CYSTIC
FIBROSIS
Western Australia

Annual Report

2022

Acknowledgment of Country

We acknowledge the traditional owners of the country on which we work, and pay our respect to elders past and present, for nurturing this precious land where we live, learn, and play.

We extend this respect to all Aboriginal and Torres Strait Islander people and extend our gratitude for their contributions to health and education.

Embracing Tomorrow

"Embracing Tomorrow" is a promise to our community that we provide care, regardless of what their tomorrow holds, recognising that everyone's journey is different.

With improvements in drug therapies and treatments, the services we provide in the future may need to change, but we will continue our pursuit of a cure and better treatments for all people living with cystic fibrosis.

CYSTIC
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Western Australia

Contents

The Impact of Cystic Fibrosis

Cystic fibrosis is a chronic life-limiting condition for which there is currently no cure. CF affects thousands of people around Australia; not just the individuals, but also their families, partners, and carers.

400

West Australians and over 3,600 Australians live with CF.

Rare disease, wide impact

- 1 in 25 Australians are carriers of the condition. That's over 1 million people, and most don't know that they are carriers.
- CF affects the whole family, not just the individual but also their parents, caregivers and siblings.

365

People with CF work hard to stay healthy every day.

Daily treatment burden

- CF often affects breathing due to the build-up of thick sticky mucus in the lungs.
- Multiple organs are affected, not just the lungs.
- Common infections can be high risk for people with CF.
- Daily CF treatments are extremely time consuming and can include physiotherapy, nebulised treatments, and multiple medications.

2.5

Anxiety and depression are 2.5 times higher than in non-CF population.

Quality of life impact

- CF is uniquely isolating. People with CF are not recommended to come within 4 metres of each other due to the risk of cross-infection.
- CF leads to significant financial burden. Hospital visits, lost income from illness and medication costs all contribute to financial stress for many people with CF.

Our Impact in 2022

Here's a snapshot of some of the ways we have been able to support people and their families living with CF in 2022; made possible with the help of our dedicated community, partner organisations and supporters.

Community Needs

The top three reasons people come to us for support are:

Support in the Home

Our team of carers, health professionals and support staff assist individuals and families at home with establishing routines, doing treatments, and cleaning and respite in periods of need.

Specialised Support

Individualised counselling, support, and peer connection programs addressing mental health, isolation and hardship.

Education and Advocacy

Support and care for people with CF through education resources, research, and advocacy.

Accessing our Services

Our services were accessed 4,498 times, including airway clearance, exercise support, psychosocial and practical support for vulnerable people or those experiencing hardship.

Advocacy

In 2022, Trikafta® access was extended for people with CF aged 12 years or older who have at least one F508del mutation, following joint advocacy efforts from the community and the combined CF Federation.

Research

In 2022, we established a dedicated Research Working Group and CFWA Research Strategy, which reflects our continued commitment to supporting quality respiratory research.

In early 2023, we awarded our first Innovation Grant, designed to fund CF research in emerging fields.

Community Events

We hosted over 30 community events across WA in 2022, including peer support events, regional outreach and chronic wet cough education. These events support and educate individuals, parents and community members.

Education

We provided tailored CF education and school action plans to over 40 WA schools in 2022, and educated over 170 individuals through our online learning platform.

Extending our Reach

In 2022, we reached over 1 million people online and through social media, spreading awareness of cystic fibrosis in the wider community.

Fundraising

With the support from an amazing community and corporate sponsors, **we organised and supported 9 major events and hundreds of community fundraising campaigns.** Funds raised and donations received totalled **over $800,000.**

Message from the Patron

It is my pleasure as Patron of CFWA to reflect on, and acknowledge, the organisation's efforts and achievements in 2022; and to say thank you to all our supporters.

2022 was a challenging year on many fronts, as Western Australians experienced the peak of COVID whilst dealing with the economic downturn, societal challenges and cost pressures triggered by the pandemic. This complexity challenged community service organisations like CFWA, with the need for support increasing significantly, at the very time income declined and risk and costs rose rapidly.

Fortunately, CFWA's successive Board and management teams have created a sustainable business model and culture that can withstand this instability. Management adapted effectively to ensure continuity of both fundraising and essential services throughout COVID. They prioritised consultation and communication with the CF community, supporters, hospital teams and other support organisations to anticipate challenges and needs, and to adapt to circumstances.

CFWA's good governance enabled a financial operating result better than budget, although market instability hit CFWA's invested funds and net results heavily.

CFWA continued to invest in people and systems, to build on its strengths, meet changing needs and ensure sustainable growth.

Together with the national CF Federation, CFWA's proactive advocacy and research endeavours are enabling enhanced care and new milestones in CF treatment. CFWA's investment in team capability continues to extend our reach and impact, such as new programs to build awareness of lung health across WA.

The achievements in this report highlight the purpose and commitment that drives all the CFWA team.

I am proud to serve as CFWA's Patron and extend my thanks to the Board and CFWA staff and to all our collaborators and supporters.

John Rothwell
Patron

Message from the President

I am delighted to serve as President and Board Chair for CFWA and proud of CFWA's continued impact in the CF and respiratory community through 2022.

It has been a challenging year for many individuals and families we support and that has led to high demand for our services. To deliver the services and supports, and fund these, the team has pivoted many times throughout the year. They have met the challenge of dealing with COVID and major changes in the settings for fundraising and operations, whilst concurrently delivering on significant new contract commitments.

As a Board, we are focused on ensuring CFWA meets community needs within our funding capacity, whilst managing risk (and not losing sight of future needs!). COVID has challenged this balancing act - we faced increased risk to our clients, staff and service continuity whilst many clients remained in need of face-to-face support. Inevitably, CFWA had to make some difficult decisions such as moving to remote services earlier than planned. However, with forward-planning for remote services and COVID safe options, we were able to include our clients in decision-making and ensure their critical needs were met.

I would like to thank our clients, partners in service delivery and supporters for their flexibility. We are very fortunate to have long-term supporters that have adapted with us through these challenges. In 2022, that included moving our 65 Roses wrapping to a remote model, where small community groups wrapped roses at home and sold them locally. This was a significant logistical challenge we couldn't have met without the flexibility of our partner, WAFEX, and our volunteer community including corporations and individuals. It is a model that was embraced by community and will be part of 2023's 65 Roses campaign.

The CFWA team prides itself on being community focused and collaborative. Our collaboration with the national CF Federation and contribution to CF Australia has helped achieved milestones like the PBS listing of Trikafta®, a CF modulator that is enabling vast health improvements, for eligible patients who have at least one F508del mutation, together with increased awareness of CF. Our collaboration with the research community and health professionals enables us to deliver on our research strategy and build CF knowledge within communities. We are also immensely grateful for the supportive contributions of the Department of Health WA, Channel 7 Telethon Trust, the Stan Perron Charitable Foundation, and Lotterywest.

I would like to thank our Patron, John Rothwell, fellow Board members and the CFWA team for their significant contributions, together with all our supporters.

Damien O'Reilly

Damien O'Reilly
President

Message from the CEO

2022 was a year in two halves for all the CFWA team, myself included. We have many achievements to be proud of and many people to thank.

The first six months was pre-occupied with adapting service delivery to COVID (and contract changes) and managing the implications. Community and staff safety remained front of mind as circumstances evolved. It was all hands on deck to stay ahead of COVID and changing rules, to source scarce masks and rapid antigen tests, to keep our clients up to date, and to backfill community support worker sessions or capacity gaps when staff were ill or isolated.

The second six months focused on re-connecting face-to-face with community, with a whirlwind of program activity, outreach and events. During the COVID peak, CFWA decided to defer all regional outreach and face-to-face CF community events. However, once the situation settled, we quickly moved to deliver these activities, which enable much needed community connection, knowledge sharing and support.

A constant throughout the year was the unrelenting pace of change. **I am immensely proud of the CFWA team's hard work and innovative thinking in response.** We restructured our Services team to focus on growing demands and new offerings were well received, particularly wellbeing subsidies, online youth peer sessions, and comfort packs for kids. Major changes were made to our school CF education model, with e-learning modernised to benefit more school staff remotely. On a smaller scale, some clever promotion of our MyABCF book, created to introduce the concept of CF to children, resulted in a flurry of orders, including internationally!

Our fundraising program was re-invented in parts, with contingencies developed to minimise COVID impact, like remote rose wrapping for 65 Roses Day. We achieved strong results overall, with a particularly strong year end bolstered by above budget results from the CFWA John Gillard Family Golf Classic and the Albany Christmas Lights for CF community fundraiser. As with every year, each community fundraiser and donation contributed to ensure vital services could continue.

Through all this, we remained focused on community needs and our vision and strategic goals. We proactively contributed to advocacy which enabled new treatment access for many; successfully delivered a new Research Strategy; and piloted new programs like the Chronic Wet Cough program to build lung health awareness in regional WA in collaboration with the Wal-yan Respiratory Research Centre. We also modernised and automated some of our office processes – so we can spend more time on services.

As I reflect on CFWA in 2022, I'd like to express my great gratitude for the support provided to CFWA. I am grateful to work with an amazing team, Board and Patron; grateful for the ongoing flexibility and support of the extended CF community; grateful for our supporters, fundraisers, volunteers, health professionals and researchers. I look forward to more collaboration with you all in 2023 and beyond.

