

2018 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.



Chairman's Report

ROSS FRASER CHAIRMAN

I am pleased to present the second Annual Report for Cystic Fibrosis Community Care Limited (CFCC) on behalf of your Board.

At the close of 2018 we had eight Directors (four from Victoria and four from NSW). The Constitution currently allows a maximum of 9 Director positions but in order to enable better rotation and more ability to bring in new directors with key skills for the future, the Board has decided to seek a small change in the Constitution in the maximum number of directors from nine to eleven. We are seeking your support for this change at this AGM.

We have continued to manage our funds efficiently, maintain our governance requirements, mitigate our risks and provide our programs and services in line with our strategic plan. In 2018 we budgeted for a small loss but through the support of our donors and improving efficiency and good management we have achieved a small year-end profit in Victoria and a smaller than budgeted loss in NSW. Please refer to the Treasurer's Report for the financial details.

Karin Knoester (our CEO) and her team working across Victoria and NSW have continued to efficiently and diligently provide the programs and services to those living with CF and their carers. Please refer to the CEO's Report for information on the operations.

The 2018 year has again been a challenging but satisfying year. There are two key matters I would like to update you on:

- The Merger – Karin has been finalising the details of the merger including putting in place changes in NSW that are now showing improving financial and operational results, turning around the decline of previous years. This is very important because CFCC serves nearly 50% of those living with CF in Australia.
- Property – The negotiations we were undertaking with Hayball Architects in 2017 were completed in mid-2018 and we achieved a good outcome for the sale of our long loved 80 Dodds Street



property. From the date of the signed sale contract we have plenty of time to continue at Dodds Street while we find and move into another suitable property. We are now seeking a new office to purchase that will serve us for the long term and serve our needs as well if not better than the current arrangement.

I would like to make a special acknowledgment of three people who are leaving our Board. They are:

- Rod Naismith who was on the CFV Board for some 5 years including as Treasurer. Rod then continued in an honorary role as Treasurer through the merger and for CFCC until now.
- Keith Cleary has resigned for family reasons after many years of service on the CFNSW Board and until recently on the CFCC Board.
- Sarath Ranganathan has just notified the Board that he is resigning. Sarath has recently been appointed Professorial Fellow, Department of Pediatrics, University of Melbourne. Importantly, while serving as a director in both CFV and CFCC he has provided important clinical knowledge to the organisation.

We thank you all for the excellent contributions you have made to CF and we wish you all well for your futures.

It takes a lot of resources to achieve what CFCC does each year. The Board is impressed by, and very appreciative of, the number of people who freely commit their time and skills to this worthy cause. On behalf of the Board I send a big thank you to all our members, volunteers, supporters, corporate partners and donors without whom we would not be able to provide anywhere near as many of the programs and services. Whether you volunteer your time or make a financial donation, or both, we sincerely appreciate your generosity.

And finally, I thank Karin and her staff and my fellow Board Directors for their dedication. It is a pleasure to work in such a committed organisation.

CEO's Report

KARIN KNOESTER

CHIEF EXECUTIVE OFFICER



It once again gives me pleasure to provide this annual report to our members in Victoria and New South Wales. 2018 gave us the first full year of operations for Cystic Fibrosis Community Care (CFCC) and I believe that we have made some significant steps toward greater efficiency and effectiveness. Mergers are never easy and there is often considerable angst within organisations going through such large strategic steps, however I believe that we are now well and truly over the teething stage. The merger has already begun to show that there are efficiencies to be had in reducing duplication and this means more funds available for programs and services.

With some considerable financial challenges at the beginning of 2018, our focus was clearly on improving the outcomes of our major events this year, particularly in NSW, and we were not disappointed with the magnificent support we received from the individuals and families who participated in the 65K 4 65 Roses walk in Sydney. We also added two events to the NSW calendar and have much more planned for 2019. At the end of the year our collective finances were looking stronger and we will continue to focus on efficiency while improving our effectiveness.

