

AUGUST 2019

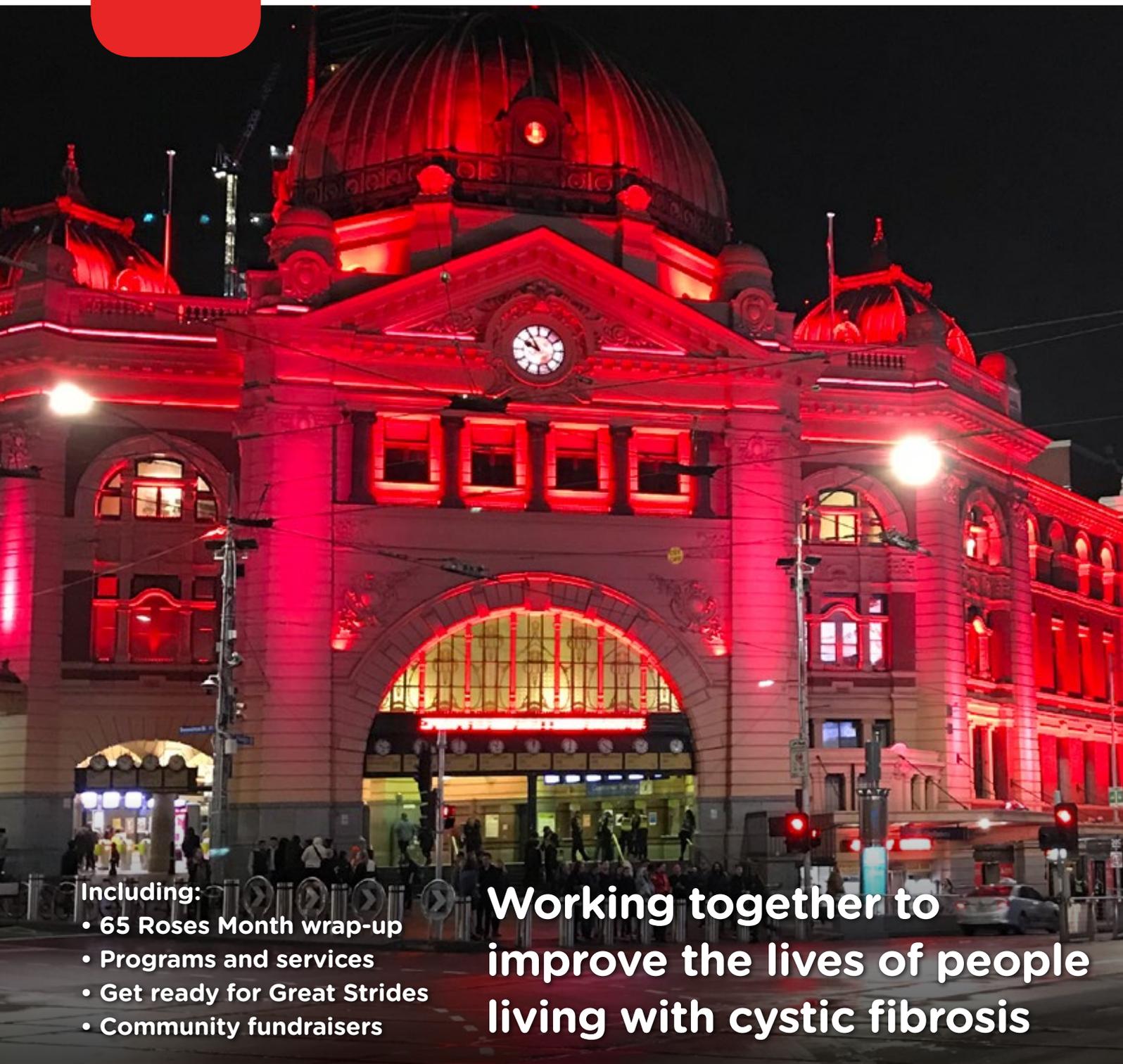
CF

Community Focus



**CYSTIC
FIBROSIS
Community Care**

Incorporating CFV and CFNSW



Including:

- 65 Roses Month wrap-up
- Programs and services
- Get ready for Great Strides
- Community fundraisers

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



CYSTIC FIBROSIS Community Care

COMMUNITY FOCUS © 2019

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WRITING, EDITING AND PRODUCTION

Justin Mansfield,
Communications and Media Manager
communications@cfcc.org.au

Cystic Fibrosis Community Care

VICTORIA (HEAD OFFICE)

80 Dodds Street
Southbank VIC 3006
P | +61 3 9686 1811
E | admin@cfcc.org.au

NEW SOUTH WALES

Suite 2A, 5 Belmore St
Burwood NSW 2134
P | +61 2 8732 5700
E | reception@cfcc.org.au

ABN 251 26 031 536
ACN 617 714 253
W | cfcc.org.au

Cover image: Melbourne's iconic Flinders Street Station was one of over 20 landmarks to light up red for CF awareness on 65 Roses Day

Contents

CF Matters

CEO Editorial 03

Getting to Know

Owen's training a new breed of champions 04

Programs & Services

Carrier screening video / New CF drugs for PBS 05

Peer support program 06

NSW support dinners / Caring for the carer 07

CFCC Community Conference 08

Fitness grants for NSW members 09

Getting away from the everyday 10

Sydney office move / Mental health first aid 12

Fundraising & Events

Tax Appeal wrap-up 13

65 Roses Month: 31 days of CF awareness 14

A Night For CF – Melbourne & Sydney 16

Community fundraising 19

Save the dates for Great Strides 20

Community fundraising 22

Living with CF

A forever friendship 23

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



CF Matters

Welcome to our second edition of Community Focus for 2019. And yes it's almost spring time as well! The year seems to have raced past and it's good to know that the wintry weather is just about behind us.

