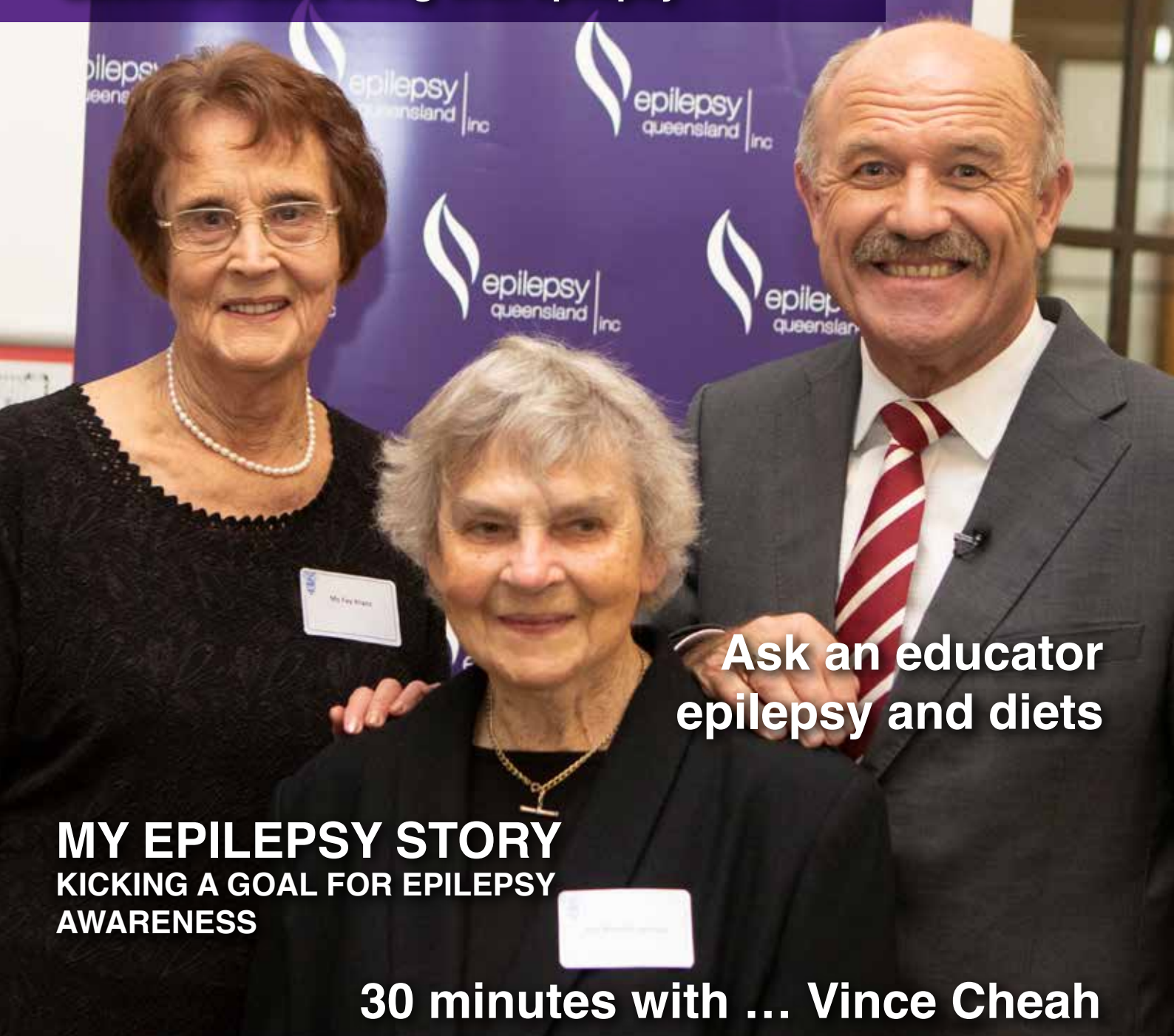


the flame

the newsletter of epilepsy queensland inc

Issue 3 – 2019

Brisbane recognises 50 years of supporting Queenslanders living with epilepsy



**Ask an educator
epilepsy and diets**

**MY EPILEPSY STORY
KICKING A GOAL FOR EPILEPSY
AWARENESS**

30 minutes with ... Vince Cheah



Motorbike Ride 4 Epilepsy

– Sunday 18 August

If you are a motorbike rider, we'd love you to join the Chair of our board, Dave Bunker for our inaugural Motorbike Ride 4 Epilepsy. The inaugural ride will be from Archerfield to Flagstone on Sunday 18 August.

Dave is an avid Ducati rider and was thrilled to be the first person to register. If you are not a motorbike rider but still keen to show your support, you can make a donation, Dave has created an Everyday Hero page in honour of his daughter and our epilepsy hero Daelle. All funds raised go directly to Epilepsy Queensland to provide information and support services for Queenslanders living with epilepsy.

“For me this ride is about my daughter Daelle, who is 20, and lives with severe and profound intellectual and physical disabilities and has complex health issues. She is loving, unique, inspiring and courageous. She has a genetic condition causing severe intellectual disabilities, uncontrolled epilepsy and a number of physical disabilities including cerebral palsy and cortical vision impairment. But Daelle approaches her life with a limitless joy and appreciation of the moment. She has great and endless love, holds no grudges, and has infinite patience.”

“Epilepsy Queensland has helped us directly, and does amazing work in the community to support people living with epilepsy, including their families, carers and clinicians. So I wanted to support them by raising money as part of my participation in Motorbike Ride 4 Epilepsy.”

To secure your entry we ask for a \$50 tax-deductible donation via <http://bit.ly/RideForEpilepsy>.

