



# Annual Report



**2024**

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*Thriving individuals,  
families & communities*

# Our Vision

*Thriving individuals, families  
and communities.*

## Our Focus

We are working to improve the lives of people and communities impacted by cystic fibrosis, respiratory conditions, and rare disease.

We're focused on empowering and supporting individuals and communities through community based services, peer connection, education, advocacy and research.

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## Acknowledgement of Country

We acknowledge the traditional owners of the country in which we live and 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.



# Cystic Fibrosis

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



## Rare Disease Big Impact

- Over **400 Western Australians** and nearly **3,800 Australians** live with CF.
- **1 in 25 Australians** are carriers of the condition. That's over **one million people**, and most don't know it.



## CF Impacts Daily Life

- CF causes a build-up of thick sticky mucus in the lungs, which affects breathing.
- **CF affects every cell in the body**, not just the lungs.
- CF treatments can take many hours per day, even when people are well.



## New Treatments Not all Roses

- **Advances in treatment have improved lung function** and life expectancy for many, but they are not a cure.
- **Many people are not eligible** for these new treatments, can't tolerate side effects, or find them ineffective.



## CF Presents Unique Challenges

- **CF is isolating.** People with CF are recommended to stay at least 4 metres apart from each other to avoid the transmission of harmful germs.
- **Anxiety and depression** are 2.5 times higher than the general population.

## CFWA Support

Cystic Fibrosis WA (CFWA) works hard to provide a range of resources and practical support to individuals and families affected by CF in Western Australia. Here are the top three reasons people came to us for support in 2024.



### Support in the home

Our team of carers, health professionals and support staff assist families and individuals at home.



### Specialised support

Our diverse team offers support programs addressing mental health, isolation and hardship.



### Education and advocacy

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

# Our Impact in 2024

A snapshot of some of the key ways CFWA has supported people and their families living with CF in 2024; made possible with the help of our dedicated community and supporters.

## Professional Care



**Almost 1,000 occasions** where individuals and families benefitted from health professional led consultations or program sessions.

## Support at Home and In Community



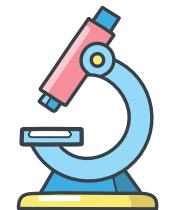
**Over 1,600 sessions** supporting treatment at home; and over 40 online sessions enabling peer connection.

## Community Education



**More than 2,000 Western Australians** educated on respiratory health; and 913 Australians undertaking CFWA's online CF learning.

## \$2 Million in CF Research Funding



**Announced a \$2m CF research** co-funding partnership, supported by the WA Future Health Research and Innovation Fund.

## Financial Support



**Over 700 financial subsidies** to help meet healthcare needs and relieve pressure on individuals and families.

## Awareness and Advocacy



**Spreading CF awareness through selling 25,000 roses**, and working with the national CF community to help secure new treatments for over 260 Australian children.

# Message from the President



*I am excited to share the achievements of the CFWA team delivering impactful outcomes for our community and clients.*

In 2024, CFWA launched a new Strategic Plan, developed with input from our clients and stakeholders. Together, our Board and staff reflected deeply on community needs and our ability to meet these.

The plan caters to the dynamic environment we are in, as we see remarkable progress in CF treatments and care, yet there are serious challenges that remain. There is still no cure for CF. Health outcomes vary greatly across the CF community, with new treatments not available or suitable for all. There are complex and changing needs as individuals age with CF and experience co-morbidities.

To meet these changing needs, we are enhancing client services, strengthening the organisation's capability and capacity; and strengthening partnerships and collaboration.

In 2024, we worked closer than ever with Cystic Fibrosis Australia in national advocacy and political engagement, which has accelerated access to new treatments and enhanced standards of care. We also entered into a co-funding agreement with the State Government's Future Health Research and Innovation Fund to invest a record \$2 million in research grants in 2025, in collaboration with Conquer CF (CCF).

During 2024, we announced our new vision; "Thriving Individuals, Families and Communities." We are committed to empowering and supporting individuals and communities impacted by CF; and leveraging our strengths to support other communities impacted by respiratory and rare diseases. We have grown our education, health promotion and support for individuals and communities impacted by other respiratory and rare conditions; in turn increasing our team's capacity and sustainability.

Our Board is incredibly grateful to the community members, volunteers, donors and organisations who partner with and support CFWA. Thank you also to long-standing member Caz Boyd, who retired this year, for her enormous contributions to benefit the CF community.

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

# Reflections from the CEO



*We appreciate your support for CFWA's life-changing work in 2024 and into 2025, our 50th anniversary, and beyond.*

In the last 2-3 years alone, health outcomes and life expectancy have changed considerably for many people with CF accessing new modulator therapies. The shifts for individuals, families and carers have been significant. Their needs are re-shaping, alongside changes in physical and psychosocial health and day-to-day life, work and social circumstances.

Our team is working to empower and support people's changing needs. In 2024, we engaged with community members and leaders in CF clinical care, allied health and research; locally, nationally and internationally. We also met with individuals and families, those with and without effective treatments. The insight gained helped to inform changes to our team and services.

We began planning new support resources on goal setting; changing CF nutrition, body image and relationships; training and employment participation, and finances and planning for the future. We renewed our research and advocacy focus areas, as there is still no cure for CF and some individuals do not have an effective treatment. We also need to better understand and advocate for the clinical and non-clinical priority needs of people aging with CF.

Strong community engagement enabled us to expand key programs, including our online CF Kids Connect forum to reduce isolation; and our Chronic Wet Cough outreach to improve Aboriginal respiratory health. We also provided increased practical and financial support in response to continued high need, similar to many charities and relief organisations.

