

JUNE 2018

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**CYSTIC
FIBROSIS**
Community Care

Incorporating CFV and CFNSW



Including:

- Read Kate's story
- Changes to Child Care Subsidy
- Join the Orkambi campaign
- McKenzie's Mission
- 65 Roses Month

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

DISCLAIMER

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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: Tax Appeal
Kate and Molly

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CF Matters

Welcome to our second COMMUNITY Focus for 2018, and our first for the year produced as a digital e-magazine.

It has been a huge first half to the year for Cystic Fibrosis Community Care (CFCC) with major events in New South Wales and Victoria keeping the teams in both states extremely busy.

As I write, 65 Roses Month is drawing to a close and I can hear the chatter of our volunteers in the room next door as they carefully wrap hundreds of magnificent roses (kindly donated by Wafex). This special month in the CF calendar has seen fantastic community fundraisers and awareness activities happening in both states, plus on 65 Roses Day (25 May) the Town Hall in Sydney, and AAMI Stadium, the Bolte Bridge and the Star Observation Wheel in Melbourne were illuminated red to recognise those living with CF.

One of our most important activities for the first half of the year is our advocacy campaign for Orkambi, which came about following the announcement that this important drug was on the Pharmaceutical Benefits Advisory Committee (PBAC) agenda for their July meeting. This is the fourth time the PBAC will consider Orkambi, and we are determined to do everything we can to demonstrate to them how important it is to recommend it to be subsidised.

As many of you will know, in late April, Cystic Fibrosis Australia led the Orkambi campaign with a march across the iconic Sydney Harbor Bridge to the offices of Vertex Pharmaceuticals. The day was a huge success with over one hundred people taking part, including members of our Sydney team.

Here at CFCC we wanted the Orkambi campaign to get as much support as possible and many of you will have received our Advocacy Kit in the mail, complete with addressed postage paid envelopes, Orkambi fact sheets and sample wording to help you to write to Health Minister Greg Hunt, Vertex and the PBAC. Across Australia we need to pull together, to make it loud and clear that Australians need Orkambi!

We've had lots of feedback that members have used the kit and sent in their letters but perhaps the most heart-warming was to hear that some schools had used the opportunity to show that children also have a voice. Classrooms of children wrote letters to Minister Hunt and Vertex telling them why it was important for their classmate to get this potentially life changing medication. Just awesome!

The campaign has received good media coverage, both on TV and in print with families sharing their stories, and as I write our social media campaign is heating up with messages going out to key influencers in the community. It was also encouraging to hear Minister Hunt speak about his hopes for Orkambi. We acknowledge that he has a real heart for this campaign, and I remain cautiously hopeful.

For those of you in New South Wales, we have appointed a new State Manager, Jacqui Oong, to lead the team. Please feel free to contact Jacqui and introduce yourself. While she is new to the CF space, she has many years' experience in the not-for-profit sector and brings a great mix of skills and passion to the cause.

Our Tax Appeal landed in letterboxes a few weeks ago and we are grateful for the support we have received so far. We realise not everyone can give every time we ask, but if you are in a position to respond, we thank you. If you are not, we would be grateful if you could pass on the appeal to a family member or friends, who may be able to support the campaign.

Over the past six months we have enjoyed generous support from a number of community fundraisers. People have cycled vast distances, water-skied the Murray, hosted golf days, sold raffle tickets at music festivals, run mini Great Strides events, or simply sold cupcakes. We are so deeply grateful for all our community fundraisers do. Without their support, there would be no services or programs to aid individuals and families with CF – thank you, one and all.

Finally, please take a moment to read about Simon's Adventure Fund for those CF'ers out there who have an unfulfilled adventure dream! We have a fund available to help you achieve your dream, so make the most of the opportunity and apply today!

That's it from me, until next time...



Karin Knoester
Chief Executive Officer



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 eNews, 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 at <http://eepurl.com/diRI-b>



Kari's Tv Performance – A Perfect Ten!

By Tom Valenta



When nine-year old Kari Prendergast entered the Sanitarium Weet-Bix Kids' TRYathlon at Sydney's Olympic Park earlier this year, she could not have known that she would be interviewed on national television.

Along with registering Kari for her third TRYathlon, her mother Renae, a school teacher, had also entered Kari for an associated competition that had a Razor scooter as a prize. In the entry, Renae wrote Kari's story, including details about her living with cystic fibrosis.

'The TRYathlon organisers contacted me and asked whether Kari would be prepared to share her story with event ambassador and Network Ten identity, Steve 'Commando' Willis on the Studio 10 program,' said Renae.

'Kari was keen to do it but was very nervous. She was concerned about any questions she would be asked about CF because of the complexities of the condition.'

Kari proved to be an outstanding advocate for CF and the TRYathlon when she appeared on the program a few days before the event at Olympic Park. A confident and articulate young person, she made a strong impression.

Fortunately, Kari was not asked too many technical questions about CF, they were more about her training for her third TRYathlon. Nevertheless, the CF message was delivered clearly and concisely.

Telecast nationally on the Ten network, Studio 10 airs between 8:30am and 12:00pm on weekdays. 'Commando Steve' is best known for his co-hosting of Australia's Biggest Loser program.

The Kids' TRYathlon is an annual event that is held in ten cities and regional areas around Australia. It is more about fun, fitness and participation than competition.

Entrants, aged up to fifteen, are encouraged to complete swimming, running and cycling events. The emphasis is on completion and enjoyment, not competition.

Kari's first event was in Melbourne and when the family moved to Sydney two years ago, she continued to participate with enthusiasm and dedication.

Kari has two younger siblings, a brother Jay who is six and sister Asha who is four. Neither sibling lives with CF. This year, Jay also entered the TRYathlon, much to his older sister's delight.

Although the Prendergast family is originally from Melbourne, Kari was born in Adelaide where the routine heel-prick blood test revealed that she had the most common strain of CF, Delta F508, which is present in some 72% of cases worldwide. As in most cases, the diagnosis was a shock to the family and they returned to Melbourne soon after the birth.

Kari has had only one hospital admission and that was in Melbourne during her first year at primary school.

The family has been living in Sydney's inner-west for the past two years. After working with the AFL Players' Association, Kari's father Ian was appointed Chief Executive Officer of the Rugby League Players' Association. A former AFL footballer, Ian played in Victoria and South Australia before working as an advocate for the players. Ian, who is a lawyer by training, does have a cousin who lives with CF.

Elite sport runs through the family. Kari's aunt Julie Corletto (father Ian's sister) played netball for Australia and was a member of two winning World Cup teams.

While Kari has not articulated her plans for the future, her love of sport and the performing arts is evident to her parents. 'She is very active,' says Renae. 'She dances, swims, plays netball and runs. She also plays the recorder, is trying the flute and sings in the school choir.'

There is little doubt that she will also continue to participate in TRYathlons.

Kate's Story – Tax Appeal 2018



Every day is precious with cystic fibrosis

Like many kids with cystic fibrosis, young Kate spent much of her childhood in and out of hospital. She endured multiple hospital stays to treat lung infections plus emergency surgery for a blocked bowel.

"When I was born with cystic fibrosis my life expectancy was just 10 years."

Every morning before school, Kate's routine was the same. First was nebuliser therapy followed by an hour of physio, and finally breakfast. After this relentless routine, if she had enough energy, Kate would head off to school. And if this wasn't enough, to aid digestion, Kate would swallow 40-50 tablets every day.

Thankfully, Kate has defied the odds and at 38 is "miracle mum" to 5-year-old Molly. But it has taken a double lung transplant and two traumatic miscarriages to get there!