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EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it. The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights. The Editor reserves the right to edit or exclude stories from inclusion in Flame at their discretion.

The Flame is published quarterly by Epilepsy Queensland – www.epilepsyqueensland.com.au



BE SEIZURE FIRST AID AWARE

One in 10 people will have a seizure during their lifetime. With this in mind, our aim is for one person in every household to know seizure first aid. Epilepsy Queensland have a range of resources available for work, home or school. Download them from our website or order online. www.epilepsyqueensland.com.au/first-aid

During the month of September we will be sharing tips and stories about seizure first aid on Facebook, Instagram, Twitter, YouTube and Linked In. Please share our posts or your own posts about your experience with seizure first aid.



www.facebook.com/EpilepsyQueensland



www.twitter.com/epilepsyqld



www.instagram.com/epilepsyqld



www.linkedin.com/company/epilepsy-queensland



<http://bit.ly/EQIYouTube>

Does your workplace or school need understanding epilepsy and seizure first aid training? Contact us for training options at our office or yours, via Zoom meetings or self-paced online webinars.

Would you like to raise funds or donate to support our seizure first aid campaign?

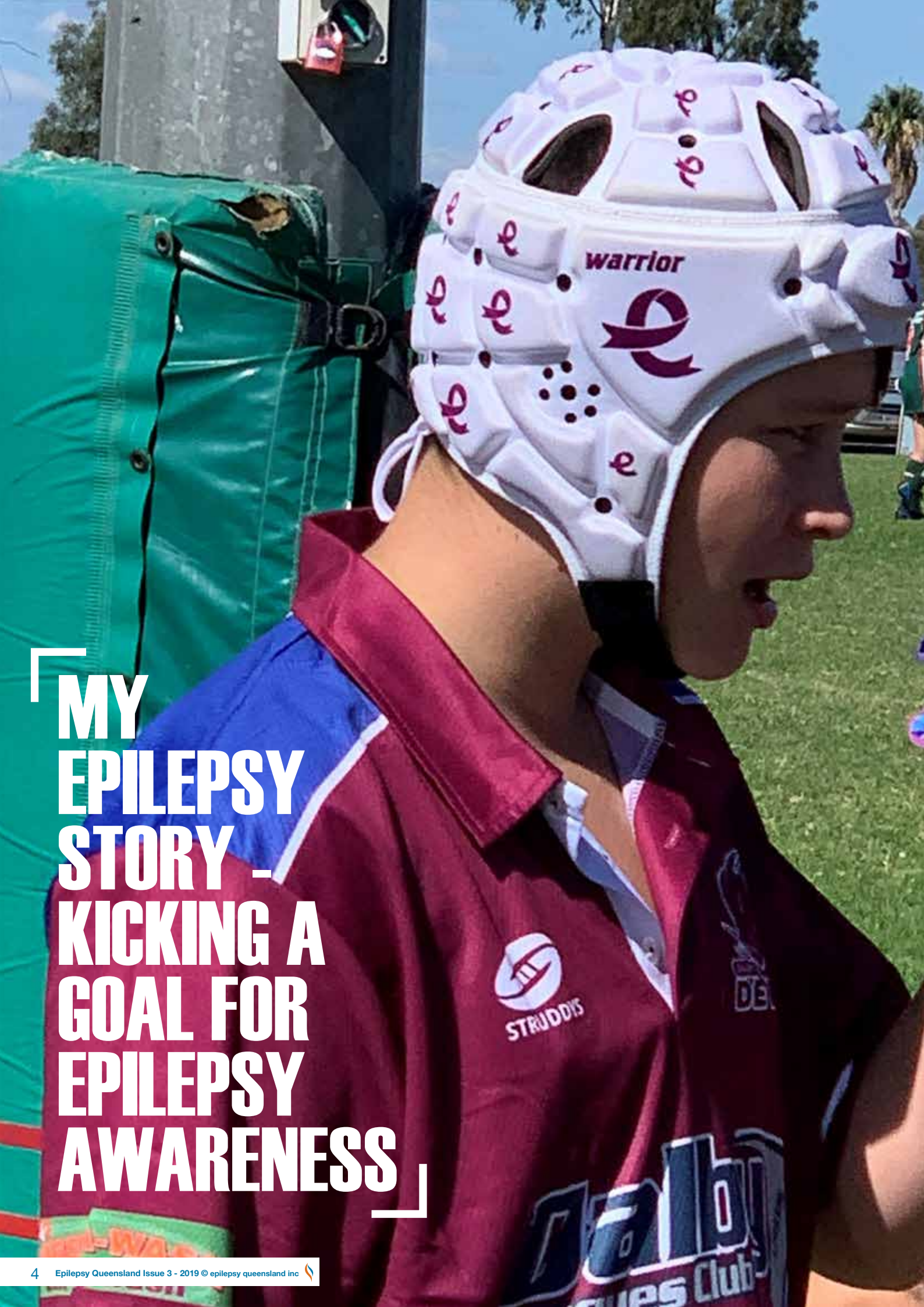


Donate online - make a secure online tax-deductible donation. Visit www.epilepsyqueensland.com.au/donate.

Contact Us

If you would like us to share your seizure first aid story through social media or local media or if you would like further information or resources.

Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)
Email: pr@epilepsyqueensland.com.au
Website: www.epilepsyqueensland.com.au



「MY EPILEPSY STORY - KICKING A GOAL FOR EPILEPSY AWARENESS」



Jack Dalton stepped to allude his opponents and ran half the length of the field to score a 40-metre try, reminiscent of his idol Wally Lewis. The similarities between Jack and Wally do not just lie in his ability on the football field, but also in his diagnosis of epilepsy and his desire to raise awareness of the condition.

