



ALLISON, LILI AND RYAN SHARE THEIR LIFESAVING NEUROSURGICAL EXPERIENCE

"When you first discover that your child has a condition which requires neurosurgery there is a lot to take in and try to understand. The whole process, not only for your child but also as a parent is quite overwhelming, however when you have great surgeons and specialists that are really passionate about their chosen field it makes the journey much easier."

"To know that you are in great hands gives you a peace of mind that you are doing the best for your child". Parents Ally and Ryan.

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NEW PATRON



His Excellency the Governor, Rear Admiral Kevin Scarce AC CSC RANR awarded Carolyn Hewson AO with NRF Life Membership at Government House in recognition of her 24 years as Patron and thanked Carolyn for her dedicated service. It is with regret that we announce that Carolyn will now be stepping down as Patron of the NRF.



However, it is with great pleasure that NRF President Dr Brian North introduced the Honourable Catherine Branson QC as the new Patron of the NRF. Catherine is a former federal court judge, former president of the Australian Human Rights Commission and now an Adjunct Professor at the University of Adelaide Law School. We welcome her to the NRF.

SA POLICE THANKED FOR DONATING \$400,000

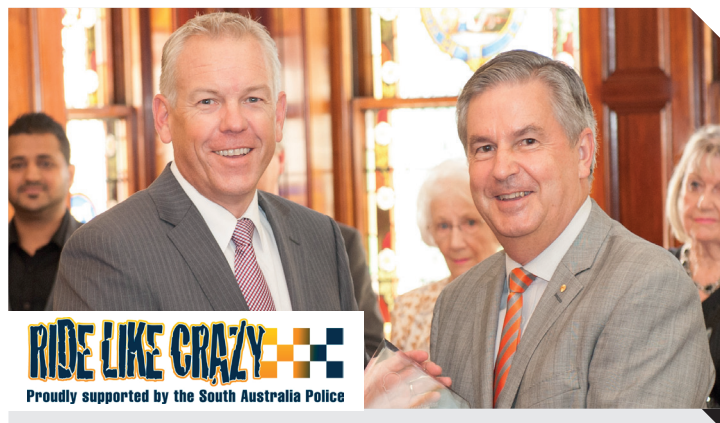


Photo: RLC Chairman Deputy Police Commissioner Grant Stevens with His Excellency the Governor, Rear Admiral Kevin Scarce AC CSC RANR

The NRF has been privileged to be involved in Ride Like Crazy since 2010. Over the past 5 years, RLC has attracted over 9,500 riders and donated \$800,000 to fight cancer.

The NRF has received \$400,000 of these funds for brain tumour research. The NRF thanked SA Police at Government House for these generous donations towards brain tumour research.



Photo:
Police Commissioner
Gary Burns handing over
\$80,000 to Professor
Robert Vink NRF Chair of
Neurosurgical Research.

The 2014 RLC money will continue to fund the research of PhD research students, specifically Kimberley Mander and Stefan Court-Kowalski who commenced their studies in 2014. Their research is focussed on looking at stopping cancer cells derived from peripheral cancers (breast, prostate, melanoma) from entering the brain and markedly reducing both quality of life and life expectancy, as well as halting the rapid growth of these tumour cells once they have entered the brain.

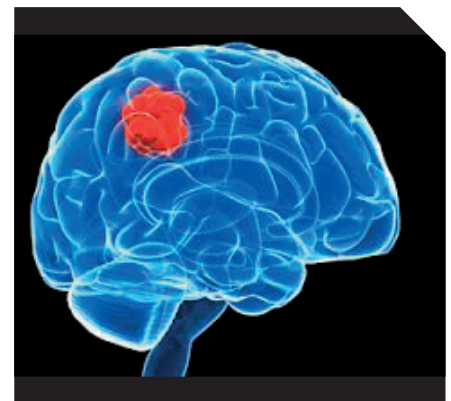
BRAIN TUMOUR RESEARCH FUNDED BY RIDE LIKE CRAZY

Brain tumours are devastating and in their various forms, they may occur at any age and inflict a terrible toll on the lives of patients and their loved ones. In recent years, a wide variety of potential new treatment strategies have been identified, but unfortunately, as yet, none have translated into effective new therapies that impact in a significant way on patients' survival or quality of life.

The issue is finding a target within the tumours that is able to be inhibited, involved in several key processes, and yet is relatively specific. Aquaporins are channel proteins that facilitate the movement of water between

cells and their surroundings. They are extremely important in maintaining fluid balance in the body and most importantly, they are linked with brain cancer progression including cell migration, blood vessel formation, and brain swelling. We can now, in world-first experiments, investigate the effect of blocking aquaporins on the progression and prognosis of brain tumours. The research conducted will have direct and immediate application in developing a new strategy for treating brain tumour patients that may potentially prolong life, reduce symptoms, and improve quality of life. Research by Stephan Court Kowalski.

