

2017



ANNUAL Report



**CYSTIC
FIBROSIS**
Community Care

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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 message

ROSS FRASER CHAIRMAN

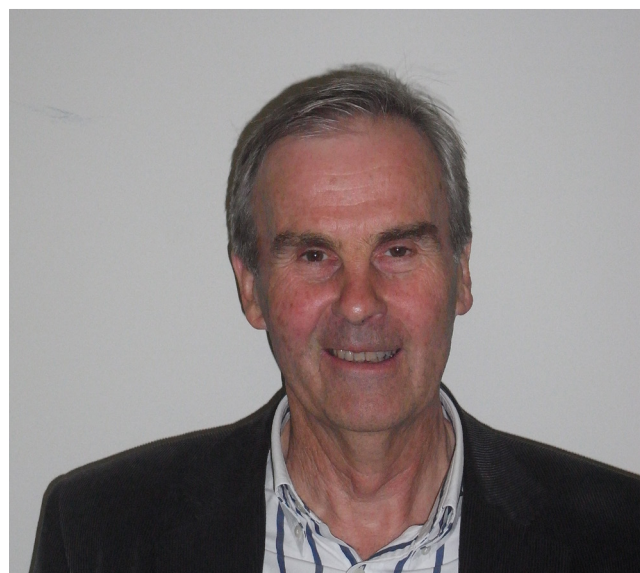
I am pleased to present the first Annual Report for Cystic Fibrosis Community Care Limited (CFCC) on behalf of your Board. The CFCC Board has eight Directors and in line with our rotation policy three are standing down and have nominated for re-election at this year's Annual General Meeting (AGM).

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. However, unlike the last few years where we made modest surpluses, the 2017 year made a small loss as budgeted.

The CEO and her expanded team working across Victoria and NSW have continued to work efficiently and diligently to provide services to those living with cystic fibrosis (CF) and their carers (please see the CEO's Report for the details).

2017 has been a challenging but satisfying year including:

- **Merger** - The passing of the resolutions at the last CFV AGM and the corresponding CFNSW Extraordinary General Meeting in March/April 2017 to merge CFV and CFNSW was achieved successfully in July. To achieve the merger CFV Inc. became CFCC Limited and CFNSW became a Pty Limited Company with its shares wholly owned by CFCC. This legal structure retains the four voting rights in the CF Federation. We must also acknowledge the excellent pro-bono contribution made by Stuart McCulloch and his team at Allens-Linklaters and our CEO who undertook most of the detailed work for the merger.
- **Property** - During 2017 we were formally approached by our neighbours (Hayball Architects) seeking to purchase our Dodds Street property to enable them to re-develop the entire site from Dodds Street through to Sturt Street. We recognise that 80 Dodds Street has served CFV well for many years but the



Board considered that we should examine the opportunity that this could provide. Negotiations are advanced and if approved by our Board we will be able to buy another suitable office with a significant advantage that we can use to benefit the CF community in both the medium and long term.

- **Research** - As you would recall CFV supported a Proof of Concept study with Loxegen Pty Ltd to test the ability of healthy CF genes being carried in nanoparticles through the mucus in the lungs of people with CF. This stage of the research has proven that the transfection of the nanoparticles is quite effective. The Cystic Fibrosis Foundation (CFF) in the USA have now considered that the proof of concept study is worth further consideration and have paid for the highly recognised Charles River Laboratory in Cleveland to undertake a range of further tests. Loxegen expect these results to be available within several months.
- **Our Community Education Campaign on Carrier Screening** has progressed well and CFCC now partner with both Spinal Muscular Atrophy and FragileX in our advocacy to government in relation to securing support for testing through Medicare.

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. I give a big thank you to all our volunteers, supporters, corporate partners and donors without whom we would not be able to provide anywhere near as many of the programs and services as we currently do. Whether you volunteer your time or make a financial donation, or both, we sincerely appreciate your generosity.

I acknowledge and appreciate the professionalism of our CEO, our dedicated staff and our Directors. It is a pleasure to work in such a committed organisation.

