

# 2019 ANNUAL REPORT



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## Our Vision

Lives unaffected by cystic fibrosis.

## Our Mission

To increase the wellbeing and quality of life of people living with cystic fibrosis, and promote broader awareness of cystic fibrosis and how it affects the community.



# Programs and Support Services

In 2019 we provided a range of programs and services to the CF community across Victoria and NSW. The financial support provided ranged from funding essential physiotherapy equipment and other CF-related expenses, to conference grants, education support and family respite. Our social work services included psychosocial support across a wide range of areas including mental health, grief and loss, family and relationships, housing, employment and transplant, and we facilitated peer support and delivered information services in person, over the phone and via email. Please see tables below for a full list of programs and services.

## Financial Support Services

Program	Number
20% reimbursement program	110
Accommodation subsidy for regional members/nights	60/84 nights
ACF Conference grants	5
Air Purifier Grants	5
Counselling grants	1
CRV Helping Hand regional vouchers	28
Education Support - families	54
Education Support - schools	100
Education - CFSmart e-learning (teachers, early childhood, kinder)	601
Emergency assistance	130
Fitness program grants	135
Happy Family grants	25
Maya's Gift grant	3
Mental Health First Aid	2
Scholarship program/Tutoring grants	16
Simon's Adventure Fund grant	3
Take-A-Break grants	9
Transplant grants	15
Transportation Assistance grants	35
TV rental while in-hospital	2,754 days
Victorian Patient Transport Assistance Scheme	8

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*"Thank you for allowing us to access the Nebuliser Equipment Program. We have loved the new nebulisers. The kids are happy to do their treatment each night as the new nebulisers are silent and they are very quick. It has become less of a chore for them."*

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## Other Support Programs

Program	Number
Advocacy (individual)	70
Boredom buster bags	31
Cabin bookings/nights	18/73 nights
Information line queries (>15mins)	92
Support sessions	72
Support while Inpatient - members	155
Massage sessions for adult inpatients (Monash Medical Centre)	163
Inpatient member visits	78
Nebuliser replacements	14
Newly diagnosed, new member, adult member kits	54
New loan equipment agreement/loan days	18 loans/1,104 days
Number of members receiving Social Work Support as part of MDT	368
Outreach Clinic days/members seen	8/38
Peer support requests	23
Peer Support for transplant patients from SA	1
Support activities & dinners/attendees	13/128 attendees

As a result of being supported by organisations such as the Commonwealth Bank Staff Social & Charity Club Vic Inc, we were able to provide Christmas food hampers to 'in need' families, Chocolate Easter bunnies to inpatients in Victoria, tickets to Gold Class, Disney on Ice, the Australian Open, AFL and NRL games, Dreamnight at Tooronga Zoo, and the Variety Christmas Party. We were also able to provide a number of Fitbits and Uber vouchers.





## Peer Support

We provided a range of peer support activities to the CF Community, including:

- One-on-one peer support matches (e.g. a person considering a double lung transplant wanting to connect with someone who has had a transplant).
- Support events where a group of people who are parents, partners, and grandparents of someone who has CF can meet and share stories and experiences.
- Ages and stages sessions at our CF Community Conference when people can meet and talk about their shared experiences.
- Our closed Facebook group for Australian women who have CF, Sister5Roses.

## Rural and Regional Programs

Several of our programs and services are targeted at people living in rural and regional areas, such as:

- Subsidised accommodation for people travelling long distances to their hospitals and clinics in Sydney and Melbourne.
- Support dinners in a range of areas across Victoria and NSW.
- Outreach clinics in Tamworth and Taree in conjunction with John Hunter Children's Hospital and John Hunter Hospital clinical teams.
- A regional nebuliser replacement program and a fitness participation program for our Central West, Hunter, New England, Mid North Coast, Northern Rivers and Central Coast CFCC members.

In 2019 we also trialled using teleconferencing to make some of our information sessions more accessible for people with CF and people in regional areas. This included information sessions about CF and schools, and two sessions at our Annual CF Community Conference.