L Bayakly

Lisa Bayakly
CEO

Message from the Treasurer

CFWA's financial performance continues to be well managed to ensure ongoing sustainability of services to people with CF and other respiratory conditions, their families, and carers.

In 2022, our financials were impacted on many fronts – a reduction in contract funding from the Department of Health WA, increasing operating costs, and declining fundraising, donations, and investment income in a challenging economy. Fortunately, we hold reserves for such situations, and in 2021, we had worked hard to increase these given the instability in our operating environment. As a result, we were able to continue services with minimal disruption.

CFWA's overall result was a net loss of just over $119k on a turnover of $2.1M in 2022, against a budgeted loss of just under $82k on comparable turnover. The total loss was heavily impacted by a $103k loss in the fair value of our investment portfolio which has to be recognised in the income statement even though it is not yet realised (per accounting standards). Despite the upheavals of the year, CFWA maintains suitable cash and reserves, with close to $1M held in cash or cash equivalents at FY22 year end.

Our operating result (i.e. excluding other income and costs such as investments) was well managed, with most of the income decline offset by successful fundraising and cost containment. Each of our major fundraising events exceeded budget, including the John Gillard Family Cystic Fibrosis Golf Classic fundraiser, 65 Roses Day, and our Matched Giving Day. Funds were bolstered by multiple community fundraisers, finishing the year on a high with the above budget performance of the Albany Christmas Lights for CF.

In addition to services and supports, CFWA continued to proactively fund and promote CF research with provision made for $37k for a Post Graduate Top Up Scholarship and $60k for further research. We also contributed to the funding of the Federation's important work in advocacy, community engagement and representation, and enhancing CF knowledge and standards of care.

I am, therefore, pleased to report the finances of the association have continued to be well managed in a manner which supports the objectives of CFWA and ensures ongoing sustainability of services.

Financial accounts are regularly reviewed by both management and the Board to ensure the costs of running the association and delivering services are properly measured and managed in line with revenue raised.

The financial statements for the year ended 31 December 2022 have been audited by Ms Nikki Shen of Hall Chadwick and a copy of the signed accounts is available for inspection by members on the ACNC website. An extract of the financial statements has been included in this report.

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 commitment to CFWA, its clients and stakeholders.

Sally Rose

Sally Rose
Treasurer

CFWA Services and Support

Our services team consists of health professionals, support staff and a team of community-based workers providing support to the person with CF, and their family, in the community. In 2022, we experienced many changes and challenges but still managed to deliver **4,498 sessions to support over 500 people** in our community.

COVID was a major factor in the beginning of 2022, forcing us to deliver many of our services remotely and postpone our community support events to the latter part of the year. This made for an extremely busy end to the year as we tried to fit our annual program of events and outreach visits into a much shorter timeframe.

2022 was the first year of our new contract with the Department of Health WA, so we were also busy adjusting our programs to deliver on new commitments effectively. As a result, we updated our school and community education program and our recording of program outcomes across the entire contract.

2022 also involved major changes and disruption to our community support worker (CSW) program as a result of COVID and a major update to their employment award. This presented some challenges, but also an opportunity to review and make positive changes including streamlining our payroll, onboarding, and ongoing training.

"CFWA team are always there when we need them with information, smiles and any advice we need."

Our services team grew in 2022 with the addition of Michelle Buck to lead our new Chronic Wet Cough (CWC) education collaboration with the Wal-yan Respiratory Research Centre. This new pilot program was funded by Telethon and involved delivering a health promotion message to regional communities in conjunction with our CF Outreach Program.

We are extremely grateful to the Department of Health WA, Telethon, the Stan Perron Charitable Foundation, Lotterywest, the CFWA Golf Classic Committee, our many community fundraisers, and other partners for their ongoing support to enable us to deliver vital services to the CF and CWC communities in 2022. We also greatly appreciate the collaboration of researchers and health professionals, particularly the hospital CF teams, on services and resources to support the community. We are continuing to build these partnerships in 2023.

"You are always happy to listen to new ideas and give support when requested. You all do an amazing job."

"Great work team! Thanks for another amazing year of helping our community thrive."

"Thank you so much Team for all you do and the help you provide to all the families!"

Financial Support

Our financial subsidy program continued to expand as demand for financial support increased significantly in 2022. Thanks to the generous support of our CF Golf Committee and WA Charity Direct, we were also able to provide crisis relief for vulnerable families this year and include a new financial subsidy for CF adults towards the cost of glucose monitors for those also living with CF-related diabetes.

Generous funding from HBF Community and the CBA Foundation contributed to our wellness program. This helped subsidise the cost of activities that improved physical or mental health and wellbeing and contributed to some of our peer support events. Our Telethon travel subsidy provided much relief to families, especially regional families, helping to cover some of the costs associated with travel to Perth for hospital admissions and clinic appointments.

> “It takes a bit of the stress out of travelling to Perth for appointments.”

CFWA CEO Lisa receiving Rapid Relief Team food boxes

	No. of Subsidies	$ Amount
Equipment Subsidy	63	$16,200
Adult Activity Subsidy	63	$18,100
Mental Health Gap Funding Subsidy	42	$4,500
Pharmaceutical Subsidy	35	$10,500
Adult Travel Subsidy	95	$5,900
Childrens Activity Subsidy	41	$8,300
CBA & HBF Wellness Grants	42	$6,100
Crisis Payments	19	$6,600
Glucose Monitoring System Subsidy	14	$5,900
Telethon Childrens Travel Subsidy	115	$9,100
Telethon Metro Travel & Basic Needs	61	$4,417

Community Support Program

Our community support workers (CSW) provide in-home support for airway clearance, exercise, and occasional respite.

COVID continued to impact our delivery of this program in 2022 with rising case numbers and close contacts significantly reducing the number of face-to-face sessions delivered. Additional personal protective equipment (PPE) like masks and gloves, frequent rapid antigen testing (RATs), and rescheduling visits to other support workers enabled us to continue to prioritise face-to-face delivery to the most vulnerable members of our community. Other services were increased when needed, to ensure families and adults with CF were still supported.

An update to our CSW employment award in 2022 prompted significant changes to our program delivery. Following a comprehensive review, we invested in a new payroll platform and timekeeping system, ready for the start of 2023.

Ongoing disruption and uncertainties led to CSW turnover, so recruitment continued throughout the year to ensure continued services. Fortunately, we have developed online modules to streamline onboarding and ongoing training of CSWs, in collaboration with an external party, CFPhysio.com. Investing in this collaborative project will enable us to standardise the information given to new staff and ensure it is always up to date and of an extremely high standard. We look forward to working with CFPhysio.com in 2023 to further progress this initiative.

2,441

Community Support Worker Sessions Delivered

16

Newly Diagnosed Nutrition Support Bags

42

Monkeys

65

PCH Snack Packs

Along with a network of supporters, we aim to reduce the financial and emotional burden associated with living with CF for our community.

Thanks to Telethon, and in collaboration with Perth Children's Hospital (PCH), we have been able to provide nutrition packs to our newly diagnosed families and medical equipment to our CF children. We have also provided Foodbank referrals and Rapid Relief Team food boxes to those families facing food insecurity, and distributed toys, complimentary tickets, vouchers, gifts, and prizes to our community throughout 2022. Thank you to all our generous support organisations and to the many individuals who also make and donate gifts.

Alongside our work in the community, we also provide support to individuals with CF and their families when they are admitted to hospital. Our hospital packs include food to supplement hospital meals, toiletries, and toys. Our monkeys have proven to be very popular and have had many adventures with their buddies when admitted at PCH.

> **"It costs us approximately $400 to attend clinic. Without CFWA support we may not be able to afford to attend."**

> "I am convinced that this service has contributed to my child's good health and positive attitude towards cystic fibrosis.
> Thank you CFWA."

Community Education and Resources

CF Smart is a national CF e-learning resource that is widely used across Australia. CFWA maintains this resource to ensure educators are well prepared and informed to support a child with CF in an education setting.

A new Department of Health WA contract in 2022 prompted a comprehensive redevelopment of our school education program including updated online learning modules and the introduction of tailored Student Action Plans and School Management Plans. These initiatives were developed to individualise school and community education and address any gaps resulting from a reduction in delivery of face-to-face or remote education sessions.

One of the major achievements of the year was the launch of our new CF Smart website, **cfsmart.org.au**

The website has seen significant uptake in its first year, with over 600 individuals completing 929 online learning modules Australia-wide. The website offers a range of educational resources and online courses, which have been developed in response to the changing needs of our community.

CF smart
cystic fibrosis education program

Feedback on these initiatives has been extremely positive and we will continue to review and develop this program in 2023 to further enhance our education delivery.

2022 Education

28 Number of Student Action Plans Developed

41 Number of School Management Plans Distributed

171 Individuals in WA completed 245 modules

9 Face to Face/Remote Education Sessions Delivered

17 Starting School Resource Packs Distributed

In 2022, a priority focus was ensuring all our current resources were up-to-date and easily accessible for our community. We worked on transitioning many of our hard copy resources to online, meaning we were able to keep our community more readily informed of developments within the CF space.

Nutrition for Infants Webpage and Workshop

In collaboration with the lead CF dietician at Perth Children's Hospital (PCH), we produced a hub of nutritional information for parents and other carers of infants with CF from birth to one year of age. Thank you to PCH for supporting this project.

