



**CYSTIC  
FIBROSIS**  
Queensland

**2023**  
Annual Report



*Embracing Tomorrow*



*You cannot catch  
cystic fibrosis,  
you are born  
with it.*

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# SECTION ONE

Overview of cystic fibrosis

*Cystic Fibrosis Queensland works hard to alleviate the financial, emotional, and physical burden of the disease.*



## WHAT IS CYSTIC FIBROSIS?

Cystic fibrosis primarily affects the lungs and digestive systems due to an exocrine malfunction that is responsible for producing saliva, sweat, tears and mucus. There is currently no cure.

People with cystic fibrosis develop an abnormal amount of excessively thick and sticky mucus within the lungs, airways, and the digestive system. This causes impairment to the digestive function of the pancreas and traps bacteria in the lungs resulting in recurrent infections and leading to irreversible damage. Lung failure is the major cause of death for someone with cystic fibrosis.

From birth, a person with cystic fibrosis undergoes constant medical treatments and physiotherapy.

## HOW IS CYSTIC FIBROSIS DIAGNOSED?

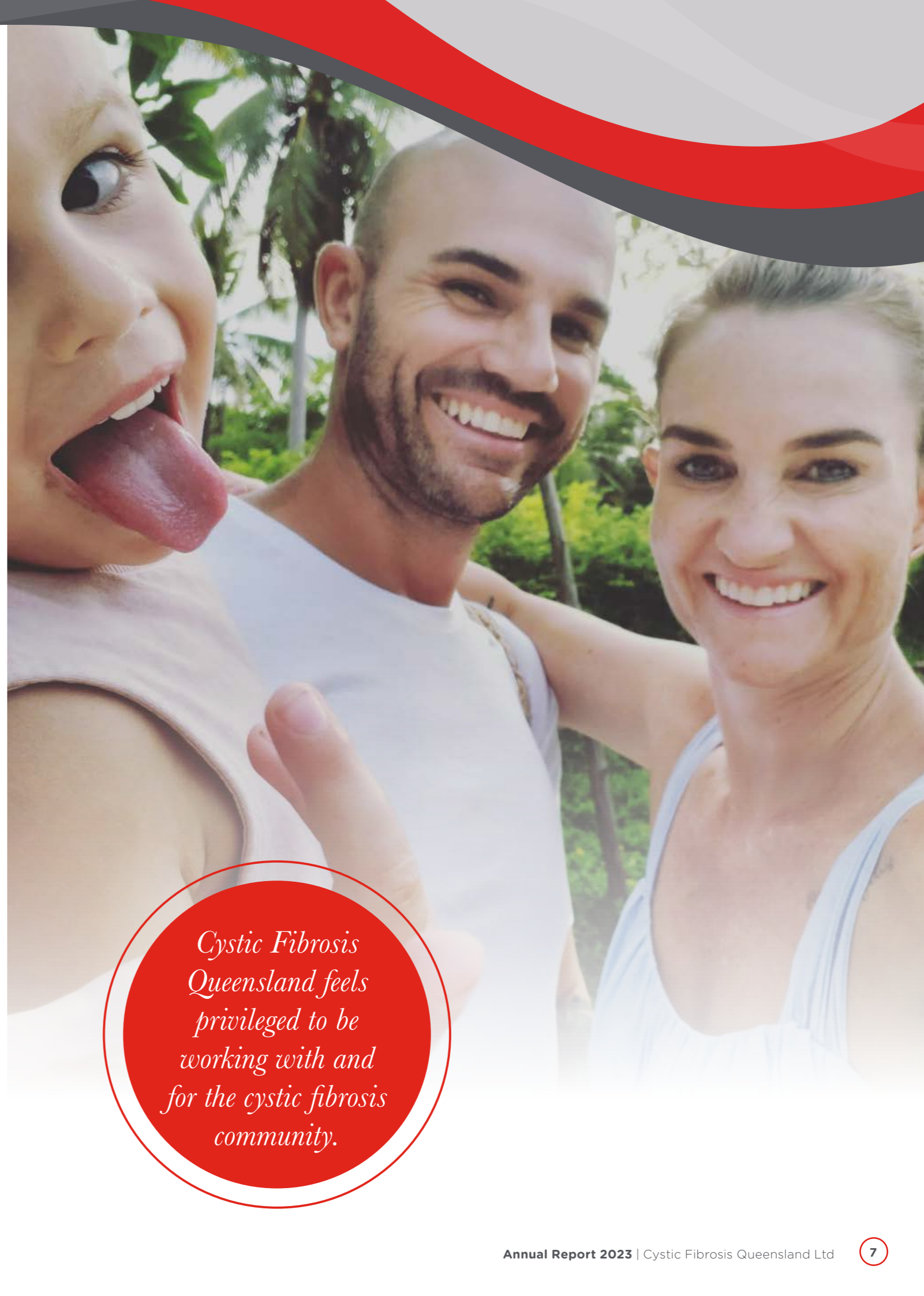
Since 1986, all newborns have been subject to a heel prick test. This test is used to screen for several conditions, one of which is an indicator for cystic fibrosis. Diagnosis may also result after a baby is born with obvious cystic fibrosis symptoms such as bowel blockage or failure to thrive.

The heel prick test does not detect cystic fibrosis in everyone, and the sweat test continues to be the definitive test, as high levels of salt in perspiration is extremely common amongst those with cystic fibrosis.

## YOU CANNOT CATCH CYSTIC FIBROSIS

The cystic fibrosis gene is inherited from both parents, and it can skip generations. It is autosomal recessive meaning that it occurs equally in males and females. In Australia, one in 2 500 babies are born with cystic fibrosis, that is one every four days. On average one in 25 people carry the cystic fibrosis gene and most are unaware that they are carriers. Because carriers of cystic fibrosis are unaffected and therefore show no symptoms, it is hard for them to appreciate that cystic fibrosis may be a real risk.

Any one of us could be a carrier and not know it. There are about one million unaware carriers in Australia. In Tasmania, one in 20 people carry the cystic fibrosis gene. This is the second highest rate in the world behind Ireland.



*Cystic Fibrosis Queensland feels privileged to be working with and for the cystic fibrosis community.*

## HOW IS CYSTIC FIBROSIS TREATED?

Management and treatment of cystic fibrosis is lifelong, ongoing, and relentless. A person living with cystic fibrosis may consume up to 80 capsules daily to help digest food and may require four hours of airway clearance physiotherapy each day. It is important for people with cystic fibrosis to visit a cystic fibrosis treatment centre several times each year so their progress can be monitored.

### Treatment generally involves:



A nutritious diet that is also high calorie, high salt, and high fat.



Enzyme replacement capsules with food to aid digestion.



Intensive daily physiotherapy to clear the lungs.



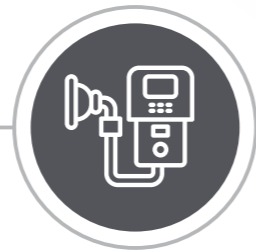
Salt and vitamin supplements.



Daily exercise, which is important to help clear the airways and build core strength.



Antibiotic therapy to treat lung infections.



Aerosol mist inhalations via a nebuliser to help open the airways.

*Any one of us could be a symptomless cystic fibrosis carrier.*

A person living with cystic fibrosis must do all of this while continuing their normal daily activities like going to school or work.

People with cystic fibrosis are encouraged not to socialise with each other. The risk of cross-infection and exacerbation of lung conditions is too great. This means cystic fibrosis can be a lonely existence because people with cystic fibrosis cannot personally interact to share experiences and offer support.

## CARRIER SCREENING

Cystic fibrosis came into the human genome about 5 000 years ago and it has survived and spread. Today there is thought to be almost 2 000 mutations that lead to cystic fibrosis, some of which are particular to individual families. At the other extreme, one mutation, Delta F508, is present in some 72% of all cases worldwide.

Carriers are symptomless and live normal lives. They are overwhelmingly unaware of their cystic fibrosis carrier status. Yet they have every chance of passing on the gene to the next generation and that generation to the next and so on – it is only a matter of time before a member of the carrier's family is born with cystic fibrosis.

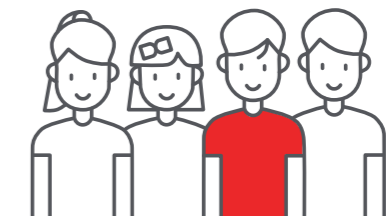
Nine out of ten children born with cystic fibrosis are born into families with no known family history of the condition. To have a child with cystic fibrosis, both parents must be carriers of the gene change that causes cystic fibrosis.

## WHAT HAPPENS WHEN TWO CARRIERS HAVE CHILDREN?

If both parents are carriers of the cystic fibrosis gene, then with each pregnancy there is a 25% risk of that child having cystic fibrosis. Being a cystic fibrosis carrier does not mean you have cystic fibrosis and carriers usually display no symptoms of cystic fibrosis.



2 in 4 chance the child will be a carrier of cystic fibrosis (having one copy of the cystic fibrosis gene)



1 in 4 chance the child will not have cystic fibrosis (will not have a copy of or be a carrier of the cystic fibrosis gene)



1 in 4 chance the child will have cystic fibrosis



Two carrier parents have a 25% chance of having a child with cystic fibrosis with each pregnancy



*People living with cystic fibrosis are living longer and healthier lives than ever before.*



### WHAT IS CARRIER SCREENING?

Cystic fibrosis carrier screening services are available to help prospective parents find out whether they are among the one million Australians who carry the cystic fibrosis gene. Carrier screening is as simple as having a blood test or a saliva swab. A typical cystic fibrosis screening will identify the most common cystic fibrosis gene in Australia. However, there is still a small risk that you may be a carrier of a rare cystic fibrosis gene.

People with a family history of cystic fibrosis are encouraged to tell their GP, obstetrician, or gynecologist before providing a sample for screening. This will ensure that testing is for the most common cystic fibrosis gene as well as the specific gene relevant to their family.

From 1 November 2023, cystic fibrosis was included in the list of chronic illness eligible for the Medicare genetic carrier screening rebate.

Under the Federal Government program, the cost of testing of a patient who is pregnant or planning pregnancy, to identify carrier status and reproductive risk of cystic fibrosis, will be covered by Medicare. Subsequently, if this patient is found to be a carrier, their reproductive partner can also receive testing covered by Medicare, to determine the couple's reproductive risk of cystic fibrosis. There is a one test per lifetime limit associated with this testing.

### CYSTIC FIBROSIS QUEENSLAND'S POSITION ON GENETIC TESTING

Cystic Fibrosis Queensland encourages people to make an informed choice about knowing their cystic fibrosis carrier status as early as possible. The earlier carrier status is known, the longer carriers have to make a thorough, informed and considered choice about their reproductive options. These include (but are not limited to) understanding the impact of having a child with cystic fibrosis, understanding the risks of having a child with cystic fibrosis, and exploring IVF options.

Cystic Fibrosis Queensland encourages people interested in understanding their risks of being a carrier for cystic fibrosis to consult a genetic counsellor and supports efforts to make carrier screening accessible for anyone who is interested in learning about their cystic fibrosis carrier status. This includes raising awareness of cystic fibrosis, raising awareness of carrier screening services, and addressing other potential barriers to access and informed choice.



# Cystic Fibrosis Queensland Strategic Plan 2023 and Beyond



## OUR VISION

Lives unaffected by cystic fibrosis - together we are:

*Embracing Tomorrow*

## OUR MISSION

To support those living with cystic fibrosis, and their families, through education, support programs and advocacy.

## OUR OBJECTIVE

To support people living with cystic fibrosis to live a full and complete life.

## OUR VALUES



To be relevant to our community.



To work collaboratively and advocate for our community.