We collaborated with State Government to broaden understanding and support for the CF community. This enabled a 5-year renewal of core services funding; and \$1m investment in CF research by the Future Health Research and Innovation Fund. WA Health is also undertaking a business case review of options to better meet adult outpatient needs.

We can only deliver these outcomes with the support of the CF community, ambassadors, volunteers, donors and collaborative partners including WA's innovative researchers and health professionals. Thank you to long standing funding supporters, Department of Health WA, Channel 7 Telethon Trust, the Rothwell Family Foundation, the Stan Perron Charitable Foundation and Lotterywest. Thank you for contributing to vital research, services and awareness-raising events like 65 Roses Day.

**Lisa Bayakly**  
Chief Executive Officer

# Treasurer's Report



*Together with my fellow Board members, I am committed to maintaining CFWA's strong history of effective financial management.*

Our financial sustainability is vital to meeting both new and ongoing needs of the CF community, together with growing demand for CFWA support to other communities impacted by respiratory and rare disease.

I am pleased to report a strong financial result in 2024, with CFWA delivering a surplus of circa \$330,000. Our equity position remains strong, holding reserves to cater for future investment in research and capability building.

Importantly, CFWA has made excellent progress on several funding strategies to prepare us for the future and challenges and risks facing the not-for-profit sector, including the following:

- Diversifying our funding sources, by increasing our engagement with, and income received from, corporations, foundations and major donors.
- Enhancing supporter engagement, to encourage individuals and organisations involved in much-loved community fundraisers to continue supporting CFWA beyond events.
- Reviewing our program and grant portfolios to prioritise grant application in areas of greatest strategic alignment.
- Exploring new research funding opportunities, resulting in a major co-funding collaboration with the WA Government's FHRI Fund, and CCF.

In 2024, CFWA's strong financial performance was largely enabled by savings in fundraising event costs and positive movements in CFWA's investment portfolio.

I would like to congratulate and say thank you to our CEO, Lisa Bayakly, the CFWA team and our fantastic volunteers. We would not be able to achieve the outcomes we have this year without their ongoing hard work and support.

I would also like to thank our President, Damien O'Reilly, and my fellow Board Members who generously volunteer their time and expertise to CFWA. Thank you also to Sally Rose, who served as Treasurer until August 2024.

Finally, I am also extremely grateful to all of CFWA's supporters and add my thanks to those of our President and CEO. Your support has been invaluable and CFWA does not take this for granted. We are deliberate and purposeful in ensuring funds are best utilised to support current and emerging client needs.

If you would like to know more about our finances, please visit [www.cfw.org.au](http://www.cfw.org.au)

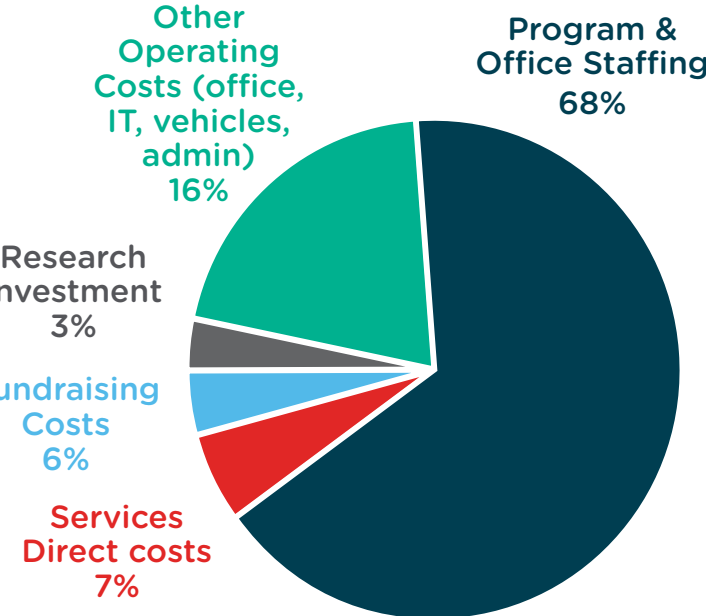
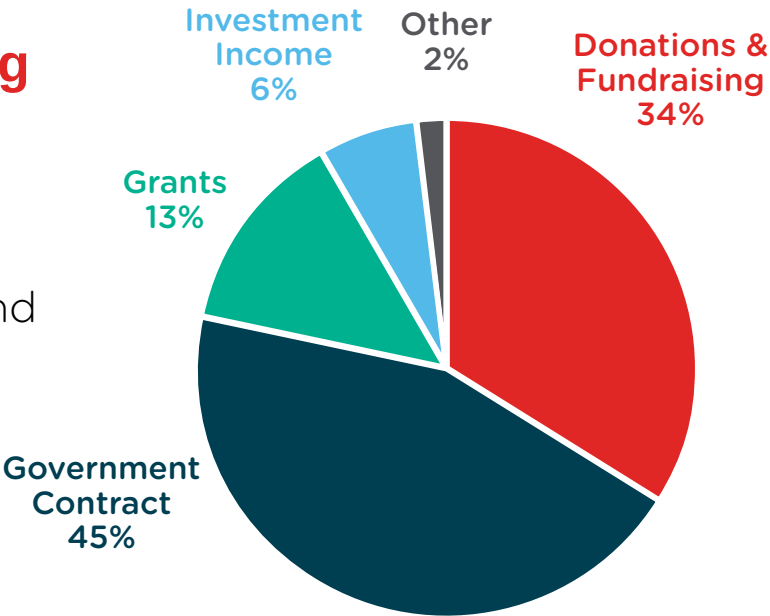
**Linda Smith**  
Treasurer

# Financial Snapshot

Year	2023	2024
Total Income	\$2.7m	\$2.6m
Total Expenditure	\$2.6m	\$2.3m
Annual Surplus (deficit)	\$110,500	\$332,403
Total Equity	\$2.0m	\$2.3m

## Where the funding came from

Almost 50% of our income comes from fundraising efforts and securing grants and donations.



