

MARCH/APRIL 2019

# Community Focus



**Including:**

- 65K 4 65 Roses wrap-up
- Our new website launched
- 2019 programs and services
- 65 Roses Challenge
- Community fundraisers

**Working together to  
improve the lives of those  
living with cystic fibrosis**



# CYSTIC FIBROSIS Community Care

COMMUNITY FOCUS © 2019

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Cystic Fibrosis Community Care complies with the National Privacy Principles as specified in the Privacy Act 1988.

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**Cover image:** Sydney's 65K 4 65 Roses Walkathon, which raised over \$400,000 for the fight against CF.

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### Are you getting your monthly dose of PASSwords?

Stay up-to-date with all the latest news from Cystic Fibrosis Community Care's Programs and Support Services teams by signing up to our monthly e-news, PASSwords.

PASSwords is the place to find out about important CF news, grant opportunities, significant dates to remember and upcoming events in New South Wales and Victoria.

Best of all PASSwords is delivered direct to your inbox!

Subscribe to PASSwords today on our website [cfcc.org.au](http://cfcc.org.au)



# CF Matters

**Hello everyone! It seems like we've whizzed through January and February, and here we are already with March turning into April.**

The school year has well and truly started and our Programs and Support Services team has been very busy talking to teachers and students, ensuring that the school year is a smooth one for all students with CF.

We have had over 300 people undertake the CFSmart Teacher Training which is a great testimony to those educators who put the needs of their students at the forefront of their planning. In Victoria, we also helped to organise a joint Educators' Day with both RCH and Monash Children's Hospital which for the first time was telecast to a number of regional centres. This extended our reach significantly and helped regional schools and teachers participate where they might not have been able to before.

We know that children with CF can have a particularly difficult time starting in the school system and the resources that school community has available to it, through CFSmart, help to ensure that the school experience runs as smoothly as possible.

We have just held a massive 65K 4 65Roses Walkathon at Iron Cove in Sydney and it was a fantastic day. About 1,200 people stepped up to walk either all or part of the 65 kilometre walk. Amazing to see large family support groups such as Team Simon, Team Elizabeth, Team Jon and Grace, the Alfinators and Team Josh Jones, as well as other family groups and individuals come together to support CF Community Care and the Children's Hospital at Westmead. The drizzly weather did nothing to dampen the enthusiasm of all of our participants. Congratulations to everyone who participated and to those who raised vital funds to support services for the CF community.

We have a number of key dates coming up including 65 Roses Month and our new event a High Tea in Sydney. You will be hearing more about the activities that we will be engaging in throughout May. The CF Community Care team will be setting its own '65' goal, so stay tuned!

We are also hearing some very exciting outcomes from the Phase 3 studies of the triple combination of the next-generation corrector VX-445, tezacaftor and ivacaftor resulted in statistically significant improvements in lung function (ppFEV<sub>1</sub>) in two Phase 3 studies in people with cystic fibrosis (CF). Data from the trials has shown increases of up to 13.8 percentage points in ppFEV<sub>1</sub>.

Over the course of the next month or so I would like to establish a Consumer Advisory Panel in both Victoria and New South Wales. The purpose of the panel would be to represent the community's view and help CF Community Care determine the right balance of services and to hear what the community wants us to focus on. If you are interested in joining the panel, please do drop me an email at [ceo@cfcc.org.au](mailto:ceo@cfcc.org.au). The best outcomes are those that are a result of working together.

Until next time!



**Karin Knoester**  
Chief Executive Officer





# Missed something the doctor said?

**Recording your appointments gives you a chance to go back.**

**You're in a consultation with your doctor and you've just been told you have a serious medical condition. You're in shock, and find it difficult to take in anything else the doctor says during the remainder of the appointment.**

Research shows receiving bad news can impact people's ability to understand and absorb information. Specifically, it affects the processing of information and memory formation.

People who are unwell and managing difficult health situations will often find it hard to remember important and complex medical information. This might include their diagnosis, prognosis, treatment plans, appointments, and when to take their medication.

Since the 1970s, researchers have been experimenting with audio recording medical consultations to combat this problem.

Many studies and reviews since then have found patients who are given personalised recordings of their medical consultations feel their recall and understanding is improved.

We don't yet have evidence that directly links the

recording of medical consultations with improved health outcomes. But we know people who understand and remember important medical information are better placed to remember to attend scheduled appointments, to decide on the best treatment options, and to take their medication correctly.

This is commonly referred to as health literacy, and people with higher health literacy are known to have improved health outcomes. So we have good reason to believe recording medical appointments might positively impact people's long-term health.

## **Could recording your medical appointments benefit you?**

While most research around medical consultation recordings has been done with people diagnosed with cancer, the process could help any person in any medical situation.



People who speak English as a second language find recordings of medical consultations particularly useful.

And consultation recordings are not just useful for patients. Family members and friends often play a significant part in the care of a loved one who is unwell. Recordings give them the opportunity to be involved and informed – even if they cannot attend the appointment in person – as recordings are easily shared.

Patients in a recent study described using the recording to replay important sections to their family, to remind themselves of words to look up, and to prompt questions to ask their doctor.

In addition, recordings have

been shown to improve patient trust and satisfaction with their doctor.

Health professionals including doctors and nurses believe consultation recordings benefit patients, and improve the care they are able to provide.

Patients have described which appointments they feel are most useful to record. These include appointments at diagnosis of a health condition, appointments where important information is discussed, or appointments where treatment plans are made. Others think recording every appointment would be useful for them.

The great thing about recordings is they are under the control of the patient, so they can be made and used in the way that suits the person best.

### Ethical considerations

People are already using their mobile phones to record their doctors' appointments. One study from the UK found 69% of people were interested in recording consultations on their phones.

Although this is usually done with the doctor's permission, it's sometimes done covertly. This may diminish the trust and openness that should characterise any doctor-patient relationship, and may even be unlawful in some states.

So you should always seek your doctor's permission before recording.

Importantly, if a health service endorses and provides a means for you to record your medical consultations, the recording is seen as forming part of your medical record.

By law in Australia, hospitals have a responsibility to safely store all parts of your medical record, including copies of consultation recordings made in this context.

Our team at the Peter MacCallum Cancer Centre has developed a smartphone app called SecondEars as part of a research project. This app will enable patients to record their consultations and share the recordings with family and friends.

Importantly, because this app has been designed to be integrated and supported by hospitals and other health services, once it's implemented in a health service, recordings will be able to be uploaded and saved in the patient's medical record.

