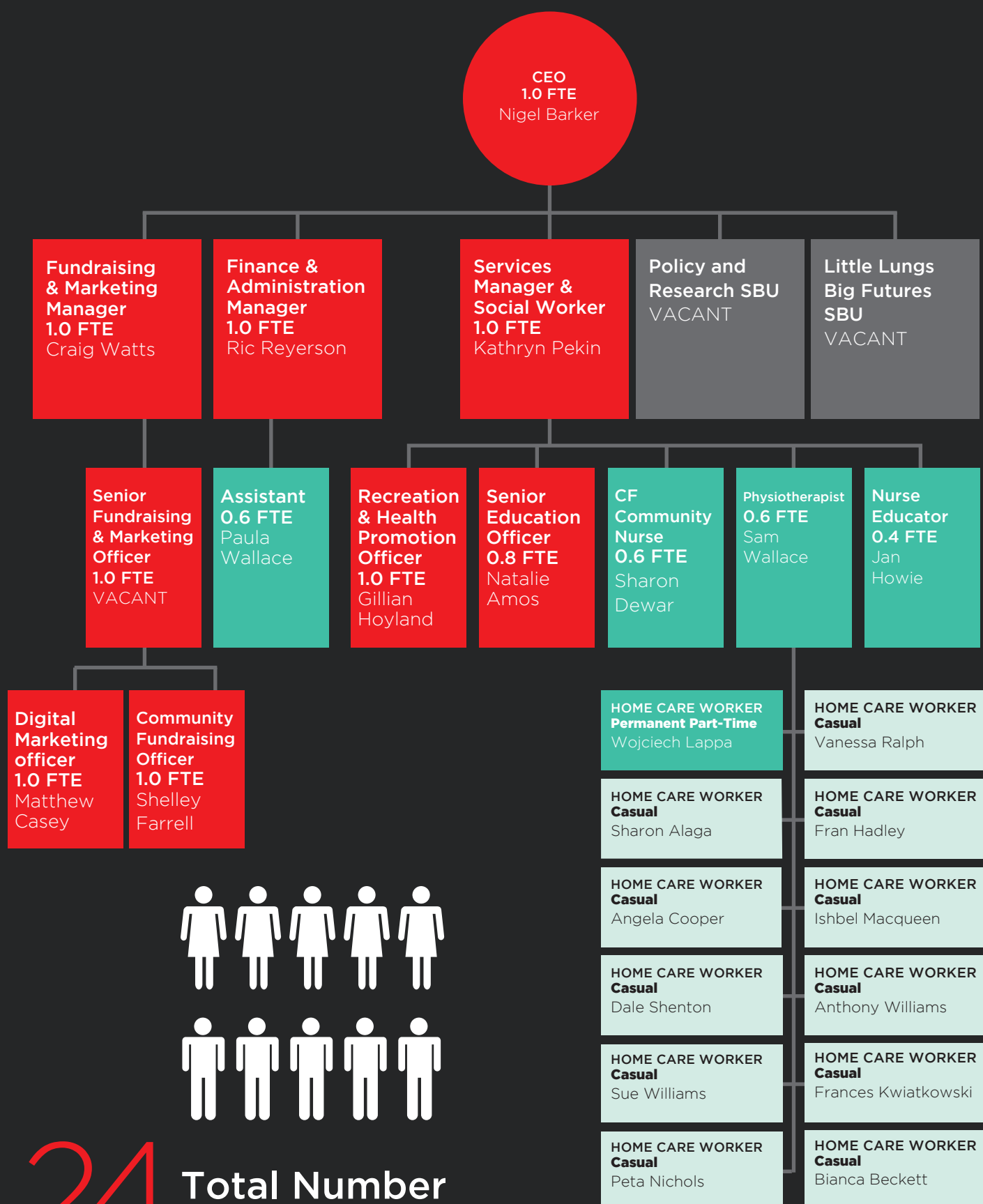
With the appointment of Nettie Burke as the CEO of CF Australia, we warmly welcomed back to the board VP Simon Martin who had been seconded to the position to the end of May. Special thanks also to Ray Gard who back filled the position of VP for CFWA during Simon's temporary leave of absence.

I am also delighted to report that we also welcomed back Rachael Hosking as a co-opted member to the board. Rachel previously served as a board member from 2006 to 2012. She brings with her both valuable legal expertise and the unique perspective of a parent.