## Where the money was spent

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



# Research Highlights



CFWA CEO Lisa Bayakly and board member Steffan Crausaz at the FHRI announcement.

***“We look forward to delivering an impactful grant program to promote innovative research and sustainable careers in CF research in WA.”***

## WA Cystic Fibrosis Research Collaborative Program

**\$2m in CF research grants committed for 2025**

In December 2024, at the Future Health Research and Innovation (FHRI) Fund Open Day, the WA State Government announced a new partnership between the Fund and CFWA, in collaboration with CCF.

This partnership followed an extensive two stage assessment process, which provided the Fund with assurance as to the calibre of CFWA’s research program. The partnership will bring a significant increase in funding to quality CF research in WA, with grants awarded totalling \$2m in 2025. CFWA and CCF are excited to see the impact that this increase in grant funding will deliver for the CF community.

CFWA have appointed a dedicated Project Coordinator with research expertise to facilitate this program.

## Postgraduate Top Up Scholarship

CFWA funds postgraduate top up scholarships, to encourage researchers to pursue and maintain CF related careers.

In 2024 we awarded Danni Li a post-graduate top up scholarship, funded by the CFWA Golf Classic event. Danni is the 15th scholar supported to complete postgraduate research studies since program commencement.

Danni is researching the use of Trikafta in pregnancy and breastfeeding, an area of increasing importance to people with CF and their families.



Danni Li (left) with CFWA CEO Lisa Bayakly.

## Innovation Grant

Dr Chris Malajczuk was awarded the CFWA Golf Classic Innovation Grant in 2024, for an exciting project combining AI with bacteriophages to combat antimicrobial resistance.

Antimicrobial resistance is rising and poses a significant threat to global health, especially for people with CF.

This innovation grant was made possible with funding from the CFWA Golf Classic event.



Innovation Grant recipient Dr Chris Malajczuk.

## Research Update: CF-Related Liver Disease

Dr. Nikhil Awatade was awarded the CFWA Golf Classic Innovation Grant 2023 with a project to shed light on CF-related liver disease and the impact of new modulator therapies on the liver.

Liver studies have traditionally been very invasive for patients; however, Dr Awatade is developing a novel technique to isolate and reprogram blood cells from CF patients to turn them into induced pluripotent stem cells (iPSCs). These can be further developed into liver ‘organoid’ models to assess liver disease and the effects of modulator therapies.

This project is a stepping stone to personalised medicine which may ultimately improve the treatment outcomes of CF patients.



Innovation Grant recipient Dr. Nikhil Awatade.

## Phage Therapy Research Support

A generous donation from Allegra Capital was used to directly support ongoing phage therapy research at the Wal-yan Respiratory Research Centre.



# Services in the Community

**The CFWA team provides information, education and support to those affected by CF across Western Australia.**

In 2024 we focused on reviewing our service offerings and the structure of our team as we negotiated a new contract with the WA Health Department. The needs of many people living with CF have changed over the past few years and we are focused on adapting our services and resources to ensure the community is well supported.

In 2024 we continued to trial new ways of connecting our community, expanding our online CF Connect program to include siblings and offspring of people with CF and CF Youth. Our face-to-face connection for carers underwent some changes, replacing the parents retreat with two parent dinners, one in collaboration with The Kids Research Institute.

We collaborated with Perth Children's Hospital (PCH) on The Frog Project, improving sputum sample collection rates significantly across the clinic. We also worked together with PCH and Sir Charles Gairdner Hospital (SCGH )

teams to support inpatients and those in hardship with practical resources and financial support.

2024 was a busy year for our team; our community support worker and financial assistance programs continued to be in demand and the need for psychosocial support also remained high. We are extremely grateful to all our supporters, collaborators and funders who enable us to continue to meet the needs of our community.

*"CFWA are amazing. Always so helpful and pleasant to deal with. We couldn't be more thankful"*



Sharon from our Community Support team, delivering in-home care.

*"We just feel so supported and like we have a huge team looking out for our family"*

# Community Support Program

**Our Community Support program continues to provide hands on, face to face support to our community, in their homes.**

Our dedicated team help with airway clearance, exercise and respite, helping families manage the high treatment burden and promoting good routines.

Support workers receive regular training and supervision to ensure best practice and high quality care.


We also engage with external support agencies to provide support for families living regionally or with more specific needs.



The Community Support team help families to make treatment fun and effective.


## Community Support 2024 Snapshot

1,382



Airway Clearance Support Sessions in 2024.

*"Thank goodness for this service. Gives me a weekly break from battling to get Physio completed"*



264

3<sup>rd</sup> party exercise and airway clearance sessions in 2024.

*"The difference it makes for someone to come and help a couple of times a week - honestly its hard to explain"*

12

13



# CF Outreach

Over a quarter of people with CF in WA live regionally. CFWA’s regional outreach program aims to deliver meaningful services and support across the state.

Community connection is really important for our regional families who have an added layer of isolation due to their location.

In 2024 we travelled to 7 regional areas, connecting with our families while providing CF education to schools and health professionals.

This important program is funded by Channel 7 Telethon Trust and reduces isolation for vulnerable regional children with CF and their families.



Sam and Michelle from the team on one of our outreach trips.



A quick stop at the mines between family visits!

# Year of the Frog Collaboration

In 2024 we collaborated with Perth Children’s Hospital to launch ‘Year of the Frog’, a health promotion campaign to increase the number of sputum samples submitted for testing from children with CF aged 6+.