## Information and Resources

The development and launch of our new cfcc.org.au website has provided us with a new platform that we can build upon to provide more targeted and relevant information to the community. This includes using different ways of communicating information such as the short videos we released on a range of CF-related topics in late 2019. At the end of the year we received a significant grant through the NDIA to continue to develop our website with an information portal specifically for adults with CF. As this develops over the next two years members will have the opportunity to contribute through telling their own stories, developing blogs and videos and providing important community input through the consumer advisory group which informs the project.

The most common requests for information were on issues relating to Centrelink, the treatment pipeline, CF carrier screening, and education.

## Advocacy

In 2019, we provided individual advocacy support to over 70 community members. Some of most common individual advocacy issues included financial (including Centrelink and NDIS), education, clinical issues, legal issues and housing.

An important element of what a State based CF organisation can do is support the more global advocacy issues such as the new drugs which are being developed. Cystic Fibrosis Australia plays a critical role in ensuring the all the CF organisations lobby together for the speedy passage of new drugs through the PBAC and PBS. CFCC is committed to ensuring ongoing support for these important campaigns and will not only support the collective of CF organisations in Australia, but will provide additional opportunities for members to be involved in state based advocacy campaigns.

CFCC is also actively engaged in the promotion of CF carrier screening and in 2019 we became involved in the Mackenzie's Mission project which is a pilot program examining the efficacy of a national population screening program for a number of genetic conditions. CFCC's work in this area has been long standing and we are delighted that CF, along with other conditions, might be part of a permanent screening protocol.

## Engagement with State Government and CF Clinics/hospitals

Throughout the year CFCC has met with a number of State based politicians in an effort to support not only the critical passage of new drugs, but also to seek support for our community through additional funding which was lost as a result of the NDIS. We had the pleasure of inviting The Hon Ben Carroll, Minister for Crime Prevention, Corrections, Youth Justice and Victim Support to open our new office in Carnegie, Victoria.

Great Strides Melbourne received television media coverage via the Hon Greg Hunt MP Minister for Health who attended the event and announced that from 1 December 2019 the federal government will provide PBS funding for CF medications Symdeko (for people 12+ years) and Orkambi (for children 2-5 years). This announcement topped off our Great Strides series for 2019!

Our teams regularly engage in a range of workshops and consultations such as the consultation on improving the NDIS experience and the Royal Commission into Victoria's Mental Health System. We regularly engage with clinic teams and hospitals in relation to consumer feedback and we participate in hospital advisor and consumer groups including the Alfred CF Advisory Group, the Thoracic Clinical Update, St Vincent's Lung Transplant team and others.

Two inter-clinics were held in NSW 2019. In Parramatta - topics included The NSW Palliative Care Landscape, Scedosporium and Lung Transplantation in CF and Patients' best interests: How do you know when they have had enough? In Newcastle - Newcastle - topics included Complex CF and CFRD, New Developments and Medications, identifying domestic violence and AVO's, Nebulised Tranexamic Acid.

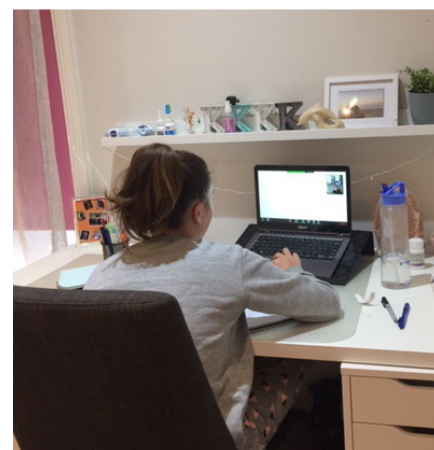
## Education Support

While we have always recognised the importance of ensuring that school aged children with CF are well supported in order to reach their full potential, our education program has expanded considerably to include not only schools, but also kindergarten and childcare centres. In Victoria our Education Liaison coordinator provides crucial information about how these facilities can support children who have CF and their families. Activities in this area have included working with the Children's hospitals in Melbourne and facilitating workshops and information sessions for educators either through face to face meetings or via teleconference. This program is funded through a specific grant and every effort will be made to secure ongoing funding to include both Victoria and NSW in the future.