CEO's Report

KARIN KNOESTER CHIEF EXECUTIVE OFFICER



It gives me great pleasure to provide this report to our members across Victoria and New South Wales. As many of you know 2017 was a significant year in that Cystic Fibrosis Victoria changed its name to Cystic Fibrosis Community Care (CFCC) in March and in July CFCC merged with CFNSW. Both organisations retain their ABN and relevant legal rights and responsibilities with overall control and management under the banner of CFCC. Over time the Boards of both organisations envision greater effectiveness, a unified messaging and approach and a larger member base from which to garner support and leverage influence with decision makers. CFCC now cares for a total of 1638 people living with CF and their families. To put that in perspective, we now provide support and services to half of the total number of people living with CF in Australia.

As CEO, I work across both states with a new State Manager employed in 2018 to manage the office on a day to day basis in NSW. Our fundraising and programs teams are working together to create systems and procedures to deliver high quality services and activities. Our finance function has been consolidated and is now run from Victoria. Our team are smart, caring, motivated workers and now we have the ability to capitalise on knowledge sharing. We look forward to creating even more cost efficiencies over time as we move forward.

Advocacy continued to be a focus cross Victoria and New South Wales for CFCC and we provided advocacy support in 80 individual cases. Areas of support included care and services while in hospital, housing, education, accessing subsidised gym services, government benefits, and the NDIS.

The role out of NDIS has had a significant impact on our members, with most adults and children who were receiving in home airway clearance support in NSW being denied access to the NDIS. The

matter has been escalated to both state and federal government representatives in health and disability, and we are now providing advocacy support to several adult CF clients at the Administrative Appeals Tribunal and challenging NDIA's decision.

In February I travelled to Canberra in advance of the protest at Parliament House to meet with Catherine King MP, Member for Ballarat and on 9 February I attended the CFA protest on the lawn of Parliament House. We contacted each Federal member from Victoria including Greg Hunt, Health Minister, and introduced them to children in their electorates who were waiting for Kalydeco. We received significant media coverage with a lengthy piece on Channel Seven news about Kalydeco and the children who were waiting. Greg Hunt took the opportunity of the protest to announce that Kalydeco would be made available to the 30 Australian children with the G551D mutation. We have now turned our attention to Orkambi and commit to supporting Cystic Fibrosis Australia who take on the role of national advocacy and getting this medicine listed on the Pharmaceutical Benefits Scheme.

Our advocacy efforts in Victoria in relation to the changes to the CF Clinic at the Alfred Hospital resulted in significant consumer consultation and while the new spaces do not yet meet international best practice in terms of infection control, they are an improvement of what was initially proposed. We will continue to press for all clinics to meet the rigorous infection control standards we need to ensure the health and wellbeing of our CF community while in hospital or clinic. We continue to collaborate with nine major hospitals across both states to help provide assistance and services to our CF community members. The government funding model in NSW determines that we provide social worker support to the CF clinics, and while this has

on occasion been a challenge, NSW continues to meet its service obligations. At the Interclinic in Newcastle in November I took the opportunity to meet with a number of people including clinicians and allied health staff from Westmead and John Hunter Hospital.

Cystic fibrosis is perhaps not as well known in the general population as we would like, so a wide range of awareness raising activities were executed in 2017. Public displays, speaking events at clubs and schools and engaging high profile media all help to share the story of CF in our community. We enjoyed prime time promotion on Channel Nine and Seven. Importantly we sought to engage the decision makers in our community and we instigated a successful engagement plan including the delivery of a rose and rose lapel pin to every Victorian parliamentarian. We also sent 65 prominent Victorians a rose pin with the request to share the CF story with ten people. A personalised letter from the CEO was sent to every federal MP in Victoria with the number of people living with CF in their electorate, enclosed with a lapel pin. These activities all centred around 65 Roses Day (Friday, 26 May) and it was wonderful to see the Bolte Bridge and AAMI Park Stadium both be lit red to mark the day.

