



# Annual Report

2023

# Acknowledgement 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.

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CFWA continued to push boundaries and make significant strides in advocacy and research through continued collaboration with the national Cystic Fibrosis Federation, health networks and the research community. Through collaboration, new treatments and advances in care continue to occur; with ongoing efforts to ensure all individuals with cystic fibrosis can access better treatments.

**John Rothwell**

Patron, CFWA

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Achievements included successfully advocating for increased resources in the adult cystic fibrosis clinic; supporting the National advocacy campaign for access to new treatments; and the introduction of a new significant research Innovation Grant. CFWA also continued its post graduate research scholarship funding, building on its successful history since 2010.

**Lisa Bayakly**  
CEO, CFWA

# Impact Report

## THE IMPACT OF CYSTIC FIBROSIS

Cystic fibrosis (CF) 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.



### Rare Disease

- Over **400 West Australians** and over **3,700 Australians** live with CF.
- **1 in 25 Australians** are carriers of the condition. That's **1 million people**, and most don't know that they are carriers.



### Quality of Life

- **Anxiety and depression are 2.5 times higher** than in non-CF population.
- 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.
- **Significant financial burden.** Hospital visits, lost income from illness and medication costs all contribute to financial stress for many people with CF.



### CF Impacts Daily Life

- CF often affects breathing due to the build-up of thick sticky mucus in the lungs.
- **Multiple organs affected**, not just lungs.
- Common infections can be high risk for people with CF.
- CF treatments can take **1-4 hours per day**.



### CFWA Support

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.
- **Specialised support:** Support programs addressing mental health, isolation and hardship.
- **Support and advocacy:** Support and care for people with CF through education resources, research, and advocacy.

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## A NEW ERA FOR CF

Clinical, research and advocacy efforts are enabling treatment advances. These treatments help enhance lung function and life expectancy. The CF community continues to strive for better outcomes for all, and ultimately a cure.

## CYSTIC FIBROSIS WA - OUR IMPACT IN 2023

A snapshot of some of the key ways we have supported people and their families living with CF in 2023; made possible with the help of our dedicated community, partner organisations and supporters.



### Financial Support

We provided **667 subsidies to 193 people** totalling over **\$100,000 in direct financial support** for equipment and essential needs.



### Support in the Home

Provided **3,054 support sessions** in the home, including airway clearance, exercise, and respite.



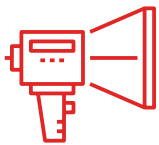
### Building Community Connection

Created the CF Connect Program, hosting **25 moderated online sessions for children** with CF, who can't meet in person due to infection risk.



### Building Community Respiratory Knowledge

Expanded our Chronic Wet Cough education program, **trained 20 regional community champions** and **visited 14 regional towns**. Educators **completed 235 online CF learning modules**.



### Advocating for the Community

Through advocacy, children aged 6-12 years were **granted access to a new modulator treatment**, Trikafta®, which is **increasing quality of life and life expectancy**.



### Funding Quality Research

We **invested over \$205,000 in cystic fibrosis research**, helping enable 4 unique research projects.

# Patron's Report

I am proud to share this report on another momentous year for CFWA.

In 2023, the COVID pandemic continued to challenge the health sector globally. CFWA faced increasing client needs driven by greater isolation, hardship and mental health challenges in society; changing community engagement patterns; and ongoing staffing and resource constraints.

CFWA continued to make a meaningful impact by adapting its processes and strengthening its team in areas of great need such as psychosocial support and peer connection. The use of technology and online programs enabled CFWA to reach more individuals in need. CFWA also expanded its CF education and respiratory health promotion activities, drawing on its knowledge and expertise to raise CF and respiratory health awareness across the State.

CFWA continued to push boundaries and make significant strides in advocacy and research through continued collaboration with the national CF Federation, health networks and the research community. Through collaboration, new treatments and advances in care continue to occur; with ongoing efforts to ensure all individuals with CF can access better treatments.

These achievements are thanks to the ongoing support of the cystic fibrosis community and many fundraisers and supporters; and the tireless efforts of CFWA's Board, staff and volunteers.

As my term as Patron comes to an end after a fulfilling 14 years, I wanted to express my heartfelt gratitude for the opportunity to serve as Patron. It has been a privilege to be a part of such a dedicated and passionate community working towards a common goal. CFWA will remain close to my heart and I look forward to seeing the impact of its endeavours in years ahead.

I invite you to review this annual report to learn more about the impact of CFWA's work. Your continued support, in time, resources, and expertise; is vital in helping CFWA make a difference in the lives of those in need.



**John Rothwell**  
**Patron, CFWA 2010-2024**

A handwritten signature in black ink, appearing to read 'John Rothwell'.



# President's Report

As I reflect on the journey of CFWA over the past year, I am proud of the organisation's achievements and resilience. The environment we operate in continues to change rapidly, however CFWA has maintained its strong governance, financial standing and reputation for delivering outcomes.

The needs of the community continue to drive everything we do; and their positive feedback demonstrates our impact, empowering and supporting individuals and families and their quality of life.

Through effective planning and management of finances, we have been able to support a growing number of community members impacted by cost of living pressures, challenging circumstances and mental health challenges. We have also grown our services and research investment and made great strides in advocacy outcomes. On behalf of the Board, I extend my thanks to the CFWA team, and the health and research professionals we collaborate with, for their efforts throughout 2023.

These achievements would not have been possible without our major supporters and donors, including our Golf Committee; and our many dedicated fundraisers and volunteers. My particular thanks to the Department of Health WA, Channel 7 Telethon Trust, the Rothwell Family Foundation, Lotterywest, and the Stan Perron Charitable Foundation for their ongoing support.

I am also incredibly thankful to our Patron and my fellow Board members for volunteering their time and expertise. Our Patron, John Rothwell, has provided stewardship, counsel and support to CFWA leadership over 14 years, always in a generous and modest manner. Although we say goodbye to John as Patron, we know he remains an ally and supporter of the CF community.

In 2023, Feliciano Sanchez (Felice) retired from the Board, after many years of service to CFWA. Felice's insight and knowledge greatly assisted CFWA through many challenges over the years. He was also pivotal to CFWA's research impact, bringing both passion and wisdom to capital raising endeavours and research promotion. I pay tribute to Felice, his wife Vanya and their service on your behalf.

During 2023, Amanda Bearcroft also retired from the Board. We are grateful for her service and pleased to continue to collaborate with Amanda through the CF Adult Consumer group. These changes provided opportunities for Board renewal, and we were fortunate to welcome new and different skills in incoming directors, Maria Andacic, Steffan Crausaz and Ingrid Laing. They joined Vice President and Treasurer, Sally Rose, Caz Boyd, Rowena Smith, Linda Smith and myself.

Our Board remains focussed on CFWA's purpose – improving the lives of the people and communities we serve. We have a clear new strategic plan and a capable and strong team to deliver upon that purpose.



