2022

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ANNUAL REPORT

FOR THE FINANCIAL YEAR 1 JAN 2022 - 31 DEC 2022



CYSTIC FIBROSIS TASMANIA INC. 2022 ANNUAL REPORT

(Financial Year: 1 January 2022 - 31 December 2022)

Table of Contents

Organisation Details	3
Office Bearers 2022	3
Staff	3
Accounts Review	3
President's Report	4
Chief Executive Officer's Report	6
Treasurer's report	9
2022 Snapshot of Income	. 10
2022 Snapshot of Member Services	6
The History of CF Tasmania	. 14
CF population in Tasmania	. 14
Overview of services provided by CF Tasmania	. 17
Member Services	. 18
Fundraising Activities	. 23
Grants	. 26
Major donations & bequests	. 26
Social media	. 27
Financial statements	. 29

Organisation Details

Cystic Fibrosis Tasmania Inc.

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Email:	<u>general@cftas.org.au</u>
Website:	cysticfibrosis.org.au/tas

Office Bearers 2022

Scott Lancaster
Judi McGee
Steph Apted
Eva Ewe
Judi McGee

Staff

Paula Wriedt Chief Executive Officer 2 days per week

Jes Jackson Events & Fundraising Officer 2 days per week

Janet van Dongen Administration & Member Services Officer 2 days per week

Accounts Review

Bentleys Tasmania Audit Pty Ltd 2nd Floor, 39 Sandy Bay Road HOBART TAS 7000

President's Report

The Cystic Fibrosis Transmembrane Regulator (CFTR) gene that causes Cystic Fibrosis (CF) was discovered in 1989. At the time, the discovery was held to offer great promise for developing treatments that would target the cause of CF rather than just treating its symptoms.

So, when our daughter was born some ten years later and diagnosed with CF, my wife and I, our extended families and our friends lived in the hope that a breakthrough in treating CF might be imminent. And after 22 years of waiting, that imminent breakthrough arrived.

2022 was the year when Trikafta became available in Australia for people with at least one copy of the F508del mutation (provided you were aged 12 or over). Listing Trikafta on the Pharmaceutical Benefits Scheme (PBS) was one of the last acts of the former Liberal Federal Government before the last Federal Election was called. It is a decision for which I will forever be grateful. It's also tremendous to see that the 'new' Labor Government has continued to answer the needs of Australians with CF, recently announcing that from 1st May 2023 Trikafta will be subsidised on the PBS for 6-11 year-olds who have at least one F508del mutation.

The arrival of Trikafta does appear to be a game-changer. I read a story about an 11 year-old girl in Victoria who had been granted access to Trikafta on compassionate grounds and after two weeks on the medication she was literally doing cartwheels. I imagine her parents were too, even if only in spirit.

We must stop and smell the roses and celebrate that this life-changing therapy is now available at a reasonable cost. We should also recognise the part that Cystic Fibrosis Australia and organisations like CF Tasmania, not to mention our members, played in getting Trikafta listed on the PBS. It is a fantastic example of what the CF community can achieve when we work together.

While this is all tremendously positive, not everyone in Australia with CF can benefit from Trikafta. We cannot rest until everyone in this country has access to effective therapies. This includes people with rare mutations and those who do not respond to, or can't tolerate, gene modulators. And even then, our work is unlikely to be done.

Interestingly, 2022 was also the year that government-imposed COVID restrictions were eased, most Australians stopped wearing face masks and many became complacent about the risks that COVID still poses. And yet the vast majority of Australia's COVID-19 related deaths to date occurred in 2022.

Trikafta is not a cure. People with CF still face significant challenges and CFT will be ready to support them. Despite recent advances in treating CF, we will not become complacent about the risks that CF still poses. Our services may evolve as the needs and expectations of people with CF change. But we will continue to serve and advocate for people in Tasmania with CF as long as we are needed.

With that in mind, it is pleasing to note that, measured purely in dollar terms, CFT provided more member support services in 2022 than ever before. Whether through the CF Healthy You program, the Little Day Out program that's now open to children and adults with CF alike, or the ongoing provision of free nebuliser pumps, the demand for services has never been stronger.

On average, in 2022 we provided just over \$900 in services per member, not including the costs of delivering those services or the value of things like CFT's advocacy work. And on top of that, in response to some unexpected financial headwinds affecting CF Australia, we provided an additional contribution of \$9,000 to fund CFA's advocacy in 2022 (on top of the \$3,500 we expected to pay). That we were able to do all this and operate at a small deficit (just over \$5,000), which followed a modest surplus in the previous year, is another cause for celebration. Thank you to our Chief Executive Officer, Paula Wriedt, the part-time staff in the CFT office, our volunteers, Committee members, sponsors and growing supporter base for making all of this possible.