It is recommended that children with CF submit 4 samples per year to ensure that bugs and viruses growing in their lungs are identified and eradicated as soon as possible. Obtaining those samples in children and adolescents is often challenging, particularly since the introduction of the new modulator medications.

Sputum samples are often referred to as ‘frogs’ and ‘coughing up a frog’ is encouraged for children with CF. The campaign included two short videos, educational handouts, frog paraphernalia in clinic, frog passports to record sputum samples submitted and incentives to encourage kids and their families to submit samples for testing.

Early results have shown a 73% increase in the number of sputum samples collected. The number of children over 6 years who provided no sample dropped by 50%. This collaboration will continue in 2025.



Kids returned their completed passports to claim their prize.

**73% Increase**  
in number of sputum samples collected during the initiative.



Sputum collection in action.

## 2024 CF Outreach Snapshot

**7 Regional Areas**

visited in remote WA, providing face to face support.



**360 Occasions**  
of service provided to our regional CF community.



**Over \$25,000**

in direct financial support provided to people with CF and their families in regional areas.



**219 Subsidies**

provided to people with CF and their families in regional WA.



# Financial Support

Our financial support subsidies provided vital assistance to people in need, with demand increasing in 2024.

We offer a range of subsidies that target better health outcomes by supporting exercise, improving access to CF related pharmaceuticals, attending hospital appointments and improving mental health and wellbeing.

Thanks to the ongoing support of the Health Department of WA, Channel 7 Telethon Trust, and fundraising, we were able to provide over 700 subsidy payments totalling over \$103,000.

## 2024 Subsidies

Subsidy Type	No. of Subs	\$ approx.
<b>Adult Support</b> <i>Exercise, equipment and mental health support</i>	171	\$44,400
<b>Family Support</b> <i>Exercise, equipment and mental health support</i>	102	\$17,500
<b>Travel &amp; Parking</b> <i>Attendance at clinic or a hospital admission</i>	381	\$22,900
<b>Crisis &amp; Mental Health Funding</b> <i>Acute financial distress and mental health gap funding</i>	82	\$11,100
<b>Glucose Monitoring</b> <i>CF-related Diabetes sensors</i>	19	\$7,800

Over  
\$103,000



In direct financial support provided to people with CF and their families across WA in 2024.

*“Being able to afford going to the gym has kept my body strong and healthy”*



## CFRD Support

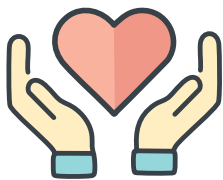
CF-Related Diabetes (CFRD) affects up to a third of the adult CF population, resulting in two chronic diseases to manage.

Although it has a similar health burden to type 1 diabetes, it does not fall under the National Diabetes Services Scheme which provides subsidised access to products and services to help people with diabetes manage their condition.

Our glucose sensor subsidy helps to manage the cost of these products whilst we continue to advocate for CFRD to be recognised under the Scheme.

# Other Practical Support

252  
Respite  
Sessions



And other home help for people and families experiencing hardship or acute need.

69  
Hospital  
Care Bags



And food packs delivered to people in hospital and families experiencing hardship.

28  
Nebulisers



Equipment and accessories to support regular treatment and airway clearance.

77  
Incentives



And sponsored gifts to encourage treatment adherence and program participation.



Hospital support packs being prepared for delivery.

*“Taking the financial stress out of hospital trips makes our life so much easier.”*



We provide incentives to children with CF as part of various initiatives - made possible with support from organisations like Good360.

# Community Connection

Connection with our community comes in many forms, however we can't host face-to-face events for people with CF due to the risk of sharing harmful bugs and germs. This limits social interactions and has an isolating effect on the person with CF and the whole family.

We have worked hard to create alternative ways for our community to interact and our flagship CF Connect Program is an example of this. CF Connect provides a safe online space for community groups to come together, build friendships and share experiences.

Facilitated by our services team, the sessions are age appropriate and provide an opportunity to engage and build networks.

## CF Kids Connect Program

The CF Kids Connect Program targets groups of children with CF, their siblings and children of adults with CF.

These moderated online groups are a safe space for young people impacted by CF to meet and connect. The sessions run throughout the school term and include a range of activities like joint Lego building projects and a virtual "Bake-Off".



In 2024 we held 40 online connect sessions for 64 children and parents.



*"CF Connect sessions are not just beneficial but transformative. They provide a sense of belonging that is so vital in his life, which can be isolating due to the CF cross-infection risks."*

# Online Engagement

## Expanding CF Connect Groups

Following the success of the CF Kids Connect sessions, we expanded the program in 2024 to include multiple CF Kids Connect Groups for different ages, and a CF Connect Playgroup for parents of children with CF aged 5 and under.

### CF Connect Snapshot



40  
Sessions



64  
Participants

*"CF can create a sense of isolation, but the warmth and dedication of CFWA's team bring light into this challenging journey."*



CF Connect sessions are important for people and families who can't meet in person.

## Private Facebook Groups

Our private Facebook groups, one just for adults with CF and another for parents and carers of people with CF, continue to grow in membership.

These groups offer a private space for engagement, connection and somewhere to share experiences and seek advice among peers.



Facebook Group	Number of Members
Adult Group	105
Parent and Carer Group	161

## Online Engagement in 2024



46,000  
Website  
Visitors



5,500  
Newsletter  
Readers



5,200  
Facebook  
Followers



2,100  
Instagram  
Followers



# Community Events

Our face-to-face community events provide opportunities for family members and carers to connect, share experiences and build important social networks. We hold events for parents and carers, grandparents, siblings and children of adults with CF.

