Getting to Know Cystic Fibrosis Community Care
Contents

CF Matters
Editorial by CEO Karin Knoester 03

Getting to Know
Cystic Fibrosis Community Care (CFCC) 04
Penny France and her Campaign for Kalydeco 06
A Gift of Life 07

Health & Research
Latest Research 08
The 12th Annual ACF Conference 09
Managing Anxiety 10
Research on Treating Stress 11

Programs & Services
Hospital Tips 12
CF at School 13
Variety Smile Program 13
Are you CFSmart? 14
Carrier Screening 15

Fundraising Events
65 Roses Day 16
65km for 65 Roses 17
Bluesfest 17
Peaks4CF 18
A Community That Cares 20
A Night for CF Ball 21
The 2017 Tax Appeal 21

Community News
Volunteer’s Corner 22
In Memoriam 22

What’s On 24
Hello everyone and welcome to the very first edition of CommUNITY Focus – the quarterly magazine for our newly merged organisation Cystic Fibrosis Community Care (CFCC).

Where ever you may be reading this article – from Warrnambool to Wagga Wagga, or Northcote to Newcastle I hope that you will engage and get benefit from CFCC. The name of the merged organisation reflects what we want to focus on – you, our members. The name of the magazine again reflects on our shared vision of Community and UNITY – between Victoria and New South Wales, between CFCC and you, between CFCC and the other Cforganisations in Australia, if we all pull in the same direction, great things can happen. I hope that you will support our work, so that we can support and care for you and/or your family member with CF. I know these are big statements – I am confident that together we can achieve a great deal.

A number of people have asked me about how we will distribute services. Well these things won’t change immediately. Funds held by CFV and raised in Victoria, just like funds held by CFNSW and raised in NSW will be distributed in their respective States in the same way as they have been prior to the merger. Of course we are hopeful that as we ramp up our connections to philanthropic trusts and foundations, we will be able to secure grants that will serve the whole CFCC community.

We would love for as many people as possible to join CFCC at this exciting time. For those of you who are not currently members, I urge you to get on board. If you are an adult with CF, under the newly formed CFCC, your membership fee is optional. Families with a child with CF will pay an annual membership fee. This where it gets a little bit complicated for legal reasons… If you are a current CFV member your membership will immediately carry over and you will automatically become a member of CFCC. If you are a current CFNSW member, you will still need to apply for membership to CFCC as soon as possible, even if you have recently paid your membership fees to CFNSW. This is a legal formality and just a quick piece of paperwork that should only take a few minutes to complete, and your fees will carry over. If you are a new member living in Victoria or New South Wales, and you apply for membership, you will immediately become a member of CFCC. You do need to be a registered member in order to receive the CFCC services in your state. If that’s not confusing enough…. please ring your local office to discuss any concerns you may have in regards to this matter.

As much as we have been busy behind the scenes, you will not see a dramatic change in the way that you access our programs and services. The transition to a fully integrated CFCC will be a slow one. Rest assured, I will keep you in the loop as we travel through this process together. Make sure you are a registered member of CFCC. Those people who were members of CFV are automatically members of CFCC. For those people in NSW, and those Victorians not registered, please make sure you register your membership so that you can access services and sign up to receive our monthly E-news bulletin and other notices.

This really is an exciting time for CFCC and I look forward to journeying ahead with you all. Of course, if you have any concerns, questions, ideas then you can contact me directly at karin@cfcc.org.au, or call the Melbourne office on 03 9686 1811.

Until next time…

Karin Knoester
Chief Executive Officer
Cystic Fibrosis Community Care (CFCC)

Q&A with the CEO: Karin Knoester

What is your nickname? In the work place I’m called KK, or ‘Rocket Booster’.

What is your favourite food? Food that is shared with friends.

What is your favourite family recipe? My mother’s Dutch apple cake.

What is your favourite movie? Has to be Shawshank Redemption.

What is your favourite holiday destination? Anywhere underwater – Palau.

What are your hobbies? Reading and diving.

What celebrity would play you in a movie of your life? Has to be Meryl Streep because that’s what some people used to call me.

What makes you laugh? My granddaughter and her little antics… I just love her to pieces.