We also facilitated an online nutrition workshop for parents of toddlers, covering nutrition, mealtime behaviour and routines. This session was collaboration between CFWA and the Perth Children's Hospital CF dietician.

Factsheets

We continued to create new factsheets in response to community need, as well as ensuring existing factsheets remained up-to-date and relevant.

"My ABCF is such a beautiful way to start a discussion with our kids and help them understand their condition in a simplistic yet imaginative way."

My ABCF Book

Developed in 2021, My ABCF continues to provide an important tool for parents to start the conversation about CF with their young children and families. We now sell the book through our website and sales have been strong nationally and internationally. We are looking to produce a similar book aimed at children starting school in 2023.

> **"It's full of information about CF and things I do like doing my physio with the abacus and PEP tube and going to the hospital. I like the pictures and love spotting the roses on each page!" Oli, aged 9.**

Community Connection

Connecting people within our community is an important part of our role.

Due to the risk of cross-infection, people with CF are unable to connect in person, and we provide a range of online services and supports catering to their needs. However, the rare and isolating nature of CF can also be challenging for the whole family.

Our services events target parents and other family members, providing them with respite and the opportunity to meet and build relationships and support networks within the CF community.

Despite COVID restrictions, we safely facilitated all our annual service events in 2022. Thank you to Telethon and Lotterywest for supporting our Sibs and Kids Camp, and to Carers WA for contributing to funding our Parents' Retreat.

Sibs & Kids Camp
Sept 2022

"Thank you for taking wonderful care of my daughter and making the Sibs' Camp awesome as you all always do. My daughter had the best time making friends."

Sibs' Day Out
Jan 2022

Ladies' High Tea Sept 2022

"Love, love the ladies high tea. The games are great fun and it's so nice to talk to other families."

Parents' Retreat Oct 2022

"Had a fabulous, relaxing time away. The team do an amazing job and love all their support."

Grandparents' Morning Tea Nov 2022

"Thanks so much for the morning tea. It was lovely to connect with other grandparents and hear their stories."

Community Connection Online

As well as events for family members, we have a host of other ways in which people with CF or close family members can connect to help address the issue of isolation.

Connection enhances mental health and wellbeing which has a direct correlation to treatment adherence and therefore physical health.

Community Facebook Groups

Our two private Facebook groups, one for adults with CF and the other for parents, grandparents and carers, continue to grow and provide a positive forum for groups in our community to come together and share experiences and information.

Adults Facebook Group

101
No of Members

2
Average Posts Per Week

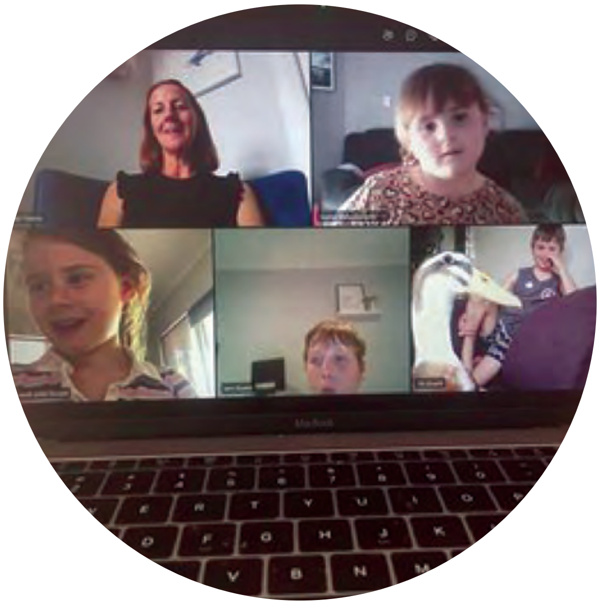
Parents & Carers Facebook Group

151
No of Members

4
Average Posts Per Week

CF Kids Connect

The Virtual Catch-Ups for CF Kids is an online program available to children with CF aged 6 to 12 years. The program aims to connect children in a safe forum where they share experiences and meet other kids with CF. Conversations are facilitated by our Occupational Therapist, keeping the chat flowing and navigating questions, show and tell, and activities to promote connection and learning about CF. We thank Lotterywest for its support of this program and look forward to expanding its reach to other age groups and cohorts in 2023.



“I enjoy the virtual catch-ups and meeting other kids with CF. I have enjoyed making friends with other kids with CF, even though I have a brother with CF, it’s nice to see other people my age with CF too. It makes me feel I’m not alone.“

Regional CF Support

Visiting our CF community in the regions is an important part of our Outreach support program. Travelling to different parts of the state providing face-to-face support helps those in isolated locations strengthen their localised peer support networks. It also enables us to deliver CF education to health and education professionals with the aim of achieving better health and wellbeing outcomes for people with CF in regional communities.

As a result of the ongoing impact of COVID, our 2022-funded Outreach Program was not able to be delivered until the second half of the year with two of our trips canceled, and subsequently postponed, until early 2023. The first half of 2022 was spent providing telephone or online support to our regional families and providing opportunities to connect with the community through virtual catch-ups, webinars, and our private moderated Facebook group for CF parents in WA. Once travel commenced, we were able to visit five locations from the Pilbara to the Great Southern.

We were also fortunate to collaborate with Telethon Kids Institute (TKI) to present a research update in Albany on phage therapy to address antimicrobial resistance in people with CF. These types of events help to translate research so that it can be understood by the families it is impacting and provide hope for the future. We look forward to continuing this important collaboration with TKI in 2023.

Thanks to Telethon for their amazing support of this program!

Sam and Michelle providing support and education in the Goldfields

188

Financial subsidies

121

Remote support sessions for people with CF and their families

27

Face-to-face support sessions for parents and carers

46

Teachers and health professionals received face-to-face education

Other Respiratory Services

At CFWA, we are passionate about applying our knowledge and skills to help build better lung health across WA. We also plan to use our capabilities to provide valuable services to people with other respiratory conditions beyond CF. We are expanding our funding and services to enable this.

> "Love that you are reaching the more remote areas of WA, so important. Thanks again."

Chronic Wet Cough

In 2022, we successfully delivered a **pilot community-based Chronic Wet Cough education program in regional WA**. This was made possible with generous funding from Telethon. This program was delivered in collaboration with the Telethon Kids Institute BREATH team and the Wal-yan Respiratory Research Centre, a partnership between the Telethon Kids Institute (TKI), Perth Children's Hospital Foundation and Perth Children's Hospital.

For more information,

visit: www.cfwa.org.au/chronicwetcough

What is **Wet Cough?**

A wet cough in a child for more than four weeks could indicate ongoing infection in the lungs.

In many Aboriginal communities in WA, wet cough has become 'normalised' and there is a low level of community awareness of related diseases. If chronic wet cough goes undetected/untreated, the ongoing infection and inflammation can lead to irreversible long-term lung damage which can impact quality and duration of life. The shared goal was to work towards contributing to improved, equitable access to best practice respiratory health care for all WA children.

"It's exciting thinking about what we might be able to achieve over the next few years!"

"Thank you for supplying us with this valuable session along with resources."

PROUDLY SUPPORTED BY telethon 7

TELETHON KIDS INSTITUTE

The BREATH Team
Building Respiratory Equity for Aboriginal and Torres Strait Islander Health

Our long-term goal is to empower a network of local navigators to ensure ongoing awareness of chronic wet cough in the community. Early awareness of chronic wet cough, and treatment and support closer to home, will help enable children to live longer, healthier lives.

We welcomed Michelle Buck to our team as our Chronic Wet Cough Community Educator. The pilot program Michelle is undertaking involves extensive planning with stakeholders; and travel to regional and remote areas, connecting with health professionals, educators and community members, in a variety of settings, including playgroups, Aboriginal health services, and schools.

We also met with government health agencies to deliver the key message, “If your child has a wet cough for more than four weeks, bring them to clinic quick!”

Bronchiectasis and PCD

Our team was also welcomed into a newly formed Bronchiectasis and PCD (Primary Cilia Dyskinesia) consumer group established by TKI and we look forward to understanding consumer needs and extending relevant knowledge and support in future.

> **“It was lovely to meet you in person today to chat about opportunities to the promote information regarding Chronic Wet Cough Syndrome. Wishing you all the very best with the navigators and the help to get the message out there.”**

Travel Stats

6,248k
by Plane

3,168km
by Car

655km
by Train

Travel Stats	No.
Regional Towns of Western Australia Visited	12
Parents Educated	67
Children Aged 0-16 Years Educated	80
Health Professionals Educated	77
Community Groups /Early Learning Visited	46
Teachers/Educators Educated	19
Resource Packs Delivered	53

Policy, Research and Advocacy

We help bring together the extended CF community and policy and decision-makers to further research endeavours and enable enhanced treatment and support for all people with CF, their families, and carers.

National Collaboration

CFWA is fortunate to be part of a national Federation of CF organisations, including CF Australia, CF Community Care (NSW and Victoria), CF Queensland (also supporting NT), CF ACT, CF South Australia and CF Tasmania.

CFWA contributes financial support, leadership expertise and resources that help enable the Federation's important work in advocacy; community engagement and representation; and enhancing CF knowledge and standards of care.

A key focus of the Federation's efforts in 2022 was proactive advocacy, led nationally by Cystic Fibrosis Australia (CFA)'s new CEO, Jo Armstrong, for timely access to the latest modulator treatment Trikafta®.

