



**CYSTIC  
FIBROSIS**  
Western Australia

# Annual Report 2020

*"I opened the door tonight to 'Xmas' with a lovely man bearing gifts of toilet roll and hand sanitiser - which is like gold dust!! It was so amazing to receive, and we are very grateful."*





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*Left – Members of the CFWA team in lockdown.*

*Front cover – CFWA Volunteer Chris Brambleby with essential supplies.*

# Message from the Patron



**The year 2020 has certainly been one to reflect on and the team at Cystic Fibrosis WA (CFWA) should be proud of continuing to deliver strong outcomes by maintaining a focus on members and being on the front-foot with meeting changing needs.**

From early in the year, we knew things were going to be different as the global and Australian economy, and social and health networks felt the pressures of the COVID-19 pandemic. For the CF community, the focus on infection control and community wellbeing was very familiar. However, the challenges of living with a chronic disease were exacerbated in many ways, from practical issues like access to services and equipment, through to the stress of protecting oneself or a loved one from exposure to a widespread virus which the medical world was still coming to understand.

I am pleased that CFWA adapted quickly to support members, ensuring the CF community had continued access to key services but also the essential supplies, equipment and financial support needed. CFWA also provided a vital support network to the CF community through social networking forums, digital resources, and counselling and mental health support.

Fundraising activities disrupted by COVID-19 were re-invented, creating new ways for sponsors, volunteers, and donors to contribute. Continued community support, state and federal government support and robust financial discipline enabled CFWA to maintain a strong balance sheet for the future.

CFWA continues to support research endeavours which contribute to achieving our vision of *Lives Unaffected by CF*, working in close partnership with organisations like Telethon Kids Institute. It is the talent and courage of researchers, health practitioners and consumer participants worldwide that is leading to new treatments such as Trikafta® – which is currently being

considered for regulatory approval – and the better health and wellbeing experiences and outcomes people with CF want.

However, there is much more to be done. Cystic fibrosis is a complex disease and the CF community is still building its understanding of the impact and effects of newer treatments. More research is needed to understand and manage the intricacies, and provide further treatment options, as no one treatment will suit all. Many children and adults living with CF will continue to face the long-term degenerative impacts of this disease such as bronchiectasis and CF-related co-morbidities. They are encountering new challenges (and opportunities) as they grow older with CF. A long-term cure for this cruel disease is yet to be attained.

**Your input and support are vital to us to meet changing member needs and continue to support research. 2020 has shown us what can be achieved together and I encourage everyone to continue to dig deep to support us in the years ahead.**

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

“”

***I am pleased that CFWA adapted quickly to support members, ensuring the CF community had continued access to key services...***

# Message from the President and CEO

**With 2020 undoubtedly a disruptive year for CFWA, we are fortunate to have started the year in a strong position, with a capable and innovative team, comprehensive service offering, and strong financial position. This has enabled us to continue to deliver valued services through much disruption, with many members expressing their heartfelt appreciation.**

When COVID-19 hit, we were already investing in our digital capacity, with new technology platforms, online groups and digital resources being implemented and able to be ramped up quickly. We had secured additional financial support aimed at growing needs for mental health support for adults, families and carers. This proved timely, with counselling, youth mental health outreach, and mental health gap subsidies in strong demand as the pandemic continued.

The CFWA team quickly adapted to the changing lockdown and infection control environment, ensuring home care workers were equipped with the training, additional personal protective equipment and technology options needed to provide continuity of service. Our home care worker team were willing and able to provide services face-to-face, or remotely if desired by adults, families and carers. Three new private Facebook groups were created and Zoom sessions were used to connect members. Education and training, — for schools and health practitioners — moved to remote delivery during restricted/lockdown periods, and new short video content on good hygiene was well utilised.

With the support of state government, Lotterywest and the Telethon Trust, emergency relief and support programs for vulnerable families were put into place. Much-needed essentials, like toilet paper and hand sanitiser, were quickly distributed, to the relief of

many members; with more equipment and financial subsidies providing flexible options for home-based exercise and airway clearance, and for safe travel to healthcare clinics when required.

Our supporters and sponsors also rallied around us to re-invent traditional fundraisers and deliver amazing community fundraising outcomes. Selling beautiful fresh roses on 65 Roses Day was no longer an option, yet the pivot of this campaign to online virtual roses enabled \$44,000 to be raised. Our annual Golf



**Lisa Bayakly**  
CEO

A handwritten signature of Lisa Bayakly in black ink.



**Caz Boyd**  
President

A handwritten signature of Caz Boyd in black ink.

Classic and Christmas Lights fundraisers also broke new records, with the former raising over \$260,000. The CFWA team was delighted to see volunteer contributions highlighted, when a regular volunteer, Chris Brambleby, won the Fundraising Institute of Australia's **National Volunteer of the Year Award**.

This ongoing generosity of volunteers, donors, sponsors and the community enabled fundraising to recover by year end. With this fundraising result, robust financial discipline, and state and federal government support, CFWA maintains a strong balance sheet for the future. Our Treasurer's Report outlines this position further.

Fundraising also enables CFWA to contribute to consumer-focussed research and advocacy. 2020 marked the 10-year anniversary of our PhD Top Up Scholarship program, with two new scholarships awarded and over 12 scholars funded since inception.

Most importantly, after many years advocating for new therapies, the 2020 year ended with Trikafta® listed for PBAC review in March 2021 – providing much promise to the CF community given the better health outcomes being seen by individuals on trials, or with compassionate access. We actively advocated for approval and immediate compassionate access – together with other CF state and territory bodies – with the hope that this drug will be made available in 2021 for many members of the CF community.

A large component of our services is delivered through programs funded by the WA Department of Health. However, a planned re-tender of these services was delayed due to the pressing need for WA government and the health system, to respond to COVID-19. The co-design process for the next round of procurement has now commenced, with CFWA able to provide input on consumer needs and service delivery priorities.

CFWA also revised its constitution in November 2020 to enable services to be expanded to address other respiratory conditions where our skill set aligns and where funded externally. We see this as an important emerging need given the prevalence of bronchiectasis and other complex respiratory conditions in the community, and potential service gaps. Services in these areas will be complimentary to, not at the expense of, the services currently provided to those living with CF, their families and carers.