What song would you sing karaoke? Oh dear, ‘Dancing Queen’.

What did you want to be when you were small? Initially a mothercraft nurse, but later a doctor.

What was your first job? While at school I worked with my mother who was a caterer. I washed lots of dishes.

Do you like or dislike surprises? I am not crazy about surprises – it’s the control freak in me!

What is the best gift you have ever been given? Life.

Are you a dog or cat person? I think I’m a bit of both, but don’t have either. I enjoy my kids dog and cats.

What is your proudest personal accomplishment? Raising two of the most wonderful young women I’ve ever known. Or walking the Annapurna Circuit in Nepal, or managing one of Australia’s largest fundraising events.
20 staff

450+ volunteers

1638 people living with CF

CF Clinics:

SYDNEY CHILDREN’S HOSPITAL
ROYAL PRINCE ALFRED HOSPITAL, SYDNEY
THE CHILDREN’S HOSPITAL AT WESTMEAD
WESTMEAD HOSPITAL
GOSFORD HOSPITAL
JOHN HUNTER CHILDREN’S HOSPITAL, NEWCASTLE
JOHN HUNTER HOSPITAL, NEWCASTLE
THE ROYAL CHILDREN’S HOSPITAL, PARKVILLE
THE ALFRED HOSPITAL
MONASH MEDICAL CENTRE
MONASH CHILDREN’S HOSPITAL
In the haze of diagnosis at the Royal Children’s Hospital in Melbourne, Paul and I heard some brighter news. Anna was in a small percentage of children with CF that could access a new drug in the future called Kalydeco.

Kalydeco had only just been approved by the PBAC for children aged six and above. Looking to other countries, we realised that there was potential in Australia for the age group to be extended to two years and above.

From this point, I didn’t think too much beyond Anna turning two in terms of her CF treatment. I blocked out any possibility of her needing more than regular clinic check-ups, daily physio, antibiotics and her other daily medications.

I didn’t have blinkers on - I know very well the frightening long-term implications of CF - but my optimistic mindset made having CF in our lives far easier to deal with. All we had to do was keep her as healthy as possible and focus on the milestone of her second birthday.

In my mind, it was only a matter of time before Kalydeco was extended. We rallied our family to write submissions during the PBAC community consultation and endured the long wait to hear the meeting outcome.

In the days leading up to Christmas (and weeks before Anna turned two), we found out that the PBAC had deferred their decision to list Kalydeco on the PBS for children aged two to five.

There must have been a mistake. How could this possibly happen? Research around the world had demonstrated how effective it was, especially when taken from a younger age.

We were devastated. But more than ever, we were determined to make Anna’s voice heard and push harder for the best treatment available. We felt that Anna had been let down by the system that was meant to protect her.

Every day we felt like we were losing precious time. We wrote countless letters to the Health Minister (in the middle of an expenses scandal, no less), Vertex, our local federal MP, and media outlets.

We were lucky to secure an article in The Age and Sydney Morning Herald in early January, plus the opportunity to speak on 3AW Breakfast alongside CFA CEO Nettie Burke.

Wrapping our heads around the political lobbying process took time and we often felt disheartened by the lack of immediate response. However, the outpouring of support from friends, family and broader networks kept us going.

Our campaigning was not done in isolation. Anna was one of 30 children waiting to access Kalydeco. The campaign united a tight-knit and determined community of CF families across the country, including those campaigning for Orkambi, plus families who didn’t stand to benefit from either drug.

CFA and CFV (and the other state bodies) worked tirelessly to navigate the higher-level political...
A second chance of life. A double lung AND liver transplant!! I’m only the 4th in the state to undergo the procedure! Although only 10 days prior to the surgery I had two very intensive lung bleeds that required an emergency embolisation that landed me in a two-day stay in ICU.

The last 12 months have been big for me. I have travelled to US, been listed for transplant, had a sister hit by a car (she’s ok!) and had two dry runs for lungs, the second of which I was on the table to be opened when the transplant was cancelled. My old lungs did not like the ventilation. It took quite a while for me to recover. In fact, a further hospitalisation occurred as a result of my intubation.

