EDITION 3 • NOVEMBER 2022

CYSTIC FIBROSIS
South Australia

ROSE REPORT

MEMORIAL SERVICE • IT'S A TWIN THING • CRAZY HAIR DAY

WHAT IS CYSTIC FIBROSIS

Cystic Fibrosis (CF) is the most common serious genetic condition affecting children. More than half a million Australians carry the CF gene. One in every 2,500 children will be born with CF.

The CF gene causes normal mucus to change to a thick, sticky substance which clogs the tiny air passages in the lungs and traps bacteria. Repeated infections and blockages cause irreversible lung damage and death.

People who have CF must have regular, intensive daily chest therapy to combat the build-up of mucus in the lungs. Most must also take digestive enzyme replacement tablets with food and drink to aid digestion. This can mean taking up to 40 tablets a day. Having CF means frequent hospitalisation for periods of 2-3 weeks at a time for intravenous drug treatment.

ABOUT CYSTIC FIBROSIS SA

Cystic Fibrosis SA supports CF families, adults and carers through provision of practical services and support programs, education, research and advocacy.

WHAT IS 65 ROSES?

The phrase "65 roses" is simply another way of saying cystic fibrosis. It came into being in 1965, when a young boy with cystic fibrosis overheard his mother talking about the disease on the phone. When she said the words "cystic fibrosis", he thought she said "65 roses". The mother was touched by her son's mistake because, he saw something beautiful in a disease that can be so devastating.

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DEADLINE FOR NEXT ISSUE

If you would like to contribute to our fourth edition for 2022, please contact is before Friday 25 November 2022

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Note: The opinions expressed in the articles appearing in Rose Report are those of the writers and not necessarily the official view of CFSA.

DO WE HAVE YOUR CORRECT DETAILS?

If not, please contact us and let us know so we can keep you informed

FACEBOOK
/cfsamembers

INSTAGRAM
@cysticfibrosissa

LINKEDIN
/company/cysticfibrosissa

MESSAGE FROM THE CEO

By Christine Umapathysivam

Life Returning to Normal

Since the last Rose Report, life at the Cystic Fibrosis SA (CFSA) office has been very busy as we prepare to start holding events again; most notably the annual Memorial Service. This important event has been delayed a number of times but finally, it was held on 8 October 2022 in the beautiful gardens of Government House. Approximately 65 friends and family joined the service conducted by Carl Aiken. The weather was magnificent and really showed off the gardens at their best.

Later this year, our co-patrons the Governor of South Australia, Her Excellency the Honourable Frances Adamson AC and her husband Mr Rod Bunten, will host a reception in Government House to mark 50 years of CFSA. Although CFSA was founded in 1970, we did not have the opportunity to properly celebrate the occasion in the year of the 50th anniversary, as with many of other activities we planned for 2020, the COVID pandemic forced us to postpone many public events.

There is an anniversary point worth celebrating;

When CFSA was first established in 1970, parents were told that they should expect their children to live for between 8 and 10 years. Improvements to clinical care and our understanding of CF as a disease, along with improved medications mean that children born with CF today can expect a much longer life and be able fulfil similar goals to the general population and these are achievements worth celebrating!

A New Model of Care

CFSA's Partnership Group is a hard-working consultation committee that brings together the clinical staff (doctors, nurses and allied health professionals) from the Royal Adelaide and Women and Children's Hospitals and CFSA. The Committee meets bi-monthly and has been supporting Dr Morton and Reanna Gray in their review a Model of Care document for patients with CF being cared for in the CF Clinics and wards at either the RAH or WCH. After an extensive process of drafting, discussion and redrafting the (almost final) document was ready for consultation with the broader CF Community, including CFSA members. It was shared on our Facebook page and mailing list, with the feedback collated and provided to the document authors and their other members of the Partnership Group.

The information gathered during the consultation was considered and the Model of Care Document changed to reflect some of the suggestion made. The documentation is now ready to present to the CEO of SA Health and the Minister of Health and Wellbeing, Mr Chris Picton MP. I will circulate the final document once it has the Minister's endorsement.

