

# 2023 ANNUAL REPORT



# CYSTIC FIBROSIS TASMANIA INC.

## 2023 ANNUAL REPORT

(Financial Year: 1 January 2023 – 31 December 2023)

### Contents

|  |            |
|--|------------|
| Organisation details .....             | Page 3     |
| President's Report.....                | Page 4     |
| Chief Executive Officer's Report ..... | Page 5     |
| Treasurer's Report .....               | Page 6     |
| 2023 Impact Statement.....             | Page 7     |
| Committee Members.....                 | Page 8     |
| History of CFT .....                   | Page 11    |
| CF Population in Tasmania.....         | Page 11    |
| Snapshot of Income 2023 .....          | Page 14    |
| Member Services.....                   | Page 15    |
| Snapshot of Member Services 2023 ..... | Page 23    |
| Fundraising Activities .....           | Page 24    |
| Grants .....                           | Page 25    |
| Major Donors & Bequests .....          | Page 26    |
| Social Media .....                     | Page 26    |
| Sponsors & Supporters.....             | Page 27    |
| 2023 Financial Statements.....         | Attachment |

## Organisation Details

### Cystic Fibrosis Tasmania Inc.

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Email: [general@cftas.org.au](mailto:general@cftas.org.au)  
Website: [www.cftas.org.au](http://www.cftas.org.au)

### Office Bearers 2023

|                 |                 |
|-----------------|-----------------|
| President:      | Scott Lancaster |
| Vice President: | Judi McGee      |
| Secretary:      | Steph Apted     |
| Treasurer:      | Eva Ewe         |
| Public Officer: | 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  
2<sup>nd</sup> Floor, 39 Sandy Bay Road  
HOBART TAS 7000

## President's report

2023 was characterised by challenging economic conditions: rising interest rates, cost of living pressures and continued ongoing recovery from the pandemic. Around Australia, this affected many charities, who found it more challenging to generate income while, in many cases, facing increased demand for their services (and increased costs in delivering those services).

Cystic Fibrosis Tasmania was no different, and we posted a \$23,000 loss (equating to around 9 per cent of turnover). Even as we look back on 2023, these challenges are set to continue for the foreseeable future.

However, 2023 was also a good year for CFT because we delivered over \$90,000 in direct services to people with CF in Tasmania and their families, not including the overheads that CFT unavoidably incurs in providing those services. There was more demand for help than ever before, although, interestingly, the mix of support that people with CF need appears to be changing.

With broader access to modulator therapies under the Pharmaceutical Benefits Scheme, most noticeably Trikafta, in 2023, there appeared to be an increase in the demand for things like assistance towards the cost of services relating to physical activity, such as gym memberships and CF Sports, and a decrease in the demand for services associated with hospitalisation.

We closely monitor CFT's finances, and any overspending against our budget is always scrutinised – except when its money is spent on member services. While we must find ways to fund it, over-spending on services to members is a sign that those services are of value to the CF community and a positive, rather than negative, budget variation. Nonetheless, our focus in 2024 will be on raising the income we need to continue meeting the demand for the services that people in Tasmania with CF need.

Lastly, I want to highlight an achievement that doesn't show up in any financial summary of CFT's expenditure on member services but demonstrates the importance of having a peak body to advocate for the Tasmanian CF community. In 2023, CFT successfully lobbied Tasmania Police to lift its automatic exclusion on applications from people with Cystic Fibrosis to join the police force, given improvements in the medical management of CF. While Tasmania Police's decision may not lead to a queue of people with CF at the doors of the police force's recruitment office, it provides a great example of the service that CFT can provide in pursuit of the overarching goal of the CF movement in Australia of 'lives unaffected by CF'.

As always, thanks to our Chief Executive Officer, Paula Wriedt, the hardworking staff in the CFT office (Jes and Janet), our volunteers, Committee members, sponsors and supporters for making all of this possible.

Live long and prosper.

**Scott Lancaster**  
**President**



## CEO's report

2023 was yet another year of challenges, although we had the opportunity to celebrate several new announcements of listings on the PBS of modulator drugs. Whilst not a cure, they are as close as we can come to one at the moment, and importantly, they treat the underlying causes of CF, not just the symptoms.

As valuable as these CFTR modulators are, they are not suitable for everyone with CF because they have rare genetic mutations or cannot tolerate them. So, we must work hard to ensure that research continues and that no one with CF is left behind.

It's been fourteen years since I started with CFT in 2010. The outlook for our members living with the condition was vastly different back then – with an average life expectancy of 37 years of age. Advances in research leading to modulators and enhanced treatments have significantly increased life expectancy. This increase is exciting but presents new challenges for our members and the Association. We will continue working with the allied health professionals at the CF Clinics around Tasmania and be flexible enough to adapt our services to our members' needs.

