



**CYSTIC  
FIBROSIS**  
Western Australia

# Annual Report 2018



“”

**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.**

**Our vision**



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# Message from the Patron



## **In December 2018, Deloitte forecast a continuing, albeit slow and steady, improvement to the WA economy.**

That's really important for the not-for-profit charitable sector, which is reliant on a vibrant economy to achieve its mission.

According to Deloitte, Western Australia's Gross State Product (GSP) grew by 1.9% in 2017-18, reversing a decline of 1.8% in 2016-17. The signs are positive for 2019, notwithstanding global turmoil resulting from the USA's tensions with China and the challenges in Europe with Brexit. But we cannot afford to be complacent.

Like any business, Cystic Fibrosis WA (CFWA) needs to contain costs and leverage technology to deliver cost-effective and relevant services to people whose lives are affected by CF. I am pleased, therefore, to see that costs are being contained and even reduced across operations whilst maintaining and even expanding service delivery in certain areas.

This is particularly noticeable in the areas of mental health and education. I must commend the efforts of the services team particularly, in developing a range of resources to address the increasingly important area of mental health. This will require further investment and I am confident that the team will source the additional funds needed in the near future.

I remain constantly moved and impressed by the resilience of particularly young people living with CF. Not only do they have to cope with the demands of modern life and the double-edged sword of technology but also with a chronic, degenerative disease.

The development of new drugs mentioned in the joint President and CEOs' report means that most children born with CF today will successfully transition into adulthood and hopefully lead relatively normal lives with careers, homes and families to look forward to. None of that would have been possible without a global effort driven by passionate parents and supporters.

I meet many of these parents and supporters within CFWA and within the wider community and I am constantly impressed by their efforts. Whilst there may be many different CF organisations around the world, they are all like the spokes of a wheel, all focussing on a common goal to keep lungs healthy and cure this disease. I encourage these organisations to work together to ensure that the hard-won funds raised align in the pursuit of this common goal.



*I believe that we are fortunate indeed here in WA to have community-based organisations like CFWA and Conquer Cystic Fibrosis working together to support the provision of services and world class researchers at the Telethon Kids Institute and the Institute of Respiratory Health. I encourage even closer collaboration to ensure we achieve our vision of Lives Unaffected by CF.*

The work of CFA should also be recognised in driving an effective and successful national advocacy campaign to get new drugs listed on the Pharmaceutical Benefit Scheme and agreeing to bring the 13th Australasian CF Conference here in Perth in August 2019.

Finally, 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**  
Patron



# Message from the President and CEO

**Stepping into the shoes of past president Richard Simons last year was more of a 'step up' than a 'step in' although sometimes I thought I'd stepped right in it! But I have to say that this has been one of the most satisfying years of my life as President and Chair of the board.**

I have been supported by a fantastic board, professional and dedicated staff and wonderful volunteers. I have also had the opportunity to serve as CFWA's nominee director on the board of CFA. This has given me a local, national and global insight into the fantastic progress that is being made. It's also made me appreciate just how fortunate we are in WA.

During 2018, we saw the fruition of our exhausting, but ultimately successful, nation-wide campaign led by CFA, to get Orkambi® listed on the Pharmaceutical Benefits Scheme (PBS). This drug is potentially providing relief to over 70% of people who have cystic fibrosis in WA. But the fight is not over as we continue to lobby for label extensions.

Initial results from phase three clinical trials of a new drug, Symdeko™, are very encouraging. When we add this to the stable of Kalydeco® and Orkambi®, these new drugs promise to provide relief for over 95% of people living with CF. Our dream is to accelerate the listing of Symdeko™ on the PBS once TGA approval has been received. These drugs, and the care we provide, will take us tantalisingly close to achieving our vision of Lives Unaffected by CF.

Of course, here at CFWA, whilst we have invested heavily in research, thanks in large part to the generosity of the late Stan Perron and our wonderful Golf Committee, we are very much at the coal face of community care and education. We are the community extension to the multidisciplinary teams operating in the Perth Children's Hospital and Sir Charles Gairdner Hospital. Together we are striving to keep lungs healthy so that they can benefit from these new drugs as soon as they come on line.

We have completed the first year of our three-year strategic plan and are making good progress, particularly in mental health support services. Our changes to the fundraising strategy are yet to bear fruit but we are hopeful that our investment in technology, particularly our website and the growth in community fundraisers, planned giving, and our new gifts in wills, will soon show positive results. We are very appreciative of the support that we have and continue to receive from Telethon, Lotterywest, the Department of Health WA, sponsors and supporters.