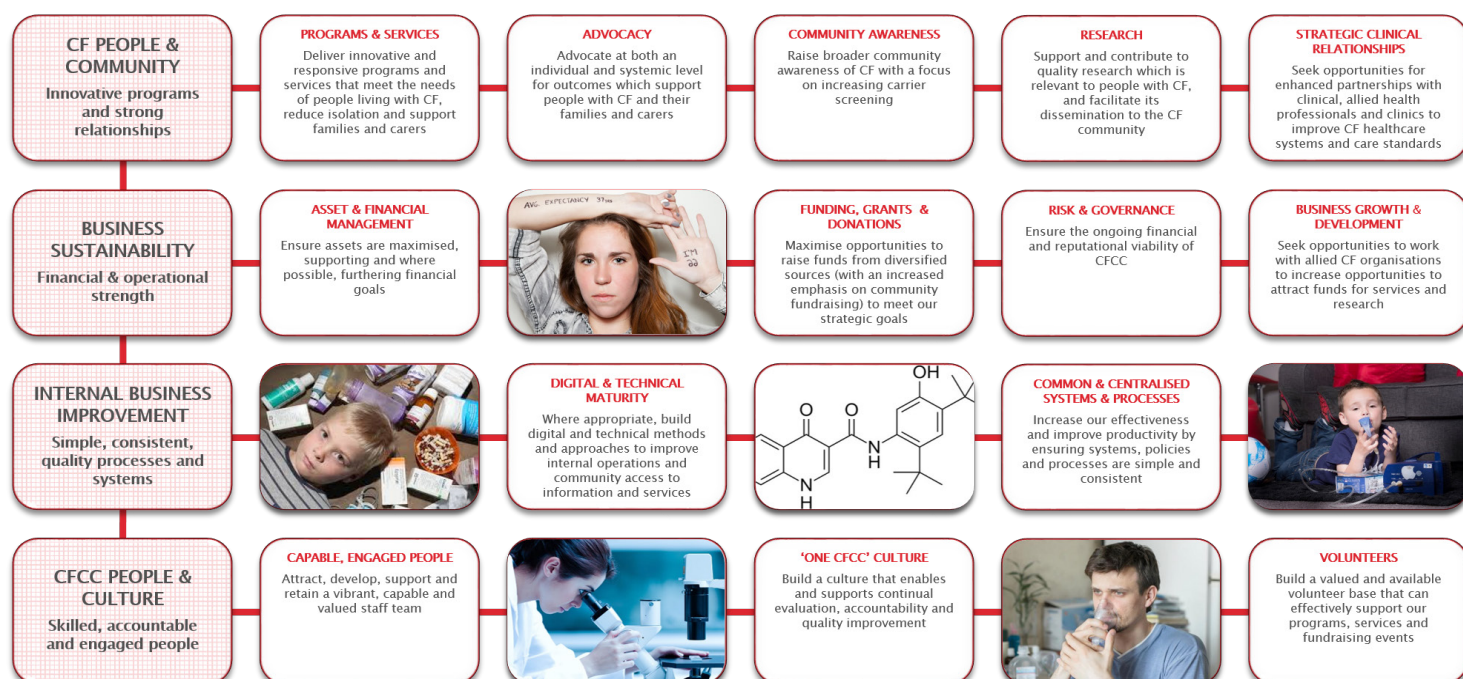


A great deal of what we do relies heavily on the willing hearts and hands of our volunteers who have supported us through all the major events. I would like to take this opportunity to thank each and every one of them for their generosity. Included in this are our wonderful community fundraisers, donors and supporters, corporate partners and others who all contribute to ensure that we can continue to deliver support and services to the CF community.

I would also like to thank the Board of CFCC who give their time, skills and experience so willingly, and for their support of me and my staff throughout the year. And finally, my team in Victoria and NSW – thank you for your professionalism, enthusiasm and passion.

With the merger came the opportunity to refine our strategic plan and I am happy to share this with you here. I also share with you CFCC's highlights of 2017.

CFCC Strategic Plan 2018 to 2023



2017 highlights



CFSmart – cfsmart.org

CFCC worked with CFWA to create a national education website called CFSmart www.cfsmart.org. This resource is for teachers, parents, students and health professionals, and was made possible thanks to funding from The Ian Potter Foundation.

“The CFSmart e-learning modules have given staff an understanding of CF which they lacked. It’s provided needed professional development that has helped her keep up with her schooling.”
School Wellbeing Officer

CFSmart offers four e-learning modules for teachers to learn all they can about cystic fibrosis and what it means for their students. 171 teachers have completed the modules so far, a great benefit to CF students in their care.

Education Programs

Thanks to funding from Newman’s Own, CFCC employed an Education Support Coordinator (ESC) to work with struggling CF students in Victoria.