To be effective in the work we do for our community.



To be respectful of our community, our stakeholders and each other.



## Our Strategic Priorities

1. To continue to proactively drive the agenda by being a leading voice for our community.
2. To be relentless in our pursuit of programs which increase our members' overall well-being and mental health.
3. To be a strong advocate for our community, increasing the access and equity to service and support programs.
4. To ensure our charity remains financial.

## IMPACT

Cystic fibrosis is a life-long and complex disease. Cystic Fibrosis Queensland provides the only source of hope for many people living with cystic fibrosis. Our charity is in a privileged position and has a special role working with and for the cystic fibrosis community.

As the peak not for profit community charity, we assist our members to live fuller and healthier lives. We do this by funding research, raising awareness of the diseases, advocating for members, providing information and education, and funding practical support, service, equipment, and psychosocial programs for the increasing number of people born with cystic fibrosis.

## EVOLVING OUR MODEL OF CARE

The past 20 years have seen developments in clinical and practical care for our members. The more we learn about cystic fibrosis, the more equipped we are in treating the cause and comorbidities. While the search for a cure continues, it is essential that we meet the needs of an increasing and ageing cystic fibrosis population.

1. Acknowledging individual members' needs is at the core of our programs. Our population is diverse, no two people are on the same cystic fibrosis journey at any one point in time.
2. Advocating for health equity is paramount when it comes to supporting people whose management of their comorbidity is now their primary concern.
3. Working with clinicians to expand the core cystic fibrosis team to include specialists who support wellness i.e., occupational therapists, physiotherapists, pharmacists, social workers, and psychologists.
4. Contribute to care coordination by evaluating programs and services to ensure that we remain in lock step with the leading model of cystic fibrosis care. Continue to relieve the burden of cystic fibrosis for our members, our clinical teams and Government.

# Our Federation Five Pillars

## COLLABORATION AND ADVOCACY

1. Community Advisory Committee - engage, listen, and collaborate with our members.
2. Federal Government - access to NDIS, NDSS and the Health Care Card.
3. QLD Health - with a focus on overall well-being and mental health; align and scaffold services to support members' clinical adherence.
4. Federation - stronger together; work in partnership not only with Federation members but with all NFPs seeking to improve the livelihood outcomes for people living with cystic fibrosis.

## RESEARCH

1. ACFRT - support research projects and promote outcomes.
2. ACFDR - support the national data registry.
3. CFRL - continue to build collaboration between the two trusts.

## FUNDING

1. Create a sustainable proposition to secure the long-term needs of our charity.
2. Develop innovative campaigns to raise both awareness and donations.

3. Improve the lives of our members through our fundraising efforts.

## EDUCATION

1. Be the voice and tell the cystic fibrosis story
2. Champion knowledge on behalf of our members and families.
3. Champion CFSmart: volunteers, teachers and educators, families, and supporters.
4. Continue to work alongside Queensland Health to advocate for our cause.
5. Reach out to non-cystic fibrosis clinicians and healthcare workers to inform and educate, building a community of support.

## VISIBILITY

1. Thank and acknowledge membership advocacy.
2. Thank and acknowledge donors, grantors, and supporters.
3. Proactively engage with media to raise awareness and the profile of our cause and our plight.
4. Represent all members, no matter where they live, in an ethically, responsible, and inclusive manner.

# Our Future

## OUR GOALS AND OBJECTIVES

To increase advocacy, awareness, and fundraising for our cause through a national, unified voice.

## OUR ATTRIBUTES AND RESOURCES

1. Governance - continue to improve the effectiveness and efficiency of our governance and management processes.
2. Advocacy - continue to invest in policy development and advocacy.
3. Evidence-based practice - continue to demonstrate our impact to our stakeholders.
4. Financial resources - maintain financial sustainability. This may include:
  - a. Identifying more efficient ways to deliver services.
  - b. Partnering with like-minded NFPs and our partner Federation members.
  - c. Prudently and effectively managing investments.
5. Team - develop our culture to enable support and development of staff.
6. Stakeholders - always engage with and listen to our stakeholders.
7. Innovation - encourage innovation of services and fundraising within the charity.
8. We remain brave - we take mitigated risks, we encourage and support each other to step outside our comfort zone, to explore new and diverse opportunities, to be truth seekers and in all actions, make decisions that best serve our members.

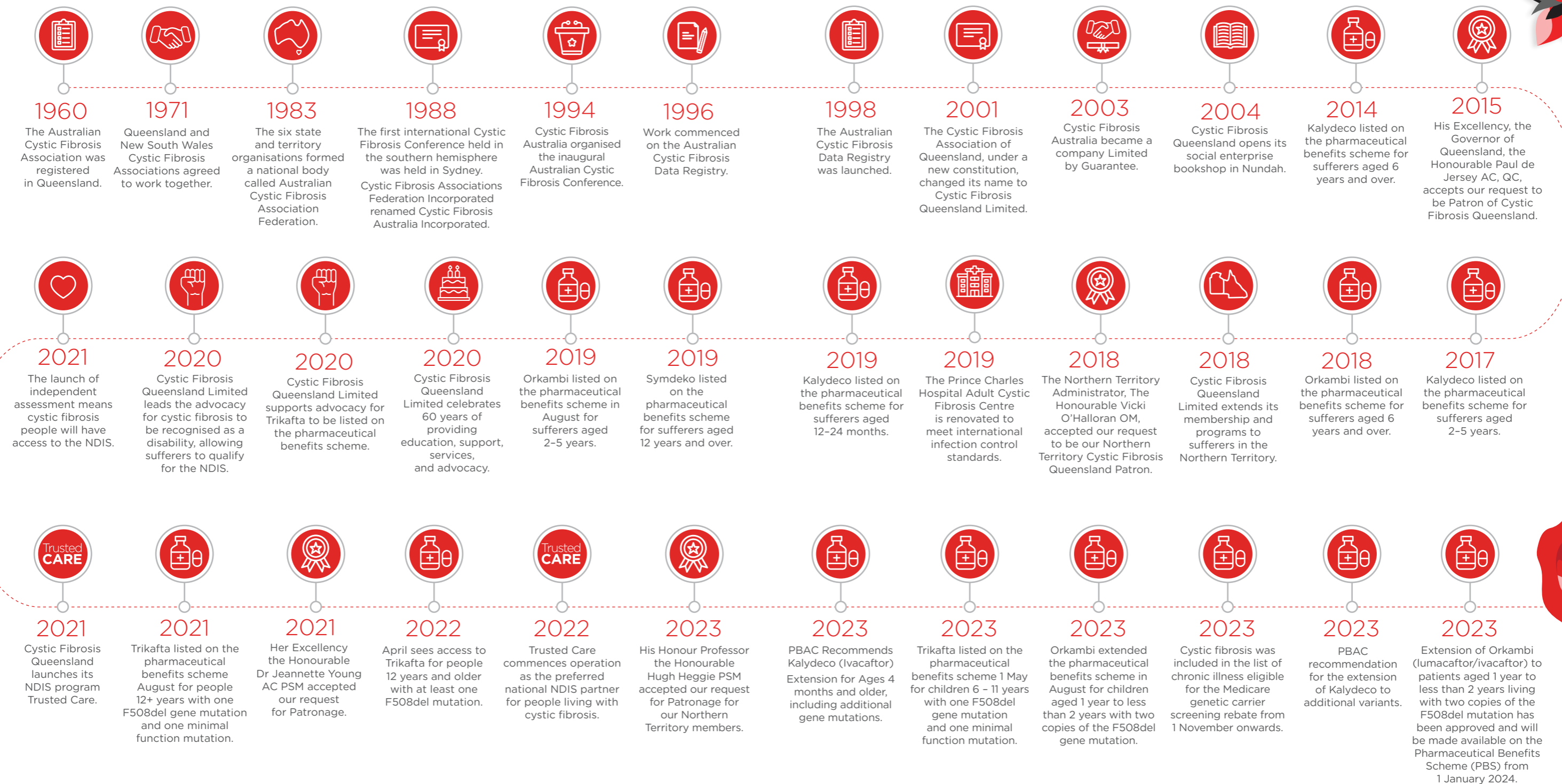
*Join the fight to breathe.*





# Our history—our timeline

Since our founding in 1960, we have worked alongside the cystic fibrosis community, clinicians, and researchers to effectively transform a genetic disease in a single generation — making cystic fibrosis one of the most amazing stories in medicine today. Read about the milestones we've achieved in pursuit of a cure for cystic fibrosis.





# Where do our members live?

QUEENSLAND, NORTHERN NEW SOUTH WALES  
AND THE NORTHERN TERRITORY

*We believe in equity  
and access to services  
and support for all  
people living with cystic  
fibrosis; no matter  
where they live.*

14 DARWIN

38 CAIRNS

43 TOWNSVILLE

30 MACKAY

36 ROCKHAMPTON

47 BUNDABERG

74 SUNSHINE COAST

58 TOOWOOMBA &  
DARLING DOWNS

266 BRISBANE

114 MORETON BAY

59 IPSWICH

143 GOLD COAST

77 NORTHERN NSW

 **CYSTIC  
FIBROSIS**  
Queensland





## A message from our Queensland Patron

As Governor and Patron-in-Chief of Cystic Fibrosis Queensland, I am proud to support an organisation that is firmly committed to serving Queenslanders who live with this complex genetic condition.

In 1960, when Cystic Fibrosis Queensland first opened its doors, most individuals diagnosed with the disease died in childhood. Fortunately, in the years since then, medical advances have seen a continually increasing life expectancy.

This welcome, yet changing landscape has required a corresponding evolution in approach, as the organisation extends its efforts to cater for a growing range of needs, to ensure that people living with cystic fibrosis have the information, equipment and help they need to manage their condition at home.

Alongside practical assistance, Cystic Fibrosis Queensland continues to be a committed champion for its members. Thanks to many years of determined advocacy, we have seen cystic fibrosis now included in the Medicare funded carrier screening program, and together with the addition of life-saving modulator therapies to the PBS, these advancements will forge a much more hopeful future for many.

Yet, while the drugs work for some, they do not suit all, and this is where Cystic Fibrosis Queensland continues to initiate the life-changing research projects that hopefully one day soon will lead to a cure.

The organisation is to be congratulated for another outstanding year, driven by innovation, and informed by the needs of the community it serves.

On behalf of all Queenslanders, I thank Cystic Fibrosis Queensland, its Board, staff, volunteers, donors and supporters for working so hard to give all Queenslanders the "right to breathe".

**Her Excellency the Honourable Dr Jeannette Young AC PSM**  
*Governor of Queensland*

## A message from our Northern Territory Patron

As Northern Territory Patron of Cystic Fibrosis Queensland, I take this opportunity to say how proud I am of your work. As a former GP, research pharmacologist and Chief Health Officer, I share your commitment and passion to ensure equitable healthcare is available to all our community members and that people living with cystic fibrosis have access to therapy and care needed, as well as driving continuing research for a cure.

We have some big advocacy wins to congratulate you on this year. Your advocacy to have modulator therapies listed on the Pharmaceutical Benefits Scheme brought terrific results. While not all people with cystic fibrosis are eligible for this therapy, we can celebrate the improvements in quality of life and health for those who have access to drugs for their gene variant. We also must also note your years of advocacy for cystic fibrosis to be included in the Medicare-funded carrier screening program, which yielded success in the past year. These are two such concrete examples of the ways that Cystic Fibrosis Queensland is supporting, improving and changing the lives of community members and their families.

While it is always difficult to run and manage a charity, it would have been a bigger challenge in today's economic climate, so I find it remarkable that you that you have balanced your social enterprise, NDIS provider businesses, fundraising and donations to create a solid basis for your work, never forgetting the community members and their families to whom you are providing support.

