



2022 ANNUAL REPORT

A NEW TREATMENT FOR CYSTIC FIBROSIS

**Trikafta: A New Hope
for Cystic Fibrosis**



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About us

What is Cystic Fibrosis?

Cystic Fibrosis (CF) is the most common recessive genetic condition affecting young Australians. Primarily affecting the lungs and the digestive system, CF results in ongoing damage to lung tissue and can also cause malnutrition, bowel and liver disease, diabetes and osteoporosis.

Who are Cystic Fibrosis South Australia?

Cystic Fibrosis South Australia Inc (CFSA) is the single representative body for all people with CF in South Australia.

We started our journey in 1970 when a group of passionate parents of children with CF joined together to create a support group. They recognised that working together to access the best care and medications would give their children the best chance at life.

Organisation Details

CFSA Staff

As at 31/12/2022

Christine Umapathysivam **Chief Executive Officer**
Allison Smith **Board and Executive Support**
Carolyn O'Grady **Member Support Coordinator**

CFSA Patrons

As at 31/12/2022

The Honourable Frances Adamson AC and Mr Rod Bunten
Phil Hoffman

Business/Charity Licences

Australian Business Number 32 285 368 919
Deductible Gift Recipient 900 137 117
Charity Licence Number CCP3218

Registered Office

Level 3 / 85 North East Road
Collinswood South Australia 5081
Telephone: 08 8221 5595
Email: cfsa@cfsa.org.au

About this report

This report is designed to give our stakeholders a comprehensive overview of the activities and finances of Cystic Fibrosis SA Inc. in 2022

Services Delivered in 2022

We help people living with cystic fibrosis in South Australia to lead better and longer lives.

Our services include medical support, health & wellbeing, employment, education and community support. They are designed, not only for those living with CF, but also to help parents, siblings, grandparents, friends, partners or spouses and families. **In 2022 CFSA had 290 Financial Members**



38

CFSA Members received pharmaceutical subsidies totalling over \$11,590

63

CFSA Members received a fitness subsidy with a total value of over \$24,126

82

CFSA Members received new equipment or parts, totalling of \$22,270



Over \$19,409 was provided in financial assistance to members.

President's Report



The highlight of 2022 was the listing of Trikafta for people over the age of 12 on the Pharmaceutical Benefits Scheme (PBS) bringing this life-changing drugs within (financial) reach of many of the members of Cystic Fibrosis Community. As the prescriptions were written, Members started to report the benefits of Trikafta and the sorts of new activities in which they were able to participate, sometimes for the first time. This encouraged further advocacy for the listing of Trikafta for children between the ages of 6 – 11 and in November 2022, the Pharmaceutical Benefits Advisory Committee (PBAC) made a positive recommendation to Minister Mark Butler MP and the scene was set for a new round of advocacy.

Although a wonderful addition to the treatment armoury in the management of CF, Trikafta is not the answer for everyone, especially for those with rare mutations, and acknowledging this, the Board of CFSA invested in a number of research projects and more information about these is provided later in this report.

Even though the COVID Pandemic is still lurking, and continued to negatively impact on our capacity to hold fundraising events, a more fully vaccinated and informed population resulted in the removal of a number of government mandates and this (finally)

enabled the holding of the annual Memorial Service in the beautiful gardens of Government House. On a day when the weather was made to order, the event was attended by the our joint Patrons, the Governor of South Australia the Honourable Frances Adamson AC and her husband, Mr Rod Bunten. Live music was provided by a small ensemble from our charity partners, the Adelaide University Medical Orchestra (AUMO). This is an orchestra completely organised and filled by medical students. It was a lovely addition to the service conducted by Dr Carl Aiken OAM.