Financially, we budgeted for a small loss of \$24,158 in 2018. Budgeting for a small loss is both possible and strategic, thanks to the reserves that we have built up which enable us to embrace calculated risk. We have further capacity to make strategic investments going forward to maintain momentum in research and service delivery. Although budgeting for a small loss at the end of 2018, we ended up with a small profit of \$26,139 on a turnover of \$2,333,493. This was achieved thanks to improved efficiencies in service delivery and a generous gift in will from the late Doreen Letcher.



*Included in this turnover is \$250,000 allocated to our Little Lungs Big Futures research project run out of the Telethon Kids Institute and donated by the late Stan Perron Charitable Foundation. Importantly, every cent of this donation has gone to the researchers as the cost of the fundraising has been borne by CFWA.*



Details of our audited accounts are included in the Treasurer's Report. CFWA remains financially strong and able to meet its debts, as and when they fall due.

Looking forward, Perth is hosting the 13th Australasian CF Conference in August 2019 and the Biomedical Translation Fund have committed up to \$20m to Respirion Pty Ltd, a spin-off company of Telethon Kids Institute, to fund an exciting project to develop new treatments for patients with cystic fibrosis.

At the forthcoming Annual General Meeting, past President and past Treasurer Richard Simons will be stepping down from the board after nine years of dedicated service. Richard's contribution has been priceless. The success of CFWA is in no small part due to his calm professionalism, mentorship and support. He will be sorely missed. Both Nigel and I thank you Richard from the bottom of our hearts.

In closing, we would both 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 and the hundreds of volunteers who support us throughout the year. It is an exceptional team.

*Finally, we would like to thank you, the members, sponsors and supporters. The year ahead looks fantastic*

but we are aware that we cannot do it all on our own. So, if you have an opportunity to spread the word, please do. If you have an opportunity to engage with friends, relatives and workplaces to establish community fundraisers or regular payroll deductions, please do. It is amazing what just the price of a cup of coffee a day makes if enough people do it. If you have a desire to leave a gift in your will, please do, although we'd like to say there's no rush on this last one.

Working together, we will achieve our vision of Lives Unaffected by CF a lot sooner than we ever dreamed was possible just a few years ago.

**Caz Boyd**  
President

**Nigel Barker**  
CEO

# Policy, Research and Advocacy



**In 2018, we continued to fund Little Lungs Big Futures researchers at the Telethon Kids Institute (TKI) thanks in large part to the outstanding contributions from the Stan Perron Charitable Foundation, the Golf Committee and private benefactors.**

We believe that we are tantalisingly close to achieving our goal of a 50% reduction in structural lung damage in infants under five. Early intervention and treatment will allow them to take full advantage of the new small molecules like Kalydeco®, Orkambi® and Symdeko™ currently being rolled out to reach their full potential unencumbered by CF.

We were also able to support the Australian Cystic Fibrosis Research Trust (ACFRT).

Founded in 1989, the ACFRT has funded over 300 projects valued at over \$6m. Its funded research covers a wide range of topics from hypertonic saline to antimicrobial resistance.

Although not a huge fund, the ACFRT will often provide funds to researchers to enable them to get sufficient data to apply for larger grants from funders such as the National Health and Medical Research Council (NHMRC) and Medical Research Future Fund (MRFF). This is reflected in the work of our PhD Top Up scholars.

2018 also saw success in lobbying to get Orkambi® listed on the Pharmaceutical Benefits Scheme (PBS). This was a national advocacy effort led by CFA but involving literally thousands of people across the nation and employing a mix of direct action, social, print and electronic media.

We hope that the pathway for getting Orkambi® listed can now be used to get other disease-modifying drugs like Symdeko™ on the PBS sooner than would otherwise be the case.

In 2018, CFWA was one of the most significant contributors of funds to CF research in Australia.

It's important to let people know where these research dollars are being spent and what is being achieved. So, in 2018, we again co-hosted the special Evening with CF Scientists at TKI. We also expanded our regional Evening with CF Scientists to include Albany as well as Bunbury, fulfilling a long-term goal of taking research into regional WA.

On the policy front, we won the right to host the 13th Australasian CF Conference here in Perth, to be held in August 2019.

We have continued to update all our resources and placed these on our website [www.cfwa.org.au](http://www.cfwa.org.au) and have brought CFSmart, our schools education program in-house in collaboration with CF Community Care (Vic) to deliver world class e-learning resources. We have integrated these with our new and evolving social media strategy working in close relationship with the CF clinics at PCH and SCGH and other members of the CF Federation.



*Finally, this report would not be complete without special mention of the significant contribution made by the late Stan*

*Perron. His Charitable Foundation has been a long-time supporter of not only CFWA, but also 150 Western Australian charities.*

In recent years, the Charitable Foundation stepped up its commitment to CF by pledging \$1.5m to our Little Lungs Big Futures research campaign. Whilst Stan may have passed away last December, his legacy and the Charitable Foundation will live on and we are looking forward to working with the trustees in the future.

