

the flame

the newsletter of epilepsy queensland inc

Issue 3 – 2017

Purple Day

bringing epilepsy
out of the shadows

Seizure first aid

*Navigating your way
through epilepsy*



Doris and Robert Kemp



Robert Kemp and Little Poss

Vale Robert Kemp

Doris Kemp was the founder of Epilepsy Queensland. She was motivated to do so through her son Robert's experience of epilepsy. Since leaving school, Robert had been employed in a number of jobs, but the effects of his condition were not widely understood, resulting in his services being terminated repeatedly. In 1968, no laws ensured equal employment opportunities for people with disabilities and a great deal of ignorance and misunderstanding existed about the management of epilepsy, despite its existence being quite prevalent. Doris with the support of her husband Arthur, decided to try and change things. This all led to the inaugural meeting of Epilepsy Queensland (then known as Epileptic Welfare Association of Queensland) on 19 February 1969.

For more than 10 years, the Epilepsy Association operated out of the Kemp family home in Wavell Heights. Doris Kemp was a driving force behind the association for many decades and was awarded the Order of Australia Medal for her work with epilepsy in 1980. The Doris Kemp Memorial Award is presented annually to a tertiary student who has meritoriously completed an epilepsy-related project.

In 1997, Arthur passed away at the age of 87 followed by his wife Doris in 1998 at the age of 88. Robert continued to live

independently in his family home for over a decade until he was ready to retire to St John's home for men, where he happily lived until he passed away in April 2017 at the age of 71.

Robert's cousin Peter told us of his close and loving connection to family, his happy disposition and fatalistic approach to life. Robert had a range of social interests including a love for billiards and regular visits to the Irish Club. He took great pleasure from listening to music and Robert held season tickets to the Lyric Theatre and other QPAC venues. Peter remembers Robert's great sense of style, attending the theatre dressed sharply in a black dinner suit, fancy shirt and bow tie to match.

Robert will be sadly missed but we are very grateful that the legacy of the Kemp family will continue through a generous bequest from Robert. The Kemp family established Epilepsy Queensland in 1969 and bequests such as these, will ensure we can continue to advocate for people living with epilepsy into the future. Epilepsy Queensland will celebrate its 50th year in 2019.

There is a quote by author Nelson Henderson: "The true meaning of life is to plant trees, under whose shade you do not expect to sit." The commitment of Robert and the Kemp family to the future of Queenslanders living with epilepsy will not be forgotten.

To find out more about making a bequest to Epilepsy Queensland or the upcoming 50th anniversary celebrations contact Leigh Gilbert on **07 3435 5000, 1300 852 853** (outside Brisbane) or email **pr@epilepsyqueensland.com.au**.

Contents

- 2 vale Robert Kemp
- 3 help us create epilepsy awareness this September!
- 4-5 ask the educator – seizure first aid
- 6-7 my epilepsy story - love overcomes seizures

- 8-10 purple day - bringing epilepsy out of the shadows
- 11 events and fundraising
- 12-13 profile: navigating your way through epilepsy
- 14 -15 .. 30 minutes with Dr Sasha Dionisio
- 16 active fundraising

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 his/her discretion.

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



Step up for epilepsy awareness this September!

Let's make September the month we bring epilepsy out of the shadows by participating in the Little Poss Appeal and/or September Sizzle at your school, workplace, business or home.

Little Poss Appeal

Help us create positive change for children living with epilepsy by raising awareness and much needed funds. Epilepsy Queensland's mascot, Little Poss, has epilepsy as some possums do. He helps children learn about epilepsy and how to deal with seizures, medication, teasing and schoolwork.

How you can help?

Help us sell our range of cute merchandise including pens, Poss badges and awareness wristbands - plus gorgeous plush possums. This year we have reintroduced both the finger and hand puppets as well as a 25cm possum. 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.

Each order comes with a compact counter display box, Little Poss stickers for retail staff to wear and promotional posters. It's easy to do your bit! As the merchandise is sent on consignment - there is no cost to you. (conditions apply)

Alternately you can buy little Poss merchandise from a participating pharmacy or securely online: www.epilepsyqueensland.com.au/shop.

Epilepsy Queensland would like to thank the following for their kind and valued ongoing support:



September SIZZLE for Seizure First Aid

In September 2017 Epilepsy Queensland will hold its first September Sizzle for Seizure First Aid. 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. Join with us by hosting a sausage sizzle or other event (Breakfast, BBQ, Dinner Party Morning/ Afternoon Tea) to raise vital funds to increase awareness and understanding of seizure first aid.