## Sibs & Kids Camp



## Sibs Day Out



# Community Events

## Parents' Dinner

In 2024 our Parents' Dinner also included a presentation from the magnificent team of researchers at The Kids Research Institute. This engaging evening was attended by 45 parents who were given an update on the exciting advances happening in the world of phage therapy, as they focus their research on treatments to target antimicrobial resistant infections.



## Ladies High Tea





# Community Education

Our CF Education program, CFSmart, aims to ensure students with CF feel supported and better understood in their local community. It is a national resource for teachers, educators and community members, equipping them with resources to meet the needs of the children with CF in their school or community setting.

The Education team at CFWA support young children and their families on their journey through school from day care, kindergarten, primary and finally into high school. Face to face and remote education sessions, CF action plan development, resource sharing and online learning are all provided both in hard copy format and digitally.

In 2024 we created new CF Smart factsheets and resources to better address the needs of our main community education cohorts; early learning, primary school and high school. These resources covered key topics including a quick guide to CF, enzymes, infection control, cross-infection and also highlighted the CF daily treatment burden.



The CFSmart website includes a range of downloadable resources

## 2024 CF Education

38 Student Action Plans

36 School Management Plans

21 School Education Sessions

217 People completed CF online learning in WA

913 People completed CF online learning in Australia

*“The team are so well informed. They took the time to address the environment and every question the staff had regarding CF”*

# Communication & Resources


CFWA has developed a variety of communication methods and styles to engage and share resources with groups within our community.

In 2024 we continued to develop new resources and factsheets in response to community need, as well as ensuring our existing resources remain up-to-date and relevant.

## Tailored Newsletters

In 2024 we sent out 10 targeted ‘ages and stages’ newsletters to various groups within the CF community, detailing specific supports and services available to them.

Community response to this approach has been extremely positive, with an open rate of over 60%.



6,400 Downloads

CF resources in 2024, including fact sheets, brochures and booklets

## Downloadable Resources

We develop and maintain a large selection of downloadable fact sheet resources, covering a range of topics related to life with CF and different aspects of CF care.

## My ABCF At School Book

In 2024 we expanded our My ABCF series with a second book, **My ABCF at School**. The book is designed for educators to read in early learning settings (K-2) to help students learn more about CF. The story follows our characters navigating their way through the alphabet while learning more about CF. From coughs, to germs, to lunchboxes and medicine, this book will encourage conversations in the classroom about CF and initiate a greater understanding of how we can help our friends with CF stay healthy at school.

To support the book, we also developed a set of resources, including a student bookmark, note for parents, and educator information sheet for further classroom learning. This resource pack was delivered to schools in 2024 alongside our tailored school action plans.





# Supporting Regional and Indigenous Families

## LungSmart

2024 saw a marked increase in engagement with our Indigenous health promotion Chronic Wet Cough program, which was rebranded as LungSmart. We were excited to launch our children’s book, *Let’s Stop That Cough* and distributed over 400 copies to vulnerable communities. This book enabled us to engage with a much wider audience, sharing the simple message;

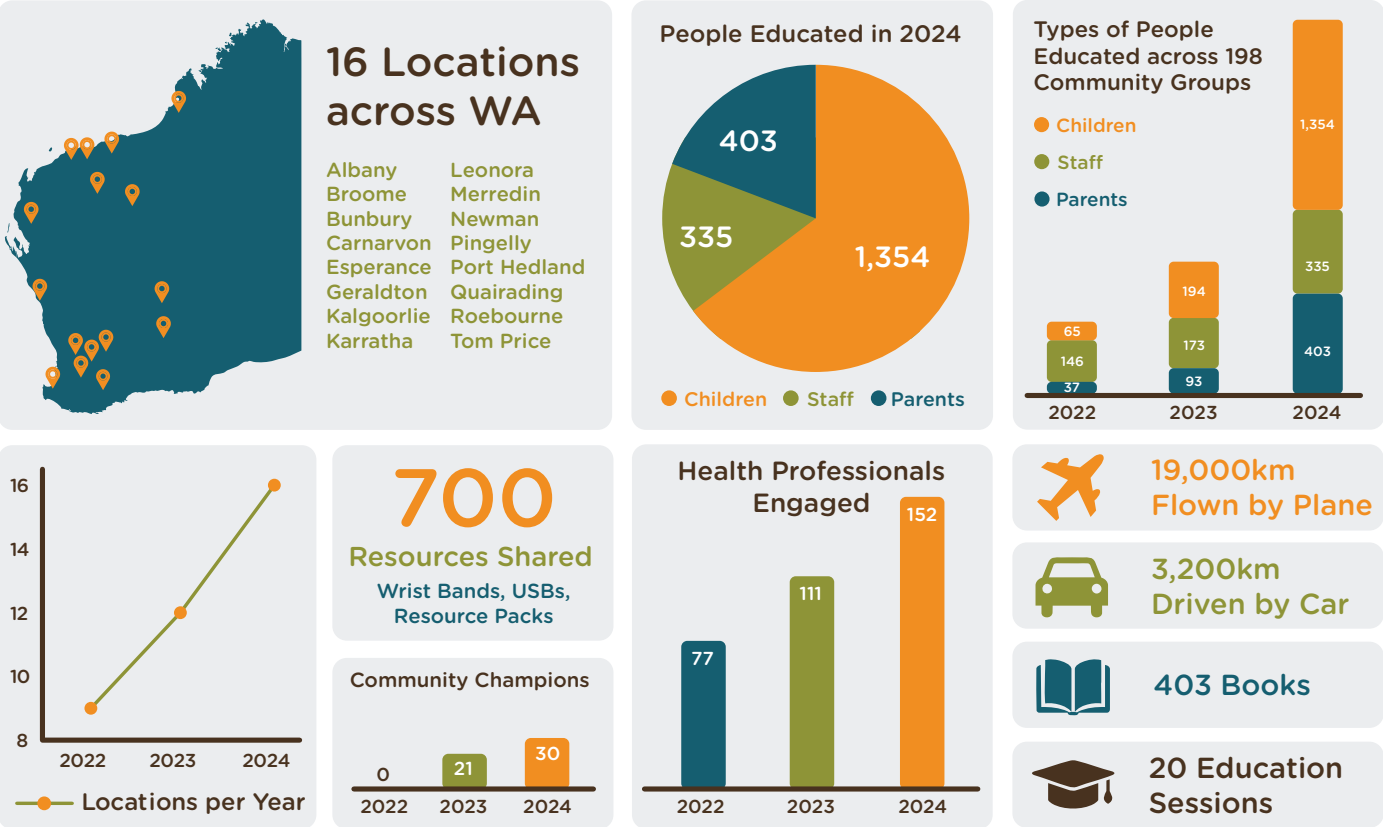
*“If your little one has a wet cough for 4 weeks, get to clinic”*