Before the transplant, I felt the real struggle you do with cystic fibrosis. I intensely felt the real daily grind and the hardship of not having the energy of the health to simply function as a person day to day. My days were filled with not much and a lot of solitary confinement, bed rest, coughing and nebs.

Today is a very different story. I can walk, talk and walk quite fast without restraint or getting out of breath. To be able to walk along the length of a beach in the sand without getting breathless is an activity I have not been able to do in several years! Life has truly turned a 180 and although I’m restricted to the same diet as pregnant women, the road ahead looks very, very promising!!
Study finds differences in lifespan between Canadians and Americans with cystic fibrosis

People with cystic fibrosis are living longer than ever before, but their lifespan is almost 10 years longer in Canada than in the United States, according to research published March 14 in the Annals of Internal Medicine.

The median age of survival for individuals with cystic fibrosis in Canada is 50.9 years compared to 40.6 years in the United States, said Dr. Anne Stephenson, a respirologist and cystic fibrosis researcher at St. Michael's Hospital in Toronto, which has the largest adult CF clinic in Canada.

In addition, after taking into account factors such as age and the severity of the disease, the risk of death among people with cystic fibrosis was 34 per cent lower in Canada than in the United States, according to the research by lead author Dr. Stephenson and colleagues.

Although the study was not designed to explain why the lifespan differs in the two countries, Dr. Stephenson said there were several possible reasons: transplants, diet and medical insurance.

“Survival has increased in both countries, but Canada began to see greater improvements than the United States starting in 1995, with an even more dramatic increase in the survival rate in Canada noted in 2005,” said Dr. Stephenson.

Canadians with cystic fibrosis were exposed to a high fat diet in the 1970s, which was not implemented in the United States until the 1980s. In people with cystic fibrosis, higher caloric intake results in better nutritional status which and in previous studies has been linked to improved survival. Individuals born in the 1970s and exposed to good nutrition from birth could explain why Canadian survival rates saw improvement in 1995. This would suggest that countries where aggressive nutritional support was instituted in later decades should see the survival benefit in the near future.

Lung transplantation is one of the few treatments for cystic fibrosis that can positively impact survival almost immediately and a higher proportion of CF patients received a transplant in Canada than in the United States during the study period. The survival difference increased dramatically in 2005 which coincided with the year that the United States began using a lung allocation score to prioritize people on the lung transplant waiting list. This score is not used...
Survival has increased in both countries, but Canada began to see greater improvements than the United States starting in 1995.

Cystic fibrosis is an inherited chronic disease that affects the lungs and digestive system. A defective gene and its protein product cause the body to produce unusually thick, sticky mucus that clogs the lungs and leads to life-threatening lung infections and obstructs the pancreas and stops natural enzymes from helping the body break down and absorb food. The most common reason for death in cystic fibrosis is due to progressive lung disease.

Survival difference increased dramatically in 2005 which coincided with the year that the United States began using a lung allocation score.


Managing Anxiety

I like to think that there is anxiety, and there is ANXIETY. We need sensible levels of anxiety in our lives. Without it we’d all be smoking like chimneys, not wearing seatbelts, and eating food that is clearly off.

Anxiety about the risks stops us from doing this stuff. Without us noticing though, healthy anxiety can sneakily grow by degrees (anxiety) when we are not watching into ANXIETY.

There is plenty of research to tell us that the CF community suffers anxiety and depression at rates that are at least 2-3 times higher than that of the general population. The research includes children over 12 with CF, parents of children over CF and adults with CF, but it seems likely that siblings, carers, partners, friends, children, grandparents are all at increased risk. Anxiety and depression are alarmingly contagious. The problem with both these disorders is that 1) we tend to ignore them and 2) in people with CF they lead to treatment non-adherence and that leads to more need for antibiotics and hospitalisations. So, for all of us who care about people with CF, one of the ways we can show we care is to work at maintaining our own mental health which supports them to do the same. How can we do that?

“Regular exercise (preferably at least three times per week) and preferably outside the house will make a difference.”

Exercise is a big-ticket item here. Regular exercise (preferably at least three times per week) and preferably outside the house will make a difference.