- Sign up for September Sizzle** - Host your own sizzle from backyard BBQ to black tie, at work, school or your home. www.epilepsyqueensland.com.au/sizzle
- Be a Seizure First Aid Hero** – share your story to raise funds and awareness of seizure first aid. www.everydayhero.com.au/event/septembersizzle
- Celebrate your birthday for seizure first aid** – Are you celebrating your birthday or a special occasion in September? Ask your family and friends to donate to Epilepsy Queensland in lieu of gifts. Set up your celebration page at: www.everydayhero.com.au/event/celebrateforepilepsy
- Buy/sell merchandise** - visit our online shop, download and return an order form. www.epilepsyqueensland.com.au/little-poss-appeal
- Donate online** - make a secure online tax deductible donation. Visit www.epilepsyqueensland.com.au/donate
- Promote on Facebook** – During the month of September we will be sharing tips and stories about seizure first aid on Facebook. Please share our posts or your own posts about your experience with seizure first aid. www.facebook.com/EpilepsyQueensland

Contact Us

So what are you waiting for?

Register today for the Little Poss or September Sizzle activity of your choice or contact us for further information.

Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)

Email: pr@epilepsyqueensland.com.au

Website: www.epilepsyqueensland.com.au/sizzle

Ask the educator – Seizure first aid

Q: I understand that seizure first aid might be different to other first aid, is that true?

A: Yes. There are many different seizure types and they can present very differently with each person. It can be frightening to witness a seizure for the first time. Therefore, it is important to be able to recognise the type of seizure the person is having in order to best respond with the most appropriate first aid.

The following are the most common seizure types along with the recommended first aid response.

****** In the event of a seizure follow instructions in the individual's seizure management plan.

Tonic Clonic Seizures (formerly called grand mal)

During a tonic clonic seizure, a person's body stiffens and they fall to the ground which is the tonic phase. Their limbs then begin to jerk in strong, symmetrical, rhythmic movements and that is the clonic phase. The person may have excess saliva, go blue/grey or red in the face, and occasionally lose control of their bladder and/or bowel.

This type of seizure can be frightening to watch. The seizure itself is unlikely to seriously harm the person having the seizure. They may however vomit or bite their tongue and can sometimes injure themselves if they hit nearby objects as they fall or convulse. The seizure generally stops after a few minutes. Afterwards the person is usually confused and drowsy, they may have a headache and want to sleep. This drowsiness can last for a number of hours.

✓ DO

- Stay calm - remain with the person.
- Time the seizure.
- Protect from injury - remove any hard objects from the area.
- Protect the head - place something small and soft under their head and loosen any tight clothing.
- Gently roll the person on their side as soon as it is safely possible to do so and firmly push the angle of the jaw forward to assist with breathing.
- Stay with the person until the seizure ends naturally and calmly talk to the person until they regain consciousness, usually within a few minutes.
- Reassure the person that they are safe and that you will stay with them while they recover.

✗ DO NOT

- restrain the person's movements.
- force anything into the mouth.
- give the person water, pills or food until they are fully alert.

Call an ambulance - 000 - if:

- the seizure activity lasts five or more minutes or a second seizure quickly follows.
- the person remains non-responsive for more than five minutes after the seizure stops.
- the person is having a greater number of seizures than is usual for them.
- the person is injured, goes grey/blue in the face or has swallowed water.
- the person is pregnant or has diabetes.
- you know, or believe it to be, the person's first seizure.
- you have any doubts.

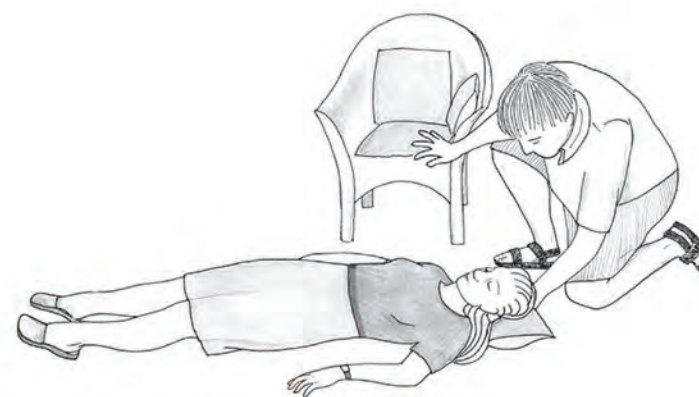
NB: Prolonged, continuous, or repetitive tonic clonic seizures require urgent medical attention.