Nettie's appointment to CFA has brought a renewed sense of optimism to the Federation, particularly in the areas of community, fundraising and advocacy. She has hit the ground running and our own CEO, Nigel Barker, now the longest serving CEO in the Federation, has been working closely with her particularly in the advocacy for Orkambi® and the workings of the CF Federation.

I am very grateful to our Treasurer, Andrew Walsh, who has worked hard throughout the year to lift the standard of reporting at our monthly board meetings to a very high level.

In closing, I would like to thank all of my fellow board members, the staff, volunteers, members and sponsors for your unwavering support. This support will be even more critical in 2016.



24 Total Number of Employees

CEO's Report

NIGEL BARKER
CEO

Despite economic challenges, services continued to grow in 2015, achieving a 5.86% increase in occasions of service compared to 2014.

The listing of Kalydeco® in 2014 was the first of the new class of drugs to address the underlying cause of cystic fibrosis (CF). In 2015, we have been working hard with the other members of the CF Federation to get the next drug in the CF pipeline, Orkambi®, listed in 2016. This will provide relief for people with the more common F508del mutation.

This campaign, led by CFA, has been very well received and we hope to hear results in the first half of 2016. These, and other small molecules in the drug development pipeline, represent real and tangible hope for people living with CF.

They will come to the market within the next few years. They are not a cure, or even a faint hope of a cure, but core treatments which will transform the trajectory of the disease. They will help us achieve our vision of Lives Unaffected by CF; helping people

with CF reach their full potential unencumbered by the disease.

In 2015, we also continued to make a significant contribution to resource development within the Federation in the fields of CFfood, nine new fact sheets and the globally successful CFsmart animation "Good Clean Hands", funded by Lotterywest.

All of these resources are being branded CFA where possible to enable all members of the Federation to use them. We have also made the CFsmart collateral available to the CF Foundation in the USA.

On the research front CFWA have continued to drive the national agenda with significant leadership gifts received from the Stan Perron Charitable Trust, John and Denise Rothwell, the Allingame family and Conquer Cystic Fibrosis who, together with the Golf Committee, have contributed over \$1.6m to the Little Lungs Big Futures research project being led out of the Telethon Kids Institute with collaborators in Australia, the USA and the Netherlands.

At a local level we continued to fund PhD Top Up Scholarships and are particularly grateful to the Golf Committee for providing funding to the 2016 scholarship and to CFA for managing the selection process through the Australian Cystic Fibrosis Research Trust

In 2015, we have been working hard with the other members of the CF Federation to get the next drug in the CF pipeline, Orkambi®, listed in 2016.



Financially, CFWA continued to be impacted by the economic downturn which has resulted in a small loss for 2015 of \$71,788. This includes a non-cash loss of \$26,898 relating to the depreciation of the office refurbishment funded by Lotterywest.

We anticipate this highly competitive environment to continue well into 2016.

Our balance sheet remains strong however, and we do not anticipate any reduction in our core services. We have also put in place strategies to reduce costs and grow revenues in 2016 which are already producing results.

Fundraising income, whilst down on budget expectations, nevertheless generated over \$700,000 with a net contribution of over \$180,000 for the year.

Our public awareness continued to perform very strongly with over \$1.25m of exposure including four front page stories and TV coverage whilst special events including 65 Roses Day sponsored by WAFEX, the Deloitte Spring Rose Art Exhibition, and Great Strides all contributed.

Of special note this year was the level of community fundraising with outstanding performances from our Golf Committee, the 65 Roses Challenge, Serve It Up for CF, Go RED, Crazy Hair Days, Convicts for a Cause run by the Rotary Clubs of Perth and Mount Lawley, and the inaugural Red Tie Dinner Dance run by Fremantle Sailing Club. Details of these events are found in the fundraising section of this annual report.

Despite economic challenges, services continued to grow in 2015, achieving a 5.86% increase in occasions of service compared to 2014. This was driven by increased referrals from the hospitals and more diverse flexible support services.

This has been possible thanks to the unwavering support of the state government which saw the

signing on 1 April of a new outcomes-based contract valued at \$5.4m over a five year period (3 plus 1 plus 1). It has also been made possible by the support we have received from members, Telethon, Variety, PMH, SCGH, and RPH. I would like to thank the hundreds of sponsors, Commonwealth Bank staff community fund, Capel Vale, donors, fundraisers, volunteers and other supporters who made a contribution to our organisation in 2015.

