



**CYSTIC
FIBROSIS**
Western Australia

Annual Report 2019



Our Vision

“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



Traditionally, annual reports look back at the year that has been and the achievements of the company in meeting the needs of their customers profitably. This report is no different in that respect and we should celebrate the achievements of the team at Cystic Fibrosis WA (CFWA) in delivering some outstanding outcomes, not only financially, but also from a service delivery aspect.

Over the course of 2019, we have seen the range of services adapt to meet the changing needs of clients as the full benefit of new treatments becomes felt and the nature of the disease changes.

No longer is CF an early death sentence for newborns. Many living with CF today will see their disease transition from a degenerative disease to a static bronchiectasis and with appropriate treatment, will achieve our vision of Lives Unaffected by CF.

Last year, I commented on the need to source additional funding to ramp up mental health services and I am delighted to see this was achieved thanks to the support of the state government and agencies like Lotterywest and Telethon.

I am also pleased at the progress that has been made by our CF researchers, particularly here at the Telethon Kids Institute, and I am looking forward to seeing some early runs on the board in the area of phage therapy in late 2020. This is vitally important research which offers a viable alternative to the ever-decreasing pool of antibiotics available to fight infection, not only for people living with CF, but for everyone.

As I sit down to write this summary however, it is against the background of a coming storm called COVID-19. This pandemic has already disrupted

business across the world and the not-for-profit sector. The sector that relies on a strong and vibrant economy for its success is now under serious threat.

CFWA is better placed than some to weather this storm. This is thanks to prudent management, good governance and the performance of the WA economy in 2019. This has given us a strong balance sheet which, in turn, has allowed CFWA to be proactive in managing its affairs during this crisis.



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CFWA has got on the front foot early and has invested in online technology which will counter the loss of income from mass participation events. Sadly, this includes the HBF Run for Reason and the Conquer Cystic Fibrosis Ball in 2020, the latter of which has made a significant contribution to CF research over the past few years.

Now more than ever we need to work together to unite our efforts in pursuit of our common cause. I am confident that the power and passion of our supporters will see us through, and I encourage everyone to dig deep to support us in the year ahead.

A stylized, handwritten signature in black ink, consisting of a large loop and a trailing line.

John Rothwell AO
Patron

Message from the President and CEO

2019 will surely go down in the annals of Cystic Fibrosis WA's history as a year to remember. It was the year when we hosted the 13th Australasian CF Conference and witnessed an unprecedented 20% growth in attendees across both the medical and lay delegates. The figures at the conference reflected the strength of the CF community here in Western Australia. It gave many of our members a unique once-in-a-lifetime opportunity to attend an international conference on a matter deeply embedded in our hearts. Thanks to Cystic Fibrosis Australia for agreeing to bring the conference here to Perth.

2019 also saw the benefits of new therapies such as Kalydeco® (listed in 2014), Orkambi® (listed in 2018), and Symdeko® (listed in March 2019) really start to be felt and with Tricafort® and Elexacaftor® in the pipeline, we are seeing unprecedented transformation of cystic fibrosis from a degenerative disease to a static bronchiectasis.

The CFWA team has been proactive in developing new programs and services to meet these needs and will be participating in the development of a new Model of CF Care in 2020.

In 2019, our services team focused on the implementation of our mental health strategy to increase engagement, resilience and self-care. This is thanks to funding received from Lotterywest and Telethon. This included the employment of a new social worker; subsidies to enable carers to attend the Australasian CF Conference; a new mental health gap subsidy; and fitness subsidies particularly increasing engagement with the increasing number of adults living with CF.



Nigel Barker
CEO



Caz Boyd
President

“”

We are indeed fortunate to have had the opportunity to build up the reserves of the association to weather this storm, which is likely to have a profound impact across the whole of society and particularly the not-for-profit sector.

In addition, we received outstanding support from the Department of Health WA to deliver our comprehensive home care services, regional respiratory training program, regional outreach programs and a massive increase in our schools education program.

Recognising the growing importance of online communications, we are proud to have established a dedicated communications team which is responsible for all our print and electronic media across both service provision, fundraising and administration. This has already shown results with huge increases in online traffic and a well maintained up-to-date information resources.

The wider community has never been more engaged with our fundraising. 2019 saw almost 30% increase in revenues for 65 Roses month, a wonderful 16.5% increase in Golf Classic revenues and over 21% increase in revenues from our collection tins thanks to the wonderful work of our in-house volunteer Chris Brambleby.