Advocacy continues to be an essential part of our work with CF Australia. We also advocate for individual members who need help and for issues related to state government. November 2023 saw carrier screening for CF funded by Medicare for the first time due to many years of lobbying by CF Associations. With Tasmania having the highest rate of carriers of CF in Australia and the second highest rate in the world, this is an important tool for those considering starting a family.

Some of the questions I often ask myself are "Do we know what impact CFT is making in the lives of our members?" and "Do others know the extent of what we do?". While the CFT staff, committee members and our event volunteers can see firsthand the enormous amount of work our small team does, not everyone has that insight.

To answer this question, we compiled a snapshot of our services for our members throughout the year, which is on the next page. With over 115 Tasmanians living with CF and members of our Association, our support extends further – to their family members through our services. In 2023, we processed 236 individual requests for assistance through our various programs.

Reflecting on 2023, I sincerely thank everyone who assisted CFT throughout the year. I am extremely grateful to work with a small but incredibly dedicated team of staff – Jes Jackson and Janet van Dongen. My thanks to all of the allied health professionals in the CF clinics whom we work with to ensure our members are getting all that they need.

Finally, my sincere thanks to the many volunteers who assist throughout the year– helping out at events, through community fundraising, members of the committee of governance, offering help to the CFT office and more. As a small organisation, your support is invaluable. It is this assistance that enables us to continue to provide services for our members throughout Tasmania.

Kind regards,

**Paula Wriedt**  
Chief Executive Officer



## Treasurer's report



2023 was a year that had its challenges in the fundraising area. With the sentiment of the economy reflected in the reduction in donations, CFT staff, volunteers and event organisers have had to work doubly hard to generate income. Despite the overall reduction in income generated from fundraiser events, each event was successfully delivered.

During the year, CFT has also seen an increase in member assistance uptake. CFT's positive financial performance between 2019 – 2021 has provided CFT with the financial position required to continue meeting members' needs. With the economic sentiment continuing into the 2024 year, the continued efforts of CFT supporters will be fundamental for CFT to continue delivery much required services to members.  
Kind regards,

**Eva Ewe**  
**Treasurer**

The CF Federation's Tag Line



**CYSTIC  
FIBROSIS**  
Tasmania

# 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.

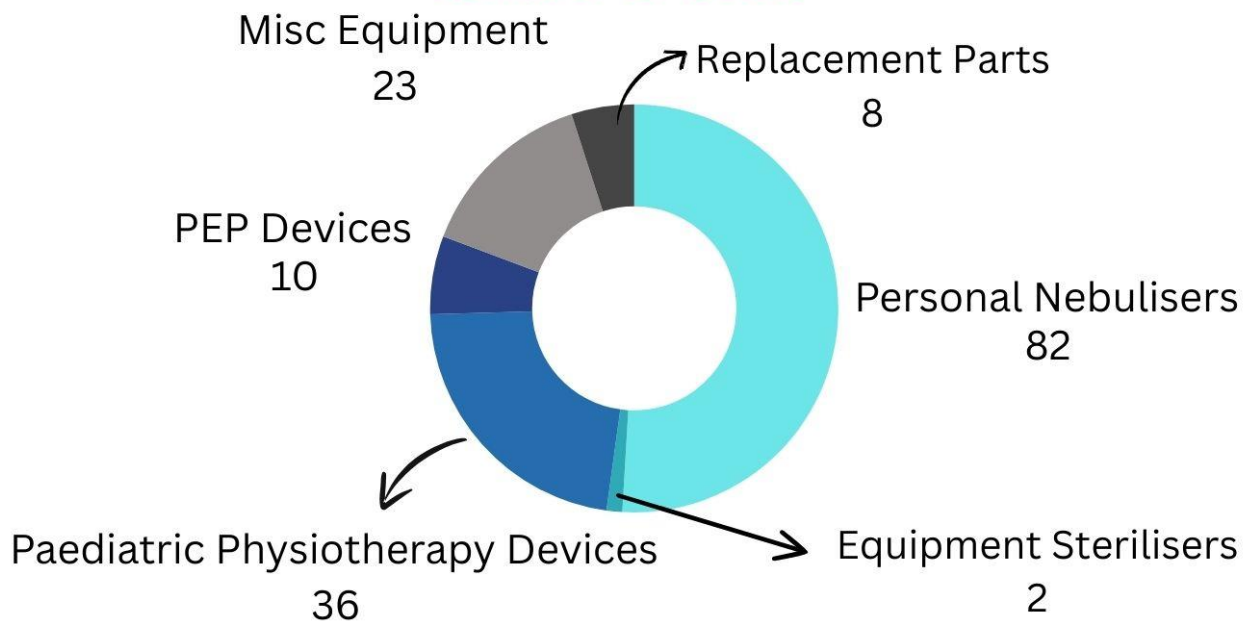
# 2023 Impact Statement



[www.cftas.org.au](http://www.cftas.org.au)

