



# Annual Report 2017

# Our Purpose

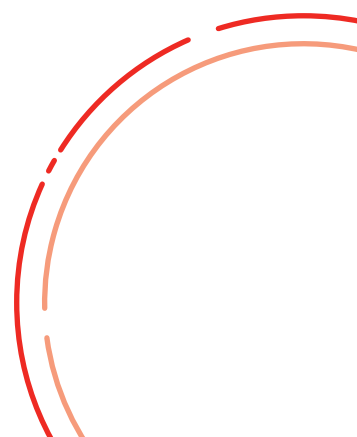
Our vision is  
**'lives unaffected by CF',**  
where every person  
born with CF will be  
able to reach their  
full potential,  
unencumbered  
by the disease.

Every day we strive  
a little closer to  
achieving that vision.



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# Message from the Patron



**According to a recently released report from Curtin University, there are nearly 5,000 registered charities in WA. Together these charities generate incomes of around \$12.7bn per annum and employ around 7% of the work force.**

That's 100,000 full and part time staff; the same number as is employed in manufacturing. The not-for-profit sector therefore, is a significant part of the State economy. It is also a sector which is growing faster than the national domestic product.

The growth of the sector is reliant not only on a vibrant and healthy economy but also on good governance, good management, passion and like many commercial businesses, an entrepreneurial flair and appetite for risk.

I was pleased therefore, to see that Cystic Fibrosis WA (CFWA) had taken a longer term strategic view of emerging trends during 2017. It has worked hard to position itself to exploit those trends in areas of fundraising and service delivery by investing heavily in cutting edge technologies, thanks in large part to funding from Lotterywest.

Social media continues to evolve at a frightening rate. Relatively recent innovations like Facebook founded in 2004, may still appear new and mysterious to some but is now considered passé for the new millennials joining the workforce.

New platforms are constantly evolving, and it is absolutely vital that businesses and the not-for-profit sector particularly, understand how these disruptive technologies are shaping our future, in much the same way as Computer Aided Design and Manufacturing revolutionised my ship building business over the course of my career.

It takes courage to change direction and let go of some historically significant activities. This is not without an element of risk. Having a strong, well managed association allows us to take these risks. The results from 2017 would indicate that these risks are being properly managed, and CFWA will be more resilient, effective and sustainable as a result.

Importantly, during 2017, the day-to-day work of the association has continued unabated. CFWA has delivered more quality, relevant services to people living with cystic fibrosis (CF) than ever before, whilst our investment in research has broken all previous records.

Finally, collaboration with our sister organisations and centre directors, has won CFWA the opportunity to host the 13th Australasian CF Conference here in Perth in 2019. It is an opportunity to showcase Perth and CFWA to the world. This would not have been possible without the support of our local businesses, sponsors, volunteers and members.

**CFWA has delivered more quality, relevant services to people living with cystic fibrosis (CF) than ever before.**

Thank you to everyone that has contributed. I look forward to the year ahead and being part of the exciting developments to come.

**John Rothwell AO**  
**Patron**

# Message from the President and the Ceo



**The landscape for CF has changed significantly over the past two years with advances in both treatment, technology and changes to our social, political and technological environment. The challenge for CFWA, has been to keep ahead of the curve.**

In 2017, CFWA recognised that the ways in which people chose to give to our association and access our services, was changing. These changes were brought about largely through changes in technology. Consequently, we reshaped our fundraising strategy. We invested heavily in new technology, thanks to Lotterywest, our social media platforms, our new website [www.cfw.org.au](http://www.cfw.org.au) and our online resources for CFSmart.

We funded more research than ever before, including our 7th and 8th PhD Top Up Scholarship and worked closely and collaboratively with the Health Department of WA, the CF Clinics and our sister organisations to deliver more services to meet the needs of our clients.

We became more vocal in our national advocacy through Cystic Fibrosis Australia (CFA), lobbying for access to disease modifying drugs like Orkambi. Sadly we still haven't got Orkambi across the line but are not about to give up.

Overall these changes have impacted positively on the Association and the CF population.

To continue to keep CFWA ahead of the curve, we embarked upon our strategic planning process in 2017. This involved gathering feedback from our members and has helped position ourselves for future growth. Thank you to everyone that participated.

Financially, we budgeted for a small surplus of \$8k in 2017 however, thanks in part to a large bequest of **\$160k** from the late Doreen Letcher in December, our surplus for the year is **\$189k**. This is on a turn-over of **\$2.82m** compared to a turnover of \$2.16m in 2016. Details are included in the Treasurer's Report and audited accounts. The large increase in turnover is due mostly to the generosity of donors Stan Perron and the Allingame family, who contributed a total of **\$550k** to our Little Lungs Big Futures CF research project. Importantly, every cent of these donations has gone to the researchers as the cost of the fundraising has been borne by CFWA. Even allowing for these large transactions, this is an excellent

result for the year. We are pleased to report that the organisation remains financially strong and able to meet its debts, as and when they fall due.

The forthcoming Annual General Meeting will mark the conclusion of my four-year fixed term as President of CFWA. The past four years has been a period of great change for our Association in terms of the scope and breadth of the services and support provided to members, the growth of our contract with the Health Department of WA and the substantial advances that have occurred in CF research and of course the listing of Kalydeco on the PBAC. It has been my privilege, and indeed honour, to have served as President and to have worked with such a committed Board, CFWA executive and staff, volunteer and supporter group. I will continue as a member of the Board and will offer my support to the incoming President.

In closing, we would like to thank the Board for their support, guidance and professionalism. We would also like to thank the staff of CFWA for their dedication and loyalty. It is an exceptional team. Special mention should also be made of two of our longest serving home care workers who retired in 2017. Wojciech Lappa and Fran Hadley who between them clocked up over 50 years of service. We wish them all the very best in the future.

