



The Great Escape Oz Escapades Newsletter

Raising Funds & Awareness for CURE 4 CYSTIC FIBROSIS FOUNDATION

November December 2019

G'DAY ALL,

After 18 years, a new start, a new name, a new format and a new arm of Cystic Fibrosis and, but still the good ol' fashion fun, adventure travelling along different tracks, through different towns, always with different people to meet. It doesn't get much better than that and the most important thing is, it continues!

Many of you would have received or seen on Facebook post last month that CFA had decided to step away from the Great Escape in 2020, so I decided to continue the event and looked for another Cystic Fibrosis related charity. This new charity has been around for some years and is making its mark in Cystic Fibrosis Research and they are making a difference. Its name; CURE 4 CYSTIC FIBROSIS FOUNDATION, you will learn more about CURE4CF further in the newsletter.

CFA deciding not to continue with the event was very sad for me being the co-parent of the Great Escape along with Jamie Lawson back in 2002. If I had not made that call to Jamie in 2001, the Great Escape may not have happened. But it did and over 600 people have joined the GE family over that period, adding many benefits to the National CF Community, particularly the CF National Data Registry. In 2002 the Aust CF DR was way out of the international ranking in regard to having an instrument of knowledge. Australia was at best about 10th in the world. My background told me that this was one of the most important instruments that all strata's within the medical/clinical, researchers, allied health and the patients needed. To improve outcomes, we needed a greatly improved Data Registry. To bring all those people together was a task in its own, knowing the privacy issues, the format that was going to be used and the massive cost. We needed money to run this costly annual project (in excess of \$200,000 per year) so that is how and why the Great Escape evolved. Thanks to the funds raised by the entrants of the GE, by 2012 the National Data Registry for Australia had achieved the well-earned place as number 3 in the world. Short and long term it was going to make a difference to the CF community.

History is a wonderful thing to lament on, but you need to look forward, review what you know, improve what you can, and develop new relationships and that's what 'The Great Escape Oz' is about. It will still and always will be an event for Cystic Fibrosis as that community needs us.

So where are we going, when & what to look forward to in 2020. We have covered a lot of ground during those 18 years. In addition to the new areas travelled, on occasions we have doubled back across tracks and towns a number of times, so you have had a bird's eye of the Aussie bush from many angles.

7 DAY RALLY and other Changes.

As many of you know this will be a **7-Day Rally**. Many have requested it and others have come on board for the new time plan. It is from Saturday to Saturday. I know you will be saying that is 8 days. The first Saturday that is normally set aside for registration and scrutineering will now be a travel day as Nuriootpa/Kapunda South Aust is a long drive for most with the Welcome Dinner to take place on the Saturday night at Nuriootpa. To reduce the admin, a Scrutineering sheet will be sent out to each entrant after they have filled in all the paperwork and paid the entry fee. They will take the responsibility of inspecting the vehicle, either doing it yourself or having it done and tick off the points checked, return the signed Scrutineering sheet to me one week prior to the start of the Rally.

On Saturday evening, the Registration Desk will be opened at the lovely Vine Inn, Barossa Hotel/Motel Nuriootpa SA from 5.00 to 6.00pm. The Welcome Dinner will start at 6.30 for 7 pm, same location. So our plan is to get all the fundraising funds and forms in NO LATER than ONE WEEK prior the Welcome Dinner. By doing this, registration will be quick and slick where you will receive your TRACK BOOK ready to start the next morning. This gives everyone another full day to get to Nuriootpa. We will do random checks on cars from your scrutineering sheet, making sure everyone is being legitimately honest. We start on Sunday and finish on Saturday so a true 7-day rally. We finish at the wonderful Bonus Downs, near Mitchel in Qld. Those who were with us in 2016 when we were flooded out and by chance, we were able to stay at this magnificent sheep property, we spent 2 unbelievable nights with our hosts, Madonna and Lyle, and we will relive some of that fun.