We know that if you exercise with others you are more likely to continue exercising. So if you have a child with CF and you know that s/he will need an exercise lifestyle, now is the time for you to join the surf club, touch football club, or whatever and make it a family affair. For when you can’t get out of the house, or you need to exercise alone, there are free apps that you can use to help you exercise healthily and stay exercising (the hard bit).

Check out the apps and find the one that works for you. Consider:

- Sworkit (used by our Exercise Physiologists) - Apple and Android – Free
- The Johnson & Johnson 7 Minute Workout App - Apple and Android – Free
- Charity Miles – Apple and Android – Free This one donates money to the charity of your choice every time you run, walk or bicycle. We are working on getting registered with this group.
- FitStar Personal Trainer - Apple and Android – Free
- FitStar Yoga - Apple and Android – Free
- Daily Yoga - Apple and Android – Free

This list is not exhaustive and there are heaps more options. Check out the online reviews like ‘best free exercise apps’ or if you like to use the computer or smart TV check out ‘best free online exercise programs’ or ‘yoga programs’.

Of course, there is much more we can do to anxiety proof us. Next edition we will look at other strategies.
University of Queensland PhD candidate Erin Brown and the CHRC Children’s Burns and Trauma Research Group conducted an 18-month study involving 92 families of burns patients aged between one and six at Brisbane’s Lady Cilento Children’s Hospital. Whilst having a focus on burn victims, the research and outcomes from this study are appropriate to apply to children living with CF.

In this research, Erin noted that parents often carried a lot of anxiety and guilt and that this could get in the way of them helping their children, even though it is the parents’ primary aim. She also found that parents who believe they know what to do to make a positive difference to their children’s experience feel less anxious and that when parents are less anxious and more confident, so too are the children and this decreases their experience of pain.

Erin’s research led to the following conclusions:

“While it’s common for parents to reassure their child with comforting phrases such as ‘it’s okay, it’ll be over soon, be brave’, these words actually kept the child’s attention on the pain”.

“What to do
• Distract your child early on in the treatment (toys, food, music, pictures, TV, conversation, nursing, pacifier. You know what works best).
• Some kids like to watch, others don’t. If they want to, let them but also keep encouraging distracting behaviour.
• Encourage your child to do deep breathing exercises. This is something you can do together to slow down your and your child’s heart rate.
• Prepack snacks and share them during the procedure.
• Say things like “look at me and squeeze my hand,” “who is that on the TV?,” “can you tell the nurse what we are going to do after this?,” “remember when we went to the park and […]” and “show me how you do deep breathing”.

“What to avoid
• Scaring them with how painful the medical treatment will be or “how bad it looks”
• Criticising their behaviour
• Minimising their experience (“you’re okay,” “almost done”) • Encouraging the pain (“I know it hurts a lot”)
Preventing for a hospital stay

- **Find out what facilities the hospital has that you can use.** Many hospitals provide laundry facilities, Wi-Fi, parent/family rooms, kitchens with access to a microwave, fridges and freezers and gyms etc. Knowing what is available can help you plan what you need. There is often a patient services guide on the hospital website or you can ask your CF Team.

- **Look into what government subsidises are available for patient travel.** Both the Victorian and NSW Governments have travel assistance programs (VPTAS and IPTAAS) for people who travel long distances to medical appointments that may help subsidise some of the cost of travel and accommodation.

- **Ask your CF Team about parking discounts.** Hospitals often have discounted rates for concession card holders or for long stays.

- **If you are at school or university, ask your teachers/lecturers for the work they will be covering while you are in hospital.** They can provide you with notes or a study guide so you can study while in hospital. Your school may even want to make contact with the teachers at the hospital so they know what you/your child should focus on.

What to pack

- **Don’t over-pack.** Rooms can be small and there is not always a lot of storage space.

- **Take your own pillow and doona/blanket.** This will give you will have something familiar to brighten your room. Also take a couple of books, magazines, colouring books and pencils, toys, etc.

- **Take ear plugs and an eye mask.** Hospitals can be noisy and bright places.

- **Take snacks, drinks, bottled water, and packaged and frozen meals.** Also take microwave-safe bowls with lids to cook them in (check you have access to a fridge, freezer and microwave). Food options at the hospital may be limited and can be expensive – we’ve been told porridge sachets are a great option.