I've recently returned from Perth where I attended the 13th Australasian CF Conference. Those who attended agree that this year was a highly informative conference with a great breadth of topics. Mental health was once again a focus, and the growing acknowledgment of the importance of the mental health of people with CF and their families is a positive development. If you couldn't make it to the conference, you can catch up on many of the sessions on CFA's Consumer Connect portal.

Our Programs and Services teams in NSW and Victoria have been busy. In NSW we have a number of new grants that will help support people with CF to keep fit, and our Support Dinners have proven popular among the community as a way for families to connect with others who are also on a CF journey.

We've recently held the first of our Starting School workshops for parents of children with CF who will be making the transition to a new school or pre-school. Twenty families attended our first session for families whose child will be starting primary school next year. A second workshop will be happening in coming weeks.

In June, Victoria hosted its *A Night For CF* gala ball. This glamorous event was an enormous success, and again proved to be one of the highlights of our Victorian events calendar. Attended by over 400 people, the ball raised \$67,000. Soon it will be Sydney's turn to frock up as the harbour city holds its own ball.

We're also casting an eye forward to October and our big community fun runs and fun walks, Great Strides, which will be held in Melbourne, Bendigo and Sydney. I'd love to see you at one of our Great Strides events – as well as raising money to help us provide services to people with CF and their families, they are also wonderful community occasions. We have a lot of large teams that walk in honour of a family member or friend with CF, and the buzz generated by the teams makes the atmosphere at Great Strides quite special.

Finally, I'd like to acknowledge the contribution of Ross Fraser who stepped down from the position of Chairman of Cystic Fibrosis Community Care at our recent AGM. He remains on our board. Ross's acumen and insights as Chairman over the past five years have been important in helping our organisation grow sustainably and enabling us to pursue our vision of 'lives unaffected by CF'. I'd also like to welcome our new Chair, Katherine Kaspar, who has been a board member since 2012.

Until next time!



Karin Knoester
Chief Executive Officer



VALE

The team at CF Community Care were deeply saddened to learn of the passing of Sam Durrant.

Sam was a vibrant personality who was well known in both the cystic fibrosis and transplant communities. She loved everything about life, but mostly her partner Mark and her fur baby Lilly.

Sam was a much loved and highly valued member of our staff, and a friend to many. We extend our deepest and most sincere condolences to Mark and Sam's extended family.

We would also like to express our sorrow at the passing of a wonderful supporter, Mrs Patricia Begg OAM.

Patricia was a renowned expert and published author of ceramics, and a lover of the decorative arts. She had been the guest speaker at our annual 65 Roses Luncheon for over 27 years

She is survived by her loving husband, Chris, and her devoted family.

Owen's training a new breed of champions

His passion for training show cattle also gives him a unique way to manage his CF.

Sixteen-year-old Owen is a fifth-generation farmer, living and working on the same property that's been in his family's hands for years. He has a love of the land and livestock.

"My parents and I live on our property near Glen Innes. And my twin sisters are 20 and they are both at university so still come home to visit. Mum runs a coffee shop in town.

I am in year 11 at school but completing my year 12 primary industries course this year so am going to finish school at the end of this year. I am employed by my parents as a school based trainee as part of that primary industry course, I also occasionally work for other local farmers doing stock work and ploughing crop planting and so on.

I have a particular love for Hereford cattle that my great-great-grandfather began breeding on the property we live on, which is 17 km South East of

Glen Innes in northern NSW. We also own another property 16km North of Glen Innes.

My favourite interest is showing cattle. This firstly involves finding the right style of calf.

This includes looking at each calf's size, frame, muscle, fat coverage, and a nice quiet nature. Once the calf is chosen my role is teaching them to lead and respond to my commands. They also need to be taught to stand whilst being washed, dried, clipped and groomed.

I train cattle two to three times a week for about twelve weeks. Each training session lasts one to two hours. When I'm preparing for a show I train everyday leading up to the event. I have been doing this for four years at school and two years on my own. I compete in local shows regularly and the Brisbane Royal Show.

I find that participating in cattle showing helps manage my CF symptoms, as the training requires a lot of physical movement. It's like a high intensity workout and it also takes my mind off CF for a little while." ■



Owen with one of his prized cattle at the Brisbane Show

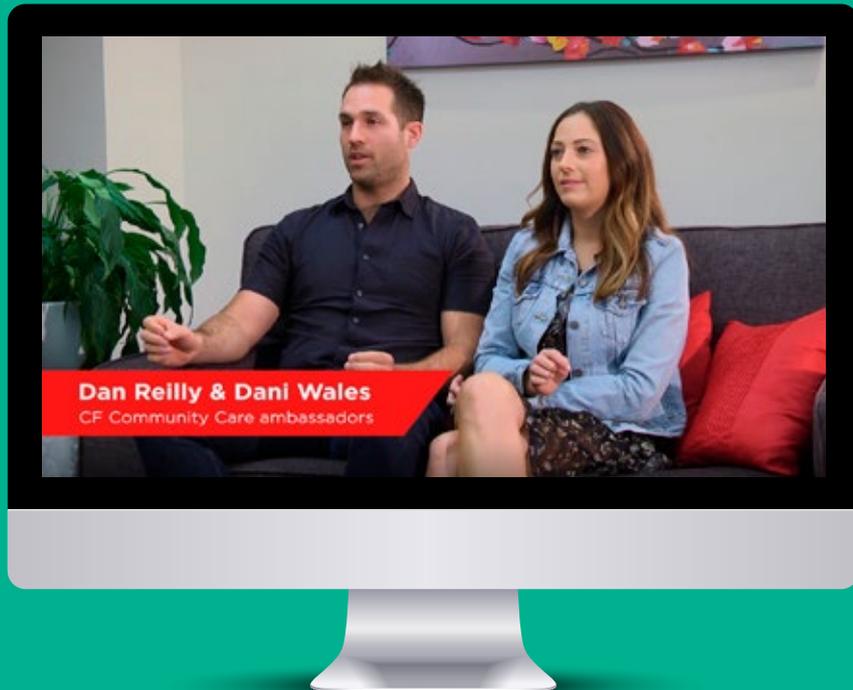
New video raises awareness of carrier screening

Nine out of ten children born with cystic fibrosis are born into families with no known family history. Carrier screening lets prospective parents find out whether they are among the one million Australians who carry the CF gene change.