Finally, we would like to thank you, the members, the volunteers, sponsors and supporters. We are part of something special and together are moving ever closer to our vision of Lives Unaffected by CF.

**Richard Simons**  
President

**Nigel Barker**  
CEO



# Services in the community

In 2017, CFWA provided support to the CF community through various channels, including home and hospital support, school and health professional education, financial support, outreach to regional communities, resource development and member support events.



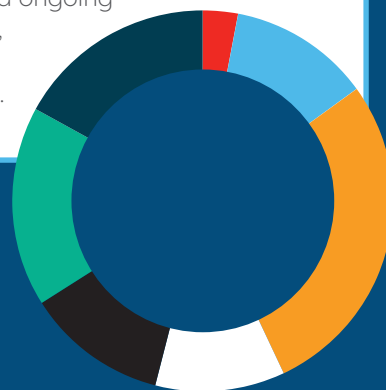
## Home Care Worker (HCW) Support

We continue to deliver vital services to the CF community of WA under our Health Department Contract. This special relationship with our state government has ensured quality care and education in our state.

In 2017 our ten home care workers (HCWs), located throughout the metro area and Bunbury, provided **5,428** essential occasions of service to families and individuals with CF; these services included support with airway clearance and exercise, respite, light home duties and other general support as required.

To support this ongoing care, HCWs receive structured monthly training and ongoing supervision, and in 2017 were given specific training in working with babies, toddlers and teens. Support in the community improves adherence to treatment and medications, directly correlating to better health outcomes.

### HCW Metro Visits by Location



Community nurse  
Sharon delivering a  
hospital bag to Lyla

## Hospital Support

Our social worker and community nurse visit Princess Margaret Hospital (PMH) and Sir Charles Gairdner Hospital (SCGH) once a week to offer support to inpatients and their families. In 2017, they delivered:



Child Hospital Bags

**161**



Adult Hospital Bags

**128**

## Financial Support

CFWA provided three specific subsidies throughout 2017, including:



Activity Subsidy



Equipment Subsidy



Adult Regional Travel Subsidy

Number of subsidies	33	53	65
Total cost	\$5,544	\$8,870	\$5,000

## Face-to-face Support

734 occasions of face-to-face support (including counselling, social work, community nursing and physiotherapy) were provided by the social worker, community nurse and physiotherapist.

## Regional Support

We are able to deliver support to families in regional and remote areas of WA thanks to vital funding from Telethon.

### In 2017, we provided:

**13**  
regional  
visits

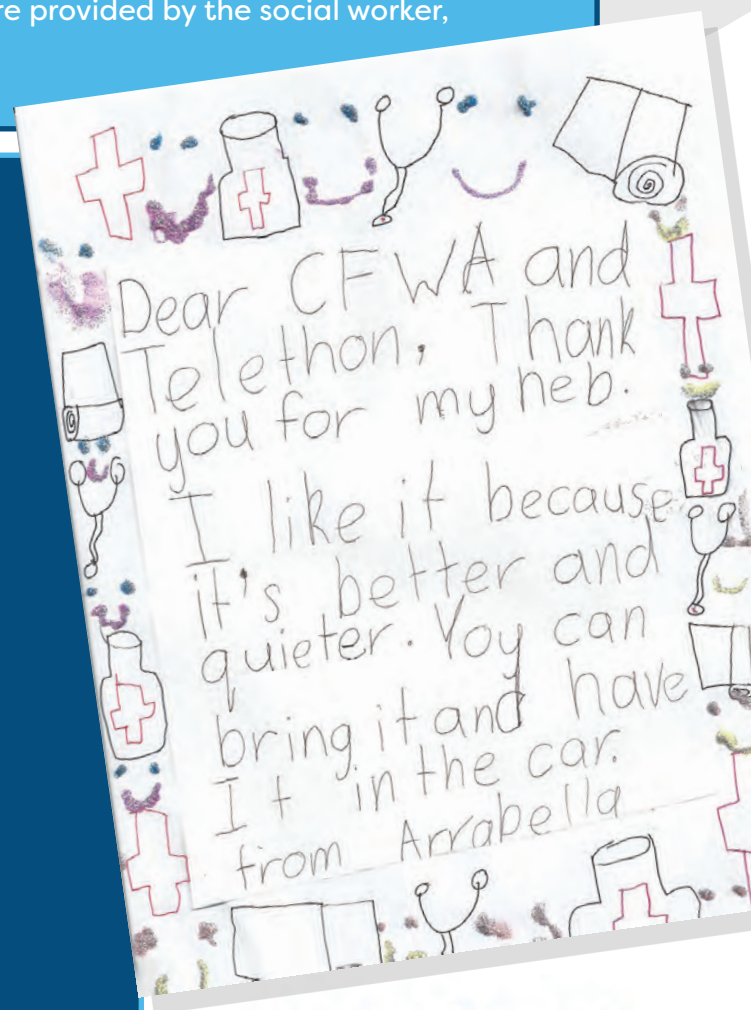
Including education to schools, day cares and hospitals, as well as social support for local families.

**97**  
subsidies

For the Telethon Country Patient Assistance Subsidy, to assist regional families to attend clinic and/or hospital appointments.

**21**  
nebulisers

Gifted to regional children with CF, upon referral from PMH.



Thank you CFWA and Telethon

## CFSmart Education Program

**CFSmart is a national education program for teachers, parents and children in the school community.**

It was initially developed by CFWA, in collaboration with the other sister CF organisations, health professionals, parents and young people with CF from around Australia. The aim of the CFSmart program is to improve the understanding of the needs of students who have CF, so that they feel more supported and understood while at school.

Here is a timeline of how the program has developed:

**2012**

A range of resources to support students with CF in day care and school were developed and housed in a basic website

**2013**

CFSmart Facebook page was developed to share resources and information with parents, teachers and anyone else who was interested to join.