### Finally, a few words of thanks.

CFWA has greatly benefited from the leadership provided by its recently retired CEO Nigel Barker (and his predecessors who led with the vision). In 13 years, Nigel oversaw significant growth in CFWA's services, making a real difference to the lives of people with CF. He bolstered the organisation's capacity – increasing fundraising, contracted services to government and collaborative research programs – and strengthened our technology, infrastructure, and team capability. With a passion for knowledge, Nigel led CFWA in building a strong education and resource library for the CF community, and his passion for better outcomes for people with CF will undoubtedly continue beyond retirement from CFWA.


CFWA home care workers delivered over 4,000 occasions of home care services, often face-to-face, sometimes remotely – a service level consistent with prior years despite the changing COVID-19 environment.

Thank you to the CFWA team that went above and beyond in 2020 to deliver outcomes and introduce new initiatives such as the youth mental health offering, the Calm Kids Happy Families program, and the short video series of lived experience stories.

Thank you to the CFWA board who volunteered much more time than normally expected to enable organisational responsiveness to change.

Lastly, thank you to the CF community for its continued positive engagement, proactive input and openness to change.

We are excited about working together to continue to pursue our vision of *Lives Unaffected by CF*. In 2021, we look forward to engaging, listening and collaborative problem solving with the entire CF community for better health and wellbeing outcomes.



***Thank you to the CFWA team that went above and beyond in 2020 to deliver outcomes and introduce new initiatives such as the youth mental health offering, the Calm Kids Happy Families program, and the short video series of lived experience stories.***

# A History of CFWA



**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.

**1976**

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

**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.



**1990s**

We 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 Department of Health WA funding and the Comprehensive Homecare Service began.

**Late 1980s**

The constitution of CFWA was changed to allow it to use the skills of people from the wider community to help manage the organisation.

**1983**

Following the results of the survey, the Home Support Service began and state government funding enabled the employment of home care workers and a counsellor.

**2002**

CFWA moved to its current home at 'The Niche' in Nedlands.

**2010**

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

**2011**

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



**2017**

We provided \$30,000 seed funding to help establish an adaptive platform trial to shorten clinical trials and time to bring new drugs to market, started a major ICT upgrade and launched [www.cfwf.org.au](http://www.cfwf.org.au) website

**2016**

The total raised in WA for the Little Lungs Big Futures collaborative research project reached over \$2.6m. We also won the prestigious state Telstra Business Awards Charity category.

**2014**

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



**2018**

We successfully lobbied to have Orkambi® listed on the PBS. We increased 65 Roses Day sales to a record 15,000 stems, up from 1,250 in its first year, raising much-needed funds.

**2019**

We hosted the 13th Australasian CF Conference here in Perth achieving 20% increased delegate numbers. 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 completed funding for the Little Lungs Big Futures research project. We enhanced our digital communications and fundraising strategies.

**2020**

We re-invented many of our major fundraising events and services in response to COVID-19, revised our constitution, and developed a new strategic plan to meet current and emerging needs.

# Policy, Research and Advocacy



**In 2020, we developed a new Strategic Plan for 2021 – 2023 that will guide our priorities in servicing members and pursuing our vision of *Lives Unaffected by CF*. CFWA members helped shape the plan through an online questionnaire and needs analysis to capture how much members value different services. Importantly, members were supportive of all services and of a continued, relatively balanced focus on funding of services and research. Members provided exceptionally high ratings for equipment and financial support, programs that CFWA has expanded in response to emerging member needs in recent years.**

With 2020 being a challenging year for a COVID-19 hit economy, your feedback reinforced the importance of focussing not just on current needs, but also anticipating members' future needs. We will continue to evolve our policies and services in response, and advocate for broader community support.

Such individual and state-based advocacy in 2020 was vital to supporting our members during COVID-19. Locally, we continued to participate in the Child and Adolescent CF Consumer Reference Group made up of parents of children with CF. Other representatives include an adult with CF, CFWA, an adult sibling, researchers from Telethon Kids Institute (TKI), and the Perth Children's Hospital (PCH) CF Centre Director. Our participation enables us to ensure a strong focus on the consumer perspective to both clinical and research aspects of cystic fibrosis.

At a state level, we liaised with key government agencies and industry participants to ensure timely access for the CF community to PPE and essentials during COVID-19; and through the support of Lotterywest and the Telethon Trust we were able to distribute much-needed emergency relief, essential supplies and assistance to vulnerable families.

Nationally, under the leadership of Cystic Fibrosis Australia (CFA), CFWA advocated alongside other state and territory CF organisations for greater awareness and support for the CF community. CFWA has supported CFA in promoting and ensuring data collection which will inform best practice, support

advocacy, and extend lives. The Australian Cystic Fibrosis Data Registry (ACFDR) was a great resource during COVID-19 – an input to international research and collaboration which will help inform research projects to come.

In 2020, our advocacy also continued to focus on the timely approval of drug access for people with CF. Past campaigns, the listing of Symdeko® on the PBS, and extensions to the labels for Orkambi® in 2019, provided much momentum leading into 2020. Finally, in December 2020, the listing of Trikafta® for the PBAC April 2021 agenda provided the platform for collective advocacy to ensure access to this treatment which delivers the better health outcomes people with CF are seeking. We are all hopeful this leads to approval and availability of Trikafta® for a much broader group in 2021, with safe access for those 12 and under then next to follow.



***We have awarded a total of 12 PhD Top Up Scholarships to inspiring WA scholars since 2010.***



Joshua Iszatt  
CFWA PhD Scholarship recipient



Maggie Harrigan  
CFWA PhD Scholarship recipient

In 2020, we celebrated the 10-year anniversary of our PhD Top Up Scholarship program, focussed on encouraging CF-related research. We awarded another two such scholarships in 2020, bringing the total to 12 since inception. The two scholarships were awarded to Joshua Iszatt and Maggie Harrigan. Joshua's research focusses around the development and investigation of a therapeutic agent that could be used to treat multi-drug resistant bacteria that frequently causes persistent lung infections in children with cystic fibrosis, while Maggie's research is focussed on the development and evaluation of a "social connectedness toolkit" in the form of an online social connectedness group education program for adults with CF. Existing research that continued to be funded under our PhD Top Ups in 2020 included combatting antimicrobial resistance using bacteriophages; therapies that target the more rare CF mutations; and airway clearance and lung functioning in adults.