In 2019, we continued to invest heavily in research, thanks in large part to the generosity of the late Stan Perron, our wonderful Golf Classic committee, sponsors and supporters. These funds supported AREST CF at Telethon Kids Institute as well as two new PhD Top Up Scholarships for 2020.

Financially, a challenging year turned out to be a stellar year, thanks to the efforts of our fund managers at Entrust, fundraising, communications and services teams which together delivered a profit of \$165,502 on a turnover of \$2,446,858. A proportion of this is unrealised, but nevertheless, we finished the year well ahead of budget having delivered in excess of our contracted outcomes to meet the needs of people whose lives are affected by CF. Special thanks should go here to our dedicated home care workers who delivered over 4,000 occasions of service to people in their own homes and to our small but highly efficient

admin team who ensured that all grants were properly acquitted and all administrative tasks were completed on time and on budget.

Details of our audited accounts are included in the Treasurer's Report.

Financially and structurally, the organisation is well placed to meet the challenges in the year ahead. Our Patron, John Rothwell AO, has touched on these challenges in his report so we will not repeat them here. We are indeed fortunate to have had the opportunity to build up the reserves of the association to weather this storm, which is likely to have a profound impact across the whole of society and particularly the not-for-profit sector.

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 exceptionally challenging. Now, more than ever, we will be reliant on the goodwill and philanthropy of everyday Australians. 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. And if you have an idea for an online fundraiser, please get in touch with us.

Working together, we are moving closer to our vision of Lives Unaffected by CF a lot sooner than we ever dreamed possible. In 2020, we will be working hard to position CFWA as a service provider of choice for people living with CF and striving hard to ensure that no one is left behind.



Policy, Research and Advocacy



In 2019, 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 Classic committee and private benefactors.

We were also able to award two PhD Top Up Scholarships – taking the total funded to 10 – thanks to the CFWA Golf Classic committee which is on track in 2020 to crack over \$1m in donations since its establishment 10 years' ago.

The work that we commenced funding under the Little Lungs Big Futures (LLBF) campaign has achieved some remarkable results. Over 200 publications in 10 years, citations from researchers at 160 institutions in 90 countries and data used to support funding applications to FDA, EMA and TGA for cystic fibrosis transmembrane regulator (CFTR) modulators. These modulators have resulted in a paradigm shift in the treatment of CF such that they are now being introduced at 2-years of age in the US. The nature of the disease itself is on course to transition from a degenerative disease to a static bronchiectasis in adults and prevention in children.

One of the exciting outcomes of the LLBF project has been the development of new unique phage therapy program at TKI.

With the world running out of new classes of antibiotics, consumers identified preventing lung disease progression and antimicrobial resistance (AMR) as their two top priorities in a survey of over 1,900 people living with CF. The WHO declared AMR a major threat with up to 10 million annual deaths possible by 2050 if not addressed.

The team at TKI, led by Professor Kicic, is making good progress in the establishment of a bio bank of viruses and is on track to secure compassionate use for certain patients with CF in late 2020. None of that would have been possible without the core funding from The Stan Perron Charitable Foundation, the Golf Classic committee and private benefactors.

We hope to secure further funding to fast track this project in 2020.

2019 also saw success in lobbying to get Symdeko® listed on the Pharmaceutical Benefits Scheme (PBS) and extensions to the labels for Orkambi®. This was a national advocacy effort led by CFA but involving literally thousands of people across the nation.

In 2019, 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 2019, we again co-hosted the special Evening with CF Scientists at TKI and in the regions. The advent of the COVID-19 pandemic has forced the delay of these presentations, however, we are looking at using video conferencing as an alternative to ensure that people don't miss out in 2020.

On the policy front, we hosted the 13th Australasian CF Conference here in Perth in August 2019 with record numbers of attendees in both the lay and medical streams.

We have also made significant updates to all our print and electronic resources and placed these on our website www.cfwa.org.au

We are particularly proud of our collaboration with CF Community Care in delivering CFSmart – our schools education program – across the whole of Australia.

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

Services in the Community

In recognition of the diverse needs of our CF community, we have implemented a range of new initiatives to engage meaningfully with people with CF, parents and carers. Currently in WA, we have more adults than children living with CF and more males

than females. As new modulator therapies emerge, health outcomes continue to greatly improve. Services and education work alongside these treatments to help maintain and improve health.

