CYSTIC FIBROSIS
Western Australia

Annual Report 2021

CYSTIC
FIBROSIS
Western Australia

Working together towards our vision:

Lives unaffected by cystic fibrosis

Connor and Charlotte selling roses on 65 Roses Day.

Sibs Camp 2021.

Contents

Front cover – *Tatiana Joannides and Michael Cahill, our 2021 Bring it on Bridge Climb ambassadors.*

Big impact in 2021

Here's a small snapshot of some of the things we've achieved in 2021; made possible with the help of our dedicated community, partner organisations, and supporters.

4,338
times our services were accessed

including airway clearance, exercise support, psychosocial and practical support for vulnerable people or those experiencing hardship.

$2.6M

in revenue secured to support adults and families living with cystic fibrosis, thanks to government and generous supporters.

1,381 **people**

were delivered CF education for their workplaces and schools, empowering them to enhance support for people with cystic fibrosis.

36,481 **visits**

to our websites to access CF-specific resources and information for further education and support.

3
CF research projects funded

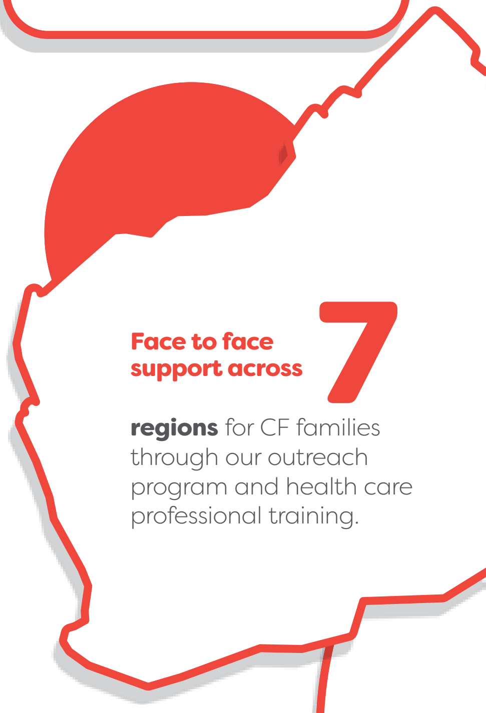
to continue investing in promising CF research being undertaken here in WA.

925,545 **people reached**

on social media, spreading awareness of cystic fibrosis in the wider community and staying connected online.

17,600

roses were sold on 65 Roses Day to raise vital awareness and funds for people living with cystic fibrosis.



Face to face support across **7** **regions** for CF families through our outreach program and health care professional training.

Message from the Patron

2021 was quite a year for CFWA all round. The team continued to navigate COVID, striving to stay ahead of emerging issues and ensuring the CF community had information and support at hand.

COVID had a significant impact on CFWA's fundraising revenue and service delivery requirements. We received some JobKeeper funding, however this was for the first quarter of the year only. Despite the financial and logistical challenges, the CFWA team remained determined not to compromise on services to people with CF. They introduced new fundraising initiatives and successfully secured new grants to secure vital funds, and successfully negotiated a new 3-year contract with the Department of Health WA.

CFWA continues to be a well governed and managed organisation, thanks to its leadership. In 2021, we welcomed new board members who bring skills and an understanding of CF in Amanda Bearcroft and Rowena Smith; and our new CEO, Lisa Bayakly, built stronger relationships with the community and key stakeholders.

This year will be Caz Boyd's last year in her term as President, four years in total in this role.On behalf of the CF community, I extend enormous thanks for Caz's commitment, contribution, and strong advocacy for all those living with CF.

In a year of much change, all of the CFWA team kept the focus on the CF community front and centre, particularly in advocacy, both nationally and locally, and in helping ensure community preparedness and support for COVID surging.

Thank you to the CFWA staff for this focus and to all those in the extended CF community for your support. CFWA's success is only possible due to collaborative efforts of government, specialist hospital teams, the research community, grant providers, sponsors, individuals who give and fundraise, and of course, people with CF, their families and carers.

John Rothwell AO
Patron

Message from the President and CEO

What a year 2021 has been for everyone!

For me personally, it has been an absolute honour to take on the CEO role and work with the CFWA team and the CF community. It has certainly been a busy year, full of new challenges.

We are not alone – many other not-for-profits similar to CFWA have struggled with growing demand, unanticipated COVID management costs, and reduced funds coming in. Most organisations have had to change the way they operate, impacting staff and client services.

I know many people with CF and their families have also felt the pressure this year, with COVID continuing to impact people's daily school, work and social interactions and the threat of a major outbreak constantly on the doorstep.

Fortunately, the CFWA team understands the CF community and always advocates for your needs. Like me, they are inspired by the spirit and generosity of the CF community and work hard to honour that. I am grateful for the team's support and proud of their achievements.

L Bayakly

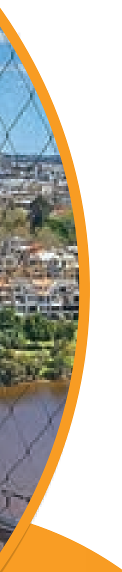
Lisa Bayakly
CEO

CEO Lisa Bayakly, President Caz Boyd and board member Amanda Bearcroft on CFWA's Bridge Climb event in 2021.

The CFWA team maintained services, community peer events and regional outreach through COVID and worked with hospital teams to understand risks and impacts for the CF community and to share these with you.

They negotiated a new 3-year contract with the Department of Health WA, and in the process built a much better understanding of the needs of people with CF. Whilst the pressures on the health system have led to some funding cuts, we had the support of CF specialist teams in advocating for our services and the Department of Health was very focused on outcomes for people with CF.

The CFWA team remained focused on building awareness and community engagement, with the publication of new resources such as books for young children; and through securing the continued support of Lotterywest, Telethon Trust and Perron Foundation; and new grants to support adult wellbeing and community education initiatives through 2022.



CFWA delivered net fundraising targets through new initiatives such as the Bridge Climb and CFWA's first Matched Giving Day, thanks to participants, matched givers and donors. They helped ensure the continued success of events like the John Gillard Family CF Golf Classic and Albany Christmas Lights, which couldn't happen without the Golf Committee and community leadership.

We continued to advocate and invest in research in 2021 and enjoyed hearing from Anthony Kicic and Anna Tai at CFWA outreach and events. Nationally, we collaborated with CF Federation organisations to advocate on many issues affecting the CF community.

Our shared push for Trikafta® access delivered with its PBS listing for eligible individuals over 12 years in 2022.

Thank you to our patron, board and all the team; to the Department of Health, hospital teams and researchers who are focused on both care and cure; to each sponsor, volunteer, supporter and to all the CF community.

It has been an honor to serve as President.

Caz Boyd

President

Policy, Research and Advocacy

Our collaboration with the CF community continued in 2021 to further research endeavours, drive policy and decision-making and advocate for better treatment and support for all people with CF (and their families and carers).

State-Based Collaboration

Locally, we continued to participate in the Child and Adolescent CF Consumer Reference Group made up of parents of children with CF. Other representatives include an adult with CF, an adult sibling, researchers from Telethon Kids Institute (TKI), and the Perth Children's Hospital (PCH) CF Centre Director. Our participation enables us to ensure a strong focus on the consumer perspective to both clinical and research aspects of cystic fibrosis.

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

We supported the Adult CF Clinic team and Adult Consumer Group in advocating for increased resources, sharing with senior hospital leadership our insights from national comparative hospitals and the impact of current gaps on the adult CF community. This is helping inform decision-making on priority resourcing needs for the increasing CF adult community.

Unfortunately, COVID once again disrupted our annual Evening with CF Scientists Perth event, held at Telethon Kids Institute. However, we were able to host a regional Great Southern Outreach Research evening with a presentation from guest speaker Associate Professor Anthony Kicic from Telethon Kids Institute who provided an overview of his breakthrough research in bacteriophage (phage) therapy. Phage therapy is a unique way to treat anti-microbial resistant microbes which are becoming a common and significant global issue.

Attendees at our AGM were also excited to hear from Anna Tai regarding her work through the Institute for Respiratory Health on the emerging treatments for drug-resistant infections in people with cystic fibrosis.