Our Golf Classic Committee – through the Golf Classic fundraising event – has been part of our research funding success since the early days. In 2020, funds raised were just over \$260,000 gross, thanks to the commitment of the Committee, sponsors, volunteers, and participants.

Unfortunately, COVID-19 disrupted our annual Evening with CF Scientists events held regionally and in Perth. However, we continued to deliver CFSmart – our schools education program – remotely when needed. We also made significant updates to all our print and electronic resources and placed these on our website [www.cfw.org.au](http://www.cfw.org.au)

Our research, advocacy and policy priorities are informed by emerging needs and member input to drive us closer to our vision of Lives Unaffected by Cystic Fibrosis.

# Services in the Community

What a year 2020 turned out to be! A busy start to the year saw us hit the ground running as we looked forward to a packed schedule of programs and events. The arrival of COVID-19 however, changed things dramatically, and we quickly had to adapt to a changing landscape and the emerging needs of our CF community.

## Staying Connected Through COVID-19

“““

*Keep up the great work guys - helping to keep the rudder steady in these stormy seas.*

“““

*Thank you so much for the much-needed gift. We are very grateful.*

Thanks to **Lotterywest**, we provided immediate emergency relief to families feeling overwhelmed, both financially and emotionally. We sourced essential items including hand sanitiser, toilet paper and basic pantry food items, and delivered them out into the community via staff and volunteers. We even managed a trip to the South West to deliver to local families and provided vouchers for those families further afield.

“““

*This makes me want to cry. Seriously. Oh my goodness. In a time when I'm trying to remain calm and*

*not let all these million zillion thoughts whizzing around in my head regarding CF and Corona come out in a massive, very unpretty explosion, you guys seem to be 749 steps ahead. Thank you doesn't cover it. But thank you xxxx*

Adhering to social distancing protocols, we became an important support network and contact with our community doubled throughout this period. We adapted our programs to suit and continued with the rollout of our new 2020 projects and initiatives.

“““

*This year has been a tough one. CFWA you have supported us well. Thank you*

**212**

**emergency relief packs  
delivered to the  
CF Community  
March - May**



**736**

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

**8**

online webinars facilitated, bringing together targeted groups of CF adults

**100+**

members in our new CFTalk Facebook group for parents

**125+**

members in our CFTalk adult Facebook group

**15**

new factsheets created and uploaded onto our website

**21**

member stories captured and uploaded to our website [www.cfw.org.au/what-we-offer/resources](http://www.cfw.org.au/what-we-offer/resources)

We created a new **Parents and Carers** webpage providing information to parents, siblings/offspring, partners, grandparents and others taking a caring role

**133**

Instagram CFWA Youth followers

“““

*Just wanted to thank you for organising the session today. Found it helpful to speak with others that have been through the same experiences. Much appreciated.*

## CFTalk Short Film Series

The “lived experience” and the sharing of stories greatly enhances feelings of connection and wellbeing. Lotterywest funded our series of CFTalk short films for adults and families, where members share their stories and experiences of what it’s like living with CF.



## Calm Kids, Happy Families

“”

*Calm Kids, Happy Families and the work Mel does is vital; she’s giving us the strategies to help my daughter. As a parent you get a bit lost in helping your child through these traumatic events, she has helped my daughter get back to her normal happy self.*



We initiated a new Telethon-funded program called Calm Kids, Happy Families which includes occupational therapy support for some of our vulnerable families. A short film funded by Lotterywest was also developed to showcase this new program.







## Youth Mental Health Program

Our Lotterywest-funded Youth Mental Health Program has increased face-to-face support for young people. Our new youth Instagram page allows this young cohort to share their stories and connect online. The program also includes new mental health resources and a new “Building Resilience” program to support tweens aged between 8-11 years.



# Financial Support

Our suite of subsidies continued to support adults and families in the community.

						
	Equipment Subsidy	Adult Activity Subsidy	Kids Activity Subsidy	Adult Regional Travel Subsidy	Telethon Childrens Regional Subsidy	COVID-19 Relief Subsidy
No of Subsidies	46	77	25	55	93	62
Total Cost	\$10,244	\$19,291	\$3,677	\$5,425	\$9,875	\$6,100

The adult activity subsidy continued to be popular in 2020, and during lockdown we adapted it to support personal gym equipment and online gym classes to encourage ongoing physical activity within the home.

Analysis of the post subsidy feedback we received showed that the biggest barrier to exercise was financial and 75% of recipients scored their physical and emotional wellbeing as good or excellent by the end of 2020.

## Feedback - Adult Activity Subsidy

“““

*I've really appreciated the funding and support from CFWA for this subsidy. Being able to gain access to assistance has been so generous and beneficial. Please, where possible, continue to support those of us living with CF to access these subsidies. Thank you.*

“““

*Since training hard, my lung function has improved by 20%. Currently the fittest I have ever been in my whole life.*

“““

*Helped us greatly, especially as I've had to take so much unpaid sick leave this year*

## Feedback - Telethon Regional Travel Subsidy

“““

*We are a CF family from the Great Southern region who are currently receiving the Telethon Regional Children's Travel Subsidy. We feel extremely grateful for being able to have this service available to us. Knowing that financial help is available reduces the pressure of finding extra funds to get us there. Thank you so very much to Telethon and CFWA.*



Ruby using her InnoSpire Go nebuliser



**33**  
InnoSpire Go Nebulisers Gifted to the Community



**142**  
Hospital Support Packs



**74**  
Christmas Hampers

# Member Events

**Due to the risk of cross-infection, people with CF are unable to come together. This can have a detrimental effect for the whole family and can initiate feelings of isolation and loneliness. Social and educational events facilitated by CFWA provide an invaluable opportunity for family members and carers to meet, build networks and share stories which is critical for the mental health and wellbeing of the whole family. It also provides a chance for carers to unwind, take a break and enjoy some well-deserved respite.**

Despite the social distancing guidelines and lockdown we were able to safely facilitate the whole suite of support events throughout 2020.