I do, however, have to conclude on a sad note. In 2022, we lost the vibrant Toni Miles-Bennett to her CF and our former CFT Committee member and CF Australia board nominee Sean Collins also passed away unexpectedly. Both were fun-loving, inspirational and caring individuals taken from us before their time. I will always be grateful for having known them and for their service to the CF community. It is one of the gifts that my involvement with the CF community has brought me over the years – the remarkable people I have had the privilege to meet and get to know.

Live long and prosper.

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Scott Lancaster President

COMMITTEE MEETINGS ATTENDED (1.1.2022 – 31.12.2022)

Board Member	Eligible meetings	Meetings Attended
Scott Lancaster	4	4
Judi McGee	4	4
Bridget Caplice	4	4
Sam Fox	4	2
Nicole Bryant	2	2
Eva Ewe	4	2
Emily Stride	4	2
Donna Emery	4	2
Steph Apted	3	3
James Kleinig	4	3
Lynden Leppard	3	3

2022 Snapshot of Member Services



Chief Executive Officer's Report

Some events of last year caused me to reflect on why I continue to work hard for the Tasmanian CF community, even while juggling multiple other commitments.

Last year was one of our most successful years ever for fundraising, bringing together hundreds of our supporters and volunteers and creating new records. The 65 for CF Challenge eclipsed all previous challenges, raising a staggering amount of \$81,434. Yet another record was set for the 65 Roses Ladies Lunch. We held our regular events like the high tea and quiz and were the beneficiaries of several community fundraising activities.

All of this excites me because the additional funds we raised through these activities enabled us to spend even more money on member services and programs. Thanks to the phenomenal success of the 65 for CF fundraising, Bucket of Sparkles was added to our suite of programs. This is just a small way that we were able to bring a little extra to our members.

I'm also proud that we support our community to maintain their physical well-being through fitness equipment, gym memberships and sports registrations. Our members are increasingly taking up these options. But I know that looking after our mental health is also vital. So we continue to increase our focus on this area with our CF Healthy You program and offer free counselling support for members and their loved ones.

In the middle of 2022, members of the CF Federation adopted a new tagline, "Embracing Tomorrow". This statement reflects a promise to our communities that we provide care, regardless of their tomorrow, recognising that everyone's journey is different. It reflects that with improvements in drug therapies and treatments, the services we provide in the future may need to change. Importantly, we see it as a reflection of powerful stories of fully lived experiences, the resilience of our communities and a statement of hope for the future.

As we provide all of this member support, I realise how rewarding my role within this organisation continues to be. Knowing that a program we've developed has put a smile on a member's face, or has helped ease someone's financial challenges, is why I continue to strive to do my best for our community.

But sadly, 2022 also showed me personally the dark side of CF. In early November 2022, Toni Miles-Bennett lost her hard-fought battle with CF at the age of 51 years. It was only in last year's annual report that I wrote how one of my highlights in 2021 had been helping her celebrate turning 50 while we drank champagne and watched the sunrise from the top of Mt Wellington/kunanyi.

Everything about CF that I learned in my early days in the role, I learned from Toni. When I was the lone employee, she offered to volunteer, and we quickly became friends. She was one of the strongest and brightest people I had ever met, and she didn't let CF define her in any way. She made me laugh – a lot. She taught me so much about not sweating the small stuff, resilience, and a positive attitude. Now it's her memory that motivates me to work for our members – to provide programs,

advocacy, and raise awareness. And, importantly, as our new "tagline" says, her memory reminds me to continue "embracing tomorrow".

With two new team members starting in the CFT office just before Christmas, Jes Jackson (Events and Fundraising Officer) and Janet (Admin and Member Services Officer), we are more determined than ever to continue to work hard for our community. But we cannot do it alone – we may be a fierce and committed team, but we are only a small one compared to the number of paid staff at other charities. So we continue to rely on the many volunteers throughout the year to help us achieve our goals.

Thank you to the Committee members of CFT who volunteer time in their hectic lives to take part in meetings, planning days and taking on various activities to further our aims. Your contributions are all greatly appreciated.

I would also be remiss not to acknowledge Steph Apted and the tremendous work she contributed to CFT's successful fundraising activities throughout 2022. Our various events have many volunteers who contribute in different ways – seeking donations, setting up, brainstorming ideas, connecting us with sponsors and much more. Each volunteer is invaluable to us, and we can't thank you enough.

