

# Annual Report **2016**



**CYSTIC  
FIBROSIS**  
Western  
Australia

## Organisation Details

Cystic Fibrosis Western Australia (Inc)  
(Cystic Fibrosis WA)  
ABN: 19 156 339 182

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## Patron

John Rothwell AO

## Front Cover

Willow at the Cystic Fibrosis WA  
office on 65 Roses Day

## Cystic Fibrosis WA Board of Directors

### Office Bearers

**President** Richard Simons  
**Vice President** Simon Martin  
**Treasurer** Andrew Walsh

### Elected Members

Carolyn Boyd  
Simon Martin  
Jackie Ormsby  
Feliciano Sanchez  
Ken See  
Richard Simons  
Andrew Walsh  
Ray Gard to April 2016  
Darryl Gaunt to April 2016

### Co-Opted Members

Rachael Hosking

### Chief Executive Officer

Nigel M Barker

## Board Attendance Register

Elected Members	Eligible to Attend	Attended	%
Carolyn Boyd	12	9	75
Simon Martin	12	8	67
Jackie Ormsby	12	6	50
Feliciano Sanchez	12	9	75
Ken See	12	9	75
Richard Simons	12	10	83
Andrew Walsh	12	11	92
<b>Co-opted Members</b>			
Rachael Hosking	11	8	73

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Making a  
Difference



# Message from the Patron

**JOHN ROTHWELL AO**  
PATRON

**T**he Australian Charities and Not-for-Profit Commission (ACNC) has brought a welcome level of scrutiny and accountability to not-for-profits across Australia. Indeed, Australian charities are now amongst the most scrutinised and accountable entities anywhere in the world. This is important as donors need to have confidence that the worthy causes they support are being run as efficiently as possible.

I was particularly pleased, therefore, to see that Cystic Fibrosis WA were the inaugural winners of the prestigious Telstra Business Award – Charity category here in Western Australia. This award is an independent measure of CFWA's operations. The judging is undertaken by highly qualified people from business and consulting firms across Australia. It is a measure of our success which has been forged over the past ten years and is, in my opinion, very well deserved.

This award has shown to the world that CFWA is being well governed, well-managed and achieving its strategic goals in delivering our vision of Lives Unaffected by Cystic Fibrosis. It has helped open the doors to big corporations like Telstra, Commonwealth Bank of Australia and Hawaiian group. These major corporations are now actively engaged and supporting our 65 Roses Day campaign. This campaign continues to grow from strength to strength and with the support of these large corporations now has the potential to grow nationally.

On the research front, we have been overwhelmed by the generosity of donors and particularly by the unwavering support of The Stan Perron Charitable Trust who recently committed a further \$1m to our Little Lungs Big Futures research project.



This project, led out of the Telethon Kids Institute, is on track to reduce structural lung damage in infants by 50% within 5 years.

Importantly, the cost of running this campaign nationally has been met from CFWA's reserves through a series of loans to CFA. This means that every cent donated has been allocated to the researchers. We have so far achieved a pleasing 5:1 return on our investment. The campaign continues and will hopefully be taken public in late 2017.

Our major contract with the Health Department of WA continues to deliver outcomes focussed on preventative care for people with CF. The CF Model of Care here in WA is seen to be world's best practice and is being looked at closely by other health departments across Australia.

Increasingly strong ties with the CF Federation in Australia and the CF Foundation in the USA bodes well for the future. We continue to share resources and ideas working collaboratively and advocate with one voice for the listing of new drugs as they come on to the market.

In closing, I would like to thank the community for their support. It has been a financially challenging year for many charities in Western Australia as we adjusted to the post boom economy. I believe that this challenge has been well met by CFWA and that could not have happened without your support.



# President's Report

**RICHARD SIMONS**  
PRESIDENT



**I**n 2016, like many not-for-profit organisations across Australia, CFWA faced a challenging and uncertain future as WA adjusted to a post boom economy.

Changes to the way in which Government allocated resources and particularly the discussions around the nation's National Disability Insurance Scheme and WA's version of it, My Way, forced us to reaffirm our core business, seek out opportunities to improve efficiency and decide just exactly where we wanted to position ourselves to best serve our clients. This was really important as we determined that CF is not in itself a disability but like many diseases it may lead to one. Our business was and is, first and foremost, about keeping our clients out of hospital and assisting them to reduce the impact of the disease underpinned by our research which has short-term clinical applications. Our Government contract gave us the means to achieve that. In reality, we needed to look no further than our vision statement of Lives Unaffected by CF.