To enable regional members to attend our important member events, we offer a subsidy to cover travel costs, including our Parents' Retreat, Parents' Dinner, Sib's Camp, Sib's Day Out, Ladies' High Tea, and Grandparent's Morning Tea. We also host regional dinners as part of our outreach program to allow regional families to make connections within their community.

## Sib's Camp

“”

*Thank you CFWA and staff for a wonderful Sib's Camp. My daughter had a blast and loved it.*

lotterywest  
supported



“”

*Thank you CFWA, my son had a ball and wants to go every year now and see all his friends he met.*

## Ladies' High Tea

“”

*I thoroughly enjoy going every year. The event is very important to me because I get to unwind, meet others alike and have some fun.*



## Parents' Retreat

“”

*These events are so important. We had a few things on but decided to prioritise this. Friday night we all talk CF then we just relax.*



“”

*CFWA are always there to help us in anyway*



# Home Care Worker Support

## The CFWA Home Care Worker Service

Support in the home continued during the COVID-19 lockdown and subsequent restrictions. Our Home Care Workers (HCW) are well educated around cross-infection, however Personal Protective Equipment (PPE) was increased to ensure everyone's safety. Over half our families preferred to maintain face-to-face airway clearance support, while others moved to digital support such as FaceTime.

Our HCW service was identified in our 2020 member needs survey as one of the most valued CFWA services.

Our HCW's can provide support with airway clearance, exercise, respite and light cleaning. The HCW program is supported by our tertiary hospitals and we collaborate to ensure best practice and quality of care for people with CF and their families.



“““

*I cannot stress how valuable our home care worker is for our daughter. There have been numerous times when she has become non-compliant in doing her physio. We were at a loss as physio is vital in treating her illness. Both my husband and I were exhausted physically and emotionally.*



**4,465**

HCW Occasions of Service



**32**

Regional Airway  
Clearance Support



**198**

Occasions of Service  
Third-party Services  
(Cleaning/Respite)



## Hospital in the Home (HiTH)

**HiTH provides extra support to families so they can leave hospital and continue their prescribed treatment in the comfort of their own home.**

“

*Our HCW has been there to support us during some very challenging times. We would be lost without the service and is highly appreciated by our family.*

“

*We would be lost without this service and our HCW.*

## Education - Schools and Community

**CFSmart is a national education program for teachers, parents, carers and children. It aims to improve the understanding of CF within the school community and provide support to students with CF so that they feel supported and understood in terms of their health, education and emotional needs.**

CFSmart continues to grow in resources and viewership and is also available for the workplace and the general community.

COVID-19 presented a challenge for face-to-face education sessions during our traditionally busy period. We adapted our program and offered online sessions for teachers and educators accompanied by downloadable lesson plans and electronic resources. We were able to resume face-to-face education in the latter half of the year.

We created three short videos for children about germs and handwashing.



**How to Wash Your Hands**



**Why Soap is Important**



**How Germs Spread**



We educated:

**340**  
adults

**252**  
children



Our germs and handwashing videos received

**4,215**

views on Facebook and YouTube



**44**

CF education sessions delivered in 2020



**626**

CFSmart e-learning modules completed



**7**

Regional school education sessions including Albany, Bunbury, Kalgoorlie, Merredin and Narrogin.



**1,369**

Good Clean Hands video viewings on YouTube

“““

*We were really impressed with Maggie's presentation about CF and hand/personal hygiene habits. We thought it was high quality, accessible education for our students. Just pitched perfectly and timing great, too. Thanks for coming.*



Our Education Coordinator delivering classroom education to students in Albany

# Health Professional Education



COVID-19 significantly affected face-to-face health professional education in early 2020 and forced us to adapt to online teaching, offering sessions via video conferencing. We were able to reschedule our annual Regional Respiratory Training Program and present the full program face-to-face in late 2020. We can now offer delivery of training in both formats as required.

“““

*Heaps of knowledge and resources to bring back to my hospital colleagues, renewed motivation and enthusiasm.*

“““

*The course consolidated a lot of my skill but also expanded on the connection within the body/co-morbidities and complications associated with respiratory conditions - Loved it!!!*

Health professional training for regional nurses and physios improves access to best-practice respiratory health care throughout regional WA.

| 95

Health professionals trained in 2020 from: Kimberley, Pilbara, Mid-West, Gascoyne, Goldfields, Wheatbelt, Great Southern, South West

## Competency-based Spirometry Training for Regional Health Professionals

Developed in response to an identified need in the regions, the Spirometry Training Program was a new initiative launched late in 2020. The course was facilitated by CFWA and delivered by Spirometry Learning Australia and Perth-based Senior Respiratory Scientists.

“““

*We are currently working with CFWA with the plan to facilitate a spirometry training course at Hedland Health Service so that our outpatient nurses and local Aboriginal Medical Services can also become competent in this area. Living in a rural town has many challenges, but if we are able to provide a good service and be confident in this space, it allows community members to access this diagnostic tool without leaving their hometown.*



# Fundraising

**Cystic Fibrosis WA is very proud to have a community of passionate supporters that donate, fundraise and participate in our events. In 2020, our supporters came out in force, given the challenges of COVID-19, for events and fundraising. The ongoing individual support from our thousands of committed supporters enabled a strong fundraising result overall.**

The continued generosity of our supporters allows CFWA to provide essential support services to the CF community in WA and provide ongoing funding for critical research that one day will enable us to achieve our vision *Lives Unaffected by CF*.

Being able to pivot existing fundraising campaigns and implementation of several online opportunities was the focus in 2020. We also focussed on expanding on our extremely popular major event, the George Jones Family Foundation Cystic Fibrosis Golf Classic, and increased support for our large volume of community fundraisers, especially the Albany Christmas Lights, who continued to deliver strong results.