All my best wishes to Cystic Fibrosis Queensland, your tireless CEO, Board members, staff, volunteers, supporters and donors for your current and future work. On behalf of Territorians, thank you and congratulations.

**His Honour Professor the Honourable Hugh Heggie PSM**  
*Administrator of the Northern Territory*

# Chief Executive Officer's report



This year has been one of many highs and lows for Cystic Fibrosis Queensland. When I first joined Cystic Fibrosis Queensland, the average life expectancy for a person living with cystic fibrosis was less than 40 years. Today, modulator therapies have significantly increased life expectancy presenting new and exciting challenges for our members and our charity.

Cystic Fibrosis Queensland rejoiced and celebrated every announcement by the PBAC to list a modulator drug on the PBS. These drugs are the closest thing our community has to a cure and are quite literally life-changing for those who have access for their gene variant. Modulator therapies are designed to target the underlying genetic mutations responsible for cystic fibrosis and address the dysfunctional protein responsible for the disease.

The effectiveness of these therapies can vary depending on the specific genetic mutations present in an individual, and not all cystic fibrosis patients are eligible for modulator therapies; therefore, the search for a cure must continue. There is no doubt that these drugs have dramatically changed the landscape when it comes to support and services for people living with cystic fibrosis.

After many years of advocacy, November 2023 saw cystic fibrosis being included in the Medicare funded carrier screening program. With one in 25 Australians being symptomless carriers of the genetic disease, this is an important information piece of the puzzle for many prospective parents.

Cystic Fibrosis Queensland remains committed to advocacy as we believe that equitable access to health care is not too big a request to make on behalf of our members. And while it is wonderful to be able to share our success stories, there remains plenty to still achieve.

Disappointingly, the Federal Government is yet to decide on expanding the NDSS to people living with CFRD beyond 21 years and our Trusted Care team continues to hold many on-going discussions

with the administration of the NDIA, educating people about the comorbidities of cystic fibrosis to ensure that as many eligible people as possible can receive NDIS funded supports and services.

Like all businesses, rising inflation across 2023 has dramatically impacted our fundraising. We have seen a reduction in donations and fundraising efforts, seeing us achieve a mere 50% of our budget. But the lessons learnt from the initial 2020 covid lock down, and throughout the natural disasters of flood and fire, have held us in good stead. Our social enterprises: the Cystic Fibrosis Queensland Bookshop and Trusted Care, our national NDIS provider business, have meant that unlike many charities, we have multiple, robust income streams to allow us to manage the fundraising peaks and troughs. Consequently, I am proud to present a strong balance sheet this year which includes significant investments.

I am very grateful to the Cystic Fibrosis Queensland team whose commitment to our members continues to shine through. They all stepped up to ensure the charity's future is sustained in the long term.

With life expectancy of our members continuing to grow, so too does their changing needs. The Board remains committed to building a financially strong charity to meet the needs of our members today, whilst steadfastly remaining focused on the future. Our work is more important than ever.

I am proud of our performance and the impact we delivered to our members and to our Trusted Care clients. This annual report provides an overview of the challenges we faced as a charity and as a community during 2023, as well as the strategies we have in place for the future.

Petrina Fraccaro  
**Chief Executive Officer and Managing Director**  
*Cystic Fibrosis Queensland Limited and Trusted Care*

# Board Chair and President's report

On behalf of the Board, I am pleased to introduce the Cystic Fibrosis Queensland 2023 Annual Report. As a Professional Director and former Chief Financial Officer, I have a stake in ensuring that the charity is professionally run and financially viable. I am also a cystic fibrosis grandparent, and I am grateful for the work of Cystic Fibrosis Queensland regarding the listing of life-saving drugs on the PBS.

Like most of our community, the Board has been keenly following the modulator therapy journey which many people living with cystic fibrosis have been on; including my grandson. The changes to the demographic of our community delivered by these drugs have shaped our programs to ensure that we continue to meet community need.

Research and the search for a cure must continue and, in the meantime, our support and service programs play a critical role in the physical and mental wellbeing of our community. With no designated government funding, Cystic Fibrosis Queensland continues to remain a robust charity, delivering impact and changing lives.

Cystic fibrosis is no longer a childhood disease. As the peak not for profit community charity, we have seen an increasing need for our programs as the practicality of living with cystic fibrosis affects a growing number of adults.

With rising inflation impacting our fundraising, I am proud to report that our charity remains financially viable. Our CEO, Petrina Fraccaro, continues to remain positive and her vision and ability to pivot has certainly held us in good stead. Petrina has transformed our charity and diversified our income streams. We are a resilient charity, one which embraces change and looks forward to a prosperous future.

Our members and the people we serve are central to our decision making. Our Community Advisory Committee, made up of adults living with cystic fibrosis and the parents of cystic fibrosis children, continues to grow. These people inspire us daily and their input to our programs, services and research objectives is invaluable.

Our Cystic Fibrosis Queensland Donors Club, launched in 2020, has also continued to grow and our investments remain strong. Many contributors to the membership base of this club came from our community and their immediate contacts. I feel both humbled by and proud of this achievement, given that so many Australians are facing financial ruin brought on by the pandemic, natural disasters, and rising inflation, and at no fault of their own.

The Board would like to thank the CEO and her team for the fantastic job done over a very difficult year. The Board remains focused on strong financial outcomes for Cystic Fibrosis Queensland to allow us to deliver impact to our members. Through our NDIS provider business, Trusted Care, we will be in an even stronger position to provide the level of care and support our members need and deserve.

I am proud of Cystic Fibrosis Queensland and the role it plays in ensuring today we create a better tomorrow for people living with cystic fibrosis, and like everyone, I look forward to 2024.

Margaret Walker  
**Board Chair and President**  
*Cystic Fibrosis Queensland Limited and Trusted Care*

# CYSTIC FIBROSIS Queensland



*With no designated government funding, for many people living with cystic fibrosis, we are their only hope.*



## Our people

### OUR QUEENSLAND PATRON

Her Excellency, the Honourable Dr Jeannette Young PSM, Governor of Queensland.

### OUR NORTHERN TERRITORY PATRON

His Honour Professor the Honourable Hugh Heggie PSM, Administrator of the Northern Territory.

### CYSTIC FIBROSIS QUEENSLAND BOARD MEMBERS

Our voluntary Board supports the CEO in delivering the strategic plan and provide advice in their area of expertise.

| Name  | Position and appointment |
|---|--------------------------|
| Margaret Walker BCom, GAICD   | Chair and President 2016 |
| Petrina Fraccaro BA, Dip CS, GradCert Bus, GradDip (PR), MBus (IMC), GAICD                          | Managing Director 2020   |
| Ken Freer B. Pharm, MBA, FAIM, MAICD  | Director 2019            |
| Connie Arundel LLB, GDLP  | Company Secretary 2020   |
| Ashleigh Beauchamp BBus (Acct), CA, JPQual  | Director 2017            |
| Shane Colquhoun   | Director 2018            |
| Su-Jin Yap BA (Mass Communication), GradCert (IMC), MBUS (Prof Acct), CA                            | Treasurer 2020           |
| Heather Allan GAICD   | Director 2021            |
| Helen Barker B. App Sc., B Sc (Nutr), MBA, GAICD  | Director 2022            |
| Stephen Pavis B Social Work, PG Dip Mgt, Dip Procurement and Contracting                            | Appointed Aug 2023       |
| Jennifer Finch DipPhys, MBA, M Health, and Int Dev, GradCert Health Service Evaluation and Research | Appointed Aug 2023       |



## CYSTIC FIBROSIS QUEENSLAND TEAM MEMBERS

Working across our head office, our NDIS provider Trusted Care, and our social enterprise bookshop, a team of 8 (7.6 FTE) dedicated staff drive the organisation. Staff are supported by university internships, work for the dole candidates, and volunteers to increase capacity. By maintaining low overheads, we continue to return a high percentage of our revenue to our members through our programs.

### Cystic Fibrosis Queensland

| Name  | Position  |
|---|---|
| <b>Petrina Fraccaro</b> BA, Dip CS, GradCert Bus, GradDip (PR), MBus (IMC), GAICD | Chief Executive Officer and Managing Director, Cystic Fibrosis Queensland, and Trusted Care |
| <b>Maddison Sherriff</b> BHSc   | Services Administrator  |
| <b>Jennifer Mocker</b>  | Fundraising Coordinator   |
| <b>Rohan Wotherspoon</b> CertIII Retail   | Bookshop Coordinator  |
| <b>Shannon Nelson</b> BSocSc (Psy)  | Bookshop Coordinator  |
| <b>Kristy Windle</b> BBus (HR), B (Psy) (1st)                                     | Trusted Care Services Manager   |
| <b>Tahli Knight</b>   | Trusted Care Services Manager   |
| <b>Katrina Carey</b>  | Trusted Care Team Leader  |

## CYSTIC FIBROSIS QUEENSLAND COMMUNITY ADVISORY COMMITTEE

| Name                         | Position               |
|------------------------------|------------------------|
| <b>Maddison Sherriff</b>     | Services Administrator |
| <b>Penne Kaddatz</b>         | Cystic fibrosis parent |
| <b>Kim Holley</b>            | Cystic fibrosis parent |
| <b>Vanessa Tulenew</b>       | Cystic fibrosis parent |
| <b>Sarah Davies-Richards</b> | Cystic fibrosis parent |
| <b>Amanda Whitehead</b>      | Cystic fibrosis adult  |
| <b>Ashton Greaves</b>        | Cystic fibrosis adult  |
| <b>Connie Arundel</b>        | Cystic fibrosis adult  |
| <b>Jessica Ceasar</b>        | Cystic fibrosis adult  |
| <b>Katherine Alpert</b>      | Cystic fibrosis adult  |

## CYSTIC FIBROSIS QUEENSLAND VOLUNTEERS

| Name                    | Position             |
|-------------------------|----------------------|
| <b>Margaret Douglas</b> | Support and Services |
| <b>Andrea Varen</b>     | Office               |

## CYSTIC FIBROSIS QUEENSLAND INTERNSHIPS

| Name                     | Position             |
|--------------------------|----------------------|
| <b>Victoria Zuber</b>    | Fundraising Services |
| <b>Jie Wang</b>          | Support and Services |
| <b>Elizabeth Jacklin</b> | Support and Services |
| <b>Josephine Gehrlee</b> | Support and Services |



*Our relationship with the Government and the Department of Health has been integral to our success.*





## CYSTIC FIBROSIS QUEENSLAND BOOKSHOP VOLUNTEERS

| Name             | Position           |
|------------------|--------------------|
| Anita Janssen    | Bookshop volunteer |
| Anne Brehmer     | Bookshop volunteer |
| Boyd Newman      | Bookshop volunteer |
| Brian Milburn    | Bookshop volunteer |
| Bryan Nicolson   | Bookshop volunteer |
| Carole Rooney    | Bookshop volunteer |
| Damien Shalley   | Bookshop volunteer |
| Daniel Purvis    | Bookshop volunteer |
| Deb Kong         | Bookshop volunteer |
| Debbie Withers   | Bookshop volunteer |
| Jillian Keane    | Bookshop volunteer |
| Joanne Flint     | Bookshop volunteer |
| John Ray         | Bookshop volunteer |
| Karen Long       | Bookshop volunteer |
| Lachlan McDonald | Bookshop volunteer |
| Liz Tennant      | Bookshop volunteer |
| Louen Wright     | Bookshop volunteer |
| Lynette Weymouth | Bookshop volunteer |
| Meri Casalaina   | Bookshop volunteer |
| Roslyn Eyles     | Bookshop volunteer |
| Ruth Hurst       | Bookshop volunteer |
| Shirley Higgins  | Bookshop volunteer |
| Titi Kiswari     | Bookshop volunteer |

## Structure and management

Cystic Fibrosis Queensland Limited registered with the Australian Charities and Not-for-profits Commission (ACNC).  
All Cystic Fibrosis Queensland Directors contribute on a voluntary basis.