We also attended community events and centres to share our health promotion message with over 1300

children, 400 parents and 300 staff; and held education and awareness sessions, reaching over 150 health professionals.



## LungSmart 2024 Snapshot



# LungSmart Partnerships

## UWA Collaboration

Our LungSmart team collaborated with University of Western Australia Rural Clinical School in 2024 to expand the reach of our wet cough program. Four medical students living in regional WA undertook a service learning project to spread the wet cough message in their local community.

This resulted in our program being shared with new groups, and an expansion of our focus to provide information targeted at health professionals.



## Toybox Funding

A new partnership with Toybox in 2024 enabled CFWA to support regional families with children living with respiratory and rare conditions including CF, primary ciliary dyskinesia and bronchiectasis. Thanks to Toybox’s generous support, this program is continuing in 2025, providing much needed practical support and respite.



## Binar Futures Collaboration

In 2024 we embarked on a collaborative project with fellow charity, Binar Futures, attending their Basketball Carnival and Health Embassy events. These events attracted Indigenous young people from around the state, playing basketball and engaging with health services to learn about health conditions. This program attracted large numbers of young people, parents, carers and coaches, extending the LungSmart program reach significantly.





# Advocacy for CF Needs

**CFWA's advocacy is focussed on equitable access to treatments, enhanced care and financial support for healthcare needs.**

We collaborate with Cystic Fibrosis Australia, other CF organisations and community ambassadors to ensure a strong and credible voice to decision-makers.

Together, we continued to make advances in 2024. Through sheer focus and determination over many years, access continues to be expanded to life-changing modulator treatments. In 2024, access to Trikafta and Kalyedco was extended to younger children, to help better protect young lungs from long term damage due to health exacerbations.



CF Federation members and consumer advocates met with Hon Michelle Landry MP (centre left) as part of an ongoing Parliamentary Friendship Group.

Access to new treatments means people with CF are living longer and fuller lives. We are actively engaged with stakeholders in WA government to ensure our health system caters for this growing population.

In 2024, we were able to meet with the Minister for Health's advisers and secure a commitment to a business case considering re-development or replacement of WA's only adult outpatient healthcare facility. We also advocated nationally to ensure people with CF-related diabetes have equitable access to diabetes support. A formal petition to Federal Parliament, with close to 2,000 signatures, will be tabled with the new Federal Health Minister post-election.

We will continue to raise awareness of the impact of CF and the need to address ongoing and emerging needs. This includes ensuring all people with CF gain access to an effective treatment and modern facilities and care to manage health complexities.

Overall, there is still much more to be done. There is still no cure for CF. Not all individuals have access to an effective treatment and health outcomes still vary widely.



Our CEO Lisa and CFA CEO Dr Jo Armstrong at the Federal Parliamentary Friendship Group.

# Raising Awareness of CF

**In 2024, we continued our work to highlight the ongoing challenges of living with CF, and raise awareness of CF in the wider community.**

We achieved this through a mixture of advocacy, engaging with community ambassadors and working to secure media coverage to highlight key issues.

## Community Advocacy

Through advocacy and consumer representation, we make sure community needs are known. With greater understanding, health administrators and politicians can commit to changes needed, including timely passage of new and advanced treatments and accelerated investments in facilities and care.

Thank you to everyone in the community who shared their stories in 2024 to support our advocacy and awareness raising efforts.



Consumer representative Sophie (left) shared her experience in the media to advocate for improved facilities at the WA Adult CF Outpatient clinic.

## CF In the Media

**We use our 65 Roses month in May to secure media coverage that raises awareness of CF in the community. Here's a snapshot of some of the outcomes we achieved.**





# Fundraising Achievements

With the support of many generous individuals and organisations, we raised almost \$900,000 in fundraising income in 2024.

We are thankful to our fundraisers, volunteers and donors for showing support to the CF community and contributing to life-changing research and services.

Key highlights for the year included:

- Our most successful 65 Roses campaign ever, with over 25,000 roses sold across the state and over \$160,000 raised.
- Our Matched Giving Day, the biggest ever thanks to a generous \$100,000 donation alongside the contributions from matched givers and community.
- An increase in individual giving and contributions from corporations empowering new service programs and research grants.
- Another outstanding community result at HBF Run for a Reason.



2023 Little Telethon Star, Connor, at the Telethon Family Festival CFWA stall.

Fundraising Snapshot

2,800

Donations

\$895,000

Raised



Some young fundraisers in their red shirts at the HBF Run for a Reason finish line.