We also made significant updates to all our education resources including a major update to our adult nutrition resources, a collaborative effort between CFWA and the dietitian teams at Sir Charles Gairdner and Fiona Stanley Hospitals.

> All our resources are available on our website **www.cfwa.org.au**

National Collaboration and Advocacy - Trikafta®

Nationally, under the leadership of Cystic Fibrosis Australia (CFA), CFWA advocates alongside other state and territory CF organisations for a range of issues affecting the CF community.

In 2021, a major advocacy focus for the CF Federation was the push for approval for access to Trikafta®, a CF modulator that treats the underlying cause of CF. In December 2020, the listing of Trikafta® for the PBAC March 2021 agenda brought hope to the CF community that access to this treatment was not far away. Unfortunately, the outcome of this meeting was not positive, with the PBAC deferring recommendation of the drug. Thankfully, CFA, the state and territory organisations, and many incredible community advocates were not dissuaded, and we continued our advocacy efforts. In January 2022, Trikafta® was recommended for PBS listing for patients with CF aged 12 years or older who have at least one F508del mutation, and finally listed for this group on 1 April 2022.

We are all hopeful this approval of Trikafta® will pave the way for safe access for those 12 and under, and for future treatments to help those that Trikafta® is not suitable for.

We would like to acknowledge Nettie Burke, CEO of CFA who stepped down from the role after seven years. Her long-term awareness raising and advocacy with CFA has put the federation in a great position for future CF advocacy efforts, now under the capable leadership of Jo Armstrong, new CEO at CFA.

Thank you to all in the extended CF community for raising awareness, personal advocacy and in sharing stories and supporting the advocacy push, which continues to deliver vital change.

CFWA Funded Research

In 2021, we continued our PhD Top Up Scholarship program, focussed on encouraging CF-related research. We awarded another scholarship to Andrew Vaitekenas in 2021, bringing the total to 13 scholarships awarded to date. We also awarded research grants to Julie Depiazzi and Crystal Bourke from PCH; and Dr Luke Garratt, made possible with funds raised through the 2020 CFWA Golf Classic event.

Andrew Vaitekenas CFWA PhD Scholarship recipient

Andrew's project is investigating how bacteria, specifically Pseudomonas aeruginosa, changes in response to phage therapy. By understanding how the bacteria changes, or becomes resistant to phages, Andrew hopes to ensure that phage resistance can be prevented when used to treat the lung infections of people with CF. Antibiotic resistant infections are a significant threat to modern healthcare, yet there is a lack of investment in developing new antibiotics. The increase in resistance and lack of new antibiotics is of concern to people with CF given antibiotics are currently essential to treat frequent airway infections and maintain a person's health. Therefore, development of alternative treatments to antibiotics is considered a significant priority.

Julie and Crystal's research project is investigating the health consequences of Tracheobronchomalacia (TBM) in children with CF. In WA, children are diagnosed with CF through newborn screening. Part of the early management includes a bronchoscopy in the first 12 months of life. Around 41% of children in WA under the age of 4 years have been reported to have TBM, a condition where parts of the windpipe, or airways, are floppier than normal. With this further diagnosis of TBM, parents naturally question the effect that it may have on the long-term health of their child. Julie and Crystal's research asks, "Does a diagnosis of Tracheobronchomalacia affect health outcomes in children with cystic fibrosis?"

Dr Luke Garratt
CFWA PhD Scholarship recipient

Dr Luke Garratt's project is researching neutrophils which perform an important immune function in the body, however, for people with CF, they can actually behave harmfully, causing lung damage. Dr Garratt is a dedicated CF and respiratory researcher and member of the CF team at the Wal-yan Centre, which is a partnership between Telethon Kids Institute, Perth Children's Hospital Foundation and Perth Children's Hospital. He was CFWA's first PhD top up scholarship winner in 2011 and has gone on to receive a FutureHealth WA Merit award, as well as both fellowship and project grant funding from the National Health and Medical Research Council Early Career.

Thank you to the Gillard Family and the other dedicated volunteers on the Golf Committee for their continued support which has made this research funding possible.

Our research, advocacy and strategic direction continue to be informed by community needs and input, to drive us closer to our vision of *Lives Unaffected by Cystic Fibrosis.*

How CFWA Funds Research

All applications for CF research funding are assessed by an independent scientific advisory committee through the Australian Cystic Fibrosis Research Trust (ACFRT). The purpose of the trust is to allocate funds for high quality CF research and secure public and corporate support. This trust is administered by Cystic Fibrosis Australia.

Service Report

Services in the Community

This year marked the end of an era in services at CFWA with the resignation of Kathryn Pekin as Services Manager, to take up a new role in Geraldton. Kathryn was a strong advocate for mental health support and services for adults and this will remain a focus moving forward. Sam Wallace has stepped into the role of Services Manager having worked alongside Kathryn for many years as CFWA physiotherapist and managing the Community Support Program.

Sam Wallace
CFWA Services Manager

> *Dear all the wonderful team at CFWA - thank you for all that you have done for our family over this past year.*

Given the ongoing COVID-19 situation, we continued to adapt our service delivery to reflect the needs of our community. We focused on facilitating online connection and developing online resources to enable people to share their experiences and access information and support. We were still able to deliver our much-loved community events, provide financial assistance and nebulisers, travel to the regions and provide education to schools, health professionals and the wider CF community. We are grateful to Telethon, Lotterywest, the CFWA Golf Classic Committee, and the Stan Perron Charitable Foundation, our many community fundraisers and other partners for their ongoing support.

2021 was also the final year of our current Department of Health WA contract and a great deal of time was spent negotiating the terms of our new agreement. We look forward to continuing our successful partnership with Department of Health WA to deliver services to the CF community in 2022.

> *Thanks again for all the support you and the CF team give to my family. It is always appreciated, more than I can ever express.*

> *Thank you for your support and helping my daughter to reach her goals.*

CFWA Program Spotlight

CFWA offer a range of programs and services to suit the needs of our growing CF community. We engage in meaningful relationships within our community to understand need and can quickly adapt, or introduce new initiatives which reflect the changing CF landscape. In 2021, one of our areas of focus was providing comprehensive support to members of our CF community through our Vulnerable Families and Psychosocial Wellbeing Programs.

Vulnerable Families Program

Support for vulnerable families aims to improve the health and wellbeing of all children and families with CF through early intervention, education, and equitable access to specialist care. Key components include:

- CFWA's Calm Kids Happy Families Program, run by Mel, our Occupational Therapist, which supports families with routines, self-regulation, and positive communication
- Education support for children who need extra assistance with schoolwork
- Financial assistance to access local support agencies and external services
- Travel and parking subsidy to assist with the cost of accessing specialist CF care
- Financial crisis assistance

> *I love Mel's positivity; she is a great asset for CFWA and our families and she completely 'gets it'. It also allows me to acknowledge that managing the day-to-day challenges of parenting and delivering CF care is hard.*

50

Crisis Support Vouchers distributed to those experiencing financial hardship in 2021.

144

Support Packs gifted including hospital bags, snack packs, and Christmas toy bags.

462

External support provided including personal training, airway clearance, cleaning services and respite.

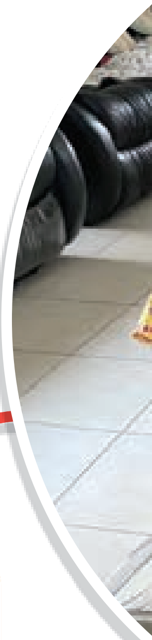
Psychosocial Wellbeing Program

Our Psychosocial Wellbeing Program includes a range of initiatives for children, adolescents, adults, and their families to focus on their mental health and wellbeing. Our team of health professionals collaborate to offer a wraparound service including counselling, social work, occupational therapy, and practical support to people with CF and their families. We provide financial support to access external counselling or clinical psychology and subsidise exercise participation as a form of mental health support.