Working together and joining forces has enabled us to do much more than what we as individual organisations might have achieved. This way of working extends to external partners as well and we were very pleased to again partner with the Children's Hospital at Westmead and the Sydney Children's Hospitals Foundation to deliver an excellent donation to the children's CF Clinic at Westmead. In Victoria, we have had the opportunity to work alongside the Monash CF Foundation where we were able to collaboratively purchase a number of Hepa Filtration units in the CF clinic.

Our community education campaign on carrier screening has continued to build and we have

invited both Fragile X Syndrome Australia (FXA) and Spinal Muscular Atrophy Australia (SMAA) to join our reference committee. In the second half of the year we were advised that the Government has committed to a \$20 million pilot carrier screening program for conditions including CF. While this was not solely the work of CFCC, particular recognition needs to go to SMAA who have lobbied for many years for a study such as this. Under the working title 'Mackenzie's Mission' the reference group hope to be involved in the pilot program.

In the second quarter a good part of our focus was on supporting CFA's advocacy campaign for Orkambi which was listed for the PBAC Agenda on 4 July. CFCC collaborated with WeNeedOrkambi to push the message as far and wide as we could and we also engaged our community by providing an advocacy kit which included sample letters, information about Orkambi and its benefits, and the people to whom we wanted members to write. Of course we now know the outcome and many in our community with two copies of the f508del gene change have commenced on Orkambi. Once again however, it is important to note that even with two copies of f508del, Orkambi isn't for everyone. Advocacy on issues such as access to affordable medicines is critical and as a community it is important that we all push together in the same direction to achieve the best outcomes. In 2019 our focus turns to Symdeko.

A great deal of the work that we do is made possible by the generous contributions provided by individual donors. During the middle of the year we were delighted to receive two significant donations and this has enabled us to restore a number of support programs for people with CF in NSW. The feedback from the NSW community who take advantage of these supports has been very positive and we have been able to structure these donations to ensure that these services are available for the next four years.

In 2018 CFCC received a number of donations targeting research and the first allocation of those funds (\$40,000) went towards a research project conducted by the Lung Infection and Inflammation Group at QIMR Berghofer Institute of Medical Research, in Queensland.

Using state-of-the-art gene sequencing techniques, this project will investigate why antibiotic resistance is so common in epidemic *Pseudomonas Aeruginosa* compared to non-epidemic strains and whether this increased resistance causes more severe disease. Additionally, the project will investigate the potential of a new technique for quantifying antibiotic resistance in sputum as an improved method of antibiotic selection compared to conventional methods. If successful, this could lead to improved clinical outcomes and shortened hospital stays.