Cystic Fibrosis Australia CEO, Jo Armstrong, with the Hon Mark Butler MP at the press conference where the Health minister announced the welcoming news Trikafta was to be listed on the PBS for those eligible within the 6 to 11-year age group from 1 May 2023.

Advocacy for Treatment Access - Trikafta® Access

Trikafta® is a CF modulator that treats the underlying cause of CF. Unfortunately, Australia has been lagging other countries in access to this treatment which is enabling vast improvements in health and wellbeing.

To address this gap, community members and the Federation continued the push for access to Trikafta® relentlessly throughout 2022, with many hurdles and delays.

After much representation to government, many community members sharing stories, and hundreds of letters and appeals to parliamentarians, Trikafta® was finally listed on the PBS on 1 April 2022 for patients with CF aged 12 years or older who have at least one F508del mutation.

Advocacy continued throughout the year for the 6-11-year age group who were not eligible for access under this listing. In December 2022, a positive recommendation was made for 6–11-year-olds who have at least one F508del mutation on the CFTR gene. Finally, PBS listing for this age group was confirmed in April 2023, with listing from 1 May 2023.

Whilst this is very positive progress, there is still more to do to ensure everyone has access to effective therapies, including people with rare mutations, people ineligible for current therapies, or people unable to tolerate or respond to current modulators. National advocacy work continues in this space, alongside pushing for access to other necessary supports for better health and wellbeing.

Advocacy for Coordinated Healthcare and Support

CFWA also advocates to ensure people with CF and their families and carers have access to coordinated healthcare and support within the community.

We advocate with, and on behalf of, individuals and families in need as they navigate the health and education systems. In 2022, we developed advocacy guidance material and resources to help inform effective self-advocacy; and we enhanced our referral supports to external organisations.

We also advocate for more significant system changes, where a need is identified by client input either directly and/or through Consumer Reference Groups.

We participate in the Child and Adolescent CF Consumer Reference Group, comprised of parents of children with CF, 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.

We are also active members of the Adult CF Consumer Reference Group and collectively we were able to successfully advocate to meet increased resource needs at Sir Charles Gairdner Hospital in 2022. When Trikafta® was listed for the 12 plus age group, we advocated successfully for increased CF pharmacy resources to enable timely rollout. Later in 2022, we also advocated to leaders at hospital, health services, and at the ministerial level, for additional psychology and social work resources for the adult CF outpatient clinic, with new resources approved for 2023.

Research Funding and Promotion

We continued our commitment to fund quality CF-related research again in 2022, with the establishment of a dedicated Research Working Group and CFWA Research Strategy, which reflects our continued commitment to post graduate research (encouraging emerging researchers to pursue careers in respiratory research) and strategic, innovative research endeavours. We continued to collaborate with the Australian Cystic Fibrosis Research Trust (ACFRT), administered through CFA, to ensure appropriate, objective oversight of grant award and research completion and reporting.

We awarded a Post Graduate Top Up Scholarship to Rohan Flint in 2022, bringing the total to 14 awarded to date. Rohan's research project is investigating the use of aerosolised bacteriophage to administer phages as an alternative therapy for bacterial infections that have become resistant to a large number of antibiotics.

We also advertised a new Innovation Grant, designed to fund CF research in emerging fields, with the grant awarded in 2023.

Thank you to the Gillard family, the Golf Classic Committee, Golf supporters and volunteers for their continued support which has made this research funding possible, together with "Cash for Can" proceeds collected by Eric and Ronele Gard.

Once again, we collaborated with TKI to host a regional research evening with a presentation from TKI researchers who provided an update on bacteriophage (phage) therapy. Thank you to TKI for their continued collaboration to ensure our community is well informed on the exciting research being undertaken here in WA, nationally and globally.

Fundraising and Our Supporters

CFWA is incredibly fortunate to have a passionate, supportive community. They take on fundraising challenges, sell roses, donate and volunteer their time to ensure every campaign is a success. Despite COVID once again surging at the start of 2022 with new restrictions in place, it was still a strong fundraising year. The fundraising portfolio consists of a diverse mix of online and physical fundraising campaigns. This approach provides many varied opportunities for the CF community to show their support and raise awareness.

The generosity from our supporters allows CFWA to deliver 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 of Lives Unaffected by CF.

Our 65 Roses Day campaign was most affected by COVID restrictions from February through to May. Despite this, our community embraced wrapping their own roses from their home or workplace as we were unable to host our volunteer rose wrapping day. We sold nearly **15,000 roses** including **350 bouquets!** Our Virtual Rose Garden enhanced our public reach with **3,314 virtual roses** sold raising **$51,000.** Combined with the Virtual Rose Garden, we had our strongest 65 Roses Day campaign ever, raising over **$133,000!**

The John Gillard Family Cystic Fibrosis Golf Classic, now in its 12th year, is another huge campaign in the calendar and is well supported by the golf and corporate community. Though registration revenues were slightly down, this was more than made up for with the silent and live auctions sales, with a net result of **$147,500** one of the best performing years from this event.

Our amazing community fundraisers raised over **$228,000** in 2022, of which the largest fundraiser was the Albany Christmas Lights for CF. Once again, passionate community fundraisers Lorraine and Jeremy Stevenson exceeded all expectations and raised **$89,099** through their magnificent Christmas Lights display! We were fortunate to receive a grant from the City of Albany recognising this as a Regional Event meaning there was greater exposure which attracted **5,555 people from outside Albany.**

Other fundraising efforts in the year include our appeals which raised over **$50,000**; our second Giving Day which raised over **$72,000** thanks to a very generous surprise **$10,000** donation; our regular giving program which raised **$11,000**; and our tin collection program – found in over 200 locations – which raised over **$13,500** in 2022, an **increase of 12% from the previous year.**

Finally, our Bring It On Campaign returned in 2022 with the inclusion of Zip & Climb. Daring fundraisers challenged themselves to climb the Matagarup Bridge and zip back down to the shore raising **$29,350** in the process.

15,000

Roses Sold During 65 Roses Day

3,314

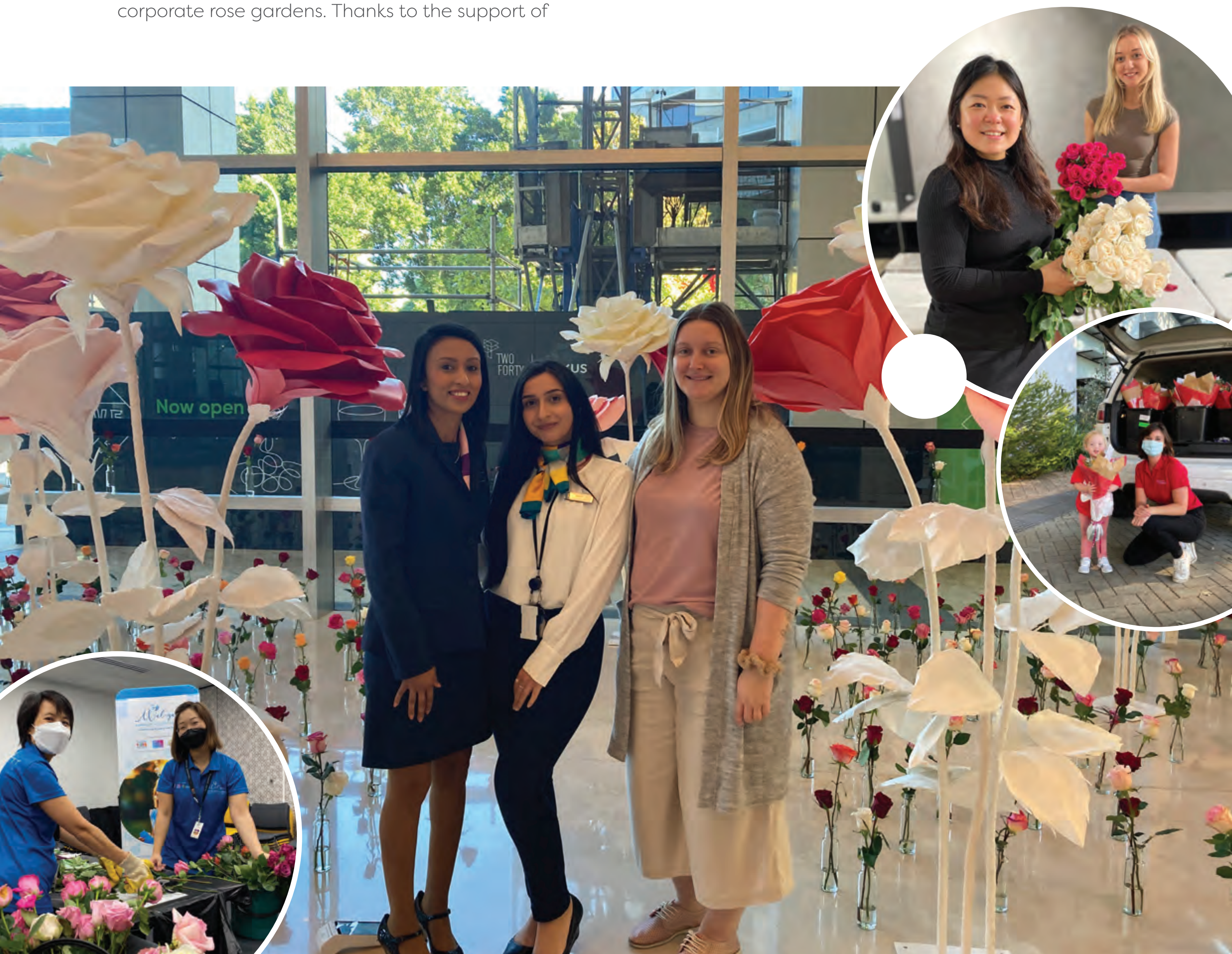
Virtual Roses Sold During 65 Roses Day in Our Virtual Rose Garden