Patients will have full control over which appointments they seek to record. It is hoped this service will be made available to health services around Australia in the future. ■

**Article by Amelia Hyatt, Senior Researcher and Ruby Lipson-Smith, Research Officer, Peter MacCallum Cancer Centre**

**Originally published in The Conversation [theconversation.com/au](https://theconversation.com/au)**

## Promising trials for new triple combination medications

Vertex Pharmaceuticals, the manufacturer of Orkambi and Kalydeco, has announced very encouraging results from late-stage Phase 3 trials of two new triple-combination CF drugs.

The first new medication combines VX-659, tezacaftor and ivacaftor and is a 'next generation' CF modulator drug which researchers believe could potentially benefit anyone with at least one copy of the F508del gene change – regardless of their second gene change.

Trials showed significant improvements in lung function after four weeks – a 14 percentage point improvement (compared to placebo) in ppFEV<sub>1</sub> for people with one F508del gene change and one minimal function gene change, and a 10 percentage point improvement (compared to Symdeko) in ppFEV<sub>1</sub> for people with two F508del gene changes.

Vertex is also trialing another triple-combination drug, which combines a compound known as VX-445 with tezacaftor and ivacaftor.

In Phase 3 trials of the VX-445 triple combination the new drug demonstrated significant improvement for patients' lung function. In one study results indicated that after 28 days those who received VX-445 combined with tezacaftor/ivacaftor had a 13.8 percent increase in lung function compared to participants taking a placebo.

The second trial compared VX-445 combined with tezacaftor/ivacaftor to tezacaftor/ivacaftor alone. People with CF who were given the triple combination had a 10 percent improvement in lung function after 28 days over those who given tezacaftor/ivacaftor only.

Vertex will make a decision in 2019 which of the two triple-combination drugs they will submit for regulatory approval as their next-generation CF drug. The company says that global regulatory approvals are planned for late 2019, which is hoped will include Australia.

# Introducing... our new website

The website, launched in mid-March, is designed to be an information portal for the CF community.

We recently launched our new CF Community Care website – [cfcc.org.au](http://cfcc.org.au).

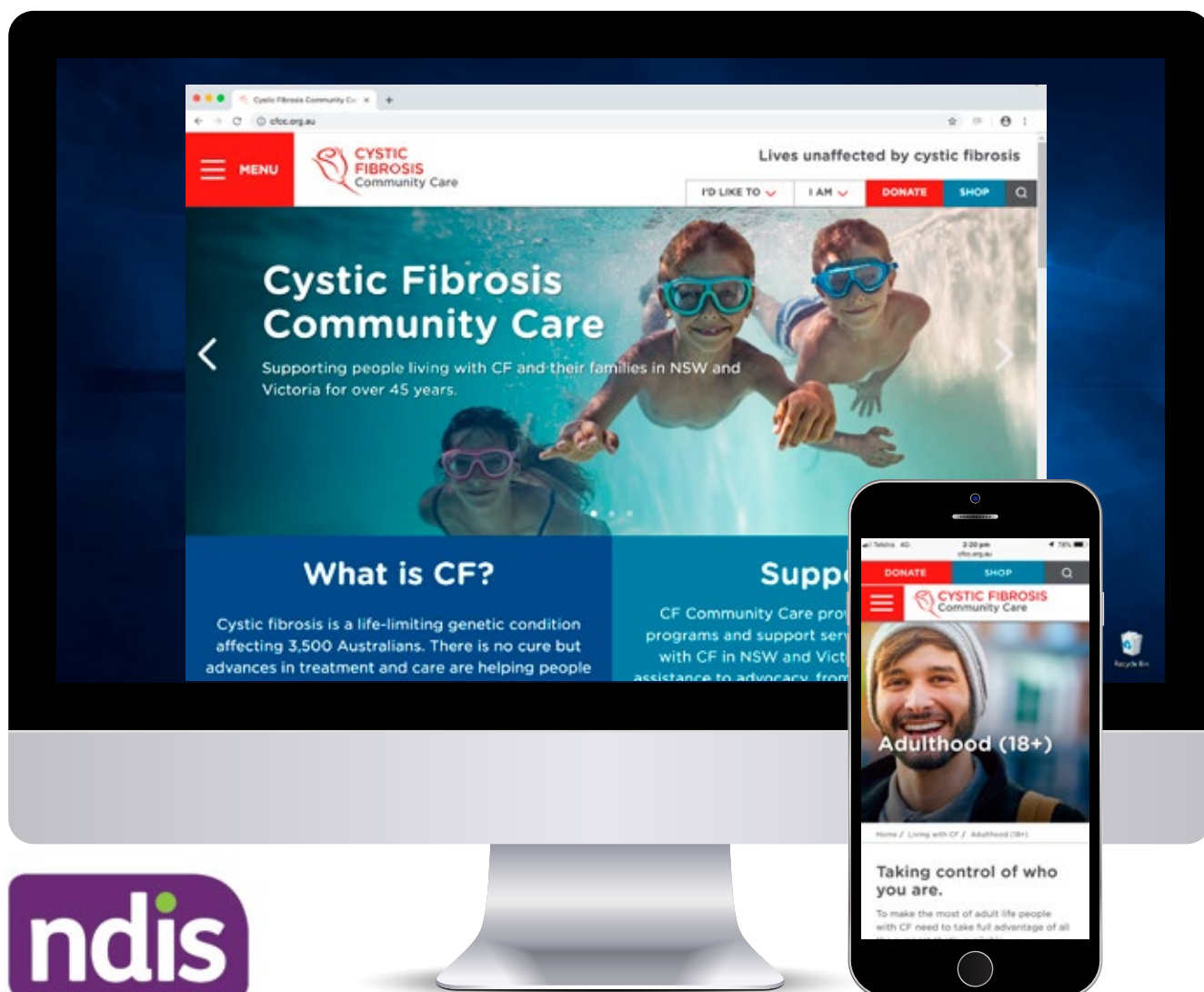
Funded by an Information, Linkages and Capacity Building grant from the National Disability Insurance Agency, the new-look website will be an information portal and resources hub for the CF community throughout Victoria and New South Wales.

Led by CF Community Care's Programs & Support Services and Communications departments, the project involved close consultation with members of

the CF community to ensure that the website featured simple navigation and useful information relevant to people living with CF, their families and their friends.