With cystic fibrosis there is still no cure. People with CF need your help more than ever, please give a gift today.

Eleven years ago Kate received a life giving gift, a new set of lungs. The double lung transplant was a success, but Kate still faces a daily battle with CF.

"We might look well on the outside, but we're really horribly ill on the inside," says Kate.

"Unless someone has a child or friend with CF, they just don't realise the struggle we are going through."

At Cystic Fibrosis Community Care (CFCC) we deliver essential services and support. We work closely with hospital CF clinical teams, we provide financial subsidies, equipment loans, social work support and referrals, plus educational support and assistance.

Help CF families like Kate's enjoy many more precious moments.

Thankfully, better treatment and care has meant there are a growing number of adults with CF. However, they depend on you for critical medical equipment and support services.

Anything you can afford to give will be so gratefully received.

All the work we do with families, providing services and equipment, is only possible when thoughtful people like you send a gift.

Will you please send a special gift for people like Kate?

Your gift will allow us to help keep Kate well, not just for her sake but for the sake of little Molly.

From the CFFC team, and from Kate and Molly – THANK YOU.

PLEASE DONATE TODAY

Donate New South Wales

<http://www.blowcfaway.org.au/event/nswtaxappeal2018>

Donate Victoria

<http://www.blowcfaway.org.au/event/VICTaxappeal2018>



From Transplant To Surf Champion In 18 Months

By Tom Valenta



The annual Flatrock Bodysurfing Invitational is a well-known, elite event on the Newcastle surfing calendar. It is held in August and attracts body surfers from many parts of New South Wales and beyond. And as the title suggest, entrants must receive an invitation to compete.

The reigning champion is forty-three-year-old Ryan Fitzgerald, a Newcastle photographer and artist. Ryan lives with cystic fibrosis (CF) and had a double-lung transplant only eighteen months before winning his title. Born in Melbourne in 1974, Ryan was diagnosed with CF at eleven months. He recalls a reasonably healthy and active childhood, adolescence and young adulthood.

The family moved to Cairns when Ryan was aged two, to Brisbane when he was ten and to Sydney at fourteen. He went to Newcastle after finishing school in 1993.

For most of his childhood and adolescence, Ryan loved the surf. At every opportunity he would hit the surf with a body board, the small, light foam board that is ridden by lying on it. He credits surfing for his relatively healthy years.

In 2001 he became ill and, to recuperate, went to the Queensland Sunshine Coast to live with his parents for nine months. There he began body surfing and discovered its healing powers.

Ryan loved it so much he bought himself a hand-plane and a pair of flippers – common tools for body surfers – and continued with the sport when he returned to Newcastle.

As most people who live with CF know, the health benefits of salt water and sea air are immense. As Ryan says; 'As soon as I get into the water and start exercising, the mucus in my lungs becomes dislodged. I have the feeling that everything gets cleared out.'

It was a group of Sydney surfers with CF who, in recent, years led scientists to research the benefits of hypertonic saline solution.

'When I was around thirty things began to go downhill. From 2005 to 2012 my fitness was deteriorating, and hospitalisation became more frequent. Eventually my lung function dropped to around the 28 to 30 per cent level,' said Ryan.

'In late 2015 it became clear that I would need a transplant. Luckily, I was only on the waiting list for two weeks. By the end of January 2016, I had my transplant which was done at St. Vincent's Hospital in Sydney.'

By October 2016 Ryan was again able to body surf. 'I was in the water most days, there was so much lost time that I wanted to make up.'

His time in the water was ideal training for the championship that he won in 2017. Ryan also had assistance from Cystic Fibrosis Community Care which contributed \$300 towards the cost of a wetsuit that enabled him to body surf year-round. The money came from Fitness Grants funding available through the Newcastle Permanent Charitable Foundation.

Ryan has two older siblings. His brother John also lives with CF and has had a double-lung transplant. His sister Kelly is CF-free.

After completing his secondary schooling, Ryan studied music at university. He returned to his studies in 2010 and obtained a Fine Arts degree from the University of Newcastle. At first, he worked as a photographer specialising in landscapes and surfing subjects. But this was a narrow and crowded field, so he moved to photomedia-based art, specialising in the wet-plate collodion process which is a 19th century photographic method.

He says on his website; 'Themes of the grotesque and the uncanny hold interest for Fitzgerald; familiar forms that have been taken over, manipulated and rearranged. He endeavours to place the viewer at an uncertain point between discomfort and recognition, skirting the grotesque and the uncanny without wholly residing in one or the other.'

Ryan's unique art and photography can be viewed on his website at <http://www.ryanfitzgerald.info/>

CF Research News

The aim of CF Research News is to bridge the gap between people with cystic fibrosis (CF) and the researchers investigating CF, providing access to patients, parents, relatives, friends and caregivers to all scientific work published in the *Journal of Cystic Fibrosis (JCF)*. The following article was published in January 2018.

'Hypertonic saline has a prolonged effect on mucociliary clearance in adults with cystic fibrosis'

Authors: Aaron T Trimble and colleagues; A Whitney Brown; Beth L Laubec; Noah Lechtzind; Kirby L Zemane; Jihong Wue; Agathe Ceppea; David Waltzf; William D Bennette; Scott H Donaldson

What was your research question?

CF causes mucus to become more difficult to clear from the lung. Hypertonic saline (HS) inhalation helps rehydrate airway mucus and speed up its clearance. We wanted to know if the effect of HS on mucus clearance lasted for at least 4 hours in adults with CF.

Why is this important?

Studies showing the health improvements (e.g. improved lung function) of HS treatment in CF patients have typically been performed on teens and adults. In another study, no clinical benefits were found after HS treatment in CF children who were younger than 6 years. These observations led us to question whether the duration of HS's effect on mucus clearance determines whether or not it improves health outcomes in the patient being treated. We hypothesised that mucus clearance would generally be accelerated for at least four hours in adults with CF compared to healthy volunteers where HS only has a transient effect.

What did you do?

We measured the rate of mucus clearance in 13 adults with CF at baseline (without any HS), 15 minutes after a dose of HS, and 4 hours after a dose of HS.

What did you find?

We found that, overall, HS inhalation increased mucus clearance for at least four hours. Even though individual responses varied, the rate of mucus clearance measured in an individual 4 hours after HS inhalation was about the same as the rate measured 15 minutes after a dose of HS.

What does this mean and reasons for caution?

These results suggest that HS is a longer-acting drug in CF adults than was previously realised.

The results also demonstrate that while not all patients respond to HS, the immediate effect strongly predicts the sustained effect. While these results suggest that a personalised approach to HS use in CF might be possible, we do not yet have proof that the mucus clearance response to HS predicts clinical improvements.

What's next?

Future studies should be aimed at finding ways to determine if a given individual is likely to benefit from HS. It should also be determined whether children with CF, who seem to benefit less from HS, have a shorter duration response to HS.

Original manuscript citation in PubMed:

www.ncbi.nlm.nih.gov/pubmed/29371133

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How Carrier Screening Set One Family On The Path To A Beautiful Healthy Baby Boy

By Sandy Nixon



My husband and I got married in December 2015, and were incredibly excited to start a family right away. Being the organised person that I am, I made an appointment to see my GP in February 2016 to ensure I was taking the right vitamins and ensure all was ok to start trying for a baby. My GP mentioned cystic fibrosis (CF) screening which was a simple blood or saliva test. I wasn't overly familiar with CF screening and wondered why we should have the test as neither my husband or I had any family history of CF. She told me that CF was the most common genetic disorder (1 in 25 people are carriers), however to have a baby affected by CF, both partners need to be carriers. I wanted to do everything possible to ensure a healthy baby so I was more than happy to have the blood test which I had a few days later.