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*"The Cystic Fibrosis Community Care Scholarship Program has been extremely helpful for me to stay on top of my math home work. My tutor is currently doing a maths degree at university and she has some great teaching methods that makes math more understandable. Before every test we revise the topic together, making notes that allow me to focus on the important aspects of the topic. This assistance is great and I feel very prepared for the tests. Thank you very much for supporting me in my studies".*

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# Research

Research has always been a focus for CFCC and we are consistently looks for projects that we believe will make a difference to the lives of people living with CF. Of course our ultimate goal is to find a cure, however we also recognise the importance of research which aims to improve treatment and management of CF.

This year we funded three projects and we look forward to reporting back to our members on the progress that these projects will make over the next 12 months.

- Targeting a Forgotten Cell to Prevent Cystic Fibrosis Lung Disease – Dr Shanthikumar Shivanthan – Murdoch Children’s Research Institute
- Gene Therapy Innovation Grant – Dr Shafagh Waters
- Safer Testing for Colorectal Cancer in Patients with CF - Dr Keith Ooi - ACRFT.



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*"This trip was sensational and even as I write this, I am thinking of the people and places I was able to see and experience, priceless!"*

*Thank you Simon's Adventure fund and CFCC for helping make this trip possible, and enabling me to adventure on my own and spend time with people that mean a lot to me doing something I love to do, snowboarding!"*

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# Fundraising

As you will appreciate fundraising is an important function that all parts of the organisation are involved in. Without funds we would not be able to provide support and services to our community. We are so grateful for the wonderful support that we receive from people who attend and contribute to our events.

## Community Fundraisers

We are extremely grateful to our dedicated community fundraisers who work so hard to raise funds and awareness. Throughout the year our community created, hosted and participated in some amazing events. We saw cocktail parties, yoga days, cake stalls, children cutting their hair, school fundraisers, ladies luncheons, gala balls and more all with the aim of having a positive impact in the lives of those living with CF, and their families.

Some of our many amazing community fundraisers included:

- 3773MCC Dice Run
- Andrew's Legacy
- Bianca Brady - Popped Up at Kimo
- Cassandra Jones - Mudgee Five Feet Apart Movie Night
- Charity and Fun
- Country Racing Victoria
- Elizabeth Walmsley - 5 Feet Apart Movie Night
- Cronulla RSL MEGs - Cronulla Spring Fair and Club Wine Raffle
- Cynthia Newling - Ladies Night
- Heathmont Jets Football Club
- Hugo Boss Australia
- Impreza WRX Club NSW - Great North Rally
- Junee High School - Year 12
- Kamilaroi Quilters - Raffle
- Kerry Rogers
- Kotara High School - Mufti Day
- Kye Feltham - Kye's Hair for CF
- Midstate Motorcycle Club - Ironbark Dice Run
- Montmorency High School
- Nicki Traina

- Olivia Zarb - Five Feet Apart Movie Night
- Sonja Dene Dance Studio - Crazy Sock Day
- Steve Gowty Chemmart Pharmacy
- Trekking for Simmo

## Fundraising Activities

Our fundraising activities are extremely important and enable us to not only raise funds but to engage the broader community across Victoria and NSW. We conducted a variety of events including gala balls in Sydney and Melbourne, Great Strides events in Sydney, Melbourne and Bendigo, 65 Roses months' activities, NovembHer Bottomless Brunch, High Tea, direct mail appeals, tin rattling and our 65K 4 65Roses walkathon.

## 65 Roses Month

65 Roses day is generally held on the last day of May across Australia. The primary goal is to increase the level of awareness for cystic fibrosis across the wider community as well as raising funds through various activities. Our dedicated army of volunteers venture out to various locations in the CBD to rattle tins and sell beautifully wrapped roses kindly donated by Wafex.





# Trusts, Foundations and Government Funding

We continued to receive a high level of support from Trusts and Foundations as well as government grants during 2019. The funding from the philanthropic and government sector enables the organisation to provide a portfolio of services. We are deeply indebted to those Foundations, Trusts, Clubs, Governments and organisations who make our work possible.