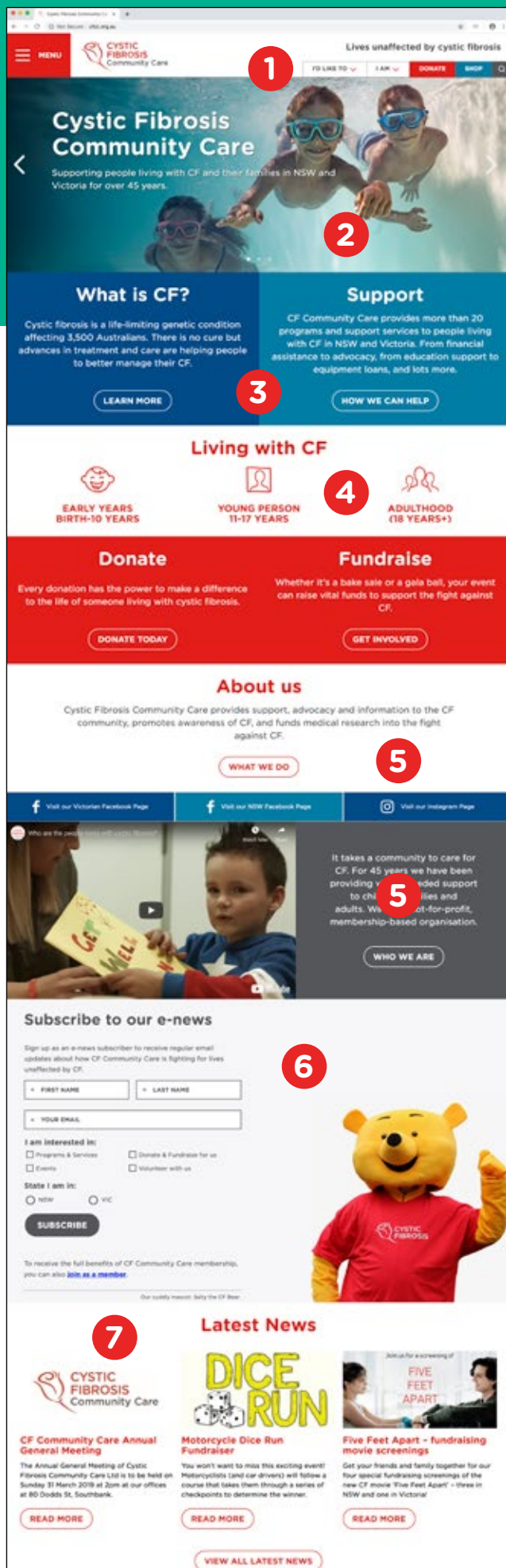
The site's interface design and its content are tailored towards the needs of people in the CF community. The layout of the site is user-focused and puts the needs of our community members first.

**Please check out our new website at [cfcc.org.au](http://cfcc.org.au)**  
**We'd love to hear your feedback and suggestions**  
**– you can email [communications@cfcc.org.au](mailto:communications@cfcc.org.au) ■**



Funded by the National Disability Insurance Agency

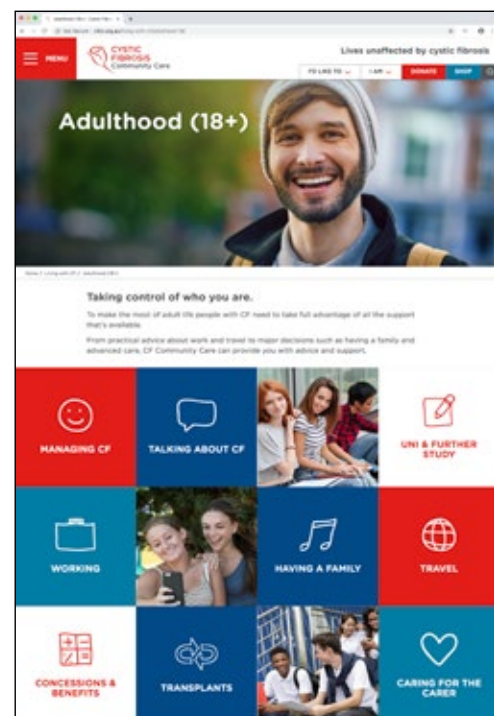




## Home page at a glance – cfcc.org.au

- 1 Quick Links let website users easily find relevant content.
- 2 Home page carousel images welcome users to the website, and showcase events and information.
- 3 'Above the fold' links to frequently-accessed information, including key facts about CF, and support services and programs that CFCC provides for people living with CF.
- 4 Tailored information relevant to people living with CF at different stages of life, as well as their families and friends.

Each icon links through to a landing page which is a springboard to deeper information. Below is an example of one of the landing pages:



- 5 Information about CFCC – who we are and what we do
- 6 Subscribe to our email list.
- 7 Catch up on the latest news, events and articles.

# Flynn's a master of martial arts

**Ten-year-old Flynn Morrison understands the importance of exercise in helping manage his CF. He's so committed to his training that he's about to become a black belt in karate!**

## Flynn's story:

My name is Flynn and my favourite sport is Karate Shotokan – a form of martial arts. This includes a type of karate called Kata, which is a sequence of moves designed to show skill, technique and self-defence, and the use of weapons such as nunchuks, swords, bo, sai, kama and sparring.

I began the sport when I was four-and-a-half years old and I train up to six times a week. In 18 months, I am going for my next black belt. To pass the test and receive my black belt, I must be able to run 5km in

*Flynn with his sensei*



*Flynn trains up to six times a week*

half an hour, plus do 70 push ups, sit ups and squat kicks in 10 minutes. To reach this goal I must group grade every term in front of my Kyoshi who is a 7th Dan black belt.

An interesting part of the sport is being able to use weapons when you are at a certain level. These include nunchuks, swords, bo, sai and kama. The bo is my favourite. This is a 6-foot bamboo staff that we have move around and pretend to hit people or sweep their legs from underneath them!

I also enjoy competing within my school and recently, my sensei asked me to compete with other schools in sparring, possibly at a state and national level in the future.

Karate Shotokan can be challenging, particularly remembering the five different katas which have twenty different moves. But I find that sparring and kata are great for my confidence, focus and discipline. It makes me feel strong, has helped me to stay fit and always makes me try to be better, faster and stronger. I've also made some good friends too!

Now that I am experienced, I am part of the leadership group at my school, which means I help teach the little dragons who are between 2-8 years old. ■



## Top tips for travel with CF

Recently we asked on our Facebook pages for the community's tips on how to have a hassle-free trip when travelling with CF.

**The common theme – be prepared!**

- Take spare physio / pep parts for when your child decides to throw it out the car window thinking that they wouldn't have to do physio on holidays!
- Make CF fun. Reward your child with some screen time after they've done their physio, make it as normal as you can. My top tip... make it a part of their lives not their life.
- Don't leave the creon at the last place you visited. In case you do forget, make sure you pack extra scripts.
- Have a good CF friend that can post an extra bottle of creon when you have miscalculated how many you'll need when away.
- Put your meds into a travel container 48 hours in your suitcase before you leave. Use them from this container in the days before departure and put them back into the suitcase after use. This way you can be confident that everything is packed.
- Always take extra meds and scripts, enzymes are a must and a small portable fridge in the back for Pulmozine.
- Make sure you double and triple check what you have packed, take double the amount of meds and most importantly enjoy your special time together.
- Get a letter from your specialist in case the airline asks why you have so much medication.
- Pack double the quantity you need – one half in carry on and the other half in checked luggage.
- Take lots of cleaning wipes as no place is ever CF-clean. And wine, you've earned it!
- Travel while you can, you never know what's around the corner. Essentials are: Glen 20 spray, hand sanitiser, extra creon (and medicine script), Milton tablets to sterilise on the go.