We encourage couples planning a pregnancy to both know their carrier status, so that they can make informed choices as they prepare for parenthood.

Recently we launched a new video featuring CF Community Care ambassadors and TV personalities Dan Reilly and Dani Wales.

Dan and Dani generously gave their time to share their experiences with carrier screening, and talk about how prospective parents can get tested.



They were kind enough to give us an inside look at the process of being screened for genes that can cause genetic conditions, such as CF. The video discusses their carrier screening journey from the initial visit to their GP, through to completing the test and awaiting the results.

To watch the video, and to find out more information on genetic carrier screening, visit CFscreening.com.au

More CF drugs recommended for PBS subsidy

After the breakthrough decision last year to list Orkambi on the PBS, the Pharmaceutical Benefits Advisory Committee (PBAC) has continued to recommend new CF medications for PBS subsidy.

In April, the PBAC made a positive recommendation for next-gen CF drug Symdeko for people aged 12 and over and to extend Kalydeco to children aged 12-24 months.

More recently, on 24 August the PBAC has recommended extending Orkambi to eligible children from 2 to 5 years old.

We are thrilled with the PBAC's decisions. Symdeko trials have shown similar results to

Orkambi, with measurable increases in lung function. Importantly Symdeko is a potential treatment for people with CF who have one copy of the F508del gene change and a residual function gene change, so it can treat more people than Orkambi. A CF physician is the best person to talk to about your eligibility for Symdeko.

Symdeko also offers choice. Overseas experience shows that some people who had bad side effects from Orkambi have been able to take Symdeko successfully.

For children who are eligible for Kalydeco and Orkambi, earlier access will help ensure the best possible health outcomes in the longer term.

Kalydeco has already been funded by the Federal Government and we await news about Symdeko and Orkambi for 2-5 year olds.

Congratulations to the CF community for all the advocacy work that has helped get these decisions across the line.

Connecting you with someone to talk to

Our Peer Support program can help you find someone who knows what you're going through.

If you're living with CF or are a family member of someone with CF, sometimes it can be helpful to chat with someone who's been in your shoes. You might want to ask about someone else's experiences. Or perhaps you'd just like to talk with someone who understands your situation. That's where our Peer Support program can help.

Sue Emery

Sue's journey with CF started in 1975, when her youngest sister Genevieve was born. Sadly, fourteen months after a lung transplant Genevieve passed away at age 37. Sue's experience with CF does not stop there as she also has a son, Chris, who is living with CF.

Sue has a passion for spreading awareness and understanding about CF, fundraising for research and supporting the community. She is an active member of CF Community Care, through the peer support and public speaking programs, as well as supporting various community events and activities.

Sue has a background in Medical Laboratory Science and Information Technology. She is married to Phil, and has another daughter, Steph. Sue wants to use her experiences with CF to make a positive difference in the lives of those with CF and their families. ■



Tony Hanna

Tony is a self-proclaimed "happy chappy" with an optimistic outlook. Throughout his childhood, he never allowed his CF to define him and to this day, he still doesn't let CF get in the way of living life to the fullest.

It hasn't always been this way though, as Tony's health deteriorated in late 2016 to the point where he began talking with his team about the possibility of a transplant. However, thanks to Orkambi, Tony's lung function doubled over the next 18 months.

Tony admits that he still works hard on his physio and fitness, but Orkambi has helped restore his health and allow him to get back to doing the things he loves – travelling, being out on his jetski, cycling, and spending time with his family and friends. He's always happy to talk to others about his experiences with CF, Orkambi, travelling, and getting involved in the CF community. ■



To learn more, or to connect with one of our peer support volunteers, contact programs@cfcc.org.au

CF community values NSW support dinners



Cystic Fibrosis Community Care hosted our first 2019 NSW support dinner in the Sutherland Shire, attended by the families of people with CF.

Parents with children of all ages joined us for the evening, which was a chance to come together in a relaxed setting and share stories and experiences.

One thing that greatly appealed to the attendees was the opportunity to meet other people with a connection to CF. The support dinner allowed them to meet other parents in a similar situation and to form their own networks.

Holly, a parent of two children with CF, said “Very thankful to have had an opportunity to attend the recent support dinner in Sutherland Shire. Supporting someone with CF can be isolating, and whilst friends and family can be a listening ear, it is refreshing to share the journey with others who know the ins and outs.”

If you are a CF Community Care member with a family member or partner who has CF, we invite you to attend one of our upcoming Support Dinners.

Upcoming NSW Support Dinners for 2019:

30 Aug – Armidale Support Dinner
20 Sept – Central Coast Support Dinner
25 Oct – Wollongong Support Dinner
8 Nov – Dubbo Support Dinner

Bookings are essential and we encourage you to RSVP as early as possible.

For more info about upcoming events or to request a support dinner for your area, contact our Programs and Support Services team.

Email: nswsupport1@cfcc.org.au

Phone: (02) 8732 5700

What does it mean to be a ‘carer’?

We all have names for ourselves – daughter, father, mother, sister, grandparent – but often we do not think of ourselves as ‘carers’. If you look after a loved one who has CF, then this might be you.

Being a carer means that you provide unpaid care for a family member or friend who has a chronic condition, mental illness, disability, addiction or is an older person with care needs. You can also be considered a carer as a young person who provides care to a sibling or parent. At any time, one in eight people in Australia are performing a caring role.

In Victoria, CF Community Care is working in partnership with CarersVic to deliver ‘Caring for The Carer’ workshops in a number of communities around the state. The workshops are designed to enhance carers’ knowledge about how to support their own health and wellbeing. We wanted to provide an opportunity to reflect on your needs, listen to other community members’ coping strategies and learn about what extra supports are out there for you and the people you care for.