2020 was a disruptive year for fundraising, leading to mixed results from our diverse income streams. However, a focus on our strong performing existing campaigns, and several new campaigns, went a long way towards addressing the COVID-19-driven shortfall.



The top performing fundraising activity for 2020 was the George Jones Family Foundation Cystic Fibrosis Golf Classic raising over \$262,000 – an increase of over 60% from 2019, a truly unbelievable result. Over its ten-year history, the George Jones Family Foundation Cystic Fibrosis Golf Classic has raised over \$1,000,000 towards critical CF research development and supporting families affected by CF in WA.

65 Roses Day and May month fundraisers were heavily affected by COVID-19. The pivoting of our traditional 65 Roses Day from selling over 16,000 fresh roses to having no roses to sell and running the Virtual 65 Rose Garden was one of the year's biggest achievements. The virtual garden raised over \$44,000. Our appeals raised over \$93,000 – an increase of 4.5% on 2019. When you combine all our amazing community fundraisers, together they raised over \$112,000, a 35% increase on 2019; another amazing result. Our collection tins, located in over 130 locations, raised over \$13,500 – an increase of 9.3% on 2019.



**1,226**

**new donors in 2020  
(compared to 428 new donors in 2019)**



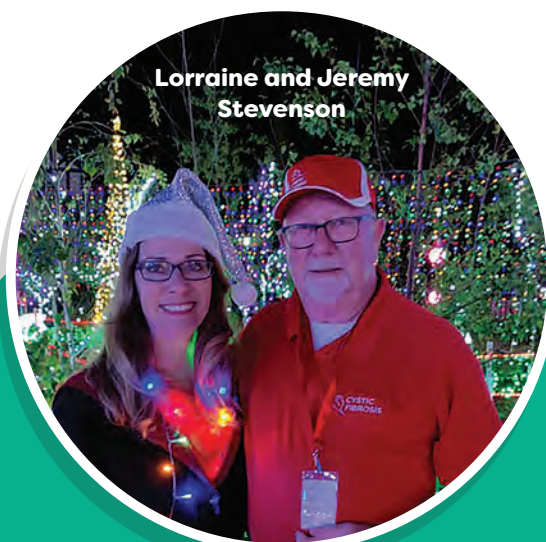
**3,204**

**donations received  
(30% more than 2019)**



**1,836**

**virtual roses sold during 65  
Roses Day - in our virtual  
rose garden**



**Lorraine and Jeremy  
Stevenson**



# Major Events and Campaigns

## 65 Roses Campaign

In 2020, we adopted the motto “Virtual Rose, Real Impact” for May – our national month of awareness for CF – and asked for our dedicated supporters to come on the journey with us to turn 65 Roses Day into a virtual event. Instead of wrapping and selling thousands of fresh roses, our wonderful community grew a virtual rose garden for the national month of CF in 2020.

1,836 digital roses were planted in the virtual rose garden and over \$44,000 was raised through donations.

## The George Jones Family Foundation Cystic Fibrosis Golf Classic

Record-breaking attendance and new fundraising achievements were the highlights of this year’s special 10th anniversary Golf Classic. There were 36 playing teams and over 280 guests at the evening dinner who gave generously.

Thanks to the incredible support of the George Jones Family (naming rights sponsor), attendees, sponsors and dedicated committee, gross funds raised exceeded \$262,000, of which \$75,000 was allocated to two CF research PhD Top Up Scholarships and over \$88,000 committed to future support projects for families affected by CF.

## 65 Roses Challenge

There were several exciting 65 Roses Challenges this year, including the Kili Trek team, led by Tatianna Joannides, who climbed Mount Kilimanjaro in January; and the return of the Vault Fitness Spin Challenge, hosted by Todd Guthridge, in November.

Murphy Family  
65 Roses Challenge



Kili Trek  
65 Roses Challenge



Golf Classic  
Range Ford team

Team Sponsors	Players	Dinner Guests
36	144	280

## Community Fundraising

**Community fundraising support remained strong despite the challenges the wider WA community were facing due to COVID-19. Special events were postponed, but community fundraising held fast.**

This year we introduced the Backyard Bootcamp, an 8-week at-home fitness challenge which helped fill the gap of the cancelled third-party running and swimming events. A special thanks goes to Shannon Dally and Sunburnt Films who gave their services free-of-charge to get the campaign up and running at short notice.

The year ended strong with two massive Christmas Light fundraisers run by the Consulate Court residents in Thornlie and Lorraine and Jeremy Stevenson in Albany, resulting in \$56,574 raised across December.

We needed our talented and committed community more than ever this year, and we were not disappointed!

Consulate Court  
Christmas Lights  
Fundraiser



Lisa Bolton, Marnie  
Thomson and Emily  
Polett - Sport Club  
Fundraiser

“

*What a great day for our club and cystic fibrosis - it was a pleasure to partner with you - Sport Club Fundraiser.*

”

*Thanks so much for our certificates. I'll be hanging our team one on our Wall of Fame this week - the team will be delighted - Corporate Fundraiser.*

Fundraising Event	Funds Raised
Community	\$53,237
Christmas Lights	\$56,574
Third Party	\$18,507
65 Roses Challenge	\$37,966
My Celebration for CF	\$12,252
Backyard Bootcamp	\$3,128

## 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.**



The Di Re family, winners of the Lappa 65 Roses Spirit Award.

Award	Recipient
Fundraiser of the Year	Tatianna Joannides
Supporter of the Year	Sunburnt Films
Volunteer of the Year	Amy Robinson
Long Service Award	Nigel Barker
Lappa 65 Roses Spirit Award	Di Re Family

### Ambassadors and Community Representatives

During 2020, more than 25 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 – including 28 online – gave the wider community an understanding of the unique journeys, challenges, and triumphs of having CF as a part of their lives.

Here are some of the many ambassadors and community representatives who helped us spread awareness for CF in 2020 across social media, newspaper, radio and television.



Nicola, who lives with CF, and her daughter, Arlo, participated in our 65 Roses campaign by sharing her story and experiences of being a mother and being affected by CF.