Without them we could not have achieved the terrific results we have. We look forward to an opportunity of celebrating with you at the Sponsors and Volunteers event at the end of November.

At CFWA we are very conscious of keeping our administration costs low without compromising our accountability and transparency.

In 2015, we migrated to a new case management software called Apricot. This low cost, cloud-based software allows real time reporting across a whole raft of metrics necessary to acquit the Department of Health WA contract and inform our decision making. Home care workers now use tablets in the field to log their visits and highlight any issues for our services team to address in real time. This has significantly reduced administration, improved accuracy and increased the quality and timeliness of service delivery to our families.

Finally, I would like to take this opportunity to thank our Patron, John Rothwell AO, who has provided leadership and sound advice far beyond what we could hope for from a Patron.

2016 is our 40th anniversary and never before has there been more hope for people living with CF. It is a very exciting future that lies ahead of us and a privilege to be involved.

NIGEL BARKER
CHIEF EXECUTIVE OFFICER



Services

In 2015, we delivered nearly 8,000 hours of support including 429 hours of counselling and social work.

The renewal of the Department of Health WA (HDWA) Comprehensive Home Care (CHC), Regional Respiratory Professional Education Program and PMH Airway Clearance contract was aligned with the development of the new Apricot database. This has allowed us to match outcomes of the contract with that of the database.

Through this alignment we are now able to accurately access live information from the field, improving responsiveness, accountability and significantly reducing time and money spent on administration.

Our home care worker support for airway clearance, exercise, respite and home duties grew by 5.86% in 2015 delivering over 5,500 occasions of service as shown in the following table.

Support also included counselling, social work, general support, community nursing and physiotherapy. Regular planning meetings held with key hospital staff help to ensure appropriate clinical case management.

Our increasingly popular Hospital in the Home (HiTH) service delivered 168 occasions of service enabling early discharge from hospital whilst our education program delivered CF education to 89 adults and 886 children in schools across WA and over 500 people in the community.

In 2015, we delivered nearly 8,000 hours of support including 429 hours of counselling social work and health coaching.

The Regional Respiratory Training Program has continued to grow in strength since its commencement in 2010. In 2015, new sessions were added including psychosocial aspects of chronic health and respiratory palliative care.

Health professional education was conducted in new regional areas including Kununurra and Broome.

Resource development was high in 2015 with the development of the CFfood program funded by the Paul Newman Foundation®.

This includes four nutrition booklets for each age milestone, due to be launched mid-2016.

SERVICE DELIVERY BY HOME CARE WORKERS

YEAR	TOTAL HRS	INCREASE	KM	INCREASE	OCCASIONS OF SERVICE	INCREASE
2011	5,325	-2%	87,954	-14%	4,396	1%
2012	5,554	4%	85,342	-2.97%	4,463	2%
2013	5,583	1%	90,180	6%	4,551	2%
2014	7,538	35%	111,364	23%	5,219	15%
2015	7,496	-0.55%	115,549	3.75%	5,525	5.86%

TOP
Sibs Camp sponsored
by Commbank Staff
Community Fund



Nine new fact sheets went through a comprehensive quality assurance process and were uploaded onto the Cystic Fibrosis Australia (CFA) website.

Another nine are currently going through quality assurance processes to be completed early 2016. The CFsmart animation "Good Clean Hands" was launched in May 2015 with global recognition. Another edition of the kids magazine 'Roze' was also launched receiving positive feedback for articles such as "The Nuts and Bolts of CF".

Several new events are planned for 2016 including a post-transplant support day, parent's dinner, newly diagnosed meet and greet and a fertility and reproduction seminar. Programs delivered in 2015 included a newly diagnosed program, child support programs, programs for parents and carers, adolescents and adults, parents with CF and transplant/palliation.

Regional Support

Thanks to the generosity of Telethon we were able to provide regional support to families, schools and health professionals in Albany, Mandurah, Northam, Manjimup, Geraldton, York, Kununurra and Broome. This complemented the Regional Respiratory Training Program, leaving a lasting benefit in these otherwise hard to service centres.