Focal Seizures (previously called partial seizures)

With this type of seizure, the person may appear unresponsive and confused as their consciousness is impaired. Automatic movements such as smacking of the lips, wandering, or fumbling movements of the hand may be present. He or she may display inappropriate behaviour that may be mistaken for alcohol/drug intoxication or psychiatric disturbance.

First Aid for focal seizures

- During a focal seizure you may need to gently guide the person past obstacles and away from dangerous places.
- As the seizure finishes, calmly talk with the person as they regain awareness and ask if they are okay.
- Reassure the person that they are safe and that you will stay with them while they recover.



Absence Seizures

(previously called petit mal seizures)

An absence seizure causes loss of awareness for a brief period. The person stares vacantly, the eyes may drift upwards and flicker. It may be mistaken for daydreaming.

First Aid for absence seizures

- Recognize that a seizure has occurred.
- Reassure the person, and
- Repeat any information that may have been missed during the seizure

Wheel Chair First Aid

If someone starts to have a seizure while confined in a wheelchair, seated on a bus, train or tram or strapped in a pram or stroller:

✓ DO

- Protect the person by preventing them from falling if there is no seat belt.
- Make sure the wheelchair or the stroller is secure.
- Protect the person by supporting their head. Something soft under the head will help if there is no moulded headrest.
- Check whether you need to move any hard objects that might hurt arms and legs in particular.
- Consciousness usually returns within a few minutes.
- Reassure the person and tell them what has happened.

NOTE: When the seizure has finished you need to ensure their airway is clear. This may involve removing food or vomit from their mouth and supporting their head to maintain a clear airway. It may or may not be appropriate to remove the person from the chair at the end of the seizure. This will depend on your assessment of the safety issues involved both for you and them.

✗ DO NOT

- Try to stop the seizure.
- Put anything in the persons' mouth.
- Try to remove them from their position. In most cases the seat rest provides some support.

To download a seizure first aid poster, visit:
www.epilepsyqueensland.com.au/first-aid.

This information is given as a guide only on the understanding that Epilepsy Queensland Inc shall have no liability arising by reason of any person using or relying on the information and whether caused by reason of any error, negligent act, omission or misrepresentation in the information or otherwise.

Epilepsy Queensland is launching a seizure first aid awareness campaign in September called the September Sizzle for Seizure First Aid. You can be involved at home, work or your club by:

- Hosting a fundraising and awareness Sizzle (barbecue or other event)
- Arrange a training session about epilepsy or seizure first aid at your workplace or school
- Tell your epilepsy story to local media, social media, community groups or the flame
- Distribute Epilepsy Queensland awareness information to local medical, school, and disability organisations.

Contact Epilepsy Queensland on **07 3435 5000** or visit www.epilepsyqueensland.com.au/sizzle.

Love overcomes seizures

For 30% of people with epilepsy, seizures are not controlled by current treatments and their epilepsy ranges in severity. For Louise Martin, seizure first aid is not a rarity, but a part of everyday life. Her eldest son William lives with Lennox Gastaut syndrome (a rare form of childhood epilepsy) that means he has all 40 seizure types. Louise shares with us her unpredictable days and how seizure first aid, a comprehensive epilepsy management plan and love can be a lifesaver.

William was first diagnosed at age six months by a Brisbane neurologist with infantile spasms after an EEG and MRI. Now at the age of 15, Louise has tried everything to abate William's seizures from the ketogenic diet and steroids, to a vagal nerve stimulator and over 12 different medications.

She explains: "William can have up to and over 200 seizures a day when he is in status. He can seizure in his sleep all night and sometimes just in the mornings. They can be so severe that he has been hospitalized for eight days and goes into non convulsive status."

Louise wants people to understand what epilepsy can mean for some families. She wants this to reduce the stigma when William has a public seizure and so that people understand basic seizure first aid and can assist. She and her younger son Toby care for William on their own.

She said "William is nonverbal, still in nappies, cannot bath and feed himself or walk on his own. He requires permanent 24/7 one on one care. He has no warnings and can have a life threatening seizure at any time. The most predictable thing about William is how incredibly unpredictable his epilepsy is. We always have to be ready for the worst but we try to keep living and it's almost impossible to explain."