### Cystic Fibrosis Queensland Board



Trusted Care is supported by a team of 30 Support Workers and both Bookshop and Fundraising is supported by approx. 50 Support Workers.



## SECTION TWO

Our impact

*Cystic fibrosis  
is a life-long and  
complex disease.  
There is no cure.*





# Providing support, services and hope since 1960

There is no cure for cystic fibrosis. Thanks to better knowledge and improved understanding about the disease, cystic fibrosis people are living longer today than ever before. This means that the growth in demand for our support and service programs has never been higher. We are no longer a charity providing care just for children. More than 52% of people with cystic fibrosis in Australia are adults, and we need to continue evolving to provide support and services which reflects their needs.

Our community and clinicians help us to shape the support and services we provide through our annual membership survey and our Community Advisory Committee.

## WORKING ALONGSIDE QUEENSLAND AND NORTHERN TERRITORY HEALTH DEPARTMENTS

Cystic Fibrosis Queensland works hard to complement clinical health. Our programs have been created to specifically support clinical adherence by reducing the frequency and duration of hospital stays, and the financial burden of the disease on our members and on Queensland Health. We also provide clinics with equipment to ensure that they assist members to adhere to clinical plans.

## RESPONDING TO THE NEEDS OF OUR COMMUNITY

Today, Cystic Fibrosis Queensland raises funds, awareness, and advocates for almost 1000 families living with cystic fibrosis.

While there is no cure for cystic fibrosis, access to modulator drugs, education, and an increased understanding of the disease itself – including the impact of diet, exercise, airway clearance and infection control – has extended the lives of many people living with cystic fibrosis. Therefore,

the number of people requiring our help, both today and in the projected future, has increased.

## ADVOCACY

The role of Cystic Fibrosis Queensland is to provide support, services, and advocacy on behalf of people living with cystic fibrosis and their families. As the peak not for profit community charity, Cystic Fibrosis Queensland focuses on keeping our members well and healthy, reducing both the frequency and duration of their hospital stays. We believe that at a minimum, a person living with cystic fibrosis should be given the same access to government support and services provided to other Queenslanders living with life-shortening health conditions. On our members' behalf, we also promote the importance of infection control, especially during periods of hospitalisation.

## WELFARE

Cystic Fibrosis Queensland provides a range of welfare subsidies to alleviate the financial burden associated with the disease. All members are entitled to subsidies for hospital parking, physical activities, and medical support. In addition, for regional, rural, and remote members, we top up their out-of-pocket expenses – beyond Government entitlements – accumulated in periods of long hospitalisation.

Members can also avail themselves of services to help them to complete various government and other charitable organisations' applications for welfare subsidies. Our NDIS business, Trusted Care, helps people live an ordinary life by securing practical home and living supports as well as management of their funding.

## EQUIPMENT

Cystic Fibrosis Queensland continues to subsidise nebulisers for our members, and has introduced the funding of Queensland Health prescribed airway clearance equipment for our members who are not eligible for the Health Care Card. We also provide oxygen concentrators on loan to members with low lung capacity who are awaiting transplant and/or at the end of life.

To support our families with the management of cystic fibrosis for our youngest members, we provide trampolines – home physiotherapy disguised as play. Members are also provided with portable fans each summer, and in response to the COVID-19 pandemic, we also introduced a funding scheme for personal spirometers which remains in place for regional, rural, and remote members.

## PSYCHOSOCIAL

Living with a chronic illness is socially isolating. Infection control is always front of mind, and to help our members take a day off from living with the disease, we support all members to have a Little Day Out.

Boredom Buster Bags remain an integral part of our psychosocial support. Age and gender appropriate bags filled with educational toys are delivered weekly to cystic fibrosis children in hospital.

Cystic Fibrosis Queensland regularly secures grants to support psychosocial informal gatherings as well as Mental Health First Aid Training. Our Community Advisory Committee hosts regular online forums, connecting carers and parents as well as to share lived experiences. All of these activities are open to members and with many taking place online, are inclusive by design.

## EDUCATION

Cystic Fibrosis Queensland educates the broader community about the disease, raising awareness of chronic illness for advocacy and funding purposes. This also alleviates the need for people with cystic fibrosis, and their families, to provide explanations.

This is delivered through a range of targeted forums, as well as our participation in

government programs such as Hospital and Health Service Here to Help You clinics, Children's Health Queensland Community Collaborative, Metro North Hospital and Health Service Board Community Advisory Committee.

Newly diagnosed parents receive Cystic Fibrosis Queensland nappy bags which are full of practical equipment, including: salt measuring spoons, nappy change mats and pill kits. The bag also includes an information book, 'The First 12 Months', produced in conjunction with the Queensland Children's Hospital cystic fibrosis team, which educates parents about what to expect and how best to care for the complexities of cystic fibrosis.

CFSmart is our free online educational resource which provides information for educators, teachers, parents, students, and health professionals. The training contributes to recognised professional development points. Our team is also available to meet with schools and discuss the learning covered by CFSmart. All Cystic Fibrosis Queensland staff and volunteers complete CFSmart when on-boarding.

This year has also seen the launch of the Cystic Fibrosis Queensland Education Scholarship which directly supports post-secondary education. This scholarship is open to all people living with cystic fibrosis who are current members of Cystic Fibrosis Queensland. To be eligible, studies must be a member's first attempt at post-compulsory education or training qualifications. The study must be undertaken through a higher education institute or registered training organisation that provides recognised qualifications. Study can be completed either full or part-time, face to face or online.

In addition to our sexual health education material targeting youths, this year saw the introduction of a transition preparedness kit for rural, regional, and remote youth. Both books are available in hard copy and online.





# Building a Future for People Living with Cystic Fibrosis

## Our Impact

### OUR CYSTIC FIBROSIS QUEENSLAND COMMUNITY

**53%** The number of our members over 18 years of age is now 53%. Cystic fibrosis is no longer a childhood disease.

**59.8%** of our members are now on some form of cystic fibrosis modulator drug therapy (Kalydeco, Orkambi, Symdeko and Trikafta).

**47.2%** of our members are female, 52.8% are male and 0.2% non-binary.

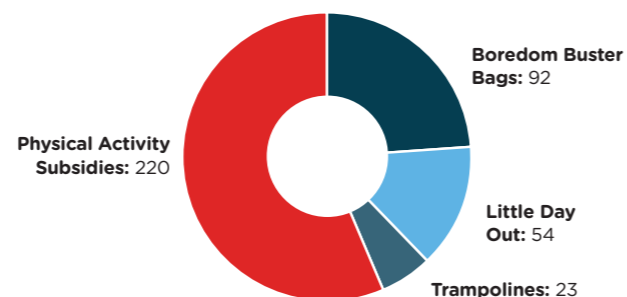
**13%** of our members are living with cystic fibrosis related diabetes.

Our youngest member is 6 months old, our oldest member is 71.

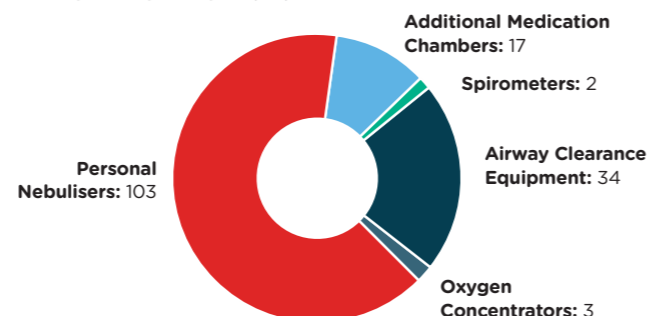
**20** of our families have more than one child living with cystic fibrosis.

### How your support has directly impacted the lives of people living with cystic fibrosis?

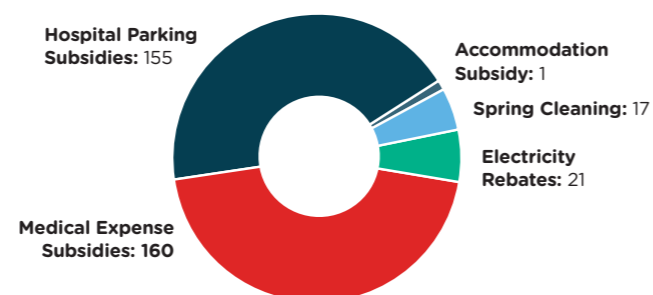
#### Improving health and wellness outcomes



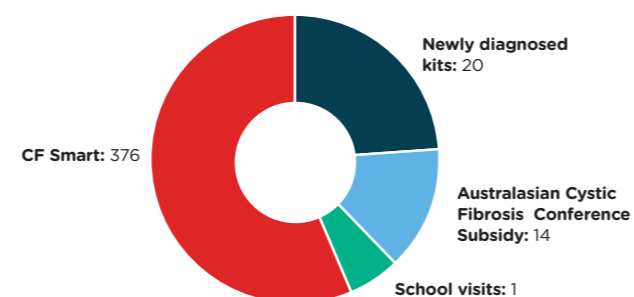
#### Providing life giving equipment



#### Alleviating the financial burden



#### Educating the community



## 2023 PROVIDED MANY REASONS TO CELEBRATE!

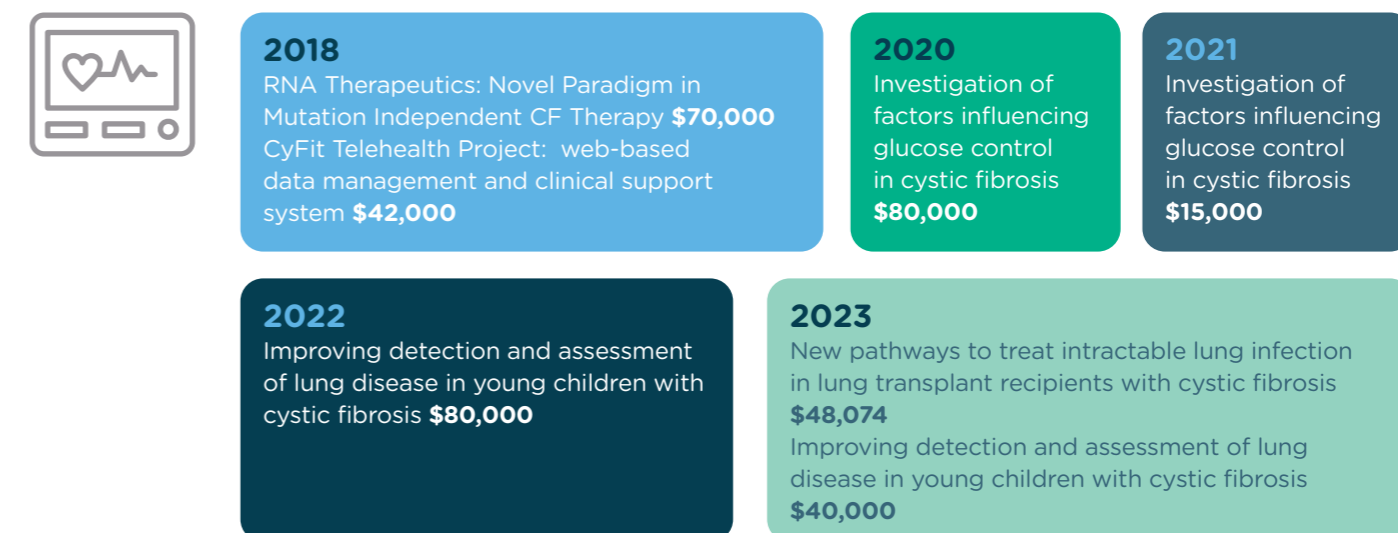
- **Trikafta listed on the pharmaceutical benefits scheme** 1 May for children 6 – 11 years with one F508del gene mutation and one minimal function mutation.
- **Orkambi extended the pharmaceutical benefits scheme** in August for children aged 1 year to less than 2 years with two copies of the F508del gene mutation.
- Cystic fibrosis was included on the list of chronic illness eligible for the **Medicare genetic carrier screening rebate** from 1 November onwards.