The 50th Anniversary of the formation of CFSA could not be celebrated on the date it occurred due to the COVID Pandemic. In 2022, restrictions had eased sufficiently that we were able to finally mark this significant occasion. Our Patrons, the Governor of South Australia, the Honourable Frances Adamson AC and her Husband, Mr Rod Bunten hosted a reception at Government House to honour the organisation's service to the CF Community. The contributions made by our community driven organisation were acknowledged and the event was attended by the State Minister for Health and Well-being, Mr Chris Picton MP and the Shadow Minister for Health Ms Ashton Hurn MP , Members of the current Board of CFSA, clinicians from the Royal Adelaide and Women's and Children's Hospital and supporters and donors from the past and present. Our (commercial) Patron, Mr Phil Hoffman AM was represented by his wife, Mrs Hoffman. It was a wonderful occasion to celebrate the many advances over the last 50 years in the understanding and treatment of Cystic Fibrosis and the role that CFSA has played providing support and advocacy for our Members.

Throughout the year, there were a number of changes to the membership of the Board and I would like to take this opportunity to thank Gloria Lancione and Floyd bullen Nichols for their contributions. Both Gloria and Floyd added their distinct community insights to the considerations of the Board. To operate at its most effectiveness, the Board relies on a combination of professional and community based input and in 2022, we have had the benefit of both. I wish both Gloria and Floyd success in future endeavours and on behalf of the CF Community thank them for their contribution to CFSA.

Peter Summers OAM KJSJ
President

CEO's Report



No consideration of 2022 would be complete without acknowledgement of the impact of the listing of Trikafta on the Pharmaceutical Benefits Scheme (PBS) which, for the first time, brought this innovative modulator drug into the financial reach of People Living with CF (PLWCF). The listing was effective as of 1 April 2022 with promises of better health and less hospitalisations and (potentially) an extended life expectancy.

Although it all seemed to happen suddenly and in a flurry of activity, this new reality was the consequence of persistent advocacy from members of the CF Community who signed and circulated petitions, made personal representations to their local member, wrote letters to the Minister for Health and Wellbeing, and gave presentations to groups of Parliamentarians to lift the awareness of the hopes and aspirations held by the CF Community.

The listing of Trikafta on the PBS for People Living with CF who had at least one gene mutation and who were over 12, by Minister Greg Hunt MP in the last week before the end of the Morrison government and this was a great legacy for the CF Community.

Our clinicians and nurses at the Royal Adelaide Hospital sprang into action working hard to ensure that all eligible patients had a prescription for the new medication and, as always, we thank them for their support of the CF Community.

Since that time, it has been a pleasure to receive many emails

and posts sharing the sort of the new (never considered a possibility) plans and activities our Members are embracing.

And so what next?

I wish to foreshadow that in 2023 we will have a listing of Trikafta for the younger members of the CF (6-11) Community firmly in our sights. We are off to a flying start with the Pharmaceutical Benefits Advisory Committee (PBAC) recommending subsidising Trikafta for children aged 6-11 to the Minister at its meeting in November 2022.

COVID is still with us and continues to have a negative impact on our fundraising activities. In response to the changing circumstances and various government mandates, CFSA trialled a number of important activities this year using COVID safe principals. Importantly, after a couple of false starts, we were able to hold the Annual Memorial Service in the beautiful gardens of Government House. Each guest was provided a small box of refreshments and a mask. The event was held outside and in a well-ventilated marquee.

We were also honoured to attend a Reception hosted by the Governor, the Honourable Frances Adamson AC and her husband Mr Rod Bunten. It was a fitting way to mark the 50th anniversary of the formation of CFSA.

Every now and again CFSA receives bequests from a supporter and, in 2022, we received a generous bequest from Mrs Kathleen Billingsley. Including CFSA in your Will leaves a wonderful legacy. Although Mrs Billingsley did not have CF and did not have any children with CF, her sister's daughter had CF. When her sister died, she left a sizeable portion of her estate to her sister, Mrs Billingsley and this estate formed the majority of the money donated to CFSA.

I am taking this opportunity to acknowledge her generosity. I also take this opportunity to thank everyone who nominated CFSA to receive donations, "in lieu of flowers" as part of their funeral arrangements. It is a wonderful gift to the future.