"Sadly, epilepsy is still kept in the shadows and frightens people. I have had many people stare at us and walk away when William has seizures in public and some people still believe you hold their tongue. It's ignorance and fear and not knowing enough about it."

William has experienced many life threatening situations due to his epilepsy. Louise shared with us: "William had a massive drop seizure and landed flat on his face. His injuries were horrific and I was so worried about how much blood he swallowed. It was one of the scariest days in my life."



Even situations that seem non-threatening can be critical for William. Louise recounted a situation with William on the bus: "William has gone into non convulsive status whilst on a bus on the way to school. They just thought he was asleep when in fact he was unconscious!"

This is one of the reasons why Louise is trying to advocate for all bus drivers and their aids to have formal seizure first aid training.

Louise said: "Queensland legislation states that bus companies do not have to have their staff trained in first aid, even if they work at a special school with very high needs children. I would love to have this changed."

"I hope one day when I have time and energy I can lobby to have it done as it may save someone's life. I make sure I educate William's carers and have a very extensive seizure management plan that Epilepsy Queensland helped me do. William's school has also done training. They are great and follow up on his management plan and training of school staff."

Like any mother, it is love that motivates Louise in her personal care for William and her drive to create change for all people living with epilepsy.

She shared: "William loves to love. He has a gift that is so beautiful that unless you're in his company and really see him, then you won't be blessed to feel this, but if you do, you will learn from him in ways that will change your life. I see this gift for those who love him. He enjoys

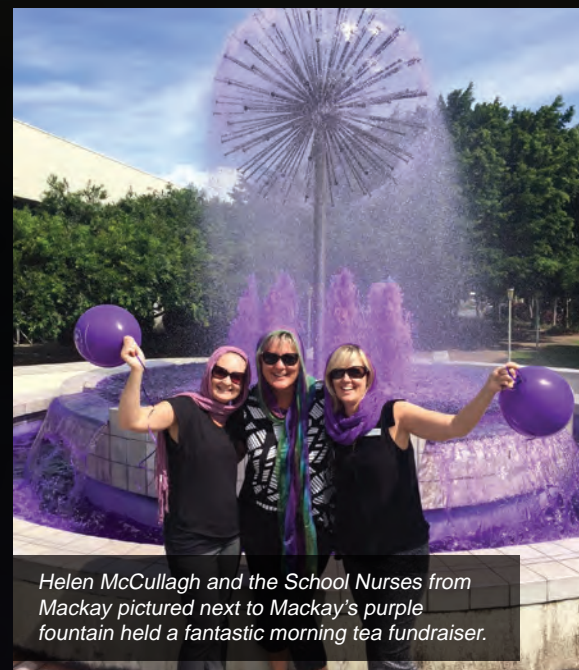
watching AFL and sports and he loves food, especially Maccas - so much so, that at times when we do the drive through he has a seizure (so damn cruel). Most of all he loves his Mum. He tells me this every day without a single word."

Louise's hope for William is that one day he will be seizure free, alert, happy and have good quality of life. She said: "I have been told he will unlikely be seizure free, but I hope and never give up."

Epilepsy Queensland can assist with the three pillars of seizure first aid – management plans, understanding epilepsy training to help recognize the different types of seizures and administration of midazolam training. Members, who have epilepsy and their immediate family, receive this training for free at Epilepsy Queensland at Woolloongabba during the daytime session or training can be conducted in your workplace for a small fee. To join Louise in her quest to create awareness and raise funds for seizure first aid, you can participate in our September Sizzle for Seizure First Aid. Details are available on the enclosed flyer. For more information on training phone **07 3435 5000**.

Purple Day

bringing epilepsy
out of the shadows



Helen McCullagh and the School Nurses from Mackay pictured next to Mackay's purple fountain held a fantastic morning tea fundraiser.

Thank you to everyone who supported Purple Day for epilepsy awareness month in March! Together we were able to bring epilepsy out of the shadows and raise vital funds for Queensland children and adults living with epilepsy. We wanted to share some great photos of our purple heroes and fundraisers, Purple Pharmacy winners for 2017 - Pelican Waters Pharmacy, supporters taking the purple pledge and some of Queensland's fantastic purple illuminations. The fight to reduce the stigma of epilepsy and build awareness in the community doesn't end with Purple Day.