After taking the test I completely forgot about it, and we even tried to fall pregnant naturally in February. However, at the start of March I received a phone call from my GP to inform me that I was a carrier for the most common CF gene change Delta F508, though again, my husband had to be a carrier also, which we assured ourselves he would be negative. My husband then went ahead and had the blood test the following day.

A week later, my husband calls me as I'm on my way to a family weekend away and informed me that he too is a carrier of a rare and severe CF gene. This means we have a 25 per cent chance of having a child with CF with each pregnancy. I was in absolute shock, this couldn't be right. I had so many questions.

For days I was quite upset as I needed to know so much more than I knew, and I realised having a healthy baby was going to be a more difficult path than we first thought. As I crumbled for those few days, my incredible husband took the reins completely. Within a few hours he had a referral from my GP to a genetic counsellor with an appointment the following day, and a referral to an IVF specialist to discuss options with an appointment later that week.

With us both working in the medical field, we knew the seriousness of being diagnosed with CF. We spoke with the genetic counsellor who confirmed all the information we had already gathered. The two options for pregnancy were to fall pregnant naturally and have the foetus tested at 12-16 weeks and then make decisions from there, or to go down the IVF path.

Thankfully, we were both on the same page as one another and agreed that if tests came back positive for CF we would not under any circumstances be able to terminate the pregnancy and would love and care for our beautiful baby no matter what (but we say this with no judgement at all to those who do chose the alternative). For this reason we chose to go down the second path. We met with an IVF specialist and she informed us of the process of IVF using Preimplantation Genetic Diagnosis (PGD) testing. Basically, this means testing the fertilised embryos for CF along with a range of other conditions with 95 per cent accuracy, and therefore implanting an unaffected healthy embryo.

Despite improvements in CF treatment, the life of a child and adult with severe CF can be life limiting and heartbreaking to say the least (but please don't get me wrong, we understand there are thousands of people living with CF who live long and healthy lives and there is a wide range of severities). In the end, we decided to avoid falling pregnant naturally, to eliminate having to make those life changing decisions. At the time, especially being a woman, I felt this was a loss (I know this may sound strange, as it wasn't like I was infertile so why was I upset, but that's just how I felt).

Then came the process of IVF using PGD. It involved a lot of steps, so I will try to simplify the journey.

First, our parents were tested (both our fathers were the carriers; this was new information to both of them; again, no family history), then we had multiple genetic counselling consultations (as per guidelines of the IVF centre to ensure we were making a completely informed decision), multiple education sessions,

countless blood tests, ultrasounds, self-administered injections (38 injections in 10 days to be exact), an egg collection procedure and embryo implantation. All my husband had to do is 'you know what' and hand it over the front counter in a brown paper bag (just kidding, he was my absolute rock throughout). We had 12 eggs collected of which three survived to be tested for CF. After the testing was complete, we had one beautiful, healthy embryo which was only a carrier for CF.

Once it came time (finally), we had the embryo implanted, and as I didn't seem to have any fertility issues, there was a 90 per cent chance of it fertilising. We had a scan at eight, 10 and 12 weeks and it was the most beautiful little 'peanut' I had ever seen. To us, he/she was absolute perfection. The process since seeing my GP for the first time to falling pregnant was 12 months.

After the long year, seeing that first scan was one of the most surreal, amazing and scariest moments of our lives. I was so worried that something would go wrong, I kept having nightmares of losing this angel during the early stages of pregnancy after the ordeal of becoming pregnant. But thankfully that never happened. I was incredibly well throughout and we were ecstatic to become parents, something we both had always dreamt of. It may sound strange, but I've always felt like I was meant to be a mother.

On 12 October 2017, our beautiful baby boy was born. And my goodness he is perfection. All of those appointments, tests, procedures and tears were more than worth it. I would do it a million times over. The 'unnatural' way he was conceived was completely forgotten the moment he entered this world.

We wanted to share our story because we want to raise awareness. Everyone who we talk to cannot believe my GP recommended the testing. No one has heard of a GP recommending this and no one was aware that such testing is available (also, not everyone goes to their GP before falling pregnant to ensure all is well).

My husband and I also truly understand that even if couples do get tested, that doesn't mean their options may be as open as ours were; we are extremely fortunate to have the means possible to go down the IVF route, but we fully understand this is not possible for everyone.

We are sharing our story to raise awareness that this is the most common genetic disorder (again, 1 in every 25 people are carriers) and that there is testing available to those who would like to be fully informed before falling pregnant. Since going through this journey, we have had family members and friends appreciate the information and have been tested themselves before starting or adding to their beautiful families. We felt a moral obligation to tell our story to do 'our part' to ensure everyone is at least aware they have the option of pre-pregnancy testing. I wouldn't forgive myself if a friend or family member said "I wish someone had told me".

It alarms me me to think how different the rest of our lives could have been had my GP not recommended the testing. I pinch myself every time I look at my healthy baby boy, we are truly lucky.



Aeroneb Go Nebuliser Update

The Aeroneb Go nebuliser is no longer being manufactured.

If you currently use an Aeroneb Go please have a chat with your CF physiotherapist about an alternative nebuliser that would work for you.

We recommend that, if possible, you chat with your physio before the need arises to replace your handset or medication cup so you have time to consider other nebuliser options.



Government Pledges \$20 Million To Mackenzie's Mission

In the federal budget announced on 8 May 2018, \$20 million was allocated to Mackenzie's Mission – a largescale pre-conception carrier screening pilot study for serious genetic conditions. Over 10 years Mackenzie's Mission will screen 10,000 couples across Australia for cystic fibrosis, spinal muscular atrophy (SMA) and fragile X syndrome.

The program is the legacy of Mackenzie Casella who was born with SMA. She died last year, aged just seven months. Her parents, Rachel and Jonny, were unaware a simple genetic test could have revealed they were both carriers of SMA before becoming pregnant. While grieving the loss of their child, they started a campaign to raise awareness about genetic disorders and lobbied the Government to fund genetic carrier testing.

This pilot study is seen as the first step to offering pre-pregnancy genetic screening for all prospective couples.

Under the program, if couples are found to be at risk of having a child with a serious genetic condition, they will be offered financial support for IVF treatment.

At present, a pre-conception carrier screening test is available, but costs \$385 and is not covered by Medicare. Screening under the trial is offered to couples at no cost.

The pilot study is expected to start in early 2019.



Join The Campaign For ORKAMBI

In early July, the life-changing drug ORKAMBI will be before the Pharmaceutical Benefits Advisory Committee (PBAC) for funding consideration. This is the fourth time the PBAC will consider ORKAMBI. On three previous occasions it was rejected.

This could be the last time makers of ORKAMBI, Vertex Pharmaceuticals, submit the drug for approval.

This is why, now more than ever, we are calling on the cystic fibrosis (CF) community to stand as one and campaign for ORKAMBI.

Australians with cystic fibrosis who have two copies of the F508del gene change could benefit from ORKAMBI.

Every Cystic Fibrosis Community Care member in Victoria and New South Wales should have received an Advocacy Kit containing:

- ORKAMBI fact sheets
- letter writing tips
- information about lodging comments to the PBAC online portal
- pre-paid envelopes addressed to Minister for Health, Greg Hunt MP and Vertex's Senior Vice President and General Manager International Commercial Operations, Simon Bedson.