In 2019, the services team focused on the implementation of a new **mental health strategy** to increase engagement, resilience and self-care amongst parents, carers and people living with CF.

Lotterywest funded a new youth engagement program, short films for parents, carers and volunteers, and Australasian CF Conference packages for parents.

A youth-friendly social worker was recruited and has since engaged with a large cohort of young people with CF between the ages of 12-23. Strategies introduced have addressed the issues of self-care, developing resilience, personal strengths, independence and adherence to treatment.



54%



46%

*Ratio of adults to children



54%



46%

*Ratio of males to females

2-3
times

Young people and their carers are more likely to experience anxiety and/or depression.

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.

85
occasions

of face-to-face counselling/social work

218

people attended CFWA events in 2019





“”

Thanks to CFWA for all the great work it does for people living with CF

Financial Support

A new 'mental health gap subsidy' was introduced late in 2019 to provide gap funding for individuals to access subsidised, community-based psychologists or counsellors.

An increased demand for financial support throughout 2019 has seen us engage with other support agencies including Foodbank and Good360.

				
	Equipment Subsidy	Kids Activity Subsidy	Adult Regional Travel Subsidy	Telethon Regional Travel Subsidy
No of Subsidies	14	29	83	129
Total Cost	\$2,544	\$4,387	\$7,350	\$15,050

Exercise is well documented to improve both mental and physical health. In 2019 we developed a very successful adult activity subsidy, that has provided equity for ALL adults to access an activity program, of their choice across the whole of Western Australia.

44
adults

received the PT Gym Subsidy totalling \$26,425

73%

said the barrier to achieving fitness goals was financial

93%

increased their exercise regime since receiving the subsidy

We were also able to provide:



493

Support Packages for members



49

InnoSpire Go Nebulisers

“““

It has now been 6 months since CFWA have contributed to my fitness grant. I entered a fitness challenge and came first out of 19 contestants. So, thankyou CFWA for this grant as it has taken my fitness to the next level with a whole new life changing experience. I will continue training hard as I have never been this healthy in my nearly 40 years of life



Home Care Worker Support



Government of Western Australia
Department of Health

We continued to deliver our vital home care worker (HCW) support program in the community. We collaborate with key stakeholders and the Health Department of WA to ensure best practice and quality care for people with CF and their families.



Our HCWs provided **4366** occasions of service to individuals and families living with CF in Western Australia. Services included support with airway clearance and exercise, respite, light home duties and other general support as required.



We delivered **240** Hospital in the Home visits. This vital service provides extra support to families so that they can leave hospital and continue their prescribed treatment in the comfort of their own home.



We provided **292** occasions of support via third-party agencies to our regional and metro families.

“““

Just a note to say thank you for all the support and care offered to us by CFWA this year. Our HCW support has been fabulous, and also the financial support has helped us through a very difficult time.

Member 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, grandparents, carers, siblings, offspring and other family members and friends.

“”

I would love to thank you for the beautiful grandparents' morning tea, lovely spread, good meeting other grandparents and great to hear all the information. Well done.

Parents Dinner at Australasian CF Conference

The biannual Australasian CF Conference (ACFC) was held in Perth after a 22-year hiatus. It provided a fantastic opportunity for our lay community to hear about the latest advances in CF care, research and treatments from experts around the world.

Both the Lay and the Medical Conferences **saw a 20% increase in attendance** to that of the previous one held in Melbourne in 2017.

Thanks to the support of Lotterywest and Telethon, we were able to provide subsidy packages to attend this two-day event in lieu of our annual parents' retreat. Our packages included support with registration, overnight accommodation, and attendance at the CF Parents and Carers Dinner where **over 100 parents and carers** came together and enjoyed an evening of networking and social support within the cystic fibrosis community.



Ladies' High Tea



“”

Thank you so much for organising such a beautiful high tea with a painting lesson to boot! Very inventive and lots of fun and laughs.



Parents Dinner



“”

I'm blown away by how much organisation went into every part of it, and it was a lovely opportunity to be among the CF community.



Sibs Camp

“”

He had an absolute blast at sibs camp. I'm sure you heard how he had only just returned from a school trip to Sydney and Canberra...

well he'll tell anyone who asks that sibs camp was better! Considering the school trip cost me \$1,500, you guys must be doing something right!



Health Professional Education

This year we welcomed a record number of nurses and physiotherapists from regional WA to our annual Regional Respiratory Training Program (RRTP).