**2014**

CFWA was awarded a Lotterywest grant to produce a short-animated film, 'Good Clean Hands', to encourage better hand hygiene amongst children in schools. Available on YouTube.

**2017**

Cystic Fibrosis Community Care (previously CFVictoria) was awarded a grant from the Ian Potter Foundation to work in collaboration with CFWA to develop a new CFSmart website and eLearning modules for teachers. The new website was launched in 2017 with great success ([www.cfsmart.org](http://www.cfsmart.org)).

### In 2017, our CFSmart stats were:



**2,876** visits to the new CFSmart website



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

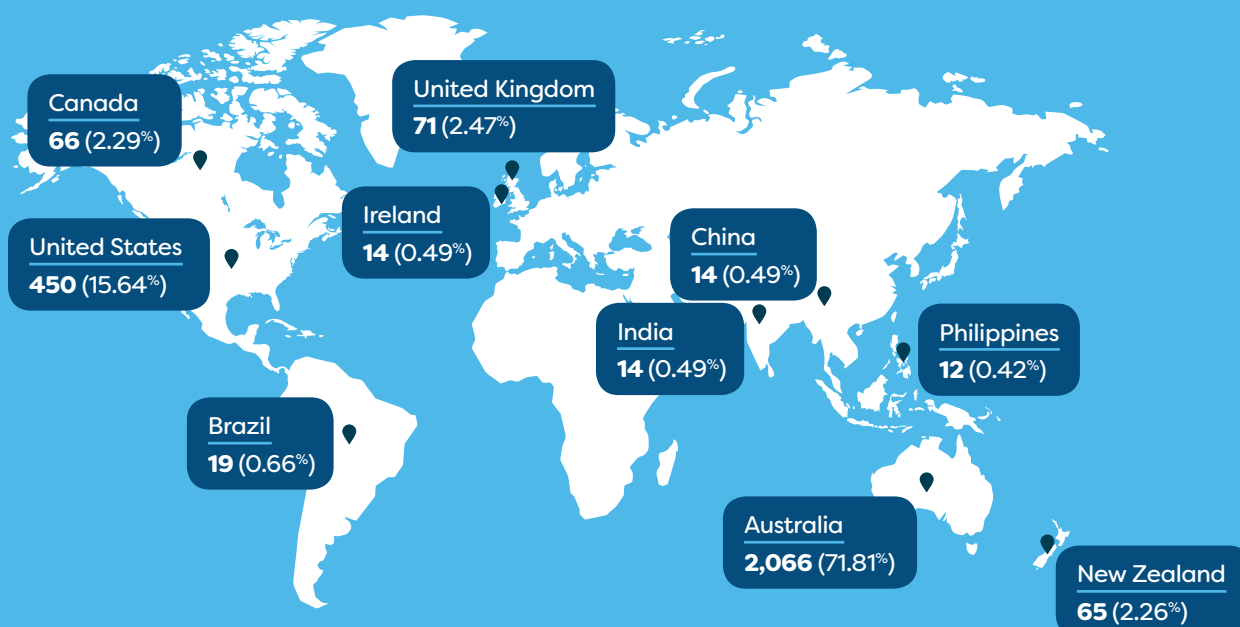


**300** eLearning modules completed by **176** people



**1,098** followers on the CFSmart Facebook Page

### Geographical reach of CFSmart website for 2017





# Outcomes

The response to the CFSmart website and resources from teachers and parents from within Australia and overseas has been very positive.

Your **tools** have been great in educating our **prep teachers**. Smooth sailing so far.

The **eLearning modules** are fantastic! Short, simple and to the point. This **CF eLearning program**, reduces the hesitation, fear and myths about CF. Well done, I wish we had this years ago.

We found the **factsheets** and templates from **CFSmart** a great tool to discuss our son's specific needs. Great work CFSmart

The CFSmart resources are used in conjunction with school education sessions, where our education officer provides a tailor-made presentation about the child's needs while at school and their treatment demands at home. Sessions are also provided to other students and groups of parents as requested.

In 2017 we provided education to:



534 Adults

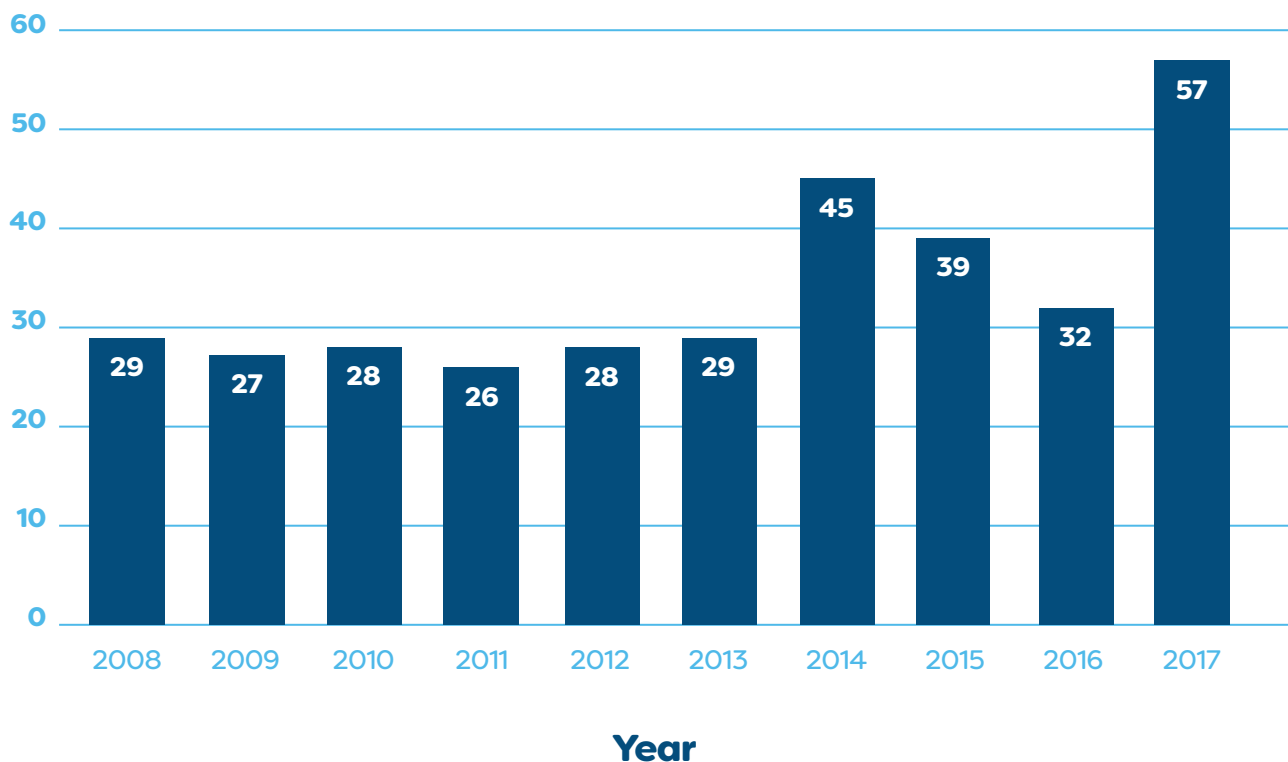


205 Children



57 school education sessions

## Number of School Visits from 2008-2017



## Education and Awareness Raising

CFWA are aware that raising the profile of CF in our community and improving health literacy amongst people and families with CF greatly improves peoples' quality of life and health outcomes. CFWA works closely with health professionals and consumers to ensure that information is accessible and targeted at the right level.

## eLearning Health Professional Training

Planning commenced in 2017 to develop eLearning for health professionals (nurses, doctors, physiotherapists) across WA and to be accessed globally.

## eLearning HCW Training

Planning commenced in 2017 to move some training components online whereby new HCWs will be able to gain knowledge and skills efficiently and their learning can be monitored.

## Regional Respiratory Training Program (RRTP)

The RRTP is a multi-faceted health education program specialising in CF but covering all aspects of respiratory disease. Developed in 2011, in collaboration with PMH, SCGH and the Lung and Heart Transplant Department at Fiona Stanley Hospital (FSH), this 5-day comprehensive training course, facilitated by CFWA, continues to educate regional nurses and physiotherapists in CF, ensuring better knowledge and care in regional hospitals and health campuses.

Each year the demand for this program increases as its reputation in the regions continues to grow.

2017 RRTP participants



2017 school education sessions

**2017 RRTP**  
attendees from  
across WA



## CFFacts

We first began developing factsheets in 2014, and over the years have continued to add to our suite. In 2017 we created 8 new factsheets and now have 39 available on our new website. They cover topical issues relating to CF and are relevant to people with CF, their families and carers and the general public.

## Rozee (Kids Magazine)

Rozee is an annually produced magazine targeted at children with CF, their siblings, and children of adults with CF, aged of 6-12 years. It is designed to educate the target audience on various CF-related topics in a way that is engaging and understandable.

## CFFood

This suite of nutritional information booklets targeted at babies, children, young people and adults was developed in 2015. These resources are still being used in 2017 and are also distributed by PMH and SCGH dietitians.

## CFFit

The suite of CFFit resources, initially developed in 2014, were reviewed in 2017 with the goal of redesigning and reprinting in 2018. The booklets are designed to support young adults and adults with CF to exercise safely in their community.

# Research

## An Evening with CF Scientists

An annual collaborative event between CFWA and Telethon Kids Institute (TKI), whereby local research is showcased through various presentations demonstrating what the research is being used for and the results. In 2017, our first “Mini” Evening with CF Scientists was held in Bunbury with overwhelming success. This will again be replicated in 2018 in both Bunbury and Albany.

### Outcomes:

The **dinner nights** are a great way to **share stories/communicate** with other parents.

Very thankful for your support of **rural areas**. Tonight was fantastic and very helpful to see the **progress** for our children.

The combo of dinner with an **educational** component is fantastic - better than a straight **social night**.



## Member Support Events

CFWA hosts a range of member support events, primarily aimed at carers, including parents, grandparents, partners, siblings, offspring and other family members who take on caring roles. Due to cross-infection issues, we are unable to host events targeted at people with CF (with the exception of those post-transplant), however we do our best to support them in other ways.

Our member support events are designed to offer respite and provide the opportunity to connect with other carers. Events include Parents' Dinner, Parents' Retreat, Sibling and Offspring Camp, Ladies' High Tea, Outreach dinners and Transplant Support Dinner.

Parents' Retreat	Ladies' High Tea	Parents' Dinner	Sibling and Offspring Camp	Transplant Support Dinner	Outreach Support Dinners
50	50	17	20	19	36

## Outcomes

Words cannot describe how much the **parents' retreat** has helped me to 're-set'. I feel **re-energised** and as though I can tackle and overcome the obstacles which come with being a carer.

**Sibs Camp** is lots of fun and you meet new people who tell you about who has CF in their family.

**Peer support** has assisted so much with improving my **mental health** and **wellbeing**.





**Ladies'  
High Tea**



**Sibs  
Camp**



**Parents'  
Retreat**



# Fundraising & Marketing

The strategic planning cycle in 2017 identified three key directions within the Fundraising and Marketing function that became the key drivers for our communications and fundraising. These resulted in the reduction of CFWA managed events to ensure that major events and products could be refined in line with community expectations and giving trends. Development of the new CFWA website through the support of a Lotterywest grant provided the framework for extending resource access.

## Our key directions for 2017 were:

- ✓ To develop an improved fundraising product mix to maximise reach, engagement and fundraising.
- ✓ To develop our communication plan around an improved CFWA website, strong stakeholder relationship management and increased use of social media.
- ✓ To consolidate and grow key partnerships in the community and within the federation to gain greater outcomes for all stakeholders.