A National Gathering

The national CF federation CEO group met once again in Adelaide to discuss a range of issues and to catch up with the work being done in each of the states. Vertex, the producers of Trikafta provided our group with a presentation about the

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MESSAGE FROM THE CEO CONTINUED

...roll out of Trikafta after its listing on the Pharmaceutical Benefits Scheme earlier this year. They spoke of the progress being made for subsidised access to be granted to children in the 6 -12 years cohort. A number of these decisions will be considered when the Pharmaceutical Benefits Advisory Committee meets in December 2022. This is a meeting we will be watching carefully and will update Members once the outcomes are known.

Fundraising

As a lover of many types of music, I was delighted to attend the annual Adelaide University Medical Orchestra (AUMO) Jazz concert (AUMO Prescribes Jazz). The venue on the Norwood Parade was packed with young people soaking up the Jazz feel of the night over a Schnitzel and a glass of beer. Later in the evening, people took to the dance floor and just generally enjoyed the music. We have been very grateful to have AUMO as a fundraising partner this year.

From Jazz to a Women's Business Network function. The Geelong Women's Network held a workshop and donated the funds raised in their raffle on the night to CFSA. I met a very inspiring group of women and made some valuable connections. We thank them for their support.

Community Fundraising initiatives continue to surprise us. They are also an ongoing source of support and financial consequence. These events not only raise much needed funds but also raise awareness of CF and this helps tremendously with future fundraising and advocacy projects.

65 Roses At Home — Online Auction

In the lead up to the 2022 on-line auction my office was full of nice-smelling goods that had been donated as part of the 2022 65 Roses At Home Online Auction. It looked like Aladdin's Cave full of treasures.

Led by Emmah Money, the online auction had a decidedly glamorous feel to it this year with goods such as a voucher from Tiffany's, a pamper voucher from Bespoke Facial and Body, protein powder, luxury handbags, wine, an adventure holiday package (think sharks) and a basketball autographed by the 36ers. There was literally something for everyone.

It was a perfect opportunity to shop for Christmas presents and support people living with Cystic Fibrosis. The 65 Roses At Home Online Auction went live on 22 October 2022 closed on 5 November 2022.

WELCOME LORRAINE SMITH

Lorraine Smith joined the CFSA community last September after her twins Genevieve and Penelope were diagnosed with CF.

She and her partner Robert were shocked to find out their twins had an incurable medical condition when they were just two weeks old.

If raising twins with CF wasn't enough of a handful, the couple also has another child Madison (3) who doesn't have CF. It is a busy household!

"We are only at the beginning of our journey but the first year was the worst so far as everything was new to us. Every cold, flu or cough worries you that they might end up in hospital."

After learning about CF and all the wonderful support the CF community provides, Lorraine was inspired to fundraise for CFSA.

"I figured the best next thing that I could do would be trying to do some fundraising, to not only help my girls, but to help those around me as well."

Lorraine started 'It's a Twin Thing' as a Christmas fundraiser in August last year. The website sells clothing for twins and parents, with customizing options available for triplets and single kids.

If you are looking for the cutest clothes for Christmas, check out Lorraine's website https://itsatwinthing.com.au/.

It's a Twin Thing

EMMAH JOINS CFSA

With a handful of things for the 65 Roses At Home Auction and wearing a smile, Emmah Money walked into the CFSA office. Although she started volunteering in last August, Emma was already playing a big part in CFSA community with her fundraising activities and multiple media appearances.

Emmah Money, the founder of CFMummy, global advocate for Cystic Fibrosis and Ambassador for CF4Cure, is a campaigner, motivational speaker and much more of a person harder to explain in words. Her unique story started at a very young age and played a huge role in who she is now.

After being diagnosed with CF at birth, Emmah was given up for adoption, from where Joy and Arnie Money took over. They were a part of the CF board and advocacy which only contributed to her involvement even more.

At the age of seven, Emmah fought for the Pulmyzone drug with her mum. Without letting her age control her, she contacted the health minister explaining her illness and the potential of the drug. The story was covered by ABC, Channel 9, Channel 10 and all major news stations. And of course, it was a success! Pulmyzone is made available for $40 a day, to inhale through a nebulizer every day.

As a fearless camera person, Emmah started her active involvement in spreading awareness of Cystic fibrosis by sharing her story in the media. She wrote to TV and radio stations describing her medical condition and was often invited to be interviewed.