Ultimately, it can be difficult to consider your own needs but if your health begins to suffer then caring for your loved one will become more difficult. Here are some tips for maintaining a balanced lifestyle.

- Try and make time to be active. Aim to do at least 20 minutes of exercise each day.
- Have regular meals and eat a balanced diet including whole grains, rice and pasta, fresh fruit and vegetables, meat, fish, beans and dairy foods. Also try to limit the amount of fat, sugar and salt in your food.
- Try and get a good night’s sleep as being tired can increase stress.
- Keep hydrated throughout the day to prevent headaches, tiredness and confusion.

CarersVic can also assist you in finding the right advice and resources for your situation. You can visit the CarersVic website – carersvictoria.org.au – or speak directly to one of their experienced staff at the Carer Advisory Line on **1800 242 636**.

Hear from the CF experts at our Community Conference

In 2019 our CF Community Care Conference will be held on Saturday 14 September in Melbourne. This year, for the first time, we will be live video-streaming some sessions to allow people with CF, as well as those outside Melbourne, to attend and interact.

The one-day conference will provide an opportunity for the CF community in Victoria and NSW to come together and learn more about the latest developments in the field of CF and provide an opportunity for discussion with medical and health experts and those affected by CF.

Planned sessions include advances in treatment and care, an update on physiotherapy, government concessions and benefits, mental health, educational support, transplant, transition, advance care planning, and more. The Conference is free for CF Community Care members to attend. Keep an eye on our website, Facebook page, and PASSwords newsletter for updates on the 2019 program. ■

CF Community Care Conference

Saturday 14 September 2019
CFCC office, 80 Dodds St, Southbank VIC

More details and to register:

Registration is required to attend both in person or to join the video stream.

cfcc.org.au/get-involved/events/cfccconference

Email: support@cfcc.org.au

Phone: (03) 9686 1811

Feedback from 2018 Conference:

"The most interesting part of the conference was networking – breakout sessions at lunch, meeting other parents with CF kids"

"Professor David was fantastic... Cindy was extremely useful discussing financial hardship. Jo was great on educational support. Judith was wonderful talking about mental health."



Improving fitness for our NSW members

Our members in Hunter New England and Wollongong/Shellharbour can access grants to help them keep fitter and healthier.

We are thrilled to announce the return of the Newcastle Permanent Charitable Foundation Grant and new Fitness Participation Program funding thanks to the generosity of the Oak Flats Lions Club. These grants are available to eligible members who live in the Hunter New England and Wollongong/Shellharbour areas.

Breathe Better Program

The Newcastle Permanent Charitable Foundation Breathe Better Program (BBP) is back, offering Fitness Participation and Regional Nebuliser Replacement programs for people in the Hunter New England Area.

People with CF in the Hunter New England Regional area, who are members of CF Community Care and who have not previously accessed support through the BBP, can now access nebuliser and fitness participation support grants.

The area-specific nebuliser and fitness program, run through the CFCC NSW Programs and Support Services (PASS) team, provides one-off grants to community members to assist with access to much needed exercise and equipment in regional areas.

As part of the BBP, grant recipients will be asked about specific health indicators. Six months later there will be a follow-up to determine how the equipment or fitness participation has helped you.

Wollongong/Shellharbour fitness grants

Thanks to the generosity of the Oak Flats Lions Club, we are able to offer a Fitness Participation Program (FPP) to current CFCC members who live in the Wollongong and Shellharbour LGAs.

The Oaks Flats Lions Club FPP grants provide funding towards gym or club fees, sporting equipment costs and pay for extra-curricular activities such as swimming lessons, karate and tennis.



The Breathe Better Program is generously funded by the Newcastle Permanent Charitable Foundation. We also thank the Oak Flats Lions Club for their Fitness Participation program grants for people living with CF in the Wollongong/Shellharbour area.

Grants such as these are possible thanks to the fantastic testimonials and information we gather from previous participants. ■

If you would like to find out more information or see if you are eligible for these programs:

Email: nswsupport1@cfcc.org.au

Phone: (02) 8732 5700

Getting away from the everyday

Grant programs that can support our members to tick off a bucket list experience, or take a break and recharge with their family.

Simon's Adventure Fund (NSW & Vic)

Simon Minson's family generously established this program in Simon's memory to support people aged 18 years and over who have CF to participate in an activity on their bucket list. It may be something that pushes the boundaries, it may be something that seems a little crazy.

Helena received support from Simon's Adventure Fund to fulfill her wish to go skydiving.

"Thank you so much! It was absolutely amazing. I loved it and cannot wait to do it again! Thanks again for this amazing opportunity, it was awesome!"

Alicia, also had one of her dreams come true thanks to the Simon's Adventure Fund.

"My partner Pete and I participated in an experience of a lifetime the 'Reef Sleep'. It was without doubt one of the best experiences of my life. For those six nights I could escape my CF and experience so many wonderful things; sleeping on Heart Reef Pontoon, snorkeling the Great Barrier Reef, a helicopter ride over the reef, jet skiing, swimming in the turquoise waters, exploring all the beautiful coral and fish on the reef. It was a sensory overload, I have never seen anything so beautiful.

"Sitting on the top level of the pontoon, with a glass of wine, watching the sunset over this beautiful place is a memory I will have forever. There is nothing quite

like laying in an open air swag, in the middle of the peaceful reef, gazing up at a sky full of stars.

"Having CF can certainly take its toll on your body physically and mentally. The break that this gave me really enabled me switch off and enjoy every little moment, appreciating all the little things in life. I will be forever grateful to Simon's Adventure Fund for this incredible experience for giving me an experience that I could only ever dream of."