2024 Matched Giving Day ambassador Lillee on 65 Roses Day.

# 65 Roses Day

Our 2024 65 Roses Day campaign was the most successful ever. Thanks to unprecedented support in the community, we sold 25,000 roses across the state and raised an incredible \$160,000.

This was made possible with generous support from our event partner and rose supplier, Wafex. In 2024, we celebrated 16 years of partnership through this event. Wafex supplies the thousands of beautiful fresh roses every year, but they also prepare the hundreds of posies and bouquets, and the team have even joined us to volunteer and sell at our stalls.



Volunteers preparing to deliver flowers to fundraisers



Staff from The Kids Research Institute joined us on wrapping day.

65 Roses 2024 Snapshot

25,000

Roses

600

Bouquets

\$35k

Virtual Roses

\$160k

Funds Raised

250+

Volunteers



# 65 Roses Day

As part of our growth plans, we secured a record number of stalls in the community. Through our long-term partnership with South Metro TAFE, over 30 events students helped run many stalls, gaining valuable real-world event experience.

65 Roses isn't just about raising funds. The campaign also promotes CF awareness, through our community ambassadors and media partner, Devahasdin enabling extensive media coverage.

Thank you to the hundreds of individuals, families and support organisations who contributed to an incredibly positive result in 2024.



A tiny number of the hundreds of volunteers and fundraisers who helped us paint WA with roses for CF on 65 Roses Day.



# Major Campaigns

## Matched Giving Day

Over 130 individuals contributed to our Matched Giving Day in 2024, including an incredible surprise donation of \$100,000 to bring the total to over \$180,000, our largest Matched Giving Day ever!

This result was made possible thanks to generous support from our Matched Givers, Mimi & Willy Packer, Philippa Craigue; Morgans Financial Limited, and Shaw & Partners Financial Services.

Our campaign featured community member Lillee and our Community Supporter Worker, Sharon who helped highlight the direct impact of contributions.

132  
Donations

\$180,000  
Funds Raised



Matched Giving Day ambassador Lillee, with a selection of the medication she takes every day.

## CF Luxury Raffle

Our luxury raffle was introduced in 2023, as part of our strategy to innovate and develop creative campaigns for the future.

Raffle campaigns enable us to reach new audiences and introduce them to our cause, whilst offering another unique opportunity to existing supporters.

We are always refining our campaigns and striving to offer an experience that resonates with both our current army of supporters and the broader community.

In 2024, we adjusted the prize offering, price and packaging of the raffle to continue to build a wider audience.

Our promotions reached a wide demographic and over 200 new people subscribed to hear more from CFWA. We're working to consolidate on this in 2025!



CFWA Finance & Admin Manager Ric, presenting early-bird winner Rosalind (right) with her prize.



# Community Support

## Community Fundraising

Support from individuals in the community continues to provide a significant contribution to our overall fundraising total and helps raise valuable awareness of CF in the wider community.

Here's a snapshot of some of the incredible support we received from community fundraisers in 2024.



### HBF Run for a Reason

**\$35,000**  
5<sup>th</sup> overall charity in fundraising thanks to support from over 30 runners.



### Navrang Cultural Festival

**\$10,000**  
We were honoured to be a beneficiary of the 2024 Navrang Cultural festival organised by Sweet Melodies. The organisers donated \$10,000 to CFWA to support diabetes monitoring equipment for community members.



### Murph Challenge

**\$13,700**  
A yearly fitness challenge fundraiser, organised by Danny, and Michael (pictured) who lives with CF.



### Eric & Ronnie Cans for Cash

**\$11,500**  
Eric and Ronnie collect tin cans and bottles, and deposit the returns to CFWA.  
They raised over \$11,500 in 2024, all from bottle and can returns!

# Community Support



### Rottneet Swim

**\$5,900**  
Hannah Chitty took on this challenging swim in support of CFWA.



### Corporate Battle of the Bands

**\$7,300**  
Annual fundraiser in support of CFWA and Youth Focus, where bands battle it out for a good cause!

## Volunteers

**250+**  
Volunteers



**900+**  
Hours given



The volunteer support we receive makes an invaluable contribution to CFWA's work; helping to keep our costs low and maximising the impact of our support programs.

The main volunteer focus was 65 Roses Day, where over 150 individuals joined us to help wrap, deliver and sell thousands of fresh roses all around the state.

Thank you to the many organisations and student groups from South Metro TAFE, Curtin University and University Western Australia for their ongoing support to help wrap roses and run the 65 Roses Day stalls.

## Collection Tins

**144**  
Locations



**\$18,000**  
Funds raised



Our collection tin program is made possible with support from two dedicated volunteers, Ron and Adrienne.

2024 was another very successful year, with Ron sourcing local businesses to host a tin, and Adrienne handling the office administration.

Thanks to their dedicated efforts, and the generosity of the Perth community dropping their spare change in our tins, they raised almost \$18,000 in 2024! It also plays an important role to keep CF visible in the wider community. Thank you Adrienne and Ron for your continued support!



# Corporate Support

## Corporate Support

**Corporate contributions to our work form an invaluable part of our fundraising, and the ability to deliver our support services in the community.**

In 2024 we made a targeted effort to increase this corporate support, with a particular focus in matching organisations with one of our support programs or initiatives most relevant to them.

Thank you in particular to the following organisations for your support in 2024.

### Allegra Capital

A major donation to support an innovative Phage research project.

### Shaw and Partners

Supported our Matched Giving Day.

### Morgans Financial

Supported our Match Giving Day.

### Concept AV

These long-term supporters continued to donate throughout 2024.