Finally, my thanks to all of the members of the CF community from throughout Tasmania. Thank you for responding to our calls to sign petitions, getting involved in our events, and being prepared to share your stories to advocate for improvements. I feel incredibly honoured to be part of the various journeys that you and your loved ones are on with CF and the trust you place in our organisations.

Here's hoping that 2023 is just as successful for CFT as we continue to care for our Tasmanian CF community whilst "embracing tomorrow".

Kind regards,

Paula Wriedt

Paula Wriedt Chief Executive Officer



Embracing Tomorrow

"Embracing Tomorrow" is a statement that reflects a promise to our communities that we provide care, regardless of what their tomorrow holds, recognising that everyone's journey is different. It reflects that with improvements in drug therapies and treatments, the services we provide in the future may need to change. Importantly, we see it as a reflection of powerful stories of fully lived experiences, the resilience of our communities and a statement of hope for the future.

Treasurer's Report

The 2022 financial year was a good year overall, with our financial performance at a close to breakeven position. Fundraising efforts through the 65 Roses Challenge produced a staggering result of \$81,434 for the year; this is a 77% increase compared to 2021's 65 Roses Challenge fundraising. In 2022, CFT received multiple grants from Hydro Tasmania, Bulk Nutrients, Harcourts Foundation and Commonwealth Bank to fund member services. Income from other fundraisers and events were steady in the year. Operationally, expenditure was also comparable to 2021.

We should however positively report that there was an increase in member services' spending. This is in line with the Committee's aim to increase awareness and access amongst members of services offered by CFT. An additional levy was also made to Cystic Fibrosis Australia (CFA) in 2022 and was deemed appropriate due to the role CFA plays in advocacy. Members' and the community's continued support of CFT's fundraisers and events have been vital in CFT's continued sustainability and delivery of services. We look forward to the success of fundraisers and events, and the increased delivery of services in the 2023 year.

Kind regards,

Eva Ewe Treasurer

2022 Snapshot of Income

and grants. This is a snapshot from 2022



Committee Members 2022

Scott Lancaster, President

Scott joined the Committee of CF Tasmania in 2001 after his first child was born with CF in 1999. Since then, he has served as the Association's Secretary, published its newsletter and spent a year as Treasurer. He became President in April 2010. In addition to holding a Bachelor of Business, Scott was a Graduate Member of the Australian Institute of Company Directors, having completed a Company Directors' Diploma in 2007.

He has also been a member of the Board of Management at Glenview Community Services, an aged-care provider in Hobart's northern suburbs, since October 2008. He served as a Director of Connect Financial before its merger with the Island State Credit Union. Scott currently works for TasNetworks as a Senior Regulatory Analyst. Scott was awarded a Life Membership of CFT in November 2018.

Judi McGee, Vice President & Public Officer

Judi's involvement with CF began when her first son, Aaron Mackrill, was born with CF in 1980. Living in Perth, Tasmania, Judi has been on the Committee since 2007 and has served as the Association's Vice President since 2009 as its Secretary and Public Officer. Judi has organised many events for CFT in Northern Tasmania, most notably the extremely popular annual 65 Roses High Tea, and she offers invaluable support to member families in the area.

After Aaron died in 2010, Judi worked with CFT to establish a scholarship fund in his name to help others with CF undertake tertiary education. She is passionate about increasing CF awareness, supporting CFT members and maintaining an active role on the CFT Committee. Judi received a Life Membership of CFT in May 2019.

Stephanie Apted, Secretary

Steph started her career in retail while at University, working as a Multi-Site Store Manager before moving into the HR field in 2020 following the completion of her degree. Steph is a long-time supporter of CFT and was inspired to get involved after her cousin was diagnosed with CF when she was a baby.

Over the past six years, Steph has been instrumental in organising many significant fundraising events for CFT, including numerous lunches, balls and other activities. After finishing University and while waiting to take up her graduate role at TasNetworks, Steph took on the role of CFT's Administrative Assistant from June 2019 to February 2020. Steph is currently a Safety and Well-being Partner at TasNetworks. She joined the Committee to CFT to further her involvement with the organisation and learn above governance and boards.

Eva Ewe, Treasurer

Eva Ewe has a Bachelor of Law and Masters of Professional Accounting from the University of Tasmania. Eva is currently a Senior Accountant at Accru Hobart. Eva qualified as a Charted Accountant in 2015. Eva volunteered to join CF Tasmania's Committee as part of her desire to be involved with the local community and to utilise the experience gained from the accounting industry. Eva has been CF Tasmania's Treasurer since 2017.