175
people attended our local Community Support events

209
occasions of phone mental health support in the community

120
occasions of face-to-face mental health support in the community



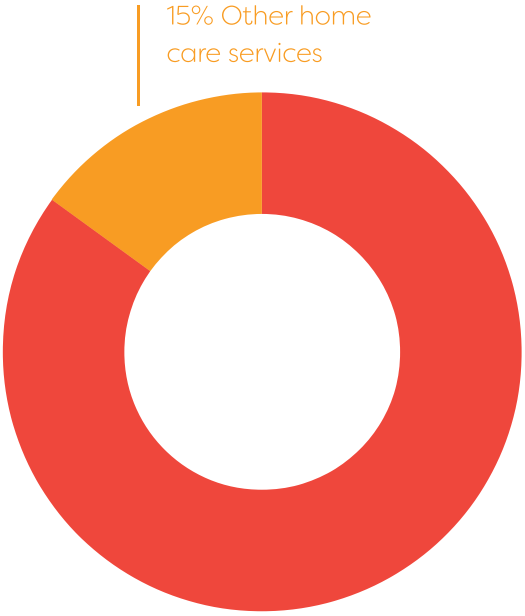
Home Care Worker Services

As one of our most valued programs, home support services continued to be delivered in 2021, with additional PPE and infection prevention strategies to ensure the safety of our community

Our team of support workers delivered over **3,700** home sessions, providing support with airway clearance, exercise, respite and home help to adults and children. The success of this program reflects the strong relationship we have with the tertiary hospitals and our CF community.

> *A review of the current WA contract included a name change for our Home Care Workers for 2022 to* ***COMMUNITY SUPPORT WORKERS.*** *We believe this more accurately reflects the valuable role they play supporting individuals with CF and their families in the community.*

Type of Home Support



Airway clearance support accounted for **85%** of our home sessions

We get regular feedback from our community and know how much this service assists with routines, reduces stress, and supports positive relationships.

Our HCW is an amazing asset to the CF community. She really helps with my exercise routine. My general health has improved since she's been working with me. She is so lovely and supportive.

The HCW service is essential to our family. It helps us immensely and we are so grateful for the option. Thank you to CFWA for hiring amazing staff who do their best to ensure physio is completed professionally and in a friendly manner. Thank you!"

Being isolated with no friends or family and a husband that is FIFO working away 2 weeks at a time this support assists me greatly with my daily requirements and mental health. I feel it is my greatest support at this current time.

We're finding having this small amount of help, even just once a week gives us such a peace of mind. A moment to recentre and gather ourselves. It really helps relieve the stress of physio.

This service has helped me create and more importantly maintain my child's airway clearance routine.

Excellent service. Good to have someone to talk to who understands your child's needs.

Regional Support

Our Regional Outreach Program aims to improve equity of access to specialist care, education, and peer support, regardless of geographical location. The program, which is partly funded by Telethon and Health Department WA includes financial support subsidies, face-to-face peer support events, educational workshops, online resources, and peer connection and engagement using social media platforms.

Outreach Program

In 2021, our regional outreach program included:

- Subsidies to regional families travelling to Perth for clinic appointments or hospital admissions
- Activity subsidies to regional adults and families for exercise and equipment
- Facilitation of regional Evening with CF Scientists event
- Resource development and distribution including books, factsheets, information booklets and short videos
- Respite and airway clearance support
- Financial support including food vouchers, mental health gap funding and crisis funding
- Support with online personal training
- Virtual Catch Up for CF Kids – online peer support program linking up children with CF
- Cleaning packages for families in crisis
- Support for regional children to attend the annual Sibling and Offspring Camp
- Face-to-face education workshops, training programs and online presentations to regional health professionals
- Face-to-face and online CF education to regional schools
- Subsidy support for regional parents and carers to attend peer support events
- Facilitation and moderation of Facebook groups for parents and carers as well as for CF adults

South-West Evening with CF Scientists

A collaborative event with Telethon Kids Institute (TKI) including dinner and a CF research presentation from Associate Professor Anthony Kicic, held in Bunbury.

TKI Researcher Associate Professor Anthony Kicic

> *A big thank you to Telethon for funding the CFWA regional trips. These trips and dinners are a wonderful opportunity to get together with families from around the region who are able to understand and share the same experiences and challenges faced living with, supporting and caring for a child with Cystic Fibrosis. Having a safe place to share frustrations, stories and worries is invaluable and as the saying goes a problem shared is a problem halved. The staff at CFWA are always positive, supportive and skillful at providing an evening full of laughs, information and making sure that attendees are making connections.*

Financial Support

More than ever, 2021 highlighted the need for financial support within our WA CF community. Thanks to the Department of Health, Lotterywest, Telethon, and other generous supporters, we were able to assist individuals and their families with the high financial burden of CF.

COVID-19 continued to have an impact on vulnerable community members. For those facing food insecurity, we provided Foodbank referrals and distributed shopping vouchers and food boxes which were generously donated by the Rapid Relief Team, a relief organisation that started supporting CF families through CFWA in 2021.

The financial burden of care in CF is high due to missed school and work, parking, travel, pharmaceuticals, nebulisers, and other medications. CFWA, with a network of supporters, aims to reduce financial hardship that individuals and families may face due to hospital and treatment related costs and reduced earning capacity due to health or caring responsibilities.

Our subsidy program for adults expanded to include CF-related pharmaceutical expenses, recognising the financial burden CF places on families, especially adults, who often do not receive government health benefits. Our Telethon travel subsidy provided much relief to families, especially regional families, helping to cover some of the costs associated with travel to Perth for hospital admissions and clinic appointments.

	Equipment Subsidy	Adult Activity Subsidy	MH Gap Funding	Pharma Subsidy	Adult Travel	Telethon Children's Travel	Children's Activity Subsidy	Food Voucher Support
No.	34	61	24	33	79	109	23	62
Total $	$9,500	$15,200	$3,200	$8,400	$4,100	$13,400	$5,300	$5,300

> *Our family has accessed the travel allowance subsidy for 16 years, approximately quarterly. This subsidy takes the edge off an expensive trip to Perth by covering both the fuel and parking costs at PCH. We are very grateful to Telethon for providing such a subsidy as it helps to make the 800km round trip more manageable financially."*

> *Without this subsidy our daughter would not have been able to join the gym. Exercise is really important for people living with Cystic Fibrosis. We are very grateful for your generous support which has had a positive impact on our child."*

Thanks to the generous support organisations of WA who have provided us with financial support, vouchers, food, tickets, gifts and prizes in 2021!

Community Connection

Connecting people in the CF community is an important part of CFWA's role. Connection helps build support networks for people with CF and their families, reducing isolation and loneliness, enhancing mental and physical wellbeing and improving the sense of security and belonging.

Online Connection

Due to the risk of cross-infection, people with CF are unable to meet face-to-face. Finding different ways to connect with others going through a similar journey can have huge emotional and mental health benefits. Social media and other online platforms have allowed people with CF and their families to connect and build online communities, enabling them to share experiences and offer support. CFWA facilitate a number of online community groups that enable people to come together and share their experiences of living with CF.

CF Talk Parents - Private Facebook Group

Our CFTalk Parents group is open to parents and grandparents of someone living with CF. The group continues to grow, and we now have 125 members, an increase of over 20 from last year. This group is a positive forum for parents and grandparents to share and offer support to each other.

125
Current members

202
Number of posts

3
Average posts per week

CF Talk Adults - Private Facebook Group

The CFTalk Adults group is specifically for adults living with CF in WA. Used for peer support, most posts are generated by the members themselves and provide an opportunity for adults with CF to share their stories and connect. The group is also a great way for CFWA to disseminate up to date information and resources directly to the community.

107
Current members

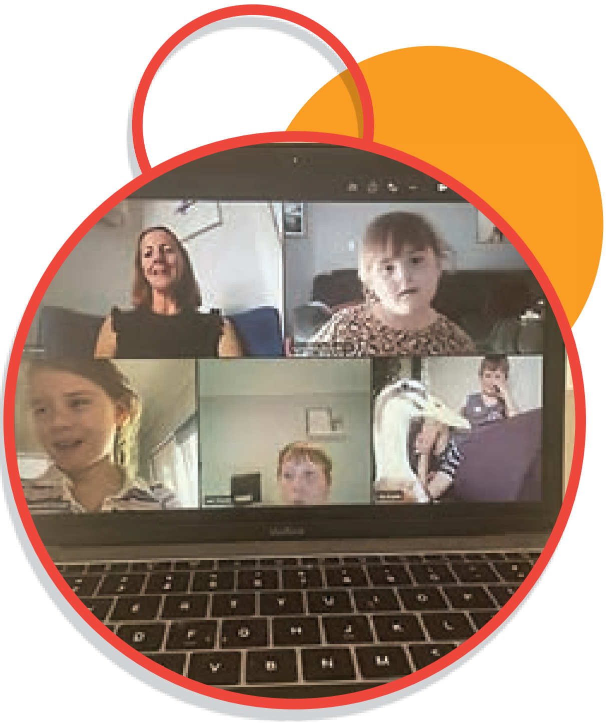
121
Number of posts

2
Average posts per week

Virtual Catch-Up for CF Kids

In 2021, we commenced a trial program to connect younger children aged 6 to 11 years in a fun and safe environment. The online program is facilitated by our Occupational Therapist and Social Worker.