Over 40 students were supported in ways such as:

- helping students keep up with school work while learning to manage their challenging chronic condition,
- equipping teachers with reliable resources,
- boosting parents’ capacity to advocate for their child’s education requirements, and
- creating a flexible and accessible environment for CF students to learn at school, home and hospital through collaborative partnerships between students, parents, teachers and hospital staff.



“When the ESC came to talk to the school with me they took the issue way more seriously. The ESC’s background in education plus the fact they represent a professional health organisation meant the school paid more attention to X’s needs.”
Parent, 2017

In NSW our Regional Support Service Worker broadened our scope to deliver education services through different media platforms to increase the service delivery to more areas of the state in a timelier and cost-effective manner. We were able to deliver sessions to 59 schools.



65k 4 65 Roses

While this event happened in the first half of 2017, under CF NSW, it is certainly worth a mention. The team in NSW delivered the 65k 4 65 Roses walkathon that raised \$500,000 to be shared between The Westmead Children's Hospital and CFCC. Over 1,200 people attended and participated in the event which was amazing to see. In 2018 we celebrate the 10th year of this event.

The Barefoot Ball

Hosted in partnership with the Newport Surf Life Saving Club and coordinated by community member, Annie Finn, the Barefoot Ball raised nearly \$40,000 for each organisation. The 300 guests enjoyed fine dining and danced the night away on the white sands of Sydney's northern Newport Beach. A superb night was had by all.



A Night for CF

In July, 315 guests attended A Night for CF in Melbourne. Guests enjoyed a 3-course meal and wine courtesy of Ros Ritchie Wines, plus superb entertainment. Fundraising activities included a silent auction, raffle, live auction and wine wall. In total \$38,241.40 was raised on the night, and the overall profit was \$43,655.27.

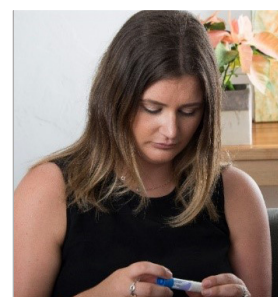
Carrier Screening Community Education Campaign

In May 2017 we launched a carrier screening awareness campaign that focused on the question

"Are you one of the 1 in 25 Australians who carry the cystic fibrosis gene".

Posters delivering this question were displayed in shopping centre amenities for three months and the poster was also featured on a call out on the Friday Night Football (AFL7) with a reach of 40,415. Further, a publicity event was held at Flinders Street Station in May where postcards with information about CF carrier screening were handed out.

CFCC is now collaborating with Spinal Muscular Atrophy Australia (SMAA) and FragileX Syndrome Australia (FragileX) to raise awareness of carrier screening. CFCC and SMAA have written to the Federal Minister for Health, Greg Hunt, seeking support for the combined three panel genetic screening test to be available on Medicare for females planning a pregnancy.





Zahra's Story

Hi I'm Zahra, I am 13 years old so I'm going into Year 8 this year. I love performing drama, being with animals and kids. When I'm older I would love to be an actress or a kindergarten teacher. I have CF (cystic fibrosis). If I could have a super power, it would be invisibility or to have a secret twin who looks like me and loves doing dishes and maths, things that I hate!

School is hard at the moment. I miss a lot due to hospital appointments, being in hospital and from just plain colds.

I need teachers to help me catch up. It's good when they communicate with me and send me work. It really helps when they make the work very clear and explain exactly what I need to do.

I love to do sport, especially swimming and skipping. I have to exercise at least 30 minutes a day as well as my physiotherapy. I love the feeling of when you're under water and then when you come up for air, it's so cool.

My favourite part of hospital, apart from feeling better, is the art room in the Monash hospital. It's really fun and the play therapists are very nice. I also love the food there. I have lots of time in hospital and I have learnt how to do a tummy roll and how to memorise a lot of numbers! When you arrive they give you a band and it says your identification number like 490825. I used to memorise that number so when the nurses came I could say it and they were very impressed!

I love my dog and I wish he could stay in hospital with me to keep me company.

A word from Zahra's Mum

Zahra is still processing her diagnosis. This takes time and, as well as her daily treatments and medications, she works hard on her mental health. She is still experimenting and learning strategies to manage her time. Finding a balance to fit her medical needs, education and social needs is an ongoing battle.