Sir Sidney Kidman

As many of you know and many have made comment on my love of history and particularly Aussie history, its towns, its heroes, its builders and its characters and this is what this rally is mainly about. Over a number of years I have become very interested in Sidney Kidman. If I can quote from many writings; *'As a barely literate youth of thirteen, Sidney Kidman ran away from home and worked as an odd-job boy in a grog shanty in outback Australia. He went on to become the greatest pastoral landholder in modern history, acquiring a legendary reputation both at home and abroad as the Cattle King, and in many ways now known as the Forgotten King'*

So our journey starts with brekkie at Sidney Kidman's home Eringa in Kapunda SA. He donated this home to the school in 1922 and was opened as a High School in 1923 and still houses the administration offices for the school. There are many buildings around the town that were owned by Kidman as he grew his business. Kapunda is also famous as it was the first mining town in Australia. *"He travelled a lot with Aboriginal companions," he said " He learnt a lot about the weather and how the country worked and I guess that gave him the idea of a grand plan...an idea of buying up country, this sort of chain of properties that followed the water courses"*. He controlled 160,000 square miles of Australia; I think that is 3 times the size of the UK.

Entry Form and pricing.

You will note from the Entrant Application sheet the small mud map will give you a reasonable idea of our course.

There are some obvious changes within the pricing structure, with Fundraising being reduced and catering working on a pro-rata basis.

Reunion.

It is in my plans to have a reunion weekend in mid to late March 2020 in the Albury area, where I am hoping to have a 4 or 5 hr mini rally on the Saturday afternoon, Frank Corby from the area will put together some interesting tracks for the afternoon. Then a get together Dinner on the Saturday night with present, retired and new entrants to come meet with old friends and make some new ones as I outline everything about The Great Escape Oz (GEO) and of course Cure 4 Cystic Fibrosis Foundation, our new friend within Cystic Fibrosis.

For more information on Cure4 Cystic Fibrosis, keep reading

INFORMATION PAPER

OUR PURPOSE

- Cure4 Cystic Fibrosis Foundation (Cure4CF) was formally established in 2007 and is a registered not-for-profit organisation with a vision for a cure for cystic fibrosis (CF).
- Cure4CF furthers this mission by raising funds across the country and directing them to support promising Australian medical research; research that has the best chance of making it into the hands of people with CF.

OUR DIFFERENCE

- We exclusively fund research into therapies and treatments that will either **cure CF or significantly extend the life expectancy** of people living with CF. This is our key point of difference.
- Cure4CF is Australia's **largest private funder** of CF research. We raise approximately \$1 million annually through community fundraising, major gifts, sponsorships and grants. To date have raised \$4M to invest in a cure for CF.
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- We have a rigorous model for our funding, with excellent governance and reporting frameworks supported by an expert Advisory Committee. Our grants process ensures **our focus is on funding translational research** – that has scientific, clinical and commercial merit and a focused pathway to clinical outcomes. Our partnership with the National Foundation for Medical Research and Innovation (NFMRI) has ensured this.
- Through our recent grant round, **we have uncovered incredible Australian research** that has the potential to transform CF treatment globally. Through targeted funding, we can accelerate this research.
- With an average lifetime cost per patient of almost \$1M to treat CF and the costs only increasing, we recognise our work in support of a cure will have a significant impact on the Australian health system and economy.
- We are a small team of just 2 staff, 3 voluntary Community Ambassadors and a dynamic Board of 9 Directors. We run a lean organisation to keep our overheads low, but our impact is great. We want to make every dollar raised count. Our volunteer strategies, such as our highly engaged Board and Community Ambassadors, are key to achieve this.

CURRENT CHALLENGES

- CF is the most common life-limiting inherited disease affecting the developed world, with one in every 2,500 children affected.
- Every four days a baby is born with CF.
- **One in 25 people** are carriers of a genetic mutation responsible for CF.
- It is a multi-organ disease, affecting the lungs, gut, liver, pancreas and reproductive tissues.
- **There is no cure for cystic fibrosis** and although recent advancements, such as Kalydeco, provide hope for some sufferers, many people with CF still have few treatment options that will extend their lifespan beyond the average of 38 years.
- In 2018 we determined that we would expand our impact across Australia. We are now expanding our Board to reflect our **national presence** and our determination to fund Australian research that makes global impact.