Submissions to the PBAC online portal closed in early June, however there is still time to show your support.

We are calling on every person with CF, parents and grandparents of children with cystic fibrosis, and relatives and friends to write to Minister Hunt and Vertex telling them how important ORKAMBI is to us.

Our Government needs to know we are dissatisfied with their efforts so far, and Vertex needs to understand that their pricing is outrageous and needs to come down.

At present, a year supply of ORKAMBI costs an individual more than \$250,000.

We urge you to tell your family, tell your friends, and send your letters voicing your support. We are a small community and only if we all rally together will our voice be strong enough to be heard.

If you need more Advocacy information contact us immediately on (03) 9686 1811 or admin@cfcc.org.au

www.cfcc.org.au

THE TIME IS NOW... LET'S GET THIS DONE!

#WeNeedOrkambi

An advertisement for Evergreen River Cruising. It features a scenic view of a river with a large cruise ship. The text reads: "Exceptional Value NEW EUROPE 2019 RIVER CRUISING". A circular badge on the right says "8 Day Rhine River Cruise from \$3,000pp* SAVE up to \$2,300 per couple* LIMITED AVAILABILITY".

evergreentours.com.au

Call 1300 383 747 or contact your Evergreen Expert Travel Agency

QUOTE "EVMA176" WHEN BOOKING



*Conditions apply. All prices based on per person twin share. Valid on new bookings only. For FULL conditions refer to Evergreen's brochures & website. Not valid with any other offer. All prices based on land and cruise components only. Prices based on: EWAB 12/10/2019 departure in Category E Stateroom includes Earlybird and Early Payment Discount with FULL payment made 12 months prior to departure date. \$1,000pp non-refundable deposit due within 48 hours of booking. Valid for bookings with deposits until 30/6/2018 and subject to availability at time of booking or until sold out. Surcharges may apply on credit card transactions. Prices, Dates, Taxes & availability correct at 21/5/2018 & subject to change. Evergreen Tours (a division of Scenic Tours Pty Ltd) ABN 85 002 715 602. Booking code: EVMA176.

Programs and Support Services – Victoria

Take A Break With Andrew's Legacy

If you're a Cystic Fibrosis Community Care (CFCC) member with cystic fibrosis (CF), aged 21 years and older, our Take-A-Break Program could be just the tonic, with up to \$500 available towards the cost of a holiday.

Funded through Andrew's Legacy, the Take-A-Break Program was the wish of Andrew Carr who sadly passed away in 2008. It was Andrew's wish that his family and friends donate money in lieu of flowers to fund the program as he wanted other adults living with cystic fibrosis to enjoy quality time away from the 'hum-drum' of life-something he and his wife Melissa found so valuable.

Since the program began, Andrew's family and CFCC are grateful to all who have contributed and continue to contribute to Andrew's Legacy.

More information
www.cfcc.org.au

Counselling Support

If you or a family member is currently seeing a psychologist, or considering going to see one, our Counselling Assistance Program may be able to help with some the cost.

Subsidies are available to CFCC members with cystic fibrosis and their immediate family, for counselling to help manage their condition.

More Information
www.cfcc.org.au

Have you renewed your CFCC membership for 2018?

To access all CFCC programs and services in Victoria, members must:

- Renew their membership by 28 February each year
- Hold current and ongoing membership

Membership must be renewed each year. This applies equally to people who are eligible for free membership such as adults with CF.

If you have not renewed your membership by 30 June 2018 access to support programs and services will be restricted. This means you may not be eligible for programs and services such as financial support and subsidies, free loan equipment, support dinners, events, and school and child care educational support.

If you are unsure about your membership status please check the expiry date on your membership card or give us a call on (03) 9686 1811.

To renew your membership call us on (03) 9686 1811 or renew online at www.cfcc.org.au



CF Community Conference

The 2018 CF Community Conference will be held in Melbourne on Saturday, 22 September 2018.

The one-day conference is an opportunity for people from the cystic fibrosis community to learn about current treatments and the latest developments from medical and health experts. It is also a great chance to meet other people from the community and share information and experiences.

Victorian Support Dinners

Each year CFCC hosts support dinners across Victoria for people with a family member with cystic fibrosis. The dinners are a chance to meet other members of the CF community, and catch up with old friends to share stories, experiences and resources. So far this year, we've hosted six support dinners in Melbourne and at regional centres across the State. To round out 2018, two more dinners are planned—the first in Geelong on Wednesday, 5 September and the second in Melbourne (south-east metro) on Wednesday, 14 November.

Registration to the dinners will be available closer to the dates.

In Hospital Support

Supporting our community is the cornerstone of everything we do at CFCC and, by lending our voice on patient advisory groups and helping to fund equipment, we are able to provide support when our members are staying at The Alfred, Monash Children's Hospital, Monash Medical Centre, and Royal Children's Hospital.

Recent CFCC funding has gone towards HEPA air filtration units for the outpatient clinic at the Monash Medical Centre and iPads and laptops to help children continue their education during stays at the Monash Children's Hospital and the Royal Children's Hospital.



CFCC was delighted to partner with the Monash CF Foundation to provide four HEPA air filtration units for the CF outpatient clinic at the Monash Medical Centre. Delivering the units is CFCC CEO Karin Knoester, with Director of Monash Health Foundation Matthew Hannan, and Monash CF Foundation's CEO, Felicity Stretch.

CFCC donated iPads to Monash Children's Hospital and laptops to the Royal Children's Hospital making it easier for children to continue their schooling while in hospital. All devices are loaded with great educational apps and software and can be loaned through your child's hospital teacher.

For more information about any of our programs and services in Victoria:

P (03) 9686 1811
E support@cfcc.org.au



Enjoy Some Timeout With Maya's Gift

Generously funded by FinancePath, Maya's Gift supports families to enjoy a day out together and a

break from the day-to-day routine and stress that comes from living with cystic fibrosis (CF).

Maya's Gift offers up to \$500 that can be used for a range of take-a-break type activities such as entry to an adventure park, the zoo, or the museum; tickets to the movies, a sporting event, or a show; accommodation; or even a dinner at a favourite restaurant.

If you are a current CFCC member, you may be eligible for Maya's Gift.

More information

P (03) 9686 1811

E support@cfcc.org.au

W www.cysticfibrosis.org.au/get-involved/support-and-services/support-and-services-information/vic

Supporting Adults With CF

You may know about cystic fibrosis (CF) education sessions for primary and high schools of children with CF. Did you know Cystic Fibrosis Community Care (CFCC) NSW offers the same service to adults?

If you are an adult with CF living in New South Wales, we can educate the people and organisations in your life, with a free CF education session. Educating people about the condition can help to create a supportive network with the following benefits reported from previous sessions:

- Improved understanding, support and communication between family members and support people;
- Increased awareness of CF in the community;
- Better understanding, communication and support for the person living with CF by the organisation, workplace or teaching staff;
- Encourages a local network of support and understanding for the person living with CF; and
- Relieves anxieties about attending a learning environment, organisation, workplace or centre.

CFCC NSW can provide resources and a tailored presentation to staff at the facility or organisation you attend, including:

- DET, TAFE, college, or university staff;
- Office manager, workplace colleagues;
- Day centre program staff and management;
- Sporting management, coach or fitness instructor;
- Management and staff at volunteer organisations or programs;
- Support organisations; or
- Psychologist or counsellor.

Likewise, if you have family members, friends, support people or a new partner interested in learning about CF, we are happy to provide resources and deliver an education session.