Jack just missed the conversion by a few centimetres and his team lost the game 28 to 18, but his Mum, Anna, who also lives with epilepsy, was pleased to report that he played really well. For Jack, this was the first time that he played wearing his epilepsy warrior headgear. Jack was inspired by Queensland Reds legend Ben Daley who wore epilepsy awareness headgear to raise funds for Epilepsy Queensland.

Anna said "He got a lot of compliments on his headgear and a lot of thumbs up and unfortunately a few negative ones but the good outweighed the bad. So he was still a winner!"

Jack, now 14, has been playing Rugby League since the under sixes competition and has never had a seizure on the field from a tackle nor a concussion.

Anna believes "Education is the key to kids enjoying the sport they love. There is no reason most kids can't play it. Sport is to be enjoyed. Jack was at one stage having 190 plus absence and myoclonic seizures a day and the only thing that kept him going was knowing that he was going to footy on the weekend. He obviously missed a few games but when he got the all clear he was straight back in."

Anna also believes in taking precautions to ensure the best and safest experience for Jack. "I had Jack's headgear specially made by IMPACT RUGBY and it is awesome! I carry his midazolam with me to every game and have never had to use it. Jack has been taught to tackle correctly i.e.: head in the right position and wrap the opponents legs up to minimise risk of injury. The first aid officers are made aware of his condition before the game and that I am carrying his medication in case of a seizure. I am also at his games and training sessions as his mother and a nurse with 20 plus years of nursing experience. So if something does happen I may take over."

"Jack gets at least 10 hours sleep the night before and drinks plenty of water and removes his headgear to cool down when he comes off for a rest. His teammates and coach are really supportive. They are aware of his condition and know what signs to look for. He tells his coach if he needs to come off and he is replaced straight away."

Jack was first diagnosed with epilepsy at the age of five. At first he had absence seizures but then he also had tonic-clonic seizures a few months later. Since then Jack has been diagnosed with Jeavons Syndrome, a type of epilepsy with nocturnal and refractory absence seizures as well as myoclonic automatisms.

Jack talks about his diagnosis "My sister thought I was daydreaming and told my Mum who is a nurse. She knew straight away and took me to see our GP, Dr Tammy Maxwell, who sent me to see Dr Geoff Wallace at Lady Cilento. He did lots of tests and told my Mum and Dad that I have generalised epilepsy."

Jack's journey of living with epilepsy has not been without challenges. Jack struggles with his school work due to the side effects of medication and seizures. Anna said "The damage from the seizures has caused learning difficulties. He has modified work and gets extra time to complete assessments."

Jack says "I get lots of headaches. I'm hungry all the time and sometimes in class I put my head on the desk because it feels "fuzzy" and wake up after everyone has left the class. Some of the teachers get cranky with me but I can't help it. Some days are better than others."

Jack has also had difficulties with developing friendships at school. "I get bullied a lot and only have a few friends. Mum says that bullies are only scared because they are uneducated or learn it from home and I should feel sorry for them. It still upsets us though."

At times the bullying has been extreme and has had a big impact on Jack's wellness. Anna shares: "On 1 November 2018 Jack was coward punched twice, whilst he was trying to protect another boy who was being bullied by a group of about 30. He had gotten the boy out of the circle that had formed around him in the schoolyard and was taking him to the office for safety when a friend of the bully ran up behind Jack and hit him in both temples from behind."

"At this stage Jack had been seizure free for almost 15 months and his Doctor was considering decreasing his medication. When I picked him up from school, he was visibly upset and was telling me what happened and had a myoclonic seizure. He had X rays to check if he had any fractures but all was clear, just bruising. He complained of a headache the next day so I kept him home."

"He slept on and off through the day and later that afternoon I was getting dinner ready and he went for a shower. After about five minutes our sausage dog started barking, which he never does unless there is something wrong and Jack's old Kelpie was scratching at the glass sliding door barking. I instantly knew something was wrong and ran to my bathroom where I found Jack on the floor of the shower having a tonic-clonic seizure. He had aspirated a lot of water and was banged up fairly bad."

"I called out to my daughter who called the ambulance as I was trying to get him out of the water and onto his side. Resuscitating your son on the floor of your ensuite is not something you want to have to do twice! He had a couple of days in hospital and an increase in his meds and we started the seizure free count again."

As a nurse Anna knows the importance of information, awareness and support. Epilepsy Queensland have been there for Anna, Jack and their family. "They have been ahmazing !!!! The things that I have learnt and read about to help me understand the types of seizures that Jack has and some of my patients is phenomenal."

"I meet a lot of parents in my role as a nurse and it is heartbreaking to see how scared they are the first time their child has a seizure and I always reassure them that Epilepsy Queensland is a huge support and a wealth of information as I have used it myself. I think that finding out that my son and I both have epilepsy somehow reassures them."

Despite the challenges and difficult experiences, Jack has a great attitude towards living well with epilepsy. "I have tried 12 different medications and we are now down to just Epilim which causes weight gain and tiredness as well as headaches. I always make sure I take my tablets at the same time in the morning and at night because it is very important."

Anna and the rest of the family are also great supports and advocates for Jack. "Realising that even though in some cases it can be a death sentence and we were told that if we don't get Jack's under control it could be, you need to realize that children need a childhood as it can sometimes be the best medicine as we found with Jack. Sunshine, fresh air and a medication regime. Obviously every case is different."

Jack loves cars and all types of machinery, so he hopes that he can get a license and a school based apprenticeship as a diesel mechanic. He also wants to help make life better for others living with epilepsy by raising awareness and funds for epilepsy services.