“I've really been able to use my story to grow up and get a platform to raise awareness for cystic fibrosis.” Says Emmah

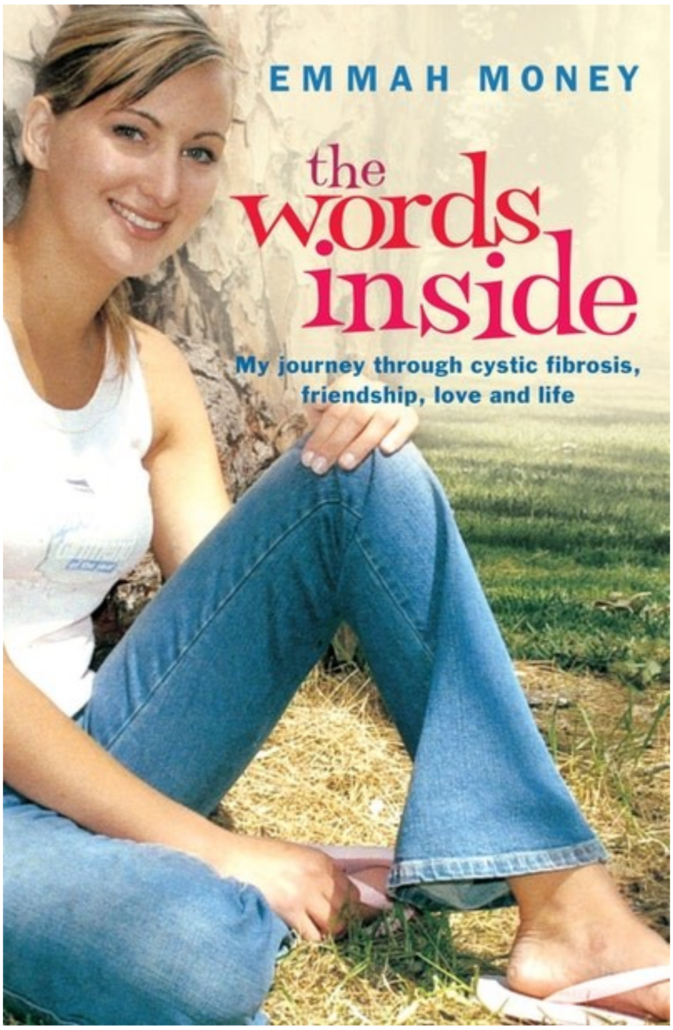
Around that time, her acting career took off through modelling. Emmah appeared in papers, making her realise she should be more than a model.

“If I'm on a poster or in a magazine, I wanted people to be able to look my name up and want to be like me or be inspired by me so that kind of aligned with my fundraising and wanting to make a difference.”

In 2005, Emmah participated in the Girlfriend Magazine competition and won the Girlfriend of the Year Award. The same day, she was asked to be the National Youth Ambassador of CF Australia.

Around that time, she found her biological parents who believed she passed away. The heart-whelming reunion and lonely times in hospital encouraged her to keep a journal, which became her first book.

Published in 2006, The Words Inside was a journey of Emmah's life through CF, friendship, love and life. She is currently working on her second book, where she describes her pregnancy time as a CF person.



Pregnancy is a challenge for people with CF due to infertility. Emmah found very little information on CF pregnancy online, along with remarks discouraging parents with CF from having children due to life expectancy. As someone who never takes no for an answer, she decided to document her pregnancy and encouraged other women to be an example.

"I wanted to show people that you can have a baby and what that looks like."

Emmah started a social media page - CF Mummy, where she ended up showing all the behind the scenes and started a community around. The page evolved to serve a whole new purpose; to raise awareness that people with CF can have children and live normal life.

Being a part of many campaigns, including getting the Orkambi drug listed in Pharmaceutical Benefits Scheme and Trikafta being approved in Australia, she dedicated her life to spreading awareness and finding a cure for CF.

"I want to find a cure for CF and be here for when that is found."

The recipient of multiple awards, including 2020 Australian of the Year and South Australian Local Hero, is currently expecting her third child.

To know more about Emmah, check out her website www.cfmummy.com.au

CRAZY HAIR DAY

More than 20 schools, preschools, Childcare Centres and businesses participated in Crazy Hair Day in 2022, with children (and big kids) from across the state dressing up and giving each other makeovers. The crazy kids created all different wacky and unique hair styles, using dye, gel and other styling tools to show off at their to schools/work with some schools even providing hair stations for those who wanted to do at school.

In addition to schools, the team at Bunnings at Mt Barker rallied together and took part in their own Crazy Hair Day.

Crazy Hair Day is not just about fundraising, but also spreading smiles and positivity in the community.