Together, policy, research, advocacy, fundraising and service delivery have combined to drive us closer to our vision of Lives Unaffected by Cystic Fibrosis.

# Services in the Community

CFtalk  
MAGAZINE

lotterywest



**2018 was a busy year! As a committed team, we passionately believe in all the services and support that we offer to the cystic fibrosis (CF) community here in Western Australia. We bridge the gap between home and hospital, and support families in a number of ways depending on their needs and where they are on their CF journey. We regularly talk to our members and adapt our programs to the ever-changing CF landscape.**

Our most recent member needs analysis and strategic plan highlighted the necessity to enhance support and services for individuals and families around mental health.

**2-3  
times**

more likely to experience anxiety and/or depression than the general population.

**82%**

of carers of teenagers in the WA community rate mental health as their biggest concern.

**64%**

of carers of younger children experience feelings of grief, stress and isolation.

To ensure our support and services address both **mental** and **physical health**, a new plan was developed outlining key goals and achievable outcomes. This included mental health training for staff and home care workers, the development of new programs, a number of new resources and financial support.

New resources have been developed thanks to the generous funding of Lotterywest called CF Talk. These include six short films and an online interactive magazine for young people. The aim is to better engage young people and children with CF, thereby improving connection, raising awareness and reducing isolation.

**737**

occasions of face-to-face support (including counselling, social work, community nursing, general support and physiotherapy)

**170**

members attended CFWA events in 2018






Cystic Fibrosis Australia (CFA), in collaboration with CFWA, facilitated separate mental health workshops for community members and health professionals from PCH, SCGH and CFWA. The presenters were mental health experts from USA upskilling WA in mental health awareness and screening.

CFWA facilitated a Mental Health and Transfer Readiness Workshop between CFWA, PCH and SCGH to identify gaps in service delivery around transition/transfer and mental health services. A summary report has been written with the view of developing more youth-friendly programs and resources to ensure smoother transition from paediatric to adult services.



## Financial Support

A New Adult Activity Subsidy was launched in late 2018 as a strategy to improve mental and physical health by removing financial barriers to access activities of choice closer to home, including regional WA. The subsidy is offered to ALL adults across Western Australia at a place of their choosing.

					
	Equipment Subsidy	Adult Activity Subsidy	Kids Activity Subsidy	Adult Regional Travel Subsidy	Telethon Regional Travel Subsidy
No of Subsidies	41	23	38	89	112
Total cost	\$6,285	\$4,492	\$4,971	\$6,850	\$14,200



## Hospital Support

2018 saw the opening of the new Perth Children's Hospital (PCH).

Our services team visit PCH and Sir Charles Gairdner Hospital (SCGH) weekly to offer support to inpatients and provide a gift bag containing toiletries, magazines and snacks.

Trampolining is fantastic exercise for children. In 2018 we gifted 25 trampolines to families.



**190**  
Child  
Hospital Bags



**124**  
Adult  
Hospital Bags

## Member Support Events

We know how important taking a break from the caring role is for the wellbeing of our parents and carers.

Member support events are designed to provide an opportunity for our community to come together, build relationships and create important support networks.

Due to cross-infection issues, we are unable to host events for people with CF; instead we target parents, carers, siblings, offspring and other family members and friends.

## Ladies' High Tea



## Parent's Dinner



***"You can't pour from an empty cup, take care of yourself first"***

## Parent's Retreat





## Sibs Camp



“”

***“the best thing is that you know that there are people out there like you”***

***“It’s great to understand how others feel”***

“”

***“It’s a great experience and you can learn more about what your sibling is going through”***

***“Go to CF camp and you will make new friends and you’ll have fun”***

“”

***“Come to camp it is an experience of a lifetime and you can get a sense of independence”***

***“It is a fun experience and a chance to have a break from your family”***

***“Very enjoyable, it’s fun”***

“”

***“Sharing something all together”***





## Homecare Worker Support

We continue to deliver vital services to the Western Australian CF community as per our contract with the WA Department of Health. We collaborate with our tertiary hospitals to ensure best practice and quality care for people with CF and their families.

In 2018, our home care workers (HCWs), located throughout the Perth metro area and Bunbury, provided **4,513 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.



Our Physiotherapist provides training at our monthly Home Care Worker meetings.



We delivered  
**230 HiTH visits**  
in 2018.



## Hospital in the Home

Hospital in the Home (HiTH) is a PCH-based program which is supported by CFWA. This vital service provides extra support to families so that they can leave the hospital environment, however, still continue their prescribed hospital treatments but in the comfort of their own home. CFWA HCWs provide daily airway clearance support which is a necessary service for this program.