Our contract with the Health Department of WA (HDWA) gave us the framework to deliver relevant and meaningful services to help us move one step closer to achieving our vision. The flexibility of the outcomes reporting framework has enabled us to continually shape our services to achieve meaningful outcomes rather than continue to produce outputs which in hindsight were inappropriate. The HDWA should be congratulated on embracing such a forward-thinking model. CFWA remains the only

CF Association in Australia to have such a close working relationship with our Health Department and the clinics and by far the most comprehensive range of services. This is the envy of our sister organisations across Australia.

Our work was publicly acknowledged with winning the inaugural WA Charity category of the prestigious Telstra Business Award which the Patron has already referred to. Shortly thereafter, we received notice of a \$1m donation to the Little Lungs Big Futures (LLBF) research project initiated by CFWA. A further vote of confidence that we are on the right track.

In 2016, we anticipated a small loss to ensure that our funding for research would not be interrupted. However, through careful control of expenses and improved efficiency of service delivery, we were able initially to turn that around to a small profit. This was subsequently adjusted on the advice of our auditors which expensed out the loans to CFA which were for the purposes of supporting the working capital requirements of the LLBF research project.

The LLBF project was initiated by CFWA as a collaborative research project in 2011, led out of the Telethon Kids Institute in Perth. The project was passed to CFA in August 2012 and became a national project with letters of support from all the CF State and Territory CF Associations. A plan was developed to raise \$10m over a five-year period: 2012/13 to 2016/17.

CFWA agreed to cash flow the project from its reserves through a series of documented, unsecured interest free loan agreements with CFA to the value of \$545,000 [between 2012 and 2014], which gave CFWA the option of recovering those monies from CFA once sufficient funds had been raised.

To date, the project has raised \$2.6m all of which has come from WA. This is the most significant amount of money raised for any CF research project in the southern hemisphere. However, and this is the key point, funds received to date and the rate of new receipts has fallen short of the \$10m target. Consequently, for accounting purposes, it is difficult to support the recoverability of the loan, the repayment of which is funded directly from the fundraising of the LLBF project.

As such we have determined that the most appropriate treatment, following discussions with our auditors RSM, is to recognise the loans to CFA for LLBF as a contingent asset. The funds provided to LLBF are now shown as a Collaborative Research Project (CRP) expense in the 2016 accounts.

The treatment does not impact the recoverability of the loan. Should the funding objectives of LLBF improve in the future, the board of CFWA continues to reserve the right to call upon those loans which are recognised in CFA's audited accounts as a contingent liability.

This action reduces the equity of CFWA by \$545,000 however, the organisation remains financially strong and able to meet its debts as and when they fall due.

At a national level, we have played a significant role in raising awareness of CF largely through participation in the Kalydeco® and Orkambi® campaigns co-ordinated by CFA whilst our educational information has all been branded CFA to enable our sister organisations to access and utilise these world class resources.

'To date, the project has raised \$2.6m all of which has come from WA.

This is the most significant amount of money raised for any CF research project in the southern hemisphere.

It has been an exciting year for CFWA and not one without its challenges. From a governance perspective, your board has worked tirelessly to continually improve its performance and maintain high levels of accountability and transparency. We will shortly be embarking on our next 3-5 year strategic planning process. I encourage you to participate in that by providing feedback to the questionnaires that will be sent out.

In closing, I would like to thank two retiring board members: Jackie Ormsby and our Treasurer, Andrew Walsh, who has lifted the standard of financial reporting to the highest level.

I would also like to thank the staff of CFWA who, under the most intense pressure, have never failed to impress me with their dedication and loyalty. Much of their efforts flies unnoticed under the radar. Often, they are the first point of contact for criticism when members are doing it tough but their resilience and enthusiasm always wins through. It is an exceptional team and we are lucky to have them.

Finally, I would like to thank you the members, the volunteers, sponsors and supporters for your unwavering support. We are part of something special and together we have advanced one step closer to achieving our vision of Lives Unaffected by CF.