## RESEARCH PRIORITIES

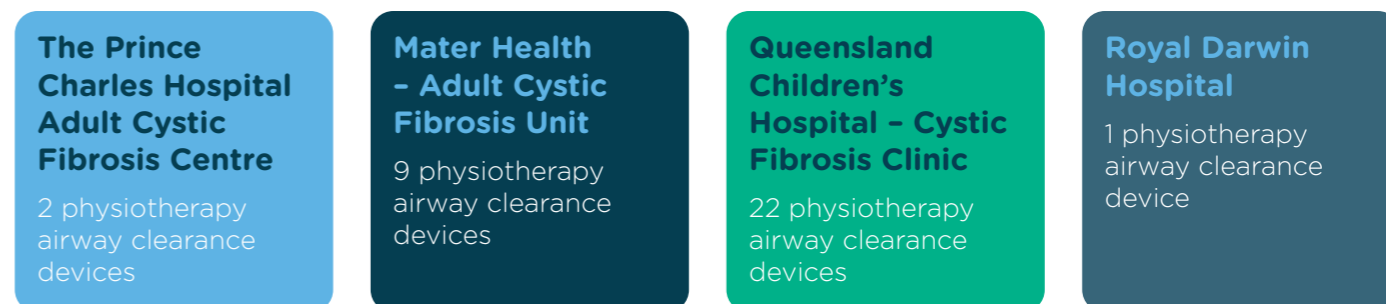
### Supporting Cystic Fibrosis Australia Programs



### Cystic Fibrosis Research Limited supporting the Australian Cystic Fibrosis Research Trust Grants



## SUPPORTING GOVERNMENT HEALTH DEPARTMENTS



# Creating a future



## AUSTRALIAN CYSTIC FIBROSIS RESEARCH TRUST

The Australian Cystic Fibrosis Research Trust continues to fund Australian cystic fibrosis researchers and in recent years, the following topics have been explored: gene therapy, cystic fibrosis transmembrane conductance regulator modulators, mental health, organoids, rare mutations, biofilms, antimicrobial resistance, macrophages, exercise and cystic fibrosis, the microbiome and gastro issues plus multiple breath washouts and CT scans.

As the cystic fibrosis survival rates improve and the community grows, the Australian Cystic Fibrosis Research Trust's commitment to funding cystic fibrosis research that will reduce the burden of the disease becomes more steadfast.

## CYSTIC FIBROSIS RESEARCH LIMITED

Cystic Fibrosis Research Limited (CFRL) was established in April 1990 by Cystic Fibrosis Queensland to administer and grow bequests and donations to further cystic fibrosis research priorities.



The objective of CFRL is to act as custodian of a 'Capital Fund' for the purpose of facilitating research into, investigation of and the eventual cure of cystic fibrosis. CFRL retains at least 10% of earnings as an inflation hedge and to grow the Capital Fund. The remainder paid out as research grants or accumulating for future research projects. Additional money may be obtained by means of grants, promises, gifts, bequests or by any other lawful means to invest any money obtained for the above purpose. The Directors of CFRL are to invest and deal with the money of the Capital Fund which are not immediately required for research funding, in a way which the Director thinks fit and is permitted by law for the investment of trust funds.

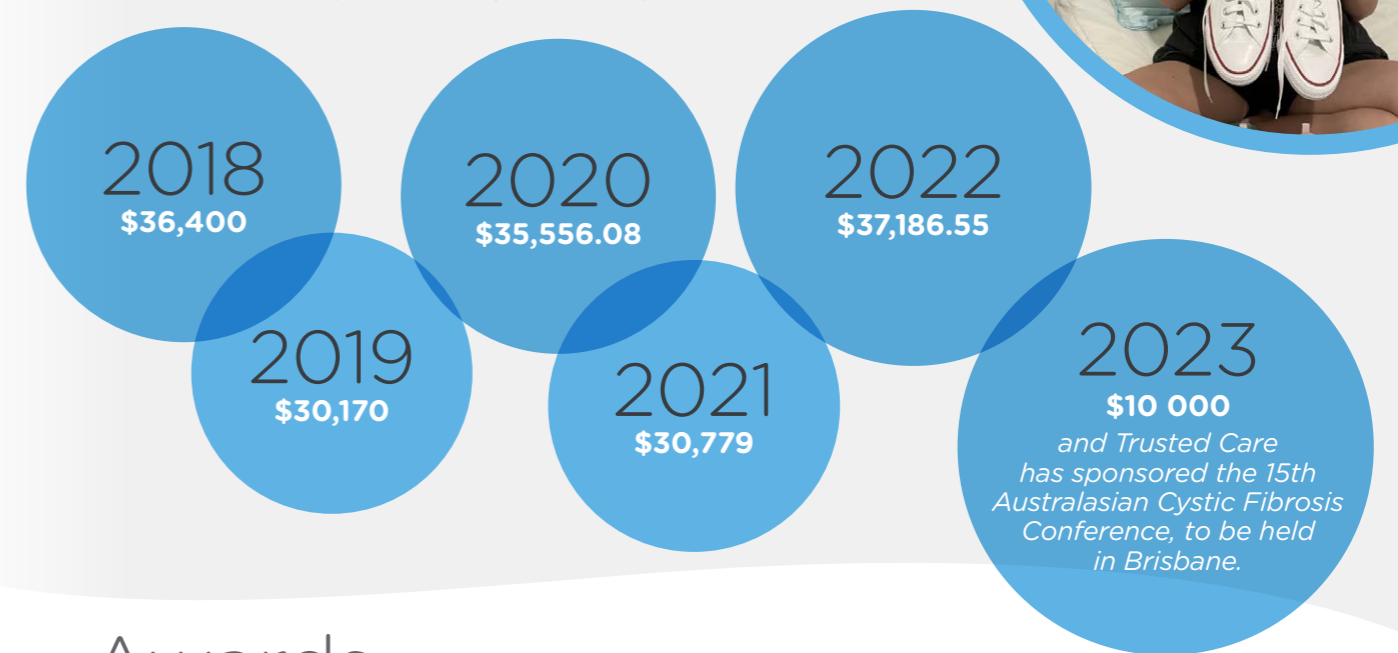
CFRL's cumulative investment in research now exceeds over \$1,000,000 in research grants funded. Most has been as seed funding in original research, many projects having started with CFRL support and graduated to major funding from organisations such as National Health and Medical Research Council and international agencies.

In assessing the merit of projects, CFRL relies on the annual scrutiny by medical assessment panels recruited by Australian Cystic Fibrosis Research Trust (ACFRT). However, the selection of which actual project it sponsors has been made by the CFRL Board.

CFRL is independently run by a board of volunteers with business expertise. Its outlays are minimal, being confined to unavoidable statutory fees. CFRL board members are supported by pro-bono specialised support in financial planning, accountancy, and audit. Cystic Fibrosis Queensland continues to support CFRL by shouldering the administration and operational costs. Cystic Fibrosis Queensland works collaboratively with both trusts to ensure funding is provided to leading cystic fibrosis research projects that will be of the greatest benefit to the most Australians living with cystic fibrosis.

## FUNDING CYSTIC FIBROSIS AUSTRALIA AND THE CYSTIC FIBROSIS DATA REGISTRY

Cystic Fibrosis Queensland directly funds Cystic Fibrosis Australia each year to assist the ongoing development of the Cystic Fibrosis Data Registry as well as other projects. The following funding has been secured through community fundraising:



## Awards

- 2023** - Australasian Reporting Award - Silver Award Winner
- 2023** - Lilley Volunteers Awards: Lilley Volunteer Award for Corporate Social Responsibility Winner
- 2022** - Australasian Reporting Award - Communication Special Award Winner
- 2022** - Australasian Reporting Award - Silver Award Winner
- 2021** - Nudgee Small Business Awards - Highly Commended
- 2021** - Australasian Reporting Award - Silver Award Winner
- 2021** - Queensland Community Foundation - Philanthropy in Focus Finalist
- 2020** - Australasian Reporting Award - Silver Award Winner
- 2019** - Australasian Reporting Award - Silver Award Winner
- 2018** - Lilley Australia Day Awards - Ted Tremayne Memorial Award Winner
- 2017** - Queensland Community Foundation - Philanthropy in Focus Winner



*Advocating for the  
entire cystic fibrosis  
community, we raise  
awareness and funds  
for our members.*

## SECTION THREE

### Accountability



*More than 60 years of providing support, services, and hope to people living with cystic fibrosis.*



## DIRECTOR'S REPORT

The directors present this report on Cystic Fibrosis Queensland Ltd for the financial year ended 31 December 2023.

## DIRECTORS

The names of each person who has been a director during the year and to the date of this report are:

Margaret Walker (Chair)

Su-Jin Yap (Treasurer)

Connie Arundel (Company Secretary)

Ashleigh Beauchamp, Shane Colquhoun, Heather Allen, Helen Barker and Ken Freer are Directors who have been in office since the start of the financial year to the date of this report, unless otherwise stated.

## PRINCIPAL ACTIVITIES

The principal activity of the company during the financial year was to advocate on behalf of, fund research, and to provide support and service programs to people living with cystic fibrosis.

## SHORT-TERM AND LONG-TERM OBJECTIVES

The company's short-term objective is to:

- Provide practical support and service programs to people living with cystic fibrosis.
- The company's long-term objectives are to:
  - Advocate and fund research with the goals of creating lives unaffected by cystic fibrosis.
  - Build a robust and sustainable charity.

## OUR STRATEGIC PRIORITIES

Cystic fibrosis is a lifelong and complex disease. As the peak not-for-profit community charity, we assist our members to live fuller and healthier lives. We do this by funding research, raising awareness of the disease, advocating for members, providing information and education, and funding practical support, service, equipment, and psychosocial programs for the increasing number of people living with cystic fibrosis.

### We commit:

1. To continue to proactively drive the agenda by being a leading voice for our community.
2. To being relentless in our pursuit of programs that increase our members' overall wellbeing and mental health.
3. To being a strong advocate for our community, increasing access and equity to service and support programs.
4. To ensure our charity remains financial.

## KEY PERFORMANCE MEASURES

The company measures its own performance using both quantitative and qualitative benchmarks. The benchmarks are used by directors to assess the financial sustainability of the company and whether the company's short-term and long-term objectives are being achieved.

# Our directors

## MARGARET WALKER | CONTINUING

### President and Chair

Margaret Walker is President and Chair of Cystic Fibrosis Queensland Limited. Margaret's previous board positions include Defence Housing Australia, Buderim Ginger, Cystic Fibrosis Australia, and Tactical Global Management. With a strong and extensive background in senior finance executive roles, Margaret brings to any board strong financial, regulatory and risk management experience as well as an informed, practical approach to corporate strategy and program monitoring. Margaret has also served the community in the past as the Queensland representative on the Cystic Fibrosis Australia Board and the Australian Cystic Fibrosis Research Trust and as a Director of Cystic Fibrosis Research Limited

## SU-JIN YAP | CONTINUING

### Director and Treasurer

Su-Jin is a manager in the Private Business and Family Advisory Division of Pitchers Partners and has over ten years' experience working in commercial and public accounting. Su-Jin works closely with business owners and managers of SMEs in various industries to provide professional services which include taxation planning and compliance, operational planning and advice, accounting software implementation and processing, as well as business advisory. Her strong understanding of government grants and experience in commercial accounting provides strong insights to the management accounts as well as financial reporting requirements for Cystic Fibrosis Queensland.