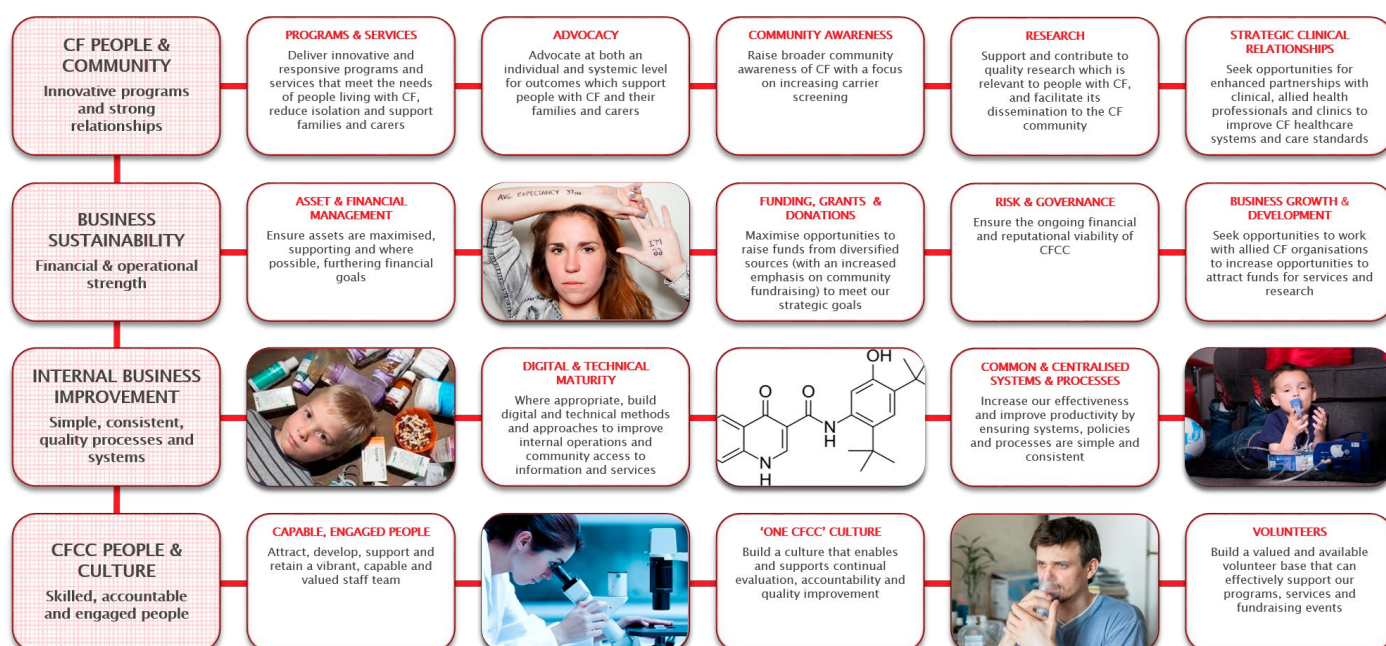
In 2019 we anticipate that another \$100,000 will be made available to fund critical research in the CF field. While we believe that it is imperative that we find a cure, with the growing number of people with CF living well into adulthood, we must also focus on funding research which explores improved treatment options for children and adults.



Without the support of our community fundraisers, our donors, our corporate partners and various foundations and trusts, what we do would not be possible, and we are extremely grateful for your support. Equally, our trusty volunteers who turn out to assist at major events or to provide administrative support in our offices, thank you so much. Thanks must also go to our wonderful staff who work hard to ensure we get the best results from all our activities. We are all part of a big team whose vision is to reduce the burden of CF on our members and their families.

My thanks also to the Board who volunteer their valuable time to support the organisation and its events wherever possible. It is not only a privilege, but also a pleasure, to work in an organisation supported by such a broad range of committed people.

CFCC Strategic Plan 2018 to 2023



Programs and Support Services

CFCC offers 25 programs and support services to individuals and families affected by CF in Victoria and NSW. As mentioned previously, as a result of two generous donations in the second half of 2018 we were able to initiate a number of programs and services in NSW which had not previously been available. The services listed below are a snapshot of the support programs we had available throughout 2018 in both states.

Financial Support Services

Program	Number
20% reimbursement program	101
Accommodation subsidy for regional members/nights	58/112 nights
In-hospital television hire	3,732 days
Emergency assistance	58
Fitness program	126
Scholarship program	10
Happy Family grant	15
Take-A-Break (Andrew's Legacy)	9
Counselling grants	8
Maya's Gift grant	10
Simon's Adventure Fund grant	6
Transplant assistance	12
Victorian transport assistance	23
Physiotherapy equipment	396

Other Support Programs

Program	Number
Total number of CF clinics attended/clients seen	134/392
Inpatient member visits	188
Cabin bookings/nights	28/96 nights
Dreamnight - 10th Anniversary	21 families/97 attendees
Support activities & dinners/attendees	10/118 attendees
Interclinic health professional attendees	59
Advocacy (individual)	58 cases
Boredom buster bags	29 bags
Newly diagnosed, new member, adult member kits	22 kits
New loan equipment agreement/loan days	31 loans/2,076 days

Information and Advocacy activities

The information and referral service continues to be a critical part of our service mix with phone calls, emails and face-to-face inquiries covering a wide range of topics including carrier screening, NDIS, transplant, Health Care Cards, mobility allowance, inquiries from families of newly diagnosed children and adults, as well as providing information to schools, child care centres and preschools.