**CEO**  
**1.0 FTE**  
Nigel Barker

**Fundraising & Marketing Manager**  
**1.0 FTE**  
Karen De Lore

**Finance & Administration Manager**  
**1.0 FTE**  
Ric Reyerson

**Services Manager & Social Worker**  
**1.0 FTE**  
Kathryn Pekin

**Policy and Research SBU**  
VACANT

**Senior Fundraising & Marketing Officer**  
**1.0 FTE**  
VACANT

**Assistant**  
**0.6 FTE**  
Paula Wallace

**Senior Education Officer**  
**0.5 FTE**  
Natalie Amos

**CF Community Nurse**  
**0.6 FTE**  
Sharon Dewar

**Physio-therapist**  
**0.6 FTE**  
Sam Wallace

**Nurse Educator**  
**0.4 FTE**  
Jan Howie

**Digital Marketing Officer**  
**1.0 FTE**  
Matthew Casey

**Community Fundraising Officer**  
**1.0 FTE** Shelly Farrel  
**1.0 FTE** Marnie Thomson  
*to June*

**HOME CARE WORKER**  
**Permanent Part-Time**  
Wojciech Lappa

**HOME CARE WORKER**  
**Casual**  
Vanessa Ralph

**HOME CARE WORKER**  
**Casual**  
Sharon Alaga

**HOME CARE WORKER**  
**Casual**  
Fran Hadley

**HOME CARE WORKER**  
**Casual**  
Angela Cooper *to Feb*  
Michelle Dewick

**HOME CARE WORKER**  
**Casual**  
Ishbel Macqueen

**HOME CARE WORKER**  
**Casual**  
Sophie Mitchell *from Oct*

**HOME CARE WORKER**  
**Casual**  
Anthony Williams *to Jul*  
Hayley Fullerton *from Sept*

**HOME CARE WORKER**  
**Casual**  
Sue Williams

**HOME CARE WORKER**  
**Casual**  
Frances Kwiatkowski

**HOME CARE WORKER**  
**Casual**  
Peta Nichols *to Jul*  
Kylie Stevens *to Oct*

**HOME CARE WORKER**  
**Casual**  
Bianca Beckett *to Jan*  
VACANT



**24** Total Number of Employees

# CEO's Report

**NIGEL BARKER**  
CHIEF EXECUTIVE OFFICER



In 2016, CFWA continued to deliver the widest and most relevant range of services tailored to meet the needs of our clients anywhere in Western Australia. This is a reflection of several factors: the close working relationship we have with the clinics; our role as the community-based extension to the multi-disciplinary team; the close working relationship we have with the HDWA and last but not least, the dedication of staff. Details of these services and KPIs are included in the Services Report.

Of particular note is the way in which we have continued to collaborate with other organisations such as SCGH who seconded dietitian Paul O'Neil to CFWA to manage the CFCooking project and CF Victoria who are helping to develop online resources based on our very popular CFSmart resources. Internationally, we are collaborating with the CF Foundation in the USA to assist in developing our mental health strategy and our planned giving program.

In 2016, our lobbying grew considerably under the leadership of CFA which culminated in the extension to the Kalydeco® label to include two to five-year-olds and although not successful in getting Orkambi® listed yet, we believe it is only a matter of time. There is a shrinking window of opportunity for Vertex Pharmaceuticals to maximise its returns due to the fact that there are 17 new drugs in the pipeline and three of these are completing phase three clinical trials. This puts pressure on Vertex to reach an agreement with the Government on pricing. So the message here is clearly one of hope for the future.

As described by the President, our investment in the Little Lungs Big Futures (LLBF) research project has paid considerable dividends raising

over \$2.6m all of which is going direct to the researchers. The cost of the campaign has been met from CFWA's reserves through a series of documented, unsecured interest free loan agreements with CFA to the value of \$545,000.

Advice from the auditors is to recognise the loans to CFA for LLBF as a contingent asset. The funds provided to LLBF are, therefore, now shown as a Collaborative Research Program (CRP) expense in the 2016 accounts which gives an on-paper loss of \$521,999 for 2016.

This action reduces the equity of CFWA by \$545,000 however, the organisation remains financially strong and able to meet its debts as and when they fall due.

Like many charities, our fundraising was hit hard in 2016, with the loss of a \$20,000 grant for services and a reduction in the number and value of community fundraisers. Whilst we were able to maintain services, this placed a lot of pressure on staff and resulted in a re-structure and re-evaluation of our fundraising activities. Plans are well in advance to turning this around in 2017 and early indications are that it is working.

Fundraising income, whilst down on budget expectations, nevertheless generated a net contribution of over \$107,000 for the year.

On a more positive note, as highlighted in the Patron's Report, we received a major boost from winning the inaugural Charity category of the prestigious Telstra Business Award in WA. This has





opened the doors to larger corporates, with Telstra, Commonwealth Bank and Hawaiian Group now on board to make 65 Roses Day 2017 the biggest and best ever.

Our public awareness continued to perform very strongly with over \$1.15m of exposure.

In 2016, we also celebrated our 40th birthday at our Sponsors and Volunteers event at the end of November. It was amazing to see the progress we have made and the changes to some of the practices over that period of time. Some of these are documented in our 40th anniversary edition of our RED magazine and if you haven't seen a copy yet make sure you check it out online.

As always, I would like to thank the hundreds of sponsors, donors, fundraisers, volunteers and other supporters who made a contribution to our organisation in 2016. Their dedication, loyalty and support has been more crucial than ever.