Jackie Fraser, who lives with CF and has recently had a double lung transplant, shared her story for our 65 Roses campaign.



Connor, who lives with CF, participated in our 65 Roses campaign by sharing a little of his story and experiences of being affected by CF.

## Grants and Pro Bono Support

### Grants

Our grants and other donations have continued to present a positive budget impact. Our grants this year were lower than previous years but still 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.



The CFWA team  
at Telethon 2020

**\$93,328**

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

**\$40,767**

donated from the estate of John T. Fletcher

**\$61,672**

donated from individuals, workplace giving and general donations

Grants		
<b>Lotterywest (2019-2021)</b>	<b>\$95,466 over 1 year</b>	<b>Mental Health Youth Program / CF Talk video series / Communications Program / Volunteer Program</b>
<b>Channel 7 Telethon Trust</b>	<b>\$114,089</b>	<b>Regional Member Support and Vulnerable Families Program</b>
<b>Lotterywest</b>	<b>\$19,950</b>	<b>COVID-19 Relief</b>
<b>NDIS</b>	<b>\$9,455</b>	<b>CF Strong - Adult Resource</b>
<b>Vertex Pharmaceuticals</b>	<b>\$1,100</b>	<b>Regional Respiratory Training Program</b>
<b>Mylan</b>	<b>\$750</b>	<b>Regional Respiratory Training Program</b>

## Gifts-in-kind

We received over \$242,900 worth of donated gifts-in-kind (goods and services) for events and member support in 2020. 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.



## Volunteers

Our volunteers rose to the challenges of social distancing in 2020 and continued their support virtually for 65 Roses Day. They drove 24% of the money raised for our virtual rose garden and seeded up to 72% of the digital roses that were planted in the garden, proving that virtual volunteering can be just as meaningful.

We also engaged several graphic design virtual volunteers who helped to create new resources including a school information postcard and the Backyard Bootcamp guide kit.

Volunteering		
Type	Number	Hours
65 Roses Campaign	44	662
General Support	15	453
Golf Classic	4	550
Board	11	155



Sunburnt Films and Shannon Dally filming Backyard Bootcamp.

# Communications and Media

## Our communications were severely tested early in 2020 with the arrival of COVID-19 and the WA lockdown.

Within weeks, the whole organisation was adapting to working from home, changing our services to meet the new environment, and communicating these changes to our members and stakeholders.

As a community health organisation, our members looked to Cystic Fibrosis WA for COVID-19 information as the situation developed, and we worked with the tertiary hospitals to deliver timely, accurate information to members. Our website was a critical resource during this time, with a 72% increase in website traffic over the year.

The period was a reminder of the importance of community connection. We used this as an opportunity to get creative with our offerings to members. Events like our Annual General Meeting and member get-togethers went ahead as virtual Zoom sessions. We created three private Facebook groups for adults with CF, parents and carers, and community fundraisers. These groups allowed us to closely engage with our members to get the right messages to the right people at the right time. These changes have now been adopted as part of our regular activities, providing greater flexibility for our stakeholders to engage with us in the ways that works for them.

## Communication Channels



CFWA Website	Facebook	Instagram	E-Newsletter	RED Magazine
<b>32,630 Visitors</b>	<b>4,319 Followers</b>	<b>1,225 Followers</b>	<b>3,450 Readers</b>	<b>760 Readers</b>

## 65 Roses Raising Awareness

65 Roses Day is one of our major fundraising events every year, but we also use the campaign to spread awareness of CF in the wider community.

### 65 Roses - Big Engagement in 2020



#### 65 Roses Month - Launch Post

Our post launching 65 Roses month and announcing the virtual rose on 1 May.

**20,920  
people**  
**1,124  
engagements\***

\*likes, shares etc.



#### 65 Roses Week

A post announcing the beginning of 65 Roses week, promoting the virtual rose.

**16,208  
people**  
**1,076  
engagements\***

\*likes, shares etc.



#### 65 Roses Day

Our "Happy 65 Roses Day" post, asking people to like and share the post to spread awareness of CF.

**16,208  
people**  
**1,076  
engagements\***

\*likes, shares etc.

### 65 Roses Media Coverage

In 2020, we engaged PR company Devahasdin for promotion of our 65 Roses campaign. Media coverage was strong in 2020, with a circulation reach of 9.1 million people and PR value of over \$530,000, albeit lower than projected due to the COVID-19-driven pivot to an online only campaign and a corresponding reduced spend.



Digital	Radio	TV	Newspaper	Local Coverage	State Coverage	National Coverage
28	6	1	9	19	20	6

# Board and Governance

The CFWA board comprises several 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

## 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**



**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**



**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**



**Judith Mahony**

Judith joined the board in October 2020.

Jude is the founder and Managing Director of Optimal Resourcing. She is a workforce of the future specialist, with lived experience leading remote, global, multi-cultural and outsourced teams.

**Board Member**



**Sally Rose**

Sally joined the CFWA board in October 2020.

Sally is a qualified Chartered Accountant and currently the Group Financial Controller of Australian Finance Group Ltd (AFG). She has practical expertise in both accounting and corporate governance.

# 2020 Board Members

**Retired**



**Angelo Karelis**

Angelo retired from the board in September 2020.

As a former Senior Partner with Deloitte, Angelo brought technology strategy and organisational transformation experience to the board.

**Retired**



**Marc Stockmayer**

Marc retired from the board in September 2020.

Marc is the Proposals and Communications Business Partner at GHD Limited, with expertise in client engagement and stakeholder communication.

**Casual**



**Andrew Walsh**

Andrew filled a casual vacancy during the year.

Andrew brought experience and insight from prior service on the CFWA board as a past Treasurer.

# Treasurer's Report 2020

**2020 delivered a profit of \$91,841 on a turnover of \$2,507,982. However, this was significantly achieved through the financial support of the Commonwealth government by way of the JobKeeper wage subsidy and the Australian Tax Office (ATO) cash flow boost; initiatives developed to support businesses and charities through the COVID-19 pandemic. Without this Commonwealth support, CFWA would have ended the year with a loss of \$264,046 against a budgeted loss of \$20,044.**

A small amount of this profit, \$10,660, was due to an increase in the fair value of our investment portfolio which, under accounting standard AASB 9, has to be recognised in the income statement even though it is unrealised. In other words, it is a paper profit.