The HiTH Program allows children to finish their treatment at home.



# Home Care Worker Feedback

We recently asked our parents to provide some comments about their HCW and the service they provide.

“”

*“Thank you CFWA and our HCW for your amazing help and support this year! We are so thankful”*

“”

*“Worth their weight in gold”*

“”

*“She is a dream.. keeps the monotony of physio positive and light. Thankyou... Her patience is commended.”*

“”

*“She is an absolute treasure and deserves massive thanks”*

“”

*“This service is brilliant as it reduces the time spent in hospital and we can continue to function as a family in our own home. It eliminates one parent always having to be at hospital”*

“”

*“I have found her service to be exceptional and she has been such a great help to me and my family. Our son isn't an easy child and she manages him really well.”*

“”

*“Our HCW has been so fabulous with our daughter and we really appreciate her assistance”*



# CF Education Program

CFSmart is a national education program for teachers, parents, carers and children in the community. Initially developed in Western Australia in 2012, CFSmart continues to grow in resources and viewership.

The aim of CFSmart is to improve understanding of cystic fibrosis within the school community. This is important to students with CF in order to feel supported and understood in terms of their health, education, and emotional requirements.

In 2018, our CFSmart stats were:



**6,500**

Clocked YouTube viewings (2014-2018) for the 'Good Clean Hands' video.



**1,173**

followers on the CFSmart Facebook page.



**383**

eLearning modules completed.

Face-to-face CF Smart education sessions provided in 2018



**39 school education sessions**



**645 children**



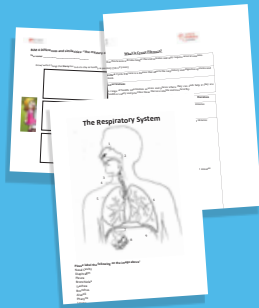
**486 adults**



Thanks to Lotterywest, in 2018 we produced a number of new resources to complement our CFSmart suite.



**Starting School with Cystic Fibrosis**



**A range of teacher lesson plans**



**New 'Sleeve Sneeze' poster**



**CF Explainer Video**



**To access and download our full range of free resources please visit [cfsmart.org](http://cfsmart.org)**

## Health Professional Education

In 2018, we provided health professional training to regional clinical and allied staff in the following areas:

*“Outstanding education opportunity for me. Going home with a new passion”*

*“A priceless tool of current research for all of us who choose to live and work regionally, a huge benefit in not only upskilling me clinically but also increasing my confidence to apply this at work”*

**In 2018 we educated 117 health professionals from regional WA**





# Fundraising & Marketing

**Thanks to the generous commitment of our CF community, 2018 included incredible personal challenges and commitments in fundraising for CFWA. Improvement of support processes and access to merchandise and promotional material meant that our community could also provide an important awareness role in our wider communities.**

Fundraising and Marketing activities in 2018 focused on building stronger relationships in our CF community and extending business relationships. Maintaining fundraising costs in line with community expectations, whilst growing our major events and providing improved community fundraising support, achieved strong engagement with workplaces and our energetic CF community.

## Key successes for 2018 were:

- ✓ Growing 65 Roses Day to a new volume of 15,000 roses
- ✓ Successful grant and fundraising initiatives to provide trampolines and nebulisers for CF children
- ✓ Growing a sustainable community fundraising model to include repeat fundraisers with community groups.



## Communications and Media

2018 was a year of great community engagement through all of our communication platforms.

### Social Media

We achieved very strong Facebook engagement with a 9.4% increase in followers in 2018. We achieved a moderate increase of 6% to our Twitter followers. We overhauled the CFWA LinkedIn account in 2018, targeting supporters with a focus on corporate engagement, and achieved an 18% growth in followers. We launched an Instagram account in January and achieved 544 new followers in the first year, our fastest-growing communications channel for the year.

### Newsletter and RED Magazine



*Our new website performed very well in 2018 with over 18,000 visitors to the site. RED Magazine was produced 4 times for the year and distributed to over 750 readers.*

### Traditional Media

We engaged PR company Devahasdin again in 2018, with a particular focus on our 65 Roses campaign and the PBAC listing of Orkambi®. With their support we achieved an incredible PR value of over \$1.1 million and circulation reach of over 2 million.

A major achievement was the Network 10 news story featuring two young sisters with CF around the PBAC Orkambi® decision. This story appeared on the Network 10 evening news (over \$100K PR value) and was viewed over 62,000 times on the Network 10 Facebook feed.