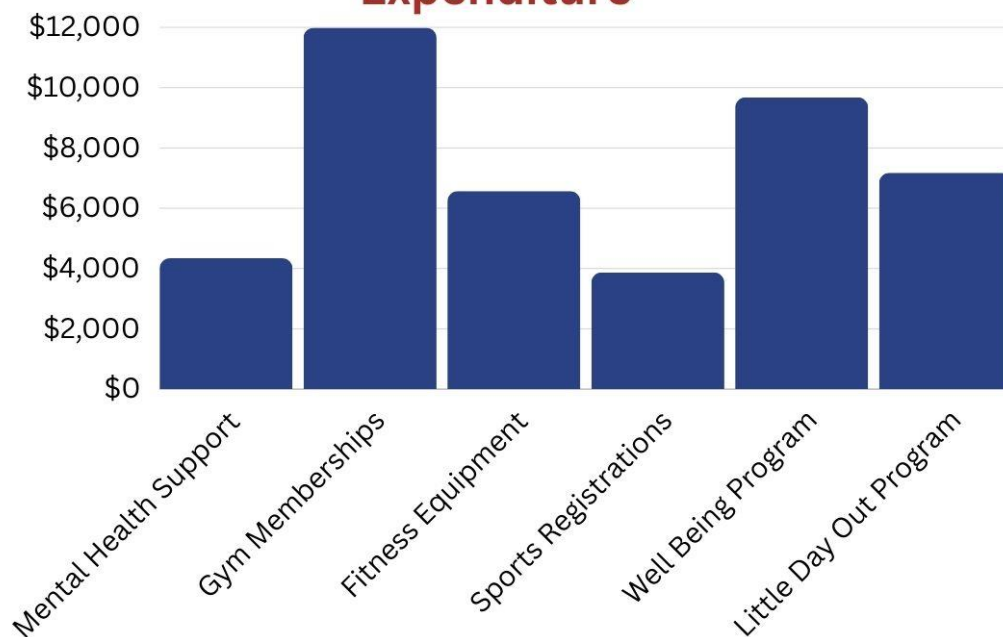
## Providing essential medical equipment

### Number of items



## Mental & Physical Health and Wellbeing Programs

### Expenditure



## **Committee Members 2023**

### **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 is 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 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, previously serving 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 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.

### **Eva Ewe, Treasurer**

Eva Ewe has a Bachelor of Law and a Masters of Professional Accounting from the University of Tasmania. She has worked as an accountant since 2012 and is currently a Senior Accountant at Accru Hobart. Eva qualified as a Chartered 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.

### **Stephanie Apted, Secretary**

Steph is a long-time supporter of CFT, having participated in multiple CF fundraisers and has organised many events over the years, including the 2019-2023 65 Roses Ladies Lunches, the 2018 and 2021 Gala Balls, two dodgeball events and the 2019 Hobart High Tea. Steph also worked for CFT for nine months as CFT's Administrative Assistant.

Steph became a volunteer for CFT as her cousin was born with CF, and her work as an advocate for those with CF inspires her. Steph joined the CFT Committee to continue and further her support of the CF community in Tasmania. Steph is currently a Safety and Wellbeing Partner at TasNetworks.



## **Bridget Caplice**

Bridget joined the Committee of Cystic Fibrosis Tasmania in October 2014 after having been 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, 17, who has CF and Gabby, 14.

Donna has been a member of CFT for 16 years and has been an avid fundraiser for the last 15 years. She has been on every Launceston Ladies High Tea organising committee for the previous 11 years and also helped with 65 Roses collection days in May, amongst other fundraisers.

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

## **James Kleinig**

James is an adult with CF who moved to Tasmania in 2014. He is a qualified jeweller and enjoys working with clients to create beautiful pieces. Although having a busy work and home life - raising three boys solo - James joined the Committee of CFT to use his own lived experiences to contribute to decisions that would benefit others living with the condition.

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

## **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 in Hobart for the past 20 years, including a year in Canada. She is currently a school principal. Sam lives in Hobart with her husband Chris and their two children, Harriet (8) and Scarlett (10), who has Cystic Fibrosis.

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

Sam's greatest enjoyment includes travelling, racing on roads 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, being involved as much as possible in advocacy, and increasing awareness of cystic fibrosis.

**Dr. Lynden Leppard**

For over 35 years, Lynden worked as a teacher school Principal and held various senior roles within the Tasmanian Department of Education, including within 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 four years, Lynden has been employed as a Senior Policy Officer with the Local Government Association of Tasmania, focusing on community health and wellbeing.

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. His most recent board position was on the Kingston Neighbourhood House, a term he completed in January 2022.

**Emily Stride**

Emily has over 17 years 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 as a workforce strategist. She is a key lead in designing and implementing some of the department's major HR transformation and strategy projects surrounding culture, service delivery, job families and talent Acquisition.

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 both temporary and permanent recruitment and more recently had been working in the role of Strategic Project Lead and Client Engagement Manager, 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, Office of the Ombudsman and The Anti-Discrimination Tribunal.