A more significant contribution to the year end profit, however, was the Golf Classic. 2020 marked the tenth anniversary of the fundraising event which saw a record \$262,571 raised. From the proceeds, \$75,000 was designated for two PhD Top Up Scholarships, and an additional \$88,243 was designated for unbudgeted and unfunded service delivery programs in 2021, driven by changing member needs. These programs would otherwise not occur.

Operating expenditure was \$2,401,329 which is 6% higher than 2019.

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. Despite the challenges

experienced through the COVID-19 pandemic in 2020, CFWA maintained the level of funds held as investments at year end, being \$1,090,791, marginally up from \$1,075,862 at the end of 2019. Thus, the association was in a solid financial position at the end of December 2020.

Consequently, I am pleased to report the finances of the association continued to be managed in a manner which supports the objectives of CFWA and that provides a solid footing for 2021.

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 2020 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.



A handwritten signature in black ink, appearing to read 'Simon Martin', written over a light blue grid background.

**Simon Martin**  
Treasurer

### Balance Sheet as at 31 Dec 2020

	2020 \$	2019 \$
CURRENT ASSETS		
Cash and cash equivalents	1,008,112	805,476
Financial assets	146,486	126,367
Trade and other receivables	84,519	2541
Inventories	7,053	7,255
Other current assets	34,438	28,269
<b>TOTAL CURRENT ASSETS</b>	<b>1,280,608</b>	<b>967,621</b>
NON-CURRENT ASSETS		
Financial assets	1,090,791	1,075,862
Plant and equipment	344,825	379,777
<b>TOTAL NON-CURRENT ASSETS</b>	<b>1,435,616</b>	<b>1,455,639</b>
<b>TOTAL ASSETS</b>	<b>2,716,224</b>	<b>2,423,260</b>
CURRENT LIABILITIES		
Trade and other payables	547,844	396,046
Provisions	378,933	328,622
<b>TOTAL CURRENT LIABILITIES</b>	<b>926,777</b>	<b>724,668</b>
NON-CURRENT LIABILITIES		
Provisions	20,950	21,936
<b>TOTAL NON-CURRENT LIABILITIES</b>	<b>20,950</b>	<b>21,936</b>
<b>TOTAL LIABILITIES</b>	<b>947,727</b>	<b>746,604</b>
<b>NET ASSETS</b>	<b>1,768,497</b>	<b>1,676,656</b>
MEMBERS' FUNDS		
Accumulated surplus		
Accumulated surplus – restricted	10,000	10,000
Accumulated surplus – designated	100,000	50,000
Accumulated surplus – discretionary	163,243	50,000
Accumulated surplus – unrestricted	1,495,254	1,541,656
	<b>1,768,497</b>	<b>1,676,656</b>
Financial asset reserve	-	-
<b>TOTAL EQUITY</b>	<b>1,768,497</b>	<b>1,676,656</b>

### Income Statement for year ended 31 Dec 2020

	2020 \$	2019 \$
Revenue	2,507,982	2,446,858
Cost of sales	(14,812)	(24,354)
Employee benefits expense	(1,436,127)	(1,290,562)
Depreciation	(46,879)	(43,781)
Motor vehicle expense	(10,903)	(10,119)
Insurance expense	(38,970)	(37,638)
Other expenses	(868,450)	(874,902)
<b>Operating Surplus/(Loss) for the year</b>	<b>91,841</b>	<b>165,502</b>
<b>Total Surplus for the year</b>	<b>91,841</b>	<b>165,502</b>
Accumulated surplus at the beginning of the year	1,676,656	1,511,154
Transfer to accumulated surplus		-
Surplus allocated to:		
Designated funds	50,000	(11,250)
Discretionary funds	88,243	-
Unrestricted funds	(46,402)	176,752
	<b>91,841</b>	<b>165,502</b>
<b>Accumulated surplus at the end of the year</b>	<b>1,768,497</b>	<b>1,676,656</b>