**Damien O'Reilly**  
**President and Board Chair, CFWA**

*Damien O'Reilly*

# CEO's Report

I am pleased to share our 2023 achievements with you.

Our team has worked hard to understand new and changing community needs, secure new funding, and enhance capability to meet these needs. Much of our success is thanks to a supportive community, who inspire and enable our team to make a meaningful difference.

This year, our fundraising team, in collaboration with our Golf Committee, delivered our inaugural Luxury Masters Golf Raffle which raised over \$139,000. This tipped our fundraising income over \$1 million, given new major donations and the success of other events and campaigns like the CFWA John Gillard Family Golf Classic and 65 Roses Day. We thank and celebrate all our community fundraisers, participants, volunteers and supporters for contributing to this positive result.

Building the capacity and capability of our services team enabled us to meet growing demand for mental health and psychosocial support. We were also able to extend practical and financial support to a growing number of community members experiencing crisis or hardship, 25% more than prior years. Increased staff capacity also enabled more community outreach, and regional respiratory health education; both for the people with CF and communities impacted by other respiratory conditions. We also increased online community support through playgroups and peer to peer forums, helping reduce the isolation of living with CF.

In 2023, we were delighted to see more individuals able to access the new modulator treatment, Trikafta®, following community and Federation advocacy. Locally, we also saw traction from advocacy, with additional staff resources appointed in the WA Adult CF clinic to care for the needs of a growing CF population. We also invested over \$205,000 in CF research (including our inaugural Innovation Grant to support research in emerging fields of interest). We continue our efforts to ensure all individuals can access better treatments and care.

Late in 2023, we developed our new Strategic Plan (2024-2027) which focusses on meeting the diverse needs of our clients and stakeholders. My thanks to the community members and stakeholders who provided input. Your guidance will help us enhance our client services, collaborative partnerships; and community impact.

Thank you to the CFWA team for consistently finding new opportunities and solutions to problems, to the Board for their advice and support; and to former Patron John Rothwell for your confidence and counsel. It is an honour to work with WA's health professionals and research community and to receive the support of the WA state government, organisations like Lotterywest, the Channel 7 Telethon Trust, the Rothwell Family Foundation and the Stan Perron Charitable Foundation and our generous major donors; to support the CF community and other communities in need.



**Lisa Bayakly**  
CEO, CFWA

A stylized, handwritten signature in black ink that reads "L Bayakly". The signature is fluid and cursive, with a long, sweeping underline.



# Treasurer's Report

CFWA continues to effectively manage financial performance to ensure ongoing sustainability of services to clients.

Our 2023 overall result was positive, with a net surplus of over \$110,000, significantly higher than budgeted. The surplus primarily arose from market movement in our investment portfolio, being funds held to ensure ongoing sustainability. This movement in portfolio value is recognised as per accounting standards in CFWA's income statement even though it is not yet realised.

Excluding this book value movement, CFWA's net result was effectively balanced (with an immaterial deficit of \$3,425). The association has met both its financial commitments and growing demand for services, despite the impact of COVID and a reduction in contract funding from the Department of Health WA in 2022. We achieved this through growing our income to meet expenditure demands.

I am, therefore, pleased to report the finances of the association are being well-managed to support the objectives of CFWA and ensures ongoing sustainability of services. Our equity position remains strong with suitable cash and reserves, including over \$860,000 held in cash or cash equivalents at FY23 year end.

Thank you to the CFWA team and my fellow board members for your support in achieving positive financial outcomes. CFWA is also extremely grateful to the WA government, Lotterywest and our major philanthropic benefactors, Channel 7 Telethon Trust, the Rothwell Family Foundation, the Stan Perron Charitable Foundation, and the John and Beryl May Henderson Foundation; together with our Golf Committee, community fundraisers, donors, and supporters.

Our financial highlights for 2023 are included later in this report. Key financial achievements included growing donations and fundraising by 30% from 2022 and increasing grant income by over 60%. Above budget performance enabled increased services, a record investment of over \$205,000 in research; and carefully considered investment in strategic initiatives, technology and systems to enable our team to best support current and emerging client needs.

For further financial and audit information, please visit [www.cfw.org.au](http://www.cfw.org.au).



**Sally Rose**  
Treasurer, CFWA

A handwritten signature in dark ink that reads "Sally Rose".

# Services to the CF Community

The CFWA services team are a group of dedicated professionals who provide services and programs to support, educate, empower and connect our communities. Our team includes physiotherapy, occupational therapy, social work, health promotions, community support workers and administrative support.

We are responsive to the needs of our community, which have changed post COVID, with adoption of technology, cost-of-living pressures; and as people with CF are living longer. In the CF community, these factors, combined with the impact of new CF medications, have impacted service needs. To better understand the current and emerging needs of the CF community, CFWA undertook a community consultation project in 2023 which will inform services in 2024.

New resources and supports will assist our community with emerging opportunities and challenges, in areas such as education, personal goals and physical health maintenance. They will also consider the sustained increase in need for practical and financial assistance and mental health and wellbeing supports.

## FINANCIAL ASSISTANCE PROGRAM

Our financial support program has continued to increase in demand and adapt to changing needs within the community. In 2023 we provided 667 subsidies to 193 people totalling over \$100,000. Increase in demand was most noticeable for our Mental Health and Family Crisis financial support subsidies.

Subsidy Type	No of Subs	\$
Activity Subsidy	122	28,957
Equipment Subsidy	79	30,385
MH Gap Funding & Crisis Support	94	14,161
Pharmaceutical Subsidy	64	8,939
Travel and Parking Subsidy	304	20,724

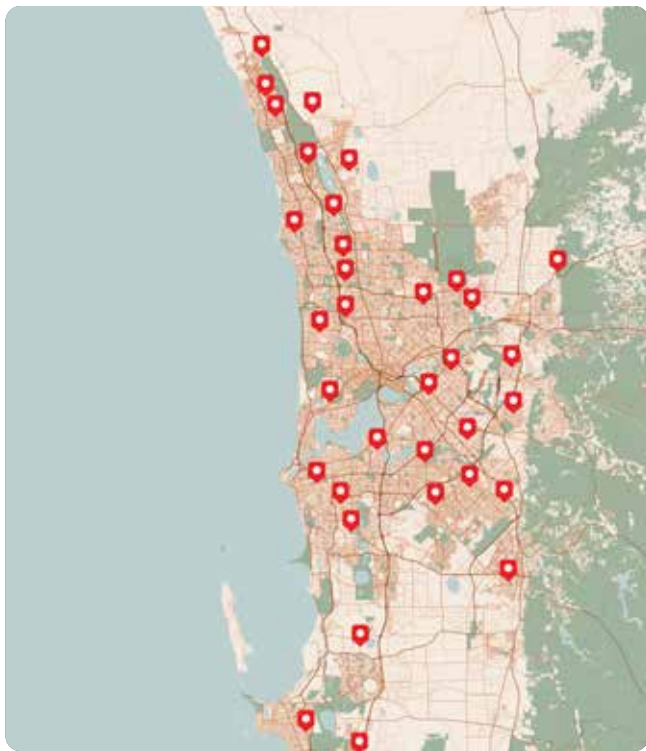


## COMMUNITY SUPPORT WORKER SERVICE

The Community Support Worker (CSW) Service provides support in the home with airway clearance (AWC), exercise and respite for individuals and families living in metro Perth.