Emily lives in South Arm with her husband Josh and is mum to 10-year-old Lottie, who has Cystic Fibrosis, and 7-year-old Sullivan.

## COMMITTEE MEETINGS ATTENDED (1.1.2023 – 31.12.2023)

| Board Member    | Meetings eligible to attend | Meetings attended |
|-----------------|-----------------------------|-------------------|
| Scott Lancaster | 5                           | 5                 |
| Judi McGee      | 5                           | 5                 |
| Bridget Caplice | 5                           | 5                 |
| Sam Fox         | 5                           | 1                 |
| Lynden Leppard  | 5                           | 4                 |
| Eva Ewe         | 5                           | 4                 |
| Emily Stride    | 5                           | 1                 |
| Donna Emery     | 5                           | 4                 |
| Steph Apted     | 5                           | 4                 |
| James Kleinig   | 5                           | 2                 |

### 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 ten-member committee. The Committee comprises people from various professional backgrounds, including people with CF and parents of children with CF.

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

In September 2012, the organisation employed a second staff, set up its first office in Hobart, and employed a second staff member. Since December 2022, CFT has grown to include a third staff member who is part-time to assist with fundraising and events. 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. Scott Lancaster was appointed to the CFA Board in late 2022 and, in April 2023, was elected as the President of CFA Australia.

As of 31 December 2023, CFT had 265 members, over 115 individuals with CF or Tasmanian families with a CF member such as a parent or carer. 2023 also marked 28 years since CFT became an incorporated association, servicing the needs of members and families throughout the state.

### **Tasmanians living with CF**

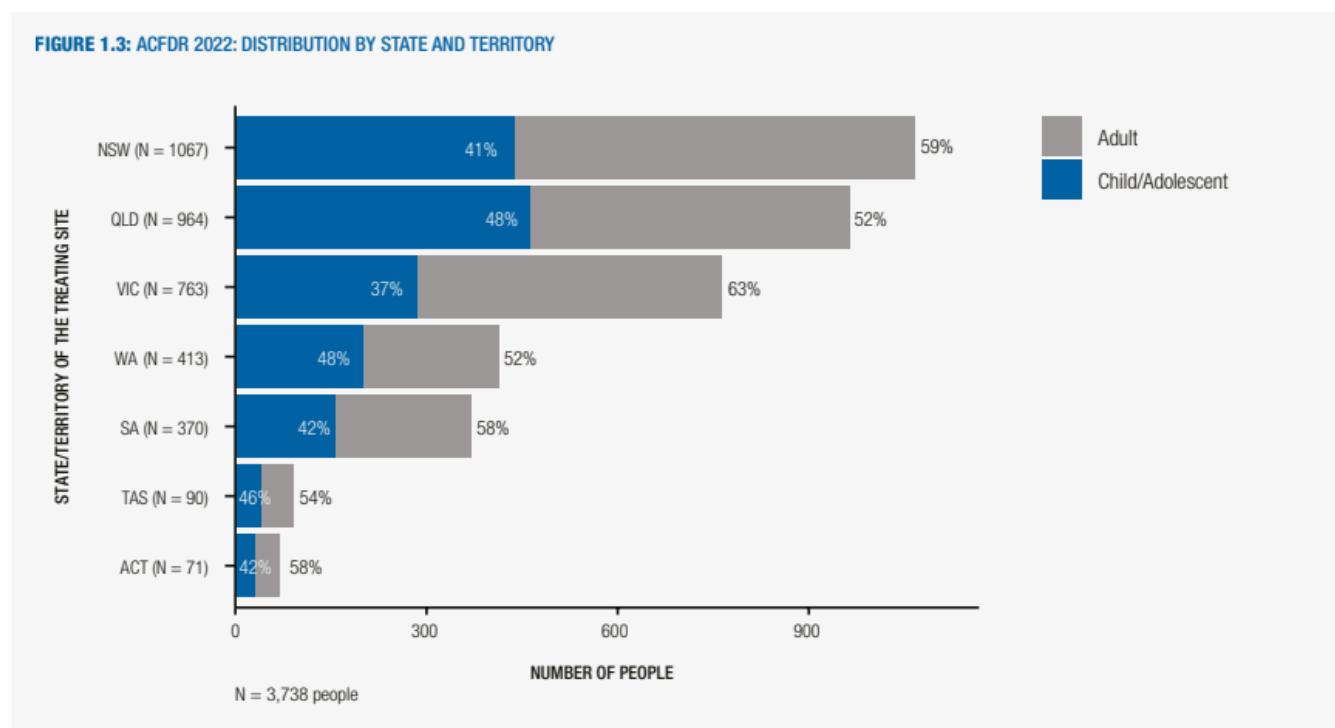
Tasmania has the highest incidence of Cystic Fibrosis in Australia and the second-highest incidence of the condition in the world, behind Ireland. Estimates vary, but even the most conservative figures suggest around 1 in 20 Tasmanians carry a CF gene, compared to 1 in 25 in the rest of the country.