The secondary spread of melanoma cells to the brain is an extension of a solid tumour, often more fatal than the primary diagnosis. Most heartbreakingly, no effective measures are available to reliably prevent this devastating stage of disease progression. It is recognized that a key event in the development of secondary brain tumours is the ability of cancer cells to breach the barrier between circulating blood and the brain itself, known as the 'blood-brain barrier'. We are in the process of developing an 'artificial barrier' in the lab to replicate



the early stage interaction of migrating cancer cells with front line cells of the brain barrier. It is anticipated that by establishing this model, we will not only ascertain the critical cellular processes at play, but also identify novel targets for the development of more effective intervention options and improved outcomes for patients. Research by Kimberley Mander.

NAT'S PERSONAL JOURNEY, LIVING WITH A BRAIN TUMOUR AND FUNDRAISING FOR RESEARCH

"Nearly 6 years ago I was diagnosed with a brain tumour on the left hand side of my brain. It was an extremely scary and surreal experience. I had been suffering with terrible migraines and was having trouble with my motor skills. I was taken to the hospital where they discovered the tumour and one week later it was removed by the amazing staff at the Royal Adelaide Hospital. I was extremely fortunate with the

location of the tumour and that it was found when it was. After the surgery came a lot of trying days, sadness and struggles. Due to this experience, I know that I am beyond lucky to be here and to have had the support and care of my family and beautiful friends, especially my husband.

Since then I married my husband, Adam and we have had two beautiful and amazing boys, Fynn and Archer.

Unfortunately last year we found out that my tumour has returned. Fortunately for me, it has been detected quite small and in the same location. I am currently living from 3 monthly MRI's to the next. My life is truly wonderful and happy, regardless of the tumours. I certainly won't let that define me and I'm sure that as a family we will get through this when the time will come and continue to live a joyful and healthy life."



Nat and family have been part of NRF Team Neuro for the last two years in the City to Bay fundraising over \$3,000 for research. Nat encourages everyone to join them, take part and fundraise. If Nat can, so can you!

Natalia Thompson

JAMES & DIANA RAMSAY FOUNDATION THANKED FOR DONATIONS TO PAEDIATRIC RESEARCH



James & Diana
RAMSAY
FOUNDATION

The NRF is extremely grateful to the James & Diana Ramsay Foundation for establishing the paediatric database.

Photo: Executive Officer Kerry de Lorme receiving award from His Excellency the Governor, Rear Admiral Kevin Scarce AC CSC RANR.

PAEDIATRIC RESEARCH FUNDED BY JAMES & DIANA RAMSAY FOUNDATION

"We continue to collect clinical data on all children with neurosurgical conditions admitted to Department of Neurosurgery at the Women's and Children's Hospital over the past 2 years.

We have conducted research to develop and validate simple and objective tools to assess children with neurosurgical disorders. This work will enhance our ability to care for these children by looking at treatment outcomes and will be able to assist with clinical trials in paediatric neurosurgery to advance knowledge, and to improve outcomes of

neurosurgical treatment in children.

We examined an area of high priority in hydrocephalus research, specifically shunt infections. This project aims to improve our understanding of the causes of shunt infections and thus the development of strategies to minimise the risk of such infections.

We also studied the demographics and recovery of paediatric patients who suffered head injuries. This data will be used as a basis for addressing head injury awareness and education in

the community and allow us to contribute to children safety and have a positive influence on the prevention of severe head injuries in children.

Our target is to collect new knowledge, translate research findings into protocols and clinical practice, and improve quality of life and health outcomes. This is certainly relevant to the vision of NRF of fostering research in the areas of causes, diagnosis, prevention and treatment of disease, injuries or malfunction of the brain, spine and nerves."