In 2023, we modernised processes to reduce administration time, enabling us to spend more time supporting clients. We also strengthened training, communication and supervision which enhanced our capacity to respond to complex and remote referrals which have increased in number.

We expanded our geographical network of AWC support by using external support agencies and local exercise practitioners.



**The reach of our CSW Team who provide in home support.**

**“The workers are really lovely and provide an extra layer of support to the family as well as my CF child.”**

**“My son and his support worker have a fun friendship. Her visits brighten his day and they play after Physio so it helps us show him Physio doesn’t just have to be boring.”**

**“Brilliant - couldn’t do without this service!”**



**140 Clients**

received

**3,054**

**AWC & Exercise/  
Respite Sessions**



We provided **83**  
**Support bags**

to **children  
and adults**  
**in hospital**



We are very fortunate at CFWA to have committed supporters, funders and collaborators who enable us to provide a broad range of services to our communities. We look forward to strengthening these relationships and expanding our networks in 2024 as we continue to respond to emerging needs.



# Community Connection

**Connecting with your community is essential to build support networks and promote a sense of belonging. This connection helps to develop mentally resilient communities and enhances overall wellbeing. However, it is too risky for people with CF to meet face to face, due to the risk of sharing harmful bacteria and cross infection. This limits connection opportunities for individuals, their carers and family members, which can be isolating.**

In response to this need for connection, CFWA provide moderated online community groups for people with CF via the CF Connect programs: CF Kids Connect and CF Parent Connect Playgroup. These online sessions provide an opportunity for cohorts to come together and share experiences and build communities.

CF Kids Connect is an activity-based online group session facilitated by our child and family therapist. The sessions aim to build friendships and connect kids living with CF across WA.

CF Parent Connect Playgroup provides connection and peer to peer support to new parents of a child with CF aged 0-5 yrs. The program helps create connection, friendship and a safe place to talk about all things parenting and beyond!

**“Thanks so much....it was so good to meet some other mums who have this shared experience... it was very supportive... I feel some weight has been lifted from my shoulders.”**

**25 CF Kids Connect sessions were hosted in 2023**



## COMMUNITY EVENTS

Our community events are designed to provide family members and carers with an opportunity to come together and share experiences and enjoy some respite from their caring roles. These events help build community and establish connections for ongoing peer support. This includes events for siblings, and children of adults with CF, who help with caring roles.

### Grandparent's Morning Tea



### Ladies' High Tea



### Men's Event





### Parent's Dinner



### Parent's Retreat



### Sibs and Kids Camp





## Kids Day Out



## Virtual Catch Ups - Bake Offs



## Virtual Catch Ups - Lego Building



# Communication and Resources

Communicating with our community is essential to share resources, programs and opportunities and provide information to empower individuals and families living with CF. Over time, communication has changed in response to the environment and technology and more recently the impact of COVID. In 2023, we enhanced our communication approach to better serve the community, delivering more targeted information relevant to their age and stage in life. We will build on this further in 2024.

## AGES AND STAGES TAILORED NEWSLETTERS

Community response to our new “ages and stages” communications approach was extremely positive, with a newsletter open rate over 70%.



## PRIVATE FACEBOOK GROUPS

Our private Facebook groups continue to support engagement and connection, growing in membership and use. These groups offer a safe space for our community to seek advice, share experiences and information.

CFTalk Parents	CFTalk Adults
157 members	104 members
Average of 4 posts per week	Average of 2 posts per week





## EDUCATIONAL RESOURCES

In 2023 we collaborated with dietitians at Perth Children’s Hospital, to produce a hub for nutritional information for parents and carers of children living with CF. This was the final chapter of our updated nutrition resources, following the development of our infant and adult nutrition webpages.

We continued to create new resources and factsheets in response to community need, as well as ensuring existing resources remain up-to-date and relevant. Two new children’s books were developed in 2023, along with resources to support a collaborative sputum sample program with PCH. These initiatives were launched in 2024.

## ENGAGING WITH THE WIDER COMMUNITY

In addition to engaging directly with clients, we continued our work to spread awareness of CF and CFWA support services in the wider community. Here’s a snapshot of how we engaged with the community in 2023.

	Website	30,800 visitors
	Facebook	5,200 followers
	Instagram	1,950 followers
	Newsletter	4,100 readers



# Community Education

CFWA provides quality education to health professionals, schools and communities.

## CF SMART EDUCATION PROGRAM

Our CF education program supports young people living with CF as they progress through preschool, primary, and secondary education. It helps equip teachers, parents, and school communities with knowledge and practical tools to support the safety and wellbeing of children with CF. This includes online learning through our CF Smart platform, Student Action Plans and training from our education team to meet individual needs.



**“Thank you for the support in creating my child’s action plan for the new school year. I met with the school staff and we had a good discussion, guided by the plan. We all very much appreciate having this assistance available – and the other resources available through CFWA.”**

## CF SMART ONLINE LEARNING






**235**  
**modules**  
completed by  
WA educators in **2023**



**1,179**  
**online**  
**modules**  
completed  
Australia wide in **2023**



## 2023 SCHOOL AND COMMUNITY EDUCATION

	Student Action Plans	25
	School Management Plans	26
	Number of online modules completed in WA	235
	Face to face and remote education sessions	15
	Starting School Resources	24



**“Thank you so much for your help, I really appreciate it. I feel so much better now knowing that the school has her information regarding her health.”**

**“CFWA had helped me with my daughter’s action plan before starting high school this year, Michelle was very helpful, knowledgeable, and provided me with reassurance and support when I needed it. Thank you so much.”**

**“I really appreciate the support and resources provided by CFWA and their staff. Michelle was able to assist with developing an action plan for ..... starting high school and the resources for teachers will hopefully help her make a smooth transition. Thank you.”**

## HEALTH PROFESSIONAL EDUCATION

Our respiratory training program helps improve care for respiratory patients living in regional WA, by providing regional health professionals with access to knowledge, practical learning and peer support from hospital and community-based specialists.



In October we held our 11th respiratory training program. We also facilitated a spirometry training program in Karratha, collaborating with senior respiratory scientists from PCH and SCGH. The workshop provided a comprehensive interactive and practical approach to reinforce key spirometry concepts for effective lung function testing.

“Information about PBB, wet cough and how to spread information and awareness among indigenous community.”

“Overview CF - was amazing thank you - interesting and succinct overview. CWC- high awareness - Highlighted some cases in community that need guidelines and protocols very useful.”

“Thank you. Course information was very useful and will be sure to share with colleagues and recommend.”