The family are big supporters of Purple Day. "It means a lot as the more awareness the better because people seem to live in the shadows for fear of being judged and excluded. We missed fundraising for Purple Day, but are in the process of organising a purple sock day at Jack's Footy Club."

Thank you to Jack and Anna for sharing their story of living with epilepsy. If you would like to help raise funds, awareness and understanding of epilepsy contact Epilepsy Queensland on pr@epilepsyqueensland.com.au or 1300 852 853.



ASK AN EDUCATOR EPILEPSY AND DIETS

Q: I've heard a lot about diets and how they can reduce seizures for people with epilepsy. Can you tell me more about these diets and where to go to access them?

There are a number of diets linked to the treatment of epilepsy. Children and adults with uncontrolled seizures may be helped by these diets however, there is no way to predict beforehand whether it will be successful. Each of

these diets should only be initiated under the supervision of a dietitian and with the approval of treating doctors and specialists.

The Ketogenic diet is a special high-fat diet that is used for difficult to treat seizures. Heavy cream, butter and vegetable oils provide the necessary fat. It is low in carbohydrates thus eliminating sugar and other carbohydrate rich foods such as bread, rice, pasta and cereals. The main source of carbohydrate is from small serves of measured fruits and vegetables.

A variety of diets have been developed over time and as a result the Ketogenic



diet for epilepsy is now referred to as the “Classical” Ketogenic Diet. This differentiates the ratio controlled diet from popular mainstream diets which may be referred to as ‘ketogenic’.

The “Classical” Ketogenic Diet is an exact diet where every meal must provide just the right amount of fat, protein and carbohydrates. The diet is calculated in terms of ratios such as 4:1, 3:1 and 2:1. In a 4:1 ratio, there is 4 times as much fat as there is protein and carbohydrate combined. The dietitian devises meal plans that complete the required fat, protein and carbohydrate for each meal.

Recipes indicate the exact gram of each food ingredient that must be accurately

weighed on a gram scale. A typical meal includes a small amount of fruit or vegetables, a protein rich food, and a source of fat such as heavy cream and butter or vegetable oil.

The Modified Ketogenic Diet (or MKD) is less restrictive than the Classical Ketogenic Diet. It allows all protein rich foods such as meat, chicken, eggs and fish to be eaten to appetite and fats are encouraged. Food does not need to be weighed and recipes do not need to be precise. Carbohydrate foods are counted and spread throughout meals with the aim to keep within the daily gram limit set by the dietitian. The MKD is often used for adolescents and adults as it allows more flexibility in mealtime choices compared with the Classical Ketogenic Diet.

Children from infancy through to teenage years and adults with uncontrolled seizures may find their seizures are reduced by either of these diets. There is no way of predicting this reduction or whether it will be successful. Children with feeding tubes and some infants are commenced on the Ketogenic diet using a special formula designed for this purpose. Teenage children and adults may find the diet difficult to follow due to its restrictions.

Normally, your body breaks down the carbohydrates in the food you eat to glucose or sugar, which is the fuel for the brain and your body. When you do not have enough carbohydrate (such as during starvation) your body starts to break down fat reserves to use as fuel for your body instead. When fat is broken down it produces a by-product called ketones. The body can use these ketones as a source of energy instead of glucose. The ketones circulate through the blood in the body and brain and then are excreted into the urine. These ketones in the brain act similar to epilepsy medications. One theory attributes the anti-seizure effect of the diet to the ketones that the Ketogenic diet produces.

The Modified Ketogenic Diet (MKD) has replaced previous terminology such as Modified Atkins Diet (MAD). Both are low carbohydrate diets although the fat content of the diets vary.

The Modified Ketogenic Diet (MKD) is more commonly used in epilepsy treatment settings.

Carbohydrate foods are counted and spread throughout meals with the aim to keep within the daily limit.

Studies following children on the diet for long periods reveal around 50% of them treated with either the Classical Ketogenic Diet or Modified Ketogenic Diet have greater than 50% seizure reduction. Greater rates of seizure reduction are seen in some children with specific epilepsy syndromes. More and more research is also being undertaken for adults, which are showing similar outcomes.

For safety and to ensure the best opportunity for seizure reduction, it is recommended that you speak with neurologists or other specialists before children, teenagers or adults commence these diets. All diets require dietary supervision. Blood tests are required before starting the diet to check for anything that might put you at risk if you were to start the diet.

Referral information:

Both adults and children using either the public or private health systems require approval from their treating neurologist and referral to a trained Accredited Practising Dietitian. These diets must be conducted under medical supervision.

You must be under the care of a Neurologist who is supportive of commencing the diet.

Those wishing to attend the Dietetics Mater Health and Wellness Clinic must be referred by a private neurologist – MKD packages are available.

Contact: 07 3163 6000

Useful Websites

www.charliefoundation.org

www.matthewsfriends.org

<http://wellness.mater.org.au/>

<http://www.mater.org.au/health/services/allied-health>

<https://www.childrens.health.qld.gov.au/service-dietetics-food/>

Acknowledgements:

Updated July 2019. Adapted with input from dietitians from Mater Health Services and the Ketogenic Diet Service at the Queensland Children’s Hospital.

30 minutes with...

Vince

Cheah



What is the exact title of your role?

My job title is Clinical Nurse.

Where do you currently work and how long have you been working there?

I currently work at the Mater Private Hospital Brisbane, I have been working there for the past four years.

I am sure you have seen a great deal of change in Epilepsy treatments. What do you think is the most exciting change and why?