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

The future is filled with excitement and hope and our hope is that you will join us and help us achieve our vision of Lives Unaffected by CF.

**NIGEL BARKER**  
CHIEF EXECUTIVE OFFICER

... 'we received a major boost from winning the inaugural Charity category of the prestigious Telstra Business Award in WA'

# Services Report

**T**he Department of Health WA (HDWA) Comprehensive Home Care (CHC), Regional Respiratory Professional Education Program and PMH Airway Clearance contract continues to track well, which is continually reviewed and adjusted to meet projected outcomes.

In 2016, home care workers (HCWs) delivered 5,359 occasions of service (OOS) to children and adults with CF, assisting with airway clearance, routines, exercise, cleaning and general support. We also employed a personal trainer in the southern suburbs to assist young people and adults with motivation, mental health and exercise which has been hugely successful. These numbers were well above yearly predictions, however, still within budget.

Other support for families and adults included counselling, health coaching, advocacy, social work and general support through equipment loans, subsidies and hospital visits. The total hours of direct support including HCW support totalled 8,126 hours.

Education, as always, is a high priority, with nearly 300 school children and teachers having received education. All visits were done in collaboration with parents and children and sometimes in consultation with the Princess Margaret Hospital (PMH) Education Liaison Officer. CFsmart has continued to grow in strength with many teachers across Australia downloading and utilising resources.

In 2017, a new CFsmart online portal will be launched to deliver resources and e-learning packages for day cares, primary school and high school teachers. New resources included: Transplant Positive Profiles booklet, CF Cooking comprising six short films featuring adults with CF, and the launch of the CFfood booklets.



*Ingrid features in our  
Positive Profiles booklet*

## HOME CARE WORKERS SERVICE DELIVERY

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%
2016	7,149	-4.63%	109,733	-5.03%	5,359	-3.00%

In 2016, home care workers (HCWs) delivered 5,359 occasions of service (OOS) to children and adults with CF







CFWA 40th Anniversary Party

CF Cooking short films

### Regional Support

The Regional Respiratory Training Program, held annually in Perth, continues in strength with many regional nurses and allied health enquiring long before registrations are open. Professional health education is offered to all regional health staff and visits are arranged accordingly.

Telethon generously provided a grant to support regional outreach which includes support dinners, education to day cares, schools, community groups and hospital/medical staff. This grant also provided a travel subsidy for regional families for each clinic and hospital visit to PMH.

### Service Events

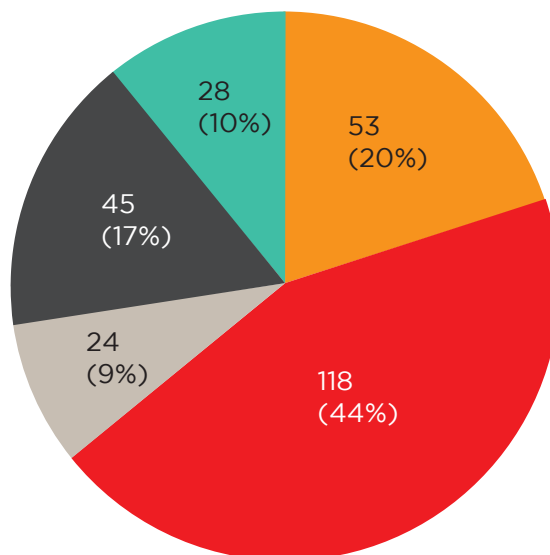
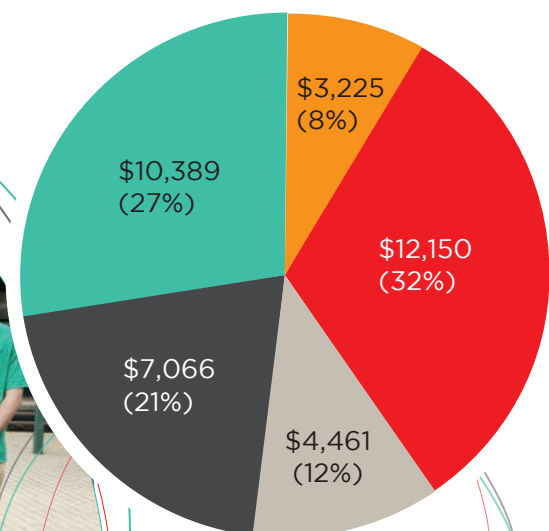
These events are essential in bringing families together to share stories and provide much needed support; they included the Parents' Retreat, Ladies High Tea, Sibling & Offspring Camp and a new event, the Parents' Dinner. We also held a Transplant Support Dinner and a new Transplant Support Day.