This high rate of carriers is mainly due to Tasmania's significant Anglo-Celtic background, and it is estimated that around 28,650 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 2022 ACFDR, published in January 2024.

The 2022 ACFDR shows that 90 people with CF lived in Tasmania and attended Tasmanian clinics as at 31 December 2022. However, the number of Tasmanians living with CF is around 115. This is because some Tasmanians who have previously received transplants are treated at clinics outside of Tasmania. Additionally, 18.4% of people with CF did not have their home postcodes recorded along with their data.

As at December 2022 3,738 Australians were recorded as having Cystic Fibrosis.



There were two new diagnoses of newborns with CF in 2023, compared to three in 2022. No CF patients received a transplant in 2022.

(\* table taken from 2022 ACFDR Jurisdiction report for Tasmania, published by Monash University, Melbourne, January 2024).

## **Financial statements**

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

## 2023 Snapshot of Income



# \$55,588

RAISED THROUGH  
65 for CF CHALLENGES



# \$31,626

RAISED AT OUR 2023  
GALA BALL - THE DISCO BALL



# \$4,534

RECEIVED FROM COMMUNITY  
FUNDRAISING ACTIVITIES



# \$17,000

RECEIVED FROM 5 MAJOR  
DONORS (over \$1,000 each)



# \$3,000

RECEIVED FROM  
GRANT APPLICATIONS



# \$15,145

FROM THE VIETNAM VETERANS  
& VETERANS MOTORCYCLE  
CLUB FUNDRAISING FOR CFT



# \$43,825

RAISED AT THE  
65 ROSES LADIES LUNCH 2023



## Snapshot of 2023 Income

CFT does not receive any Government funding. The Association relies on the generosity of donors and supporters, as well as income from fundraising activities and grants. This is a snapshot from 2023.

## Overview of services provided by CF Tasmania

# CYSTIC FIBROSIS TASMANIA

## Member Services

CFT provides a range of services to enhance the quality of life for members with CF and their families.

- ✓ Provision of airway clearance equipment, nebulisers and equipment sterilisers and face masks
- ✓ Payment of sports registration fees for individual or team sports
- ✓ Support for physical and mental health and well-being activities
- ✓ Aaron Mackrill Memorial Scholarships for post year 12 tertiary or vocational education & training
- ✓ Resources and educational events - conferences, guest speakers and regular CFT eNewsletters
- ✓ Contributions to CF research through funding partnerships
- ✓ Financial assistance through grocery vouchers and support for hardship or interstate surgery such as transplants
- ✓ Networking opportunities for the CF community through fundraising activities and other events
- ✓ Financial subsidies for inpatient hospital stays to assist with additional costs of hospitalisations
- ✓ Specialised medical equipment for day to day use or end of life care
- ✓ Subsidised gym memberships and fitness equipment
- ✓ Access to no gap fee psychology or counselling services for person with CF and immediate family
- ✓ Respite programs including Little Day Out for adults and children with CF and their loved ones
- ✓ Financial assistance for IVF procedures
- ✓ Advocacy for individual members and at a community level for issues impacting Tasmanians living with CF
- ✓ Raising awareness of CF in the broader community through the media and public engagements



## 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 resident in Tasmania (unless they have temporarily relocated to study).

### 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 simply out of reach for many patients. Unfortunately these devices are not provided by Tasmania's public health system.

The Association undertakes to cover any ongoing maintenance costs associated with the pumps, provide replacement filters and accessories, and offer 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.

In 2023, CFT purchased the following equipment, which had a total value of \$25,236. Of this total, \$2,779 was spent on a specific piece of equipment needed by one member. This item can be used later by another patient as required.

| Item                             | Number          |
|----------------------------------|-----------------|
| PEP Devices                      | 10              |
| Misc Equipment                   | 16              |
| Nebulisers                       | 82              |
| Filters (Packets)                | 13              |
| Paediatric Equipment & Resources | 36              |
| Replacement parts                | 8               |
| Sterilisers                      | 2               |
| Special Equipment                | 1               |
| <b>Number of items.</b>          | <b>168</b>      |
| <b>Total Value</b>               | <b>\$25,236</b> |

## Counselling

Eligible members of CFT can access free counselling from qualified psychologists of their choice. An annual cap applies to the amount of assistance provided to a member. However, as CFT believes this is an essential service, all requests beyond the cap are considered on a patient's personal needs. This service has been increasingly used since the Federal Government's extended number of visits paid by Medicare following COVID-19 ceased at the end of 2022.

This service is available to immediate family, parents, and carers of people with CF. With patients seeking mental health assistance more regularly, in 2023, CFT provided our members with 38% more benefits under this program.

| Item        | Number | Value   |
|-------------|--------|---------|
| Counselling | 8      | \$4,341 |

## Education & Information

Throughout this year, 31 editions of CFT e-News were sent out to keep members and supporters up to date with important information such as drug updates, member services, fundraising activities and more. This was seven more than the previous year.