- **Take containers with lids.** So you can easily wash your nebuliser pots, handsets and PEP devices.

When at hospital

- **At the time of admission always ask if you have been allocated a single room.** If you have been allocated a shared room with another patient and you are worried about infection control, speak with the staff about your concerns.

- **Keep a list of your/your child’s current medications, dosages and regime with you.** You will be asked this countless times at admission and having the information on your phone or a piece of paper saves you having to relying on your memory.

- **Ask if there is a special CF menu.** If there is, get a copy as soon as you are admitted. Where possible, opt for the adult meal even if your child is a toddler, you can reduce the size as needed when it arrives. If your child is using Creon granules, request apple puree with each meal.

- **If you/your child need to fast, make sure to list ‘no meal’ on the menu and remind the nursing staff.** There’s nothing worse than a meal being given to you/your child that you/tHEY can’t eat.

- **Always leave your contact number on the communication board.** If you are out of your room and the staff need you, make it easy for them to contact you.

Hospital stays can be stressful, especially if it’s your first admission or first stay in a new hospital. To help we asked the experts… you! We’ve compiled some of the top tips you told us make your time in hospital easier.
Lay a towel under the sheets on the adult couch/bed. Some of the adult couches can be a little uncomfortable, the towel can add a little extra padding.

Use the volunteer services. They may be able to sit with your child while you shower or get a coffee.

Contact the play therapists. They may have some toys you can borrow for the stay (this also helps reduce how much you need to pack).

More tips are available on our website at www.cysticfibrosis.org.au/vic/heading-to-hospital.

If you have other suggestions you’d like to add please contact your services team on:

Victoria: support@cfcc.org.au or (03) 9686 1811
NSW: services@cfcc.org.au or 1800 650 614.

Variety Smile Program: Medical Support Grants for Families

If you are struggling with the cost of medical and physiotherapy equipment and services for your child who has CF, you may be eligible to apply for a grant through the Variety Smile Program.

The Variety Smile Program offers medical support grants of up to $1,000 to help with expenses relating to medical appointments, nebulisers and other healthcare items, therapy, respite care, parking and fuel.


For more information about other support services if you or your child has CF please contact your CF local services team:

NSW: Web www.cfbuzz.org or www.cysticfibrosis.org.au/nsw/services, Email services@cfcc.org.au, or Phone 1800 650 614
Victoria: Web www.cysticfibrosis.org.au/vic/member-services, Email support@cfcc.org.au, or Phone (03) 9686 1811

CF at school

We want to ensure that all children with cystic fibrosis can have the best learning opportunities and experiences while managing their CF. So, in most parts of NSW and Victoria, we are available to speak with your child’s preschool, primary school or high school so that they have a full appreciation of your child’s needs and how best to support them and you.

Before speaking with, or presenting to, the staff at the school we will discuss the presentation with you and you can provide information about the particular needs of your child. This will support you in working on a care plan for your child with the school. The school gets up to date information, resources and contact details for us and the clinic staff. Everyone feels more confident.

For more information about this or other education support services contact us:

NSW: Email services@cfcc.org.au, or Phone 1800 650 614
Victoria: Email education@cfcc.org.au, or Phone (03) 9686 1811
CFCC is always seeking to improve understanding of CF within school communities, so that students who have CF feel supported and understood in terms of their health, educational and emotional requirements.

In conjunction with CFWA and with generous funding from the Ian Potter Foundation, the old CFSmart website has recently been completely renovated to include a larger range of great educational resources for educators, parents, students and other health professionals and support staff.

The most exciting and important addition to the CFSmart website is a free online teacher training resource consisting of four separate professional development modules. The modules contain key information about CF delivered through videos, images and text. Our hope is that teachers around Australia will use this resource as a go-to reputable source of information about how to best support their students with CF.

Everyone will complete Module 1 which provides a detailed overview of CF and the day to day implications of living with CF and how this impacts on the school environment and the child. Then a second module is completed and chosen according to the age range of the educational setting. Module 2 covers Early Childhood, Module 3 is for Primary Schools and Module 4 for High Schools. A quiz is provided at the end of each of the two modules taken by the participant and on successful completion of the two quizzes a certificate of completion will be provided which can be used towards a teacher’s professional development hours.