## 2016 SUBSIDIES

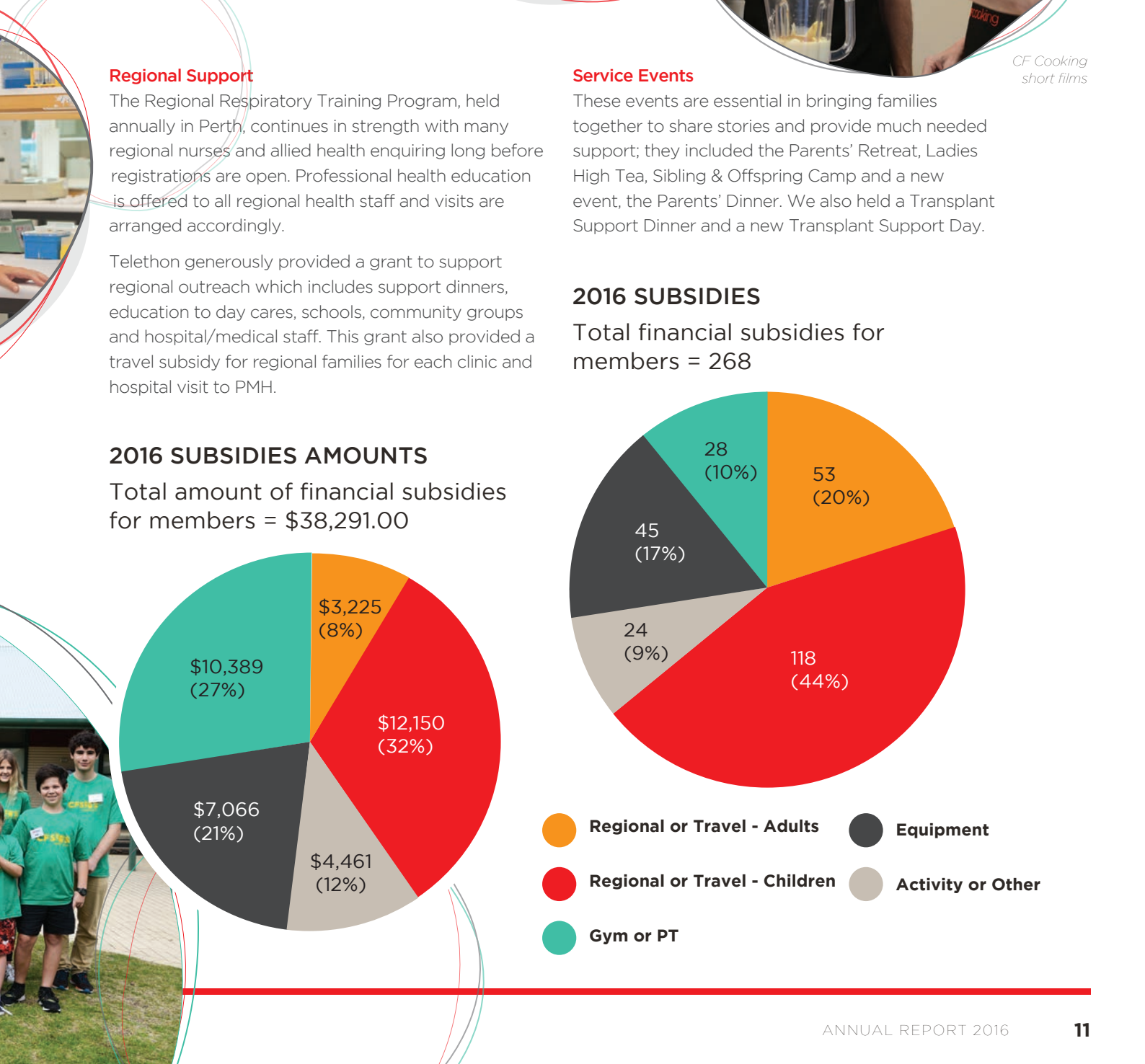
Total financial subsidies for members = 268

## 2016 SUBSIDIES AMOUNTS

Total amount of financial subsidies for members = \$38,291.00



- Regional or Travel - Adults
- Regional or Travel - Children
- Gym or PT
- Equipment
- Activity or Other



# Fundraising & Marketing

A tightening economy in 2016 saw a decrease in fundraising revenues for many charities across Australia. CFWA's fundraising was similarly affected.

**W**hilst revenues were down, additional expenditure relates in part to trying to increase fundraising sustainability in the future.

Fundraising income was generated from a range of activities. These included small community fundraisers, direct mail and our signature CFWA events.

Like many charities across Australia, we experienced decreases in the number of peer-to-peer fundraisers in large community events like the HBF Run for a Reason and the Swan River Run. This trend appears to have bottomed out towards the end of 2016 and we look forward to increased support in 2017.