Missing school has affected Zahra's academic esteem. At times she feels that she will never catch up to her peers and is not sure she is smart enough. She has missed huge amounts of school and works hard on weekends and holidays to try to catch up. She has missed some of the important building blocks of maths which makes it difficult for her to learn her current year level maths.

I am privileged to be her mother. Over the years she has been through a lot. There have been months where her health has caused her to feel tired all the time and, with increased medications and extra treatment times, she has only been able to focus on her physical health. School, friends and social events have had to be missed.

I have watched and supported her through the darkest of times and seen her inner strength shine through. She is stronger than she knows. She has a great personality and kind nature, and I look forward to watching her through the journey in life.

Zahra has endured a lot of scary, uncomfortable and painful experiences. It is very hard watching my child go through this. I would love to wave a magic wand and make it all go away. Until I find one I do everything I can to support her. This includes helping her with her education.

Programs and Support Services

The Programs and Services teams in each state offer different activities to support those living with CF. Support is provided to our community from government grants, funding from philanthropic trusts and foundations, and fundraising.

Below is a summary of the programs and services delivered in 2017.

Financial Support Services (Victoria)

Program	Number
20% reimbursement	93
Accommodation subsidy for regional members	131 nights
In-hospital television hire	3,837 days

Grants

Miscellaneous	38
Emergency assistance	52
Fitness program	76
Physiotherapy equipment (inc Variety Grant equipment)	215
Take-a-Break	11
Tutoring	8
Transplant assistance	8

Other Support Activities (Victoria)

Program	Number
Advocacy (individual)	56 cases
Boredom Busters	85 bags
In-hospital member visits	106 visits
Newly diagnosed, new member, adult member kits	15 kits
New loan equipment agreements / loan days	35 loans / 3,217 days
Support activities and attendance	9 activities / 138 attendees
One-on-one peer support	11 matches
Cabin bookings / number of nights	58 bookings / 193 nights

Thanks to generous donations from supporters and organisations we were also able to distribute a range of tickets and gifts to the Victorian CF community.

- 170+ tickets to AFL games, the tennis at Kooyong, the Royal Melbourne Show, Variety Christmas Party and the circus.
- Seven \$200 RACV resort vouchers, donated by RACV.
- Items for our Boredom Buster Bags, donated by Brody and Ellie's Helping Hand.
- Knitted toys, dolls, clothes, pillow cases and blankets, donated by Mariella and Octavio Kennedy, Lily Cain and Jill Fisher and the Nursing Home.

Further, we supplied equipment and support to CF Centres and hospitals to support the CF community.

- Ten mini fridges for use by CF patients at The Alfred and Monash Medical Centre, thanks to Tobin Brothers.

- Portable baby scales for Bolton Clarke's CF Team.
- Equipment valued at \$6,148 to establish a massage program for adult CF patients at the Monash Medical Centre, thanks to The Andrew's Foundation.
- Participated in the development of, and provided funding for the Australasian Clinical Practice Guidelines for Social Work in Cystic Fibrosis.

Throughout 2017 we also offered support activities across Victoria to give people who have a family member with CF the opportunity to meet others in a similar situation; to share stories, experiences and resources. Eight events were held across the state - three in Melbourne plus in Geelong, Bendigo, Warrnambool, and Albury Wodonga.

The annual CF Remembrance Service was also held in Melbourne.

Support Services (New South Wales)

Throughout 2017 CFNSW, and following the merger CFCC NSW, provided programs and support services to the CF community to support their health and wellbeing. In New South Wales CFCC provides psychosocial and social work support to CFCC community members throughout the state.

Our service deliverables include advocacy, education (including school and workplace visits) and public awareness, financial and practical assistance, referrals, and support services - in person at clinic, by telephone, mail or email.

Services delivered to clients who attend	Number (instances)
John Hunter Children's Hospital (paediatric)	1104
Westmead Hospital (adults)	585
Gosford Hospital / Central Coast (adult and paediatric)	117
John Hunter Hospital (adults)	241
Royal Prince Alfred Hospital (adults)	116
Sydney Children's Hospital, Randwick (paediatric)	666
The Children's Hospital at Westmead (paediatric)	621
Inpatient visits (JHCH, Westmead, JHH, Gosford and RPA)	89
Programs and Support Services assistance provided in CF clinics only (all instances)	565

CFCC NSW also offers CF community members access to a selection of grants and programs.