The session is run by our Regional Support Services worker via video conference or Skype and, because each CF journey is different, is tailored to be specific to your needs.

To learn more about our CF education resources, please contact the PASS team on: regionalsupport@cfcc.org.au or call 0420 819 698.

Changes To The Child Care Subsidy

From 2 July 2018 a new Child Care Subsidy will replace current child care fee assistance payments. The new subsidy will be paid directly to your approved child care provider.

If you receive a child care payment you must complete a Child Care Subsidy assessment to check eligibility for the new subsidy.

If you receive the Child Care Benefit and/or Child Care Rebate for approved care you should have already received a letter from Centrelink explaining what you need to do to prepare to switch to the new Child Care Subsidy.

To be eligible for the subsidy you must care for a child who:

- is aged 13 years or under and not attending secondary school (unless an exemption applies)
- meets immunisation requirements
- meets residency requirements
- attends an approved child care service.

The amount of subsidy you receive is determined by:

- your family income
- the type of child care you use
- the number of hours you spend doing approved activities (eg. working, study or training, volunteering, paid or unpaid leave, etc.)

If you have not yet received a letter please contact your nearest Centrelink office.

To learn more visit

W <https://www.humanservices.gov.au/individuals/services/centrelink/child-care-subsidy>



Helping Our Community Breathe Better

Generous grants and donations are helping the New South Wales CF community breathe a little easier, by providing nebulisers and fitness grants to eligible Cystic Fibrosis Community Care (CFCC) members.

CFCC members living in the Sydney metropolitan area can access nebulisers thanks to donations from the recent Barefoot Ball. Donations received at the

ball far surpassed our expectations and thanks to the generosity of our community we now have a stockpile of nebulisers available for those who need them. Thanks to the wonderful generosity of our community we now have a stockpile of nebulisers available.

To our members in the Murrumbidgee, southern and western regions there is still time to participate in the Perpetual Limited Nebuliser Equipment Program. Under the program, when you apply for a new nebuliser our Programs and Support Services (PASS) team will ask about specific health indicators and, after six months, will follow up to determine how the equipment has helped you. To have your current nebuliser replaced with a Philips Innospire Deluxe please have your hospital physiotherapy clinic contact our PASS team.

Generous funding from the Newcastle Permanent Charitable Foundation means CFCC members living in the Central Coast, Hunter Mid North Coast, New England, Northern Rivers, Central West, Newcastle and Port Macquarie areas can access nebulisers, nebuliser parts and fitness grants under the Breathe Better Fitness Participation Program.

To learn more and to check your eligibility to access a nebuliser or a fitness grant as explained above please contact our New South Wales PASS team on nswsupport1@cfcc.org.au or (02) 8732 5700.



A Community That Cares... THANK YOU!

The first half of 2018 has seen some fantastic fundraisers happening across New South Wales and Victoria.

As we celebrate some of the major fundraising achievements, we thank everyone who has participated in events and who continue to support the cystic fibrosis community.

Kootingal Moonbi Rugby League Football Club Charity Day

A special charity day run by the Kootingal Moonbi Rugby League Club on Saturday, 19 May has raised over \$14,000 for people living with CF.

The club rallied behind members, Joanne and Lad Jones, whose seven month old son Jesse was recently diagnosed with CF.

The day kicked off at noon with rugby league played throughout the afternoon, plus cake and craft stalls and family activities happening at the ground. The day culminated with an auction of player jerseys at the Kootingal Hotel, with the top-selling jersey going for an amazing \$700.

Thank you Kootingal Moonbi Rugby League and your supporters for this wonderful effort!

Barefoot Ball

Newport Beach in Sydney was the place to be on Saturday, 24 March when 300 glamorous guests hit the beach for the 2018 Barefoot Ball. This iconic event raised an incredible \$74,000, shared equally between Cystic Fibrosis Community Care (CFCC) and the Newport Surf Lifesaving Club.

The beach was a sea of gowns, dinner jackets and boardies when, on arrival, guests swapped their shoes for an Aperol Spritz and mingled on the sand before taking their seats in the fairy-lit marquee. What followed was an evening of fine dining, fabulous entertainment, amazing fundraising... and a whole lot of fun!

Guest speaker for the evening was Showcase Dance founder, Peter Oxford, who shared his story of living with cystic fibrosis. His is a story of sadness, hope and joy, and one that left not a dry eye in the house.

A live auction got the crowd on their feet, with guests scrambling to out-bid each other, and the silent auction that had been running in the lead up to the Ball closed, with guests taking home some fabulous items.

The major prize draw for the evening saw one lucky Ball guest taking home the incredible 15-day Splendours of Europe River Cruise for two people, generously donated by Evergreen Tours and Cruises.

Rounding out the evening was an appeal for \$500 donations to purchase nebulisers. The response was overwhelming, with hands shooting up around marquee to donate. The generosity of guests allowed CFCC to purchase 38 nebulisers for members living in and around Sydney.

Our heartfelt thanks to everyone who attended and to those who donated time, prizes, and services to this special annual event.



Results in for 65K 4 65 Roses Walkathon

CFCC is delighted to announce the final fundraising tally for the 2018 65K 4 65 Roses Walkathon is \$392,000. This event is another example of the incredible support we receive from the CF community who were prepared to brave a very early start and put their bodies on the line for CF.

Proceeds from the walk are shared between CFCC and The Children's Hospital at Westmead.

Thank you to everyone who supported yet another fantastic and successful 65k 4 65 Roses Walkathon. We look forward to welcoming you all back again next year!



Cycle 4 CF

It was all smiles when members of the Cycle4CF team dropped by our Southbank office to present CEO, Karin Knoester, a cheque for \$34,680.

The money was raised from their 1,000km Adelaide to Melbourne cycle, and will go towards funding much-needed programs and support services for Victorians living with CF.

This is the second time this committed group has put in the miles for the CF community, raising a combined total of over \$65,000!

From all of us at CFCC and on behalf of the whole CF community, thank you Cycle4CF for your amazing support.



Ski 4 CF

This incredible team were not just the first to water ski the full navigable length of the Murray River, they also raised over \$83,100 for the cystic fibrosis community in the process!

Setting off from Jingellic in the upper reaches of the Murray in late February, skiers Ben Berry and Scott Collins, and their support crew, took a little over two weeks to complete the 2,438km journey, and write themselves into the record books.

A huge thank you to the Ski4CF team for sharing your journey with us and for your immeasurable support of the cystic fibrosis community.



Peaks 4 CF

Founded in 2016, Peaks 4 CF got its inspiration from Maya Dalton who, shortly after her birth in 2014, was diagnosed with cystic fibrosis. On 12 March 2017 seven heroes, 'The Original Seven', tackled the Peaks Challenge in Falls Creek, one of the toughest single day bike rides in the world-a gruelling 235km ascending over 4,000m.

Now in its second year Peaks 4 CF have done it again and raised an impressive \$20,800 for CFCC! This year, the team reached out to cycling networks and recruited 20 riders who signed on to climb 4,065m by bike, with a month to complete the challenge. We can hardly wait to see what the Peaks 4 CF team get up to next year... but for now, great work guys and a huge thank you from the CFCC team!

Celebrating 65 Roses Month

Throughout May the cystic fibrosis community around Australia celebrated 65 Roses Month, the annual month-long campaign of fundraising and awareness activities.

Heathdale Christian College

Stepping it up this year were the incredible students at Heathdale Christian College doing their own mini Great Strides!

Everyday I'm Shufflin'

Dance superstar Nina Armstrong has been shuffling her way through 65 Roses Month to raise funds for CF! What a cool way to fundraise! Go Nina!