# 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 2020.



Government of Western Australia  
Department of Health



BIRD HEALTHCARE

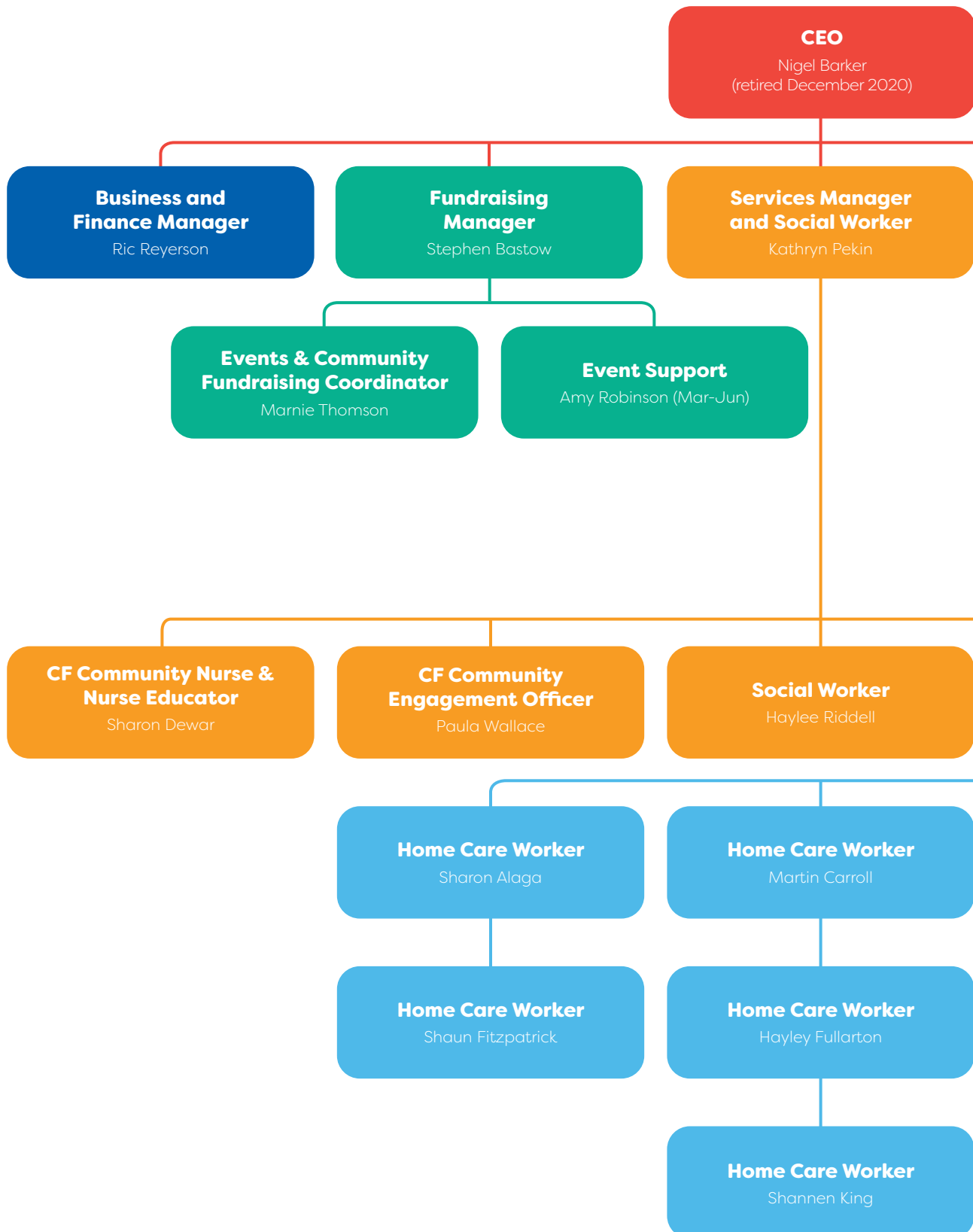


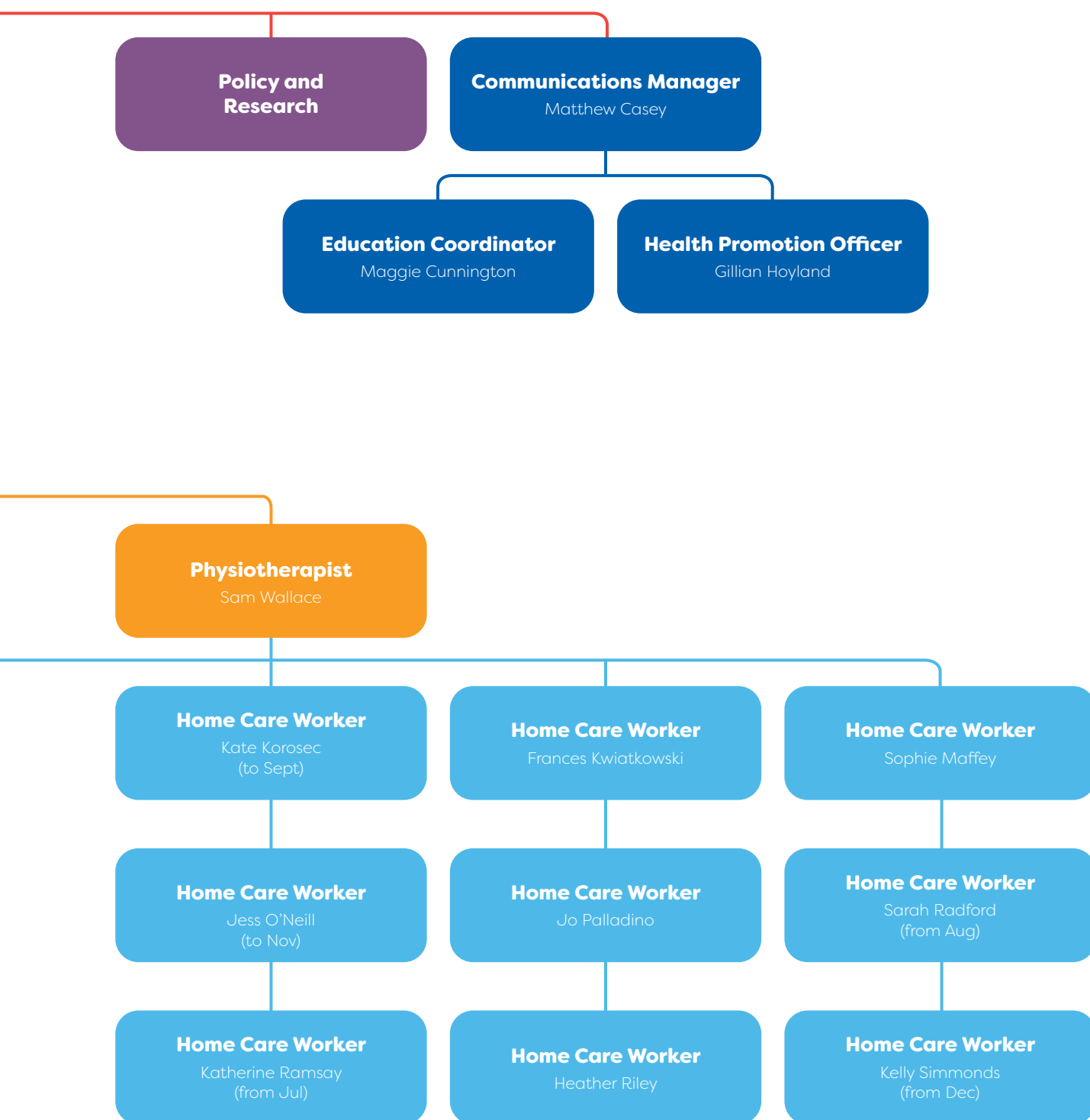
HERBERT  
SMITH  
FREEHILLS

LOMAX



# Organisation Chart 2020







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