Special Grants Program

"The phone call from CFCC about giving a bike and helmet to our son that had been generously donated couldn't have come at a better time. When he received the bike, he had the biggest smile. We can't express how thankful we are to both CFCC and the people involved in putting a smile on our boy's face and making his troubles disappear."

We have a variety of special grants which have been generously provided by individuals and families affected by CF. Simon's Adventure Fund was established by Simon Minson's family to assist young adults who have CF to participate in an activity on their bucket list.

Our Happy Family Program, Maya's Gift, and Take A Break provide grants of up to \$500 for children or adults with CF to have a special day out or weekend away with their immediate family. A break from the relentless routine of CF. These programs have been made possible by the GW Vowell Foundation, FinancePath, and Andrew's Legacy.

Education Support Program

This program supports students with CF in Victoria and has had a huge impact on the lives of many children. Our Education Support Co-ordinator has worked with students, families, schools and teachers to ensure that students with CF receive the support they need to make the most of their education.

In conjunction with Education Support, our Scholarship Program has allowed us to work closely with over 30 young people and their families to help them reach specific education goals. The assistance included providing tutors and helping students find

alternative pathways towards further education. The program has been funded until the end of 2019 and we will be seeking support to maintain the program in Victoria and to extend it to students in NSW. This program is funded by Ski4CF, Marian and EH Flack Trust and a generous bequest.

"This year has been incredibly tough for our daughter. She has only been able to attend three full days of school. With this year's relentless infections, she has missed the opportunity to learn. Luckily for us she was given a scholarship which has helped her keep up with school work. A tutor has come to our house in between her treatment times and hospital admissions. She has been able to integrate back into school without the feeling of being behind."

Physiotherapy Equipment

In both Victoria and NSW we have been able to provide assistance to families to purchase new physiotherapy equipment, such as nebulisers, which is crucial for keeping people healthy and their lungs clear. This valuable support has been made possible through funding from the Victorian Government, Newcastle Permanent Charitable Foundation, Barefoot Ball donors, FinancePath, GW Vowell Foundation, Joe White Bequest, Ski4CF, the Nightingales and the Lea family.

"Thank you for raising funds to support my daughter and others battling CF. We appreciate the new nebuliser which our daughter will use daily to fight off any infections she may have. As a CF family it is wonderful to receive this support and know others are helping us to fight this battle."

The introduction of the Exercise Self-Management program in NSW was highly successful. The results of the program indicate that people with CF benefit significantly from exercise programs delivered by an exercise professional with CF expertise, who can prescribe and oversee exercises to improve cardiovascular strength and thoracic mobility. This program was made possible by funding from a Perpetual Trustees grant.

Fundraising

Every year a large part of our focus is fundraising, as without funds it is impossible to reach our service goals and provide support to our community. Each year we are humbled and grateful for the wonderful support we receive from people who attend and contribute to our major events. One of the critical elements of our fundraising is the amazing support of our Community Fundraisers who work diligently hosting events and raising funds on our behalf.

As a not-for-profit, CFCC relies on our fantastic community of supporters to help us raise funds. Here are just a few examples of amazing things people did in 2018:

- A group of waterskiing enthusiasts skied the navigable length of the Murray River and raised over \$80,000.
- The Peaks4CF and the Cycle 4 CF teams spent long hours in the saddle, if not riding from Adelaide to Melbourne, then climbing 4,065 metres of hills!
- Alan and Jenny Tunks once again conducted a raffle at the Bluesfest – raffling off some impressive Gibson Guitars!
- Carol Bianco and friends ran A Night With Elvis and raised \$8,600 for CFCC. Carol and her friends started by talking to the team at CFCC about her idea of holding a night with an Elvis impersonator. Once everything was booked her team of volunteers emailed friends, family and local community members to buy tickets. They created flyers, promoted the event on their personal Facebook pages and also advertised at the venue. CFCC helped by creating Facebook posts too.