## SPIROMETRY TRAINING



“Great education. So beneficial being able to practice and participate in multiple spirometry tests, look at flow curves and trouble shoot.”

“Explanations very good. We were able to have hands-on practice and demonstrate new skills.”

“Great case study samples and explanations.”



# Regional Outreach

**Nearly a third of people with CF in WA live regionally. CFWA's regional outreach program aims to improve the equity of services and support across the state.**

The Outreach team offer diverse services in regional communities, providing face-to-face support to help those in isolated locations to strengthen local networks within their community. It increases community access to the CFWA team and CF information and support. Through the face-to-face delivery of CF education to professionals across health and education services, better outcomes for people with CF in regional communities can be achieved.

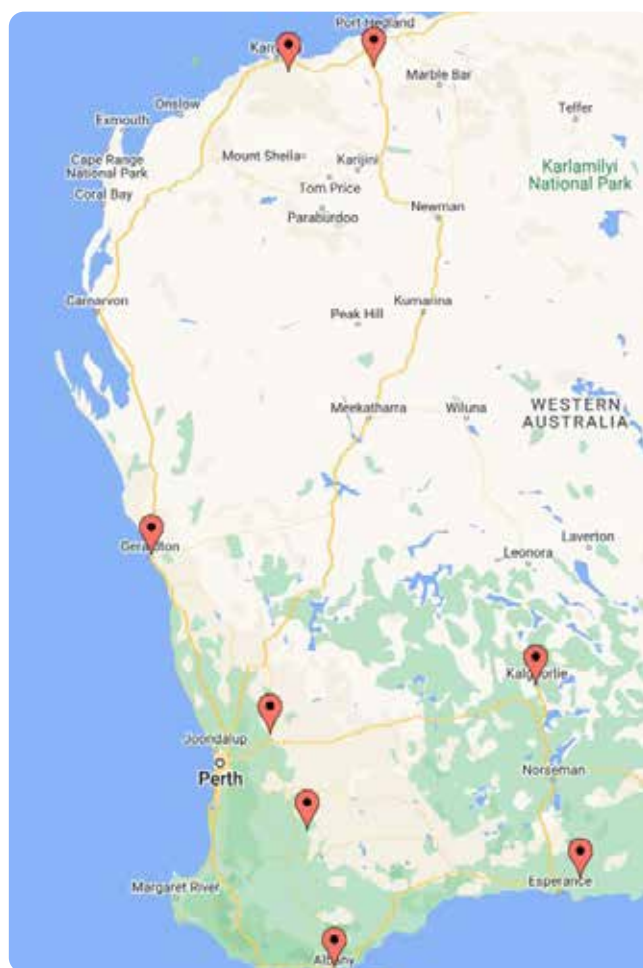
2023 started with a weekend in Bunbury combining a peer support event with a research update from the scientists at Telethon Kids Institute. Parents were able to interact with researchers and learn about the latest innovative treatments and therapies. Improved health literacy increases hope for the future and positively impacts treatment adherence and mental wellbeing.

Late in 2023, CFWA collaborated with PCH to travel to Albany to deliver health professional education to WA Country Health Services' staff, local school and day care education, individual home visits and a peer connect event for families. Ongoing collaboration highlights to regional families there is a strong team working together across the hospitals and community to support, educate and empower community.

**This program is made possible through generous funding from Telethon.**



**A Night with the CF Scientists in Bunbury.**



**Regional areas visited in 2023.**

**"That was a brilliant idea, it felt a privilege to be informed of research that could benefit our children in the future. Fantastic presentations."**



# Supporting other Communities

## REGIONAL AND INDIGENOUS FAMILIES

CFWA also aims to support other (non-CF) communities at-risk of poor health outcomes due to respiratory illness.

Primarily servicing regional Aboriginal communities, our Chronic Wet Cough (CWC) Community Education program aims to increase community awareness of the signs of respiratory infection to reduce delayed diagnosis and treatment and help children live longer, healthier lives.

In 2023, growing program momentum saw our team travel to 14 regional towns, with new trips to Tom Price and Carnarvon, building an empowered network of community champions to help us spread the chronic wet cough message across WA.



## OTHER COMMUNITIES IN NEED

Through almost 50 years working with the CF community, we have a strong understanding of the nature and impact of both respiratory and rare diseases. We continue to draw on this, to expand awareness, education and support to other impacted individuals, families and communities, where synergies and funding exist.

In 2023 we extended our engagement and networks with other peak bodies, community and health networks, to understand needs and discuss opportunities for knowledge sharing and collaboration.

CFWA staff participated in consumer reference groups for PCH patients with primary ciliary dyskinesia (PCD) and bronchiectasis and met with Rare Voices Australia and the WA Rare Care Centre. We hope through continued collaboration and sharing of experiences and resources, individuals and families will feel more supported.

**A chronic wet cough in a child** is a daily wet cough for more than four weeks and could indicate ongoing infection in the lungs. If a wet cough goes untreated, the ongoing infection and inflammation can lead to irreversible lung damage and affect life expectancy and quality. In many Aboriginal communities, chronic wet cough is normalised, often leading to a delay in treatment.

**“Knowing that Wet Cough is more prevalent in our young Aboriginal children makes it so much more important for our Aboriginal playgroups to spread the message in a safe environment and by trusted members.”**

# Policy and Advocacy

In close collaboration with the CF community, CFWA's policy and advocacy achievements include:

- Partnering with Cystic Fibrosis Australia (CFA) and Australian CF Federation members in ongoing advocacy campaigns. In 2023, we contributed to funding National advocacy campaigns and the work of CFA; and ensured WA community members were kept up to date and involved.
- Ensuring decision-makers have up to date, credible information to make informed decisions. We co-fund the work of CFA in maintaining the Australian CF Data Registry and the Australian CF Standards of Care which were updated during 2023 to help inform necessary care.
- Ensuring leaders in politics, government and the pharmaceutical sectors understand community needs. In 2023, we attended Federal and State Parliament to participate in group meetings and roundtables.
- Collaborating and networking with other organisations with shared interests; ensuring a strong collective voice. We are a member of Rare Voices Australia and collaborate with PCH's Rare Care Centre to share innovative ideas and knowledge between us.
- Promoting healthy policy settings which protect people's lungs, and having a say in important topics like the Federal Government's anti-vaping reforms.
- Facilitating opportunities for CF community representatives to share their stories and convey individual and community needs.
- Meeting with local health and hospital leaders to discuss emerging needs and highlight potential gaps in standards of care.

## Our advocacy in 2023 had a significant impact in helping West Australians with CF:

- Expanded treatments: Expansion of Trikafta™ (elexacaftor/tezacaftor/ivacaftor) access for 6–11 year-olds who have at least one F508del mutation in the CFTR gene from 1 May 2023 (benefiting more than 500 Australian children); and expansion of recommended age groups and eligibility groups for pre-existing modulator treatments such as Orkambi (lumacaftor/ivacaftor) and Kalydeco (ivacaftor).
- Greater support from the Adult CF Clinic: Through an expanded CF staffing model at Sir Charles Gairdner Hospital, with new resources to cater for increased patients numbers and unmet need for mental health supports.