I specialise in functional neurological disorders (FND) which can often look like epileptic seizures but have no electrical changes in the brain. We now have a much larger understanding of FND and how it affects the brain from a biological, social and psychological perspective. Patients with epilepsy have a higher chance of developing FND which can cause a loss in quality in life even if the epilepsy is well controlled. The most exciting change is seeing a big push of health practitioners who want to learn how to treat, manage and change the stigma associated with FND.

Where else have you worked in your life?

My first job was an English and maths tutor during my final years of high school which I continued to do during a GAP year overseas. I really enjoyed teaching younger children about English and maths in fun and entertaining ways.

Whilst studying nursing I worked as a landscaper for the old TAFE at Red Hill next to the Bronco's training ground. I always knew I couldn't do a job where I was stuck in an office and I found being outside doing manual labour therapeutic and a change of pace from studying nursing. I worked with some great people with exceptional work ethic.

My career in nursing is still relatively fresh, after graduating university I got a graduate position at the Mater and decided to stay after finishing. I have thoroughly enjoyed working with some great people at the Mater. As a graduate I presented a case at the Australian Neuroscience Nurses Association

(ANNA) conference. I worked closely with Dr Alexander Lehn on this who also ran the Functional Neurological Disorder FND clinic at the Mater. Due to working in the epilepsy unit and coming across FND, I jumped at the opportunity to join the FND team. It has been such a wonderful experience to work with such dedicated and caring people and it has really put a fresh perspective for me on the current state of healthcare.

What do you love about your job?

The part I most love about my job is being able to help people using everything I have learned through my degree and life experiences. The greatest feeling is when someone has a problem they are struggling with and I am able to help them come up with a plan or solution to their problem. The best part about working with the FND team is seeing patients improve their quality of life through treatments.

As a nurse there are many opportunities to change healthcare for the better and to fight for better care for patients. I think this is an important and enjoyable part of the job and it really motivates me to push harder for better healthcare standards especially in the realm of FND.

Where would you most like to travel?

I grew up at an international school in Hong Kong and travelled extensively with my parents throughout Asia. My parents would make a point to travel somewhere different every year which I have carried on into adulthood.

I have recently returned from Ireland where I met up with my high school friends and we travelled around the whole of Ireland in campervans. Highly recommend going to Ireland, it is such a beautiful and picturesque country with the nicest and friendliest people.

I would next like to travel to Africa, starting in South Africa and making my way up to Egypt. I would really like to see gorillas in Uganda, climb Table Mountain in South Africa and learn about and see all the big five animals of Africa just to name a few activities.

What is your favourite food?



Travelling when I was young meant that I was always trying new foods. A great way to experience people and culture is through their food. I enjoy all foods except one... celery. My favourite cuisine would have to be Vietnamese. The ingredients are always fresh and flavour abundant. My favourite dish would be Phở pronounced as "fuh" or "fur" it is a very simple dish consisting of a clear broth made from beef or chicken and rice noodles.

Describe your most embarrassing moment?

My most embarrassing moment would be when I was a graduate nurse and my manager came and told me I had a nice sounding voice and that I should sing a song at the nurse's station. I remember freaking out and didn't know what to do so I started singing happy birthday. I don't think anyone particularly enjoyed it.

What is your favourite book/author?

My favourite book is "The Power of One" by Bryce Courtenay. I first read it when I was in year 7 and it has stuck with me ever since. It's a coming of age story and really highlights the power to believe in oneself to achieve anything. I really enjoyed the first person style of writing Bryce Courtenay used and felt a close connection to the main character. I am currently reading "A dog's purpose" by W. Bruce Cameron which is a humorous tale about a dog's journey through reincarnation.

Who is the most famous person you have ever met? Or who would you like to meet?

The most famous person I have ever met is Tom Hiddleston. I was at a friend's house on the Gold Coast and he was staying next door as he was filming the movie Thor. He came and told us to turn the music down and not tell anyone he was there. I offered him some KFC chips which he happily ate then disappeared.

What genres of music do you like listening to/ favourite song?

I enjoy listening to hip hop and jazz music. I like that hip hop has strong roots in jazz and many samples used in hip hop come from jazz and other genres of music. Some of my favourite artists include: Nujabes, MF Doom and Ganstarr.

Do you have any interesting hobbies you would like to tell us about?

Using my first ever pay check I bought myself a Nikon digital camera and through reading and YouTube taught myself about photography. As my skills improved and technology advanced I soon found myself doing a lot of drone photography. My photography specialties are travel and landscapes, however, I have found myself doing pet photography for fun. When I travel I usually travel with a camera, 2 lenses and my drone. The appeal of photography for me is to show people how wonderful the world is in all its natural and unnatural beauty.

What do you feel would greatly improve epilepsy care currently in Queensland?

Queensland is really lucky to have some of the most skilled health care professionals experienced in treating functional neurological disorder. Due to the close relationship that FND and epilepsy have we should be doing more to promote education and training in both fields. Of course to do this requires funding. Government funding would allow for more training and education, production of educational materials and even a specialty clinic for patients.

I also think the stigma surrounding FND is a major barrier even amongst a majority of the healthcare community, however it is a problem and it is a problem that needs addressing. The way to address this is through education, this is something that Epilepsy Queensland does well and have started to provide much needed information on FND alongside epilepsy education to their clientele.

Vince Cheah will be one of the speakers at Queensland Epilepsy Symposium on Thursday 31 October.

**For more information visit:
www.epilepsyqueensland.com.au/seminars-1**



QUEENSLAND EPILEPSY SYMPOSIUM – THINKING OUTSIDE THE BOX

For more than ten years Epilepsy Queensland has delivered current and cutting edge information around epilepsy and its management, along with world renowned presenters and scientists and 2019 is no different.

In this our 50th year, Epilepsy Queensland is holding the Tenth Annual Queensland Epilepsy Symposium, thinking outside of the box!