The program allows kids across WA to meet other children with CF, often for the first time, and share their stories, support each other and talk about life with CF. The aim of the sessions is to build friendships and connections to reduce feelings of isolation. In each session, children are given the opportunity to do a show and tell or talk about what's been going on in their life. Questions are asked and experiences are shared in a safe and fun environment.



> *My daughter LOVED the zoom catch up; I'm so grateful for the opportunity for her to chat with other kids who know what she's going through.*

> *Wow this is so fantastic and such a vital tool to assist with peer connection.*

CFWA Youth Instagram

Our Youth Instagram page allows young people living with CF to share stories and connect up and is a great tool for CFWA to share services and supports available to this cohort. The group currently has 164 followers.

Cystic Fibrosis WA
– A space for young people with CF to connect and share in each other's journeys.
– Our instagram is monitored Mon, Weds + Thurs
linktr.ee/CFYouth

164 **Instagram CFWA Youth followers**

Community Events

CFWA facilitates face-to-face events for carers and other family members to bring people together to share stories and experiences and build communication channels which help them to feel less secluded. The events also provide a chance for everyone to unwind, take a break and enjoy some well-deserved down time. We know how important that is for the wellbeing of the whole family.

Despite some COVID restrictions, we were able to facilitate all of our annual service events; this included our Parents' Retreat, Sibling and Offspring Camp, Ladies' High Tea, Transplant Dinner, Parents & Carer's Night Out, Sib's Day Out and Grandparents' Morning Tea.

Thanks to Lotterywest and Telethon for the ongoing support for some of our key events.

...Look at all the fun we had!

CF smart
cystic fibrosis education program

School and Community Education

The CF Smart education program was developed by CFWA in 2012 and continues to expand and grow. This national resource, widely used across all states in Australia, is an educational tool used to improve the understanding of CF within the school community, enabling schools to accommodate the needs of children with CF.

It is a broad program that encompasses multimodal educational resources for schools and community groups, including online learning modules, videos and resources for teachers, schools, and families. Much of 2021 was dedicated to conducting a comprehensive review and update which involved a greater focus on the online delivery of school education.

The aim of CF Smart is to ensure that students with CF feel supported and better understood in terms of their health, education, and emotional wellbeing.

2021 Statistics

390 **Adults educated**

493 **Children educated**

41 **Educations sessions**

413 **Online modules completed**

One of our students talking to her classmates about her life with CF.

Teacher Feedback

“Made information relevant to a particular child”

“Alerted us to some unknowns which has helped inform us for student planning”

“It gives me a good understanding about CF and will assist me with supporting the student”

“Useful specific information regarding the student within the classroom in addition to general information about CF”

Health Professional Education

In 2021, CFWA delivered education to 85 health professionals working in regional WA through our metro-based Regional Respiratory Training Program and local collaborative workshops.

Access to training and educational programs provides regional health professionals with current evidence-based research and best practices. Participants are also able to network with their tertiary peers and develop communication channels and pathways for referral, ensuring regional staff feel better prepared, confident, and more supported when they return to their local communities. These training opportunities also allow our regional CF adults and families to access health care locally from health professionals who better understand their challenges and needs.

Regional Respiratory Training Program

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

> *I am a lot more knowledgeable now and feel confident in being able to access and link clients and myself to services and support.*

> *This program is great for regional nurses because we are isolated from all the city resources. Knowledge is power.*

> *Good refresher and explanation of management, useful for training staff around the hospital.*

> *Great online and in-person course. Thoroughly enjoyed and feeling more knowledgeable and confident about spirometry. Thank you.*

Collaborative Workshop

In partnership with Asthma WA, Telethon Kids Institute and other health organisations, we were able to deliver face-to-face respiratory workshops in Port Hedland, Manjimup and Bunbury, and a hands-on spirometry workshop in the Pilbara. We also participated in a pregnancy study day for midwives at King Edward Memorial Hospital with our colleagues from Perth Children's Hospital.

New Resources

In 2021, we developed a range of new resources for the CF community, using many formats, to engage our community in different ways and reach a wide audience. We developed books, factsheets, webpages, booklets and short videos.

My ABCF Book

My ABCF was created in response to a gap in current health literacy resources for young children. The story aims to give children with CF a greater understanding of how their body works, the importance of treatments, and knowing there are many other children with CF just like them.

> *I just wanted to say a heartfelt thank you to you and the team at CFWA for the gorgeous book! My ABCF is such a beautiful way to start a discussion with our kids and help them understand their condition in a simplistic yet imaginative way.*

Do Not Lick This Book - CF Edition

CFWA worked with the authors to create a special edition of Do Not Lick This Book just for the CF community. The story introduces children to the strange, unseen world of microbes with a special section about the mucus and germs that live in the lungs of people with CF.

Our Baby Has 65 Roses Book

This lovely book was published by CF Ireland. It is a beautiful story of a little boy whose baby sister has been diagnosed with CF.

Adult Nutrition Webpages

In a collaborative project with the CF dieticians at Sir Charles Gairdner Hospital (SCGH) and Fiona Stanley Hospital (FSH), we produced a new hub of nutritional information for adults living with CF. Thank you to SCGH and FSH for your support in this project.

CFWA Factsheets

Responding to demand for topical information, we produced a range of new factsheets.

Information for New Families

A booklet for families following their baby's diagnosis, prepared and reviewed with the support of Perth Children's Hospital (PCH).

CF Fact

What is a Bronchoscopy

CF Fact

CF Fact

Partners

CF Fact

For CF Carers

CF Fact

CYSTIC FIBROSIS Western Australia

CYSTIC FIBROSIS WA

Information For New Parents

CFTalk Sibling and Offspring Short Video

As part of our CFTalk short film series, we created a new video specifically for siblings and offspring. This video featured three families sharing their experiences having either a sibling or parent living with CF and the impacts this has on their lives.

CF at School Short Video

A useful tool for teachers and students in which students with CF share some of their experiences going to school.

Grants and Pro Bono Support

$83,371

donated from our Pre-tax and Christmas Appeals

$62,972

donated from individuals, workplaces and general donations

$171,824

total funding from grants

Our grants and other donations have continued to present a positive impact. Our grants this year were lower than previous years but still funded a number of specific programs that have proven beneficial to the cystic fibrosis community in WA.

Donations through our Pre-tax and Christmas Appeals, combined with regular giving and general donations, remain strong and reflect the generous nature of the CF community, both individuals and workplaces in supporting CFWA and our outcomes.

Grants

Channel 7 Telethon Trust	**$70,000**	Regional Outreach, Regional Sibling Support, Travel subsidies for regional families and Vulnerable Families Program
Lotterywest*	**$47,728 over 1 year**	Final of 4 installments for 2-year pilot program for mental health youth, sibs camp, and volunteer support
Commonwealth Bank Staff Community Fund	**$10,000**	CF Wellness Activity Programs for 2022
Stan Perron Charitable Trust	**$10,000**	Vital equipment to support children's health
CFCC	**$9,455**	CF Strong
HBF Community	**$9,091**	CF Wellness Activity Programs for 2022
City of Albany	**$5,000**	Albany Christmas Lights for Cystic Fibrosis
Stan Perron Charitable Trust	**$5,000**	Albany Christmas Lights for Cystic Fibrosis
Mediplast	**$1,650**	Regional Respiratory Training Program
Vertex Pharmaceuticals	**$1,100**	Regional Respiratory Training Program
WA Association of Mental Health	**$1,000**	Member Support Programs
Carers WA	**$800**	Member Support Programs
Viatris	**$500**	Regional Respiratory Training Program
Bird Healthcare	**$250**	Regional Respiratory Training Program
AstraZeneca	**$250**	Regional Respiratory Training Program

*Lotterywest also provided significant grant support, through The Niche Association, to CFWA and fellow tenants to ensure suitable facilities for our clients with vulnerable health and infection risks to visit safely.