## CONNIE ARUNDEL | CONTINUING

### Director and Company Secretary

Connie Arundel is a Contracts Lawyer with the University of Southern Queensland, Toowoomba. Connie has cystic fibrosis and has received a double lung transplant. Connie brings both youth and experience to the Board as a recipient of medical services over her lifetime. She has a particular interest in ensuring that basic standards are met in health care and has empathy for people who live with the disease. Connie is also the current Director of Cystic Fibrosis Research Limited.

## ASHLEIGH BEAUCHAMP | CONTINUING

### Director

Ashleigh Beauchamp has over 10 years' experience in professional services and has been with BDO since 2012. Having worked within business services, risk advisory and financial management and consulting roles, she brings knowledge and experience of reporting, accounting, and taxation to Cystic Fibrosis Queensland Limited.

## SHANE COLQUHOUN | CONTINUING

### Director

Shane has 25 years in the real estate industry and 20 years as the director/business owner at LJ Hooker Nerang and greater LJ Hooker Solutions Gold Coast group of offices. He is a past President of the LJ Hooker Franchise Owners Council, serving within the elected group since 2010. Shane's group of offices have been proud

supporters of the cystic fibrosis community since 2003 when introduced to CF through the LJ Hooker 'Partnership in Caring' arrangement which was established in 1998. LJ Hooker Corporate and its network of offices have contributed well over \$5 million to help people with cystic fibrosis and their families.

## KEN FREER | CONTINUING

### Director

Ken has over 25 years' experience in fast-moving consumer goods with senior roles in general management, sales and marketing having worked for PepsiCo Foods International (Frito-Lay) and Lion Nathan and as Managing Director of Castlemaine Perkins. Currently he is COO with BlueMount Capital. Ken has previously held roles as General Manager for the Lexmark Indy 300, Director of Motorsport for IMG, and the CEO for Queensland Rugby and the Reds.

## PETRINA FRACCARO | CONTINUING

### Managing Director

Petrina has a depth of knowledge about the sector and understands the value of building robust communities. With an executive background in marketing, public relations, and corporate communications, she has led mergers and transformed businesses domestically and internationally in both the public and private sector. Committed to mentoring and encouraging leadership, she has been an active committee member of Fostering Executive Women, QUT's Postgraduate mentoring programs. Petrina is a current member of the Metro North Hospital and Health Service Board Community Advisory Committee and is a member of the Queensland Children's Hospital Community Collaborative. Petrina is also a member of the National Patient Organisation Network Standing Committee and a current Director of Cystic Fibrosis Research Limited. In 2022, Petrina received a Harvard Foundation Scholarship to the prestigious Strategic Perspective in Nonprofit Management program.

## HEATHER ALLAN | CONTINUING

### Director

Heather has over 25 years' experience in CEO and senior management positions in four countries - Canada, Hong Kong, New Zealand, and Australia. Heather has run her own consulting business, worked for the New Zealand Government, and was Executive Director of the largest Canadian Chamber of Commerce outside of Canada. To the board Heather brings experience in organisational leadership, strategic planning and implementation, corporate communications, advocacy, project management, financial management and program and policy development. Her last position before retirement was as CEO of Lung Foundation Australia. Heather served on the National Advisory Board to the Australian Charities and Not-for-Profit Commission (the regulatory body overseeing Australian charities and not-for-profits) from November 2017 - December 2019. In 2018, she was appointed to the Board of YMCA Brisbane and currently holds the position of President.





## HELEN BARKER | CONTINUING

### Director

Helen has worked across the public and private healthcare sector for the past 15 years, including more than 10 years in management. Helen is a Director at Axis, leading a team to deliver healthcare services to corporate organisations, and consumers under insurance schemes including NDIS. Helen brings a strong understanding of the NDIS sector, coupled with broad management experience to the Cystic Fibrosis Queensland Board.

## JENNIFER FINCH | AUGUST 2023

### Director

Jenny is a physiotherapist by background with a diverse range of clinical and health management experiences both in Australia and internationally, in less industrialised countries. She has an extensive background in health service development and workforce reform. Previous roles include leadership and senior management roles within Queensland Health, the Commonwealth Department of Health, the Department of Foreign Affairs and UNICEF.

## STEPHEN POVIS | AUGUST 2023

### Director

Steve has nearly 40 years' experience working in the human services sector with a primary focus and commitment in aged care but with significant experience in disability services. This has included direct social work service delivery as well as policy and program development and management of the aged care social services for a large London Local Authority and in the Queensland State Government in Health and Community and Disability Services. Steve's past Queensland State Government work has been as Director, Home and Community Care (HACC) and more recently led the development and implementation of the Queensland Community Support Services (QCSS) program which commenced in 2019 following Queensland's full transition to the National Disability Insurance Scheme (NDIS). After leaving state government, Steve worked for three years as an aged care and disability advisor and project officer for a major not-for-profit Aboriginal and Torres Strait Islander Community Controlled Health Organisation (ATSICCHO) operating across Southeast Queensland.

## Meeting of directors

During the financial year, ten meetings of directors were held. Attendances by each director were as follows:

### DIRECTORS MEETINGS

| NAME               | NO. ELIGIBLE TO ATTEND | NO. ATTENDED |
|--------------------|------------------------|--------------|
| Margaret Walker    |                        |              |
| Su-Jin Yap         |                        |              |
| Connie Arundel     |                        |              |
| Ashleigh Beauchamp |                        |              |
| Shane Colquhoun    |                        |              |
| Ken Freer          |                        |              |
| Petrina Fraccaro   |                        |              |
| Heather Allan      |                        |              |
| Helen Barker       |                        |              |
| Jennifer Finch     |                        |              |
| Stephen Povis      |                        |              |

The company is incorporated under the Corporations Act 2009, but now governed by the Australian Charities and Not-for-Profits Commission Act 2012 and is a company limited by guarantee. If the company is wound up, the constitution states that each Director is required to contribute a maximum of \$1 each towards meeting any outstanding obligations of the company. At 31 December 2023, the total amount that Directors of the company are liable to contribute if the company is wound up is \$1.

## AUDITOR'S INDEPENDENCE DECLARATION



### AUDITOR'S INDEPENDENCE DECLARATION UNDER SUBDIVISION 60-C OF THE AUSTRALIAN CHARITIES AND NOT-FOR-PROFITS COMMISSION ACT 2012

As auditor of Cystic Fibrosis Queensland Limited for the year ended 31 December 2023, I declare that, to the best of my knowledge and belief, there have been:

- a) no contraventions of the auditor independence requirements as set out in the *Australian Charities and Not-For-Profits Commission Act 2012* in relation to the audit; and
- b) no contraventions of any applicable code of professional conduct in relation to the audit.

**Peter Sheville, Director**  
Registered Company Auditor (16082)

14 February 2024

Level One, 180 Main Street  
Kangaroo Point, QLD, 4169

[www.cnas.com.au](http://www.cnas.com.au)

Limited liability by a scheme approved under the Professional Standards Legislation

ABN: 50 511 378 343  
T: 07 3391 6322



## Treasurer's report

I am pleased on behalf of the Board to present the financial performance of Cystic Fibrosis Queensland for the year ended 31 December 2023.

The organisation ended the year with a net profit of \$579,045 (2022: net loss of 3284,219) and reported a strong net asset position of \$923,151 (2022: \$344,106).

Although the year ended with a strong surplus, the 2023 financial year was even more challenging than the year before. Fundraising efforts continue to prove challenging with fundraising revenue declining to \$295,418 (2022: 336,158) and grant income decreased by \$25,206 (17%) in comparison to 2022. The organisation was fortunate to receive a generous bequest of \$746,719 which help ensured that services provided to members were not impacted by the overall decline in other revenue streams.

Trusted Care continued to expand and pivot to better meet the needs of members and beyond. Revenue generated by Trusted Care for 2023 year was \$987,774 (2022: 244,525) and the loss attributed to Trusted Care was \$90,695 (2022: loss of 216,982). The Board is confident that the increasing demand for a NDIS provider in the cystic fibrosis community will drive the Board's focus on growing Trusted Care.

By keeping a close eye on the monthly financials, the organisation managed to keep expenses at a level which reflected the decline in fundraising revenue without impacting the delivery of services to members. Overall expenses decreased by 17% except for Trusted Care and Support Services expenses.

The Diamond Jubilee Anniversary Donors Club has a total of 109 members as at 31 December 2023. A total of \$109,000 donors club member donations as well as additional excess funds have been invested in a portfolio managed by BDO. The investment portfolio was valued at \$642,502 as at 31 December 2023.

The Board is anticipating similar challenges in 2024 and continue to have long term investment plans to sustain a strong net asset position in order to sustain and grow services for members.

We continue to rely on the CEO's foresight and the team at Cystic Fibrosis Queensland and Trusted Care to navigate through the challenges each year. The Board would also like to thank our members, donors, volunteers and supporters for all your continued support. Last but not least, we would also like to thank the team at Right Source for their accounting assistance, BDO for their guidance in managing our investment fund, and the team at C&N Audit Services for their audit assistance throughout the period.

**Su-Jin Yap**  
Treasurer, Cystic Fibrosis Queensland



## STATEMENT OF PROFIT OR LOSS AND OTHER COMPREHENSIVE INCOME

For the year ended 31 December 2023

|  | NOTES | 2023<br>\$         | 2022<br>\$         |
|--|-------|--------------------|--------------------|
| <b>Revenue</b>   | 5     | 2,737,534          | 1,655,221          |
| Interest income  | 6     | 2,589              | 44,277             |
| Net (loss)/gain on fair value movement of financial assets | 5     | 37,001             | (37,753)           |
| <b>Total income</b>  |       | <b>2,777,124</b>   | <b>1,477,192</b>   |
| <b>Expenses</b>  |       |                    |                    |
| Administration   |       | (568,230)          | (522,028)          |
| Advocacy   |       | (38,814)           | (50,537)           |
| Cost of sales  |       | (54,141)           | (85,173)           |
| Depreciation and amortisation - ROU                        | 15    | (93,119)           | (88,800)           |
| Depreciation and amortisation - PPE                        | 13    | (21,908)           | (24,718)           |
| Events   |       | (19,823)           | (67,103)           |
| Finance cost   | 6     | (13,409)           | (16,267)           |
| Fundraising and marketing                                  |       | (144,440)          | (255,012)          |
| Occupancy  |       | (8,645)            | (50,131)           |
| Support services   |       | (157,081)          | (119,702)          |
| Trusted Care costs   |       | (1,078,469)        | (481,940)          |
| <b>Total expenses</b>                                      |       | <b>(2,198,079)</b> | <b>(1,761,411)</b> |
| <b>Profit (loss) before income taxes</b>                   |       | <b>579,045</b>     | <b>(284,219)</b>   |
| Income tax   |       | -                  | -                  |
| <b>Total comprehensive income for the year</b>             |       | <b>579,045</b>     | <b>(284,219)</b>   |