We know from our email programs that members read these newsletters regularly and then use the handy links to click through to access member services, buy tickets, or read other articles. We look forward to continuing to engage with our community in this way in 2024.

## Transplant Assistance

CFT members are provided with financial support to assist with the costs of undergoing organ transplants (or other medical procedures) that are not performed in Tasmania. To reflect the increased costs since the subsidy was set at \$1500 in 2016, the amount available per transplant doubled in 2023 to \$3,000. However, in 2023, no Tasmanian CF patient received a transplant. This is consistent with the national statistics that show a declining number of transplants for CF patients as the positive impacts of the CFTR Modulators take effect.

## Financial Assistance

CFT provides members various financial assistance through various programs, including specific hardships. All applications are assessed case-by-case and assisted by a hospital social worker. Assistance provided to members for special financial assistance throughout 2023 increased by 20.7% from the previous year. Since 2021, the funding provided to members through this program has increased by nearly 54%. In 2023, \$10,204 was provided to Tasmanians living with CF and their families to help them with household and medical bills.

CFT also appreciates that the rising cost of living is impacting all Tasmanians, especially our members, who also have the burden of pharmaceutical bills. Like the previous year, in 2023, eleven members received grocery vouchers to assist them and their loved ones in the lead-up to Christmas.

| Item                         | Number    | Value           |
|------------------------------|-----------|-----------------|
| Special financial assistance | 16        | \$10,204        |
| Hardship – Grocery Vouchers  | 11        | \$1,100         |
| <b>TOTAL</b>                 | <b>27</b> | <b>\$11,304</b> |

## Hospital Inpatient Assistance

CFT appreciates that when someone with CF is hospitalised, many additional costs are incurred. These include parking, the need for more mobile data, different food and, importantly, good coffee. Since its introduction four years ago, the Hospital Inpatient Assistance program has provided CFT members \$100 per hospital stay. Members with specific dietary requirements due to conditions such as gluten intolerance or diabetes receive an additional \$50 per stay.

Fewer CF patients are being hospitalised each year thanks to medical research and treatment advances. However, some members have regular, lengthy hospital stays, putting significant financial stress on them and their loved ones.

| Item                          | Number | Value   |
|-------------------------------|--------|---------|
| Hospital Inpatient Assistance | 12     | \$2,619 |

## Gym Membership subsidies, Fitness Equipment and Sports Registrations

It's been pleasing to see another significant increase in members accessing one of our programs designed to encourage physical activity for increased mental and physical well-being. Thanks to our subsidies, four more members took up the option of gym memberships in 2023 and 7 more members registered for some sort of sporting activity last year. In 2023, CFT expended 25% more on physical activity-related programs than the previous year.

Members also continued to embrace the option of working out away from a gym environment and took advantage of our fitness equipment subsidy. Items purchased included home gym equipment, a surfboard, a skate ramp, a rowing machine, mountain bikes and mini trampolines.

Our members continue to enjoy a diversity of different sporting activities. Sports registrations funded by CFT in 2023 included swimming and dancing lessons, gymnastics, netball, skateboarding, futsal, cricket, golf, touch football, diving, BMX biking and soccer.

| Item                 | Number | Value           |
|----------------------|--------|-----------------|
| Gym Memberships      | 19     | \$11,990        |
| Fitness Equipment    | 13     | \$6,566         |
| Sports Registrations | 17     | \$3,871         |
| <b>Total</b>         |        | <b>\$22,427</b> |

## CF Healthy You

Two years ago, in 2021, thanks to our fundraising activities' high income, we were excited to introduce a new program for our members. CF Healthy You was developed to assist members with a more holistic approach to their physical and mental health and well-being. CF Healthy You Provides members with up to \$250 each year towards something they believe would benefit them, physically or mentally.

The response to this program continues to be strong. Members have the freedom to select something specific to their individual needs that they believe would benefit their physical and mental health and well-being. It was rewarding to see how members spent their allocation.

## CF Healthy You

| Category   | Number of Vouchers | Value          |
|--|--------------------|----------------|
| Gift vouchers for fitness equipment such as shoes, clothing, etc | 23                 | \$5,031        |
| Gift vouchers for books  | 4                  | \$ 450         |
| Gift vouchers for well-being activities                          | 16                 | \$3,219        |
| Gift vouchers for hobbies  | 6                  | \$ 983         |
| <b>Total</b>   | <b>37</b>          | <b>\$9,684</b> |

## 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 Tasmanian Health Service and State and Federal politicians.

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 2023, the primary focus of our advocacy was the expansion of Trikafta and Kalydeco's listings on the PBS. We celebrated the inclusion on the PBS of Trikafta for children aged 6 – 11 with one F50del gene mutation and one minimal function mutation. Orkambi's listing was also extended for children aged 1-2 years with two copies of the F508del gene mutation.