Gifts-in-kind

CFWA has again been well supported by our very generous community and has received over $292,678 worth of donated gifts-in-kind (goods and services) for events and member support in 2021.

This extensive list of donations supports all aspects of our organisation, including fundraising campaigns and programs offered to the CF community. Thank you to all our supporters who donated goods or services during 2021. We would like to especially thank WAFEX for their support of 65 Roses Day for over a decade, and their donation of tens of thousands of fresh roses.

The beautiful fresh roses for 65 Roses Day are supplied by our long-term supporters, Wafex. They have donated tens of thousands of roses over the life of the event.

65 Roses Day on
Channel 7 Local News!

Our annual Cystic Fibrosis Golf Classic event is made possible with help of some very generous supporters, including Simpson Estate and Otherside Brewery, who donated their product for the event.

Fundraising Reports

Fundraising

Cystic Fibrosis WA has such an extremely passionate community that supports us time and time again, whether it's participating in an event, raising funds through a fundraiser, taking on amazing personal challenges, or making a donation. In 2021, our supporters were there again, even with the ongoing challenges from COVID. The continued support from the thousands and the performance of some key campaigns delivered a result above expectations.

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

The extension of our online campaigns delivered above budgeted results and was a focus in 2021. We also focused on our key campaigns: 65 Roses Day with the first joint traditional roses sales and the virtual rose garden, and the John Gillard Family Cystic Fibrosis Golf Classic. Our team also continued support of our large volume of community fundraisers, especially the Albany Christmas Lights for Cystic Fibrosis, who had another record year.

The top performing fundraising activity for 2021 was the John Gillard Family Cystic Fibrosis Golf Classic, raising over $163,000 net. This is the second highest amount raised – only topped by last year's record amount over its 11-year history.

After the effect of COVID on our 65 Roses Day last year, it was wonderful to see this incredibly special day back to how our community loves to see it; selling fresh roses. In 2021 we sold over 17,600 fresh roses, which is our highest amount in the history of the event. As well as selling fresh roses, the virtual rose garden had over 1,200 virtual roses planted, and combined with 65 Roses Day, raised over $119,000, which was the highest amount raised in the event's history.

Our appeals raised over $83,000 and when you combine all our amazing community fundraisers together, they raised over $142,000, a 26% increase on 2020. The standout community fundraiser again was the Albany Christmas Lights for Cystic Fibrosis, another amazing display.

2021 saw two new additions to our fundraising campaigns: The Bring it on Bridge Climb that raised over $47,000, and the hugely successful CFWA Giving Day that raised over $72,000.

Our collection tins, found in over 200 locations, also raised over $12,000; in line with last year.

Conquer Cystic Fibrosis representatives Taryn and Connor, presenting a cheque to CFWA CEO Lisa. Thank you to Conquer Cystic Fibrosis for the continued support!

870
new donors in 2021

3,421
donations received in 2021

17,600
roses sold during 65 Roses Day

1,217
virtual roses sold during 65 Roses Day in our virtual rose garden

Major Events and Campaigns

65 Roses Day

In 2021, we were delighted to bring back our traditional 65 Roses Day on Friday 28 May. The day saw our incredible volunteers take to the shopping centres in both metro and regional areas and the Perth CBD to sell roses. A record 17,600 beautiful fresh rose were sold, supplied by our long-term supporters Wafex. Our Virtual Rose Garden also returned, selling 1,217 virtual roses. We would also like to acknowledge Equiem for allowing us the use of the foyer of 240 St Georges Terrace to set up a dazzling display of giant paper roses and fresh roses. An event such as this wouldn't be possible without the support of our CF community and our dedicated volunteers. There was a very positive energy in the room on our rose wrapping day at our office in Nedlands!

The team at PCH sold roses on 65 Roses Day.

The John Gillard Family Cystic Fibrosis Golf Day

In 2021, the Golf Classic took on a new name in respect and gratitude of a wonderful long-time supporter of CFWA, John Gillard, who will be truly missed, and the amazing work the entire family have done over a decade. The John Gillard Family Golf Classic is now in its 11th year and thanks to the extremely hard-working golf committee, the attendees and sponsors, the event raised over $163,000, with $75,000 of the funds raised allocated to funding two cystic fibrosis research PhD Top Up Scholarships, and the remaining funds allocated to support programs for families affected by cystic fibrosis. There were 31 teams of four who took to the green on the day, and they were accompanied by their guests in the evening to enjoy the dinner and entertainment. The silent and live auctions were very generously supported. Our thanks go to the golf committee for once again putting on such an enjoyable and successful golf day.

Sock It 2 CF

This year, Doc was joined by Sock Jnr as we introduced our first ever children's Sock it 2 CF sock to the range. It was more than just a sock – it could be turned into a fantastic sock puppet too! Our much-loved socks launched just in time or Christmas with many being gifted throughout December. In 2021, we raised over $5,000 through sock sales.

Bring it on Bridge Climb

Thirty-seven intrepid climbers joined us for our first ever 'Bring it on Bridge Climb' of Matagarup Bridge in September 2021. Our climbers all had an amazing experience and collectively exceeded our fundraising expectations, raising a whopping $47,000 from 750 donations. We look forward to adding this challenge to our annual fundraising events calendar.

Thank you to Matagarup Zip + Climb for your support and your generous donation of $820 which was a lovely surprise to receive on the day.

Bridge Climb photos taken by Matagarup Zip + Climb.

Giving Day

In December, we launched our first ever Matched Giving Day. With the help of our incredible community, we achieved our goal and much more! We're pleased to announce our first Giving Day raised $72,033! Thank you to our community for donating and our generous matched givers: Calibre Robe Valley Sustaining Project, Philippa and Daniel Craigue, and an anonymous donor. By 10:30am we had reached our original goal of $40,000, our bonus goal of $60,000 by 12:30pm, and our final goal of $70,000 later in the afternoon. Without the generosity of our community, our first ever CFWA Giving Day would not have been possible or as successful as it was.

Community Fundraising

Our community support remained strong in 2021, despite the continued challenges hosting events and fundraisers with COVID.

Community Fundraising

Our wonderful community came together again in 2021 to host some incredible fundraisers throughout the year. Kate Spaapen and her family held their annual Serve It Up dinner parties throughout May raising over $4,000.

$4,000+

raised by Kate Spaapen and her family

65 Roses Challenge

Once again, our CF community took up the challenge, whether that was 65 burpees a day for a month, running, cycling or walking 65km throughout the month of May, running a marathon for the first time, tackling the Cape to Cape trek, or any other challenge to get our community out of their comfort zone – they did it! Owen Fretwell ran his first marathon in 2021 and raised $3,000 for cystic fibrosis to honour his friend.