- Beth Peach Robinson and her partner put on their CF t-shirts, strapped on their backpacks, and set off on The Great Northern Walk – a 268km walk from Circular Quay in Sydney to Queens Wharf in Newcastle – to raise funds and awareness for CFCC. They chose this particular route as it was symbolic of the regular Newcastle to Sydney trips that a young girl they know with CF has to make to attend CF clinic. Subsisting on determination, instant coffee, freeze dried meals and the kindness of others, they walked for 12 days and raised over \$3,000!



- Crazy Hair Day has been going from strength to strength in both Victoria and NSW in the past few years. A total of 139 schools, organisations and childcare centres participated in Crazy Hair Day and raised \$27,000. Schools were asked to encourage their students to come to school with crazy hair and raise funds for those living with CF.

Volunteers

Of course we could not have achieved half of what we did in 2018 without the assistance of our dedicated volunteers both in the office and at our events. They really are the lifeblood of any charity. During 2018 a total of 585 hours of work was carried out by our office volunteers alone.



"I retired recently, so I looked to see what might interest me as a volunteer. CFCC grabbed my attention as when I was working as a school teacher I had taught a beautiful girl with CF and a previous co-worker's husband lives with CF. The wonderful team at CFCC HQ have been so understanding, helpful and appreciative. I very much enjoy being part of a warm and welcoming environment where I can play a part."

Maureen Dillon, Administration Volunteer



Communications

New website

In March 2019, CFCC launched our new website – **cfcc.org.au**. Funded by an ILC grant from the National Disability Insurance Agency, the new-look website is intended to be an information portal and resources hub for the CF community.

Electronic communications

CFCC's Facebook pages in Victoria and New South Wales reached a combined following of over 13,000 people. The audience of our two pages combined gave us the largest Facebook presence of any Australian CF organisation. Our monthly PASSwords e-newsletter for programs and services also continues to be very popular among our members as a way to share information about the services available to them.

Community Focus magazine

CommUNITY Focus is a three-times-a-year publication distributed to all CFCC members. It features program and support services news, fundraising updates and upcoming event information, human interest stories, research articles and self-help advice. The magazine is sent in both printed copies and digital editions to over 1,500 members across Victoria and NSW.

Media coverage

CFCC was successful in receiving mainstream media coverage for a number of major events and announcements, including the PBAC Orkambi announcement, the 65K 4 65 Roses Walkathon and Great Strides.

**Our sincere thanks to all the grants, trusts, foundations,
companies and individuals that have assisted CFCC in 2018 through
grants, donations or sponsorship.**

Abbie Fennessy Trust
Allens Lawyers
Bright & Duggan
Commonwealth Bank Australia
Commonwealth Bank Staff Social & Charity Club
Country Racing Victoria
Dooley's Catholic Club
East Malvern Community Branch Bendigo Bank
Equity Trustees
Evergreen Cruises and Tours
Flora & Frank Leith Charitable Trust
G & W Hydraulics
GW Vowell Foundation
Harcourts Foundation
Herbert Smith Freehills
Holding Redlich Lawyers
Joe White Bequest

Lord Mayor's Charitable Foundation
Marian and EH Flack
Mazda Foundation
Melbourne Conveyance
Michael and Mary Lea
Murphy Family
Newcastle Permanent Charitable Foundation
Nightingales
Perpetual Trustees
Royal Agricultural Society of Victoria
St Mary's Rugby League Club
Suttons
System Partners
The Andrews Foundation
Therapon Foundation
William Angliss Charitable Trust



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



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



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

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

VICTORIA (HEAD OFFICE)

80 Dodds Street
Southbank, VIC 3006

P | +61 3 9686 1811
E | admin@cfcc.org.au

NEW SOUTH WALES

PO Box 4113
Homebush South, NSW, 2140

P | +61 2 8732 5700
E | reception@cfcc.org.au

ABN 251 26 031 536
ACN 617 714 253

W | [**cfcc.org.au**](http://cfcc.org.au)