## STATEMENT OF FINANCIAL POSITION

For the year ended 31 December 2023

|                                | NOTES | 2023<br>\$       | 2022<br>\$     |
|--------------------------------|-------|------------------|----------------|
| <b>Assets</b>                  |       |                  |                |
| <b>Current assets</b>          |       |                  |                |
| Cash and cash equivalents      | 8     | 324,881          | 75,555         |
| Trade and other receivables    | 9     | 21,926           | 13,061         |
| Inventories                    | 11    | 10,111           | 12,704         |
| Contract assets                | 12    | 39,625           | 2,270          |
| Other                          | 14    | 12,274           | 4,788          |
| Total current assets           |       | 408,817          | 108,378        |
| <b>Non-current assets</b>      |       |                  |                |
| Other financial assets         | 10    | 642,502          | 340,688        |
| Property, plant and equipment  | 13    | 42,232           | 60,439         |
| Right-of-use assets            | 15    | 194,412          | 283,672        |
| Other                          | 14    | 23,772           | 14,865         |
| Total non-current assets       |       | 902,918          | 699,664        |
| <b>Total assets</b>            |       | <b>1,311,735</b> | <b>808,042</b> |
| <b>Liabilities</b>             |       |                  |                |
| <b>Current liabilities</b>     |       |                  |                |
| Trade and other payables       | 16    | 100,493          |                |
| Employee benefits              | 17    | 34,476           | 41,349         |
| Contract liabilities           | 12    | 13,972           | 36,710         |
| Lease liabilities              | 15    | 99,377           | 91,532         |
| Total current liabilities      |       | 248,318          | 244,016        |
| <b>Non-current liabilities</b> |       |                  |                |
| Employee benefits              | 17    | 27,332           | 10,694         |
| Lease liabilities              | 15    | 112,934          | 209,226        |
| Total non-current liabilities  |       | 140,266          | 219,920        |
| <b>Total liabilities</b>       |       | <b>388,584</b>   | <b>463,936</b> |
| <b>Net assets</b>              |       | <b>923,151</b>   | <b>344,106</b> |
| <b>Equity</b>                  |       |                  |                |
| Retained earnings              |       | 923,151          | 344,106        |
| <b>Total equity</b>            |       | <b>923,151</b>   | <b>923,151</b> |



*A child is born  
with cystic fibrosis  
every four days.*

## SECTION FOUR

Support our cause



## Raising funds and awareness

Cystic Fibrosis Queensland continues to innovate and pivot when it comes to creatively promoting fundraising campaigns. Digital platforms became the standard for all peer-to-peer fundraising and direct charitable donations. We are thankful to our major donors and community fundraisers for embracing the digital transformation and continuing their generous support to secure on-going services delivered by Cystic Fibrosis Queensland.

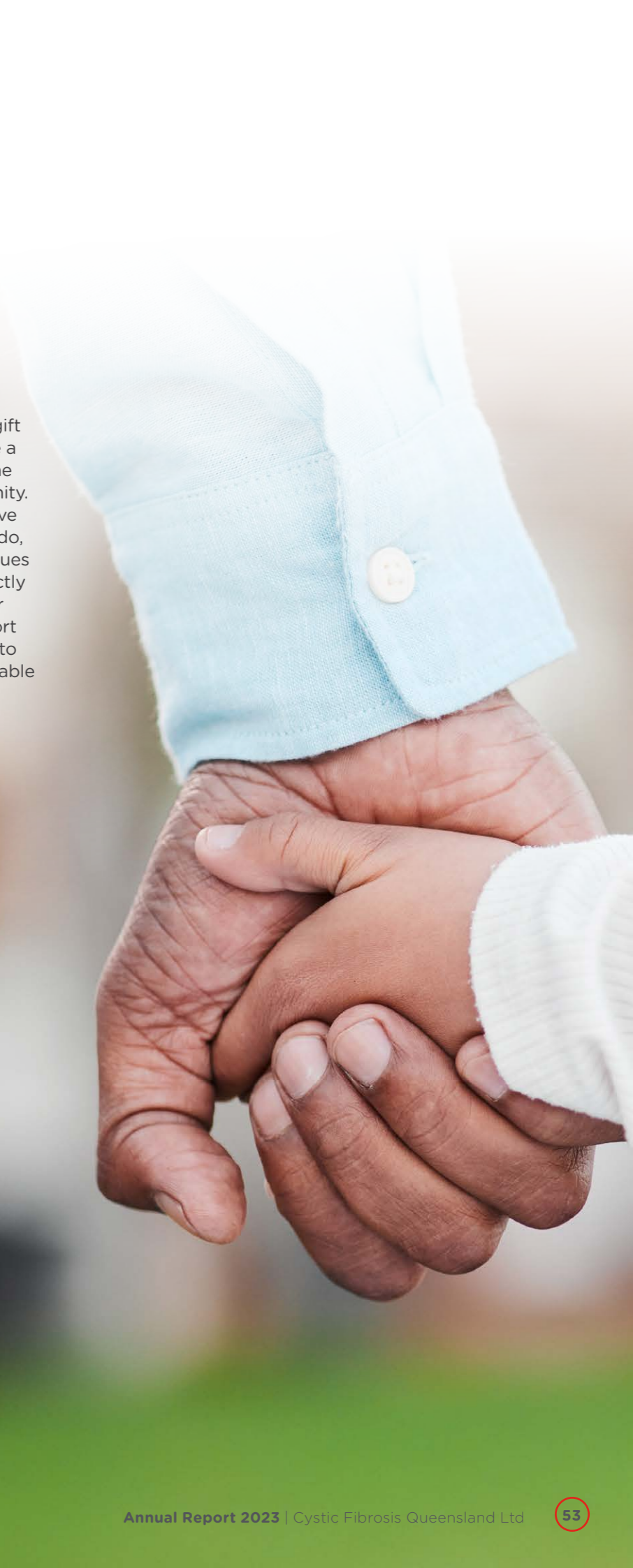
### THANK YOU TO OUR MAJOR DONORS AND COMMUNITY FUNDRAISERS

| OVER \$1,000               | OVER \$5,000                   |
|----------------------------|--------------------------------|
| Daniel Mathews             | Hayden Fraser                  |
| Georgie Valentine-Smith    |                                |
| Ella Sinclair              | OVER \$10,000                  |
| Nikki Telford              | Alan Tunks                     |
| Mitch Jarrett              | Vivienne Court Trading Pty Ltd |
| Andrew Lister              | Grady Thomson and Natalie Wood |
| Dianne Lelliot             | Special Mention                |
| Pamela and Paula Roberston | Allan and Jenny Tunks          |
| Rosemary Locke             | Grady Thomson and Natalie Wood |
| Frank Reynolds             | Karen Mowles                   |



### WILLS WEEK

Leaving Cystic Fibrosis Queensland a gift in your Will is a wonderful way to leave a legacy and the gift of life to some of the most vulnerable people in our community. This may even be the one chance to give the largest gift of your life, and as you do, to show your family and friends the values you hold most important. You will directly help Cystic Fibrosis Queensland deliver practical equipment and welfare support programs, fund research and continue to advocate for the vulnerable in an equitable manner.





## CYSTIC FIBROSIS QUEENSLAND DONORS CLUB

What started as an investment account to acknowledge our 60 years of service to our community soon grew from strength to strength. Today we have 65 members.

Thank you to all who are committed to ensuring that our charity will retain funds to purchase life-giving equipment for our most vulnerable members. Membership of the donors' club remains open and for as little as \$1 000.00 you can invest in the future of our charity.

### THANK YOU FOR JOINING OUR DONORS CLUB

|                                    |                               |   |   |
|------------------------------------|-------------------------------|---|---|
| The Wood Family                    | Fernleigh Family              | Kate Edwards                              | Rosemary Locke                              |
| William Bennett                    | Freer Family                  | Katherine Gibson                          | Rotary Club Ashgrove/The gap                |
| Yandina United Football Club       | Frank Reynolds                | Kim Colyer                                | Sandra Elliot                               |
| Anonymous                          | Fundraising Services          | Kimberly Musolino                         | Sandra Mitchell                             |
| Anonymous                          | George Dyer                   | Libby Nash                                | Seabeen Tapas Bar and Resturant             |
| Anonymous                          | Grant Brown                   | Kishtoo Family                            | Sealy of Australia                          |
| Andrew Eaton                       | Gary Holmes                   | Leanne Judith Campbell Memory             | SEME Solutions                              |
| Anton Gaudry                       | Geoffrey Watson               | Leonie, John and the late Emma Markwell   | Sewell Family                               |
| Adrian Narayanan                   | Gaudry Foundation - Give 52   | Les Hanifin                               | Simon and Kylie Drury                       |
| Archers Family                     | Goodstart Coopers Plains      | Leon Fitzharris                           | Shane Colquhoun                             |
| Andrew Doolan                      | Hammertime Kitchens Pty Ltd   | Lesley Johnson                            | Son's of the Southern Cross Motorcycle Club |
| Anne Stewart                       | Hazen and Jeanette Rota       | Les Clarence in Memory of Nathan Clarence | SSS Austraila                               |
| Andrea Fernliegh                   | HealthMatch                   | Loose Kid Industries Pty Ltd (LSKD)       | Seven Toomey                                |
| Amanda Howard                      | Helen and Gordon Jardine      | Lowood Slimmers                           | Stewart Family                              |
| Archers Army                       | Harrison Smith                | Maker Pt Douglas                          | Sunbather                                   |
| Asher Best Family & Friends        | HLB Mann Judd                 | Melcolm Davidson                          | Suncorp Bank                                |
| Australasian Order of Old Bastards | Holley Family                 | Mango Hill State School                   | Tamborine Village Lions Club                |
| Beavis & Bartels Plumbing PTY LTD  | Homely Group                  | Mariangela Stagnitti                      | Team Isla and Maeve                         |
| Bendigo Bank                       | Holley Cleaning Group         | Maunuri Gunawardena                       | Tony Cleland                                |
| Brett Twycross                     | Ian George-Plate Marketing    | Markus Balodis                            | Telford Family                              |
| Bracken Ridge Tavern               | Ian McDonald                  | Maxine Russell - 4 Points Insurance       | Terry McAndrews                             |
| Breathe 21 Healthcare              | Imperial Outlanders Australia | Michael White                             | Trent Stark                                 |
| Christine Deambrogio               | In memory of Jake Stark       | Mediplast                                 | Trina White                                 |
| Cindy Clenton                      | In memory of Amanda Romeo     | Micheal Jensen                            | Tom Boadle                                  |
| Carol Harrison                     | Jackson McLean                | Mr David Schwarz                          | The Flint Family                            |
| Conrad Almeida                     | Joy McGuiness                 | Mrs Betty Dunn                            | The List Fmaily                             |
| Carey and Emmalee Fell             | Jaimee Schmburg               | Raine Ward                                | The Nelly Group                             |
| Connie Arundel                     | Joanne Chapman                | Neil Baker and Paul Jones                 | Thompson Family                             |
| David Romeo                        | Joanne Flint                  | Peter Davis                               | William Bennett                             |
| David Holmes                       | Justine Crompton              | Penni Drummond                            | Whitney Webb                                |
| Dion List                          | Janet Newton                  | Peter Baker                               | Toni Minis                                  |
| Debbie Nankivell                   | Janice Paris                  | Piccones IGA                              | Vertex Pharmaceuticals                      |
| David Lodge                        | Jock Given                    | Pitcard Partners                          | Strategix Training Group Pty Ltd            |
| David Lodge                        | Juanita Jensen                | Reefpeak Pty Ltd                          | The Estate of Gerri Underhill               |
| Donna Holley                       | K Ganley                      | Renee Evans                               | The MacAndrews Family                       |
| Dreambrogio Family                 | Katy Balodis                  | Richard Spurrell                          |   |
| Dianne Lelliot                     | Kylie Lamprecht               | Ronald and Glenyce Black                  |   |
| Drury Farming Co                   | Karen Mowels                  |   |   |
| Emmelee Fell                       | Kay Dunn                      |   |   |
| Edwards Family                     | Kenneth Freer                 |   |   |

## 65 ROSES FOR CYSTIC FIBROSIS MONTH OF MAY

Our signature fundraising month remained strong ensuring we were able to provide our most vulnerable members with nebulisers, spirometers, and airway clearance equipment in between lock downs! Thank you to everyone who signed up for a 65-themed challenge and those who purchased a real and/or virtual rose.