MIDDLE
Commbank Staff Community
Fund present cheque to CFWA
(Sibs Camp)
RIGHT
Sibs Camp 2015
LEFT
Ladies' Pamper Day

Service Events

There were a number of service events held in 2015 including the celebration of life ceremony, the increasingly popular ladies' support dinner, the parents' retreat, siblings and offspring camp and our coffee mornings.

We are very grateful to our sponsors and supporters – too many to mention here – for supporting our work in 2015 and look forward to working with you in the year ahead.



Fundraising & Marketing

It was a challenging year for fundraising with 76% of our budgeted fundraising income of \$947,948 achieved.

Fundraising income was generated through 72 streams ranging from large events such as the Golf Classic through to sales of merchandise in our shop. Our diverse mix of income streams is due to the increasing cost of running events and campaigns, now representing on average 24% of each activity.

Six fundraising streams are responsible for 66% of fundraising income including the Golf Classic and unsolicited donations as the two largest single revenue earners.

Diminishing returns on fundraising investment will necessitate the streamlining of family favourite Great Strides, and is prompting a review of our Christmas appeal and our merchandise shop in 2016. We also saw lower participation rates and lower peer-to-peer support of community fundraisers which all contributed to weaker returns.

Communications, PR and Social Media

We continued to strive to raise awareness for cystic fibrosis and Cystic Fibrosis WA through news, campaigns and events. Strategic communications agency, Devahasdin, continued to deliver exceptional results with media coverage received totalling \$1,264,193 in PR value compounded by 4 front page stories, 17 other newspaper articles, 34 online articles, 2 radio interviews and 3 television stories. This is a return of 126 times our investment.

We added The Big Bounce to our growing suite of brands and campaigns which raised \$13,273, thanks largely to the Oakley family who kicked off the trampolining fundraiser.

Facebook and Twitter combined surpassed E-News in readership and popularity, however, E-News continued to generate more tangible outcomes for CFWA and the community. Facebook followers

Fundraising & Marketing	Budget	Actual*
Income	947,948	722,762
Expenses	619,634	542,592
Net Profit	328,274	180,170

*These figures exclude grants which are reported in this section of the annual report.

*These figures include cost of sales and a donation of \$47,268 to CFA for the Little Lungs Big Futures research project.

increased by 7.5% to 2,568; Twitter followers increased by 15% to 937; E-News was published 24 times to a readership of over 3,000; RED Magazine was published 4 times; and, the CFWA website was visited 11,874 times with 59% being new visitors.

The most popular Facebook post was in relation to Telethon (reaching 3,982 people); the top tweet was an advertisement for the "12 Months of Mousse" calendar which was seen 806 times thanks largely to Community Newspaper Group; and the most visited page on our website was "Learn about CF" with 1,559 views.

The CFsmart website was visited 8,733 times and gained international recognition. Its most visited page was "Kindergarten to Year 1 Resources for Teachers" which was viewed 1,159 times. A press release regarding Kalydeco® was the most popular story on 2015 in our E-News.

We trialled Facebook-targeted advertising for the first time with 12,345 people having an interest in fitness aged 25-35 reached, and evidence of follow through to the Great Strides website achieved. This exercise is helping us with our marketing campaign planning for 2016.



Great Strides 2015 Perry Lakes



Major events

CFWA has a stable of three major fundraising events we organise each year.

65 Roses Day, the national day of awareness for CF, and associated May month activities raised \$41,420 in net proceeds. A record 6,500 roses sold with rose stems donated and subsidised by WAFEX.

The record sales were helped due to two new initiatives: the delivery of roses to rural areas thanks to TOLL (Kalgoorlie, Broome, Esperance, Katanning, Bunbury, Busselton) and new office displays. Campaign junior ambassador Joel Schaeche-Odine championed our cause and helped us to generate much needed publicity.

The Deloitte Spring Rose Art Exhibition continues to be our flagship corporate event attracting Deloitte, Kott Gunning and Capel Vale as three of the key sponsors. The Art Exhibition Committee headed by Mariana Atkins continues to provide artistic direction for this sought after event on the arts scene.

The Exhibition made a net profit contribution of \$17,507.

Great Strides is the CF community's annual family fun day out. It featured Ruby Henshall as the junior

The Art Exhibition Committee headed by Mariana Atkins continue to provide artistic direction for this sought after event on the arts scene. The Exhibition made a net profit contribution of \$17,507.

ambassador. The walking and running event is complemented by a small carnival and income is generated largely through peer-to-peer fundraising.