Bridget Caplice

Bridget joined the Committee of Cystic Fibrosis Tasmania in October 2014 after being friends with someone who sadly lost her battle with CF several years ago. Bridget has a Bachelor of Business and Bachelor of Laws from UTAS and has previously worked as a lawyer at a private Hobart law firm, Worrall Lawyers. Bridget now works within the State Government in the Department of Premier and Cabinet.

Donna Emery

Donna Emery is an Administration Support Officer with the Office of the Education Registrar and has worked there since 2016. She is married with two children, Luke, 16, who has CF and Gabby, 13.

Donna has been a member of CFT since Luke was a baby (about 15 years) and has been an avid fundraiser for the last 14 years. She has been on every Launceston Ladies High Tea organising committee for the past ten years and helped with 65 Roses collection days in May, amongst other fundraisers.

Donna has also been involved with advocating for a new medication for CF with trips to Canberra and NSW with CFA to meet with members of the Prime Minister's office and with the PM himself. Donna has been on the Committee of Cystic Fibrosis Tasmania since 2018.

Sam Fox

Sam has a Bachelor of Human Movement degree (teaching) with a double major in Outdoor Education and Sport Science. Sam has worked as a high school and college teacher for 22 years. She is currently a principal across several schools in the Derwent District. Sam lives in Hobart with her husband Chris and their two children, Harriet (6) and Scarlett (9), who has Cystic Fibrosis.

Sam has been a member of the Cystic Fibrosis Tasmania Board since 2015. She has also been involved in campaigning with CFA, including the successful Kalydeco campaign.

Sam's enjoyments include travelling, racing road and mountain bikes, white water kayaking, rafting and being in the mountains, whether bushwalking, skiing or snowboarding. Her latest passion now comes from introducing Scarlett and Harriet to each of these opportunities and being involved in the advocacy and increasing awareness of Cystic Fibrosis.

James Kleinig

James is an adult with CF who moved to Tasmania in 2014. He is a qualified Jeweller and enjoys the challenges of designing beautiful pieces. Although having a busy work and home life - with three boys under twelve years of age - James joined the Committee of CFT to use his experiences to contribute to decisions that would benefit others living with the condition.

Outside work, he has been involved in his children's School Community Association. James joined the CFT Committee in April 2020.

Lynden Leppard

For over 35 years, Lynden worked as a teacher and school Principal and held various senior roles within the Tasmanian Department of Education, including in curriculum design and professional development. He has a Bachelor of Arts, Diploma and Masters of Education and a Doctorate of Education (EdD) in complex systems' ethical decision-making.

For the past three years, Lynden has been employed as a Senior Policy Officer with the Local Government Association of Tasmania, focusing on community health and well-being.

Lynden developed an understanding of CF as a chronic and life-shortening condition following the birth of his great-niece, Charlotte, in late 2009. Lynden has extensive board experience with various organisations within the community and arts sector.

Emily Stride

Emily has over 17 years of experience in Recruitment, Business Development, Human Resources Project and People Management and holds qualifications in Human Resources and Business Management. Emily currently works for the Department of Health and Human Services. She is a key lead in developing and delivering a Culture Improvement Program for the Department and other Human Resource strategy projects.

Before this, Emily worked for over 13 Years in key senior management roles with Searson Buck, leading various southern and state-wide recruitment teams in temporary and permanent recruitment. Most recently, Emily worked as Strategic Project Lead and Client Engagement Manager and was responsible for the facilitation and delivery of complex HR and workforce development projects for various State Government Departments.

Emily's experience includes working with the Salvation Army Employment Plus, the Office of the Ombudsman and The Anti-Discrimination Tribunal. Emily lives in South Arm with her husband Josh and is mum to 9 1/2-year-old Lottie, who has Cystic Fibrosis, and seven-year-old Sullivan.

The History of CF Tasmania

Cystic Fibrosis Tasmania (CFT) was established as an incorporated association in 1995 and is a registered charity with deductible gift recipient status. CFT receives no ongoing financial support from the government, relying on its fundraising efforts and the wider community's generosity.

CFT is a volunteer-led not-for-profit organisation governed by a voluntary board (of up to ten members). The Committee comprises people from various professional backgrounds, including people with CF and parents of children with CF.

The Committee is elected each year at the Association's Annual General Meeting. General Committee meetings are held quarterly, with special board meetings as required throughout the year.

In March 2010, CFT employed its first staff member, a part-time Executive Officer, who continues in this role today.