Like us on Facebook:
www.facebook.com/EpilepsyQueensland
to be the first to know of upcoming events and campaigns. Your support means the world to us!

Continue next page →



Pelican Waters Pharmacy were the winners of the Purple Pharmacy for 2017 and helped spread awareness on the Sunshine Coast.

Fundraising Challenges

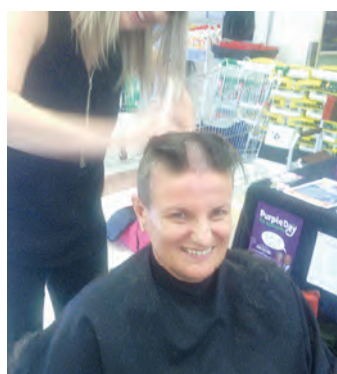
Racheal Johnson faces her fear of heights!

Each year people take on challenges to honour a family member or friend living with epilepsy, or for those with epilepsy to show they won't let epilepsy beat them. Through these fantastic efforts our purple heroes raise awareness and help reduce the stigma of epilepsy.

Brisbane resident Racheal Johnson (see cover photo) is terribly afraid of heights, but took on the Story Bridge Climb for her daughter Isla on Purple Day as the bridge lit up purple. Racheal wanted to raise as much money as possible so that others continue to have access to the same vital services that made such a difference when her daughter was newly diagnosed. She did a fantastic job raising \$1,532!

Racheal said: "After attending a workshop with Epilepsy Queensland and having spoken to them over the phone a number of times I was amazed how knowledgeable and supportive they are and really wanted to give something back to them. I wanted to do something out of my comfort zone as many times Isla is faced with appointments, examinations and tests that she doesn't want to do! So I decided to conquer my fear of heights."

Sally shaves her head for epilepsy awareness in Cairns



Cairns has its own Purple Hero, Sally Morse, who took on an almighty challenge on behalf of her daughter and little hero Natalie! Sally shaved her head with a crowd looking on at Redlynch Shopping Centre on Saturday 25 March. The head shaving raised \$1,617 and great

awareness for epilepsy including news coverage by the Cairns Post.

Sally's message is: "Epilepsy can be very challenging, whether it is you that is living with it or someone you love and care for. Purple Day is our opportunity to give something back, but also get a bit silly and have fun along the way."

Rhiarnie Coyne receives a close cut for her brother and cousin

Special thanks go out to brave 16-year-old Rhiarnie Coyne, who cut off her hair for her brother and cousin who both live with epilepsy. The shave held at Freedom Aged Care raised a fantastic \$718.85.

Rhiarnie said: "I remember when my brother Jack had his seizures. I felt scared and helpless. I remember



watching Mum crying. My biggest fear was watching the ambulances (sic) working on Jack. If I can help make a difference and bring epilepsy out of the shadows I will be happy."

Schools



↑ The purple EpiApe visits St Joseph's Catholic Primary School at Gayndah.



← Thanks to the staff and students at Saint Francis Xavier School at Goodna. Their colouring-in competition and crazy hair day for Purple Day raised \$635 for epilepsy.

Hospitals

The Cairns Hospital Neurology Department turned purple with a fantastic morning tea for epilepsy on their clinic day.



A fantastic array of cakes and all things sweet from the Lady Cilento Children's Hospital Neurology and ketogenic diet team.

Purple Pledge

Renee Williams presenting Epilepsy Queensland Acting CEO Natalie Lee with over 300 signatures that she collected on the Purple Pledge. Renee held a stall at Bundaberg Base Hospital and raised awareness featuring in the Bundaberg NewsMail, as well as the local ABC Radio and Channel 7 News.



Events and Fundraising

Accounting group shows support for Queenslanders living with epilepsy

People with epilepsy have received a boost following a donation from accounting and financial services network Walker Wayland Australasia. The donation of \$5,000, presented to Epilepsy Queensland Patron Wally Lewis, is the first by the network through its recently established Walker Wayland Foundation.

Walker Wayland Australasia Executive Director Stephen Roger said: "Our team chose Epilepsy Queensland during our annual conference in Toowoomba on Queensland's Darling Downs as it is a cause of particular interest to our Queensland members.

"We were delighted to be able to make the first donation a substantial one after launching the Foundation only two months ago. It follows generous support for our conference by software provider Reckon APS."

Paul Hilton, CEO of conference host firm Power Tynan and Walker Wayland Australasia Chairman, said: "We are delighted that this donation to Epilepsy Queensland is the first of many grants through the Foundation to support a variety of causes to strengthen Australian communities."