The RRTP is endorsed by the Australian College of Nursing. It is a collaborative project supported by the major tertiary hospitals. The five-day intensive program aims to improve CF knowledge, awareness and professional connection within the regions.



Outreach Program

2019 was a busy year! Families living in regional WA are supported through our outreach program.

We target our visits to families and their individual requirements. The visit may include school education, health professional education at a regional centre, or face-to-face support for the family.



In 2019, we educated 76 health professionals from regional WA

“““

Thank you. This program is a priceless tool of current research for all of us who choose to live and work regionally.

CFSmart Education Program

CFSmart is a national education program for teachers, parents, carers and children which improves the understanding of CF within the school community. This is important for students with CF in order to feel supported and understood in terms of their health, education, and emotional requirements. Initially developed in Western Australia in 2012, CFSmart continues to grow in resources and viewership.

“““

I loved this presentation. It was informative, easy to understand and very thorough.



“““

This session helped me understand how I can plan my lessons in advance and the precautions I can take to help those children.

2019 Education Stats



8,014

Clocked YouTube viewings (2014-2019) for the 'Good Clean Hands' video.



1,216

followers on the CFSmart Facebook page.



601

eLearning modules completed.

We provided face-to-face education to:

Adults	Children	Education sessions delivered
592	318	48








CFWA Early Learning Night for Parents






The Early Learning Night, for parents of children starting school in 2020, was a highly informative and well attended event which addressed concerns regarding CF in the school community. This event included wonderful guest speakers from Perth Children's Hospital and the Ronald McDonald Learning Program, as well as lots of information and support from CFWA. The 2019 Early Learning Night has increased communication with parents and educators and boosted the interest of CF education sessions within schools in WA.

“““

I liked that I could chat with the other parents and it reinforced what I knew and where to get the support from.

Snapshot of CFSmart Website Reach for 2019

					
Country	USA	Canada	United Kingdom	Ireland	China
Views	1,779	114	187	47	125

					
Country	Philippines	Australia	New Zealand	Brazil	India
Views	51	3,604	31	18	31



Fundraising

Cystic Fibrosis WA is very proud to have a community of passionate supporters that donate, fundraise and participate in our events. Incredible personal challenges and ongoing individual commitments were the foundation of CFWA fundraising in 2019.

The generosity of our supporters allows CFWA to continue to provide essential support services to the CF community in WA and provide funding for critical research that one day will enable us to achieve our vision 'Lives unaffected by CF'. Extending business relationships and building stronger relationships in our CF community was the focus in 2019. Expanding on our extremely popular major events and increased support for our large volume of community fundraisers has continued to deliver strong results.

In 2019, we saw most of our diverse income streams deliver above 2018 figures. The top performing fundraising activity was the George Jones Family Foundation Cystic Fibrosis Golf Classic raising over \$162,000 – a 16.5% increase from 2018. 65 Roses Day and May month fundraisers raised over \$97,000 combined, which was an increase of 29.8% on 2018. Our appeals raised over \$89,000 and when you combined all our amazing community fundraisers, together they raised over \$83,000. The HBF Run for a Reason raised over \$35,000 and our collection tins, located in over 120 locations, raised over \$12,000 – an increase of 21.7% on 2018.



428
new donors in 2019



2,424
is the number of
donations received



16,500
roses sold during 65 Roses
Day – a record amount



Major Events and Campaigns

65 Roses Campaign

The 65 Roses campaign, including our signature awareness and fundraising event 65 Roses Day, and activities held in celebration of the national month of awareness for CF, were a great success again in 2019. On 65 Roses Day, we sold 16,500 roses and had hundreds of rose sale sites and community fundraising activities occurring across the state.

Through the support of hundreds of volunteers, fundraisers, supporters and sponsors, the campaign raised a total net profit of \$76,889.

Metro Stalls	Regional Stalls	Community Stalls
30	12	150

65 Roses Challenge

The Cape Crusaders made their debut appearance and took on the Cape to Cape Trek. Board member and CFWA member Rachael and her friend, Kathryn, donned their capes and trekked in support of CFWA. They raised more than \$7,545 through online and face-to-face fundraising.

The Vault Fitness Spin Challenge occurred again, this time across three days with Vault Fitness' Todd cycling all three days in support of CFWA. They raised a total of \$8,880 for CFWA.