### Data #3

Donated several computer devices to enable our support staff.

### RAC

Contributed by donating unclaimed funds.

### Allens

Made a generous donation to our Virtual Rose Garden recognising 65 Roses Day.



Kingsley McGarrigle and Andrea Riveros from Data #3 visited the CFWA office to gift laptops for our mobile workforce.

## Pro Bono and Gifts in Kind

In addition to supporters of our programs, we have a range of organisations who support CFWA through pro bono donation of their service and gifts in kind support of their goods.

This support is integral in providing expertise, and reducing the cost of our service delivery.

### Herbert Smith Freehills

Provided pro bono legal advice.

### Rapid Relief Team

Provide food boxes for families in hardship.

### Good 360 and Special Children's Christmas party

Provide toys that we use for gifts and incentives for young people in our community.

# Grants

## Telethon



Telethon's continued support has enabled significant growth in our Thriving Families and LungSmart programs, with increased funding allowing us to expand their reach and impact.



Telethon funding has enabled us to expand our LungSmart community education program.

Thriving Families continues to provide essential care for vulnerable children with CF and their families, including therapy, support services, regional outreach, and financial aid. The additional funding has strengthened our ability to support more families, ensuring equitable access to critical services.

Previously known as the Chronic Wet Cough Community Education Program, LungSmart has received increased funding to extend its reach. The program enhances respiratory health awareness in regional Aboriginal communities, empowering families to seek timely medical advice, while equipping health professionals with the knowledge to diagnose and treat respiratory infections more effectively.

## Lotterywest



Lotterywest, a valued and steadfast supporter of CFWA, funded our annual Sibs & Kids Camp and has also contributed to our CF Connect Program, which provides an opportunity for siblings and children of people with CF, who are young carers themselves, to connect and form friendships with others in similar circumstances.

In addition, Lotterywest has provided additional funding for our brand-new pilot project, CF Futures. CF Futures is a community-based set of resources designed for the changing CF environment. As treatments improve and lifespans increase, people with CF face new challenges. This project will equip them with the tools and knowledge to navigate these changes, empowering them to live healthier, more fulfilling lives.



Our annual "Sibs & Kids" camp is an opportunity for young carers to build relationships with their peers.



Unable to meet in person, our Kids Connect sessions allow people with CF to meet safely online.



# Grants

## Stan Perron Charitable Foundation

CFWA welcomed an increased contribution from Stan Perron Charitable Foundation supporting our range of services, particularly to children in the CF community. Projects include peer connection activities, mental health support and school and community education activities.

## Rothwell Family Foundation

Thanks to the Rothwell Family Foundation's ongoing support, we were able to extend CF services and support; and grow our LungSmart capability.

This support enabled us to develop new LungSmart resources and travel to major community events, where we engaged with over 800 young people, coaches, parents and families in 2024.



## Perpetual Trustees

A Perpetual Impact Grant enabled us to continue a digital enablement project, to uplift and enhance our technology environment.

This project has set the foundations for a more digitally enabled future, embracing new and emerging technologies to expand and enhance service capability.

## Pilbara Minerals

Indigenous Literacy Day is a vibrant occasion that honours Aboriginal and Torres Strait Islander cultures, stories, and languages. This year, we were thrilled to join the festivities for the third time, interacting with over 150 attendees, including 85 children and 64 adults from Yandeyarra, Strelley and Worralong Remote Community school. Thanks to the generous support from the Pilbara Minerals community grant, we were able to bring 100 copies of our new children's book, "Let's Stop That Cough," for every child in attendance.



## Toybox

CFWA has proudly partnered with Toybox Australia to deliver the new Regional Respite Pilot Program, which provides support to regional families living with either CF or other respiratory conditions. This provides practical support and respite for caregivers to ensure they can manage their own needs.

## Carers WA

Carers WA supported our annual Parents Dinner, ensuring an opportunity to build community by connecting parents and carers, sharing stories and building trusted relationships with the CFWA team.

# Valued Partners & Sponsors



# Our People

We are a diverse team of professionals working to provide support, education and raise awareness of CF in the wider 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**  
Vice President



**Linda Smith**  
Treasurer



**Rowena Smith**  
Board Member



**Marija Andacic**  
Board Member



**Ingrid Laing**  
Board Member



**Steffan Crausaz**  
Board Member



**Carolyn Boyd**  
Board Member  
*Retired June 2024*

## Administration Team



**Lisa Bayakly**  
Chief Executive  
Officer



**Ric Reyerson**  
Finance & Admin  
Manager



**Lawrence Liew**  
Project  
Coordinator

# Our People

## Services Team



**Sam Wallace**  
Services  
Manager



**Paula Wallace**  
Services Support  
Coordinator



**Michelle Buck**  
Education Team  
Lead



**Emily Guyton**  
Community  
Educator



**Stella Ray**  
Psychosocial  
Support

## Community Support Team

Our Community Support team deliver in-home support across the Perth metro area.

## Fundraising Team



**Jackie Parker**  
Head of  
Fundraising  
*Leave cover to Feb 26*



**Jess Hollinshead**  
Head of  
Fundraising  
*Extended leave to Feb 26*



**Chelsea Ong**  
Senior Fundraising  
Coordinator



**Cesare Papa**  
Grants  
Officer



**Rachael Coltrona**  
Fundraising  
Administrator

## Communications Team



**Matt Casey**  
Communications &  
Systems Manager



**Gillian Hoyland**  
Health Promotions  
Coordinator



**Zoe Wolski**  
Digital Marketing  
Coordinator



# Thank you for your support

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Together we'll achieve our vision  
*Thriving individuals, families and communities.*

## Cystic Fibrosis WA (Inc)

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