\$161... and rising

Stepping Out In Style

Nanny Barb has been hard at work during 65 Roses month, holding not one but two fundraisers... a delightful Postie Fashion show and a function at Preserve Kitchen. Barb hosts community fundraisers throughout the year... get in touch to find out how you can get involved.

\$1300

Making Connections

Sheryl Mcleary and Locky discovered they both worked at NAB, so they teamed up and held a stall in the foyer of their office building selling roses, caps, and more! Great teamwork guys!

\$500

Din Dins

Sticking to the culinary theme, Rosa Petsinis held a scrumptious dinner at the Epping Hotel where food, wine and funds were flowing to help support CFCC. Rosa is a regular fundraiser throughout the year so a big thank you from us!

And to You We Give This Rose

Pakenham Secondary College has done it again selling over 650 roses to students who eagerly bought them to give to friends, family and hopefully a few teachers too. Thanks guys, you did an amazing job!

\$1364

Sizzle Sizzle

Serving it up, Mick Harris fed the hungry hoards at a tasty sausage sizzle through the Geelong South Barwon Lions Club to raise funds for 65 Roses Month. I'll have sauce with mine, thanks Mick!

Keeping Fit

Go Shae go! Doing a different exercise each day during May, Shae worked 65 Roses into her challenge by doing 65 reps of each exercise while friends and family cheered her on, and supported her by donating.

\$1055

Ask And You Shall Receive

One amazing family asked friends and family to reach out and support our cause! It's astonishing what you can achieve if you just ask! Thanks Melissa for your kind words and your support!

\$337

Walkin' On Sunshine

A big shout out to Christine and Tony who walked 6.5km every day for the month of May. What a great way to get fit, and fundraise at the same time! Great work guys!

\$1505

Here's To Ladies Who Lunch!

A huge thank you to the incredible Jan, Jen and Belinda who once again pulled together an outstanding event at the Charity and Fun Ladies Luncheon! The day was a huge success and everyone had an amazing day!

\$16,570

Rise N Grind Serves Cuppa For A Cause

Shout out to the cafes who led the fundraising charge by serving up coffees for a donation to CFCC on 65 Roses Day. Thank you... Sketch Coffee meets Art | Arthur Street Cafe | Michel's Patisserie | Quotes Cafe | Cafe one9 | Mr Phillips... cheers to you all!



Congratulations!

A big congrats to Barry and family on the birth of Rani, what an exciting addition to the family. Thank you for thinking of us during this special time!

\$839

Woollies A Winner For CF

A huge thank you to Roslyn Vaughan and the Sou' Westers who have been selling their amazing winter woollies for CF. All hand made by volunteers with three stalls still to go! This warms our hearts ladies!

\$5006 and rising

May The 'Merch' Be With You!

Huge thanks to members of our community who sold CFCC merchandise throughout 65 Roses Month! Not only did our members sell boxes of our merch... they mixed it up with raffles, cake and Mother's Day stalls and rose selling!

Gym Junkies Unite

Getting physical was the amazing Renae Prendergast who partnered with Fitness Local Mortlake to put some exercise lovers through their paces at a group fitness class, with the cost of entry donated to CFCC. And if this wasn't enough, daughter Kari followed up with a CF talk, sold merchandise, and served well-deserved refreshments.

\$2002

Stepping Up

Rising to the top was Cherie Monte who climbed an impressive 10,065 steps during 65 Roses Month. Phew!

Mixing It Up

When one exercise just isn't enough... call on Rachel Galloway who skipped, walked and jogged 65km during 65 Roses Month to raise money for CFCC. Cheers Rachel... awesome effort!

\$800

Bloomin' Marvellous

Thumbs up to our bloomin' marvellous rose sellers who between them sold nearly 800 roses for CFCC. Huge thanks to Kerry Rogers for selling over 600 roses, Rebecca Castor 100 roses and Ben Mayhew 50 roses.

\$3,000 and rising

FestiveAle

Shout out to our friends at Wayward Brewing for our favourite tippie, Rose Kolsch, and hosted the official keg tapping event. During 65 Roses Month punters could enjoy a drop with \$2 from every beer sold going to CFCC. Support the venues who support us... His Boy Elroy | MoshPit | Webster's Bar | Basement Brewhouse Bankstown Sports | The Taphouse Old Canberra Inn | Reub Goldberg Brewing Machine | Keg & Brew | Carlisle Castle Hotel | The Duck Inn | Wandering Cooks | Zero Fox | Tap'd Bar at The Prince Alfred Hotel

Lighting It Up For 65 Roses

The month-long series of 65 Roses Month activities culminated with 65 Roses Day on 25 May, public buildings and structures in Sydney and Melbourne were lit red in honour of cystic fibrosis. In Sydney, passers-by were treated to a vision of the Sydney Town Hall bathed in red and in Melbourne the city was painted red with AAMI Stadium, the Bolte Bridge and Melbourne Star Observation Wheel all illuminated red for the occasion.

Spreading The Word For 65 Roses

Sixty-five Roses Month saw CFCC continue its commitment to raising awareness of cystic fibrosis to the broader Australian community. This year Cystic Fibrosis Community Care's Chief Executive, Karin Knoester, wrote to 65 influential and inspiring Australians asking they wear the CF lapel pin enclosed with the letter, and share the CF message to at least ten others. This single act has the potential to educate at least 650 others about CF and the day-to-day struggles the CF community face.



Meet the team



Jacqui Oong—State Manager (NSW)

CFCC is delighted to welcome Jacqui Oong to lead the New South Wales team. Jacqui has extensive senior management experience in the not for profit sector, including several roles as CEO in small to medium-sized organisations.

Most recently, Jacqui led an organisation through the transition to the NDIS, including developing and implementing new service models and systems to accommodate the scheme. Before this she worked with stakeholders, including board members, government departments, staff and services users to achieve the merger of two not for profit organisations in western Sydney, following which she was appointed CEO of the newly formed company.

Jacqui has a passion for providing high quality, sustainable support to those in the community who require extra assistance to live full and meaningful lives. She has worked across a range of areas including disability services, aged care, migrant and refugee services. As a strategic thinker with the capacity to balance mission and fiscal responsibility without losing focus on the people at the centre of the service, Jacqui has strong people management skills and enjoys working with teams to resolve challenges and innovate for new service solutions. Jacqui holds a Bachelor of Arts Degree, majoring in Psychology.



Dan Boyd—Project Coordinator (VIC)

The most recent recruit to the Victoria CFCC team is Dan Boyd who will be assisting with programs and support services, and coordinating the peer support program in Victoria. Originally from a small town in Canada, Dan moved to Australia 3 years ago to find kangaroos (he's still looking)... and complete his Master's degree in Public Health, with a focus on Environmental Health.

Dan previously spent time working in community health, and volunteering with one of Canada's largest fundraisers for CF research. When not at work, you can find Dan on the golf course, at the ice hockey arena, or at the beach.



Volunteer Corner

Volunteers are critical to the success of everything we achieve at CFCC. Over the past few months our wonderful volunteers have continued to help us by so generously giving of their time.

National Volunteer Week in late May was the perfect opportunity to celebrate our volunteering community. In Victoria we hosted a thank you evening to recognise volunteers who have been so giving over the past 12 months.

The 2018 Volunteer Week theme, 'Give a little. Change a lot', so accurately represents our CFCC volunteers who willingly give a little their time and make a profound positive impact on the CF community.