## Communications, PR and Social Media

Our Cystic Fibrosis WA events and advocacy continued to raise awareness for cystic fibrosis through news, campaigns and events. Free exposure totalling \$1,155,989-worth was achieved through our PR campaign.

Throughout the year, Community Newspaper Group (CNG) continued to support us covering community fundraising stories, Spring Rose Art Exhibition, Halloween Fun Run and Convicts for a Cause. A significant benefit to the production of RED magazine was the development of an agreement for pre-press services through CNG along with a competitive printing opportunity allowing the cost of RED magazine to be reduced with an improvement in quality.

CFWA became the recipient of the inaugural Telstra

Business Award Charity category for WA. This award provided the opportunity to develop a relationship with Telstra that provided in-kind support for events which will flow into the 2017 year for our 65 Roses Day campaign.

Facebook followers increased by 380 to 2,918 during 2016, along with Twitter increasing by 172 to 1,109 followers. E-news continued to provide current and relevant information to the CFWA community. E-news was published 25 times in 2016 to over 3,000 readers. E-News had an average open rate of 21.2%. Our RED magazine was published four times, and our CFWA website was visited 12,120 times with 60% being new visitors.

The CFsmart website providing information to parents and teachers was visited 9,190 times, with regular international visitors appearing in the analytics.

During 2017, continued focus on improving communications through social media, website, E-news and RED magazine will aim to strengthen existing corporate and community relationships to build future support for events and fundraising.

Fundraising & Marketing	Budget	Actual
Income	\$707,313	\$673,649
Expenses	\$479,341	\$566,036
Net Profit	\$227,972	\$107,613





## Major events

CFWA runs five major events each year.

The **George Jones Family Foundation CF Golf Classic** at Lake Karrinyup Country Club is coordinated by a dedicated volunteer committee supported by CFWA staff. Continued sponsorship by the George Jones Family Foundation in 2016, in conjunction with a full list of registered teams, saw the event achieve both significant awareness and fundraising outcomes.

Chaired by Brad Coutts, the committee achieved continued support from corporates and individuals in registrations, donations, and subsequent auction and raffle support. A total of \$155,835 was raised with \$78,780 allocated to research and our sixth PhD Top Up Scholarship. This event highlights the huge achievements CFWA can make with our CF families and friends as volunteers for our event committees and on event days.

**65 Roses Day**, the national day of awareness for CF, and associated May month activities continues to grow and exceed expectations. In 2016, it raised \$64,611 in net proceeds. A record 9,750 roses were sold with rose stems donated and subsidised by WAFEX. Fantastic support from regional centres, distribution through more suburban shopping centres, and greater corporate support allowed



Golf Classic 2016



Red Tie Dinner Dance 2016

for this growth to occur and has set a framework for continued growth in 2017. Improved volunteer engagement with individuals and organisations including Bentley TAFE was achieved. Wonderful support from our 65 Roses ambassador, Willow Leary, and her family made a significant impact on our public profile. In 2017, Telstra, Commonwealth Bank and Hawaiian group have pledged support to create an even bigger event.

The **Deloitte Spring Rose Art Exhibition** continued to be supported by Deloitte, Kott Gunning and Capel Vale as three of the key sponsors. The Art Exhibition is brought together by a staff and volunteer initiated committee, continuing to provide artistic direction for this wonderful collaboration of artists and corporate supporters. The Exhibition made a profit contribution of \$17,793.

The **Halloween Fun Run** is the CF community's annual family fun day out. CF adult Ceri Ovans was a brilliant ambassador for this event, along with the school community from Mindarie Primary School. The fun carnival with a themed approach to this year's event resulted in improved participation, however, peer-to-peer fundraising was utilised by less participants. The Halloween Fun Run continued to be supported by the Community Newspaper Group and Spirit Events. This event will require significant increases in participants and stronger corporate support in 2017 to remain within our core events.

**Convicts for a Cause** was well supported with a larger crowd in 2016 netting \$21,120 through collaboration with Rotary Clubs of Perth and Mount Lawley, Diabetes Research WA and Reflections through Reality.

## Corporate Supporters

Continued support from corporate organisations in 2016 through sponsorship, in-kind and cash donations, fundraising events, subsidies and workplace giving highlight the strong belief in CFWA in our broad community. Capel Vale and WAFEX once again maintained strong support of our flagship events ensuring costs were contained and partnerships strengthened. Community Newspaper Group expanded their support through pre-press services for RED magazine and continued story coverage in local papers. Deloitte continue to sponsor and provide a venue for the Spring Rose Art Exhibition; Freehills provide countless hours of pro bono legal advice. The Good Guys provided broad support over events, in conjunction with their in-store giving program. Commonwealth Bank continued to support our Sibling & Offspring Camp along with providing event banking support and championing a 'convict' for our Convicts for a Cause event.