This website will be continually updated with new ideas and examples of what is working well for children with CF in their different educational settings.

Let’s all promote this wonderful resource to your child’s school and teacher. Make sure they know that it’s there and accessible for all interested staff. CFV is also actively advertising CFSmart to schools and teachers.

cfsmart.org

Are you CFSmart?
To coincide with 65 Roses Month and as part of the Community Education Campaign on Carrier Screening we have launched a public awareness campaign. This campaign consists of posters on the back of toilet doors in selected Victorian metropolitan and regional shopping centres as well as a targeted social media campaign. The campaign will run from May – July. For more information on carrier screening go to www.cfscreening.com.au
65 Roses Day

65 Roses Day 2017 was celebrated in a BIG way.

In Victoria, the staff worked very hard to raise awareness of cystic fibrosis in the wider community. Cystic Fibrosis Victoria wrote to the Victorian federal MPs and 65 influential Victorians with a lapel pin and asked them to mark the occasion with a social media post. CFV Ambassador and Fox FM Announcer Keegan Bakker, Ann Peacock of Crown Resorts and Collingwood Football Club Coach Nathan Buckley were amongst those who threw us their support.

Every Victorian state MP was sent a hand written card, long stem rose and lapel pin. 9 of them posted a photo and message to social media and another 2 contacted the office directly to support our cause.

At night, The Bolte Bridge, Melbourne Star Observation Wheel and AAMI Park were all lit red in honour of our day and those living with CF. A 30 second promo spot on Friday Night Football (AFL) which was also syndicated to a national audience. This is in addition to selling over 1,000 roses.

In NSW, 65 Roses Day was marked in a number of ways. Over 1,500 long stem roses were wrapped and sold by volunteers and staff. Meanwhile, our friends at Wayward Brewing Company crafted their specially made rose kolsch beer. All proceeds from the sale of this product go to our organisation and are these funds go towards supporting people living with CF.

On top of all of this, Rise n’ Grind was a big success. 14 fabulous cafes from Newcastle to Wollongong gave free coffee to customers who made a donation to CFNSW.

A massive thank you to everyone who contributed to making this 65 Roses Day one of the best yet!
FUNDRAISING EVENTS

65K 4 65
Roses Walkathon

In 2007, Pat O’Donovan, a parent of a child living with CF, had an idea to complete an endurance event, walking 70kms around the Iron Cove Bay in Sydney. The following year in 2008, 27 people joined him and together they raised $43,000.00. 9 years later, things have changed, and his event is a whole lot bigger.

In February this year a little wet weather wasn’t enough to deter record numbers completing the same challenge. Over 1,200 people walked in various distance categories. For the 65k walk group though, this meant a 2:00am start!

Original committee members Pat O’Donovan and Pat Borg have both been instrumental in the growth of the event, driving marketing and sponsorship. They were blown away at the 2017 results, 1,268 supporters who collectively walked or ran 30,669km, and raised $530,000.

Next year’s goal: a one-day stroll around the Earth. It is only 40,030km...

Bluesfest

Through rain, hail, shine and lots of mud, Alan and Jenny Tunks have been selling raffle tickets at Bluesfest and fundraising for CF for over 20 years. They have raffled over 40 mainly highly prized Gibson Guitars, sold over 100,000 raffle tickets, managed over 500 volunteers and raised over $533,000. They are truly a remarkable duo.

Each year Gibson Guitars USA kindly donates 3 guitars to Alan and Jenny and through the course of the 5-day festival, Alan manages to have the guitars signed by artists performing at the festival. Obtaining access to all areas to seek signatures is no small feat but this comes with the incredible and long standing support of Bluesfest owners and organisers Peter Noble and Anika Oman.

By the end of the festival the guitars are truly unique and one of a kind items, highly valued by the winners who come from all over the world.

Most festival goers and many returning artists are now very familiar with the CF marquee and the teams of volunteers in red t-shirts and can often be greeting each other like old friends.

Many thanks to Gibson Guitars, Peter Noble and Anika Oman for their support of our organisation and of people living with CF.
Tackling the Bicycle Network’s Peaks Challenge in Victoria’s high country, the challenge covers 235km, 4000+ metres of climbing and is one of the world’s most difficult single stage bike rides.