With this year's collections, we not only help CF patients in need, but also show them the power of smiles and support, reminding that we are right behind them to catch when they fall.

If your school, childcare centre, or work missed out on holding a Crazy Hair Day, don't fret. Crazy Hair Days can be held anytime throughout the year. Just visit www.crazyhair.com.au to sign up.

MEMORIAL SERVICE

In October we were fortunate to once again hold our Memorial service in the magnificent grounds of Government House.

The memorial service has always been a special occasion as it allows those who have suffered bereavement time together to remember and celebrate their family and friends who have lost their lives to CF.

We would like to thank everyone who participated in this event. Special thanks goes to our Patrons, Her Excellency the Honourable Frances Adamson AC and Mr Rod Bunten for hosting Cystic Fibrosis SA, families and friends.

GEELONG WOMEN'S BUSINESS CLUB

In late September, the Geelong Women's Business Club came to Adelaide for a special Empowering, Inspiring, & Inclusive Networking Event featuring an incredible line up of SA Women in business.

The event was created specifically for women interested in widening their knowledge about building a personal brand and business and to say it was an unbelievable success would be an understatement with over $1200 raised for Cystic Fibrosis SA.

A big thank you to our charity partner for September, Geelong Women's Business Club and all those who worked hard to make this event happen.

GEELONG
Women's
BUSINESS CLUB

Stride For Cystic Fibrosis

Your Great Strides is back and we want you to join in the fun

Your Great Strides will be held over a week from Saturday 26th November to Sunday 4th December and features 3km, 5km & 10km Strides Registration is FREE and this year it's virtual, meaning all you have to do is pick a time that suits you, map out your own route, and get striding!

Jump online and get moving to support people living with cystic fibrosis and their families.

With every step we take towards our fundraising goal, the closer we are to helping people with cystic fibrosis and their families.

Register now or donate at
https://greatstrides.raisely.com/

Your GREAT STRIDES

UPCOMING EVENTS

UPCOMING

26th Nov— 4th Dec	Your Great Strides

LATER

Late December	Sock it 2 CF

COLLECTION TINS

We have freshly restocked our fundraising collection tins which are perfect for a business countertop or your next fundraising activity

If you would like to collect a fundraising tin, please contact cfsa@cfsa.org.au

FACEBOOK FUNDRAISERS

Fundraising with Facebook is quick, easy and best of all, every dollar you raise goes directly to Cystic Fibrosis SA. Popular reasons for a fundraiser are birthdays, anniversaries, sporting club BBQs, dinners or charity events.

Get started at https://www.facebook.com/fundraisers/

If you need help setting this up, call the CFSA office on 8221 5595, and we will walk you through it.

MEMBERS BIRTHDAYS

October

Maddie A , Craig C , Kieran E , Emmah E , Brianna G , Charlotte G , Casey H , Corey K , Tobias KW , Barry L , Tyler L , Brock M , Megan N , Kimaya P , Vanessa P , Michael R , Otto S , Hunter S , Julian T , Alana W , Evan W , Franco Z

November

Natalie C , Jamie C , Chris D , Rani F , Dion F , Amy G , Grace H , Beau H , Simon H , Emma K , Troy L , Harrison L , Jimmy L , Vanessa M , Stephen M , Abbey P , Emma P , Kai P , Jessica S , Christopher T , Douglas T , Susan T , Boyd T , Tegan W , Logan W , Zane W

December

Nate A , Mikeila A , Liandra B , Jamie B , Raffaelle C , Alicia C , Lachlan D , Parker d , Gavin D , Kristy F , William G , Joanne H , Brad H , Amarli Grace J , Gloria L , Ashley L , Lilliana M , Cameron M , Jax M , Harrison O , Rebekah P , Lara P , Tanya R , Simon R , Savannah Rose S , Justin S , Jo T , Max T , Guiseppe V , Airlee W

ENTERTAINMENT MEMBERSHIP

Entertainment memberships give you more ways to enjoy every day, containing thousands of up to 50% off and 2-for-1 offers from popular restaurants, cinemas, hotels, the arts, and sporting events. There truly is something for everyone!

Not only does your Entertainment membership provide you with great value but your purchase contributes to our fundraising. Help us achieve our goal by sharing this link with your friends and family, and buy your Entertainment Membership online today! https://au.entdigital.net/orderbooks/162a139