## NSW Support Dinners roll out across the state

Each year our Programs and Support Services staff host Support Dinners throughout the state. This year we are pleased to announce that we will be hosting events in the following locations:

**31 May – Sutherland Shire Support Dinner**  
**30 Aug – Armidale Support Dinner**  
**20 Sept – Central Coast Support Dinner**  
**25 Oct – Wollongong Support Dinner**  
**8 Nov – Dubbo Support Dinner**

If you are a CF Community Care member and have a family member who has CF please come along and join us.

Support Dinners are a great way to meet other families who are or have been in a similar situation. You will have the chance to swap stories, and share experiences and resources.



CF Community Care will cover the cost of meals for current members. Non-members are also welcome to join us but will need to pay for your own meal.

Bookings are essential. We will require final numbers at least two weeks prior to the event, so please RSVP your intent to attend as soon as you can. If you would like to be involved or would like to nominate your local area as the location for a Support Dinner, then please speak with a staff member of our Programs and Support Services Team.

**For more information and to register today:**  
**Email: [nswsupport1@cfcc.org.au](mailto:nswsupport1@cfcc.org.au)**  
**Phone: (02) 8732 5700**

## Peer Support Program: Someone to talk to about CF

Sometimes it's great just to talk with someone who knows what you are going through. But the risk of cross infection means that people with CF and their parents, partners and siblings aren't able to meet others in their situation as easily as they might like.

The reality is that CF can be isolating for families as they miss out on the opportunity to socialise with other CF families and share their unique experiences.

That's why we've set up the CFCC Peer Support Program, connecting individuals affected by CF from across Victoria and New South Wales with trained volunteers.

When you speak to someone who understands your situation, you can open up and talk about things you might typically keep to yourself. A father who recently spoke with one of our peer volunteers said "We had a great chat. It was a big relief to hear from someone else with a similar story." And while the conversation can help the person receiving support, the relationship can be mutually beneficial.

This was exemplified when one of our peer volunteers reported back after speaking about his CF experiences with a parent. "He said that he found it useful talking to me but I really enjoyed the chat too. It gave me a chance to talk about a lot of things I don't ever talk about or share".

When you connect with one of our peer volunteers, you can get an unbiased opinion, nonjudgmental advice, or simply a listening ear. Your conversations are completely confidential and you can call when it best suits you. If you are a member of our CF community and think you could benefit from an informal and confidential chat, please contact the Cystic Fibrosis Community Care office on **(03) 9686 1811** and ask for the PASS team, or email [programs@cfcc.org.au](mailto:programs@cfcc.org.au)

## Australasian CF Conference 2019

The thirteenth Australasian Cystic Fibrosis Conference (ACFC) will be held in Perth in August 2019 and plans are well underway. The Lay Conference will be held from 3-4 August and the Medical Conference from 4-6 August.

Dr Andre Shultz is the Conference Chair and he has set the tone with his inspirational concept of 'Celebrating Partnerships'.

Both the Medical and Lay Conference programs are complete and all set to 'celebrate partnerships' in informative and inspirational ways.

Twelve international cystic fibrosis luminaries are taking the podium at the 13th ACFC with topics from infection to infertility on the agenda.

### 13TH AUSTRALASIAN CYSTIC FIBROSIS CONFERENCE

3-6 August, 2019 | Crown Towers Hotel, Perth

Jane Davies, Stuart Elborn, Lisa Saiman and Felix Ratjen are just a few of the overseas speakers and the full list including impressive biographies can be found on the CFA website at [www.cysticfibrosis.org.au/what-we-do/cystic-fibrosis-conferences/speakers](http://www.cysticfibrosis.org.au/what-we-do/cystic-fibrosis-conferences/speakers).

Over 30 Australasian CF specialists have also been invited to present in Perth and all medical and allied health disciplines will be well represented.

Early Bird registrations are now open and this will not only save you money but possibly secure a \$150 Travel Grant for those traveling by plane to WA, if you get in quick.

CFA is excited about the Perth CF Conference and the Crown Towers venue is the perfect setting for 'Celebrating Partnerships' both lay and medical sharing information and appraising innovation.

Go to [www.cysticfibrosis.org.au/acfc](http://www.cysticfibrosis.org.au/acfc) to read more about the 13th ACFC or contact CFA directly.

# CF Educators' Day: Teachers learn about cystic fibrosis

**On 13 March, 140 teachers, educators and child care workers took part in Victoria's CF Educators' Day. Attendees heard from CF experts about how to help kids with CF make the most of their education.**

The Educators' Day was delivered in person at both The Royal Children's Hospital and Monash Children's Hospital. The two live-sites were linked by video-conferencing and the sessions were also broadcast live to six regional Victorian hubs so that teachers could join in from all over the state.

A fantastic collaboration between The Royal Children's Hospital, Monash Children's Hospital and CF Community Care. Next year we hope that the Educators' Day can be delivered even more widely so that even more teachers can become CF-aware. ■



*CF experts from Monash Children's Hospital, Royal Children's Hospital and CF Community Care were connected by video link as they prepared for the Educators' Day.*

*Associate Professor David Armstrong from Monash Medical Centre presents in-person to the attendees at Monash Children's Hospital, and is broadcast live to those attending at RCH and six videoconferencing hubs around Victoria.*





# Supporting students to receive opportunities in education

**In the second half of 2018, CF Community Care gave out ten educational scholarships to support Victorian students and families with a grant of up to \$500.**

Our 2018 scholarships were given for a variety of reasons including:

- Tutoring grants to help our members to catch up with the schooling they missed when unwell and/or in hospital.
- Assistance towards funding vocational college courses for young people who were no longer in full time education and had moved to alternate educational pathways.
- Contributions towards technology to support members doing VCE who were spending a lot of time in hospital.

The feedback we received from the recipients and their families was very positive and showed the direct impact that the scholarship grants had:

- “This grant really assists in taking some of the financial pressure from providing our child’s care and education. Our child wants to finish year 12 and gain employment, this is helping facilitate that possibility.”

- “My daughter is studying Year 11 in 2019. She is doing fairly well, but her health has deteriorated over last 6 to 12 months. She will need to have regular check-ups every term in 2019. Having the laptop will help her keep on top of her studies at home and while in hospital.”