Participation rates were lower in 2015 and event costs remained high.

The net proceeds raised were \$24,718, 25% lower than budget. With increasing costs and flat revenue, we will outsource as much of the Great Strides carnival as possible in 2016 to minimise costs and will run a Hallowe'en theme to revitalise the event.

Great Strides continues to rely heavily on support from our members, Community Newspaper Group and Spirit Events for its ongoing success.



Red Tie Dinner Dancing at Fremantle Sailing Club



The Aerodrome Management Services team at the George Jones Family Foundation Cystic Fibrosis Golf Classic.



Deloitte Spring Rose Art Exhibition 2015

Corporate Supporters

We continued to receive support from the corporate world in the form of sponsorship, in kind and cash donations, fundraising events, subsidies and workplace giving.

For many years now, Capel Vale has been the main provider of complimentary wines at our events; WAFEX donate and subsidise thousands of roses for 65 Roses Day; Community Newspaper Group have provided much publicity; Deloitte continue to sponsor and provide a venue for the Spring Rose Art Exhibition.

Freehills provide countless hours of pro bono legal advice; Karrinyup Shopping Centre continues to host our fundraising activities and Menu Magazine has continued with their free publicity and generous in kind donations.

Commonwealth Bank staff community fund have stepped in as a strong supporter of our cause. The end of financial year continues to attract donations from businesses. Workplace and matched giving remained a weak fundraising source for CFWA but Woodside continues to be our main supporter in this area.

Community Fundraising & Campaigns

The George Jones Family Foundation CF Golf Classic at Lake Karrinyup Country Club is the largest community fundraising event for us and raised a total income of \$164,087, of which \$47,268 was donated to CFA for the Little Lungs Big Futures research project.

Our sincerest thanks to the dedication of Brad Coutts and his organising committee on their significant contributions to our community. The event would not be a financial success without sponsorship from the George Jones Family Foundation, Capel Vale, Lake Karrinyup Country Club, Alcoa and a suite of other sponsors.

The most significant new community fundraiser for the year was Fremantle Sailing Club's Red Tie Dinner Dance which made a net profit of \$14,811.



TOP

Felice and Vanya Sanchez at the Sponsors and Volunteers Awards Night

BOTTOM

Spring Rose Art Exhibition Committee Mariana, Colleen, Matt

65 Roses Challenge, a campaign based on fundraising around the number 65, raised \$27,612. Fundraiser of the year, Christ Church Grammar School student Hunter Jackson, ran 65 kilometres from Two Rocks to Cottesloe in 6 hours 41 minutes to raise \$15,754 in support of his sister who has CF.

Other fundraising campaign themes such as Serve It Up for CF, Go RED for CF and Crazy Hair Day also continued to be popular in the community and with schools.

The year was our most successful school fundraising year in recent history thanks to a mailing campaign, with a total of \$19,600 raised by 20 schools and colleges. Marmion Primary School topped the table raising \$3,888 for CFWA.

Large community health events such as HBF Run for a Reason, Chevron City to Surf, Karma Resorts Rottnest Channel Swim and the WA today Swan River Run are helping to generate good revenues through peer-to-peer fundraising, totalling \$37,296 in net profit for us for the year.

The most significant new community fundraiser for the year was Fremantle Sailing Club's Red Tie Dinner Dance which made a net profit of \$14,811. Proudly supported by Tail Lift Transport, Marooomba Airlines, Robinson Insurance, Yates Electrical, Stage & Studio, Toxfree, the Power Section of Fremantle Sail Club and many others. Convicts for a Cause also continues to consistently deliver good returns for 4 charities netting \$16,917, thanks largely to the Rotary Clubs of Perth and Mount Lawley.

Grants

Successful grant applications totalling **\$100,963** enabled our team to deliver a range of services to members:

CARERS WA

\$2,280 for the parents' retreat and wellness expo.

COMMONWEALTH BANK OF AUSTRALIA STAFF COMMUNITY FUND

\$10,000 for Sibbs camp.

SILICON VALLEY COMMUNITY FOUNDATION

\$3,520 for Great Strides.

TELETHON

\$60,163 for our community outreach program.

VARIETY WA

\$25,000 equipment grant.