Listed below are programs offered in 2017, and the number of community members who accessed each program.

Program	Number
Newcastle Permanent Grant Equipment Program	33
Newcastle Permanent Grant Fitness Program	24
Celebration of Life	2
Interclinic (Sydney)	30
Interclinic (Newcastle)	44
Financial assistance (Coles vouchers)	24
Dreamnight	30 families

Volunteers

Volunteers play an integral part in the success of CFCC and we rely heavily on their generosity and commitment to support the many events and activities we host throughout the year.

During 2017 we were extremely lucky to have been supported by more than 200 volunteers, who tirelessly gave their time to assist our major fundraising events including 65 Roses Day, Great Strides and Barefoot Ball.



We recognise our volunteers' time is precious, and we endeavour to make their volunteering experience memorable and fun.

Our volunteers bring skills and knowledge to our events that we otherwise would not be able to access and we thank them for their ongoing commitment and support ... we could not achieve what we do without you!





Brothers, Lucas and Ned

Ned's Story

Hi, my name is Ned and I am 11 and have cystic fibrosis (CF). This is a photo of me with my brother Lucas, we are both pretty good basketballers. There is one year between me and my brother. We do most things together.

I was diagnosed with CF the day after I was born. I had Meconium Ileus and was taken to the Royal Children's Hospital, Melbourne for surgery. I stayed there for about 13 weeks until I was strong enough to come home. I've been in and out of hospital since then. Some years are better than others. I seem to go for a tune-up every 18 months but sometimes I've been in twice a year.

I get frustrated when I'm in hospital. I like to run around and stay active and I miss playing with my brother and friends and being at home. I like being home doing my own thing and I really don't like having the IV drip in my arm all the time. It makes me feel claustrophobic.

I really like the CF team especially my specialist Dr. Colin Robertson, who always makes me feel calm inside. I can get very anxious about having CF and what this means. I don't like people staring at me when I take my enzymes.

I love to keep active. My brother and I play basketball out the front every night after school. I'm also in a trampoline squad where we both train for four hours a week. I know by keeping active I'm helping keep my lungs strong. When I do get sick, I get very tired and I find it harder to run on the court for the whole basketball game. I do physiotherapy every morning before school and take lots of tablets throughout the day. Sometimes I get over taking tablets but most of the time it's ok.

I want to be an NBA player. I worry that my CF won't let me grow to be tall enough. I try to eat as much as I can so I'll grow taller. I'm going to be an NBA player.

Fundraising

Fundraising is vitally important to CFCC as without the support of the community attending our events, donating to our appeals and running their own fundraisers we would not be able to offer many of the programs we do.

Support comes from individuals, corporations, clubs, schools, foundations, trusts, members and others.

Thank you to everyone who has supported us throughout 2017 and helped us achieve the fundraising results celebrated below.

Victoria ... Fundraisers at a glance



A NIGHT FOR CF

300 guests

\$44,000



65 ROSES MONTH

13 community fundraisers

\$37,000



CRAZY HAIR DAY

67 schools

\$14,411



TAX & XMAS APPEALS

combined result

\$41,000



GREAT STRIDES

1400 attended

\$134,000

Victoria ... Fundraisers in focus

Peaks4CF






In early March the 'Peaks4CF' Team travelled to Falls Creek to take on the three peaks ride and conquer Tawonga Gap, Mt Hotham and Falls Creek. Designated hors categorie (meaning unable to be categorised) the three peaks is one of the most challenging rides in the world. Their amazing effort saw the team raise over \$35,000 plus \$7,500 in corporate sponsorship.



The Nightingales

As a vital part of our community fundraising mix for over 30 years The Nightingales have supported the maintenance and refurbishment of our respite cabins. With the sale of the cabins pending The Nightingales will now provide funding, to be allocated annually to agreed services. This group help with many of our events including the Christine Doran lunch and Great Strides, as well as running their own fundraising events.