- “Our daughter was given this scholarship which has helped her keep up to date with school work. A tutor has been able to come to our house and work in between all her treatment times and hospital admissions. We thank the scholarship fund from the bottom of our hearts.” ■



*Meesha, one of the recipients of the scholarship program.*

## Need a new neb or PEP device?

If you need a new nebuliser, medication cup for your neb or even a new PEP device we can help!

In 2018 we helped with the cost of over 250 items of essential CF-related physiotherapy equipment for our members through our Physiotherapy Equipment Grants.

If your nebuliser or PEP is not working properly or not meeting your needs please chat with your CF physiotherapist about the best options. They will send us a referral and we will contact you.

To find out more, visit our new website at [cfcc.org.au](http://cfcc.org.au) or contact your local Programs and Support Services team:

**NSW:** (02) 8732 5700  
[nswsupport1@cfcc.org.au](mailto:nswsupport1@cfcc.org.au)

**Victoria:** (03) 9686 1811  
[support@cfcc.org.au](mailto:support@cfcc.org.au)

## Membership renewals due

If you are a 2018 Cystic Fibrosis Community Care member and have not yet renewed your membership for 2019, your renewal is now overdue.

**Access to our services will be restricted if your membership has not been renewed by 12 April 2019.**

You can download our membership form from our new website: [cfcc.org.au/get-involved/become-a-member](http://cfcc.org.au/get-involved/become-a-member)

Or to check your membership status, contact your nearest main office – NSW on **(02) 8732 5700** or Victoria on **(03) 9686 1811**.

## NSW Programs & Services update

There is a growing range of programs and support services available to our New South Wales CF Community Care members in 2019.

The services available now include:

- Hospital visits
- Support from our staff members at clinic
- Counselling
- Grant funding programs
- Physiotherapy equipment program
- Reimbursements towards the cost of CF-related expenses
- A weekend adventure or weekend away with your family
- Transplant assistance
- Accommodation assistance for our regional community members.

If you have any questions about these or would like to know more about how the Programs and Support Services team can best assist you then please contact the Programs and Support Services Manager on [nswsupport1@cfcc.org.au](mailto:nswsupport1@cfcc.org.au) or call **(02) 8732 5700**.

## Accommodation assistance for regional members

Our Accommodation Assistance Program can help our regional members who travel to Melbourne or Sydney for CF-related clinics or hospital stays.

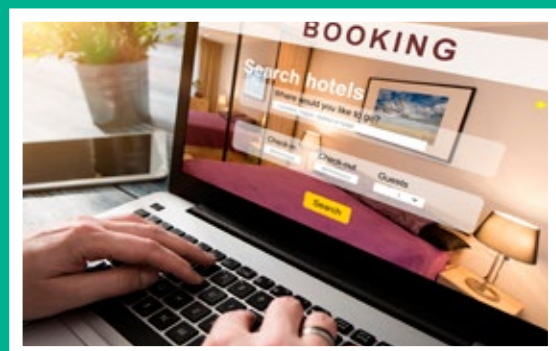
Last year we booked and subsidised 112 nights of accommodation for our regional members. This included accommodation for:

- Newly-diagnosed families who needed to stay in the city to spend time with their CF Team to learn about CF and how to manage it
- Partners and kids who travelled to the city to spend a few days with their loved one who has CF and was having a tune up
- Adults and kids who had multiple clinics over several days and couldn't travel back and forth each time
- People with early morning CF clinic appointments – it's safer to stay locally the night before the appointment than get up and drive for hours for an 9am appointment.

To find out more, visit our new website at [cfcc.org.au/about-cfcc/support](http://cfcc.org.au/about-cfcc/support) or contact your Programs and Support Services team:

**NSW:** (02) 8732 5700  
[nswsupport1@cfcc.org.au](mailto:nswsupport1@cfcc.org.au)

**Victoria:** (03) 9686 1811  
[support@cfcc.org.au](mailto:support@cfcc.org.au)



In addition, the Victorian and NSW Governments have patient transport assistance schemes to help with the cost of travel and accommodation for people who have to travel to access medical specialist services. Visit [cfcc.org.au/about-cfcc/support](http://cfcc.org.au/about-cfcc/support) for more information.

# Programs and support services guide

Our range of services available to CF Community Care members in 2019.

## Info & Support

If you're looking for CF-related info, support, or general enquiries about our programs and services, check out [CFCC.org.au](http://CFCC.org.au), email [support@cfcc.org.au](mailto:support@cfcc.org.au), or call (03) 9686 1811



## Hospital Visits

Let us know if you're in hospital and would like a visit, as we regularly visit the CF centres in Melbourne to chat with our members.



## Time Away

Need some time away to reset and recharge? Whether it's going to the zoo or taking a family holiday, we have grants that can help make this possible!



## Advocacy

We represent the needs of the CF community by advocating for members at the local, state and national levels, as well as providing one-on-one support.



## Fitness and Physio

Do you play a sport, train at the gym, or take dance lessons? You may be eligible for a subsidy to help with the costs of fitness activities and physio equipment.



## Peer Support

If you've ever wanted to talk to someone who has similar lived experiences with CF, let us know. Regardless of your situation, we have someone who's ready to connect.



## Equipment Loans

Members are able to borrow essential medical equipment for a short period of time, including nebulisers, oxygen concentrators, and a wheelchair.



## Education Support



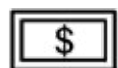
Whether you're a student, parent, or educator, we have free online training and scholarships to help you, along with access to our Education Support Coordinator.

## Accommodation Assistance



Are you a regional member attending clinic in Melbourne? We may be able to assist with the cost of accommodation for you and your family during your admission.

## 20% Reimbursement



The expenses can add up, but we're here to help. We may be able to reimburse 20% of your CF-related expenses, from medications to hospital parking fees.

## Transplant Assistance



To help relieve some of the financial stress during recovery, you may be eligible for up to \$500 to assist with transplant-related costs.

## Community Events



Come along to one of our community events whether it's a support dinner for CF families, the Community Conference, or our annual Great Strides fun run.

## Emergency Assistance



In times of crisis, lengthy hospital stays, or following sudden changes in health, we may be able to provide support for your urgent CF-related needs.

## TV Hire in Hospital



Are you a CFCC member who's in hospital for a CF-related stay? We may be able to help cover the cost of your TV hire.

Please note that some services are state-specific, depending on funding arrangements. Contact your local office for more information.



# Thanks for your Xmas Appeal donations!



Sickness won't stop Ari's cheeky smile

**A huge thank you to everyone who supported our Christmas appeal. All of us at CF Community Care are also very grateful to Ari's family for sharing their story for our appeal.**

Adorable Ari has a cheeky little smile that never fades, but his daily struggle with cystic fibrosis will be lifelong. The challenges of CF will always be there and at times things can be very tough.