- Alfred Felton Trust
- Club Rivers Grant
- CMV Group Foundation
- Commonwealth Bank Staff Foundation
- Flora and Frank Leith Charitable Trust
- G W Vowell
- Helen and Peter Devereux Fund
- Hornsby RSL Club Grant
- Ian Berry Foundation
- The Jack Brockhoff Foundation
- Joe White Bequest
- John T Reid Charitable Trust
- Keith Maxwell MacKenzie Trust
- Lord Mayors Charitable Foundation
- The Marian & E H Flack Trust
- The Walter and Eliza Hall Trust
- National Disability Insurance Agency (NDIA)
- New South Wales Ministry of Health
- Newcastle Permanent Charitable Foundation
- Oak Flats Lions Club Grant
- Qantas Foundation
- QBE Foundation
- Sawtell RSL Club Grant
- Therapon Foundation
- Victorian Department of Health and Human Services
- The William Angliss (Victoria) Charitable Trust

We currently have two grants from the National Disability Insurance Agency (NDIA) - National Disability Insurance Scheme (NDIS) Information, Linkages and Capacity Building (ILC). These national ILC grants are very competitive and this is our second successful application.

## CF Circle ILC Grant 2018-20

In March 2019 we launched our new [cfcc.org.au](http://cfcc.org.au) website. The website was developed in consultation with a working group of community members to ensure it reflected the information needs of the community. Since its launch we have added more content, including 10 short videos on different topics, including Living with CF: Adulthood, Living with CF: Being a teenager, fertility, a parent's experience, transition and more.

## CF Strong ILC Grant 2019-22

In late 2019 we received confirmation that we were successful in our application for another grant from the NDIA. CF Strong is a 3 year project to build upon our website and develop a new national online resource that will provide information for adults who have CF, their families and support networks around key transition points in their lives. This includes transition to adult care, transplant, employment and tertiary education, relationships and family and end of life care.

We will be establishing an advisory group of adults who have CF to participate in the project. In addition, we will be working with CFWA and community members from across Australia to develop a range of resources such as videos, podcasts, blogs that share the experiences of adults who have CF and online learning modules for employers and universities.

The difference and positive impacts that these grants have on the lives of people living with cystic fibrosis, their families and carers is significant and deeply appreciated by all in our community. We acknowledge the following trusts, foundations, organisations and government grant entities who have provided their generous support in 2019 - thank you.

# Corporate Support

We are very grateful for the support we receive from our corporate partners who play a vital role in enabling us to achieve our mission. In 2019 we would like to thank all of our corporate supporters who, through sponsorship, donations or gifts in kind, made a significant difference to the lives of people living with cystic fibrosis.

Some of our wonderful corporate partners include:

- Allens Lawyers
- Antarctica Flights
- Bella Box
- Bendigo Community Bank (Malvern East)
- Bright & Duggan
- Carmans
- Carra Holmes Pty Ltd
- Colgate-Palmolive Australia
- Country Racing Victoria
- Dooleys Lidcombe
- G&W Hydraulics
- Herbert Smith Freehills
- Holding Redlich
- Kelp & Co
- Mamma Mia
- Mitre10 Stawell
- Michael Grech
- Ritchies IGA
- St Marys Rugby League Club
- Suttons
- Tobin Brothers
- Vertex Pharmaceuticals (Australia) Pty Ltd
- Wafex
- Woodlands Golf Club



# Bequests and In Memoriam Gifts

CFCC has been very fortunate to be the recipient of a number of bequests and 'In memory' gifts in 2019. We acknowledge that many gifts are given at a time when the family is going through a tragic period and we are grateful to them for giving thought to how their loss can provide for something positive in someone else's life. We offer our condolences to all those families who experienced the loss of a family member or friend in 2019.

We also acknowledge with gratitude:

- Georg Herbert Lich Bequest
- Alfred Noel Curphy Bequest
- Ulae Isobel Mason Bequest

# Volunteers

Throughout the year we are fortunate to have the support of a large number of volunteers who give freely of their time and talent. We've had the pleasure of hosting teams of volunteers from NAB and Cisco as well as all our wonderful event volunteers who support our Great Strides, 65 Roses month, tin rattling and general fundraising activities.

In addition to that we've had fantastic assistance in our offices in Victoria and NSW. We are grateful to each and every one of you. We do need to acknowledge some particularly unique contributions: Doug Cameron and Lilly Taraborrelli have very generously given over 200 hours of work to help us move our files from a server to Sharepoint. This is no small feat and we are very grateful for their expertise in setting up our system, training our staff and ensuring that we get the efficiencies that we were seeking.