In September 2012, the organisation set up its first office, located in Hobart, and casually engaged the Executive Assistant's services through a local employment agency. As of 1 July 2015, the Executive Assistant's job was employed directly and made a permanent part-time position. The Association's office is co-located with the Pharmacy Guild of Australia – Tasmanian Branch in Montpelier Retreat, Battery Point.

CFT is a member of the national CF Federation and works collaboratively with other Federation members, including CF Australia, through the Federation Leadership Group, comprising Presidents and CEOs. As a CF Federation member, CFT nominates a director for election to the CF Australia board.

As of 31 December 2022, CFT had 245 members, over 115 individuals with CF or Tasmanian families with a person with CF. 2022 marked 27 years since CFT became an incorporated association, servicing the needs of members and families throughout the state.

CF population in Tasmania

Tasmania has the highest incidence of Cystic Fibrosis in Australia and the secondhighest incidence of the condition in the world, behind Ireland. Estimates vary, but even the most conservative figures suggest around 1 in 20 Tasmanians carry a CF gene, compared to 1 in 25 in the rest of the country.

This high rate of carriers is mainly due to Tasmania's significant Anglo-Celtic background. Based on the Tasmanian population figures from the 2021 ABS census, it is estimated that around 27,500 Tasmanians are symptomless carriers of the CF gene.

Cystic Fibrosis Australia funds the Australian Cystic Fibrosis Data Registry (ACFDR). The ACFDR, managed by Monash University, collects data from CF Centres nationwide. The most recent report is the 2021 ACFDR report published in October 2022.

The 2021 ACFDR shows that 90 people with CF lived in Tasmania and attended Tasmanian clinics as at 31 December 2021. However, the number of Tasmanians living with CF is higher. The current figures are based on the postcode of the CF clinic that members attend rather than their home postcode—some Tasmanians who have CF choose to attend interstate clinics for treatment. The numbers can also vary based on the completeness of data in the ACFDR at the time of publication. Additionally, most CF patients who have had a transplant no longer attend CF clinics, so they are not counted on the CF Data Registry.

It is understood that the total figure of Tasmanians living with CF is closer to 115-118 people. From 2022 onwards, the recording of home postcodes will increase the accuracy of the information on the numbers of Tasmanians living with CF in future years of the Data Registry report.



FIGURE 1.5: ACFDR 2021: DISTRIBUTION BY STATE/ TERRITORY

Figure 1.5 shows the distribution of people with CF across Australian jurisdictions, including paediatric vs adult distribution. Jurisdiction is based on the CF centre location, rather than the postcode of the individual from 2021.

There were two new diagnoses of newborns with CF in 2022, one less than the previous year. No CF patients received a transplant in 2022, but sadly, one of the Tasmanian CF community members lost her hard-fought battle with CF in 2022. She was aged 51 years.

The percentage of people with CF having no hospital admissions in a year is higher in Tasmania, at around 73%, compared with 60% in other states.



A higher proportion of CF people in Tasmania received COVID vaccinations and flu shots compared to those living with CF in other States.

Table 12: Influenza vaccination status

10 Hospitalisation

Vaccinated	TAS	Other jurisdictions
Yes	72 / 90 (80%)	1,790 / 3,526 (51%)
No	10 / 90 (11%)	726 / 3,526 (21%)
Not known	8 / 90 (9%)	1,010 / 3,526 (29%)

Table 13: Covid vaccination status (16+ years)

Vaccinated	TAS	Other jurisdictions
Yes	45 / 52 (87%)	1,706 / 2,160 (79%)
No	3 / 52 (6%)	175 / 2,160 (8%)
Not known	4 / 52 (8%)	279 / 2,160 (13%)

* Tables are taken from the 2021 ACFDR report published by Monash University, Melbourne, October 2022 and ACFDR Jurisdiction Report 2021 (Tasmania), published by Monash University, Melbourne, October 2022.

Overview of services provided by CF Tasmania

MEMBER SERVICES





Member Services

CFT provides a range of equipment and services to members. To be eligible, members must meet a range of criteria, including being a current financial member of CFT and a resident in Tasmania (unless they have temporarily relocated to study). These services include the following:

Medical Equipment

CFT purchases equipment people with CF use to deliver medication to the lungs and the clearance of airways, such as nebuliser pumps and some physiotherapy-related items, for use by members on a loan basis. These nebulisers are vital life-saving equipment for people living with CF, with the fastest and most portable ones priced at up to \$1,500 each, making them out of reach for many patients.