## BIG Engagement in 2018



CFWA Website	Facebook	Instagram	E-News	RED Magazine	Twitter	LinkedIn
18,178 Visitors	3,598 Followers	544 Followers	3,200 Readers	750 Readers	1,261 Followers	168 Followers



### Pre-Orkambi® PBAC Decision / 19 April 2018

Young sisters Isobel and Ruby with mum Christine shared their story with Network 10 evening news in the lead up to the PBAC Orkambi® decision.

**Facebook video achieved over 62,000 views, 314 likes, 759 shares and 86 comments.**



### 65 Roses Optus Stadium / 21 May 2018

Junior ambassador Jayton Carter and brother Patrick in front of the Optus Stadium, lit red for cystic fibrosis on the week of 65 Roses Day.

**Facebook post reached 22,362, had 1,898 engagements (likes/shares etc.) 2,146 website clicks.**



### Alex, 65 Roses West Australian Article / 22 May 2018

Alex shared her story with the West Australian from hospital during 65 Roses week, with a call to action to join Cystic Fibrosis WA on the streets of Perth for 65 Roses Day.

**West Australian online article achieved \$138,435 PR value and was shared by Alex on her social media page with over 13,000 followers.**



### Orkambi® Successful PBAC Listing / 17 August 2018

The announcement that Orkambi® had been listed for reimbursement on the PBAC achieved great engagement in the CF community.

**Facebook post reached 21,246 people, generated 2,284 engagements (likes/shares etc.) and 2,784 website clicks.**

## Major Events and Campaigns

### 65 Roses Day Campaign

In 2018, the 65 Roses Day campaign, our month-long awareness and fundraising campaign that culminates in the selling of roses on one day across WA, achieved more awareness and rose sales than ever before. Together with partners WAFEX, Telstra, South Metropolitan TAFE, and new sponsor Iris Residential, a new sales total of 15,000 roses was achieved through our amazing volunteers and supporter organisations across the state.

Our 2018 rose sales were boosted by a new range of bouquets and posies with the support of our dedicated and experienced volunteer florists. Our regional teams once again took on the added role of arranging wrapping events in their local communities before delivering and selling roses, with regional transport companies transporting roses to all our regional locations.

Fundraising achieved a net profit of \$68,615, and our PR campaign achieved a circulation reach of 2,148,998. Our 44 stalls were bolstered by individuals selling roses in schools and businesses.

Metro Stall Locations	Regional Stall Locations	Total Volunteers
34	10	300+

### 65 Roses Challenge Campaign

Every year committed fundraisers take on personal challenges through our 65 Roses Challenge campaign. In 2018, fundraisers challenged themselves to some amazing feats.

The teams at Vault Fitness and Exchange Tower hosted the two-day '65 Roses Spin Challenge' where teams from Exchange Tower and surrounding buildings challenged themselves to a short, intense spin cycle activity raising money for CFWA.

The CF Goldfields group smashed their fundraising target within the first week for their 'Cape to Cape Walk'. Regular fundraisers Shari and Mathew took on an amazing six day Nepal Trek. Challenges in Shark Bay and Bridgetown rounded out our campaign that raised a net profit of \$61,349.







## The George Jones Family Foundation CF Golf Classic

This year's Golf Classic moved to the second half of the year with renovation of the greens at Lake Karrinyup Country Club affecting the previous April schedule. The move to November was very successful and will be continued in 2019 allowing our two major events to be spread over the calendar year.

The George Jones Family Foundation continued as the naming rights sponsor and the event was strongly supported with 31 registered teams. Net income was \$92,752, of which \$75,000 was allocated to CF research.

## Community Fundraising

Partnerships with annual fundraisers including the Corporate Battle of the Bands, NIBA Lunch, Red Tie Dinner Dance, and Busselton Golf Day continue to produce successful events with positive outcomes. The Red Tie Dinner Dance included the new 'Fund a Need' initiative that raised \$18,200 for 52 nebulisers.

Third-party events such as the HBF Run for a Reason, Rottnest Channel Swim, Chevron City to Surf, the Colour Run and CBRE Walk for a Wish were again successful in engaging fundraisers for CFWA, achieving a total of \$29,120 funds raised.

Community partnerships initiated in 2018 facilitated new fundraising opportunities such as the Consulate Court Christmas Lights fundraiser which occurred across December, raising \$9,311 through donations and the merchandise sales.

Thank you to all the people who gave their time, energy and resources to raise significant awareness and much-needed funds for children and adults living with cystic fibrosis in WA. Community fundraisers continue to be appreciated in support of our members through services programs.







## Sponsors, Supporters and Volunteers

**During 2018, our team of 300+ dedicated and generous volunteers gave over 1,500 hours of their time towards awareness and fundraising for cystic fibrosis.** This is an amazing outcome and CFWA looks forward to continued strong volunteer support.