Whilst there was positive progress in 2023, we continue to advocate to ensure everyone can have access to effective therapies and this includes people with rare mutations, people who are not eligible for current therapies, or who do not respond to modulators. We continue to work alongside key stakeholders to push for more coordinated care and support for the needs of individuals pre or post-transplant, those impacted by comorbidities like CF-related diabetes; and those experiencing hardship or crisis.

To inform our focus areas, we undertook a major project in 2023. We consulted people with CF and families, researchers and health professionals and received valuable input on current and emerging community needs. This includes the needs of all people with CF, including both those eligible; or ineligible or unable to tolerate modulator treatments.

RESEARCH MILESTONES

The John Gillard Family Golf Classic marked a milestone \$1 million raised for CF research, with the Committee, teams and supporters ensuring a long-lasting community impact.

We invested \$205,000 in research grants, backing well established researchers to explore new ideas; and supporting the careers of emerging leaders.

- Dr Nikhil Awatade was the inaugural recipient of the CFWA Golf Classic Innovation Grant to study CF liver disease characteristics.
- Dr Yuliya Karpievitch received a donor funded grant to research the use of artificial intelligence in phage therapy to treat antibiotic resistant infections.
- Rohan Flint received a top-up grant to support his higher degree research studying aerosol application of bacteriophages to treat antibiotic resistant infections.
- Jack Canning received a top-up grant to support his higher degree research to identify bacteriophages to treat Burkholderia cepacia infection.

Our research investment was bolstered by our community fundraisers Eric and Ronele Gard and their multitude of ‘cash for cans’ supporters; and through other fundraising and donations.

“It is evident, time and time again, that when we unite, we can help drive progress....”  
CFA CEO - Jo Armstrong





RAISING THE PROFILE

In 2023, we engaged with our long-term PR partners, Devahasdin, to help promote 65 Roses Day and continue to raise the profile of CF.

We achieved strong media coverage in 2023, particularly during May, with a circulation reach of over 9,840,000 - an increase of over 24% on 2022. This coverage included a Channel 7 weather report, Channel 10 News, and Channel 7 News Perth.

Thank you to the generous people who shared their stories in the media to help us raise awareness of CF in the wider community.

2023 65 Roses Media Coverage

			
Digital	Print	TV	Radio
134	8	5	11





# Fundraising Overview

**Through the generosity of our community, we saw our donations and fundraising income lift to over \$1 million in 2023, well above recent post-COVID levels. This is thanks to the collective spirit of our fundraisers, volunteers and donors who have supported both long-standing events and new campaigns.**

We continue to innovate and diversify our fundraising income streams to weather the challenging economic and fundraising climate. In 2023, we launched the inaugural Luxury Masters Golf Raffle, with outstanding first year ticket sales of over \$139,000. We also made changes to enhance the donor experience on all CFWA websites, with a community shift to giving online.



We celebrated some remarkable contributions, such as:

- Records broken by The John Gillard Family Cystic Fibrosis Golf Classic, with \$157,000 raised in 2023.
- A milestone \$1 million contribution to CF research achieved through the Golf Classic and Golf Raffle (with close to \$600,000 also contributed to vital service programs).
- A tremendous return of HBF Run for a Reason post-COVID, with over \$45,000 raised for CFWA.
- An unprecedented 65 Roses Day, with over 20,000 roses sold across the state thanks to rose supplier WAFEX and 150 fantastic volunteers.
- Individual giving through donations, appeals and workplace giving grew to over \$145,000.
- Our donation tin program tipping over \$20,000 for the first time, thanks to the drive and commitment of our valued volunteer Ron.
- Our fantastic community fundraisers in the Bring It on Bridge Climb raised close to \$25,000 through their networks.



## LITTLE TELETHON STAR SHINES

They all had their own stories to tell about their health struggles, but the 2023 Little Telethon Stars share two common attributes - they never give up and won't let their difficult circumstances dictate who they are.

Connor Barrett was one of the Little Telethon Stars for 2023 and bravely represented children living with CF. Aged 8, Connor battles CF which leaves him unable to digest food, damages his lungs and gives him excruciating pain in his digestive system.

Connor's mum Taryn was able to meet with Prime Minister Anthony Albanese, who noted the impact of research and new CF treatments.



PROUDLY SUPPORTED BY  
**telethon 7**

**20,000**  
**roses**  
sold during **65**  
**Roses**  
**Day**

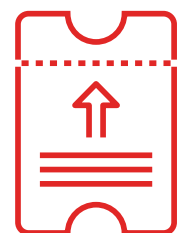


**57** of our  
**fundraisers**  
participated in  
**HBF**



**Run for  
a Reason**

**558**  
**Golf Raffle**  
**tickets sold**





# Major Events and Campaigns

## 65 ROSES DAY

Our volunteers embraced being back onsite at our office in Nedlands, wrapping roses and brightening people's day by delivering fresh roses in the community.

We ordered a record 21,500 roses from our major campaign supporter Wafex, to be sold across WA. Distribution spread as far north as Denham, down to Mount Barker and across to Merredin. The official 65 Roses Day was Friday 26 May, and we raised over \$125,000 through rose and bouquet sales, our virtual rose garden and generous donations. As well as our main display

and stall at TwoForty, we introduced two new CBD activations at Central Park and Brookfield Place.

We were pleased to celebrate 15 years of partnership with Wafex as our rose supplier in 2023. We're also grateful for the long running relationship with South Metropolitan TAFE and their course leaders and students who make the day possible. Thanks to our community ambassadors speaking about their experiences with CF, we received extensive media coverage of the campaign to raise CF awareness.





## THE JOHN GILLARD FAMILY CYSTIC FIBROSIS GOLF CLASSIC

The John Gillard Family Cystic Fibrosis Golf Classic celebrated its 13th year in 2023. Thanks to the incredibly hard-working golf committee, event sponsors and our CFWA volunteers, the event raised over \$157,000.

A record 36 teams took to the golf course and over 225 guests joined in the evening dinner and entertainment provided by emcee Steve Mills, who generously donated his time once again. We would also like to thank our guest speaker, Sophie Longton, who captivated the audience with her lived experience of CF.

The focus of the golf committee is to support research into CF. In 2023, over \$100,000 of the funds raised were allocated to world class research and over \$50,000 of the funds raised were allocated to support programs for families impacted by CF. Our thanks go to the golf committee for once again putting on such an enjoyable and successful Golf Classic.



## GOLF RAFFLE

2023 saw the launch of our first Luxury Masters Golf Raffle, an exclusive premium raffle targeting golf enthusiasts from across WA. The raffle offered two incredible prizes, with the first being a bucket list trip to the US Masters in Augusta for two people and second prize was a Bali golf trip for four people. Tickets were sold from August to November, with ticket sales closing just after the Golf Classic.