Looking back on the past 12 months, over 300 volunteers have donated their time to help CFCC across all aspects of our community and organisation.

In both Victoria and NSW, office volunteers have been crucial in the day-to-day running of the offices, helping out with filing, mail outs, answering the phone, data entry and anything else that needs to be done.

In March our Melbourne volunteers took to the streets (sometimes in the pouring rain!) to shake a tin for CF, raising money and awareness of our cause.

The volunteers who helped at our annual remembrance service played a role in making this special and emotional event all the more special.

Of course, our biggest events, 65K 4 65 Roses and Great Strides Melbourne and Bendigo saw a huge volunteer turn out, making for very exciting and community-filled days.

Public speaking is a daunting prospect for most people but our volunteer speakers take it in their stride delivering educational talks and sharing their story with community groups across Victoria.

Volunteer tutors who offer their services free of charge help kids with CF keep up with their school peers when hospital visits mean they are missing class.

We have loved having corporate teams come into the office to help us with anything from stocktakes to making origami roses! A special thank you to the 70 National Australia Bank employees who have helped us over the past 12 months.

Other notable volunteers are those who helped at our Bunnings sausage sizzle, our gala ball committee, ones who have wrapped roses, and our incredible ambassadors.

This May, volunteers helped at our first ever Trivia Night and before we know it, it will be time to recruit volunteers for Great Strides!

From CFCC and the NSW and VIC CF communities, thank you to each and every person who has volunteered their time over the past 12 months, no matter how big or small. We would not be the strong community we are without your undying support.

Sister5Roses—members welcome!

If you're a female aged 18 years and over with cystic fibrosis, we invite you to join our closed Facebook group Sister5Roses.

With 80 members already part of the group, Sister5Roses is a safe online community where you can drop in for a chat, make new friends, have a laugh and share you views on things that interest you...CF-related or not.

Joining is easy. Simply type Sister5Roses in your Facebook search bar and send us a request to join.

If you would like to know more about the group please contact us at programs@cfcc.org.au



AGM Wrap Up

The Annual General Meeting (AGM) of Cystic Fibrosis Community Care Limited (CFCC) was held at 80 Dodds Street, Southbank, Melbourne on Sunday, 15 April 2018.

Approximately 20 people attended the meeting, including members in New South Wales who attended via teleconference.

At the meeting the CFCC board adopted the Minutes of the previous AGM held on 2 April 2017, and received the 2017 Annual Report including the Chairman, Chief Executive and audited financial reports for the year ending 31 December 2017.

An election for three vacant Board positions resulted in the re-election of all three sitting members—Mr Jong Chung, Professor Sarah Ranganathan and Mr Bryson Vaughan.

Read the 2017 Annual Report at www.cfcc.org.au

Look out Victoria... Great Strides is COMING

Save the date, kick-start your training program and get set for the biggest family day in CFCC Victoria's calendar.

Great Strides, our premier annual community event, is coming to Bendigo and Melbourne again this year, bigger and better than ever.

You will be able to register soon, so keep an eye on our Facebook page where we will announce when they open. For now... pop these dates in your 'must do list'!

Great Strides Bendigo
Sunday 21 October

Great Strides Melbourne
Sunday 28 October

Fulfil your dreams with Simon's Adventure Fund

We're on the hunt for people who need a bit of help to make their dreams of adventure come true.

Set up by Simon Minson's family to honour their much-loved adventurous son, Simon's Adventure Fund is available to adults with cystic fibrosis who want to tick off an adventure from their bucket list. It can be something that gently pushes the boundaries, or something that's out there!

If you have dreams of an adventure you would like to fulfil we want to hear from you. All you need do is tell us who you are; what your adventure is; why you want to do it; what is holding you back; how much money you need to make your dream come true; and where and when you want the adventure to happen.

If this sounds like you, please get in touch.
Call (03) 9686 1811 or email support@cfcc.org.au

About Simon Minson

Simon had cystic fibrosis. He was an avid traveler and adventurer, who had a wonderful positive attitude and love of life. From snowboarding to skydiving, bungee jumping to swimming with sharks, there was no adventure Simon wasn't up for. In 2014, while holidaying with mates in Vietnam, Simon passed away from CF related complications. Simon's family has set up Simon's Adventure Fund to help people with CF live life to the fullest.



Biggar View

By Susan Biggar

It finally happened this last Saturday night. The kids all went out and my husband, Darryl, and I were left alone at home. We built a fire, opened a bottle of pinot and a bar of dark chocolate, and watched a movie. No interruptions, no disagreements about what to watch, no spills, no worrying about getting people to bed. For us, as Bob Dylan would say, the times they are a-changin'.

As our kids are nearly grown, I am able to reflect further on the pressure that illness has had on our relationship. There's no doubt that all relationships have stress points and all couples have their disagreements, but some of the real doozies for us have been related to CF.

Such as, how should we respond to the four-year-old who stretches dinner into an hour-long dawdle, knowing full well the less he ate the more anxious we became. Just as I would be preparing to descend into 'Zoom, here comes the airplane with your mashed potatoes,' Darryl would hop up, clear the offending child's plate and say 'Fine. Dinner's over.' It irritated me at the time, but I must admit it definitely did the trick. A couple of bouts of midnight hunger and our little boy became a very efficient dinnertime diner.

We also disagreed about risk-taking in relation to possible bacteria. Once when I was in Sydney for a long weekend, Darryl took the three boys to our regular beach. They all ended up playing some nutty game in the brackish water near the entrance to the beach—an area I had always defined as off-limits due to its tendency to become stagnant. I was steaming that night when he told me what they had been up to that day, and absolutely ropeable two weeks later when one of the kids grew Pseudomonas.

You may know from personal experience that the stress and anxiety of illness can break a relationship, whether you are parents or partners impacted by illness. There is pretty good evidence that illness anywhere in the family increases overall stress and, therefore, can add enormous strain



to all family relationships—as the social worker unhelpfully warned me just weeks after our oldest son's diagnosis.

But there is also research showing no significant difference in long-term marital (or other cohabiting) relationship satisfaction between those with illness in the family and those without it. At least one study, specific to CF, found that though there was greater strain, there was no notable difference in relationship satisfaction to those without CF in the family. Importantly, there is evidence that the type of mechanisms couples develop for coping, and most everyone has them, can greatly improve their ability to manage illness in the family and limit its potential impact on key relationships.

For Darryl and me, having an agreed game plan—'how we will get through this'—has helped us stick to our guns on the things that we think are most important. When things have gone south in the relationship, despite the plan, we have called in expert advice (counseling) for help working it through. For us, it seems obvious, but it often comes down to the willingness to compromise and communicate, particularly when we really don't want to do either!

I still don't know if the social worker was right to warn me about the stress and strain so many years ago, so early on, in such a long road. But I do know that celebrating our relationships and the big and little successes in them, with or without wine and chocolate, is something none of us can ever do too much.

Ask Kirsty

By Kirsty Bowness

Sibling rivalry. For most of us who have siblings, we know all about this. It is considered a very normal and expected part of the family experience. However, when one of those siblings has a chronic illness, this can add another dimension to the experience and create more distress for both the siblings and their parents.

Sibling rivalry has many contributing factors. It is largely a result of each child trying to find their place in the family and getting their needs for attention met. A common cause for sibling rivalry is jealousy or a perceived imbalance of care and attention given to one sibling over another. This can of course be at a higher incidence in families with a child managing cystic fibrosis.