If you would like to find out more about Take A Break or any of our other programs and services please visit our website at cfcc.org.au/about-cfcc/support/#takeabreak or contact the programs and support services team in your state

NSW: nswsupport1@cfcc.org.au or (02) 8732 5700

VIC: support@cfcc.org.au or (03) 9686 1811

Take A Break Program (Vic)

Earlier this year our Take A Break program supported Geoff, one of our Victorian members, to have a short break with his family.

Geoff, his wife Terri, and his gorgeous son Seb had an amazing time in Queensland.





They flew to Cairns where they relaxed at Trinity beach. They visited the Skyrail Rainforest and enjoyed the fantastic 360-degree views, swam in Cain's Lagoon (Seb just loved it and didn't want to get out), and went on a glass bottom boat at Green Island to see the Great Barrier Reef and its gorgeous fish. Geoff and his family also stayed in Port Douglas and walked some of the 4 Mile Beach, before taking in a river cruise in the Daintree Rainforest and visiting the beautiful Mossman Gorge.

"Our trip was amazing. It was so nice to finally get away for an actual holiday just the three of us. We had the best weather and the most amazing time away with the best memories."

The Take A Break Program is generously funded by Andrew's Legacy. Andrew's family and CF Community Care are grateful to all who have contributed and continue to contribute to Andrew's Legacy to make it possible for Geoff and others to get away for a break.

If you would like to find out more about Take A Break or any of our other programs and services please visit our website at cfcc.org.au/about-cfcc/support/#takeabreak.

VIC: support@cfcc.org.au or (03) 9686 1811 ■



Oscar's excellent snowy adventure

My adventure started the day my best friend Edward asked me to be a groomsman for his wedding at a snow resort in Canada.

Being asked to be a groomsman was an incredible honour. I grew up with Ed and he knows and understands my health needs and has always been supportive of my CF. I knew that I wanted to be there to share this priceless moment and milestone with him and his family.

Attending the wedding would also be my biggest solo trip, and I would need to make sure I was feeling well and was prepared.



With some help from my family, the team at CFCC and Simon's Adventure Fund the trip became a reality. I arrived a few days before the wedding. It was the end of the Canadian winter so the snow was melting and wasn't too thick, but made setting up for an outdoor wedding challenging.

On the day of the wedding I was decked out in a spiffy grey suit with ski boots for shoes standing in the most picturesque snow setting you can imagine. The wedding was stunning!

After the wedding. I spent time snowboarding, with a local music festival in between, before soaking up the sights in Vancouver.

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

Thank you Simon's Adventure Fund and CFCC for helping make this trip possible, and letting me spend time with people who mean a lot to me doing something I love to do, snowboarding!

Our Sydney office has moved to Burwood

Our Sydney office has moved to new premises in Burwood, just around the corner from Burwood railway station.

You can find us at **Suite 2A, 5 Belmore St, Burwood**. Our phone number remains the same – **(02) 8732 5700**.

Our thanks also go to Jendar Interior Design for their amazing work on the design, project management and build of our new office. We couldn't have done it without their support.



Watch videos from the Aust CF Conference

Feedback from people who attended the recent Australasian Cystic Fibrosis Conference was that it was the best one ever.

Even if you couldn't make it over to Perth for the conference, you can still catch up on the informative and insightful discussion.

Sign up and log in at CFA's Consumer Connect portal to access conference videos:

cfa.padlokt.com/my-account/login

Mental Health First Aid: Lady Gaga says: 'It's okay not to be okay'



Lady Gaga is passionate about promoting mental health first aid for young people. And we agree!

In a recent video from her Born This Way foundation, she says "Quite frankly, my dream is that this happens in every school. With teen Mental Health First Aid, we like to say, it's okay to not be okay."

Plenty of us know how to give first aid for physical injuries. And mental health first aid is similar – it's about offering support and assistance, as a first step in providing care.

One of the best ways you can support young people who are close to you is to get skilled up. We can assist CFCC members to find mental health first aid training that's right for you, and we can also help cover the cost.

For more information on course options, visit the Mental Health First Aid website: mhfa.com.au

To discuss how we can help with the cost of a course, please contact our Melbourne office.

Email: programs@cfcc.org.au
Phone: (03) 9686 1811

Thank you for your generous support of our Tax Appeal

For sisters Isobel and Ruby, sticking to their daily cystic fibrosis treatment is a routine that they help each other get through.

When Ruby was born and diagnosed with CF, her parents Christine and Gerard knew what they were dealing with. Two years earlier, Ruby's sister Isobel was also born with CF. With two older brothers, the routine required to manage CF in their household was already understood.

Everyone has a role to play, with Isobel and Ruby working together every day, helping each other through their treatment, and older brothers acting as great hospital visitors and carers when the need arises.

Isobel, Ruby and their family, are passionate about raising awareness for CF and we are very pleased to be the face of the 'You can't ignore it. CF is for life' tax appeal.

In collaboration with Cystic Fibrosis WA and Cystic Fibrosis Queensland, the appeal aims to raise awareness and funds for the vital services and programs provided by the CF organisations. Gaining insight to daily life of families affected by CF, helps educate the broader community on the relentless need for treatment and vigilance in daily CF life.

During the past month Isobel and Ruby will have each swallowed more than 1500 tablets and spent over 30 hours doing physio and their nebulisers. That's when they are well. If the girls are sick or have complications with their health these figures can significantly increase.

This is just one month of their life-long medical routine. The girls are very positive, however, it can be emotionally draining on tough days.

Christine reflects that she and Gerard want the same thing for all their children: 'to live a happy, healthy full life and to grow old surrounded by

loved ones'. At CF Community Care we help improve people's quality of life by providing specialist medical equipment, in-hospital support, education services and financial crisis support.

Please help us to spread our 'You can't ignore it... **CF is for life**' message. Together we can change the future for CF families.

From the CF team here, and from Isobel and Ruby, thank you. ■

If your family would like to participate in future awareness and fundraising campaigns, please contact Fran at donors@cfcc.org.au or on (02) 8732 5700.