## Communications, PR and Social Media

Raising awareness about CF and CFWA remained our primary communications goal in 2017, with a strong focus on promotion of fundraising products and the engagement of volunteers for services and fundraising events. Targeted social media resulted in higher volunteer numbers for events and increased growth in key CFWA events and community fundraising income.

Our partnership with Telethon provided the opportunity to participate in the Telethon Beneficiaries day where we raise awareness in the broader community.



Facebook	Twitter	E-news	RED Magazine	CFWA Website	LinkedIn
<b>3,286</b> followers	<b>1,190</b> followers	<b>3,000</b> readers	<b>780</b> readers	<b>14,076</b> visitors	<b>139</b> followers

## Grants and Other Income

Grants		
<b>Telethon</b>	<b>\$88,654</b>	Providing support for regional members including education, travel subsidies and social events.
<b>PEACH</b>	<b>\$6,690</b>	To purchase exercise equipment to be used in our personal training program.
<b>Lotterywest</b>	<b>\$131,196</b>	Grants received for: <ul style="list-style-type: none"> <li>• Strategic Plan</li> <li>• Parents' Retreat</li> <li>• IT upgrade and website</li> </ul>
<b>Allens</b>	<b>\$2,727</b>	To purchase trampolines to gift to children with CF.
<b>Carers WA</b>	<b>\$500</b>	Contribution towards our annual parents' dinner.
<b>City of Nedlands</b>	<b>\$500</b>	Contribution towards our annual parents' dinner.
Other Income		
<b>Donations</b>	<b>\$71,750</b>	Regular giving and unsolicited donations net income
<b>Appeals</b>	<b>\$72,736</b>	Pre-tax and Christmas appeals net income

# Fundraising & Marketing



## CFWA Major Events

### 65 Roses Campaign

May is the focus of our 65 Roses Campaign, with increased awareness activities and community fundraisers culminating in 65 Roses Day, our national day of awareness for CF. Thanks to the generous support of WAFEX, Telstra and South Metropolitan TAFE we were able to continue to grow and extend the reach of 65 Roses Day across WA. Our generous and hardworking volunteers in the Perth metro and regional areas wrapped and sold roses achieving a new sales record.

The campaign including 65 Roses Challenges and community fundraisers continued to provide fantastic fundraising and awareness outcomes in existing and new areas of the community. A renewed partnership between Vault Fitness and Exchange Tower to run a spin cycle event for CF proved a sensational event for both organisations and a great fundraising outcome for CFWA. The team was presented with our Fundraiser of the Year award for 2017 and they are working towards a bigger event in 2018.

Future growth in the awareness impact and fundraising will continue in 2018 with our partners and supporters.

65 Roses Day 2017 was a huge success. Thank you!



<b>\$65,037</b> net income	<b>12,600</b> roses sold	<b>300+</b> volunteers wrapped roses and sold them on the streets of Perth
Metro sale locations (not Telstra)	Telstra sale locations	Regional sale locations
<b>16</b>	<b>17</b>	<b>10</b>
Media campaign value <b>\$1,075,159</b>		



### The George Jones Family Foundation CF Golf Classic

Lake Karrinyup Country Club is the location for CFWA's premier fundraising event. Coordinated by a dedicated committee made up of volunteers and CFWA staff, our 2017 event was a wonderful day. Continued sponsorship by the George Jones Family Foundation in 2017, in conjunction with a full list of registered teams, saw the event achieve a strong fundraising outcome.



Net Income

**\$101,315**



Teams Participated

**32**



## Community Fundraising

Community fundraising continues to strengthen awareness and raise funds for CFWA. Strong engagement with member families and the extended community continued in 2017 with fundraisers hosted by individuals, schools, businesses and community groups.

**Serve It Up for CF**, **Go RED for CF** and **Crazy Hair Day** continue to be popular community fundraisers, particularly for day care centres and schools. Marketing focus on schools and day care centres resulted in increased engagement for education, awareness and fundraising.

Large third-party community events like the HBF Run for a Reason, Chevron City to Surf, Karma Resorts Rottneest Channel Swim, and Colour Run contributed well to fundraising. HBF Run for a Reason included over 45 participants, achieving an astonishing \$27,404 in fundraising. Strong branding and media engagement was achieved through traditional and social media platforms.

Community events such as the Corporate Battle of the Bands, Pink Boot Charity Ball, Red Tie Dinner Dance and Busselton Golf Day, along with fundraisers including the Shellabears logo competition and Kwinana Football match, proved to be effective fundraisers and awareness raising opportunities.

Thanks to all our community fundraisers for their commitment, energy and fundraising. Their efforts help us to support our members through our service programs.



## Sponsors, Supporters and Volunteers

Our 300+ volunteers played an incredible part in our 2017 achievements. Contributions from cutting ribbons, to delivering collection tins, wrapping and selling roses and hosting community events, our volunteers bring energy and commitment, and help us to contain costs whilst contributing to fundraising outcomes. Our partners, through both sponsorship and pro bono support, enhance our fundraising strategy and delivery.

Our Sponsors and Volunteers Evening held in December allowed CFWA to recognise the huge contribution made throughout the year by both sponsors and volunteers. The event saw over 60 sponsors and volunteers gather for a relaxed evening.

Our 2017 awards were presented to:

<b>Fundraiser of the Year</b>	Exchange Tower and Vault Fitness
<b>Supporter of the Year</b>	Telstra WA
<b>Volunteer of the Year</b>	Denise Sharpe
<b>Long Service Award</b>	Liz Balding
<b>65 Roses Award</b>	Ron Bragg

PhD Top Up Scholarships were also presented on the evening. We are looking forward to updates on these research projects during 2018.