"A society grows great when old men plant trees in whose shade they shall never sit."

Greek Proverb.

Christine Umapathysivam
CEO

Strategy 2022-2025

The CF community is, and will always remain, the focus of CFSA. We will continue to provide support, advocacy, promotion, and fund research relevant to people affected by CF.

Our 2022-2025 strategy will guide us in meeting the needs and expectations of the CF community. The plan will be reviewed regularly to ensure that we remain on track whilst remaining agile enough to respond to the changing needs of our members and the CF community.

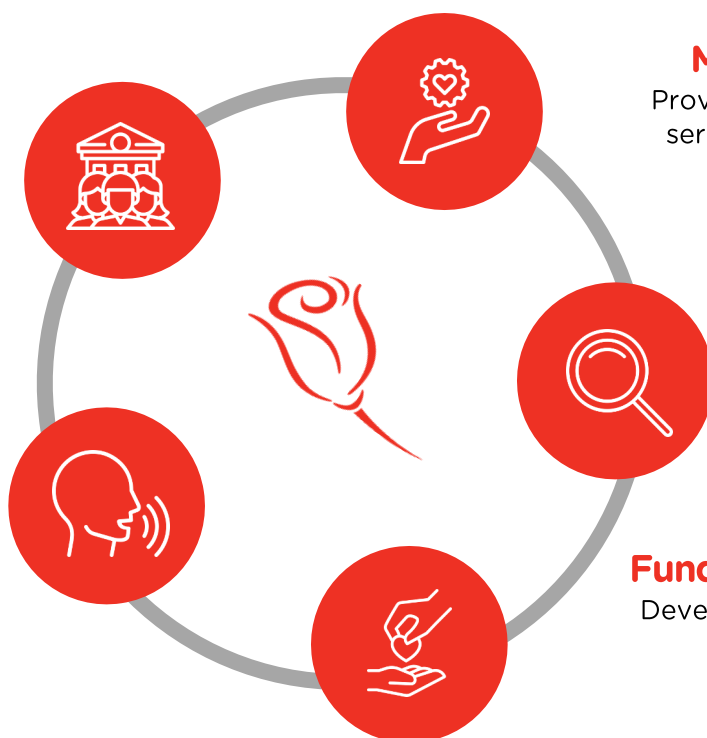
Pillars & Goals

Governance

Promote strong governance frameworks that provide confidence to members, donors, supporters and stakeholders.

Advocacy

Strive to be the voice for people living with Cystic Fibrosis and their families.



Member Services

Provide range of relevant services and support for the CF community.

Research

Supply support for understanding CF, its characteristics and treatments.

Fundraising & Awareness

Develop sustainable fundraising and awareness raising that supports CFSA's services

Outcomes

Governance	CFSA business is grounded in sound governance principles including transparency, statutory compliance, accountability and evidence-based decision making
Members Services	Provide services and subsidies to assist PWCF with focus on; financial relief from costs associated with CF; the correct equipment and medicines are provided and; encouraging physical activity.
Advocacy	Regularly communicating CF community concerns to all levels of government, key stakeholders and disability groups, with members engaged and informed CFSA supports CFA's national advocacy programs
Research	CFSA funds research programs and supports local research initiatives in conjunction with our Hospital Partners and will contribute to undertaking research through the Australian Cystic Fibrosis Research Trust.
Fundraising & Awareness	CFSA raises funds, seeks grants, donations and sponsorship to support the financing of its member services, operations and the development of new services.

Research

Research is a pillar of CFSA and along with the Australian Cystic Fibrosis Research Trust (ACFRT), we are committed to fund research to advance our understanding and treatment of cystic fibrosis and to provide better support for those with CF and their families. We are consistently looking for projects that we believe will make a difference to the lives of people living with CF.