New South Wales ... Fundraisers at a glance

 BAREFOOT BALL 300 guests \$37,000	 COMMUNITY FUNDRAISERS 102 fundraisers \$93,430
 CRAZY HAIR DAY 241 schools \$22,849	 TAX & XMAS APPEALS combined result \$90,179
 65k 4 65 ROSES 1200 attended \$500,000 (gross)	

New South Wales ... Fundraisers in focus

Bright & Duggan/Express Glass Charity Golf Day

In late October, around 80 golfers braved an early morning and torrential rain to gather at Moore Park for a day of golf and fundraising for CFCC. As luck would have it, just before tee off, the rain clouds disappeared and a very pleasant morning of golfing was enjoyed by all. With the game over, it was back to the clubrooms for a delicious lunch, prize raffle, and a few cheeky ales.

Organised by long-time supporters Bright & Duggan and Express Glass, and making over \$11,000 for CFCC, the day was a definite hole in one!



Breathe Better Program

The Newcastle Permanent Charitable Foundation (NPCF) granted over \$92,000 to support children and adults in the Hunter New England area of New South Wales. The grant consisted of two funding streams, the first to replace old nebulisers and nebuliser related equipment, and the second a personal exercise program. The exercise program gave 24 people, including 11 adolescents, access to 13 plus sessions of a planned self-managed exercise program. The program resulted in clear physical gains as measured by participating exercise physiologists or personal trainers.

*"I keep up with my friends better and stairs aren't as tiring.
I feel more awake, and it's easier to breathe when I am
doing stuff with my friends."*

**Elizabeth Walters (participant) CFCC NSW and Newcastle Permanent
Charitable Foundation Breathe Better Program 2017**



Proudly supported by

**NEWCASTLE PERMANENT
CHARITABLE
FOUNDATION**

Communications

CommUNITY Focus

Following the mid-2017 merger of CF VIC and CF NSW a new joint magazine, CommUNITY Focus, was launched. CommUNITY Focus is a quarterly publication, distributed to all CF members in Victoria and New South Wales.

The magazine is used to communicate our program and support services news, fundraising updates and upcoming event information, human interest stories, research articles and self-help advice.

The printed CommUNITY Focus magazine is sent to over 1500 members across the two states, and the digital version is available on our website and through our Facebook pages.



Social Media

Facebook continues to be an important communications vehicle for CFCC and is used extensively to promote programs, events and activities to our Facebook followers.

From 1 January to 31 December 2017 the Facebook following in Victoria increased by nearly 14% - from 6038 to 6867.

During the same period the number of followers in New South Wales grew from 4,990 to 5,578, an increase of nearly 12%.

Media coverage

Some pleasing media coverage was achieved in 2017, including a double-page carrier screening feature in The Age newspaper in October. This publicity resulted in a 120% increase in traffic to the carrier screening information on our website. Read the full article here: <http://bit.ly/CFscreening>

Cystic fibrosis awareness also publicised when 9 News Melbourne, AFLPA and the Collingwood Football Club covered Jarryd Plischka's visit to the club, and \$5,000 cheque presentation.



The Grigsby family who featured in the Age Newspaper carrier screening article in October 2017



Our sincere thanks to all the organisations and community groups who supported Cystic Fibrosis Community Care during 2017.

Corporates, Trusts and Foundations

Allens Lawyers
Bright & Duggan
Commonwealth Bank Australia
Commonwealth Staff Social & Charity Club
Dooley's Catholic Club
East Malvern Community Branch Bendigo Bank
Equity Trustees
Evergreen Cruises and Tours
GW Vowell
Hall Chadwick
Harcourts
Holding Redlich Lawyers
Ian Potter Foundation
Joe White Bequest
Lord Mayors Charitable Foundation

Marian and E.H Flack
Mazda Foundation
Newcastle Permanent Charitable Foundation
Newman's Own Foundation
Perpetual Trustees
Royal Agricultural Society of Victoria
Rotary Club of Balwyn
St Mary's Rugby League Club
Suttons
Tennis Victoria
The Andrews Foundation
Therapon Foundation
Tobin Brothers
Variety Victoria
William Angliss Charitable Trust

Thank You

There are so many individuals, families and friends we would like to thank - too numerous to list individually. Please accept this as our heartfelt thanks to you for all you have done to support Cystic Fibrosis Community Care and our community throughout 2017.



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

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