Through your amazing gifts, we can continue to fund vital services and programs throughout Victoria and New South Wales. We wish Ari and his family all the best for the year ahead.

Our Christmas Appeal raised over \$38,000 across both states, which will make a huge difference to the lives of many CF families. We thank everyone who donated!

Each year we run two appeals, alongside our colleagues in other cystic fibrosis organisations. This collaboration allows us to share resources and provide a consistent awareness campaign across Australia. In April we will be launching our end-of-financial-year Tax Appeal.

Sharing stories of remarkable families and individuals brings hope and spreads awareness throughout the community and beyond.

If you would like to be part of a future campaign by sharing your family's CF story, or your business can help with pro bono support please contact Fran Hay at [donors@cfcc.org.au](mailto:donors@cfcc.org.au) or on (02) 8732 5700.

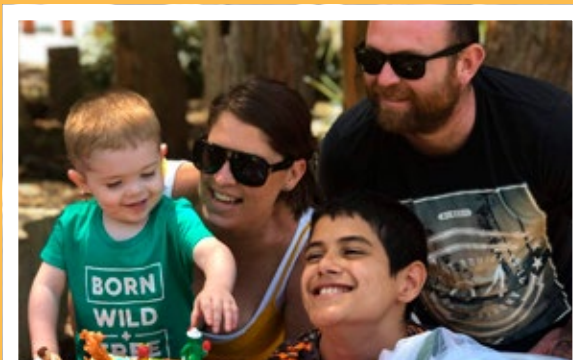
**If you missed our campaign you can still make a donation online. All gifts go towards funding essential services and programs. Please indicate your gift is for the Christmas Appeal 2018.**

## Donate in New South Wales

[shop.cysticfibrosis.org.au/nsw/donation-cfccnsw](http://shop.cysticfibrosis.org.au/nsw/donation-cfccnsw)  
or donate by phone: (02) 8732 5700

## Donate in Victoria

[shop.cysticfibrosis.org.au/vic/donation-cfv](http://shop.cysticfibrosis.org.au/vic/donation-cfv)  
or donate by phone: (03) 9686 1811 ■



## How's Ari now?

Little Ari's parents have told us that he has been hospital-free and has only had three rounds of antibiotics over the last 12 months.

This is such an improvement on his first year when he was hospitalised six times and had eight rounds of antibiotics.

That's great to hear and we hope that Ari's health news continues to be so positive!

**Coming in April: Watch out for the launch of our Tax Appeal**

# 65K 4 65 Roses: Our community unites





On Saturday 23 February at Iron Cove Bay, Sydney, there were so many beautiful stories of admiration and love to be heard. Over 1,200 people registered for 65K 4 65 Roses, taking on different distances in the name of a loved one living with CF.

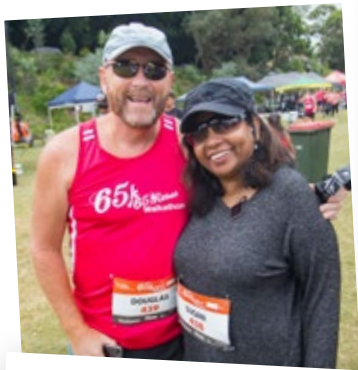
The 65km walkers were ready to go at 2am with the last walkers coming through the arch at 5pm. What an effort!

The Western Sydney Wanderers and NSW Swifts were on hand to delight children at the event. Entertainers

from the 501st Legion and Star Dust Kids roved around putting smiles on faces.

We'd like to thank our sponsors Suttons, Bright and Duggan, and G&W Hydraulics who helped make this event possible.

Lastly, thank you everyone who registered and fundraised to support the work of CF Community Care and The Children's Hospital at Westmead. Through your amazing combined efforts we reached our target of over \$400,000 raised! ■





## Get your tickets for our night of the year

Dust off your finest gown or tux and step into a fabulous world of glamour and intrigue. The night of the year awaits...

Your ticket to A Night For CF includes a three course meal, beer, wine and soft drinks and excellent entertainment in the glamorous Peninsula Room, Docklands. Get your table together now and prepare to be indulged.

An open mind, generous spirit and attitude for fun is a must. Participation in our fundraising activities is strongly encouraged and everyone has the chance to go home a winner.

Secure your place at CF Community Care's night of the year by purchasing your tickets today.

Last year's event sold out two months before the night, so make sure you coordinate your family and friends early. The 2018 event raised over \$75,000 to fund CFCC's programs and services. Tickets are on sale now for 2019: [hub.benojo.com/campaigns/a-night-for-cf-2019](http://hub.benojo.com/campaigns/a-night-for-cf-2019)

NSW will also be running A Night For CF later in the year on Saturday 7 September at The Westin. To flag your interest and get on the mailing list email [frcoordinator@cfcc.org.au](mailto:frcoordinator@cfcc.org.au).



## Are you ready for the month of May!

65 Roses Month in May is fast approaching and it is time to motivate your friends, family and colleagues to come together and help us raise awareness and funds for CF.

### Take the 65 ROSES CHALLENGE

FOR CYSTIC FIBROSIS

The annual 65 Roses Challenge encourages individuals, community groups, organisations and anyone with a desire to take on an event or challenge. This challenge must be associated with the number 65. These challenges aim to raise funds for cystic fibrosis but more importantly create awareness. Let's turn May into CF month!

Here are four ways you can join in:

1. Run a community fundraising event around the number 65 – such as a lunch, high tea or cocktail party for 65 friends, run a yoga class for 65 people, or hold a wine tasting night for 65 people.
2. Create a challenge. Here are some ideas but you can always create your own!
  - Complete 65 squats per day
  - Do 65 hours of skipping during the month
  - Hold a dog wash and wash 65 dogs
  - Play 65 sets of tennis at your tennis club
  - Hold a high tea and invite 65 people
3. Sell merchandise – Contact us and we'll send you a merchandise box of goodies to sell at work or at school. In Victoria email [events@cfcc.org.au](mailto:events@cfcc.org.au) and in NSW [communityfr@cfcc.org.au](mailto:communityfr@cfcc.org.au).
4. Join an existing challenge – If you want to keep it simple you can join our challenge to walk 65km during the month of May in support of people with cystic fibrosis. To register: [walk65kinmay.fundraise.digital](http://walk65kinmay.fundraise.digital)

To register your challenge or for more info, email [communityfr@cfcc.org.au](mailto:communityfr@cfcc.org.au) in NSW or [fundraising@cfcc.org.au](mailto:fundraising@cfcc.org.au) in Victoria.

# It takes a community to care for CF

**We've prepared a Fundraising Toolkit to help you plan and run a successful community fundraising event.**

As a not-for-profit organisation, CF Community Care relies on our fantastic supporters to help raise funds for our work. To help make the most of your fundraising, we have developed a Community Fundraising Toolkit designed to assist you to organise your own activity or event.