Along with Laureate Professor Ingrid Scheffer, Assoc Professor Lata Vadlamudi and Dr Ubaid Shah, there will be information on a number of exciting research projects, developing devices for epilepsy and the science of sleep. A panel of people speaking about the influence of epilepsy on their lives will be moderated by Dr Dan McLaughlin.

Over the years the symposium has gained the support of many talented and respected researchers and medical professionals. We

have had conversations about medicinal cannabis, the brain changing itself, how our adolescents manage the transition from children's clinics to adult ones as well as lots of wonderful discussion around how genetics are changing the face of the treatment of epilepsy.

We have had presentations and video link ups with eminent neurologists in the USA, UK's finest speak from a paediatric perspective and some touching conversations with people who live day to day with the challenges that come their way either for themselves or their children.

We've gone from 'why drugs fail' to 'epilepsy and spirituality', from surgery to dietary therapies, and from disease modifying therapies to epilepsy and mood. From epilepsy and men to epilepsy and pregnancy.

Below is a symposium timeline. How time flies when we are thinking outside the box!

2010 –
Andres M Kanner
David Reutens
Cecilie Landers
Stephen Malone
Harry McConnell
Graham Scambler
Mal Hopwood

2011 –
Orin Devinsky
Baroness Susan Greenfield
Helen Cross

2012 –
Renzo Guerrini
Lakshmi Nagarajan
Karin Borges
Robert Campbell
Harry McConnell
Roy Beran
James R Doty
Sophie Calvert

2013 –
Barbra Arrowsmith-Young

Harry McConnell
Kate Riney
John Paul Leach

2014 –
Chris De Giorgio (Skype)
Terry O'Brien
Roy Beran
Harry McConnell

2015 –
Martin Brodie
Helen Cross
Kate Riney
David Reutens
Kate Thompson
Cecilie Lander
Harry McConnell
Christian Gericke

2016 –
David Reutens
Lindy Jeffree
Kate Thompson, Angela Spencer
& Yvette McMurtrie
Anastasia Suraev & Jordyn Stuart

Kimberley Irwin
Paul Pun
Karin Borges
Dan McLaughlin
Cecilie Lander
Sandra Petty

2017 –
Sasha Dionisio
Piero Perucca
Harry McConnell
Rian Rob
Ruth Blackburn
Cecilie Lander
Dan McLaughlin
Lata Vadlamudi

2018 –
Sean Pittock
David Reutens
Glenn King
Stephen Malone
Terry O'Brien
Karin Borges
Peter Jones
James Wheless

We hope you can join us for the Tenth Annual Queensland Epilepsy Symposium on Thursday, 31 October 2019.

For more information visit: www.epilepsyqueensland.com.au/seminars-1



RESEARCH UPDATE

REFRACTORY EPILEPSY

GENOMICS PROJECT

This project is funded by Queensland Genomic to improve the diagnosis and treatment of Queenslanders living with neurological disorders. Refractory epilepsy is the pilot neurological disorder for the project.

Epilepsy is one of the most common neurological disorders affecting more than 50 million people worldwide and is characterised by the occurrence of seizures. One in 26 people will develop epilepsy during their lifetime. People living with epilepsy experience a global impact on most aspects of daily living such as employment, driving, life insurance and lifestyle adjustments, leading to substantive psychological and socioeconomic impacts.

There is a genetic basis to the majority of epilepsies of unknown cause and this project looks at the genome, which is a complete copy of a person's genetic information. The first step of the Refractory Epilepsy Genomics project will be to test if integrating genomic testing into refractory epilepsy patient care improves health outcomes. Queensland neurologists will be referring their patients who meet the criteria for genomic testing, to determine if there is a genetic basis for their epilepsy.

If genomic changes are identified in patients, the next step is to understand whether these changes have a functional impact to cause epilepsy. Each person has a genomic landscape and it is this individual landscape we are trying to understand, to better personalise drug treatments for epilepsy patients. One way to do this is by using induced pluripotent stem (iPS) cells.

iPS cells can be made from blood cells by using chemicals to make these cells earlier versions of themselves, which then have the potential to become other cell types. iPS cells can be differentiated into various types of neurons and even interconnected mini tissues that resemble the human brain. We can learn a lot by studying iPS cells made from samples collected from epilepsy patients. They can help us understand how variations to genes can result in epilepsy in a particular person and can be used to investigate potential treatments for their epilepsy.

Potential impact of this research

A major outcome is the potential to find a cause, to end the “diagnostic odyssey” of repeated investigations and hospital visits, for some epilepsy patients. The health impacts of this are substantive in terms of patient and family quality of life.

Genomics is being increasingly integrated into clinical care and its role for both clinical utility and cost-effectiveness has been clearly established in the severe epilepsies of infancy. It is timely for these studies to be applied to children and adult patients with refractory epilepsy as health care costs are increasing for this group at the same time as genomic testing costs are decreasing.

The Refractory Epilepsy Genomics project will also review the optimal way to obtain samples for genomic testing; the strengths and utility of various genomic technologies; and facilitate the establishment of multi-disciplinary approaches and capabilities for improved patient care.

With the rapid increase in gene discovery in epilepsy, studies like this will facilitate a deeper understanding of the cause of epilepsy as well as enable the search for more effective drug treatments (repurposed or novel) to reduce the burden of disease for this debilitating disorder. The future lies in developing bespoke treatments, based on the functional genomics outcomes for individual patients, to ultimately cure this debilitating disorder.