**CFWA Golf Classic Scholarship:** Kelly Martinovich  
**The Hardie Foundation Scholarship:** Samuel Montgomery

The contribution by individuals and businesses during 2017 in support of our events, programs and services is incredible. We thank and applaud you for your contribution to our vision of 'Lives Unaffected by CF'.



# A History of CFWA



In **1975**, a dozen parents of children living with CF came together for a meeting with members of the Perth Jaycees, a volunteer group who helped with the formation of an association.



In **1976**, the group was formally incorporated under the Associations Incorporation Act (WA) and began to hold monthly meetings, fundraise and organise camps for children.



Evie with nebuliser

## 1970s

## 1980s

Telethon



In the **early 1980s**, an office was set up in a donated space in Mount St, Perth. Funding was obtained to employ an Education Officer who coordinated a needs survey of members. The results highlighted physiotherapy and respite as the number one concerns.



In **1983**, following the results of the survey, the Home Support Service began, and federal funding enabled the employment of Homecare Workers and a counsellor.



In the **late 1980s** the Constitution of the organisation was changed to allow the organisation to use the skills of people from the wider community to help manage the organisation.





The **1990s** saw the continued growth of CFWA and the development of more services for the CF community, as well as better links with the clinics based at Princess Margaret Hospital (PMH) and Sir Charles Gairdner Hospital (SCGH). By the end of the 90s, CFWA had obtained Health Department funding and the Comprehensive Homecare Service began.



Joel & Jeslyn

## 1990s

## 2000 onwards...



In **2002** CFWA moved to its current home at 'The Niche', Nedlands



**2010** saw the launch of our first PHD Top Up Scholarship, a funding incentive to young researchers looking to explore further learning (PHD, MD or equivalent) in the area of CF.



In **2011**, CFWA called researchers around the world to submit expressions of interest for a five year \$10-20m collaborative research project.



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 **2016**, the total raised in WA for the Little Lungs Big Futures collaborative research project reached over \$2.6m. In 2016 we also won the prestigious **State Telstra Business Awards** charity category.

In **2017** we have continued to achieve remarkable things:

- ✓ CF researchers and CFWA took their research forum to the Southwest.
- ✓ Funded two additional WA PhD Top Up scholarships, taking the total number of PhD Top Up Scholarships to eight.
- ✓ Provided \$30,000 seed funding to help establish an adaptive platform trial to help shorten the time taken in clinical trials to bring new drugs to market.
- ✓ Thanks to Lotterywest we embarked upon a major ICT upgrade, replacing ageing computer hardware and transitioning to cloud.
- ✓ We launched our new website [www.cfw.org.au](http://www.cfw.org.au)

Lyla & Missy



Caz & Mitch



## Policy, Research and Advocacy

Thanks in large part to the generosity of the Stan Perron Charitable Foundation, the Allingame Family, the Hardie Foundation, the Golf Committee and private benefactors who prefer to remain anonymous, we have had a record-breaking year funding CF research.

Funds raised have been allocated to our Little Lungs Big Futures CF research project designed to reduce structural lung damage in infants by 50% within five years and add 20 years to average life expectancy at birth. We have also provided seed funding through the Australian Cystic Fibrosis Research team (ACFRT) to develop an adaptive clinical trial platform, which subsequently attracted \$3.4m from the Medical Research Future Fund and finally we funded our 7th and 8th PhD Top Up Scholarships which seek to apply a molecular band aid to a faulty CF gene in a range of stop code mutations and investigate the role of a certain chemical in inflammation in the lungs.

Applications for the PhD Top Up Scholarships are peer reviewed and managed by the ACFRT 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.

Over the past five years CFWA alone has allocated \$3m to CF research.

In 2017, we co-hosted a luncheon with Preston W. Campbell III, M.D., president and chief executive officer of the Cystic Fibrosis Foundation in the USA and acknowledged his organisation's sustained funding for the CF research team led out of the Telethon Kids Institute (TKI).

We also co-hosted the special Evening with CF Scientists at TKI where ground breaking yet-to-be-published results are made available to the public. For the first time in 2017, we took this event into regional WA. In 2018 we will expand this to include a second regional centre; taking research into regional WA has been a long-time goal of both TKI and CFWA.

Our lobbying activities are coordinated nationally through CFA and the focus in 2017 has been to get Orkambi listed on the PBS. Unfortunately, our strategies have been unsuccessful to date and whilst there is no denying that we have raised our profile in

**Over the past five years CFWA alone has allocated \$3m to CF research.**

Canberra, we are yet to achieve this goal. Collectively we will be revisiting our strategies in early 2018 and hope to establish a pathway for getting Orkambi listed which can then be used to get other disease modifying drugs like Symdeko on the Pharmaceutical Benefits Scheme (PBS) sooner than would otherwise be the case.