On March 12, the Peaks4CF team of seven riders all converged at Falls Creek. With all their hard training and preparation behind them, our riders began the challenge in the wee hours of the morning, departing from the start line with 235kms to ride and a forecast of heavy rain ahead of them.

After setting off as a group, it was during the decent of Falls Creek our riders began to disperse and lose touch with one another. Spread across the road, all seven riders completed the Falls Creek decent and negotiated the first climb of the day up Tawonga Gap.

On the road between Tawonga Gap and Harrietville our riders were met by several groups of friends and family members who had created large banners and cheered passionately to spur our riders on. Some of our riders regrouped at the Dinner Plain rest stop after the Mt. Hotham climb and shared a quick bite to eat. The Dinner Plain rest stop also saw the first casualty of the day, with Brett Jenkins withdrawing from the event. It was a brave effort and a great accomplishment for Brett to have completed the first two very challenging climbs and over 110km.

The ride from Dinner Plain to Omeo and then on to Anglers Rest was very challenging. Open undulating roads with some short climbs, heavy swirling winds and hot beating sun all took their toll. Drained but not beaten, all our six remaining riders arrived at the final rest stop Anglers Rest, before tackling the legendarily difficult climb that is the back side of Falls Creek. Three riders (Brendan Cusack, Brett Capron and Caspar Graham) were spread out and tackling the final stages alone. Mark Dalton (Maya’s father), Stuart Isaacs and Bree Knoester managed to regroup in the final stages to ride together.

The climb of the back of Falls and towards the finish line was incredibly challenging after 200km in the saddle. All of our riders had tired, heavy legs and suffered immensely. It was at this point doubt crept in and some riders even questioned their ability to complete the climb. But, with mission of not letting a little three-year-old girl down, the six remaining riders all completed the final climb of the day and crossed the finish line at Falls Creek. Well within the 13-hour time limit, our riders were met at the line by their supporters. With many big smiles, hugs, handshakes and a few tears (for the record, only the men cried) they successfully accomplished their mission to raise awareness and $37,000 for Cystic Fibrosis Victoria.

Well done Peaks4CF! What an effort.
We would like to thank the following community fundraisers who have shown their support by raising much needed awareness and funds:

- **Mercedes-Benz Melbourne** who held a Sweet Treats Day and raised $329
- A big thank you to **Chadstone Harlequins Cricket Club** who held their annual charity cricket match in March which raised $1,000
- **Bright, Duggan and Suttons** for their ongoing support of the 65K 4 65 Roses Walkathon
- A big thank you to **The Moody Chef** who started Rise n Grind in NSW
- **Terang Harness Racing Club** who donated $500 from their Celebrity Race
- **Roll the Dice Race Night** for raising $3,000
- A big thank you to **Andi Moore** and **Power House Yoga** for running their community yoga class which raised $172
- **Glenn Currington** who last year organised The Frozen Butt motorcycle ride, clocking up 51,000 km in 3 days and raising over $12,000.
- **Kirsty and Stephen Bowness** who for the fourth year running held their Red Party and raised $1,100
- Thank you **Laurimar Primary School** for running a market stall and raising $45
- The wonderful team at **LJ Hooker Nhulunbuy** for raising $165.05

A Community that Cares
A big thank you to everyone who helped stand by us in this year’s Tax Appeal. Through your generous donations we can continue to fund critical services throughout Victoria and New South Wales.

As part of our community, you are already aware of the daily challenges that people with CF have to go through. It’s for this reason that we focused our campaign around the idea of there never being a day off from CF. We know this sentiment resonates with the community and we are very grateful for your support. Together we can and have made a difference in the lives of many families and we have you to thank for it.

We would also like to extend a big thank you to Coen and his family for working with us to put together this year’s campaign! Your assistance, positivity and partnership has made this year’s campaign the success it has been.

Tax Appeal

“We have to fight every day to stay alive. If someone can stand behind me, then I can stand and fight this, and try and get as long and as positive a life as I can.”