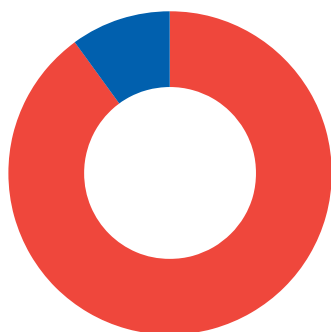
'Team Adventurers', led by Tracy Hill, participated in the Gibb Challenge and raised significant funds for CF and CFWA. We had many other fundraisers take on creative and unique challenges across the year, and together they all raised a net profit of \$50,234.

"We are very happy to help out such a wonderful charity!" – Regular 65 Roses Challenger

“My

My favourite part is the pleasure of talking to people about this important cause and seeing the joy they got in buying roses.

– Rose selling volunteer



90% Single rose stems
10% Rose bunches



45% Metro Community
23% Perth CBD
18% Regional
14% CFWA and Telstra Stalls



The George Jones Family Foundation Cystic Fibrosis Golf Classic

Spirits were high at the Golf Classic this year, despite the rainy weather, with 32 teams registered to play at the beautiful Lake Karrinyup Country Club.

Thanks to the generous support of the George Jones Family Foundation (naming rights sponsor), the teams, guests, event sponsors and hardworking committee, the event raised a net profit of \$117,457 of which \$75,000 was allocated to two PhD Top Up Scholarships to support CF research.



Team Sponsors	Players	Dinner Guests
32	128	220

“”

Congratulations on another brilliant fundraiser at Karrinyup.
- Team Captain

Many thanks for a wonderful day, had by all, which was truly appreciated.

- Golfer

“”

Community Fundraising

Once again, our dedicated and generous community got behind us and helped to raise significant awareness and funds for the CF community.

Peer-to-peer fundraising remained strong in 2019. Third-party events such as the HBF Run for a Reason, Rottneest Channel Swim (RCS) and Chevron City to Surf (C2S) attracted over 45 runners, walkers and swimmers who participated in support of CFWA. Facebook Fundraising and PayPal Giving Fund grew in popularity across the year, resulting in the growth of 'My Celebration' and other community fundraisers.

Partnerships with annual fundraisers strengthened, with events such as Corporate Battle of the Bands and the Consulate Court Christmas Lights going from strength to strength.

Collection tins and money spinners grew again in 2019 thanks to the commitment of volunteer Christopher Brambleby, who is a great ambassador for CF in the wider community.



Fundraising Event	Funds Raised
Community	\$53,377
Third Party (HBF Run, RCS, C2S)	\$34,925
My Celebration for CF	\$27,976
Corporate / Collaborative	\$10,443
Crazy Hair Day	\$4,853

Volunteer Chris' 2019 Achievements

No. of Locations	Kilometers Travelled	Visits Made	Funds Raised
120+	1,500+	300+	\$12,900

“”

Thank you to everyone who gave their time, energy and expertise to raise much-needed funds and awareness for children and adults living with CF in WA. Your efforts are helping to make a big difference in the community!



Sponsors and Supporters

Supporter Community

In December, we held our annual Sponsors and Volunteers Evening where we recognised the work of our sponsors, supporters and volunteers and thanked them for their efforts. We also recognised five very special groups and individuals who went above and beyond to make a difference with our awards.

We are thankful for all the efforts of our sponsors, supporters and volunteers.

Ambassadors and Community Representatives

In 2019, more than 20 CF families and individuals shared their stories in the media during May, the national month of awareness for CF, and throughout the year. The stories they told gave the wider community an understanding of the unique journeys, challenges and triumphs of having CF as a part of their lives.

Some of our ambassadors included Sisters Isobel and Ruby, who live with CF, and shared their unique stories for our Pre-tax Appeal which was also rolled out nationally.

Charlotte, who lives with CF, and her mother Sarah, participated in our Christmas Appeal by sharing their story and experiences of being affected by CF.

Award	Recipient
Fundraiser of the Year	Consulate Court Christmas Lights
Supporter of the Year	Rachael Hosking
Volunteer of the Year	Liz Balding
Long Service Award	Marathon Print
Lappa 65 Roses Spirit Award	Nyssa and Cody Bashford



Grants and Other Income

Our grants and other donations have continued to present a positive budget impact. Our grants this year have funded a number of specific programs that have proven beneficial to our members. Donations through our Pre-tax and Christmas Appeals, combined with regular giving and general donations, remain strong and reflect the generous nature of the CF community (individuals and workplaces) in supporting CFWA and our outcomes.