Our annual Sponsors and Volunteers Awards Evening held in December recognised the contributions made by volunteers and sponsors for CFWA events and campaigns throughout the year. This year, the 65 Roses Award was renamed the “Lappa 65 Roses Spirit Award” to honour the memory of Wojciech Lappa, an inspirational role model who was an integral part of the cystic fibrosis community.





Award	Recipient
Fundraiser of the Year	CF Goldfields Group
Supporter of the Year	South Metropolitan TAFE Bentley
Volunteer of the Year	Kandace Boyd
Long Service Award	Michael Mansell
Lappa 65 Roses Spirit Award	Brooke Murphy

## CFWA Ambassadors and Community Representatives

**Every year, generous members from the CF community share their stories with local and national media to help spread awareness and raise funds for CF.**

In 2018, over 20 CF families shared their stories in the media during 65 Roses month and through the year. The stories of our ambassadors and community representatives showcased the different journeys and experiences that people living with CF go through, raising important awareness for the cystic fibrosis community. Thank you to everyone who has been involved in 2018 for helping to spread awareness for cystic fibrosis.

**Here are just a couple of the many ambassadors and community representatives who helped us spread awareness of CF in 2018.**



Sam was one of our junior 65 Roses Ambassadors in 2018. He and his family shared their story in the local media and volunteered their time on 65 Roses Day.



Lyla was one of our junior 65 Roses Ambassadors in 2018. Lyla's family and friends ran a 65 Roses fundraiser at their school and a local shopping centre.

## Grants and Other Income

Grants and other donations continued to have a positive budget impact with a number of specific programs supported through grants. Donations through our Tax and Christmas Appeals along with regular giving and general donations, continue to reflect the generous nature of individuals and workplaces in supporting CFWA outcomes.

**A generous gift in will was also received in 2018 from the estate of Doreen Letcher**

Grants		
<b>Lotterywest</b>	<b>\$45,516</b>	<b>Parents' Weekend / Newly Diagnosed Resources / CF Talk / Communications Program</b>
<b>Channel 7 Telethon Trust</b>	<b>\$83,350</b>	<b>Providing support for regional members including education, travel subsidies and social events</b>
<b>BankWest Easy Grants</b>	<b>\$182</b>	<b>Ladies' High Tea</b>
<b>Aurizon</b>	<b>\$8,864</b>	<b>Trampolines</b>
<b>Cadbury Community Grant</b>	<b>\$400</b>	<b>Patient Support (subsidies)</b>
<b>Mazda Foundation</b>	<b>\$2,757</b>	<b>Sibs Camp</b>
<b>Carers WA</b>	<b>\$700</b>	<b>Parents' Dinner</b>
<b>City of Nedlands</b>	<b>\$909</b>	<b>Parents' Dinner</b>
<b>Vertex Australia</b>	<b>\$7,884</b>	<b>Mental Health / Transition Workshop</b>
Gifts in Wills		
<b>Doreen Letcher Estate</b>	<b>\$137,550</b>	<b>Gift in Will</b>
Appeals		
<b>Tax and Christmas Appeals</b>	<b>\$83,826</b>	<b>Individual and workplace donations supporting direct appeals</b>
Regular Giving and Donations		
<b>Donations</b>	<b>\$41,959</b>	<b>Individual and workplace giving, and general donations</b>

# 2018 Gifts-in-Kind and Pro Bono Support

## Volunteers

1,500+ volunteer hours

300+ volunteers

## Pro Bono

\$5k pro bono legal from Herbert Smith Freehills

\$1.5k pro bono freight support for 65 Roses Day

## Gifts-in-Kind

\$73,476 of donated gifts-in-kind for events and member support





# 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.



## 1970s

## 1980s



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 Home Care 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 Home Care Service began.

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 Telstra Business Awards state charity category.



In **2017**, we 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, embarked upon a major ICT upgrade, replacing ageing computer hardware and transitioning to cloud and launched our new website [www.cfw.org.au](http://www.cfw.org.au)



In **2018**, we continued to achieve remarkable things:

- ✓ Successfully lobbied to get Orkambi® listed on the PBS, only the second drug to treat the underlying cause of CF.
- ✓ Increased rose sales to a record 15,000 stems, up from 1,250 in its first year raising much-needed funds during 65 Roses Day.
- ✓ Successfully lobbied to host the 13th Australasian CF Conference here in Perth in 2019.

# Board 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
- ✓ Supporting our fundraising and lobbying

## Board Attendance Register

Elected members	Eligible to attend*	Attended	Attendance %
Carolyn Boyd	11	10	91%
Simon Martin	11	9	82%
Rachael Hosking	11	9	82%
Feliciano Sanchez	11	5	45%
Ken See	11	10	91%
Richard Simons	11	8	73%
Co-opted members			
Simon Trevisan	6	4	67%
Tim Sharp	5	5	100%

**President**



**Carolyn Boyd**

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 and President in 2018.