The donation will help Epilepsy Queensland reach out to more Queenslanders affected by epilepsy through practical training sessions and the toll-free Epilepsy Helpline. If you or someone you know would like to speak to someone about epilepsy, please contact the team at Epilepsy Queensland on 1300 852 853.

Is your membership due for renewal?



Your subscription to "the flame" is just one of the benefits of Epilepsy Queensland membership. To continue receiving your complementary quarterly copy, we ask you to renew your membership. If you have not already renewed your membership prior to the end of the financial year, or if you are not sure if your membership is due, contact us on 07 3435 5000.

As a valued member and important part of our family of loyal supporters, you will also receive:

- Free (daytime in-house) workshops for members who have epilepsy and their immediate families
- Discounts on publications, seminars and events
- An invitation to attend special events including the Annual General Meeting and Awards Ceremony
- Contribute to greater access to epilepsy services, support, policy, research and awareness initiatives.

To join or renew your membership today return the enclosed form or contact us on:

Phone: 07 3435 5000 or 1300 852 853 (outside Brisbane)

Email: member@epilepsyqueensland.com.au

Website: www.epilepsyqueensland.com.au/membership

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

Profile:

Navigating your way through epilepsy

Jenny Ritchie shares how the Epilepsy Helpline can be a lifeline!



a high priority for us at EQI, just being with people in their grief and in their celebrations, as well as witnessing the acceptance that comes with knowledge and empowerment. People have built up their own resilience and that always warms my heart. Sometimes I wish there were more hours in the day. For all of us I believe life gets in the way, we haven't the time to just be present and listen to each other.

We hold a Memorial Service on a biennial basis, where we come together with families who have lost a loved one to epilepsy. It is something very special that we can do to support families, to remember and celebrate the lives of people who are so important to us. We share reflections, stories, music and prayers to support each other in celebrating the life lived.

About the helpline

Tell us about the helpline. What do people call you about?

The phone calls we receive are wide and varied. They range from the practical side of things like 'where do I buy a bed monitor' or 'how do I take this medication', to assisting the school environment in epilepsy management and safety. Or from making a time to meet with a family who have a new diagnosis to booking them in for training and understanding seizure first aid. Our calls often are more about advocating for the person with epilepsy, maybe it's that their workplace is frightened of seizures. Maybe it's that the children in the classroom want to know how to help their young friend when they have a seizure. The person on the other end of the phone may just want to talk about how their moods have changed since having seizures or they want someone to explain the anxiety they are experiencing because that is something they've never had before. All these opportunities give us the chance to listen and support people through the helpline with either practical advice or emotional support.

As a counselor do you answer different types of calls to the nursing staff on the team?

We as a team at EQI, are all skilled in assisting people with their concerns around epilepsy. If we feel that another team member is able to assist more specifically we would refer them to the caller. As a counselor I suppose some calls are referred to me because of a different skill set and life experience. Just like the nurses here at EQI have a specialised appreciation of the medical side of things, I hope that I provide a secure place for people to access and understand their vulnerability in traveling through the day to day issues.

Are people often upset or worried when they call?

I can appreciate firsthand how receiving a new diagnosis can knock you sideways for a bit. It often brings up

"I greatly appreciated the empathy and information. It was actually the first time I really felt 'listened to' since my daughter's seizure. Thanks you!"

concerns and fears that we think we've never dealt with before. A lot of our consumers are frightened initially, and worried about their future. Not being able to drive anymore often brings up feelings of limitation and frustration that they haven't experienced before. We can help them understand their circumstances. We have the time to listen as they unpack what has happened to them and often provide some solutions.

Do health professionals often call the helpline and what support can you provide them?

We are very grateful to our health professional associates, such as hospital clinics and neurologists, who refer their patients to us for further consultation. We have a wealth of information we can assist their patients with and appreciate the opportunity to do so.

What hours is the helpline staffed?

The helpline is available between 9am and 4.30pm weekdays. The team is often out in the community delivering training, so if anyone is wanting to visit us in the office, it's best to make an appointment.

If people aren't comfortable or able to reach you on the phone during office hours, are there other ways they can have their questions answered?

We all have our preferred way of communicating. Some of us like to chat on the phone and some prefer to email the conversation. We are happy to communicate either way. Some people like to communicate face to face, this is sometimes difficult, however, we are happy to offer an appointment for an office visit.