Associate Professor Lata Vadlamudi will be presenting at the Queensland Epilepsy Symposium on Thursday 31 October 2019. For more information visit: <http://bit.ly/EQSymposium>



MAKE A DIFFERENCE THIS SEPTEMBER

This is your chance to make a difference for children living with epilepsy during the month of September.

Little Poss is Epilepsy Queensland's mascot who just happens to have epilepsy, as some possums do.

Purchase from the range at your local chemist and know your funds are raising awareness for children living with epilepsy and help to have a positive impact on their future.

How can you help

Order a compact kit for your school, workplace, business or home. Buy from our awareness range, which includes wristbands, possums, keyrings and much more.

Alternatively, you can visit our online shop.

Register today

www.epilepsyqueensland.com.au/little-poss-appeal or call 1300 852 853

Epilepsy Queensland would like to thank our valued sponsors



The Pharmacy
Guild of Australia



September Book Sale

Did you know we have useful resources to help children learn about epilepsy?

And Down Went Poss, Poss's School Days, Lucy's First Disco

Along with signed copies of our Patron Wally Lewis' biography Out of the Shadows

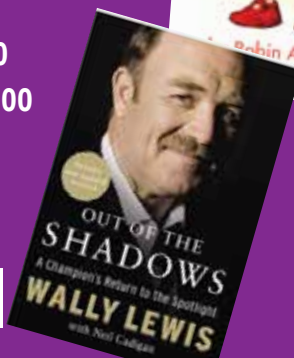
Poss's School Days @ ~~\$48.00~~ \$9.00

And Down Went Poss @ ~~\$48.00~~ \$9.00

Lucy's First Disco @ ~~\$46.99~~ \$8.00

Out of the Shadows @ \$30.00

Prices do not include GST



SUPPORTER SPOTLIGHT

Together we CAN make a difference

Iluka Woombah Rotary Pignic Race Day

Is this one of the cutest and most unique ways to raise funds for people living with epilepsy? We are incredibly grateful to Alana Alexander and the Rotary Club of Iluka-Woombah for supporting Epilepsy Queensland via their annual Iluka's Pignic Race Day.

Alana Alexander the treasurer of the Club suggested Epilepsy Queensland as a beneficiary of the day as her 14-year-old Granddaughter Charlotte lives with epilepsy. Charlotte resides in Brisbane and was diagnosed with epilepsy when she was five years of age. Alana knows how Charlotte and her family went through some difficult times when she was first diagnosed and Alana wanted to ensure that other families with young children with epilepsy are able to have access to information and support for their children.

Thank you Alana and the team at Rotary Club of Iluka-Woombah for your support.

Everesting for epilepsy

Simon Watt lives with epilepsy. He wanted to do something to challenge himself and raise funds and awareness for epilepsy at the same time. On 1 June he took on a superhuman challenge 'Everesting for Epilepsy' cycling up and down the steep side of Mt Coot-tha 45 times, 8,848m the equivalent height of Mt Everest. Simon used the challenge to raise nearly \$13,000 to help fund our information and support services for Queenslanders living with epilepsy.

Simon shared: "Cycling is my passion however when epilepsy has restricted me from driving it has also provided me with freedom to get from A to B."

Simon started his ride at midnight, cycling alone in the dark with his incredibly supportive wife Elise and a handful of family cheering him on. As day turned to light Simon was joined by a great crew of family and friends, some who took turns riding laps with him. The ride meant old friends from as far back as school reached out to support Simon's ride by making donations, sharing his story and completing the ride with him.

His crew were well prepared for the ride with a range of snacks and drinks, as well as energetic enthusiasm and encouragement to sustain Simon for the ride. Simon let us know that the sweetest treat was the beer he shared with a friend at the end of the ride.

Simon completed his ride ahead of schedule in 12 hours 56 minutes.



Thank you to
the team at Iluka
Woombah Rotary



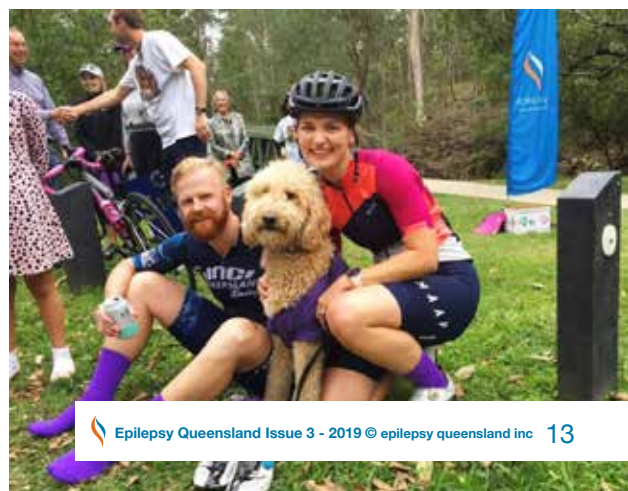
Our CEO Helen Whitehead
and Alana Alexander



L-R Lisa Locker (Epilepsy
Queensland), Simon Watt,
Helen Whitehead, Elise Watt



Do you have an idea for
a challenge or an event
you would like to take
on to raise funds and
awareness for epilepsy?
Contact our fundraising
team on 1300 852 853.





VALE AILSA GILLIES

It is with great sadness that we acknowledge the passing of Ailsa Gillies.

Ailsa was an accomplished woman. She had a science degree and a successful career in the Department of Primary Industries.

Ailsa was strongly committed to making the world a better place. Her interests were wide and she walked the talk. As well as being a financial donor, she consistently donated considerable time over 50 years to many organisations, including the Zonta Club, UQ Alumni Association, the Naturalists Club and the State Library.