**Vice President**



**Richard Simons**

Richard is the CFO for Clough and has over 30 years' experience as a senior executive. Richard joined the board of CFWA in 2009, served as Treasurer and was elected president in 2014 and Vice President in 2018. He will step down from the Board at the 2019 AGM.

**Treasurer**



**Simon Martin**

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.

**Board Member**



**Feliciano Sanchez**

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 positions and is currently a special skills Director on the Board of CFA.

**Board Member**



**Ken See**

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.

**Board Member**



**Rachael Hosking**

Rachael was formerly 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.

**Board Member**



**Simon Trevisan**

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 served on the board of CFWA from April 2017 to July 2018.

**Board Member**



**Tim Sharp**

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 served on the board from July 2017 to November 2018.

# Treasurer's Report 2018

## 2018 delivered a small surplus of \$26,139 on a turn-over of \$2,333,493.

This included a \$250,000 donation from the Stan Perron Charitable Foundation, 100% of which was forwarded to our Little Lungs Big Futures researchers at the Telethon Kids Institute.

Operating expenditure was 2.5% lower than 2017 at \$1,954,672.

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 \$803,826 compared to \$657,165 at the end of 2017. The cash holdings and funds held as investments of \$1,062,753, up from \$956,852 at the end of 2017, means 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.

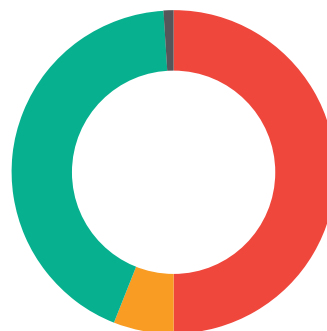
The financial statements for the year ended 31 December 2018 have been audited by Mr James Komninos of RSM Australia Pty Ltd and a copy of the signed accounts are available for inspection by members on the ACNC website. An extract of the financial statements has been included in this report – refer the adjacent page.

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

## Income 2018



**43%** Donations & Fundraising  
**50%** Dept of Health Contract  
**6%** Grants  
**1%** Other

## Cost of Sales 2018



**1%** Cost of Sales  
**55%** Employee Expenses  
**40%** Other Expenses  
**2%** Depreciation  
**2%** Insurance Expenses



# Financials

## Income & Expenditure Statement

Revenue	\$2,333,493
Cost of sales (merchandise)	-\$27,682
Employee benefits expense	-\$1,266,861
Depreciation	-\$21,421
Motor vehicle expense	-\$9,591
Insurance expense	-\$34,970
Other expenses	-\$919,431
<b>OPERATING DEFICIT FOR YEAR</b>	<b>-\$2,279,956</b>
OPERATING SURPLUS (DEFICIT) FOR THE YEAR	\$53,537
Office refurbishment depreciation	-\$27,398
<b>TOTAL SURPLUS/ (DEFICIT) FOR THE YEAR</b>	<b>\$26,139</b>
Accumulated surplus at beginning of the year	\$1,385,869
Transfer to accumulated surplus	\$99,146
Surplus allocated to:	
Restricted funds	\$0
Designated funds	\$0
Discretionary funds	\$75,000
Unrestricted funds	-\$48,861
	\$26,139
<b>Accumulated surplus at the end of the year</b>	<b>\$1,511,154</b>