周六 29th 七月 2017
7:00pm
Leonda by the Yarra

着装：正式

门票：$155 每人，$1,550 每桌

包含：3 道餐点、啤酒、软饮和现场娱乐

预订：
Email：events@cfv.org.au
电话：03 9686 1811
在线：www.cysticfibrosis.org.au/vic/gala-ball

主赞助商：RICOH

支持赞助商：Bendigo Bank
National Volunteer Week and Recognition Program

National Volunteer Week was at the start of May and it provided a great opportunity to celebrate and recognise all of the amazing work that our volunteers do.

Volunteers are constantly helping us with a range of jobs from admin assistance, stocktakes, event set up and pack down, public speaking and peer support. We understand how important volunteers are to our organisation and we want both them and the CF community to know how much we value their dedication and loyalty.

To celebrate National Volunteer Week, we launched our new volunteer recognition program ‘Caring Hands’. Caring Hands aims to recognise all of the unpaid work completed by our volunteers based on the amount of hours worked, with volunteers formally recognised at the 25, 50, 75, 100 hour milestones.

We hope that with the introduction of the Caring Hands Program we can help make volunteering a more rewarding experience for everyone involved.

Volunteering has allowed me to not only to raise awareness of cystic fibrosis but it has also given me a platform in which I can talk about my journey.

Pip Corby

Community fundraisers are so important in raising awareness of CF. It doesn't matter how big or small, it all amounts to the aim of creating a future for people living with CF.

Shani Butcher

Volunteering has given me the confidence that I once lacked and has allowed me to be a part of a community of like-minded people.

Alex Antonowicz

Volunteering is a two-way street and my time at CFV has been very satisfying and tremendously rewarding in many ways.

Margaret Duggan
Australasian CF Conference

From the 5-8 August caregivers, researchers, and medical, allied health and nursing delegates from across the region and around the world will gather in Melbourne for the 12th Australasian Cystic Fibrosis Conference.

During the conference both lay and medical sessions will be held where attendees will discuss and share ideas on the latest advances in CF research, care and drug development.

To find out more, view the conference program, and register for the conference visit http://cflivesmatters.org.au/conference or contact Cystic Fibrosis Australia on (02) 9889 5171.

Vale Kath Kilgariff

Kath Kilgariff, one of our long term volunteers, has recently passed away. Kath was a long standing supporter and member of the Victorian CF community having had three children with CF. Kath was always willing to volunteer her time and energy, from the early days of the thrift shop through to being a regular tin-rattler for CFV and volunteering at Great Strides. Kath is survived by her son David who is continuing his mum’s tradition of volunteering and gives up his time to speak about CF to groups and is one of our peer volunteers.

In Memoriam

We pay tribute to the lives of the following Victorians with who have recently passed away:

Kerry Harrison
Warren Smith

CFCC is grateful for donations received in their memory.

Cystic Fibrosis Community Care is Fundraising with entertainment

The Entertainment membership is full of over $20,000 worth of offers including all of your favorite dining, activity, accommodation and retail offers. Get your membership today and start saving and supporting our work at Cystic Fibrosis Community Care.

Contact: Alison Manser
Phone: 039686 1811 Email: alison@cfcc.org.au
Or order online at: www.entbook.com.au/186v400
What’s on

UPCOMING EVENTS

› A Night for CF Gala Ball (VIC)
  WHEN: 29 July
  WHERE: Leonda by the Yarra, Hawthorn

› 6 Frozen Butt Motor Cycle Challenge (NSW)
  WHEN: 4 August
  WHERE: Edgeworth to Hill End

› 12th Australasian Cystic Fibrosis Conference
  WHEN: 5-8 August
  WHERE: Melbourne

› Wollongong Ball (NSW)
  WHEN: 19 August
  WHERE: Novotel North Hotel, North Wollongong

› Vandermade Charity Golf Day (NSW)
  WHEN: 20 October

› Great Strides (VIC)
  WHEN: 22 October
  WHERE: Lake Weeroona, Bendigo

› Bright and Duggan Charity Golf Day (NSW)
  WHEN: 27 October

› Great Strides (VIC)
  WHEN: 29 October
  WHERE: The Tan Track, Melbourne

› Central Coast Charity Golf Day (NSW)
  WHEN: 10 November

Please note these dates were correct at the time of printing but are subject to change.