$3,000

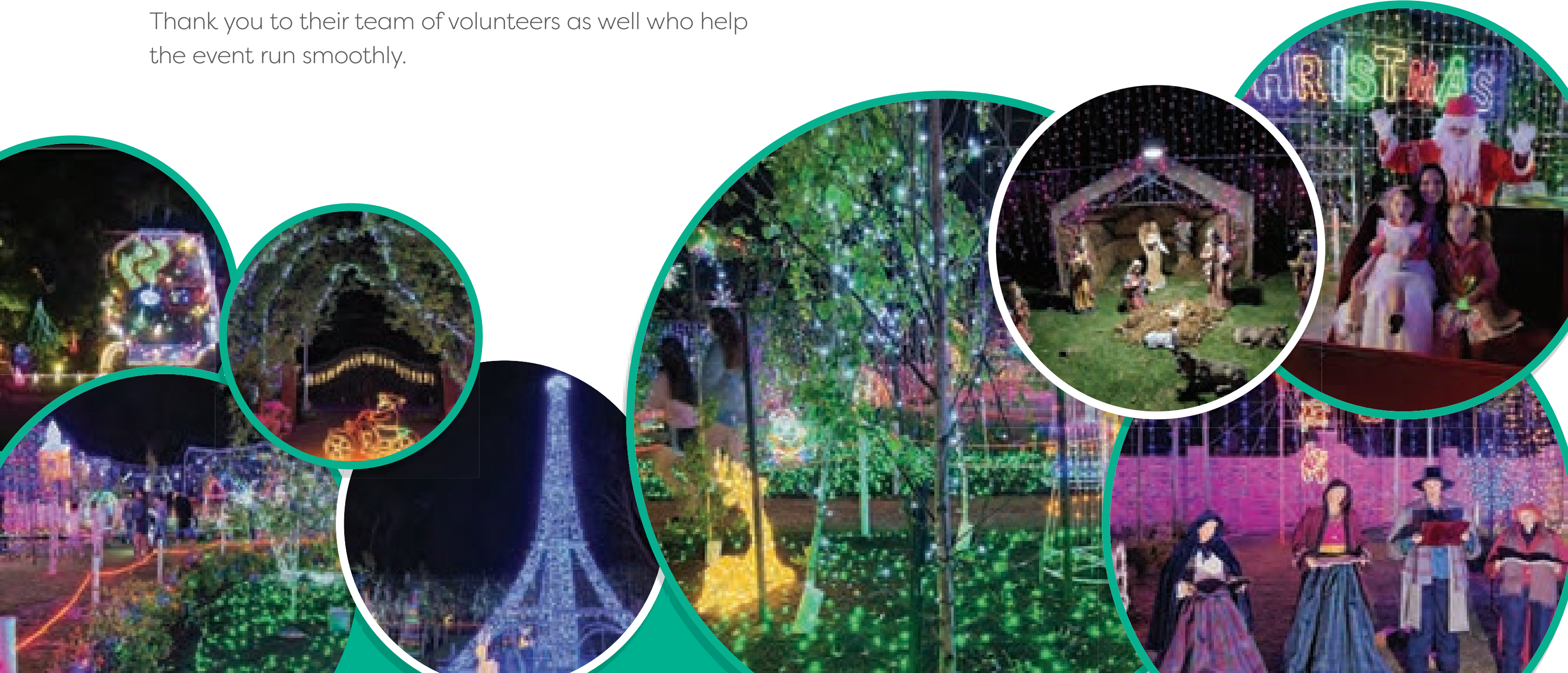
raised by Owen Fretwell to honour his friend

Albany Christmas Lights

The year ended on a high with community fundraisers Lorraine and Jeremy Stevenson once again hosting their magical Albany Christmas Lights. They shared the spirit of Christmas with families travelling to Albany from far and wide to witness the dazzling lights display at their property. Over 23 nights in December they raised over $53,000 to support families affected by cystic fibrosis and raise much-needed awareness. Thank you to their team of volunteers as well who help the event run smoothly.

$53,000+

raised by Lorraine and Jeremy Stevenson



Sponsors and Supporters

Supporter Community

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

Award	Recipient
Fundraiser of the Year	Albany Christmas Lights Team
Supporter of the Year	Anthony Kicic - Telethon Kids Institute
Volunteer of the Year	Chris Brambleby
Long Service	George and Penny Jones
Long Service	Trident Insurance Group
Lappa 65 Roses Spirit	Jackie Fraser

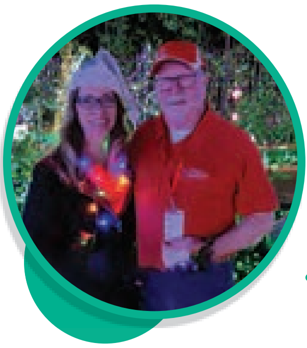
Anthony Kicic
Supporter of the Year

Chris Brambleby
Volunteer of the Year

Trident Insurance Group
Long Service

Jackie Fraser
Lappa 65 Roses Spirit

George & Penny Jones
Long Service



Albany Christmas
Lights Team
Fundraiser of the Year

Ambassadors and Community Representatives

During 2021, we were fortunate to have several CF families and individuals share their stories in the media during May – the national month of awareness for CF – and throughout the year. The stories they told gave the wider community an understanding of the unique journeys, challenges, and triumphs of having CF as part of their lives.

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

Sarah and Charlotte Potts

'No isn't an option and can't doesn't exist' is Charlotte Pott's family mantra says mum Sarah.

Charlotte, who is now 6-years old, was born with cystic fibrosis. Charlotte and her family shared their story as part of our Sock it 2 CF campaign this year.

Like any other 6-year olds, Charlotte loves playing with her school friends and older brother, singing and dancing, running around and being a silly sausage.

'Cystic Fibrosis WA provides essential support services to our family and families just like ours, which help us to overcome the obstacles related to this life-threatening illness.'

'Despite the daily challenges, we try very hard to ensure nothing holds Charlotte back from having a fun childhood filled with opportunities. No isn't an option and can't doesn't exist.'

Marlene and Charlie Blackwood

Charlie Blackwood's mum and dad's lives changed forever on 19 January when their beautiful boy was born and flown to Perth for emergency surgery at only 28-hours old. Over the next two months of Charlie's life, they spent seven and a half weeks at Perth Children's Hospital recovering from two major surgeries.

'Throughout this journey, we have been so grateful to receive support from Cystic Fibrosis WA. They provide emotional and financial support for families just like ours and continue to advocate for the cystic fibrosis community.'

Marlene Blackwood shared her family's story to support our first Matched Giving Day.

Volunteers

Volunteers are integral to all facets of our organisation from volunteering in the office packing hospital packs or merchandise packs, to collecting tins, selling roses, assisting at our fundraising events, or supporting us virtually by sharing our campaigns – we couldn't do what we do without them. 2021 was no different and we are incredibly grateful to each and every one of our volunteers for giving up their time and so enthusiastically embracing every volunteer opportunity.

On behalf of the CFWA team and CF community, we would like to acknowledge the ongoing support received from South Metropolitan TAFE who play such an integral part in the 65 Roses Day campaign. A special thank you to lecturers Kylie-Anne Stokes and Elissa Pietras who coordinate the TAFE students and contribute hugely to the campaign.

We would like to thank the John Curtin Leadership Academy (JCLA) students for volunteering their time to help plan and promote the first Bring it on Bridge Climb and then also volunteer their time on the day. Since they had such a rewarding experience, they also came back to volunteer at our Golf Classic, too!

After actively and passionately spreading collection tins across the Perth metro area for the past five years, our incredible volunteer Chris Brambleby retired in November 2021. Chris was a welcome face to many business owners across Perth while collecting tins, and he always greeted everyone with a big smile. We are so grateful for his invaluable contribution to Cystic Fibrosis WA and his willingness to lend a hand with whatever task he was given. We wish Chris well in his retirement.

Volunteering

Type	Number	Hours
65 Roses Day Campaign	230	Over 1,200
General Support	5	732
Bring it on Bridge Climb	10	68
Golf Classic	34	224
Albany Christmas Lights	64	2,490
Ladies' High Tea	3	15
Sibs Camp	3	75
Board	10	Over 250
Internships	1	37

In late 2021, we welcomed three new office support volunteers to the CFWA team including Ron Gray (Collection Tin program), Ingrid Zuijdgeest (Grants), and Farhan Ahmed (CRM assistance). We are truly grateful for the support each of these volunteers provided to our team, and the amazing results they delivered in 2021.

Communications Reports

Communications and Media

Communication proved key to keeping on top of emerging issues and best supporting CF adults and families during 2021.

The importance of our communications, particularly our online channels, was reinforced in 2021 with another year navigating WA's COVID restrictions.

We focused on providing timely, accurate information to our community in the often quickly changing landscape, working with stakeholders in WA health and the tertiary hospitals to share key messages. Thank you particularly to the teams at Sir Charles Gairdner Hospital, Perth Children's Hospital and Fiona Stanley Hospital for your continued commitment to sharing you information and processes with us to distribute to the community.

Our website was shown to be an important resource for the community in 2021, with a 20% increase in traffic over the previous year.

We continued to refine our message delivery with our social media channels catering to specific groups. These groups – for adults, parents and carers, and young people – are meeting the community where they are, delivering timely, relevant information just for them.

Communication Channels

CFWA Website	Facebook	Instagram	E-Newsletter	RED Magazine
36,481 Visitors	**4,765 Followers**	**1,413 Followers**	**3,224 Readers**	**752 Readers**

Big Engagement in 2021

CF at School Video

The introduction of our new "CF at School" video and resources obviously resonated with the community!