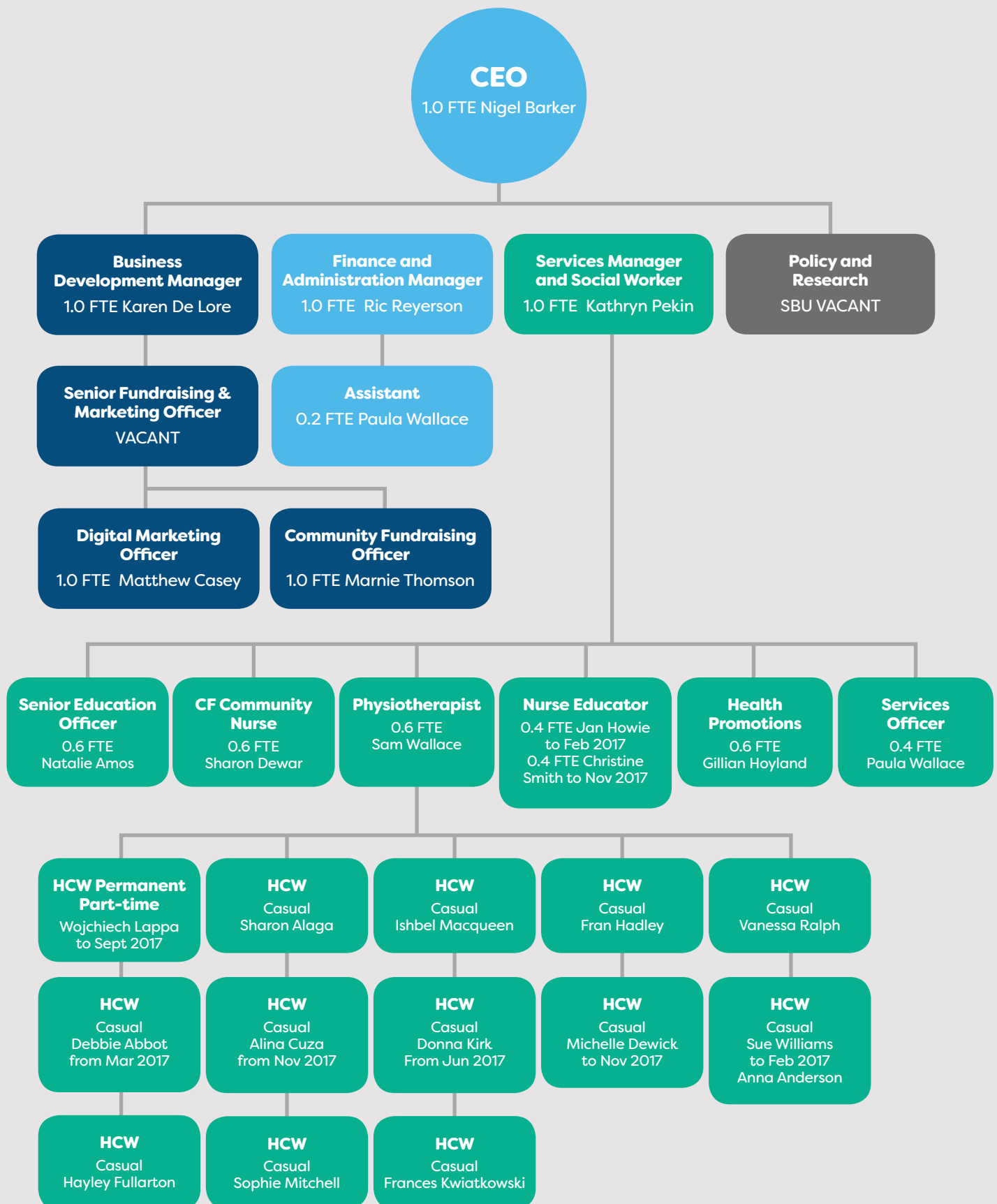
On the policy front, presenters at the 12th Australasian CF Conference in Melbourne revealed new evidence on cross-infection, and we have moved quickly to implement a range of recommendations in both our offices and the way in which our home care services are delivered.

Finally, we have updated all our resources and placed these on a newly developed website [www.cfwf.org.au](http://www.cfwf.org.au). We have also linked this to our new social media strategy to better inform and educate people about CF. This work has benefitted hugely from our close working relationship with the CF Clinics at PMH and SCGH and close working relationships with other members of the CF Federation.

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



# Organisational Chart 2017



# Board and Governance

**The CFWA Board comprises eight highly qualified directors. Each bringing technical expertise, life skills and passion to their role.**

**The Board has a wide range of responsibilities which include:**

- ✓ Setting and reviewing CFWA's strategic direction for service provision and research
- ✓ Approving Strategic and Business plans and budgets
- ✓ Ensuring compliance with contractual and statutory obligations
- ✓ Approving the annual audited accounts
- ✓ Monitoring operations and financial performance
- ✓ Setting risk policy and overseeing risk management



**Richard Simons**  
**President**

Richard is the CFO for Clough and has over 30 years' experience as a senior executive. Richard joined the board of CFWA in 2009 and was elected president in 2014. He is currently a nominee director on the Board of CFA.



**Carolyn Boyd**  
**Vice President**

Carolyn lives with CF and underwent a double lung transplant in 1994. She brings a wealth of experience to her role and is a regular speaker, fundraiser and advocate. Carolyn joined the board of CFWA in 2010 and was elected as vice president in 2017.



**Simon Martin**  
**Treasurer**

Simon is a qualified chartered accountant and the COO of WA Primary Health Alliance. He has held a range of executive positions including GM of Network TEN and acting CEO of CF Australia. Simon is a parent of a child with CF and after joining the board in 2015, became treasurer in 2017.



**Feliciano Sanchez**  
**Board Member**

Feliciano is an executive level engineer and father of a young woman with CF. Having joined the board in 2006, he has held both the president and vice president position and is currently a special skills Director on the Board of CFA.



**Ken See**  
**Board Member**

Ken is a Fellow of the Australian Institute of Management who joined the Board in 2015. A regular and active volunteer at CFWA, he brings a wealth of executive experience in the public sector and non-government organisations to the Board.



**Rachael Hosking**  
**Board Member**

Rachael is currently the Corporate Counsel for Landgate. She brings experience in legal and governance issues including development of regulatory frameworks. Rachael is the parent of a young man with CF and first joined the board in 2006.