The Association undertakes to cover any ongoing maintenance costs associated with the pumps, provide replacement filters and accessories, and offers replacement pumps as required. CFT is the only CF association in Australia that provides nebulisers for all members without charge. Requests for special equipment are considered on a case-by-case basis.

After a successful trial with several patients in 2021, CFT continued providing members with benchtop sterilisers. The introduction of this equipment has resulted in more hygienic sterilisation of nebulisers between uses, reducing the risk of residual bacteria.

Item	Number	Value
PEP Devices	60	
Misc Equipment	27	
Replacement parts	43	
Nebulisers	16	
Filters (Packets)	224	
Paediatric Equipment	36	
Face Masks	82	
Sterilisers	39	
Special Equipment	1	
TOTAL	528	\$26,076

In 2022 CFT purchased the following equipment with a total value of \$26,076

Counselling

Eligible members of CFT can access free counselling from qualified psychologists of their choice to assist with the emotional challenges of living with a chronic life-shortening condition.

This service is also available to immediate family members such as partners, siblings, parents and carers of people with CF. It was pleasing to see a significantly greater uptake of this program in 2022.

Item	Number	Value
Counselling	11	\$3,146

Transplant Assistance

CFT members are provided with financial support to assist with the costs of undergoing organ transplants that are not performed in Tasmania. In 2022 one member received a lung transplant and received a subsidy of \$1500.

Financial Assistance

CFT provides members financial assistance through various programs, including specific hardships and the Hospital Inpatient Assistance Scheme. All applications are assessed case-by-case and often assisted by a hospital social worker.

CFT also appreciates that the rising cost of living is impacting members. In the leadup to Christmas in 2022, grocery vouchers were provided to several members we knew had experienced challenges throughout the year. This assisted them in offsetting some of the costs of the festive season, which we appreciate can be very stressful for some members. The amount expended on special financial assistance in 2022 was 50.11% more than in 2021.

Item	Number	Value
Special financial assistance	11	\$9,365

Hospital Inpatient Assistance

CFT appreciates that many additional costs are incurred when someone with CF is hospitalised. These include parking, the need for more mobile data, different food and, importantly, good coffee. For the last four years, the Hospital Inpatient Assistance program has provided \$100 per hospital stay to CFT members.

We appreciate the feedback on how valuable this program has been to members. After a decrease in hospital admissions during the pandemic's peak, 20 members received assistance in 2022, with some members having multiple admissions throughout the year.

Item	Number	Value
Hospital Inpatient Assistance	20	\$2,720

Gym Membership subsidies, Fitness Equipment and Sports Registrations

Leading an active lifestyle greatly assists people with CF in keeping their airways clear. CFT offers a range of programs to assist with this, tailoring as much as possible to members' needs. It's been encouraging to see members embracing these opportunities in 2022, with CFT providing 34% more funds than the previous year.

Four more members went to gyms in 2022 than the previous year, and four more were provided with fitness equipment. Items purchased included bicycles, surfboards, exercise bikes, weights, a treadmill and a trampoline.

Twice as many members participated in organised sporting activities in 2022 than the previous year. Activities supported this year included swimming and surfing lessons, gymnastics, tennis, basketball, soccer and athletics. It's great to see so many of our members enthusiastically participating in various sports.

Item	Number	Value
Gym Memberships	15	\$9,159
Fitness Equipment	15	\$6,349
Sports Registrations	10	\$2,425
Total	45	\$17,934

CF Healthy You

Following its successful introduction in 2021, we were delighted to see an even more significant uptake by our CF Healthy You program members this year. This initiative assists members with a more holistic approach to their physical and mental health and well-being. They are provided vouchers up to \$250 each year towards something they believe would benefit them, either physically or mentally.

The most popular items in 2022 were gym shoes, bookshop gift vouchers, wetsuits, vouchers to support hobbies such as gardening or painting and sports clothing.

Category	Number of Vouchers	Value
Gift vouchers for fitness equipment such as shoes, clothing etc	29	\$5,551
Gift vouchers for books	4	\$ 512
Gift vouchers for well-being activities	8	\$1,905
Gift vouchers for hobbies	5	\$1,389
Total	46	\$9,357

Education & Information

Throughout this year, 24 CFT e-News were sent out to keep members and supporters updated with important information such as drug updates, member services, fundraising activities and more.

We know from our email software that members read these newsletters regularly and then use the handy links to access member services, buy tickets or read another article.

We look forward to engaging with our community in this way in 2023.

Little Day Out

The Little Day Out is one of our most loved programs by children and adults with CF and their families. Launched in 2011, Little Day Out provides members with Cystic Fibrosis an opportunity to enjoy an activity of their choice and, hopefully, momentarily leave behind the stresses of living with CF.