Major Events and Campaigns

65 Roses Day

In 2022, our 65 Roses Day campaign once again looked a little different due to COVID driven limitations. Despite this, 65 Roses Day raised over **$133,000**, a **new campaign record.** The official day was Friday 27 May and while we couldn't be in the Perth CBD and metropolitan area selling roses, we were out in force delivering a record **350 bouquets** to people in our CF community. We raised nearly **$12,000** from bouquet sales alone in 2022. Given we couldn't host our annual volunteer rose wrapping day either, we initially anticipated selling only 5,000 roses, but thanks to our community embracing wrapping their own roses at home or workplace, we sold nearly **15,000!** In addition, our Virtual Rose Garden thrived with just over **$51,000** raised from the purchase of **3,314 virtual roses**, including both individual and corporate rose gardens. Thanks to the support of Devahasdin PR and community ambassadors, we also received extensive media coverage to raise CF awareness.

Once again, we were grateful to have the support of our longtime rose supplier Wafex. Thank you to Equiem for allowing us to take over the foyer of TwoForty once again, and to Giant Flowers Australia for providing the magnificent giant paper roses. South Metropolitan TAFE students went above and beyond in their support in a challenging year. We would also like to thank Haydee Carman for her fantastic fundraising and awareness efforts in Mandurah, and to CBRE for their support with our Department of Communities and FOMO activation in Fremantle.



The John Gillard Family Cystic Fibrosis Golf Day

The John Gillard Family Cystic Fibrosis Golf Classic celebrated its 12th year in 2022 and thanks to the extremely hard-working Golf Committee, the attendees and sponsors, the event raised over **$147,500**.

The main focus of the Golf Committee is to support research into cystic fibrosis. In 2022, **$37,500** of the funds raised were allocated to a PhD Top Up Scholarship; **$60,000** towards future research programs; and the remaining funds allocated to support programs for families affected by cystic fibrosis. Thirty-three teams of four took to the green on the day, and they were accompanied by their guests in the evening to enjoy the delicious dinner and entertainment with Steve Mills generously giving up his time to emcee once again.

The silent and live auctions were very generously supported with three last minute live auction items raising over **$41,000**! Our guest speaker of the evening, Paige Flatt, spoke eloquently about her experience living with CF and her hopes for the future. Our thanks go to the Golf Committee for once again putting on such an enjoyable and successful event.

Giving Day

Our Giving Day was held on 1 December. Thanks to the incredible support of our CF community and a surprise **$10,000** donor, we're pleased to announce our Giving Day raised over **$72,000**. Thank you to our generous matched givers, Mimi and Willy Packer, Rosalind Clark, Philippa and Daniel Craigue, and two anonymous donors. Thank you also to Amanda Kim for generously sharing her daughter's lived CF experience; this highlights the impact of CF on the family and community which in turn raised awareness to donors for this campaign.

Bring It On Zip & Climb

The stakes were raised in 2022 when our Bring It On Bridge Climb became Bring It On Zip & Climb with the introduction of a zip component giving participants a speedy return to shore. Twenty participants bravely faced their fears on a bright Saturday morning in September by climbing the Matagarup Bridge, then ziplining their way back down across the river to the other side. Collectively they raised **$29,350**. Participants and their spectators were treated to Signature Burgers cooked by the Rapid Relief Team (RRT).

Thank you to RRT, the Matagarup Zip + Climb team, and our two ambassadors, Tahlia Posselt and Anthony Kicic.

Bridge climbers at Matagarup Zip+Climb, raising funds for cystic fibrosis.

Community Fundraising

Our community support remained strong in 2022 despite the continued challenges posed by COVID.

Community Fundraising

Our wonderful community came together again in 2022 to host some incredible fundraisers throughout the year. 2022 started off with Krystle Devine organising a hair shave event raising over **$3,100**.

Corporate Battle of the Bands was held on a very hot evening in February. Thank you to Roger Blow for organising this event once again despite COVID restrictions. It was our best year to date, raising over **$5,000**.

Kate Spaapen took a year off her 'Serve It Up' dinner parties and instead turned her hand to baking cupcakes and delicious cakes for donations instead. She raised over **$4,400** in May.

Team Giving for Western Power held a Gala Dinner for CF in October at the Westin Hotel. Guests were treated to a delicious meal, music and a live auction. The hard-working Team Giving team raised over **$11,700**.

The year ended with the Paddy Malone Memorial Golf Day at The Vines hosted by Masie Masterton raising over **$9,500** in December.

$4,400+
Raised by Kate Spaapen and her Family

$11,700+
Raised by Team Giving at the Gala Dinner in October

$9,500
Raised by Masie Masterton at the Paddy Malone Memorial Golf Day

$3,100
Raised by Krystle Devine at the start of 2022

$5,000
Raised by Roger Blow with the Corporate Battle of the Bands event

65 Roses Challenge

Once again, our CF community took up the challenge, whether that was running, cycling, swimming, or walking 65km throughout the month of May, or any other challenge to get our community out of their comfort zone – they did it! Laura Currie kicked things off early in February and arranged a mass participation walk from Cottesloe to Hillarys; a smaller walk was also held on the same day by her extended family in Scotland. Her team raised a massive **$10,565**! Tegan Micke raised over **$10,600** swimming 65km in May; Zoe Parsons ran 65km raising over **$9,600**.

Hale School took up the 65 Roses Challenge for the third year in a row. Boarders in Years 7-12 from Wilson House challenged themselves to run 65km each in honour of a fellow boarder who lives with cystic fibrosis. By sharing his story, he has inspired his fellow students and together they raised an impressive **$3,490**.

$10,600

Raised by Tegan Micke and her team for the 65 Roses Challenge

$10,565

Raised by Laura Currie through a big walk from Cottesloe to Hillarys

Albany Christmas Lights

The year ended on a high with community fundraisers Lorraine and Jeremy Stevenson once again hosting their annual Albany Christmas Lights for CF. They shared the spirit of Christmas with families travelling to Albany from far and wide to witness the dazzling lights displayed at their property.

It's estimated **30,000 people** came through their garden over the 27 nights of the display and in that time, they raised over **$89,099** to support families affected by CF and raise much-needed awareness. Thank you to their team of volunteers who ensured the event ran smoothly, while looking magnificent in their new Nutcracker inspired jackets.

Thank you to Jennifer Garlick from CBRE for generously donating the hanging monkeys which are always a popular addition to the merchandise cart. Thank you to all the Albany businesses who collectively contributed extensive in-kind support; and to sponsors the City of Albany, Southern Ports Authority, the Stan Perron Charitable Foundation, Rick Wilson MP, Correct Flow Hydraulic Services and McDonald's Australia.

$89,000+

Raised by Lorraine and Jeremy Stevenson

Sponsors and Supporters

Supporter Community

In November, 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. Our awards also recognised six very special groups or individuals who went above and beyond to make a difference.

Each recipient made their own heartfelt speech about why it is so important to them to support this cause. A special mention was also given to Board member Caz Boyd for her invaluable service and support of Cystic Fibrosis WA including the past four years as Board President.

Award	Recipient
Fundraiser of the Year	Haydee Carman
Supporter of the Year	Wafex
Supporter of the Year	South Metropolitan TAFE
Volunteer of the Year	Ron Gray
Long Service	Eric and Ronele Gard
Lappa 65 Roses Spirit	Laura Currie

On the subject of awards, Adult CF Clinic nurse Sue Morey was awarded the CF Centre Star awards at the 2022 Patron Awards coordinated by CFA for her outstanding service to patients with CF. Congratulations Sue!

South Metropolitan TAFE
Supporter of the Year (left)

Ron Gray
Volunteer of the Year

Eric and Ronele Gard
Long Service

Wafex Supporter
of the Year (Right)

Haydee Carman
Fundraiser of the Year

Laura Currie
Lappa 65 Roses Spirit

Gifts in Kind

CFWA has again been well supported by our very generous community and has received invaluable donated gifts-in-kind (goods and services) for events and member support in 2022.

This extensive list of donations supports all aspects of our organisation, including services and supports for individuals and families; and contributions to fundraising campaigns. Thank you to all our supporters who donated goods or services during 2022.

There are many individuals in our community who have generously donated gifts such as handmade quilts, self-authored books and more, which all help bring comfort and joy to people. **Thank you all!**

Rapid Relief Team (RRT) have generously supported our Sibs & Kids Camp and Bring It on Bridge Climb events by donating their delicious burgers and time. Thank you!

Our generous supporters at Wafex supply us with beautiful fresh roses every year for 65 Roses Day.

They have now supported this event for well over a decade, and have supplied more than 100,000 roses in that period.

Thank you for your support!

Grants and Pro Bono Support

Donations from our generous community are equally essential to address funding gaps. Donations through our Pre-tax and Christmas Appeals, regular giving and general donations were impacted by COVID but continue to enable extended program reach and community support.