A total of 558 raffle tickets were sold and our first raffle raised \$139,500. Thank you to everyone who supported the raffle, with special thanks to Birds Eye Media, Eurisko and Herbert Smith Freehills for providing pro-bono videography, digital marketing and legal advice respectively to inform and energise the inaugural raffle.



“... a massive thank you to CFWA for this unbelievable prize. An incredible privilege, every golfer’s dream trip!...”  
*Luxury Masters Golf Raffle Winner*

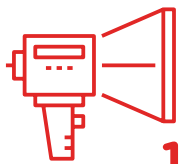
**Over 72,000  
people** reached



## MATCHED GIVING DAY

**Wednesday 6 December 2023**

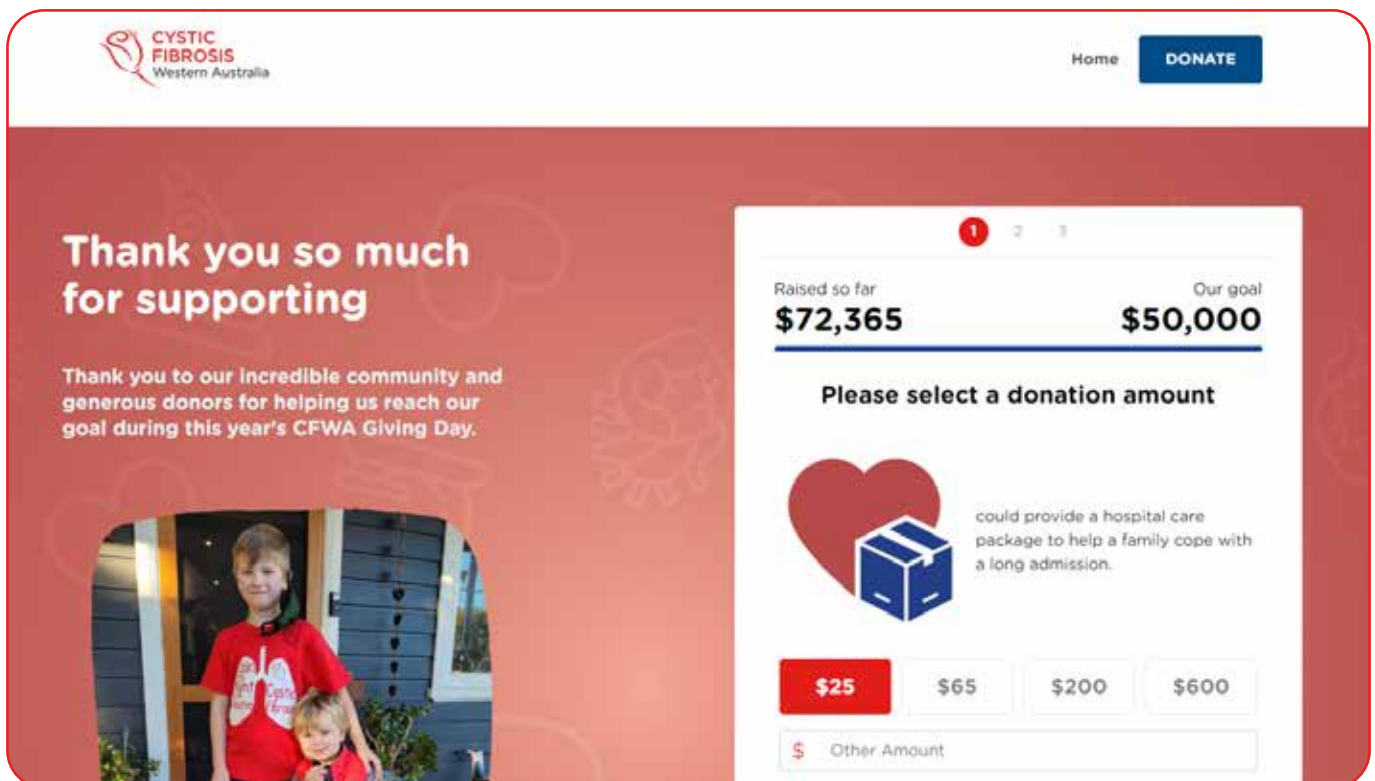
Four incredibly generous donors pledged over \$35,000 to be matched over a 24-hour period for our 2023 Matched Giving Day. Our campaign featured the amazing Anderson family, with brothers Olli and Jimmy, and drove 131 individuals to donate, ensuring another successful year of this event in the CFWA calendar.



**Promotions**  
reached over

**111,000 people**

thanks to the community  
liking and sharing!



## COMMUNITY FUNDRAISING

Our community fundraisers are special to CFWA. They make a tangible impact by bringing community together, creating awareness and inspiring others to volunteer, donate and support CFWA. Many of them are members of our community and their immediate family and friends who know firsthand what a difference the funds raised make.

In 2023, they raised over \$70,000 through our 65 Roses Challenge and other community fundraisers.

One of the top community fundraisers was athlete Murray Wesson, who took on the Comrades marathon from Pietermaritzburg to Durban in South Africa and raised well over \$2,000. When Murray took on the 88km course, he was remembering his late brother, Russell, a talented athlete who lived with CF.

Corporate Battle of the Bands was back again on a hot night in February. Seven bands took to the stage at The Charles Hotel to battle it out for the coveted winner's trophy. The night was a huge success with record crowds through the door, raising \$7,600 for CFWA.

The Murph Fitness Challenge continued to be a big hit again in 2023. This 65 Roses Challenge fundraiser was held at Sustain Health and Performance gym in Wangara, led by community fundraisers Dan McNally and Michael Cahill. The Murph Challenge is the ultimate strength and endurance test. Participants register to take on a workout consisting of a 1.6km run, 100 pull-ups, 200 push-ups, 300 air squats and another 1.6km run. In their third Murph challenge for CF in 2023 the team raised close to \$7,000.



## HBF RUN FOR A REASON

HBF Run for a Reason returned in 2023 after a three-year break due to COVID. Our community embraced this much-loved Perth fundraising event. 57 registered participants made CF their reason to run and raised over \$45,000 for CF.

One incredible young fundraiser, Duke Storer, who was inspired by a young friend with the disease, raised over \$10,000 for us and was HBF Run for a Reason's highest individual fundraiser. Thank you to everyone who took part in HBF Run for a Reason and everyone who donated to their efforts.



## MERCHANDISE

In 2023 we introduced for the first time a limited-edition pre-sale hoodie to our merchandise offering. 100 of the exclusive navy hoodies were purchased raising just over \$7,000.

We also teamed up with our Occupational Therapist Mel and the children in the CF Kids Connect sessions to create a bespoke tote bag with 'rose' imagery produced by the children during one of the sessions. The children ranged in age from 6 to 15. It was a rewarding experience for the children, and they all got a tote bag proudly displaying their creativity and artwork.