Another significant occurrence from the Federation's long-standing advocacy was Medicare rebates for genetic carrier screening. With the highest rate of carriers of the CF gene in Australia, this rebate is an important step forward for Tasmanians wishing to start a family who may have otherwise struggled with these costs. Since this rebate has been offered, the number of enquiries to the CFT office about carrier screening and CF has substantially increased.

A Parliamentary Friendship Group was established in the Federal Parliament to raise continued awareness about the impact of CF. Dr Mike Freelander MP and Dr Monique Ryan MP, both former pediatricians with a significant interest in CF co-chair the group.

On a local level, CFT advocated to the Commissioner for Police to remove the blanket ban of people with CF from entering training to become police officers. We

were delighted to receive the news that this ban would be removed due to the improvement in the health of many CF patients thanks to CFTR modulators. This now means that people with CF wishing to join Tasmania Police must only satisfy the same requirements as other entrants.

In early 2023, CFT also approached the Commissioner for State Revenue regarding electricity concessions for patients using nebulisers. While other devices have been included, despite being regarded as a "life-saving" device for CF patients, they were not recognised as this. In early 2024, we received advice that our advocacy had been successful and that concessions would begin in July 2024.

The CEO and President continue to participate in various CF Federation meetings. This provides a valuable opportunity to identify national advocacy issues, guide CFA's strategic direction, and share ideas.

## Little Day Out

Little Day Out is one of our most loved programs by adults and children with CF and their families. Launched in 2011, Little Day Out provides members with Cystic Fibrosis an opportunity to enjoy some quality time together 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. The program has become so popular that other CF Associations in Australia have adopted it.

In 2023, 44 members embraced the opportunity to have a Little Day Out, 4 more than the previous year. Once again, recipients got creative with their requests, including pop concert tickets, go-kart racing, skating or bowling parties, mountain biking, aquarium, and zoo visits.

| Category   | Number of Vouchers | Value          |
|--|--------------------|----------------|
| Gift vouchers for adventure activities or entry to wildlife parks, etc | 6                  | \$1,011        |
| Restaurant, accommodation, or flight vouchers                          | 9                  | \$1,802        |
| Experience vouchers (e.g. karting, bowling, aquarium visits)           | 23                 | \$3,569        |
| Cinema Tickets, including Gold Class                                   | 6                  | \$638          |
| <b>Total</b>   | <b>44</b>          | <b>\$7,082</b> |

## 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 old.

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, and in that time, 16 scholarships have been provided to students across a range of disciplines.

The current scholarship holders are studying in different fields, such as personal training, fashion design, law, and medicine. Aaron Mackrill's family are always delighted to hear the outcomes of these scholarships

| <b>Aaron Mackrill Scholarship</b> | <b>Number</b> | <b>Value</b>   |
|-----------------------------------|---------------|----------------|
| Continuing Scholarships           | 4             | \$2,050        |
| <b>Expenditure in 2023</b>        |               | <b>\$2,050</b> |

## 2023 Snapshot of Member Services

**12**

MEMBERS RECEIVED  
HOSPITAL INPATIENT  
ASSISTANCE



**8**

MEMBERS RECEIVED MENTAL  
HEALTH SUPPORT THROUGH  
COUNSELLING SUBSIDIES



**4**

MEMBERS SUPPORTED  
WITH AARON MACKRILL  
SCHOLARSHIPS



**\$25,236**

OF MEDICAL EQUIPMENT  
SUPPLIED



**\$11,304**

PROVIDED IN MEMBER  
FINANCIAL ASSISTANCE  
FOR HARDSHIP



**\$22,049**

FOR SPORTS REGISTRATIONS,  
FITNESS EQUIPMENT & GYM  
MEMBERSHIPS



**38**

MEMBERS TOOK PART  
IN THE CF HEALTHY YOU  
PROGRAM ACCESSING \$9,652  
OF BENEFITS



**CFT is proud of the support we provide members of the Tasmanian CF community. This is a snapshot of some of the services delivered in 2023.**

**Snapshot  
of 2023  
Member  
Services**



## Fundraising Activities

We started 2023 with great confidence and success in the fundraising space thanks to some record-breaking events in 2022. Unfortunately, the economic climate meant it was not to be. Regardless, we still delivered several highly successful events.

The Launceston High Tea is always a sell-out, and thanks to the formidable organising of CFT Committee Member Donna Emery and her great team of volunteers, the 2023 event was no exception. At last year's beautiful venue of Cataract on Paterson, guests enjoyed a wonderful afternoon of fun and friendship. Thanks to everyone's hard work, the event raised \$15,145.