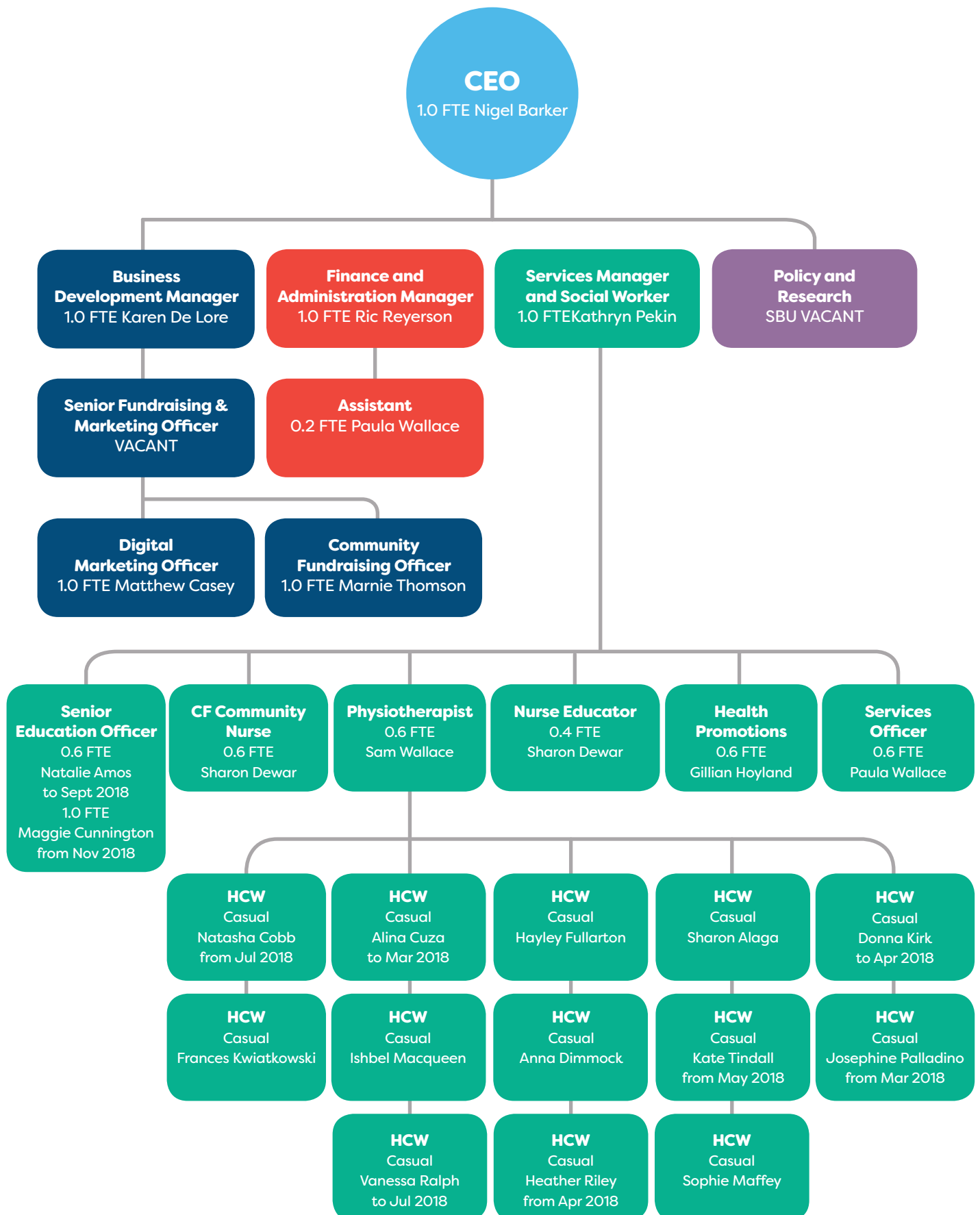
Restricted funds represent \$10,000 donation set aside for Developing Mental Health/Youth Program in the prior financial year. Designated funds represent money set aside for PhD Top Up Scholarship.

Discretionary funds represent funds set aside for research funding at the board's discretion.

## Balance Sheet for year ending 31 Dec 2018

<b>CURRENT ASSETS</b>	<b>\$</b>
Cash & cash equivalents	\$803,826
Financial Assets	\$231,083
Trade and other receivables	\$161
Inventories	\$2,958
Other current assets	\$27,009
<b>TOTAL CURRENT ASSETS</b>	<b>\$1,065,037</b>
<b>NON-CURRENT ASSETS</b>	
Financial assets	\$831,670
Plant and equipment	\$362,506
<b>TOTAL NON-CURRENT ASSETS</b>	<b>\$1,194,176</b>
<b>TOTAL ASSETS</b>	<b>\$2,259,213</b>
<b>CURRENT LIABILITIES</b>	
Trade and other payables	\$393,936
Provisions	\$333,069
<b>TOTAL CURRENT LIABILITIES</b>	<b>\$727,005</b>
<b>NON-CURRENT LIABILITIES</b>	
Provisions	\$21,054
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>\$21,054</b>
<b>TOTAL LIABILITIES</b>	<b>\$748,059</b>
<b>NET ASSETS</b>	<b>\$1,511,154</b>
<b>MEMBERS' FUNDS</b>	
Accumulated surplus - restricted	\$10,000
Accumulated surplus - designated	\$61,250
Accumulated Surplus - discretionary	\$75,000
Accumulated surplus -unrestricted	\$1,364,904
Financial asset reserve	\$0
<b>TOTAL EQUITY</b>	<b>\$1,511,154</b>

# Organisation Chart 2018



# Thanks To Our Supporters...

We receive generous support from a large number of individuals and organisations every year. Thank you to our major supporters for 2018.



Government of Western Australia  
Department of Health







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**(Cystic Fibrosis WA)**  
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