You can still make a donation to the Tax Appeal. All gifts go towards funding essential services and programs.

Donate: cfcc.org.au/taxappeal

or by phone: (02) 8732 5700 / (03) 9686 1811



65 Roses Month: 31 days of CF awareness

Victoria and New South Wales lit up, hit the streets, and fundraised in support of people with CF.

During 65 Roses Month, both the CF community and CF Community Care worked hard to raise awareness of cystic fibrosis. Throughout the month, countless challenges and activities across NSW and Victoria helped people learn more about CF.

Ride for CF

Two young female entrepreneurs who own a cycling studio in Melbourne were enthusiastic supporters of 65 Roses Month.

The event encouraged United Ride's clients, friends and the CF community to participate in two back-to-back spin cycling sessions on 25 May. The morning saw over 30 eager riders riding on stationary bikes and raised \$1,200.

Walk 65K in May

We invited participants to walk 65km over the month and over 20 people took part in this challenge raising \$1,700 and also raising awareness for CF.

65 Roses High Tea

In an unforgettable occasion, 200 guests attended our first 65 Roses High Tea at The Tea Rooms, QVB. Lots of fun – and lots of fundraising – was had in support of a good cause.

Community Fundraising

Sunbury College organised a fundraising day where they sold merchandise and requested donations for CF. The school raised an impressive \$2,300.

Midstate Motorcycle Club Dice Run in Parkes raised over \$1,700.

Our annual Rise 'n' Grind fundraiser was a huge success, with cafes across NSW donating the cost of a cup of coffee. Special thanks go to Tarn's Cakes & Cafe, Ariel's, Pick Of The Bunch, Emmaville Traders, Anna's Shop Around The Corner and Michel's Patisserie Warners Bay for their involvement.

The 'Bubbles to Breathe' fundraisers in the Sutherland Shire set out with a \$10,000 fundraising goal – and

they thought that was lofty. After a month of hard work and various activities, including a wine and canapé night, a donut day at school, a Bunnings BBQ, cake stalls, cookie stalls, and soliciting donations, they finished off having raised an astonishing \$30,681!

Edenhope College took part in a fundraising day to honour two students that have CF. The school had a red theme, sold pies and raffle tickets for gold coin donations as well as CFCC merchandise. This event was picked up by local newspaper highlighting a great sense of community. Students and staff raised around \$1,500.

Ladies Charity & Fun's annual fundraising luncheon took place on 31 May at the RACV Club in Melbourne's CBD and their efforts raised just over \$15,000 for CFCC. Three of our community members, Jan, Jennifer and Belinda, have run this event for five years and it is a must-attend event on our calendar. One of our youngest and bravest members, 10 year old Ellie-May was the guest speaker on the day and wowed the crowd. The 286 guests present enjoyed a sumptuous meal and danced the afternoon away all for a good cause.

Shine a Light on CF

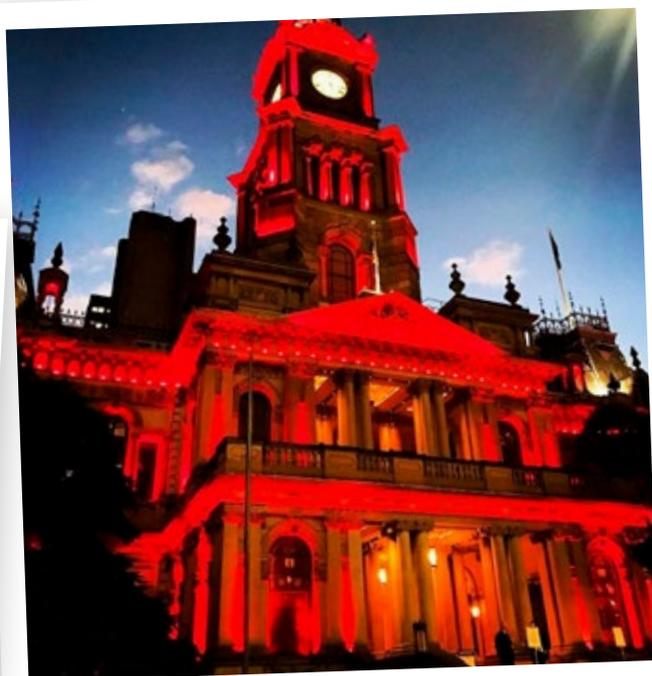
Our community awareness campaign, called 'Shine a Light on CF', asked prominent landmarks throughout Victoria and NSW to show their support of the CF community by lighting up red on Friday 31 May.

Among the more than 20 participating landmarks were the MCG, Melbourne Star, Sydney Town Hall, Melbourne Town Hall, Flinders Street Station, Newcastle Town Hall clock tower, Campbells Corner in Muswellbrook and Ballarat Town Hall.

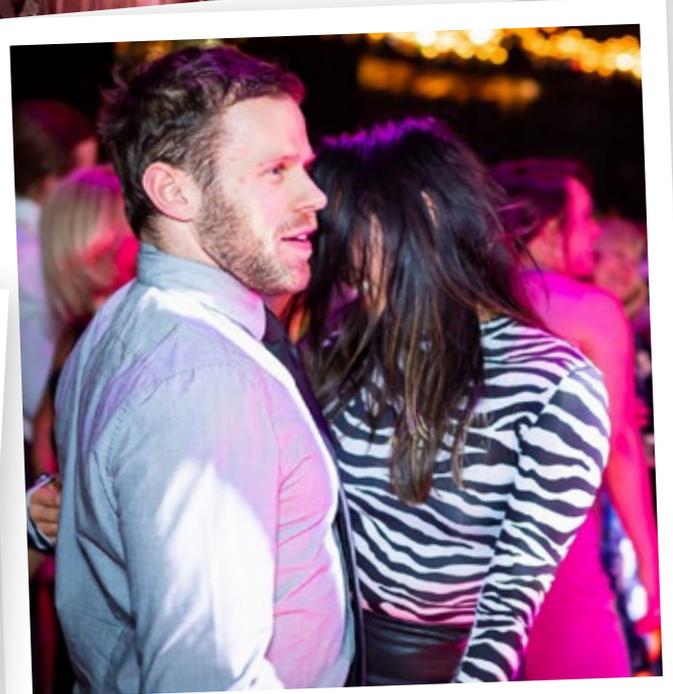
Crown Resorts also donated us space on their Kings Way billboard during May to display a carrier screening message.