Epilepsy Queensland was privileged to have Ailsa as a Board member for twenty years. She had experienced discrimination throughout her life and was particularly supportive of disadvantaged groups and the need for acceptance within the community. She retired from our Board in 2013. During this time she also actively volunteered in many different ways. We could always count on Ailsa. Staff and volunteers alike treasured her commitment to the organisation, and held her in high regard. We have fond memories of Ailsa and sincerely miss her.

THE VALUE OF MEMBERSHIP

When Sandi's son Jack was diagnosed with epilepsy in early 2018, she was looking for as much information as she could find to understand epilepsy and assist her son to live well. She was also seeking support and connection to help her get through all of the challenges of a diagnosis of epilepsy in the family.

She Googled and found the Epilepsy Queensland Helpline. This initial support and information was followed up with training at our Woolloongabba office and at Jack's school.

Sandi became a member of Epilepsy Queensland, so their initial training session at Woolloongabba was complimentary. Later in the year she also attended Queensland Epilepsy Symposium. Current financial members receive a \$50 discount on the ticket price.

"I attended the Queensland Epilepsy Symposium last year for the first time. It was so valuable to learn from the medical Professors and neurologists themselves about various developments in epilepsy, therapies and devices."

Sandi also volunteers for Epilepsy Queensland on a regular basis and is a passionate member of our epilepsy community, raising awareness and funds for others affected by epilepsy.

Your continued support is important to us - Together we CAN make a difference!

To join or renew your membership today contact us on:
Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)
Email: member@epilepsyqueensland.com.au



BRISBANE RECOGNISES 50 YEARS OF SUPPORTING QUEENSLANDERS LIVING WITH EPILEPSY



Do you have ideas about how you would like to see us celebrate 50 years of supporting Queenslanders living with epilepsy? Recently Brisbane Lord Mayor Adrian Schrinner hosted a Civic Reception to celebrate the occasion. Our Patron Wally Lewis did a live sports broadcast from the reception and was thrilled to catch up with some of our original committee members along with some current supporters, donors, ambassadors, volunteers, staff and board members.

In a speech Wally discussed his own experiences of living with epilepsy and how a seizure on air delivering the sports news changed his life. This gave him the push to investigate epilepsy surgery and now Wally has been more than 12 years seizure free. It also gave him the courage to start speaking publicly about living with epilepsy. For Wally, 2019 marks 10 years as Patron of Epilepsy Queensland.

Wally paid tribute to the original and early members of Epilepsy Queensland who were able to attend and those who are no longer with us.

"50 years ago, our founder Doris Kemp, saw the repeated discrimination of her son Robert. Back then, anti-discrimination and disability laws just didn't exist. Doris knew something needed to be done and there wasn't an organisation to assist

in Queensland. So Doris put notices in papers and spoke to everyone who would listen. From there the Epileptic Welfare Association in Queensland was formed. This was a brave and bold move. Doris faced a lot of criticism."

He added: "We are pleased to have some of the early committee members here today including Marella Jenkins, Fay Kranz and Bob and Elizabeth Williams. We also have Peter Kemp representing the Kemp family and Geraldine Young representing Cecily Young. We will be eternally grateful to these members."

Thank you to everyone who has contributed to Epilepsy Queensland over the past 50 years and helped us reach out to more Queenslanders living with epilepsy.

2019

DIARY DATES

18 August	Motorbike Ride 4 Epilepsy Join us for the inaugural Motorbike Ride 4 Epilepsy from Archerfield to Flagstone. After the ride enjoy burgers at The Barn & Scotty's Garage then return at your own pace. To secure your entry we ask for a \$50 tax-deductible donation via http://bit.ly/RideForEpilepsy .
25 August	Bridge to Brisbane Join team EpilepsyQld and raise awareness and funds for Queenslanders living with epilepsy
1-30 September	Seizure First Aid Aware One in 10 people will have a seizure during their lifetime. With this in mind, our aim is for one person in every household to know seizure first aid. During the month of September we will be sharing tips and stories about seizure first aid on Facebook, Instagram, Twitter, You Tube and Linked In. Find out more: www.epilepsyqueensland.com.au/first-aid
1-30 September	Little Poss Appeal Help us sell our range of collectible merchandise including pens, Poss badges and awareness wristbands - plus gorgeous plush possums. This is a simple yet meaningful and fun way to not only raise funds but also increases community awareness, both of which are of enormous benefit to people living with epilepsy.
31 October	Queensland Epilepsy Symposium Epilepsy Queensland has proudly presented Queensland's Epilepsy Symposium since 2010. The Symposium has presentations that will be of interest to anyone with a connection to epilepsy whether you are a person with epilepsy, a family member, a health professional or care worker. Register your interest today by contacting Epilepsy Queensland on 07 3435 5000 or services@epilepsyqueensland.com.au . http://bit.ly/EQSymposium
15 August 12 September 17 October 14 November	Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
13 November	Understanding Epilepsy Workshops (Gold Coast) For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals

Please call 07 3435 5000 for further information on any of the above events

MEMORIAL SERVICE

"The hurt you embrace becomes joy. Call it into your arms where it can change."

L

-Rumi

The Epilepsy Queensland Bi-Annual Memorial Service is an opportunity for us all to remember those who we have lost to epilepsy. It is a time where we come together to share a sacred space. In that space, we use music, personal reflections, prayer and poetry as a way of acknowledging our loss and the grief of a wider community. In addition, that space is different for us all, however it is the same grief, the same sadness and at the same time, there are the memories. It is those memories that we share with each other that are sacred.

Mercy Place, Bardon
October 12, 2019 - 2pm
RSVP and more information [Jenny Ritchie jritchie@epilepsyqueensland.com.au](mailto:Jenny.Ritchie@epilepsyqueensland.com.au)