# Volunteers

**Volunteers are an integral part of ensuring everything runs smoothly. From helping with administrative tasks, to collecting donation tins, wrapping, delivering, and selling roses, or assisting at our fundraising events – we couldn't do what we do without them. 2023 was no exception, and we are incredibly grateful to each one of our volunteers for giving up their time and embracing every opportunity to help.**

On behalf of the CFWA team, 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. We would especially like to thank lecturer Kylie-Anne Stokes who coordinates the Diploma of Events Management students and Cert III Events Management students and contributes so much to the campaign.



Our largest events wouldn't be as successful without an army of volunteers making them possible. We are indebted to our 65 Roses Day volunteer delivery drivers, rose wrappers and rose sellers who come back year after year. We would also like to thank Curtin Volunteers! and the UWA Guild micro volunteering groups for coming on board and helping us behind the scenes in the weeks leading up to 65 Roses Day. Our Golf Day volunteers do a splendid job keeping players fed and engaged in activities throughout the day that all add to the appeal and fundraising tally.

## TIN COLLECTION PROGRAM

Our Donation Tin Collection program is largely run by our dedicated volunteers Ron Gray and Adrienne Thomas. Thanks to the Perth community dropping their spare coins into the tins all over Perth, the collections totalled over \$20,000 in 2023. Placing donation tins in the community is not only a fantastic way for people to support us through giving their loose change, but also plays an important role in raising awareness about CF.

**OVER 150**  **volunteers**  
**DONATED 1,265 hours**

in 2023 to help with a range of activities including our **65 Roses campaign, collection tin program, and office administration.**

This support helps maximise our impact, and means more funds are being spent on direct community support.



# Grants and Pro Bono

Grants and pro bono support are vital to help fund specific CFWA programs and meet the needs of people with CF and other respiratory conditions, their families, and carers. In 2023, Cesare joined the Fundraising team as Grants Officer, acknowledging the increasing need to access grant funding in support of our community. Thank you to all our generous grant funders and pro bono supporters. Your support enables the delivery of many of our programs.

## CHANNEL 7 TELETHON TRUST



Long-term CFWA supporters Telethon once again provided generous grant funding for our Thriving Families and Chronic Wet Cough Community Education Programs.

Thriving Families ensures access to care for vulnerable children with CF and their families, providing therapy, support services, delivering regional outreach and financial aid while accommodating diverse backgrounds.

The Chronic Wet Cough Community Education Program enhances respiratory health awareness in regional Aboriginal communities by educating and empowering families to seek health advice, while increasing health professional awareness to diagnose and treat respiratory infections.



## LOTTERYWEST



Lotterywest, long term generous supporters of WA, funded the 2023 Sibs & Kids Camp, and contributed to our CF Connect Program.

Our annual camp is an opportunity for siblings and children of people with CF, who are young carers themselves, to connect and form friendships with people in similar circumstances. This builds a sense of belonging and strengthens community.



## OFFICE TECHNOLOGY UPGRADES

In 2023 we worked to uplift our office technology with support from two generous funders. We received an IMPACT grant from Perpetual Trustees to develop and implement our future technology strategy, and an IT grant from PEACH (Personnel Employed at Alcoa Charity Help) to fund several new mobile workstations for our services team, enabling them to remain connected to the office while on outreach trips.



## REGIONAL SPIROMETRY TRAINING

Competency-based spirometry training was made possible in 2023 with support from the Pilbara Health Professionals Network and financial funding from Connellan Airways Trust and Mediplast.



## NEBULISERS

In 2023, Variety WA provided generous financial support to fund the purchase of nebuliser accessories for our community to enable those who are most unwell to access the most efficient and effective equipment.



## REGIONAL RESPIRATORY TRAINING PROGRAM

This annual program is designed to train regional nurses in CF, bronchiectasis and other respiratory conditions. The 2023 event was made possible thanks to generous support from Vertex Pharmaceuticals, Mediplast, Alphafarm (Viatris), Bird Healthcare, Arrotex Pharma and AstraZeneca.



## PARENT'S DINNER

This annual event is an opportunity to build community by connecting with other parents and carers, sharing stories and meeting some of the CFWA team. The 2023 event was made possible with financial support from WA Association for Mental Health and Carers WA.

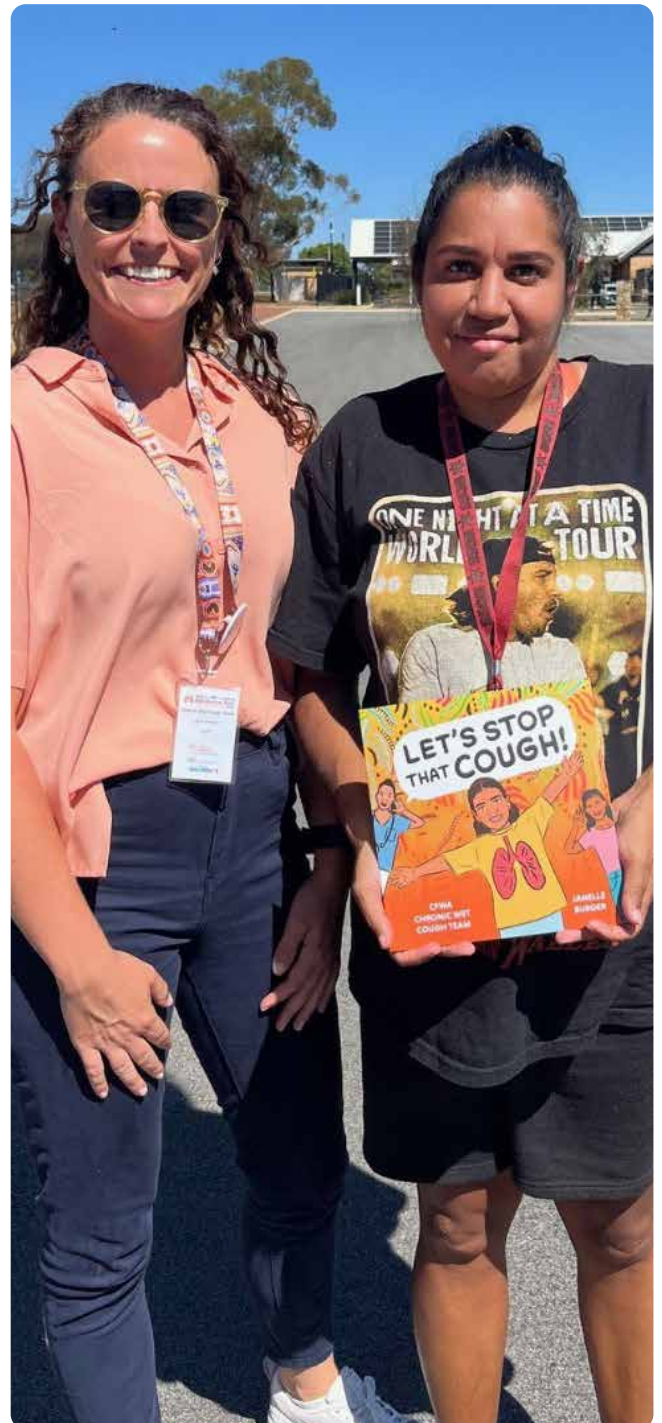


## STAN PERRON CHARITABLE FOUNDATION

Stan Perron Charitable Foundation provided generous financial support towards a range of our support services including Occupational Therapy, in-person and online peer connection events, regional outreach and education.