13,986 views

928 reactions

128 comments

99 shares

Optus Stadium for 65 Roses Day

Optus Stadium lit up red for 65 Roses Day and created a lot of interest.

10,011 views

573 reactions

22 comments

87 shares

Mel’s story in the West Australian

The CF community responded well to Mel’s story about her transformation after starting Trifakta™ in the West Australian

7,811 views

378 reactions

65 comments

73 shares

Media

In 2021, we engaged PR firm Devahasdin for promotion of our 65 Roses Day campaign and other key campaigns throughout the year. While 65 Roses Day is a major fundraiser for CFWA, it is also our best opportunity each year to raise awareness of CF in the wider community.

Media coverage was strong in 2021, with a circulation reach of just under 7 million and PR value of over $1 million achieved.

Digital	Print	Radio	TV	Total
49	13	6	4	72

Board and Governance

The CFWA board comprises several highly qualified directors, each bringing technical expertise, life skills and passion to their role. The board has a wide range of responsibilities which include:

- ✓ Setting and reviewing CFWA's strategic direction for service provision and research
- ✓ Approving strategic and business plans and budgets
- ✓ Ensuring compliance with contractual and statutory obligations
- ✓ Approving the annual audited accounts
- ✓ Monitoring operations and financial performance
- ✓ Setting risk policy and overseeing risk management

President

Carolyn Boyd

Carolyn lives with CF and underwent a double lung transplant in 1994. She brings a wealth of experience to her role and is a regular speaker, fundraiser and advocate. Carolyn joined the board of CFWA in 2010 and was elected as vice president in 2017 and President in 2018.

Vice President from July 2021

Damien O'Reilly

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

Treasurer from October 2020

Sally Rose

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

2021 Board Members

Board Member

Feliciano Sanchez

Feliciano is an executive level engineer and father of a young woman with CF. Having joined the board in 2006, he has held both the President and Vice President positions and is currently a special skills director on the board of CFA.

Board Member

Amanda Bearcroft

Amanda joined the board in June 2021. Amanda lives with CF and was born in an era when CF treatments were minimal. She is a passionate advocate for the CF Community, sitting on a variety of CF and Respiratory Committees. Amanda brings to CFWA a personal perspective around CF and provides experience with CF patients, family, and partners.

Board Member

Rowena Smith

Rowena joined the board in October 2021. Rowena is a master's qualified Human Resources professional with 19 years' experience in strategic HR. Her background is in talent strategy, workplace culture, employer brand development and performance optimisation. She has strong ties to the CF community as the aunt of a young niece living with cystic fibrosis.

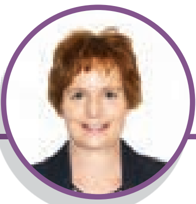
Retired

Judith Mahony

Retired from her role as a board member in June 2021.

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

Retired



Rachael Hosking

Retired from her role as Vice President in June 2021.

Rachael us a senior lawyer and the parent of a young man with CF. She first joined the board in 2006.

Retired

Kenny Paterson

Retired from his role as a board member in July 2021.

Kenny is a specialist in business development, strategy formulation and implementaion, commercial developments, marketing and operations.

Treasurer's Report 2021

CFWA's 2021 financial reports reflect a strong profit result. Our financial performance continues to be well managed to ensure ongoing sustainability of services to people with CF, their families and carers.

CFWA delivered a profit of just over **$227,000** on a turnover just over **$2.6M** in 2021, against a budgeted profit of **$63,000** on a budgeted turnover of **$2.6M**.

This result can primarily be attributed to:

- An ongoing focus on ensuring revenue continuity through effective contract management, securing grants and fundraising growth.
- A deliberate focus on containing costs to provide for future contingencies, particularly given the Health Department of WA (HDWA) undertook a major review of our contract in 2021. Fortunately in late December 2021, a new contract with HDWA was secured for the next 3 years.
- Funds from the Commonwealth Government's JobKeeper wage subsidy initiative, developed to support businesses during the pandemic, received in the first quarter of the year.
- A **$64,000** increase in the fair value of our investment portfolio which, under accounting standard AASB 9, has to be recognised in the income statement even though it is not yet realised.

2021 marked the eleventh anniversary of the event, which raised over **$163,000**. **$75,000** of the funds raised was allocated to research PhD Top Up Scholarships and project grants, and the remaining funds allocated to support programs for families affected by cystic fibrosis.

The level of cash generated and accessibility of funds in the year is of particular importance to the association in ensuring sustainable and continual delivery of services to its members. Despite the challenges experienced through the COVID-19 pandemic, CFWA increased the level of funds held as investments at year end, being **$1.2M**, up from **$1.1M** at the end of 2020.

I am therefore pleased to report the finances of the association continued to be managed in a manner which supports the objectives of CFWA and provides a solid foundation for 2022.

A detailed income statement and balance sheet is provided in the accounts. Financial statements are regularly reviewed by both management and the board to ensure the costs of running the association and delivering services are properly measured and managed in line with revenue raised.

The financial statements for the year ended 31 December 2021 have been audited by Mr James Komninos of RSM Australia Pty Ltd and a copy of the signed accounts are available for inspection by members on the ACNC website. An extract of the financial statements has been included in this report.

In preparing this report I would like to acknowledge the efforts of the CFWA team who have supported me in the conduct of my duties and for their unwavering support for the association and its members.

Sally Rose

Sally Rose
Treasurer

Financials

Balance Sheet
as at 31 Dec 2021

	2021 **$**	**2020** **$**
CURRENT ASSETS		
Cash and cash equivalents	1,015,632	1,008,112
Financial assets	201,281	146,486
Trade and other receivables	8,504	84,519
Inventories	5,825	7,053
Other current assets	42,286	34,438
TOTAL CURRENT ASSETS	**1,273,528**	**1,280,608**
NON-CURRENT ASSETS		
Financial assets	1,193,753	1,090,791
Plant and equipment	302,136	344,825
TOTAL NON-CURRENT ASSETS	1,495,889	1,435,616
TOTAL ASSETS	**2,769,417**	**2,716,224**
CURRENT LIABILITIES		
Trade and other payables	436,544	547,844
Provisions	298,228	378,933
TOTAL CURRENT LIABILITIES	**734,772**	**926,777**
NON-CURRENT LIABILITIES		
Provisions	38,815	20,950
TOTAL NON-CURRENT LIABILITIES	**38,815**	**20,950**
TOTAL LIABILITIES	**773,587**	**947,727**
NET ASSETS	**1,995,830**	**1,768,497**
MEMBERS' FUNDS		
Accumulated surplus		
Accumulated surplus – restricted	20,000	10,000
Accumulated surplus – designated	84,249	100,000
Accumulated surplus – discretionary	232,531	163,243
Accumulated surplus – unrestricted	1,659,050	1,495,254
	1,995,830	**1,768,497**
TOTAL EQUITY	**1,995,830**	**1,768,497**

Income Statement
for year ended 31 Dec 2021

	2021 $	2020 $
Revenue	2,634,276	2,507,982
Cost of sales	(27,947)	(14,812)
Employee benefits expense	(1,382,399)	(1,436,127)
Depreciation	(17,314)	(19,035)
Motor vehicle expense	(11,057)	(10,903)
Insurance expenses	(46,743)	(38,970)
Other expenses	(893,639)	(868,450)
Operating Surplus/(Loss) for the year	**255,177**	**119,685**
Office refurbishment depreciation	(27,844)	(27,844)
Total Surplus for the year	**227,333**	**91,841**
Accumulated surplus at the beginning of the year	1,768,497	1,676,656
Transfer to accumulated surplus	-	-
Surplus allocated to:	-	-
Restricted funds	10,000	-
Designated funds	(15,751)	50,000
Discretionary funds	69,288	88,243
Unrestricted funds	163,796	(46,402)
	227,333	**91,841**
Accumulated surplus at the end of the year	**1,995,830**	**1,768,497**

Our Supporters and Sponsors

Thank you to our major supporters and sponsors for 2021!