## Community Fundraising & Campaigns

**65 Roses Challenge** provides a framework for community fundraisers to create their own fundraiser with support from CFWA resources and the 65 Roses Every Day Hero (EDH) campaign website. In 2016, we achieved three significant fundraisers through this process with Paul Fowler from Broome initiating a 4,000km bike ride across Europe; Shari Douglas completed a Kokoda challenge; and Luke Ioppolo completed a 24-hour non-stop walk through the streets of Perth.

**Serve It Up for CF, Go RED for CF** and **Crazy Hair Day** continue to be popular community fundraisers for community groups, particularly day care centres and schools. Growing support from schools is allowing increased engagement for both awareness and fundraising.

Large **community events** such as HBF Run for a Reason, Chevron City to Surf, and Karma Resorts Rottneest Channel Swim all showed a decline in peer-to-peer fundraising, not only for CFWA, but also for charities across the board during 2016, with lower than budgeted income from these.

Finally, Fremantle Sailing Club's **Red Tie Dinner Dance** became the highest earning community fundraiser for 2016 with a net profit of \$25,825.

## Grants

### Telethon

**\$61,163** for Regional Support Program providing regional support get-togethers, education and a regional travel subsidy for those coming to PMH for clinic / hospital visits.

### Connect Groups Life Grant

**\$3,125** for Transplant Support Program which included a transplant support day and the Positive Profiles booklet.

### Lotterywest

**\$5,000** for Parents' Retreat held at Hillarys.

### Carers WA

**\$1,280** for Parents' Retreat held at Hillarys.

### Carers WA

**\$1,700** for Parents' Dinner – Regional Support.

### Commonwealth Bank

**\$10,000** for Sibling & Offspring Camp held at the Point Walter Recreation Camp.

## Donations

Unsolicited cash donations totalling \$72,460 were received from a mixture of individuals, trusts and businesses. The low-cost base of this stream is helped through online presence and has the potential to be improved with changes in our communications strategy in 2017.

## Appeals

The **Pre-tax Appeal** raised a net \$55,102 whilst the **Christmas Appeal** raised a net \$3,530. Direct mail appeals reflect a changing community engagement for this form of donations, which highlights the need to continue to analyse donor patterns to ensure effective donor engagement and support.







## Sponsors, Supporters and Volunteers

Our **40th anniversary celebration** at the end of 2016 allowed CFWA to recognise the founding members of CFWA along with our current members and supporters. The event was held at The Niche and heralded the launch of our CF Cooking project. Our annual awards included the inaugural 65 Roses Award in recognition of an inspirational role model who exemplifies our vision of Lives Unaffected by CF.

### FUNDRAISER OF THE YEAR

Red Tie Dinner Dance

Fremantle Sailing Club Power Section

### SUPPORTER OF THE YEAR

Deloitte

### VOLUNTEER OF THE YEAR

Chris Brambleby

### LONG SERVICE AWARD

Mitch Messer

### 65 ROSES AWARD

Paul Fowler

The support and help received during 2016 must be applauded; thousands of individuals and hundreds of businesses have supported our events, programs and services. Our generous volunteers have helped in countless ways to ensure we maximise funds raised for our services and research. Thank you for your contribution; it is greatly valued.

Together our community continues to strive towards our vision of Lives Unaffected by CF. Thank you.



Commonwealth Bank Merredin



The Donaldson Family created a "Crack a Cure" challenge for CF



# Policy, Research & Advocacy

**W**ork continues with Little Lungs Big Futures. The project remains on track to reduce structural lung damage in infants by 50% within 5 years and add 20 years to average life expectancy at birth.

In 2016, we hosted a special luncheon with visiting Professor Stephen Holgate the world's leading respiratory researchers and major donors. At the luncheon, Professor Holgate publicly recognised the research we are funding as being simply the best in the world.

As reported in our last annual report we hope to take this campaign public in 2017.

At a local level, the five CFWA PhD Top Up Scholars continued to deliver great outcomes which were reported on at the annual Evening with CF Scientists at the Telethon Kids Institute in May. These were also summarised in our popular RED Magazine.

We were delighted to award a sixth PhD Top up Scholarship in 2016, thanks to the efforts of our Golf

Committee, to Clara Mok whose work featured in the first RED Magazine in 2017.