The toolkit contains everything you need to know to get you started, including activity suggestions, helpful hints and ideas, proposal to fundraise form, and the fundraising guidelines.

Most people who fundraise do so because they know someone, usually a friend or family member who has CF that they want to support. When you think about fundraising it's good to know what your friends and family are passionate about. Is there a challenge you have always wanted to do but haven't quite had the motivation for up until now? Each person is unique and has different skills and interests. Together, you will help us reach new networks, raise vital funds and raise awareness.

While often people come to us with an idea of what they want to do, there are plenty of people who want to fundraise, but are not sure how. This toolkit has a list of great fundraising ideas that will take some of the guesswork out of it and we have included some success stories to inspire you.

There are tonnes of fun ways you can raise money. Whether it is a trivia night, running your own Great Strides, morning tea, raffle, or organising your own fun event, you'll be helping us fund much needed support and services for the CF community.

We love people getting creative so if you have an idea please get in touch! If you would like a copy of the toolkit, please email [communityfr@cfcc.org.au](mailto:communityfr@cfcc.org.au) in NSW or [fundraising@cfcc.org.au](mailto:fundraising@cfcc.org.au) in Victoria.

## Fundraiser Story: The Dice Run

Lucas Bianco became the face of the inaugural Dice Run which is being coordinated by MCC3773 Motorcycle Club. In a touching ceremony, club president Mike Terry presented Lucas with a t-shirt and badge making him an honorary member.

What is a Dice Run? Riders and drivers (yes cars are welcome!) drive on a scenic route which includes



*Lucas Bianco gets set for the Dice Run*

five stops. At each stop participants throw the dice and their numbers are recorded. The winner of the Dice Run is the person with the highest score after all the scores are collated at the final stop at The Little River Hotel. It is a great way to see beautiful part of Victoria and all while supporting CF Community Care.

## The long and the short of it!

Kye Feltham has known Isabella Borg his entire life. Inspired by Isabella, who has cystic fibrosis, 11 year old Kye wanted to show his support by raising funds and awareness for Cystic Fibrosis Community Care.

Kye spent 5 years growing his hair out but he realised it was the perfect way to grab attention and get donations for his cause. Kye worked very hard and ended his fundraiser with the big chop on 1 February, donating the hair to Variety and collecting over \$3,700. We should all be inspired by Kye's drive and generosity! ■



# 65 Roses High Tea: an exquisite afternoon

**Join us for a day of fun in support of the NSW CF Community! On Friday 24 May, CF Community Care will be holding our inaugural 65 Roses High Tea at The Tea Room QVB.**

The event is being held in May as it is cystic fibrosis awareness month. It is a time where organisations all over the world come together to raise vital funds and awareness for cystic fibrosis. We are offering our NSW cystic fibrosis community the opportunity to help us do just that while having a delightful afternoon out!

The 65 Roses High Tea promises to be an indulgent occasion. From the delectable selection of petits fours prepared by The Tea Room QVB's award-winning patissier, to the exquisite Royal Albert fine china and British silverware. Each ticket includes 11 pieces of sweet and savoury high tea, champagne and non-alcoholic beverages.

There will be live entertainment, guest speakers, an array of silent auction prizes to bid on and a raffle to be won. Funds raised on the day will allow CF Community Care to continue to provide vital support and services to people living with cystic fibrosis in NSW.



For further information and to purchase tickets, visit: [bit.ly/65roses-high-tea](http://bit.ly/65roses-high-tea)

- Friday 24 May, 11.30am–2.30pm
- The Tea Room, Queen Victoria Building, 455 George St, Sydney
- Dress: Smart casual
- Tickets: \$750 for a table of 10 or \$80 per ticket



## Rise n' Grind

#risengrind2019

Rise n' Grind is a fundraiser for cafés and coffee lovers.

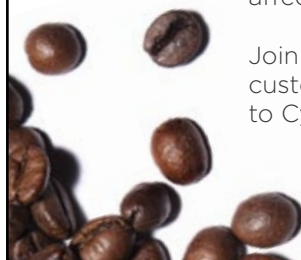
On 31 May decorate your café in red and take donations to support people with cystic fibrosis, a life threatening condition affecting thousands of young Australians.

Join in the fight against cystic fibrosis on 31 May. Ask your customers to pay what they can, because all proceeds are going to Cystic Fibrosis Community Care.

Find out more at [www.risengrind.com.au](http://www.risengrind.com.au)

**CYSTIC FIBROSIS**  
Community Care

P. 02 8732 5700  
E.[communityfr@cfcc.org.au](mailto:communityfr@cfcc.org.au)





## Movie night fundraisers

The long-awaited CF movie *Five Feet Apart* is coming to Australia in early April and we are hosting movie fundraisers in Sydney and Melbourne. *Five Feet Apart* tells the story of two teenagers with CF who meet in hospital and fall in love.

To view the trailer for *Five Feet Apart* go to: [bit.ly/5FA-trailer](http://bit.ly/5FA-trailer)

### Find a screening near you:

#### NEW SOUTH WALES

- LEICHHARDT – Thursday 4 April
- SHELLHARBOUR – Sunday 7 April

#### VICTORIA

- BRIGHTON – Thursday 4 April
- YARRAVILLE – Sunday 7 April

Tickets for all screenings are available on our online shop: [shop.cysticfibrosis.org.au](http://shop.cysticfibrosis.org.au)

## Crazy Hair Day launched

On 9 August schools are being asked to encourage their students to come to school with 'crazy hair' and raise funds for those living with cystic fibrosis.

To sign your school up head to: [www.crazyhair.com.au](http://www.crazyhair.com.au)



## Cystic Fibrosis Ladies' Luncheon returns on 65 Roses Day



Put on your favourite frock and bring some friends to the annual Cystic Fibrosis Ladies' Luncheon.

To celebrate 65 Roses Day on 31 May the Cystic Fibrosis Ladies' Luncheon is happening again at the RACV Club. So rally your girlfriends together for a great cause!

The Ladies' Luncheon will be an afternoon of fun and friendship. Indulge in delicious food, free flowing beverages and dancing to the sizzling sound of our band 'Roller Toaster'.

Held in the heart of Melbourne at the luxurious RACV City Club on Friday 31 May 2019 from 12-3.30pm.

Book your seat or a table of 10, \$140 per person by emailing [charityandfun@gmail.com](mailto:charityandfun@gmail.com).

Half the money raised will go to CF Community Care and half to support research.