Government of **Western Australia**
Department of **Health**

lotterywest
supported

CELEBRATING 50 YEARS
telethon
7

STAN PERRON
CHARITABLE
FOUNDATION

Wafex
World's Finest Flowers

HERBERT
SMITH
FREEHILLS

Perth
Children's
Hospital

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

FIONA
STANLEY
hospital

TELETHON
KIDS
INSTITUTE
Discover. Prevent. Cure.

Air Liquide

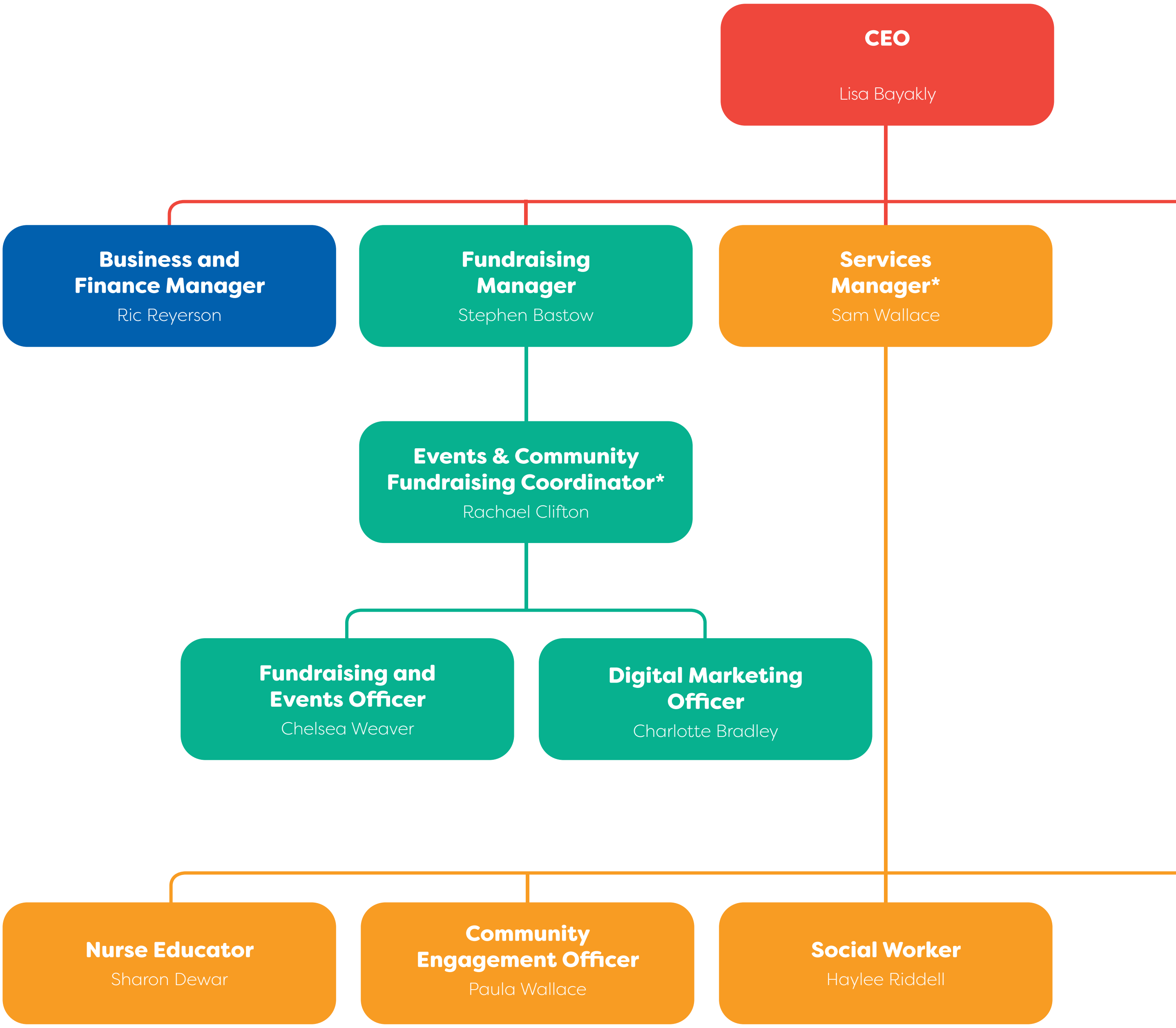
FOOD
BANK
25 YEARS

rrt RAPID
RELIEF
TEAM

Special Children's
CHRISTMAS PARTY

TAFE
WA
South
Metropolitan

Organisation Chart 2021



CEO
Lisa Bayakly

Business and Finance Manager
Ric Reyerson

Fundraising Manager
Stephen Bastow

Services Manager*
Sam Wallace

Events & Community Fundraising Coordinator*
Rachael Clifton

Fundraising and Events Officer
Chelsea Weaver

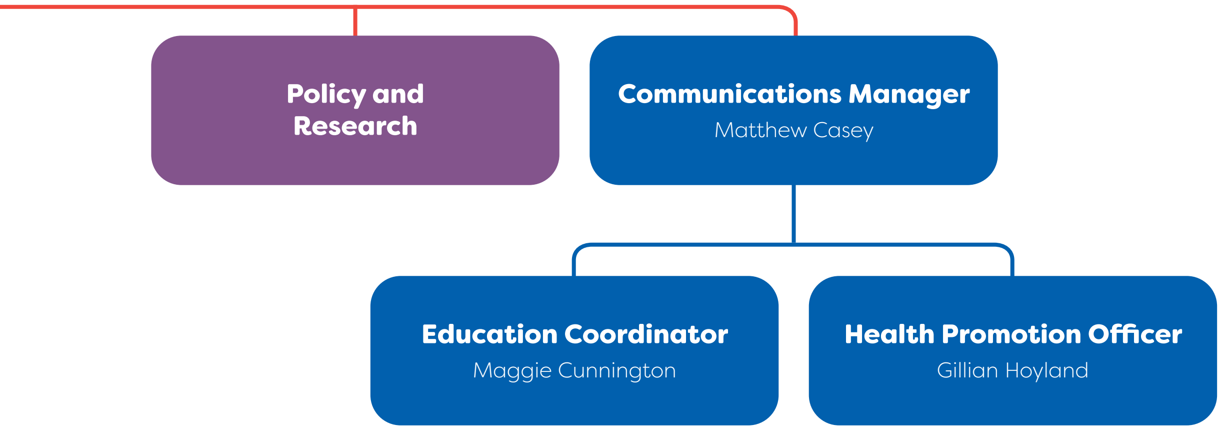
Digital Marketing Officer
Charlotte Bradley

Nurse Educator
Sharon Dewar

Community Engagement Officer
Paula Wallace

Social Worker
Haylee Riddell

CYSTIC FIBROSIS Western Australia

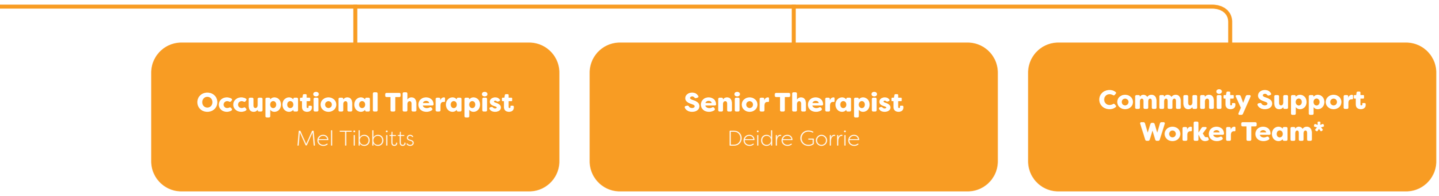


Policy and Research

Communications Manager
Matthew Casey

Education Coordinator
Maggie Cunnington

Health Promotion Officer
Gillian Hoyland



Occupational Therapist
Mel Tibbitts

Senior Therapist
Deidre Gorrie

Community Support Worker Team*

*Services Manager: Kathryn Pekin left this role in August 2021

*Events & Community Fundraising Coordinator: Marnie Thomson left this role in August 2021.

*Community Support Worker Team: Our Community Support Worker Team provide in home support across the Perth metro area.

CYSTIC
FIBROSIS
Western Australia

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

The Niche, Suite C
11 Aberdare Rd
Nedlands WA 6009

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

www.cfwa.org.au