The Hobart 65 Roses Ladies Lunch, in its 13<sup>th</sup> year, was themed 'Spots and Dots', and the 242 guests got into the spirit with many dressing to the theme. Guest speaker, CFT Member Simon Calvert, spoke eloquently as he shared his journey with CF from childhood through to the joys of new parenthood, something he never envisaged he would achieve. While the new fundraising climate made it challenging, a huge congratulations to Fundraising and Events Co-ordinator Jes and the incredible Steph Apted and her team of volunteers for raising \$43,825.

Just eight weeks later, our biannual gala ball was held. The aptly titled Disco Ball had 133 guests embracing the opportunity to dress up and show off their dance moves thanks to the fabulous DJ. CFT Committee member James Kleinig was a very entertaining guest speaker. The event raised \$31,626.

After last year's epic result from 65 for CF Challenges, we were worried that many might be too "challenge weary" to take part again. But as always, many dedicated supporters put up their hands to take on a challenge. Thanks to the team of Shredding for CFT – Zailee Jackson and Charlotte Wall, who spent a tremendous amount of time skateboarding in some epic locations and getting their photos taken. 65 locations and pictures, to be exact. They met politicians and dignitaries, skated on the Hobart airport runway, did radio interviews and appeared in the newspaper. They also raised an incredible \$35,156 for CFT, and we can't thank the girls enough, but we also give a massive shout-out to their mums, Carrie and Jes, who did so much work to enable this to happen.

Overall, 16 different challenges were held in 2023, raising a total of \$55,588. This is a fantastic result, and we thank everyone who got creative with their challenges.

Once again, this year, we were very fortunate to be the beneficiary of a great community fundraising initiative by the Vietnam Veterans and Veterans Motorcycle Club (Tasmania Chapter). The third annual 65 Roses Car and Bike Rally was held on 4<sup>th</sup> February 2023. While the weather wasn't great, it didn't stop a large turnout of cars and bikes that enjoyed a fun day around the Huon and Channel area. We were delighted to receive a cheque for \$15,145 at the Club's AGM in July.

These events would not have been possible without their volunteers, donors, sponsors and enthusiastic guests. When some charities are moving away from holding fundraising events, our community embraces these opportunities to come together for support and fun. Without Government funding, the funds raised at these events also provide us with valuable income.

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.

| <b>2023 Major CFT Fundraising Events &amp; Activities</b> | <b>Number of tickets sold</b> | <b>Profit</b>    |
|---|-------------------------------|------------------|
| 65 Roses Ladies Lunch (Hobart)                            | 242                           | \$43,825         |
| 65 for CF – 65 Roses Challenges                           | -                             | \$55,588         |
| 2023 Quiz night   | 92                            | \$5,010          |
| Launceston High Tea                                       | 115                           | \$15,726         |
| CFT Gala Ball – The Disco Ball                            | 133                           | \$31,626         |
| <b>Total</b>  |                               | <b>\$151,775</b> |

## **Grants**

Like sponsorships, applications for grants are always highly competitive – with far more applications than money available. Additionally, in recent years, many philanthropic organisations have changed their guidelines so that successful initiatives reach a broader cross-section of the community than just CFT members. CFT actively pursued several grants throughout 2023 and only successfully secured two minor grants.

| <b>2023 Grants Received</b>   | <b>Purpose of Grant</b>          | <b>Value</b>   |
|-------------------------------|----------------------------------|----------------|
| Department of Social Services | Volunteer grant                  | \$2,000        |
| Aurora Energy                 | General community services grant | \$1,000        |
| <b>Total Value</b>            |                                  | <b>\$3,000</b> |

## Major donations & bequests

We regard any bequest as an unexpected bonus when it occurs and are always grateful that someone has considered our Association in making their Will. No bequests were received in 2023, however, CFT received four donations of \$1,000 or more, which we greatly appreciate.

| Donor                         | Purpose           | Value           |
|-------------------------------|-------------------|-----------------|
| Ulverstone Lions Club         | General donations | \$1,000         |
| Hobart Dolls Club             | General donation  | \$2,000         |
| Robert Fergusson Family Trust | General donation  | \$4,000         |
| Westland Nurseries            | General donation  | \$10,000        |
| <b>Total Value</b>            |                   | <b>\$17,000</b> |

## Social media

Social media continues to be a cost-effective and fast method of communicating with our members and raising our profile. It allows us to highlight member achievements, remind audiences about CFT's member benefits, offer CF healthcare tips, thank our many volunteers and sponsors, publicise our events and much more.

The number of followers on our Facebook page continues to increase – with our reach now just over 3,322 individuals, up from 2,846 last year and 243 followers via Instagram, 36 more than in 2023. It is not uncommon for a single post to reach up to 12,500 people – punching far above our weight as a small charity.

| Platform  | Metric         | 2023   |
|-----------|----------------|--------|
| Facebook  | Page Reach     | 62,325 |
|           | Page Visits    | 13,700 |
|           | Followers      | 3,322  |
| Instagram | Page Reach     | 460    |
|           | Profile Visits | 679    |
|           | Followers      | 243    |

**CFT would like to thank the following businesses and organisations for their support in 2023**