Dr Amal Abou-Hamden

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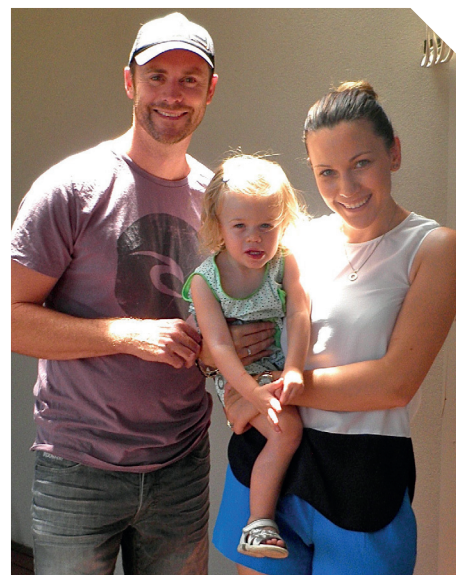
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"When our daughter Lili was 6 weeks old our paediatrician observed that her head was growing at a faster rate than was expected and this started her journey. It started with an ultrasound and then several MRI's which lead to the discovery that she had 2 significantly sized arachnoid cysts. Lili had surgery and a shunt was placed in the larger of the 2 cysts to drain the fluid out of her head and into her stomach.

We have been very fortunate that Lili has reached all of her milestones to date. Lili is now 2 years old and is having regular check-ups with her neurosurgeon.

Last year, I decided to support and raise money for the NRF in the City to Bay. Having a child who needs to be under the care of a neurosurgeon for the rest of her life and the possibility that she will need additional surgery; I now see

how important it is that neurosurgical research is undertaken to not only discover new cures but to also improve technology. Our neurosurgeons made the whole process with our daughter as stress free as possible. We are very fortunate that we have a happy healthy little girl." Parents Ally and Ryan.



CITY TO BAY NRF TEAM NEURO SUPPORTERS THANKED



The NRF recently thanked Aussie Farmers Direct and Dr Jones & Partners for their generous support of NRF Team Neuro in the City to Bay. Over three years, they have raised \$100,000 for neurosurgical research.

Photos: His Excellency the Governor, Rear Admiral Kevin Scarce AC CSC RANR with Rohit Sharma From Aussie Farmers Direct and Phil Wooding From Dr Jones & Partners.

Please join us at the 2014 NRF AGM

Wednesday 13th August

Wakefield Hospital,
3rd floor auditorium,
starting at 6pm.

The AGM will feature
presentations from the
following researchers
funded by your donations.

■ RSVP Ginta Orchard

Phone: (08) 8371 0771

Email: ginta.orchard@nrf.com.au



Investigation of APP96-110, a peptide derived from the Amyloid Precursor Protein, as a novel therapeutic agent against traumatic brain injury.
Stephanie Plummer PhD Candidate



Investigating the efficacy of pharmaceutical agents targeting brain water channels in attenuating traumatic cerebral oedema.
Joshua Luke Burton PhD Medicine Candidate



A novel treatment for brain tumours involving blocking of brain water channels.
Stefan Court-Kowalski Fourth year Medical Student undertaking concurrent PhD studies



Determining the mechanism of cancer cell entry in the development of secondary brain tumours; an in vitro approach to blood-brain barrier research.
Kimberley Mander PhD Candidate

RIDE LIKE CRAZY 2014 – 2015 EVENTS

Ride Like Crazy has developed into a series of events.

- **Le Tour de France Screening, Thursday 24th July 2014**, Stage 18 from Pau to Hauta. 8.30pm at Capri Theatre Goodwood
- **Ride Like Crazy Vietnam Cycle Challenge, Sat 8th to 22nd November**, 8 days cycling approx. 485kms Registration fee: \$700, Trip costs: \$3,855, Fundraising Target \$2,500
- **RLC Gala Dinner, Friday 16th January 2015**, with famed cycling greats
- **Ride Like Crazy 2015 Sunday 18 January 2015**
Entries open September

Go to RLC website www.ridelikecrazy.com or facebook page www.facebook.com/pages/Ride-Like-Crazy to learn more about this year's additional events and speakers.



JOIN NRF TEAM NEURO IN CITY TO BAY ON SUNDAY 21 SEPTEMBER 2014

Walk or run 3, 6 or 12km in this year's event. Join NRF Team Neuro by purchasing a t-shirt or go an extra step and recruit sponsors to raise additional funds. Start your training and fundraising today!

To register

Go to www.city-bay.org.au and join NRF Team Neuro in support of the NeuroSurgical Research Foundation.

How to fundraise online

Register at www.everdayhero.com then search under charities for NeuroSurgical Research Foundation and follow the prompts. Please ring the NRF office on 8371 0771 if you need assistance.

How to collect donations offline

We realise online donations are not for everyone. Ring us on 8371 0771 and we will provide you with the necessary forms.



NRF Team Neuro t-shirt and singlet

All participants who raise \$100 or more will receive a free NRF t-shirt or singlet.

You may also purchase a t-shirt or singlet for \$50 each.

Request an order form by ringing 8371 0771 or download one from www.nrf.com.au

Orders must be received no later than 5 September.