### CYSTIC FIBROSIS QUEENSLAND WOULD LIKE TO THANK THE FOLLOWING 65 ROSES FOR CYSTIC FIBROSIS FUNDRAISERS:

|                             |                   |                   |
|-----------------------------|-------------------|-------------------|
| Soo Hart                    | Dave Howarth      | Steps with Imogen |
| Tim Pitt                    | Evie's Dream Team | Jame's Team       |
| Grady Thompson (Team Teddy) | Kim Holley        | Mitch Jarrett     |
| Eve Daley                   | Mark Dunkley      | Chloe Absalom     |
| James Hills                 | Hannah Dunkley    | Anastasia Ward    |
| Georgie Valentine-Smith     | Karen Loughlin    | Kristy White      |
| Ella Sinclair               | Jess Caesar       |                   |

A special thank you to all the members of Parliament who wore and tweeted the international symbol for our cause - a rose - during May, and to all the councils and communities who lit the night sky red during May.

## PRO BONO SUPPORT

For a small charity like Cystic Fibrosis Queensland, the gift of services and products is incredibly valuable as it means that we do not use previous fundraising to procure these items.

### THANK YOU TO OUR GENEROUS SUPPORTERS WHO HAVE SUPPORTED OUR CAUSE:

|                            |                           |
|----------------------------|---------------------------|
| Centurion                  | Queensland Police Service |
| Eden Valley Health Retreat | Tangalooma Island Resort  |



# Our social enterprises

## CYSTIC FIBROSIS QUEENSLAND BOOKSHOP

The Cystic Fibrosis Queensland Bookshop is a well-established community hub located near the centre of Nundah. This year the bookshop hosted many NDIS community centric activities. We welcomed many new faces some of whom have even joined our fantastic volunteer team.

The support we have received in public donations of pre-loved books has enabled us to drastically increase the stock we have on display at any given time. The continuing aid from the Lord Mayor's Charitable Trust, and the donations of books that have been removed from the Brisbane City Council Libraries has also provided us with a constant supply of new stock. Of these Council sales, 30% of the funds raised are returned to council initiatives, allowing our efforts here to give back to the Brisbane community through the Lord Mayor's Charitable Trust.

The bookshop plays an important role in community fundraising, collecting donations to provide for the Boredom Buster Bag initiative. The donations received in support of this program have seen a sharp increase in 2023, as has the support for our Christmas giving appeal, providing age and gender appropriate toys as bag inserts.

As a social enterprise, the bookshop also hosts its own community events, bringing together

volunteers, council, and community. Volunteers continue to be the lifeblood of our operation and are chiefly responsible for the bookshop's place as a vibrant part of the social fabric of the Nundah community. Their hard work this year has led to increases in both revenue and market reach for the bookshop.

Our bookshop is a truly heart-warming place. Our dedicated team embraced the challenges of this year, connected Cystic Fibrosis Queensland with the wider community, supported our fundraising events, and have become local ambassadors for our cause.

## TRUSTED CARE

Our NDIS business, Trusted Care, celebrated two years of operation in July 2023. It remains as the only NDIS focused on the needs of people living with cystic fibrosis, no matter where they reside in Australia. This is a first for our sector, and it is hoped that the care provided by our support workers will be life-changing for people living with cystic fibrosis.

Trusted Care's clients will come from our community as well as all eligible NDIS participants. The revenue generated by the social enterprise will be returned to cystic fibrosis people through improved services, therefore increasing the support available to our members.

[trustedcare.org.au](http://trustedcare.org.au)

# Trusted CARE



*Volunteers continue to be the lifeblood of our operation.*



## Grants

Cystic Fibrosis Queensland receives support from a small group of philanthropic individuals and organisations that share our belief in our cause. The generosity demonstrated by these people enables Cystic Fibrosis Queensland to lighten the financial, emotional, and physical burden for our members who are living with cystic fibrosis.

Arana Leagues Club

Australia Post

Bird Healthcare

Gambling Community Benefit Fund

Gold Coast Community Fund

Harcourts Foundation

James Frizelle Charitable Foundation

Kedron Wavell

Lord Mayors Better Suburbs Grant

Lord Mayors Charitable Trust

Lord Mayors Community Fund

Mediplast

QCoal Foundation

Queensland Community Foundation Toowoomba

Queensland Check Up

Queensland Mental Health Commission

Queensland Mental Health Week

Rare Voices Australia

Santos

Sci-Fleet Toyota

Vertex Pharmaceuticals

William Angliss Charitable Foundation

## Memberships

To raise our awareness, remain informed about our sector and to influence advocacy, Cystic Fibrosis Queensland or Trusted Care hold the following memberships:



*Thank you, volunteers.  
Your contribution equates to a saving of almost \$93,000 in wages.*

## Recognising our volunteers

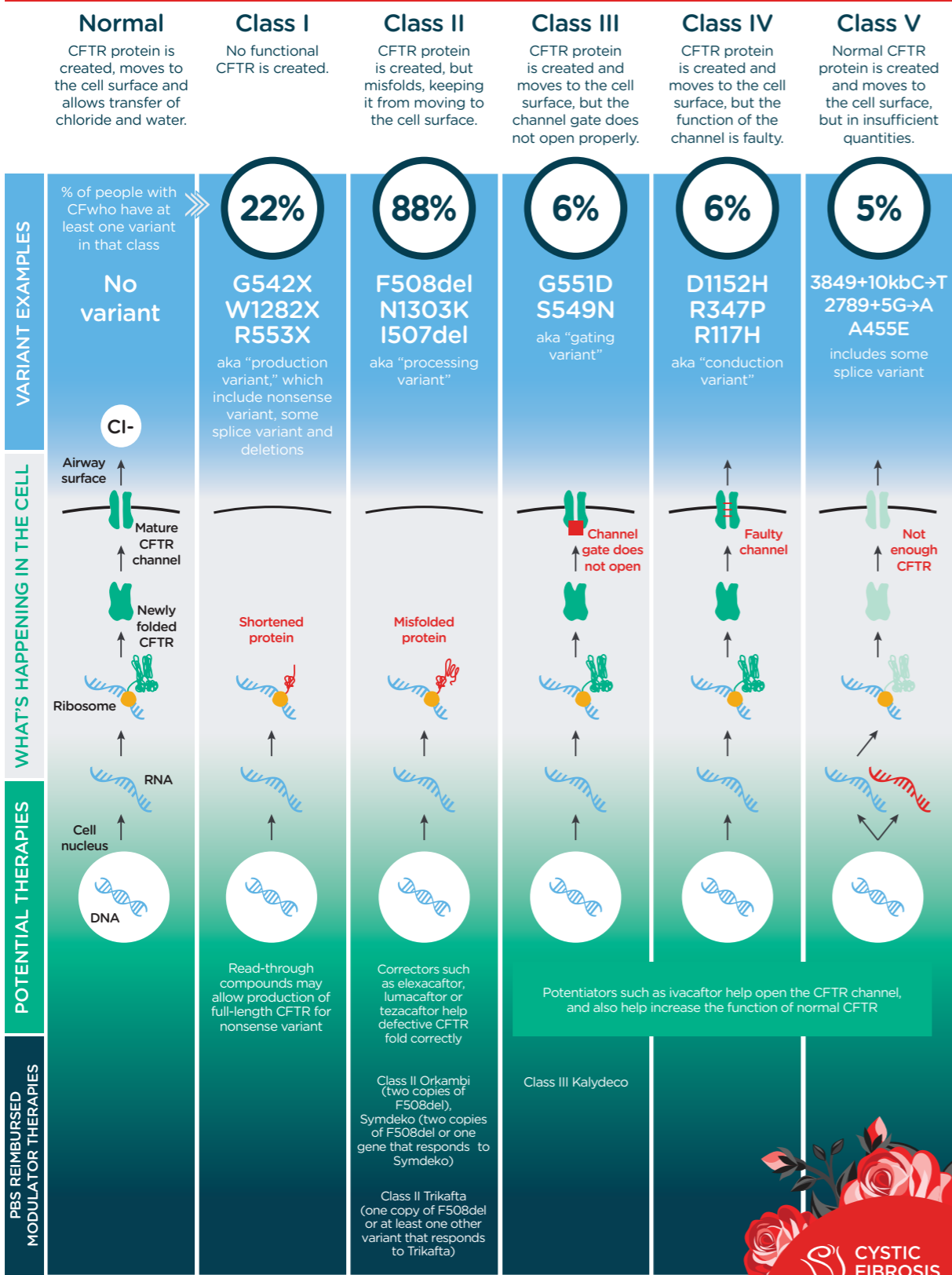
At Cystic Fibrosis Queensland, we believe that our volunteers are an important part of the wider cystic fibrosis community. Each person who contributes to our cause donates their time and their individual skills to help us grow our impact in our community. We have dedicated volunteers who make our jobs just that little bit easier and add a lot of joy and colour to our lives.

Volunteering is not about money. Volunteering is about giving, contributing, and helping other individuals and the community at large. It is working with others to make a meaningful contribution to a better community. At Cystic Fibrosis Queensland our volunteers undertake all office and reception duties, they prepare and pack our Boredom Buster Bags for our weekly delivery to children in hospital, and university students work on our marketing and social media campaigns. At the Cystic Fibrosis Queensland Bookshop our volunteers stack shelves and provide front line retail customer service. We also have an increasing number of people volunteering online and using social media to raise the profile of our cause and fundraising.

People volunteer with Cystic Fibrosis Queensland for an endless variety of reasons. Many people want to gain experience, acquire new skills, meet new people, or expand their network of contacts to get a new job or start a career. Others just want to give back to their community, to help a friend or promote a worthwhile activity. Volunteering jobs are as rich and diverse as the people who volunteer.

We are always seeking to make sure that volunteering with Cystic Fibrosis Queensland is not only rewarding, but easy to do. All volunteers complete CFSmart as part of the registration process, raising their awareness of the cause that they are supporting.

# CFTR VARIANT CLASSES



References - Cystic Fibrosis Foundation (2017) Know Your CFTR Mutation. Retrieved 3 July 2023 from <https://www.cff.org/sites/default/files/2021-12/Know-Your-CFTR-Mutations-Infographic.pdf>



*Working in partnership with clinicians, Cystic Fibrosis Queensland seeks to reduce the frequency and duration of our members' hospitalisations.*



Thank you

Thank you to our major donors and grant makers

# CYSTIC FIBROSIS QUEENSLAND LIMITED

## *Embracing Tomorrow*

### **Become a Cystic Fibrosis Queensland member**

- Volunteer your time
- Donate to our cause
- Leave a gift in your will
- Support an event
- Hold a fundraiser
- Become a corporate partner
- Support 65 roses for cystic fibrosis month of May
- Join 65 roses cystic fibrosis workplace giving
- Join our Cystic Fibrosis Queensland Donors Club

+61 7 3359 8000  
[www.cfqld.org.au](http://www.cfqld.org.au)  
[admin@cfqld.org.au](mailto:admin@cfqld.org.au)

### **TRUSTED CARE**

Your first choice for NDIS support

1800 670 990  
[www.trustedcare.org.au](http://www.trustedcare.org.au)  
[services@trustedcare.org.au](mailto:services@trustedcare.org.au)

ACN 010 549 667  
ABN 97 010 549 667  
NDIS PROVIDER 4050068857