\$89,775

donated from our Pre-tax and Christmas Appeals from individuals and workplaces

\$250,000

donated from The Stan Perron Charitable Foundation

\$52,077

donated from individuals, workplace giving and general donations

Grants		
Lotterywest	\$190,933 over 2 years	Mental Health Youth Program / CF Talk video series / Communications Program / Volunteer Program
Channel 7 Telethon Trust	\$86,337	Providing support for regional members including education, travel subsidies and social events
Department of Social Services	\$2,864	Empowering our Volunteers Program
Willet Marketing	\$400	Patient Support
Bankwest	\$182	Ladies' High Tea
Carers WA	\$750	Parents and Carers Dinner
CROWN	\$1,500	Ongoing services including hospital care packs / Foodbank vouchers / equipment subsidies
Volunteering WA	\$990	65 Roses Day volunteers

Gifts-in-Kind and Volunteering

Volunteers

Volunteering became a focus in 2019 with the aim to strengthen partnerships with existing volunteers and engage new volunteers to grow our team. Our wonderful team of volunteers gave over 2,400 hours across a variety of campaigns and activities in 2019.

Volunteering		
Type	Number	Hours
65 Roses Campaign	245	1,100
Office Support	6	705
Golf Classic	4	548
CFWA Board	10	122

Gifts-in-Kind

We received \$86,621-worth of donated gifts-in-kind (goods and services) for events and member support in 2019. These donations support important campaigns and programs offered by our organisation. Thank you to all our supporters who donated goods or services across the year.

“”

Thank you for involving our company in this great work we are proud to be a part of it.
– Regional Transport Supporter

Communications and Media

2019 was a year of strong community engagement through all our communications platforms and increased media appearances as we continued to educate and raise awareness of CF in the community.

Team Changes in 2019

In 2019, we took the bold step of separating the fundraising and marketing team into two fundraising and communications teams.

The creation of the new communications team was driven by two major factors: the need to better communicate our services and resources to members, and to reduce the span of control for the services manager in the growing services team.



Communication Channels



CFWA Website	Facebook followers	Instagram	E-News	Twitter	LinkedIn	RED Magazine
27,829 Visitors	4,006 Followers	996 Followers	3,500 Readers	1,320 Followers	208 Followers	760 Readers

Media

In 2019, we engaged PR company Devahasdin for our 65 Roses campaign. With their efforts, and the support of many members in the CF community, we achieved a PR value of over \$1.3 million to a circulation of over 5.4 million.

65 Roses Media Coverage



Digital	Radio	TV	Newspaper	Local Coverage	State Coverage	National Coverage
41	6	4	17	17	10	41

BIG Stories in 2019



Optus Stadium in Red for Cystic Fibrosis!

Community representative Marc in front of the Optus Stadium and Matagarup Bridge, lit red for CF in the week of 65 Roses Day.

This Facebook post reached 27,704 people with 4,537 post engagements.



Happy 65 Roses Day!

A "Happy 65 Roses Day" post from our flagship stall in Perth City.

This Facebook post reached 18,866 people with 2,569 post engagements.



CF Awareness

65 Roses month is not just about fundraising. During May, we use the increased engagement to help raise awareness of CF in the wider community.

This Facebook post reached 9,920 people with 768 post engagements.

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



In **2018**, we successfully lobbied to have Orkambi® listed on the PBS. We 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.

In **2019**, we hosted the 13th Australasian CF Conference here in Perth achieving 20% growth in lay and medical delegates. We worked closely with the CF Federation to lobby for the successful listing of Symdeko® on the PBS and extensions to labels for Orkambi®. We obtained funding and launched our expanded mental health services. We completed funding for our Little Lungs Big Futures Research project. And finally, we enhanced our digital communications and fundraising strategies with the launch of a dedicated communications unit.

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

Board Attendance Register

Elected members	Eligible to attend*	Attended	Attendance %
Carolyn Boyd	9	9	100
Simon Martin	9	7	78
Rachael Hosking	9	8	89
Feliciano Sanchez	9	9	100
Ken See	4	4	100
Marc Stocklmayer	6	5	83
Co-opted members			
Angelo Karelis	5	4	80
Damien O'Reilly	5	5	100
Kenny Paterson	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



Rachael Hosking

Rachael is a senior lawyer and was formerly the Corporate Counsel at 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.

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



Angelo Karelis

Angelo is a Senior Partner within Deloitte's Management Consulting Practice in Perth. His area of speciality is Technology Strategy and Business Transformation. He has 25 years of consulting experience and specialises in advising and leading business transformation and reform programs across industry sectors at a local, national and global level.