Rose Sales

Our hard-working staff and teams of volunteers sold over 2,500 roses at locations across Melbourne, Newcastle and Sydney to mark 65 Roses Day and to raise funds for the fight against CF. ■



A Night For CF Melbourne: What a dazzling night!



On Saturday 20 July over 400 guests wined, dined and danced the night away at our Melbourne gala ball to raise money for the fight against cystic fibrosis.

The CF community united for this unforgettable night, and the generosity of those who attended helped us raise \$67,000 to support people living with CF.



Sydney's night of the year is here

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

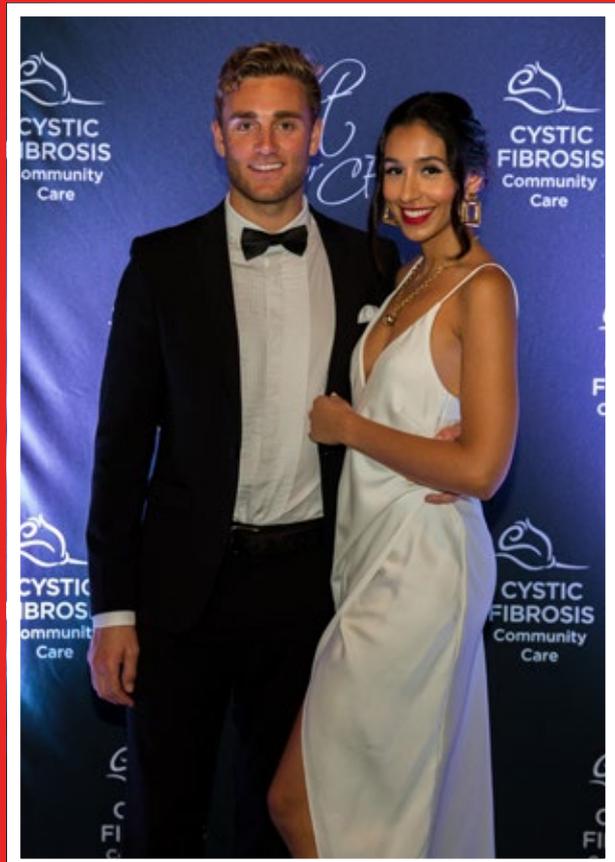
Your ticket to A Night For CF includes a three course meal, beer, wine and soft drinks and excellent entertainment at our glamorous venue, The Westin Sydney. Get your table together now and prepare to be indulged.

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.

A few tickets are still available so secure your place at CF Community Care's night of the year by purchasing your tickets today.

hub.benojo.com/campaigns/a-night-for-cf-nsw-2019

Saturday 7 September, 7.00pm – Midnight
\$1,600 for a table of ten or \$165 per person



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*Starts 1/7/19 and closes 31/8/19. Purchase any Palmolive Hair Care product from any Coles or Coles Online store and Colgate-Palmolive Pty Ltd will donate 10c to Cystic Fibrosis Community Care Ltd up to a maximum of \$30,000. Promoter is Colgate-Palmolive Pty Ltd. Full terms see www.palmolive.com.au.

10c from every purchase* goes to



For more information on how to participate further visit www.crazyhair.com.au

Community is strength

An important way to share awareness of CF and raise money to support our community.

Did you know that fundraising for Cystic Fibrosis Community Care is one of the most powerful things you can do to help provide support and services to those affected by CF?

Community fundraisers have been instrumental in our ability to raise awareness of CF. Through the support of hundreds of people across Victoria and New South Wales, we can continue to provide programs and services, listen to the voices of those who have been impacted by CF and provide financial support.

Hosting your own event can be daunting. Where do you start?

We have you covered! We've created a fun and easy to use toolkit for those who want to run their own event but are not sure where to start. There are loads of exciting and creative ways you can raise money. Whether it is running raffles, baking, movie nights or getting your school or employer to host an event.

The toolkit provides our top tips to help you maximise your fundraising and help you make your fundraiser a huge success! ■



Community Fundraising Toolkit

All you need to know to hold your own fundraising activity for Cystic Fibrosis Community Care



Download the toolkit: bit.ly/community-toolkit

Have more questions? Want to talk through some ideas? Get in touch! Our fundraising team is here to help and we are incredibly excited by the opportunity of working with you.

NSW: communityfr@cfcc.org.au or (02) 8732 5700

VIC: fundraising@cfcc.org.au or (03) 9686 1811

A 65km ride to school – for CF

On Friday 24 May, Thornton Public School participated in some awesome activities all focused on the number 65. The day started with a couple of teachers riding 65 kilometres to work.

Teacher Brian Gaffney recalled “At 5.30am on Friday morning I rolled out of my driveway on a dark and foggy morning. Kilometre number one was the easiest. On the way to school I met up with Mr Parker, who had just gotten a flat tyre.

“Mr Parker didn’t panic, he showed great resilience and worked quickly to fix his bike.

Together we rode on through the fog. On and on we rode – I was working really hard to keep up.”

“Past Morpeth and through to Tenambit. At last the sun was out and shining brightly and keeping us warm. We rode on to Thornton and started to keep a look out for excited students wearing red.”

“We finished with a lap around Thornton to round us off to a solid 65 kilometres.”



Save the dates for Great Strides

Great Strides season is one of our favourite times of the year and it's right around the corner.

Make sure you register today for one of our three big Great Strides events coming up in October! Get your walking or running shoes ready.