To start addressing the issue of sibling rivalry in these particular circumstances, it might be helpful to have an understanding of what the experience might be like for the sibling who doesn't have CF. The research shows that there is potential for both positive and negative outcomes. These siblings may have an increased risk of developing emotional difficulties such as anxiety or depressive symptoms.

Possible contributing factors towards this are an increase or change in their role/responsibilities within the family and the management of complex emotions that can arise for them. They can be navigating a range of conflicting feelings including resentment, fear, and guilt. While this experience can be more difficult for the younger siblings who may have a lesser capacity to understand the circumstances, it can be equally challenging for the older sibling who may experience a greater shift in their responsibilities within the family unit.

Alternatively, there is also evidence to show that as a result of their experience as the sibling of a chronically ill child they can have an increased capacity for empathy, tolerance, compassion, sense of responsibility, and resilience.

So in the event of sibling rivalry in the context of chronic illness, what might help?

Understanding what emotions may be underlying the rivalry can be helpful. It's important for both children to be given the space and opportunity to express their emotions and know that how they feel has been heard and understood. Help them to identify, describe, and label how they feel. Encourage expressions of 'I feel angry' or 'I feel sad' and let them know it is ok to feel this way. This open communication should go in both directions where information is both received and shared.



As the 'well' child may feel excluded at times, informing them (at an age-appropriate level) of events that may be affecting their sibling is as important as listening to them. Cystic Fibrosis Australia also has an informative booklet for siblings of children with CF available on their website that might be helpful.

While it can be challenging, prioritising one-to-one time with each child is key. Parental attention is valuable currency in childhood and children will seek it in all forms, positive and negative. Even just 10 minutes of quality and focused time with a child can be rewarding and may ease that sense of imbalance in care that can drive the rivalry.

I was surprised to learn that research has found sibling conflict is often resolved on average within 30 minutes, with or without parental involvement. If parent intervention occurs it is best done by supporting them to problem-solve rather than doing it for them.

To support this relationship, it can help to remind the siblings of a few things: It's normal and ok to feel frustrated with your sibling; there are occasions where you get along, and there are some positives to having a sibling; and it is ok to ask for help in resolving your conflict.

While it has its challenges, the sibling relationship is an important one as it is often the longest lasting relationship in the family. It is considered the child's first 'social network' and provides a great platform to learn negotiation and conflict-resolution skills, as well as provide a model for future relationships.

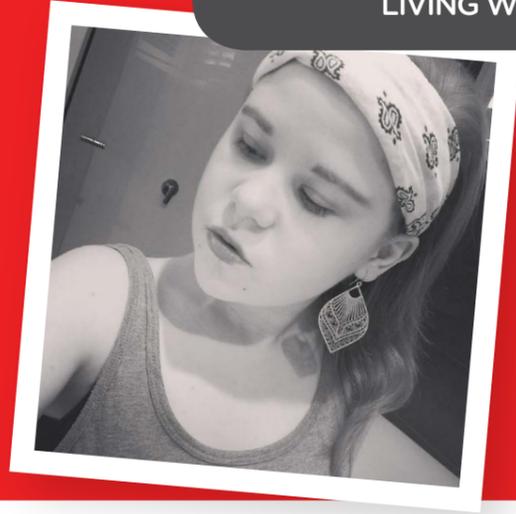
So give them the space to practice these skills, provide good problem-solving modelling, encourage them to share their emotions and perspective with you, and give them a few minutes each day of your undivided attention to let them know they are valued.

As a very apt quote states: "Siblings are the people we practice on, the people who teach us about cooperation and kindness and caring—quite often the hard way." Pamela Dugdale

Kirsty is a practicing psychologist and mother of two children, both with CF. If you have a question to ask Kirsty please send it to communications@cfcc.org.au

The Do's and Don'ts of the daily Physio Routine

By Lauren Littler



Young adult Lauren Littler shares her take on the Do's and Don'ts of a Cfer's physiotherapy routine

Listen to your body. You know your CF best. I want to provide realistic expectations of what managing this condition looks like. In my experience, no two days with living with this condition are the same and no two people living with cystic fibrosis live the same lives. In short everyone's management of cystic fibrosis is different.

I will begin to say, I do feel like a massive hypocrite when giving advice about cystic fibrosis management, as I have not always been the most compliant patient!

Throughout the years, especially in my adolescent years, I was stubborn. I've always been stubborn when doing my physiotherapy which, in hindsight, I believe led to unnecessary hospitalisations. I reached a point where I said to myself, "Lauren, you need to do this to get healthy. Sometimes you have to do things you don't want to do." I cannot stress enough what a good physiotherapy routine can do to prevent further lung exacerbations and prevent possible lung scarring.

As you well know, it is drummed into our heads from the time of our diagnosis what physiotherapy is and what it includes. I cannot fathom the enormous amount of physio information I've been given over the years, and having to process it all. If you have taken up the initiative to implement all that information into your own physiotherapy routine I applaud you, because I have not.

For me, personally, there is a lot to manage when it comes to cystic fibrosis. These are some key factors that have helped me when implementing my routine:

Physical state: For me it's important to assess how I feel before commencing any physiotherapy. This helps to ensure that I can work out a routine based on how I feel physically and emotionally. An example of this includes, focusing on my mucus production to ensure that I include more time and rest periods for my physiotherapy session.

Time management: Physiotherapy is demanding and time consuming, so I work to ensure I'm managing my treatments effectively throughout the day. In my experience a rushed physiotherapy session affects the technique.

Hygiene: Preventing infection is crucial to prevent further cystic fibrosis complications. I always wash my hands before commencing a physiotherapy session and after every session I wash my equipment in hot soapy water. Also, if I'm using exercise as a form of physiotherapy, I carry anti-bacterial wipes with me and hand sanitizer, as exercise equipment can carry lots of bacteria.

Communication: To ensure I'm not wasting time doing my physiotherapy incorrectly and putting my long-term health at risk, I have regular consultations with my cystic fibrosis physiotherapist. There is a lot to remember during physiotherapy and over the years, I have found due to the nature of this condition my routine has changed, and technique and positioning has become sloppy and outdated.

Mental state: I believe having a positive attitude helps me deal with the roller-coaster ride that is cystic fibrosis, although this can be hard to find especially during periods of illness. This may affect the way we look at treatment and it could jeopardize health. I make sure to seek support and guidance with whoever I feel comfortable with. If I'm having an issue with physiotherapy or lack the motivation, I speak with my CF Clinic Team as they may have the best solutions to my needs.

Exercise: I cannot stress enough the importance of incorporating exercise into your daily routine. I have found exercise the best solution to help loosen my secretions. I try and not be discouraged if I don't succeed in exercising the first time around. I start slowly and build myself up. I do however understand that not everyone with CF has the capability to exercise. To make sure exercise is effective for you please speak to your CF Clinic Team.

Although not a set guide, these are my tips. If you are having a difficult time setting up a routine, remember there is always support out there if you need it and speaking to people who understand you and this condition is key to effective treatments.



**CYSTIC
FIBROSIS**
Community
Care

What's on 2018

2018

members

community

UPCOMING EVENTS

- > July 6: **Crazy Hair Day**
- > July 28: **A Night for CF Gala Ball (VIC)**
- > Sep 5: **Geelong Support Dinner (VIC)**
- > Sep 22: **CF Community Conference, Melbourne**
- > Sep 16: **CF Remembrance Service, Melbourne (VIC)**
- > Oct 21: **Great Strides Bendigo (VIC)**
- > Oct 28: **Great Strides Melbourne (VIC)**
- > Nov 14: **South East Metro Melbourne Support Dinner (VIC)**

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



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