**Simon Trevisan**  
**Board Member**

Simon is MD of the Transcontinental Group and was previously a solicitor for Parker and Parker. Simon is director for a number of ASX listed public companies and joined the board of CFWA in 2017



**Tim Sharp**  
**Board Member**

Tim is a judge of the District Court of WA and the Deputy President of the WA State Administrative Tribunal. Prior to that he was the State Solicitor for WA. Tim has been on the board since July 2017

Board

## Board Attendance Register

Elected members	Eligible to attend*	Attended	Attendance %
Carolyn Boyd	8	7	88%
Simon Martin	8	7	88%
Rachael Hosking	4	3	75%
Feliciano Sanchez	8	7	88%
Ken See	8	7	88%
Richard Simons	8	5	63%
<b>Co-opted members</b>			
Simon Trevisan	5	4	80%
Tim Sharp	5	5	100%

\*Eligible to attend (Since April AGM)

# CFWA Ambassadors for 2017



Dylan was our **2017 junior 65 Roses Ambassador** and joined us selling roses all around Perth on 65 Roses Day.



**Sam Powell-Pepper**, Port Adelaide AFL player, became a CFWA ambassador in 2017. He has volunteered at our events and visited children with CF in PMH as often as he can when he's in WA. He is pictured with CFWA member, Jayton.

**Nyssa** is a mum to young twins Cole and Norah, who has CF. She and her partner Cody shared their story for our 2017 Tax Appeal campaign. They also raised over \$5,000 by running in the HBF Run for a Reason.



**John Rothwell AO** and founding director of Austal Ships has been the Patron of CFWA since 2010. John has been a major financial contributor to CF research and is active in providing sound hands-on mentoring and advice to the organisation.



# Treasurer's Report

**Income in the year increased by 30% to \$2,824,861 resulting from the inclusion of fundraising for Little Lungs Big Futures of \$550,000.**

Excluding this amount, income raised for the organisation increased by **5%** with an increase in bequests offsetting a fall in general fundraising. Operating expenditure decreased by **2%** to **\$2,085,211** due to a more targeted fundraising approach with a reduced number of events and associated running costs.

The net surplus for the year was \$189,650.

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. Overall, cash holdings improved to **\$657,165** compared to \$592,525 at the end of 2016. The cash holdings and funds held as investments of \$956,852, up from \$853,773 at the end of 2016, 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 2017 have been audited by Mr James Komninos of RSM Bird Cameron and a copy of the signed accounts are available for inspection by members **on the ACNC website**. An extract of the financial statements has been included in this report – refer to page 26.

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.



**Simon Martin**  
Treasurer

**The net  
surplus for  
the year was  
\$189,650**

# Financials

## BALANCE SHEET for year ending 31 Dec 2017

CURRENT ASSETS	\$
Cash & cash equivalents	657,165
Financial Assets	121,258
Trade and other receivables	101,442
Inventories	6,171
Other current assets	27,676
<b>TOTAL CURRENT ASSETS</b>	<b>913,712</b>
NON-CURRENT ASSETS	
Financial assets	835,594
Plant and equipment	411,695
<b>TOTAL NON-CURRENT ASSETS</b>	<b>1,247,289</b>
<b>TOTAL ASSETS</b>	<b>2,161,001</b>
CURRENT LIABILITIES	
Trade and other payables	413,187
Provisions	224,251
<b>TOTAL CURRENT LIABILITIES</b>	<b>637,438</b>
NON-CURRENT LIABILITIES	
Provisions	38,548
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>38,548</b>
<b>TOTAL LIABILITIES</b>	<b>675,986</b>
<b>NET ASSETS</b>	<b>1,485,015</b>
MEMBERS' FUNDS	
Accumulated surplus	
Accumulated surplus - restricted	10,000
Accumulated surplus-designated	61,250
Accumulated surplus-unrestricted	1,314,619
Financial asset reserve	99,146
<b>TOTAL EQUITY</b>	<b>1,485,015</b>

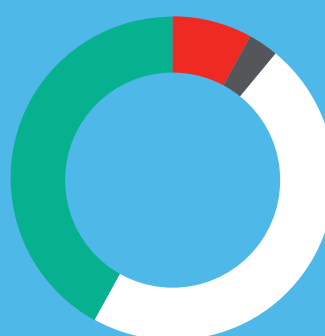
Restricted funds represent \$10,000 donation set aside for developing Mental Health/Youth Program

Designated funds represent money set aside for PhD Top Up Scholarships

## INCOME STATEMENT for year ending 31 Dec 2017

	\$
Revenue	2,824,861
Cost of sales (merchandise)	(21,288)
Employee benefits expense	(1,267,599)
Depreciation	(18,092)
Motor vehicle expense	(9,987)
Insurance expense	(32,330)
Other expenses	(1,258,517)
<b>OPERATING SURPLUS/(DEFECIT) FOR THE YEAR</b>	<b>217,048</b>
Office refurbishment depreciation	(27,398)
<b>TOTAL SURPLUS/(DEFICIT) FOR THE YEAR</b>	<b>189,650</b>
Accumulated surplus at beginning of the year	1,196,219
Surplus allocated to:	
Restricted funds	(5,000)
Designated funds	38,750
Unrestricted funds	155,900
<b>Accumulated surplus at the end of the year</b>	<b>1,385,869</b>

Other expenses include research, service delivery and fundraising expenses (refer to audited accounts on ACNC website for full details)

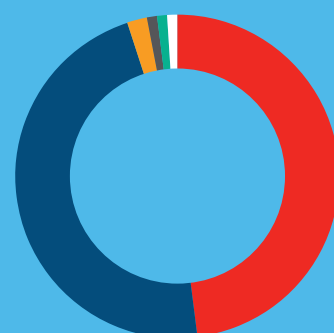


### INCOME

47% ● Donations & Fundraising  
42% ● Dept of Health Contract  
8% ● Grants  
3% ● Other

### EXPENDITURE

Employee Expense ● 48%  
Other Expenses ● 47%  
Depreciation ● 2%  
Cost of Sales ● 1%  
Insurance Expense ● 1%  
Motor Vehicle Expense ● 1%



# Thanks to our supporters...



Government of Western Australia  
Department of Health



Allens > < Linklaters







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**(Cystic Fibrosis WA)**

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Front Cover  
Dylan and Ben Cooper  
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