Applications for the PhD Top Up Scholarships are peer reviewed and managed by the Australian Cystic Fibrosis Research Trust free of charge for CFWA. This competitive process whilst ensuring the quality of research is world class, nevertheless leaves some great projects and people unfunded as there are always more worthy projects recommended than we have money for.

In December 2016, the CEO extended a personally funded visit to the USA to visit the CF Foundation in Bethesda. Valuable contacts were made and new opportunities for liaison identified particularly in the areas of education, fundraising and mental health strategies. These will be developed further in 2017 and particularly at the Australasian CF Conference which will be held in Melbourne. Here the CEO of the CF Foundation, Preston Campbell, will be the key note speaker.



Protesters from across Australia on the steps of Parliament House in Canberra





# Treasurer's Report

**ANDREW WALSH**  
TREASURER



Income in the year increased by 8% to \$2,164,816 reflecting in particular an increase from fundraising activities and securing new grants. Expenditure excluding the funds provided to Cystic Fibrosis Australia (CFA) for the Collaborative Research Project (CRP) – Little Lungs Big Futures (LLBF), which I comment on below – increased by 4% to \$2,120,673.

**'I am pleased to report the finances of the Association continue to be managed in a manner which supports the objectives of CFWA'**

I reported last year that we would continue to assess the recoverability of the loan provided to CFA based on the fundraising progress of the LLBF Project. Whilst the project has raised significant funds to date, those funds are lower than had been anticipated when the project was commenced. Consequently, the recoverability of the loan which is dependent on funds raised is now less likely. We have, therefore, made the decision in these accounts to recognise the funds provided to CFA for the LLBF Project as an expense. This treatment does not prevent the Association from recovering the funds if future fundraising improves to the extent that the loan could be repaid. You will see this recognised in a note in the accounts (note 12).

The net deficit for the year including the CRP expense was \$521,999.

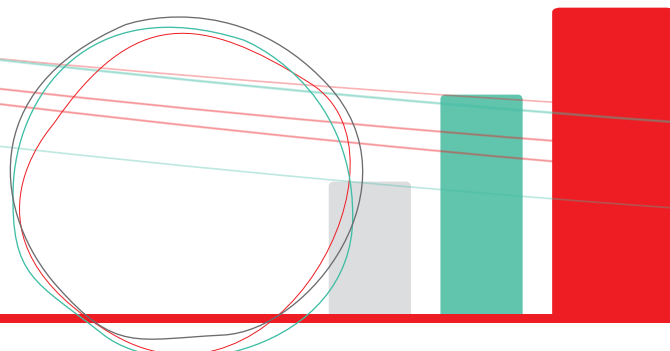
Of particular importance to the Association is the level of cash generated in the year and overall access to funds in order to allow the Association to deliver services to its members. The CRP accounting treatment has no effect on cash resources as the funds were provided to CFA some years ago. Overall, cash holdings improved to \$592,525 compared to \$185,653 at the end of 2015. Whilst this balance includes some early receipts for expenditure in 2017, the cash holdings and funds held as investments of \$703,939, up from \$577,224 at the end of 2015, mean the Association remains in a strong financial position.

Consequently, I am 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 income and expense 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.

The financial statements for the year ended 31 December 2016 have been audited by Mr James Komninos of RSM Australia and a copy of the signed accounts are available for inspection by members.

In preparing this report I would like to 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 Jaycees, a self-help group...'



'We were able to publicly describe CF as a lifetime manageable disease rather than a life shortening sentence'

In July 1975, 3-4 parents of children living with cystic fibrosis (CF) came together and established, with the help of the Perth Jaycees, a self-help group. The group was formally incorporated under the Associations Act of WA on 29 June 1976.

In the 1990s, CFWA continued to develop its services and to develop links with the cystic fibrosis clinics based at Princess Margaret Hospital for Sick Children (PMH) and Sir Charles Gairdner Hospital (SCGH). In the late 1990s, it gained funding from the Health Department of 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 passed to CFA, became an important national priority which bound together the Associations in pursuit of our common vision of Lives Unaffected by CF and became known as Little Lungs Big Futures.

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

In 2015 CFWA secured a contract with the HDWA for \$5.4m to deliver services to people living with CF over a five-year period.

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 2016, the total raised in WA for the Little Lungs Big Futures collaborative research project reached over \$2.6m with major donations from the Stan Perron Charitable Trust, the Allingame family, Conquer Cystic Fibrosis and John and Denise Rothwell.

In May 2016, CF researchers from the Telethon Kids Institute presented their latest results. The event was hosted jointly by TKI and CFWA. It was the first time that we were able to publicly describe CF as a lifetime manageable disease rather than a life shortening sentence.

July 2016 CFWA won the prestigious Telstra Business Award Charity category for WA.



**Cystic Fibrosis WA (Inc)**

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