Thank you to all our generous donors and funders.

Grant support is vital to helping fund specific CFWA programs and meeting the needs of people with CF and other respiratory conditions, their families, and carers.

$50,125
Donated From Our Pre-tax and Christmas Appeals

$10,000
Donated From Conquer Cystic Fibrosis

$58,939
Donated From Individuals, Organisations and General Donations

$301,675
Total Funding From Grants

Grants

Channel 7 Telethon Trust	**$207,684**	Combined grants supporting our Regional Outreach and vulnerable families program, Chronic Wet Cough Education Program, and funding Nebulisers and Springfusors (2022 and 2023)
Lotterywest	**$29,400**	Peer Connection, OT Resources, Sibs Camp (2022 and 2023)
City of Albany	**$20,000**	Albany Christmas Lights for Cystic Fibrosis (primarily 2022)
Stan Perron Charitable Foundation	**$10,000**	Resources, Service Programs
CBA Foundation	**$10,000**	CF Wellness Program
WA Charity Direct	**$10,000**	CF Family Crisis Support Funding (2022 and 2023)
HBF Community Engagement	**$9,091**	CF Wellness Program
Stan Perron Charitable Foundation	**$5,000**	Albany Christmas Lights for Cystic Fibrosis
Southern Ports	**$2,000**	Albany Christmas Lights for Cystic Fibrosis
Carers WA	**$500**	Parents and Carers Event

In addition, we received $49,375 from the proceeds of the 2022 CF Golf Classic to use toward service programs and medical equipment in 2023; and grants from . Connellan Airways Trust, Mediplast Australia Pty and Aurizon for 2023 activities.

Our Supporters and Sponsors

Thank you to our major supporters and sponsors for 2022!

Government of Western Australia
Department of Health

lotterywest supported

PROUDLY SUPPORTED BY telethon 7

STAN PERRON CHARITABLE FOUNDATION

Wafex
World's Finest Flowers

TELETHON KIDS INSTITUTE
Discover. Prevent. Cure.

Perth Children's Hospital

Government of Western Australia
North Metropolitan Health Service
Sir Charles Gairdner Osborne Park Health Care Group

FIONA STANLEY hospital

FOOD BANK
25 YEARS OF FIGHTING HUNGER IN WESTERN AUSTRALIA

rrt RAPID RELIEF TEAM

TAFE WA South Metropolitan

CAN

hbf

Good360
GOODS FOR THE GREATER GOOD™

Volunteers

Volunteers are integral to our organisation from volunteering in the office, to collecting tins, selling roses, or assisting at our fundraising events – we couldn't do what we do without them. 2022 was no different and we are incredibly grateful to each and every one of our volunteers for giving up their time and so enthusiastically embracing every volunteer opportunity.

On behalf of the CFWA team and CF community, we would like to acknowledge the ongoing support received from South Metropolitan TAFE who play such an essential part in the 65 Roses Day campaign. A special thank you to lecturer Kylie-Anne Stokes who coordinates the TAFE students and contributes hugely to the campaign. In 2022, Kylie-Anne and her students went above and beyond to ensure we could still provide roses to our community even though we were under COVID restrictions.

Our 65 Roses Day campaign always welcomes an army of volunteers. 2022 was no exception with our bouquet orders **increasing from 117 to 350** from last year. We are indebted to our volunteer delivery drivers who helped us deliver these bouquets across Perth and to our community-based rose wrappers. We would also like to say a special thank you to Maggie Harrigan and her daughter who volunteered to drive to Witchcliffe to deliver fresh roses to someone in our CF community!

Thanks to the John Curtin Leadership Academy (JCLA) students who had such a wonderful experience volunteering for us last year, they offered to volunteer their time again this year at the John Gillard Family Cystic Fibrosis Golf Classic. We are truly grateful for the support each of these volunteers gave to our team, and the amazing results they delivered in 2021.

Volunteering

Type	Number	Hours
65 Roses Day Campaign	110	462
Collection Tin Program	1	124
Sponsor and Volunteer Evening	4	14
Christmas Wrapping Volunteers	4	24
Corporate Battle of the Bands	3	12
Golf Classic	15	96
Albany Christmas Lights	60+	2,400+
Sibs & Kids Camp	1	25
CFWA Board	7	76

Our collection tin program is expertly lead by our volunteer Ron Gray. Ron is always looking for new locations to place collection tins and his reach is far and wide across the Perth metro area. Placing tins in the community is not only a fantastic way for people to support us through their loose change, but also play an important role in raising awareness in the community, too. Ron is a tireless volunteer and only too willing to lend a hand with whatever task he is given.

Ambassadors and Community Representatives

During 2022, we were fortunate to have several CF families and individuals share 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 part of their lives.

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

Amanda and Amelia Kim

"At just three-weeks-old, our beautiful Amelia Grace was diagnosed with cystic fibrosis (CF). You are thrown into a foreign world of hospitals, medical tests, education to learn to care for your special needs child, becoming their advocate, and the stress of all the uncertainty that will follow. You are told that your child is lucky to be diagnosed at birth, as they will not know any different. Taking handfuls of pills, doing physiotherapy several times a day, along with regular hospital trips, will all be 'their version of normal'. You are told if there was ever a time to be born with CF, then it's now.

We are beyond grateful Amelia is born in a time that better understands her condition and there is more optimism than ever with new treatments slowly becoming available; but no parent would be satisfied knowing their child has a life expectancy less than half their peers, or with how much medication they must take each day, or with the amount of treatments required daily to try and slow down the progression of this disease, or with the daily impacts to their child's quality of life."

We're grateful to Amanda for sharing Amelia's story and representing our Giving Day.

Jade and Oliver Drinan

Seven-year-old Oliver took the day off school last 65 Roses Day to sell roses at Bunbury Forum with his mum Jade. Jade coordinated roses to be sold at Bunbury Forum, Bunbury Centrepoint and Dalyellup Shopping Centre.

"We really need a cure. In the past few years, there's been amazing breakthroughs with drugs, but we need a cure. Oliver has handled his disease really well. So we wanted to get onboard and sell roses to help awareness and funds for research."

Tahlia

Tahlia was our fearless ambassador for the Bring It On Zip & Climb fundraiser in September. She is ten years old and wanted to brave the Zip & Climb to show her support for those like her big brother, Stephen (12), who lives with cystic fibrosis.

Climbing to the top of a bridge that is 72 metres high is nerve-racking!
Tahlia was completely fearless and had the best time! Upon landing on shore, she said, **"Wow! That was fun! I can't wait to do it again!"**

Paige Flatt

Paige was honoured to be guest speaker at the John Gillard Family Cystic Fibrosis WA Golf Classic and spoke about living with CF and CF-related diabetes.
Paige recently started Trikafta®.

She spoke about the impact that has made on her life as well as starting her first year at university. Thank you to Paige for sharing her experience and enlightening the audience on her day to day life living with cystic fibrosis.

Communications and Media

Communication proved key in 2022, with effects of COVID-19 still felt in both our service delivery and fundraising activities, and the wider community. This meant that providing effective, relevant communication to our community was more important than ever.

We focused on delivering clear, concise, and relevant information to meet our community's needs. COVID meant a lot of our regular activities were either modified or re-scheduled, but by keeping in touch with our community, we made it all work, from at-home wrapping on 65 Roses Day to remote Community Support Worker support.

Thank you to the multidisciplinary teams at Sir Charles Gairdner Hospital, Perth Children's Hospital, Fiona Stanley Hospital, and Telethon Kids Institute for your continued collaborative efforts on community communication and resources. Your continued commitment to information sharing is of great benefit to the whole community.

In July 2022, the CF Federation adopted a new national tagline – Embracing Tomorrow. **"Embracing Tomorrow" is a promise to our community that we provide care, regardless of what their tomorrow holds**, recognising that everyone's journey is different. It reflects that, with improvements in drug therapies and treatments, the services we provide in the future may need to change. It reflects the continued pursuit of a cure and better treatments for all people living with cystic fibrosis.

In 2022, we continued to refine our messaging across all our information resources, recognising that different groups have different needs and preferences. We began streamlining our communications to specific audiences – tailoring communication of school aged resources to relevant families for school year commencement. A review of our resource library with this in mind identified potential gaps, resulting in new resource development, like the MyABCF book to be followed by a book regarding CF at school. Through this tailoring, we aim to lessen the load and enhance the relevance and timeliness of information provided to individuals with CF, their families and carers.

Our reach was assisted by our new Digital Marketing Officer Nicole Posa, who joined us mid-year following Charlotte Bradley's departure.

Communication Channels

A snapshot of how we reached our community in 2022.