Our amazing Margaret Duggan, who has been involved with the organisation from its very beginning, over 40 years, arrived every week with willing hands and wise counsel. Margaret retired from volunteering with us in December and her contribution was recognised at our Christmas function with a gift for her long and dedicated service.

Volunteers come in many shapes and forms and we are extremely grateful to Michael Grech who manages to source so many things that we need, including our audio visual equipment, sound equipment, computer screens, chairs and printers. It's amazing. We are so grateful to have these people on our side. Thank you all so very much.





# Thank You

There are so many people who support CFCC – donors, volunteers, supporters, participants, tin rattlers, advocates... and the list goes on. Thank you so much. Thank you for your time, gifts, encouragement and especially, thank you for caring about people with cystic fibrosis. It really does take a community to care.



Cystic Fibrosis Community Care acknowledges the support of the Victorian Government.



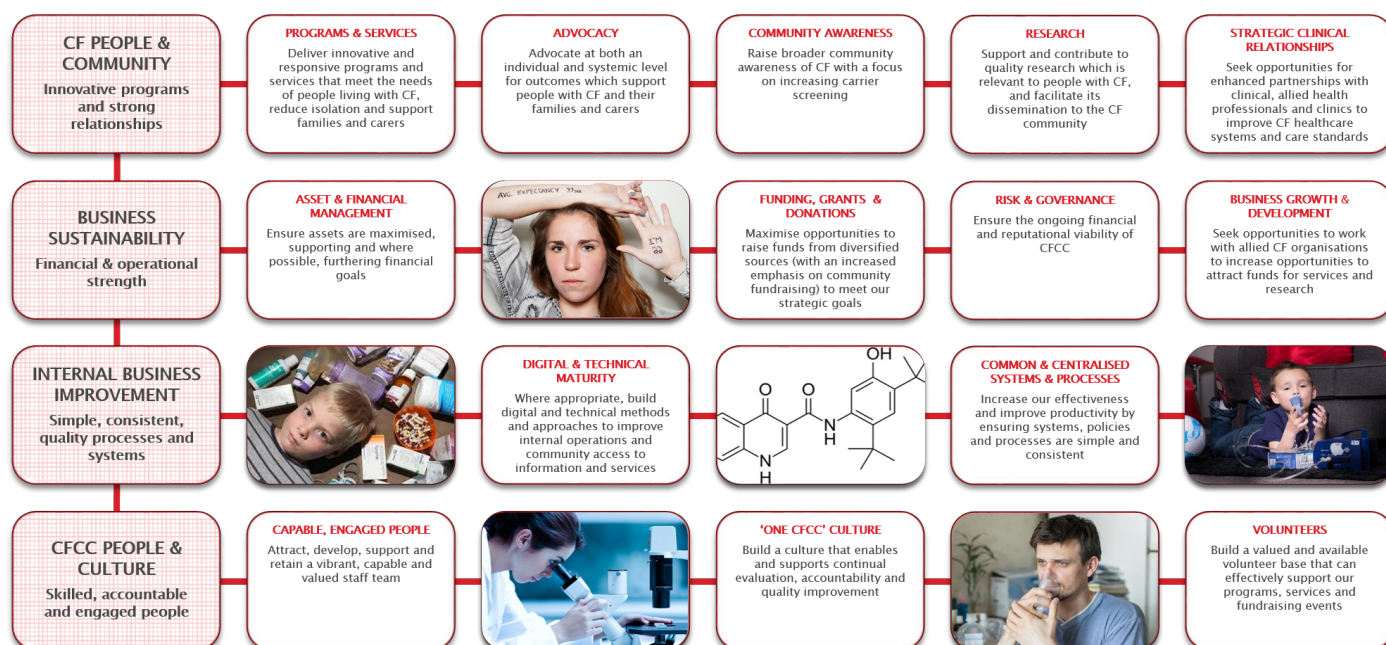
Cystic Fibrosis Community Care acknowledges the support of the New South Wales Government.



Funded by the National Disability Insurance Agency

Cystic Fibrosis Community Care acknowledges the support of the National Disability Insurance Agency in funding the development of our website and peer support program.

# Strategic Plan 2018-2023





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