Curative research progress thanks to funding from CFSA

Project—Nanoparticle Gene Therapy

Principal Researchers:
Loxegen

\$25.4K
GRANT FUNDING

This project was funded by the Jean Dunlop portion of the Vera Lane Trust.

In 2022 CFSA provided \$25,400 to Loxegen, who are developing a gene therapy treatment using nanoparticles in conjunction with other compounds, aiming to restore CFTR channel function by introducing a working copy of the CF gene to the cells in the lungs.

The funds assisted with a functional CFTR assay, an experiment involving a working copy of the CF gene being delivered to human lung cells that have CF. This experiment successfully showed the gene being transferred, with healthy cells produced that no longer had CF. This has enabled Loxegen to select final candidates for commercial development.

This is a different approach to CFTR modulators such as Trikafta, which work with the defective CF protein made by the mutated CF gene. Loxegen's approach inserts the correct gene and makes healthy CF proteins from the beginning without trying to fix the defective proteins.

This success has enabled Loxegen to attract the attention of well resourced parties in terms of future development.

Projects like this gene therapy have the potential to help all people with CF, regardless of their CFTR mutations. CFSA is aware that some people are not eligible or have had difficulties with Trikafta and will continue to support no one being left behind as we look towards the ultimate goal of a cure for all.



Patron: Phil Hoffman



the Board of the South Australian Tourism Commission. He was presented with a Legend Award in recognition of his outstanding service and support to the National Tourism Industry Training Committee in 1999 and again in 2006.

In 2013 Phil was named as a Member (AM) of the Order of Australia for “significant service to the travel and tourism industry through contributions to professional associations and the development of training standards”.

Phil Hoffmann Travel was inducted into the Family Business Association Hall of Fame in 2011, recognising Phil’s company as a first generation family business that has uniquely established itself as an icon in its industry in just 20 years. An Ambassador for Minda, Phil is a wonderfully generous benefactor who voluntarily sponsors and hosts not only his family of employees but over 50 charities, clubs and associations. His philanthropy extends to families and individuals in need and improves the well-being of many South Australians.

When Phil Hoffmann established his own agency in 1990 with a staff of two, he wanted to provide his customers with something out of the ordinary – inspiring travel experiences coupled with outstanding customer service. It’s this approach that has enabled the success of his multi-award winning business in a competitive and challenging market; building an impeccable reputation amongst the travelling public for quality, value and personalised service. Today, the proudly family owned business employs over 200 South Australians and operates from 10 branches throughout the State.

Phil’s academic background sees him forever pushing the boundaries. He was instrumental in setting up the inaugural AFTA (Australian Federation of Travel Agents) Training College. Nationally he was appointed AFTA Director for 13 years, served as National President for six years and was awarded Life Membership in 2000. During this period, Phil consistently promoted the professionalism of the travel industry in Australia and, in conjunction with his peers in the UK and USA, lobbied airlines and wholesalers alike to work together to raise the levels of integrity and credibility for the travel industry globally.

He has been an active Member of the ACTA (Adelaide Convention & Tourist Authority) Board, ardently promoting Australian Inbound Tourism and has served as the Chairman to



Governance

The Cystic Fibrosis SA board provides leadership on vision, strategy, compliance, risk management and financial sustainability. We thank the following Board Members for volunteering their time, guidance and governance of CFSA throughout the year

Our Board



Peter Summers OAM CGSJ
President



Danielle Gibb
Treasurer



Gen Handley
Board Member



Andrew Hodge
Board Member



Carl Aiken
Board Member



Floyd Bullen-Nicholas
Resigned 2022



Gloria Lancione
Resigned 2022

Treasurer's Report



On behalf of the Board of Cystic Fibrosis South Australia Incorporated ("CFSA"), I present the financial statements of CFSA and the Vera Lane Memorial Trust, for the year ended 31 December 2022.