Little Day Out allows members to do something they ordinarily wouldn't, or perhaps couldn't afford, with up to \$200 towards activities of their choice. This program has been so popular that several other CF Associations have recently adopted it.

In 2022, 39 members used their Little Day Out entitlement, 13 more than the previous year. Activities included escape rooms, restaurant meals, tickets to major attractions or events, Uber Eats gift vouchers and cinema tickets. Every year we delight ourselves in hearing about our members' short days out.

Category	Number of Vouchers	Value
Gift vouchers for adventure activities or entry to wildlife parks etc	14	\$1,729
Restaurant or accommodation vouchers	8	\$1,458
Experience vouchers (e.g. escape rooms, picnic vouchers, laser tag, go-karting).	16	\$2,672
Cinema Tickets, including Gold Class	11	\$1,521
Total	40	\$7,380

Advocacy

As the peak body representing the CF community in Tasmania, CFT promotes the interests of people with CF to all levels of government, the Department of Health and the wider community.

CF Tasmania also represents the interests of Tasmanians with CF and their families at a national level through its involvement with Cystic Fibrosis Australia and the Australian Cystic Fibrosis Federation. In 2022 a primary focus of our advocacy centred around the listing of Trikafta on PBS for children aged between 6 and 11 years and other issues such as the cost of Continuous Glucose Monitoring Devices for people with CF Related Diabetes. While interstate travel to meetings continued to be halted due to the pandemic, CFT representatives remained actively involved in the CF Federation activities and with all meetings being held via video conference, the CEO and President continued to represent Tasmania's interests amongst the CF Federation.

Aaron Mackrill Memorial Scholarship

The Aaron Mackrill Memorial Scholarship was established in memory of CFT's former President, Aaron Mackrill, who lost his battle with CF on Anzac Day 2010 at just 29 years.

Aaron wished that instead of sending flowers to his funeral, people might make donations to CFT to establish a scholarship fund to assist people with CF in pursuing education or training past year 12. In 2017 the value of the scholarships increased from \$1,000 to \$1500 for full-time study. Scholarships are paid in annual instalments. The first Aaron Mackrill Memorial Scholarships were awarded in January 2012.

The current scholarship recipients study in different fields, such as Speech Pathology, Nursing, and Law. Aaron Mackrill's family are always delighted to hear about the outcomes of these scholarships

Aaron Mackrill Scholarship	Number	Value
Continuing Scholarships	3	\$1,750
Expenditure in 2022		\$1,750

Fundraising Activities

In our annual budget process, we set ourselves stretch targets for our fundraising activities, particularly the events we host. 2022 was no exception to this. But what was exceptional this year was the outcomes that were achieved.

After the 65 for CF Challenge success last year, which raised \$45,990, we thought we'd try to achieve a target of \$65,000. That sounded like a significant number with its link to the number 65. But we didn't expect to eclipse this total by an impressive 77%. Thanks to more challenges and some significant events, we raised \$81,434 in 2022.

The most significant of these events was 'My CF Sister', an ambitious challenge set by one of our members, Lizzie Whitla. My CF Sister was Lizzie's tribute to her close friend, Cemon Free, who sadly lost her CF battle in May 2021. Lizzie walked 65km in one Day from Cornelian Bay to the Hobart Cenotaph. After setting off in the wee hours of the morning, Lizzie had a considerable contingent of fellow walkers, family and friends supporting her through rain, wind, blisters, and sheer exhaustion. We were all excited to watch her cross the finish line midafternoon. Lizzie's event attracted significant media interest and helped raise CF's life-long, chronic condition profile.

As if her physical feat wasn't impressive enough, Lizzie's fundraising was even more so. With donations flowing in after the walk, Lizzie raised \$37,000. This was the single biggest CF Challenge that we'd ever had. We can't thank Lizzie enough for her time and energy making this a huge success.

Each year since she was very young, 12-year-old Charlotte Leppard has been doing a 65 Roses Challenge, and 2022 was no exception. Getting together with her skateboarding friends from the all-female team at She Shreds for a skate-a-thon. With their quest to skate for 650 minutes, this was a great family day out with a chocolate wheel, BBQ, food van, spot prizes, balloon artist and much more. Like Lizzie's event, there was tremendous media coverage, resulting in even more donations. Charlotte and the team raised a total of \$12,705.