Website	Facebook	Instagram	E-Newsletter
36,558 Visitors	4,860 Followers	1,632 Followers	3,221 Readers

Big Engagement in 2022

Trikafta®

The announcement that Trikafta® had been approved by the PBAC for people over 12

17,715 Views

1,805 Reactions

429 Comments

96 Shares

Channel 9 for 65 Roses Day

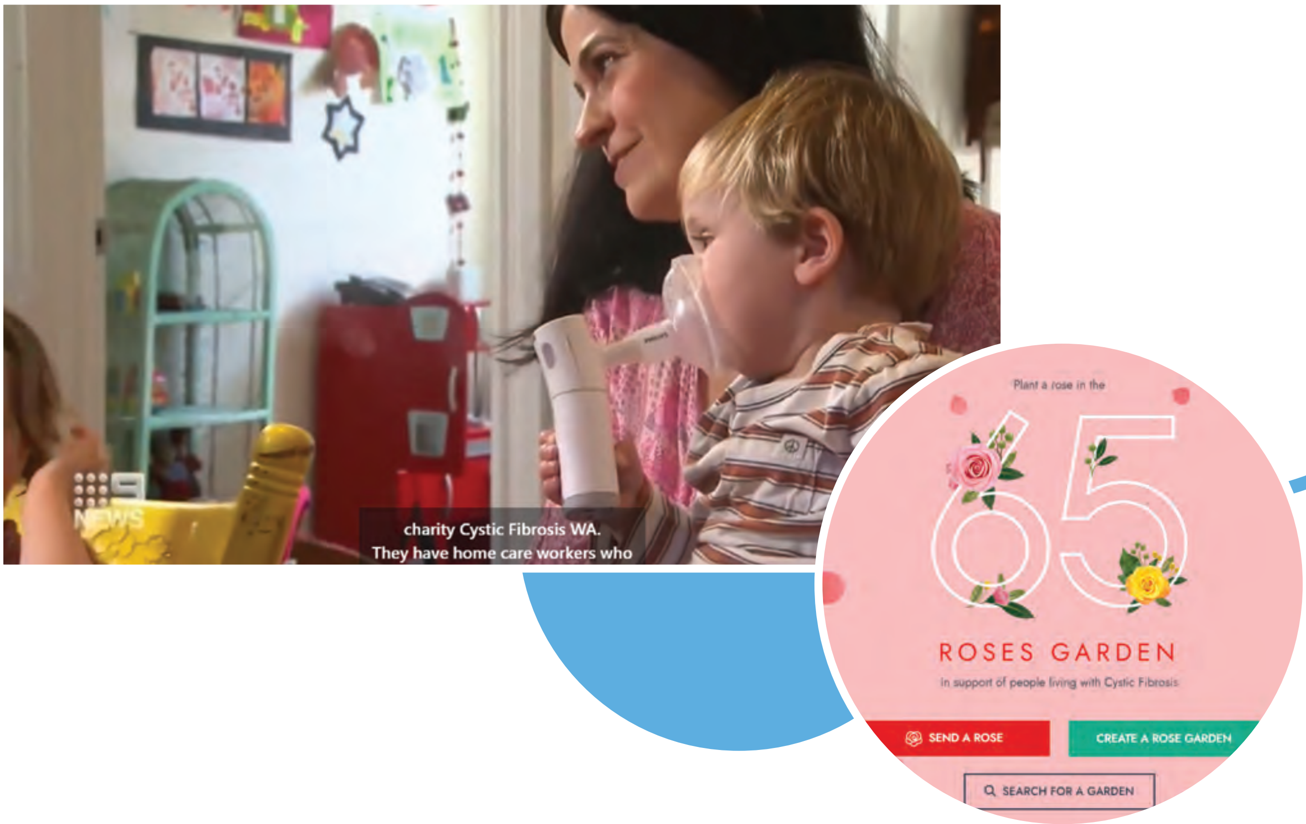
A clip from Chanel 9 featuring an ambassador family, promoting the Virtual Rose Garden for 65 Roses Day.

13,559 Views

352 Reactions

35 Comments

36 Shares



West Australian Landmarks for Cystic Fibrosis

A post promoting the WA landmarks being lit red for CF during May

13,067 views

809 reactions

89 comments

55 shares

Media

Trikafta® Advocacy

CFWA was actively involved in securing media coverage from early in 2022 as part of the continued campaign to push for Trikafta® access. Community and organisational advocacy plays an important part in helping move decision-making more quickly through the various approval stages; and our media focus complemented CFA and Federation endeavours.

CEO Lisa Bayakly and community members appeared in GWN coverage both pre and post the announcement of PBS listing of Trikafta® for eligible patients over 12 years old. This pre and post coverage enabled the need and impact of listing to be emphasised.

Following the listing announcement, CFWA engaged Devahasdin for an urgent campaign to further engage the media, securing further television coverage with Sky News; and ABC Radio coverage aired across several news segments. This positive news provided an ideal platform to raise community awareness and support.

This media interest was leveraged to highlight both the need for faster access for new treatments in future, access for younger age groups, therapies for those not eligible, and broader CF community needs.

Trikafta® access was also a strong focus of 65 Roses related media coverage in May 2022.

65 Roses

In 2022, we engaged PR firm Devahasdin for promotion of our 65 Roses Day campaign and other key campaigns throughout the year. 65 Roses Day is not only a major fundraiser for CFWA, but also a great opportunity to raise awareness of CF in the wider community.

The media focus in 2022 was the Virtual Rose Garden and gifting bouquets, two areas that were more insulated against COVID driven limitations.

Media coverage was strong in 2022 with a circulation reach of just under **8 million** and PR value of over **$1.5m** achieved; including Channel 9 prime time coverage, Sky News, community news and radio.

65 Roses Media Coverage

Digital	Print	Radio	TV	Total
176	9	9	6	200

Board and Governance

The CFWA board comprises several highly qualified directors, each bringing leadership capability, technical expertise, 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

Damon O'Reilly

President

Damien was appointed Board President in June 2022. Damien is a Senior Manager at Herbert Smith Freehills. He holds advanced qualifications in business administration and law from Murdoch and Deakin Universities, with practical expertise spanning transformation and restructuring, insolvency, forensic accounting, legal, risk and compliance matters.

Sally Rose

Vice President and Treasurer

Sally is an accounting and finance professional with more than 18 years' experience. Formally a Senior Manager with Ernst & Young (EY), Sally has worked in Perth, New York and Toronto. She is currently Group Financial Controller with a large Australian corporation. Sally joined the CFWA board in October 2020.

Feliciano Sanchez

Board Member

Feliciano is an executive level engineer and father of a young woman with CF.

Having joined the board in 2006, he has held both the President and Vice President positions and is currently a special skills director on the board of CFA.

Carolyn Boyd (Caz)

Board Member

Caz 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. Caz joined the board of CFWA in 2010 and was elected as Vice President in 2017 and President in 2018, serving in that role until May 2022.

Rowena Smith

Board Member

Rowena is a Masters qualified human resources professional with 19 years' experience in strategic HR. Her background is in talent strategy, workplace culture, employer brand development and performance optimisation. She has strong ties to the CF community as the aunt of a young niece living with cystic fibrosis.

Linda Smith

Board Member

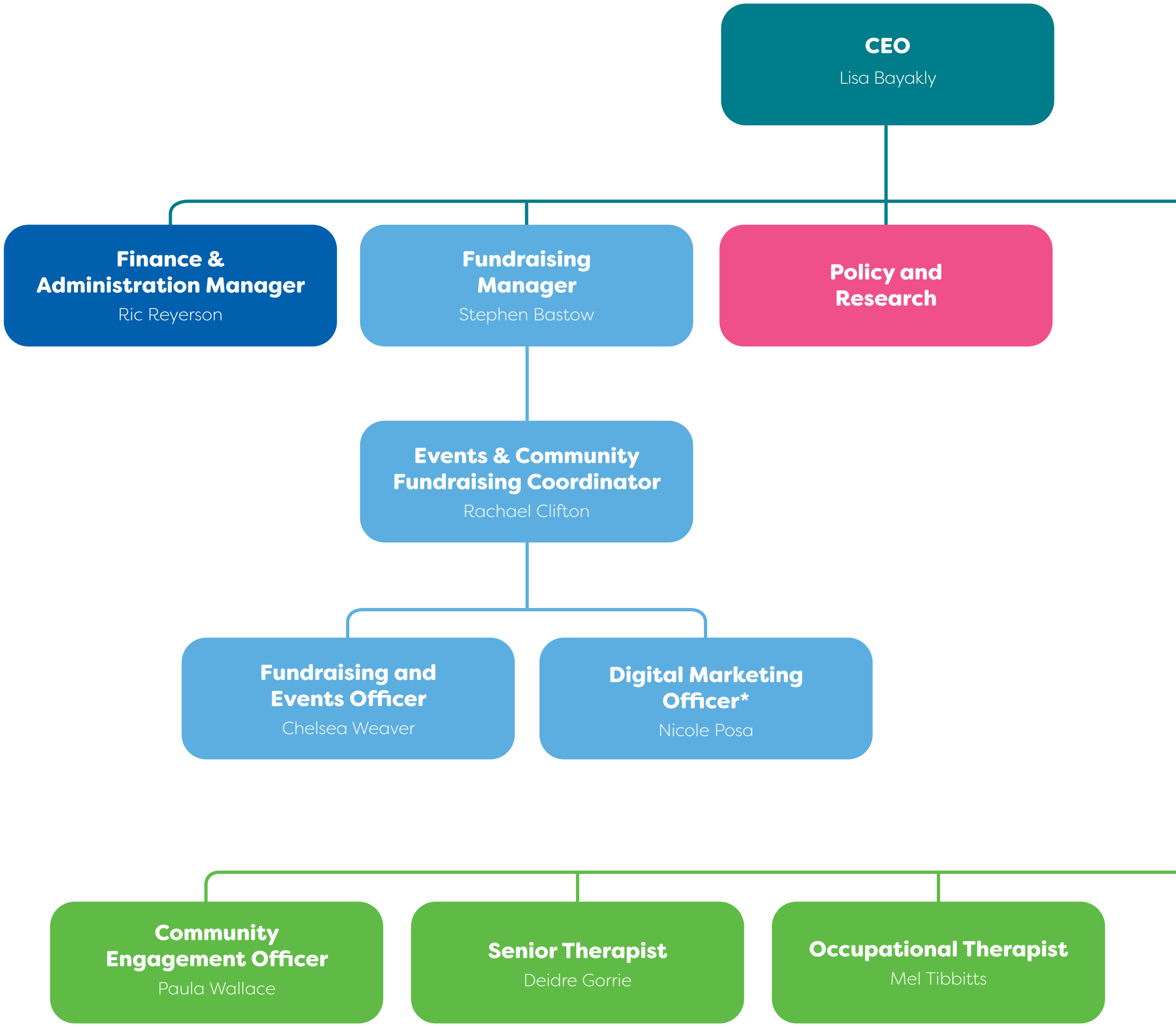
Linda is a Chartered Accountant, with an Honours Degree in Finance and Marketing and extensive experience in advisory services, audit and restructuring. She is a Partner at McGrathNicol and was previously the Treasurer for Kids Are Kids! not-for-profit organisation for several years. Linda is passionate about respiratory health, having bronchiectasis herself. Linda joined the Board of CFWA in September 2022.