As discussed at the 2021 AGM, with Government related COVID-19 payments coming to an end and the difficulty in holding face-to-face events due to people's heightened awareness of the need to social distance, CFSA has faced a couple of difficult years financially both in 2021, and again in 2022. This situation is reflected in the 2022 Statement of Profit or Loss, prepared in accordance with Accounting Standards. This shows that CFSA has recorded a loss of \$243,303. The reason for the increase in deficit from 2021 to 2022 was due to reduced income, and slightly increased expenses.

Income was significantly less due to the reduction in Government funding/grants, as well as the reduction in income received from the 65 Roses at Home events. Event income was also affected by the decision not to hold face to face events again in 2022. Our fundraising strategies / plan is under significant review at the moment and we hope that these income lines will increase in 2023 and onwards. It was positive to see that community donations remained strong, indicating strong support from the member and corporate community. CFSA was also thankful for a \$94,000 bequest during the 2022 year from Kathleen Billingsley's Estate, captured in the General Donations line.

Expenses remained relatively stable from 2021 to 2022 as expected. The costs of running the organisation are relatively fixed costs, and we monitor these costs closely. Costs did increase in the area of employee expenses (i.e. salary and wages) which was due to an increase in compulsory award rates, increase in compulsory Superannuation Guarantee rates and the hiring of a new Social Media & Fundraising Coordinator.

The accrued expenses account has been discussed at the 2020 & 2021 AGM as it was a provision for the anticipated back-pays owed to employees. There is still a balance remaining in this account as CFSA has agreed to pay monies owed to the former Executive Officer in fortnightly instalments. This arrangement will cease during the 2023 year so we will expect this accrual to be nil in the 2023 year.

Employee Benefits provisions have decreased significantly from the prior year due to a staff member leaving and having their entitlements paid out.

Whilst the statement of cash flows is showing less overall net outflow from the prior year (2022: \$136,438; 2021: \$227,041), it is still showing at a net overall outflow. The reasons for this are a reduction in fundraising income (as mentioned above), and an increase in cash outflows to suppliers which is mainly an increase in employee expenses. The increase in cash outflows to employees is also due to the cash payments being paid to the former Executive Officer for the owed backpay (discussed at both the 2020 & 2021 AGM). Where these payments are showing as a balance sheet item in the financial statements (within accrued expenses), the payments are still a 'cash' outflow and is therefore being reflected in the payments to suppliers and employees figure. This will cease during the 2023 financial year.

The Vera Lane Trust continues to see growth in both its capital portfolio and income returns from the capital. I note that the reduction income in the Vera Lane Trust accounts from 2021 to 2022 is due to a one-off income payment from one of the investment holdings in 2021 financial year which didn't occur in 2022. The portfolio continues to be managed by Halpins Wealth with oversight provided by the Trustees as defined by the original Trust Deed. The Board decided to move the management of its share portfolio to Halpins Wealth to optimise the growth of these funds. Treasurer's Report 2022 | 2 Looking ahead, the Board continues to work to ensure the financial security of the organisation. The most important aspect that is being focussed on is the income side of the ledger; from increased fundraising activities, and improved grant and government funding planning. With the hiring of a Social Media & Fundraising Coordinator during the 2022 year, as well as other strategies being implemented, we hope to see a stronger income section of the financials in 2023. Before I conclude, I would also like to take this opportunity to recognise the funds consistently raised by community fundraisers. Our community has continued to provide funds to CFSA in many ways including school fundraisers, Facebook birthday fundraising, sausage sizzles and many other ways. These funds continue to be immensely important, and I would like to personally continue to say thank you to the whole community for keeping the numbers in the income section of our financials afloat.

Danielle Gibb
Treasurer

Thank you

There are so many people who support Cystic Fibrosis SA - donors, volunteers, supporters, community fundraisers, participants, advocates, health providers... and the list goes on. Thank you all so much. Thank you for your time, gifts, encouragement and especially, thank you for caring about people with cystic fibrosis.

We thank the following organisations for their ongoing services and support



**Government
of South Australia**