Board Member



Kenny Paterson

Kenny is a director of Tarmore, an oil and gas consultancy. He is a specialist in business development, strategy formulation and implementation, commercial developments, marketing and operations. He holds an MBA from the University of Strathclyde in Scotland and a degree from the University of Aberdeen.

Board Member



Damien O'Reilly

Damien is practice lead and Managing Director of DMO Advisory. He holds advanced qualifications in business administration and law from Murdoch University with practical expertise spanning insolvency accounting, forensic accounting, insolvency law, restructuring and turnaround.

Board Member



Marc Stockmayer

Marc is the Proposals and Communications Business Partner at GHD Ltd. Responsible for a wide range of activities including managing all multiple organisation proposals and assisting client engagement groups across the operating centre with a strong track record in sponsorship, copywriting and marketing.

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.

Treasurer's Report 2019

2019 delivered a profit of \$165,502 on a turnover of \$2,446,858. However, \$109,468 of this profit was due to an increase in the value of our investment portfolio which, under the new accounting standards AASB 9, has to be brought into our P&L, even though it is unrealised. In other words, it is a paper profit. Nevertheless, even discounting this unrealised profit, we ended the year in the black with \$56,034 which was slightly ahead of our budget of \$8,159.

This included the final \$250,000 donation from The Stan Perron Charitable Foundation, taking the total level of support from the late Stan Perron to \$1.5m to fund our CF research. 100% of Stan's donation was forwarded to our Little Lungs Big Futures researchers at the Telethon Kids Institute.

Operating expenditure was \$2,281,356 which is 1% lower than 2018.

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 slightly to \$805,476 compared to \$803,826 at the end of 2018. The cash holdings and funds held as investments of \$1,075,862 – up from \$831,670 at the end of 2018 – means the association was in a strong financial position at the end of December 2019.

Consequently, I am pleased to report the finances of the association continued 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.



I am pleased to report the finances of the association continued to be managed in a manner which supports the objectives of CFWA.

The financial statements for the year ended 31 December 2019 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 to the following 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.

The financial impact of COVID-19 on 2020 results is as yet unknown but likely to be significant. I am confident that the team at CFWA is doing all they can to ensure continuity of services and welcome your support.

Simon Martin
Treasurer

Financials

Income Statement for year ended 31 Dec 2019

	2019 \$	2018 \$
Revenue	2,446,858	2,333,493
Cost of sales	(24,354)	(27,682)
Employee benefits expense	(1,290,562)	(1,266,861)
Depreciation	(16,197)	(21,421)
Motor vehicle expense	(10,119)	(9,591)
Insurance expense	(37,638)	(34,970)
Other expenses	(874,902)	(919,431)
Operating Surplus/(Loss) for the year	193,086	53,537
Office refurbishment depreciation	(27,584)	(27,398)
Total Surplus for the year	165,502	26,139
Accumulated surplus at the beginning of the year	1,511,154	1,385,869
Transfer to accumulated surplus		99,146
Surplus allocated to:		
Restricted funds	-	-
Designated funds	(11,250)	-
Discretionary funds	-	75,000
Unrestricted funds	176,752	(48,861)
	165,502	26,139
Accumulated surplus at the end of the year	1,676,656	1,511,154

Balance Sheet for year ended 31 Dec 2019

	2019 \$	2018 \$
CURRENT ASSETS		
Cash and cash equivalents	805,476	803,826
Financial assets	126,367	231,083
Trade and other receivables	254	161
Inventories	7,255	2,958
Other current assets	28,269	27,009
TOTAL CURRENT ASSETS	967,621	1,065,037
NON-CURRENT ASSETS		
Financial assets	1,075,862	831,670
Plant and equipment	379,777	362,506
TOTAL NON-CURRENT ASSETS	1,455,639	1,194,176
TOTAL ASSETS	2,423,260	2,259,213
CURRENT LIABILITIES		
Trade and other payables	396,046	393,936
Provisions	328,622	333,069
TOTAL CURRENT LIABILITIES	724,668	727,005
NON-CURRENT LIABILITIES		
Provisions	21,936	21,054
TOTAL NON-CURRENT LIABILITIES	21,936	21,054
TOTAL LIABILITIES	746,604	748,059
NET ASSETS	1,676,656	1,511,154
MEMBERS' FUNDS		
Accumulated surplus		
Accumulated surplus – restricted	10,000	10,000
Accumulated surplus – designated	50,000	61,250
Accumulated surplus – discretionary	75,000	75,000
Accumulated surplus – unrestricted	1,541,656	1,364,904
	1,676,656	1,511,154
Financial asset reserve	-	-
TOTAL EQUITY	1,676,656	1,511,154

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 2019.