Amanda Bearcroft

Board Member (Retired)

Amanda lives with CF and was born in an era when CF treatments were minimal. She is a passionate advocate for the CF Community, sitting on a variety of CF and respiratory committees. Amanda brings to CFWA a personal perspective around CF and provides experience with CF patients, family, and partners. Amanda retired from the Board in January 2023.

Organisation Chart 2022



CEO
Lisa Bayakly

Finance & Administration Manager
Ric Reyerson

Fundraising Manager
Stephen Bastow

Policy and Research

Events & Community Fundraising Coordinator
Rachael Clifton

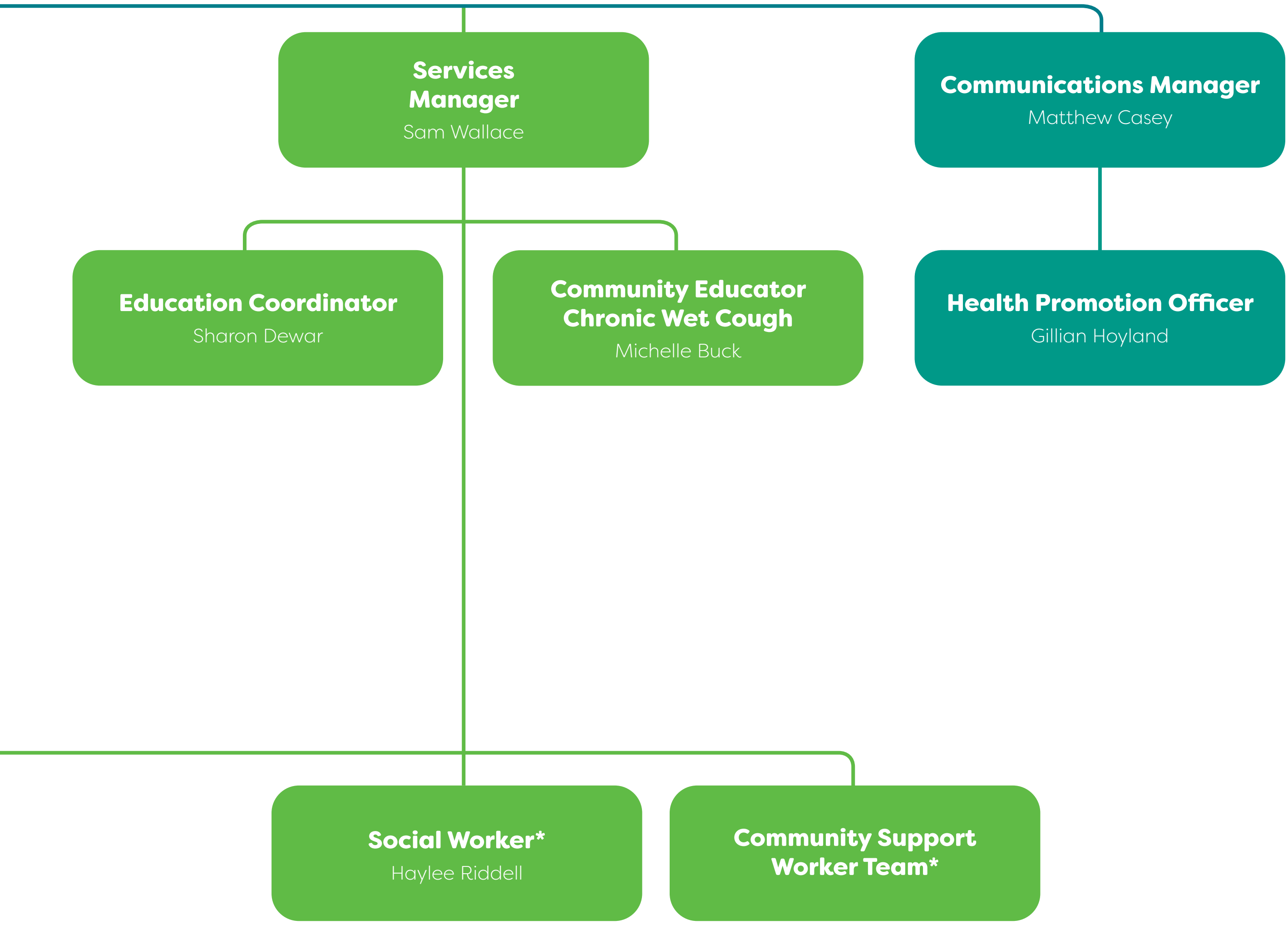
Fundraising and Events Officer
Chelsea Weaver

Digital Marketing Officer*
Nicole Posa

Community Engagement Officer
Paula Wallace

Senior Therapist
Deidre Gorrie

Occupational Therapist
Mel Tibbitts



Services Manager
Sam Wallace

Communications Manager
Matthew Casey

Education Coordinator
Sharon Dewar

Community Educator Chronic Wet Cough
Michelle Buck

Health Promotion Officer
Gillian Hoyland

Social Worker*
Haylee Riddell

Community Support Worker Team*

*Social Worker: Haylee Ridell left role in December 2022.

*Digital Marketing Officer: Charlotte Bradley left role in August 2022.

*Community Support Workers: Our Community support worker team provide in home support in the community across the Perth metro area.

Balance Sheet
as at 31 Dec 2022

	2022 $	2021 $
CURRENT ASSETS		
Cash and cash equivalents	1,005,658	1,015,632
Financial assets	236,313	201,281
Trade and other receivables	16,409	8,504
Inventories	12,011	5,825
Other current assets	41,884	42,286
TOTAL CURRENT ASSETS	**1,312,275**	**1,273,528**
NON-CURRENT ASSETS		
Financial assets	1,106,500	1,193,753
Plant and equipment	263,287	302,136
TOTAL NON-CURRENT ASSETS	1,369,787	1,495,889
TOTAL ASSETS	**2,682,062**	**2,769,417**
CURRENT LIABILITIES		
Trade and other payables	374,860	436,544
Provisions	430,870	298,228
TOTAL CURRENT LIABILITIES	**805,730**	**734,772**
NON-CURRENT LIABILITIES		
Provisions	-	38,815
TOTAL NON-CURRENT LIABILITIES	**-**	**38,815**
TOTAL LIABILITIES	**805,730**	**773,587**
NET ASSETS	**1,876,332**	**1,995,830**
MEMBERS' FUNDS		
Accumulated surplus		
Accumulated surplus – restricted	76,337	20,000
Accumulated surplus – designated	73,918	84,249
Accumulated surplus – discretionary	307,111	232,531
Accumulated surplus – unrestricted	1,418,966	1,659,050
TOTAL EQUITY	**1,876,332**	**1,995,830**

Income Statement
for year ended 31 Dec 2022

	2022 $	2021 $
Revenue	2,090,163	2,634,276
Cost of sales	(19,348)	(27,947)
Employee benefits (wages and oncosts)	(1,350,238)	(1,382,399)
Depreciation	(14,742)	(17,314)
Motor vehicle expense	(8,489)	(11,057)
Insurance expenses	(59,364)	(46,743)
Other expenses	(729,636)	(893,639)
Operating (Deficit)/Surplus for the year	**(91,654)**	**255,177**
Office refurbishment depreciation	(27,844)	(27,844)
Total (Deficit)/Surplus for the year	**(119,498)**	**227,333**
Accumulated surplus at the beginning of the year	1,995,830	1,768,497
Transfer to accumulated surplus	-	-
Surplus allocated to:	-	-
Restricted funds	56,337	10,000
Designated funds	(10,331)	(15,751)
Discretionary funds	74,580	69,288
Unrestricted funds	(240,084)	163,796
Accumulated surplus at the end of the year	**1,876,332**	**1,995,830**

CYSTIC
FIBROSIS
Western Australia

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

The Niche, Suite C
11 Aberdare Rd
Nedlands WA 6009

P: 08 6224 4100
E: info@cfwa.org.au

www.cfwa.org.au

REGISTERED CHARITY
acnc.gov.au/charityregister