- Bendigo – Sunday 13 October
- Melbourne – Sunday 20 October
- Sydney – Sunday 27 October

Registration is now open so get your teams together and start training!

Melbourne participants will have a choice of a 21km half-marathon, 8km or 4km around the Tan Track in Melbourne's Botanical Gardens. Any child under 11 who is registered in these distances will be able to participate in the 500 metre dash for free. All registrants will receive a free Great Strides singlet on the day.

Sydney people can choose from either 6km or 3km at the beautiful Silverwater Park. Any child under 11 who is registered in these distances will be able to participate in the 500 metre dash for free.

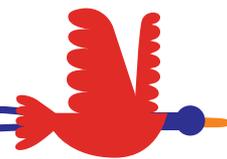
Bendigo registrants will be able to take part in either the 6km or 3km distances around scenic Lake Weeroona. Any child under 11 who is registered in these distances will be able to participate in the 500 metre dash for free. All registrants will receive a free Great Strides singlet on the day.

This is a fun way to get involved in the CF community and a great opportunity to honour a loved one though creating a team and raising awareness and funds to support people living with CF. ■

Register today!
www.greatstrides.com.au



STRIDE FOR CYSTIC FIBROSIS



13 OCT Bendigo
20 OCT Melbourne
27 OCT Sydney

Register online today!
www.greatstrides.com.au

The Sou'Westers: 45 years strong

Roslyn Vaughan, Sou'Westers CF group member, is the mother to an adult son who is living with CF. Her very active group has supported people with CF for 45 years.



"The Sou'Westers group formed in 1974 and we joined three years later, when moving into the area. Originally a parent support as well as fundraising group, many friendships made then are still maintained. In the early days we organized lots of different functions – fashion parades, dinner dances, raffles and so on, but these days only hold street stalls in Cronulla, Kogarah and Revesby from March to June. Since 1979 we've held 688 stalls and raised in excess of \$400,000 through these alone."

"Our big sellers are the handknitted baby and toddler wear, dog coats, knee rugs, tea cosies, beanies, scarves, and other various handcrafts and we thank all our volunteers who keep us very well supplied with stock and man the stalls. Being visible in our area with stalls for over 40 years has helped spread the word and we hope to keep going for a few more years yet."

The Sou'Westers CF group has already raised over \$5,000 this year, and with funds for four more stalls still coming in they expect to raise at least \$8,000 for 2019.

Ten-year-old Ethan bakes up a storm

Why did I decide to raise money for CF?

My sister has Cystic Fibrosis and I do not think that it is talked about that much.

Why did I choose to sell gingerbread?

The Gingerbread theme was decided when Hannah was in hospital recently. When she had finished an unpleasant appointment, like getting a needle or a bronchoscopy, she would get a gingerbread man as a reward.

I sold the gingerbread men at my school canteen every Friday in May. I had to speak to the Principal of our school to get him to support this. He was very supportive.



What was my fundraising goal?

I thought \$150 would be great but we actually raised \$1,000. We sold gingerbreads for \$1 each and sold out every week, I was very pleased. We also got some donations.

Who helped me achieve my goal?

My family helped me especially my Mum. Some parents and also Kelly who works in the canteen were also a huge help.

How I hope the money raised will help those with CF?

I hope the money will go towards finding a cure for CF and help people like my sister Hannah!

A forever friendship

by Clarissa Smith, Warren's mum

Ben and Warren have been friends since pre-school. They maintained their friendship throughout primary and secondary school and beyond – played soccer, tennis and rode their bikes together, to name just a few of the things they shared with a large group of mates from over the years.

In the week Warren turned fifteen he was diagnosed with cystic fibrosis; I had been trying to find out what was wrong with him for most of his life.

He was born before the heel prick test for CF was done on newborns. Warren had a wonderful network of friends who supported him with his condition but his friends certainly didn't define him by it. In their twenties many of them joined him in the annual Great Strides CF charity run around the Melbourne Tan under the name 'Team Wozzler'.

For the group of friends, life had become very busy with work, relationships, family and some living further afield. So Great Strides was as much a catch up as raising funds for and awareness of CF.

Ben was teaching at St. Joseph's Secondary School and living in Geelong and thought nothing of coming to Melbourne with his partner to support Warren. In October 2016 Warren was particularly unwell but with Ben's encouragement, he managed to rock up to the Melbourne tan and run with the team.

Unfortunately that was the last time Warren participated in Great Strides. When Ben got the call

Team Wozzler at Great Strides Melbourne



that Warren had passed away in May 2017 he was on a St Joseph's School camp in Central Australia.

Later that year about sixty members of Team Wozzler participated in Great Strides. Although Warren's absence was heartbreaking, they managed to raise a substantial amount for Cystic Fibrosis Community Care and honour Warren's memory.

Coincidentally, Ben was unable to participate in the 2018 Great Strides as he was again on a St Joseph's School camp in Central Australia. Both he and his Mum were extremely apologetic to Team Wozzler but of course everyone understood.

As I arrived at the Botanical Gardens for Great Strides last year, I received a text from Ben saying he had completed a run with a group of students just in time to see the sunrise at Uluru. He sent a gorgeous pic of himself wearing his red 'Team Wozzler' t-shirt with the beautiful crimson Uluru as a backdrop. This made the day even more emotional than usual for myself, friends and family.

Later that day Ben went on a bike ride around the base of Uluru with the students and was reminded of Warren's enthusiasm for tinkering with and riding bikes as one of the boys kept helping another mate whose chain kept coming off – just like Warren used to help!

He explained to some of the students the significance of why he needed to run that morning and what wonderful support they were to him. I was totally overwhelmed with Ben's loyalty and consequently a wonderful role model to his students.

When someone physically passes, their spiritual connection as a friend, child and relative doesn't end. Each year 'Team Wozzler' hopes to get together and support Great Strides to honour Warren's memory and raise much needed funds for those living with cystic fibrosis. ■

There are four big reasons to try number five.

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