Government of Western Australia
Department of Health



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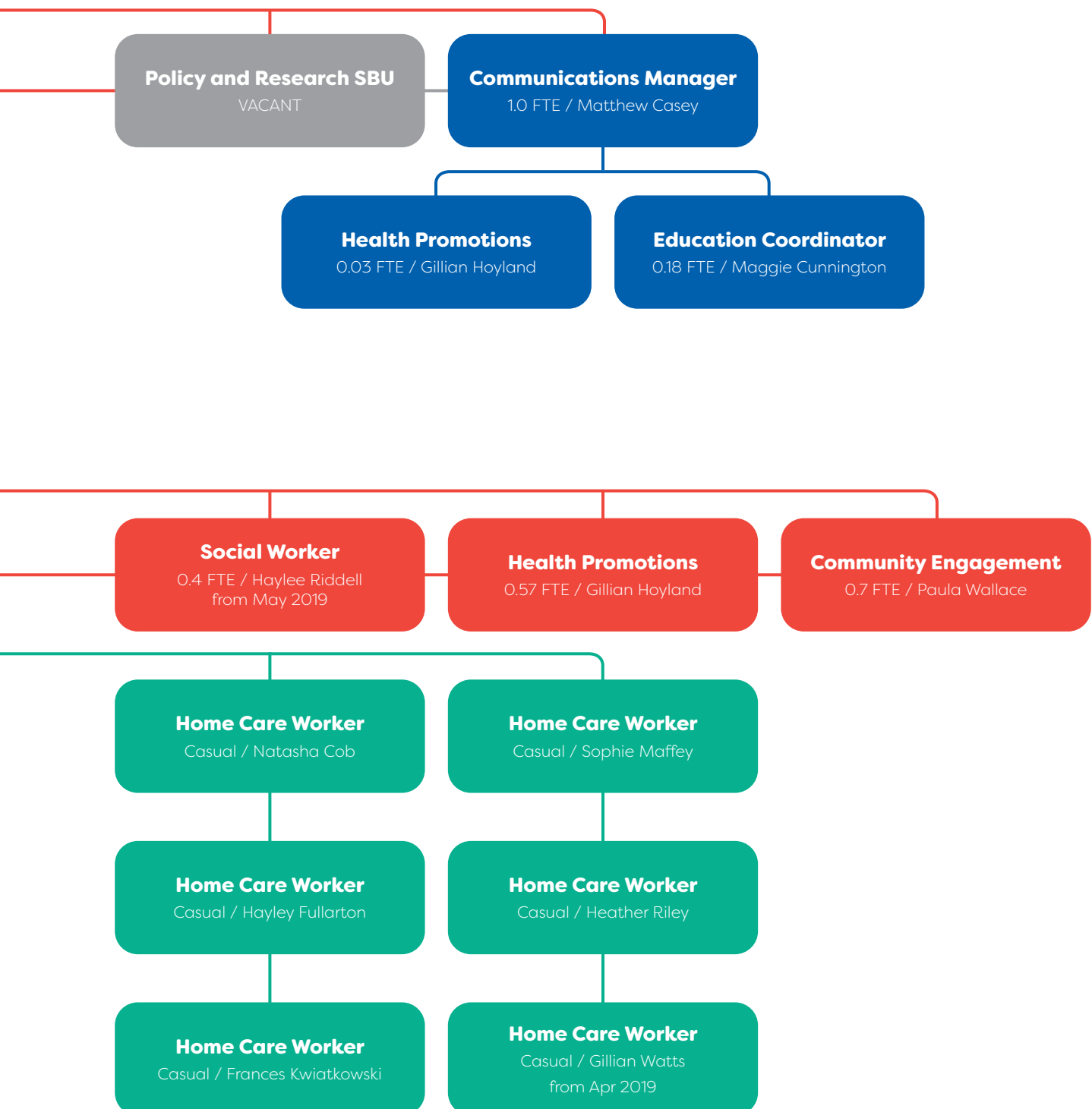


FIGHTING HUNGER
IN AUSTRALIA



Organisation Chart 2019







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