## CHRONIC WET COUGH CHILDREN'S BOOK

Thanks to a grant from Aurizon Community Giving Fund, we developed a children's book, Let's Stop that Cough! This book is helping us raise awareness of chronic wet cough, which can be a symptom of lung infection, in regional WA communities.





# Key Partners and Valued Sponsors



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

**ROTHWELL FAMILY FOUNDATION**



Government of Western Australia  
Department of Health



**EQUIEM**



**Eurisko**



**BROOKFIELD PLACE**



**BIRDS EYE MEDIA**



**JOHN AND BERYL MAY  
HENDERSON FOUNDATION**



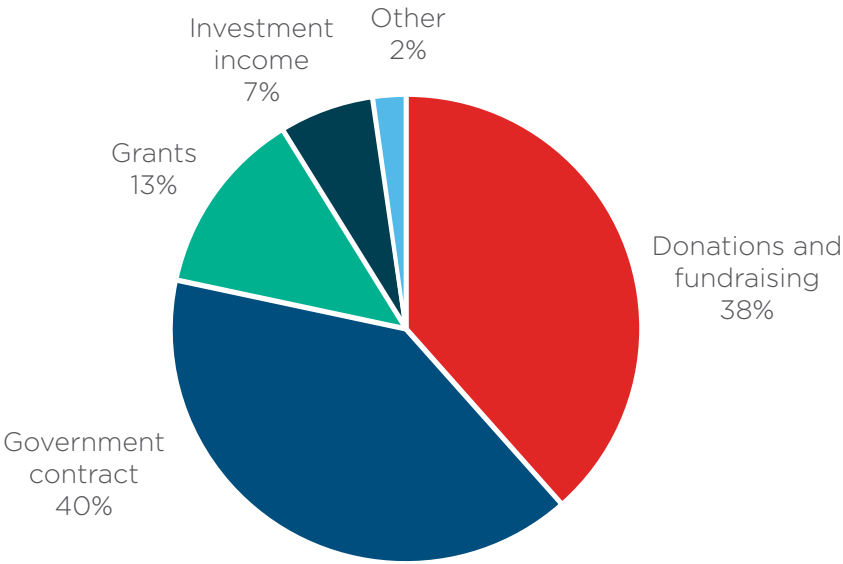
# Financial Snapshot

## FINANCIAL HIGHLIGHTS

	2022	2023
Total income	\$2.1m	\$2.7m
Total expenditure	\$2.2m	\$2.6m
Annual surplus (deficit)	(\$119,500)	\$110,510
<b>Total equity</b>	<b>\$1.9m</b>	<b>\$2.0m</b>

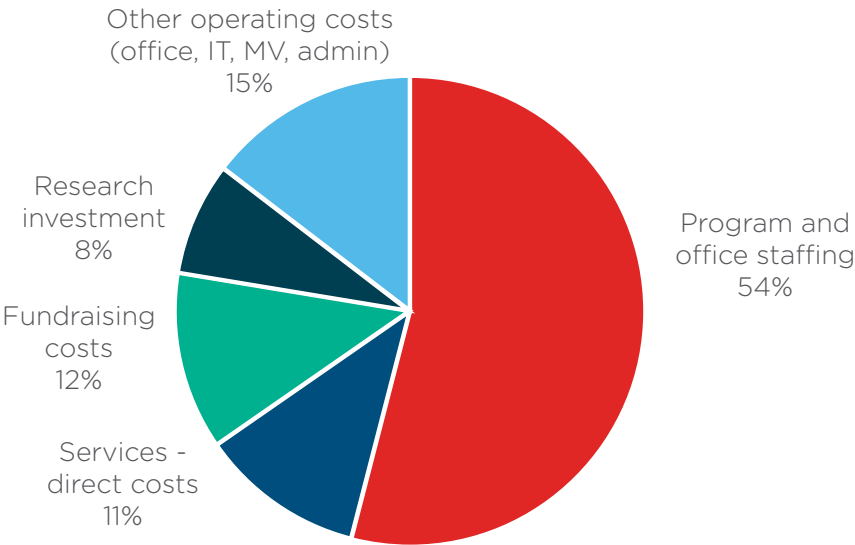
### WHERE THE FUNDING CAME FROM

More than 50% of our income came from fundraising efforts and securing grants and donations.



### WHERE THE MONEY WAS SPENT

Our greatest spend was investing in our team of professionals and support staff servicing clients and operations.



To understand key financial drivers in 2023, refer to our Treasurer’s report. For further financial and audit information, please visit [www.cfw.gov.au](http://www.cfw.gov.au).

# Our People

We are a diverse team of professionals working to provide support, educate, and raise awareness in the community.

## BOARD

Our board is comprised of a dedicated group of highly skilled directors with varied backgrounds. They volunteer their time and expertise to provide strategic direction to the organisation.



**Damien O'Reilly**  
President



**Sally Rose**  
President & Treasurer



**Steffan Crausaz**  
Board Member



**Ingrid Laing**  
Board Member



**Rowena Smith**  
Board Member



**Linda Smith**  
Board Member



**Caroline Boyd**  
Board Member



**Marija Andacic**  
Board Member

## ADMIN TEAM



**Lisa Bayakly**  
CEO



**Ric Reyerson**  
Finance & Admin  
Manager

Our team has worked hard to understand new and changing community needs, secure new funding, and enhance capability to meet these needs. Much of our success is thanks to a supportive community, who inspire and enable our team to make a meaningful difference.

**Lisa Bayakly**  
CEO, CFWA



## SERVICES TEAM



**Sam Wallace**  
Services Manager



**Paula Wallace**  
Services Support  
Coordinator



**Michelle Buck**  
Education Team Lead



**Victoria Glassey**  
Psychosocial Team Lead



**Mel Tibbitts**  
Occupational Therapist



**Felicity Creagh**  
Social Worker

## FUNDRAISING TEAM



**Jessica Hollinshead**  
Head of Fundraising



**Rachael Clifton**  
Senior Events &  
Fundraising Coordinator



**Cesare Papa**  
Grants Officer



**Nicole Posa**  
Digital Marketing Officer



**Chelsea Weaver**  
Fundraising and  
Events Officer

## COMMUNICATIONS TEAM



**Matthew Casey**  
Communications &  
Systems Manager



**Gillian Hoyland**  
Health Promotions  
Officer

## COMMUNITY SUPPORT WORKER TEAM

Our community support team provide in-home support in the community across the Perth metro area.



## **Cystic Fibrosis WA (Inc)**

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**[www.cfwaw.org.au](http://www.cfwaw.org.au)**