**C**harity **&** **F**un  
for everyone . . .

# Marina's many talents made a big impact

**Our wonderful, enthusiastic intern Marina Reinker reflects on her time spent with our Sydney office.**

**'Cystic fibrosis' - to tell the truth, back in Germany I didn't really know much about it when I just finished my A-Level degrees and was not really sure what to study. I just knew that I wanted to do something that is related with helping people.**

Besides I have always had a lot of fun organising little events and was quite interested in medicine which was one of the reasons why I decided to do an internship to be more sure about what I want to study. With the help of an international organisation I got in contact with Cystic Fibrosis Community Care and it quickly became obvious for me that this is the place where I want to do my internship.

Besides the fact that the team from CF Community Care seemed to be incredibly friendly at my first time talking to them, I was amazed by their work by helping people who have CF. I had informed myself about CF at this time and was actually shocked about this incurable condition which became one of the main reasons why I wanted to be part of CF Community Care, I wanted to help people with CF. Moreover, I knew that at CF Community Care I could combine my interest in event management and my willingness to help.

In October 2018 my internship at CF Community Care began and I was quite excited and even a little bit nervous. However, already after my first day I knew that I had made the right decision. At the very beginning, the team welcomed me and now they are like a second family for me.

The days and weeks went on and I have been becoming more and more part of the organisation and had more and more things to do. I helped out doing a presentation for A Night For CF, searched for locations for the High Tea event, did the entertainment plan for the kids for the 65K 4 65 Roses Walkathon, and a lot more.

I have learned how much work you have to do as an event manager and how much responsibility you



*Marina was a great contributor to events like the 65K 4 65 Roses Walkathon*

have. Furthermore I was surprised how long you have to start planning events before the event is held. I have to say that during my time at CF Community Care, A Night for CF was definitely one of my favourite events!

Besides that, I got to know so much more about cystic fibrosis. I was able to talk to people who have cystic fibrosis and read so many stories from people battling this disease and was impressed by their strength. I learned how unpredictable, different, and above all debilitating cystic fibrosis is.

I would like to say that I loved being part of the team of CF Community Care NSW and making my little contribution to supporting people with CF. ■



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# What's on in '19

**Feb**



7 - Geelong Support Dinner (VIC)  
23 - 65K 4 65 Roses Walkathon (NSW)  
28 - Memberships Due

**Mar**



21 - Northwest Metro Support Dinner (VIC)  
31 - CFCC Annual General Meeting

**April**



29 - Tax Appeal Launch

**May**



65 Roses Month  
4 - Grandparents afternoon tea (VIC)  
15 - South Metro Support Dinner (VIC)  
24 - 65 Roses High Tea (NSW)  
31 - 65 Roses Day  
31 - Traralgon Support Dinner (VIC)  
31 - Sutherland Shire Support Dinner (NSW)

**June**

1 - Newly Diagnosed Afternoon Tea (VIC)  
20 - Interclinic (NSW)

**July**



3 - Ballarat Support Dinner (VIC)  
20 - A Night for CF Gala Ball (VIC)

**Aug**



3-6 - Australasian CF Conference (WA)  
9 - Crazy Hair Day  
18 - Peer Support Training (VIC)  
21 - Albury/Wodonga Support Dinner (VIC)  
25 - Peer Support Training (NSW)  
30 - Armidale Support Dinner (NSW)  
30 - Warrnambool Support Dinner (VIC)

**Sep**



7 - A Night for CF Gala Ball (NSW)  
14 - CFCC Community Conference (VIC)  
20 - Central Coast Support Dinner (NSW)

**Oct**



13 - Great Strides Bendigo (VIC)  
20 - Great Strides Melbourne (VIC)  
25 - Wollongong Support Dinner (NSW)  
27 - Great Strides Sydney (NSW)  
28 - Christmas Appeal Launch

**NOV**



8 - Dubbo Support Dinner (NSW)  
10 - Remembrance Service (VIC)  
15 - Business Breakfast (VIC)  
20 - Southeast/Peninsula Support Dinner (VIC)  
28 - Interclinic (NSW)

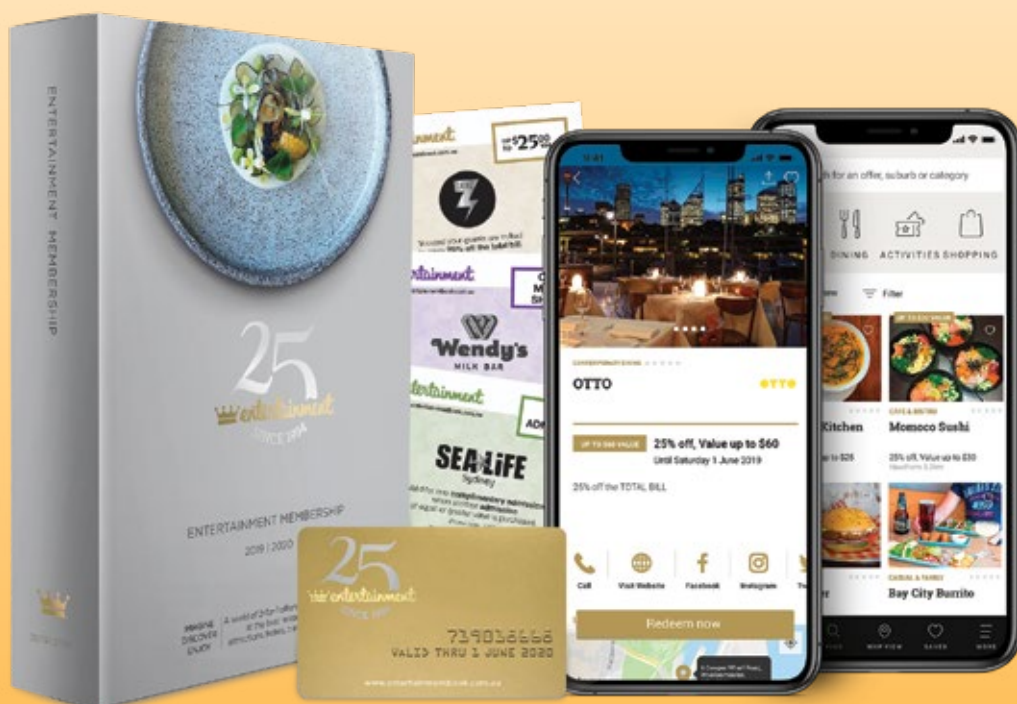
**Dec**



5 - Dreamnight at Taronga Zoo (NSW)  
23 - 6 Jan - CFCC Office Closure

## Support our fundraising. Order an Entertainment membership today!

Enjoy thousands of offers for everything you love to do.  
For every membership sold, CF Community Care will receive a donation.



Pre-order your membership today! **NSW:** [bit.ly/ent-book-nsw](https://bit.ly/ent-book-nsw) **VIC:** [bit.ly/ent-book-vic](https://bit.ly/ent-book-vic)

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