Donations

Unsolicited cash donations totalling **\$100,737** from a mixture of individuals, trusts and businesses were received. This growing income stream which also has a low cost base has been helped by our strong online presence.

Appeals

The tax appeal raised **\$32,592** and income from our Christmas appeal was **\$12,790**.

Sponsors, Supporters and Volunteers

FUNDRAISER OF THE YEAR

Hunter Jackson

SUPPORTER OF THE YEAR

Adam D'Aloia

VOLUNTEER OF THE YEAR

Gillard Family

LONG SERVICE AWARD

Herbert Smith Freehills

Throughout 2015, we have received so much help from thousands of individuals and 214 businesses; too many to now mention here in the annual report. Your contribution, whether it be as a member of our board, or our Golf or Art Exhibition Committees, or as a community fundraiser, sponsor or a volunteer that gives freely of their time is, however, greatly valued.

For a full list of supporters and sponsors please visit our website soon: **www.cysticfibrosis.org.au/wa**

We are all part of a growing community that supports cystic fibrosis here in Western Australia and our vision of Lives Unaffected by CF. Together we are making great progress.

Thank you.



TOP TO BOTTOM

Georgiou employees rose wrapping

Big Bounce launch

Angela Tsun weather cross, 65 Roses Day

Golf Classic 2015



Policy, Research & Lobbying

At an international level we have embarked upon a significant project to reduce structural lung damage in infants under 5 years of age by 50% within 5 years.

At an international, level we have embarked upon a significant project to reduce structural lung damage in infants under 5 years of age by 50% within 5 years. We have received outstanding support from our Patron John Rothwell, Stan Perron, the Allingame family, Conquer Cystic Fibrosis and the CFWA Golf Committee.

The project that originated here at CFWA is being led out of the Telethon Kids Institute by Professor Stephen Stick and has been embraced both nationally by the members of the CF Federation and internationally by the CF Foundation in the USA.

It has collaborators around the world and is on track to deliver some remarkable outcomes which will add 20 years to average life expectancy. As reported in our last annual report we hope to take this campaign public in 2017/18.

Nationally, the CF Federation advocated hard in 2014 to get Kalydeco® listed on the Pharmaceutical Benefits Scheme (PBS). Our efforts were rewarded on 1 2015 with a successful listing. A great way to start the year.

The advocacy was not without its challenges, however, and many valuable lessons were learnt in the Kalydeco® campaign. One of these was the importance of speaking with one voice.

The major advocacy achievement for 2014

Kalydeco®

has been successfully lobbying of the listing of Kalydeco® on the Pharmaceutical Benefits Scheme (PBS).

In 2015, CFA established a CF Community Advocacy Network (CF CAN) to help lobby for access to Orkambi® and other drugs as they become available and also on issues affecting people living with cystic fibrosis and their families. CFWA has recruited potential advocates from its membership who will receive formal training in early 2016.

At a local level, we will continue to work with the state government to ensure adequate provision of services for the growing number of adults living with CF, using the results of the recent clinic peer review to argue for increased resources. Special thanks to Adam D'Aloia for driving the campaign to get parking subsidized at the QEII Medical Centre.

At a local research level, the five CFWA PhD Top Up Scholarships continue to be popular and we are delighted to be able to offer in 2016 a sixth scholarship thanks to the efforts of our Golf Committee. Applications for the PhD Top Up Scholarships are reviewed by the Australian Cystic Fibrosis Research Trust free of charge for CFWA.

Together, policy, research, advocacy and services are driving us closer to our vision of Lives Unaffected by Cystic Fibrosis.



Treasurer's Report

ANDREW WALSH
TREASURER



2015, was a financially challenging year for CFWA. The association again achieved a level of income in excess of \$2 million but despite the best efforts of the team, they could not match the record level of income generated in 2014. The association has had to work hard for every dollar of grant income, donations and fundraising but none the less, has experienced a slight reduction in line with many not for profit organisations in 2015. Given the lower income, the association has had to reduce expenditure resulting in a small net deficit for the year of \$72 thousand.

Despite the lower expenditure, the association was again able to deliver the services so important to the CF community in WA. Consequently I am once again pleased to report the finances of the association continue to be managed in a manner which supports the objectives of CFWA.

A detailed analysis by major expense line is provided in the accounts. These are reviewed on a regular basis by both management and the board to ensure that the costs of running the association and delivering services are properly controlled and managed in line with Income generated.