The Launceston High Tea, held in May at Cataract on Paterson, welcomed 100 guests for an afternoon of fun, friendship, and fundraising. This year, the silver and red theme celebrated the tenth anniversary of this signature event. It was a great success, raising \$12,230. As always, the efforts of the Launceston High Tea Committee, with stalwarts such as Judi McGee and Donna Emery, did an incredible job gathering prizes and putting together such a beautiful high tea for our supporters.

When we put tickets on sale for our signature event, the 11th Annual 65 Roses Ladies Lunch, we didn't expect the 255 tickets to sell out in just 27 minutes. With a few disappointed regulars missing out, a different high tea event was held at Hadley's Hotel with 20 supporters live streaming the lunch's guest speaker, Lizzie Whitla, whilst enjoying their festivities.

The Garden Party theme was popular with guests, with many dressing to the theme, resulting in a hotly contested best-dressed competition. Thanks to some significant donors, new games, and the incredible work of so many volunteers, the ladies' lunch raised a new record of \$55,176. Special mention must go to the Lunch Co-ordinator, Steph Apted, who puts in above and beyond to ensure this event is a success. Her energy and enthusiasm are infectious.

Last year we reported on a new community fundraising initiative by the Vietnam Veterans and Veterans Motorcycle Club (Tasmania Chapter). After the successful inaugural 65 Roses Car and Bike Rally in May 2021, the event was held again in February 2022. This time leaving from Dru Point in Margate, travelling through the Huon and Channel areas, and ending at the Longley International Hotel. The

weather was spectacular, and everyone had a great time. It was particularly significant to see many CF community members participating. The event raised \$10,155. Once again, it's been an absolute pleasure working with the organising Committee on this event, as their organisational skills are second to none.

These events would not have been possible without their respective organising committees, donors, sponsors and enthusiastic guests. When some CF organisations and charities are moving away from running their fundraising events, our community embraces these opportunities to come together for both support and fun. Without government funding, the funds raised at these events also provide us with valuable income that we would struggle to obtain from sponsorships, grants or other sources.

Our sincere thanks to everyone who contributed in some way to these events. We greatly appreciate the time and effort you have put into helping make them such a success for our community.

2022 Major CFT Fundraising Events & Activities	Number of tickets sold	Profit
65 Roses Ladies Lunch (Hobart)	255	\$55,176
65 for CF – 65 Roses Challenges	-	\$81,434
65 Roses donations	-	\$4,836
2022 Quiz night	88	\$4,580
Launceston High Tea	100	\$12,230
Total		\$158,256

Grants

Like sponsorships, applications for grants are always highly competitive – with far more applications than money available. CFT actively pursued several grants throughout 2022 and was fortunate to succeed in four of the five grants we applied for. All grants were fully acquitted within the timeframe, delivering all intended goals.

2021 Grants Received	Purpose of Grant	Value	
Bulk Nutrients	CF Healthy You	\$1,000	
Hydro Tasmania	CF Healthy You	\$5,000	
Harcourts Tasmania	Little Day Out	\$10,000	
Commonwealth Bank	Counselling and medical equipment	\$10,000	
Total Value		\$26,000	

Major donations & bequests

CFT does not anticipate receiving bequests when formulating its annual budget. We regard any bequest as an unexpected bonus when it occurs and is always grateful that someone has considered our Association in making their Will. No bequests were received in 2022. However, CFT received several donations of over \$1,000, which we greatly appreciate.

Donor	Purpose	Value	
Robert Fergusson Family Trust	General donation	\$4,000	
Suzanne Barnes	General donation	\$4,000	
Westland Nurseries	General donation	\$5,000	
Stepping Stones	General donation	\$5,000	
Launceston Scale Model Club	General donation	\$1,000	
Anonymous	General Donation	\$1,011	
Total Value		\$20,011	

Social media

The CFT Facebook page continues communicating with our members and raising our profile effectively. It allows us to highlight member achievements, remind audiences about CFT's member benefits, offer CF care tips, thank volunteers and sponsors, publicise our events and much more.

Platform	Metric	2022	2021	% change
Facebook	Page Reach	95,904	60,748	+ 74.4%
	Posts	359	339	+5.8%
	Followers	3,057	2,846	+7.4%
Instagram	Page Reach	720	543	+ 32.6%
	Followers	198	175	+13.4%

These increases, together with the data about likes and reactions, tell us that the social media content we are providing engages our audiences and successfully extends its reach to those outside the CF community. It is not uncommon for one Facebook post to reach between 3,500 and 7,500 people, showing we are clearly punching above our weight for a small charity.

Sponsors & Supporters



Financial statements

A full copy of the reviewed financial statements for CFT is attached as a separate document.