As advised above, the association reported a net deficit in the year which compares to a net surplus in 2014, of \$431 thousand. The main reason for the difference between the two years is the grant we received last year for the refurbishment of facilities at the Niche. The cost of this refurbishment is now being incurred as a depreciation cost but has no related cash outlay. This has reduced the effect of the deficit on the cash holdings of the association.

The balance sheet shows a reduction in net assets

equal to the deficit reported in the year. Cash reduced as a consequence of the loss and due to the timing of some income recognised this year but received last year and some expenses where we recognised the cost last year but paid for that cost this year.

The accounts show an operating loss of \$44,890 representing a challenging year for the association.

Investment balances shown as current and non-current financial assets were broadly flat on a year on year basis reflecting the Australian investment market in general.

You will also see in the balance sheet that we have continued to show funds provided to Cystic Fibrosis Australia to support Little Lungs Big Futures as a loan, unchanged in the year of \$545 thousand. The Little Lungs Big Futures fundraising activities are continuing with some degree of success. The association will continue to assess the extent to which CFA will be able to repay these loans as the fundraising programme continues.

The financial statements for the year ended 31 December 2015, have been audited by Mr James Komninos of RSM Bird Cameron and a copy of the signed accounts are available for inspection by members.

In preparing this report I would like to once again acknowledge the efforts of the CFWA team who have supported me in the conduct of my duties and for their unwavering support for the Association and its members.

History of Cystic Fibrosis Western Australia (Inc)

'In the early 1970s, several parents of children living with cystic fibrosis came together and established with the help of the Perth Jayes, a self-help group...'

In the early 1970s, several parents of children living with cystic fibrosis (CF) came together and established, with the help of the Perth Jayees, a self-help group. The group was formally incorporated under the Associations Act of WA on 29 June 1976. 29 June 2016 will be the organisation's 40th anniversary.

In the 1990s, CFWA continued to develop its services and to develop links with the cystic fibrosis clinics based at PMH and SCGH. In the late 1990s, it gained funding from the Department of Health WA to begin a Comprehensive Homecare Service which allowed it to provide support for people with CF when they were at risk of requiring hospitalisation.

The service, which continues today, provides nursing, physio/airway clearance and home help.

In the early 2000s, CFWA moved into its current home, 'The Niche', which is on the QEII Medical Centre campus.

The services provided have continued to grow and develop. CFWA has also become a consistent contributor to CF research in Australia through the Australian Cystic Fibrosis Research Trust (ACFRT).





The regular surveying of its members continues to ensure that services meet the needs of its members, particularly as more children are surviving into adulthood. CFWA has also contributed to the national CF agenda through support of Cystic Fibrosis Australia and its work in areas such as the Australian CF Data Registry, Clinical Centre Directors group, Standards of Care working party, national website development and others.

In 2009, CFWA was successful in negotiating a new three year contract with the Minister for Health providing a significant increase in funding to better meet the needs of those living with CF and their carers.

In 2010, we launched our first PhD Top Up Scholarship which sought to address some of the workforce legacy issues particularly in the area of adult CF, recognizing that for the first time in our history, increases in life expectancy meant that we have more adults living with CF than children.

In 2011, CFWA, working closely with CFA and the ACFRT, launched a call from researchers around the world to submit expressions of interest for a five year \$10-\$20m collaborative research project.

The Collaborative Research Project, initiated by

CFWA and novated to CFA, became an important national priority which bound together the associations in pursuit of our common vision of Lives Unaffected by CF.

The refurbishment of CFWA's offices in 2014 future-proofed our association for the next 15 years and provided much needed room for expansion.

2014 also saw the listing of a new drug, Kalydeco®, on the PBS following many hours of lobbying by CF associations around the country.

This is the first drug to treat the underlying cause of the disease rather than the symptoms and represents the first in a whole new class of drugs currently under investigation.

In 2015, we started implementing a strategy to support access to a new combination therapy, Orkambi®, which will bring relief to approximately half the people living with CF with the more common homozygous F508del mutation.

In 2015, the total raised in WA for the Little Lungs Big Futures collaborative research project reached over \$1.6m with major donations from the Stan Perron Charitable Trust, the Allingame family, Conquer Cystic Fibrosis and John and Denise Rothwell.



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