For information and support contact our friendly Services team on the Epilepsy Helpline on **07 3435 5000** or **1300 852 853** (outside Brisbane). Alternately you can email **services@epilepsyqueensland.com.au**.

2017

DIARY DATES

1 – 30 September

Little Poss Appeal

Support Epilepsy Queensland's children's programs by purchasing our range of cute and practical Little Poss merchandise from your local participating pharmacy or securely online: www.epilepsyqueensland.com.au/shop

1 – 30 September

September Sizzle for Seizure First Aid

Host your own sausage sizzle, morning tea, dinner or other fundraiser and help save lives with seizure first aid awareness and understanding.

20 July
17 August
14 September

19 October
(9.30am + 5.30pm)
16 November

Understanding Epilepsy Workshops (Woolloongabba)

For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, volunteers, people with epilepsy and their families

26 July
6 September
15 November

Understanding Epilepsy Workshops (Gold Coast)

For families, people with epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals

4 November

Brisbane Adult Support Group Meeting

Also informally first Saturday of each month

1 September

Carer Support group – Friday at Bracken Ridge Library 10.30am

12 October

Carer Support Group – Thursday at Bulimba Library 10.30am

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

30 minutes
with...

Dr. Sasha Dionisio



What is the exact title of your role?

Hello, I am a consultant epileptologist and head of the Mater Advanced Epilepsy Unit, Queensland's first and only public adult level 4 epilepsy surgery centre. I also work at the Princess Alexandra Neurology Department as an epilepsy specialist.

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

I have been working at both units since 2015, when I returned from my clinical fellowship abroad.

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

To me, the most exciting change has been to bring the Stereo-EEG (SEEG) methodology to Queensland. Stereo-EEG is one of the most complicated invasive procedures and despite being around for almost 60 years, it is still the least performed and least understood invasive technique in the world. Fortunately, it is rapidly becoming more popular.

SEEG involves the insertion of electrodes into various regions of the brain. It allows patients with focal epilepsy and normal imaging, to have epilepsy surgery done. Not only has it transformed the lives of our patients (most of whom were previously told that they could not have surgery as their brain scan was normal) but it has allowed us to further understand the brain and to be able to train Queensland neurologists in this complex technique.

We are also extremely proud to have the only ROSA robot for epilepsy surgery in the Southern Hemisphere. Dr Papacostas (consultant neurosurgeon, Brisbane Clinical Neuroscience Centre) uses this during the implantation and it has been a game changer.

With the SEEG technique we have been able to utilize very advanced treatments such as deep brain stimulation (DBS) as well as the gamma knife (both with the support of the Princess Alexandra Hospital), to help our patients. In addition, we have established very strong national and international links with the SEEG program. With the consent of our patients, we often collaborate with some of the top epilepsy centres in the world. So our patients ultimately benefit from some of the best epileptologists both from Australia and Internationally. Exciting times for Queensland!

Where else have you worked in your life?

I spent 2 years at the prestigious Cleveland Clinic Foundation Epilepsy Centre (USA) where I was appointed as the chief epilepsy fellow. That was one of the greatest experiences in my life, having the privilege to train and work with 20 of the best epileptologists in the world. I did my general neurology training in Sydney and Brisbane and general medical training and med school in Dublin, Ireland.

What do you love about your job?

Absolutely everything. I always wanted to work in epilepsy and one day make a difference, even before medical school. So this is my dream and my passion. It is a great privilege to be able to help people suffering with epilepsy and seeing the positive changes. I love my entire team- we are close knit bunch and many patients feel it. We work hard, we learn together, we support each other and we never give up. We are always pushing forward with ideas and research and trying to break the boundaries of what we understand about this disease in the hope that ultimately, one day, we will cure epilepsy. It is an honour to work with my team and I am immensely proud of their achievements. This is much more than a "job" or "work" to us.

Where would you most like to travel?

One thing I have always wanted to do is spent time with the Indigenous people of Australia. If they were willing, I would love to learn from their immense knowledge and spiritual links with nature and the earth.

What is your favourite food?

I will give anything a try. I wish I could be more vegetarian though and eat less meat.

Describe your most embarrassing moment?

Drinking from a hand wash bowl during a dinner meeting...there was a slice of lemon in it and I mistook it for tea. Obviously, the lemon wasn't only in the bowl...

What/who is your favourite book/author?

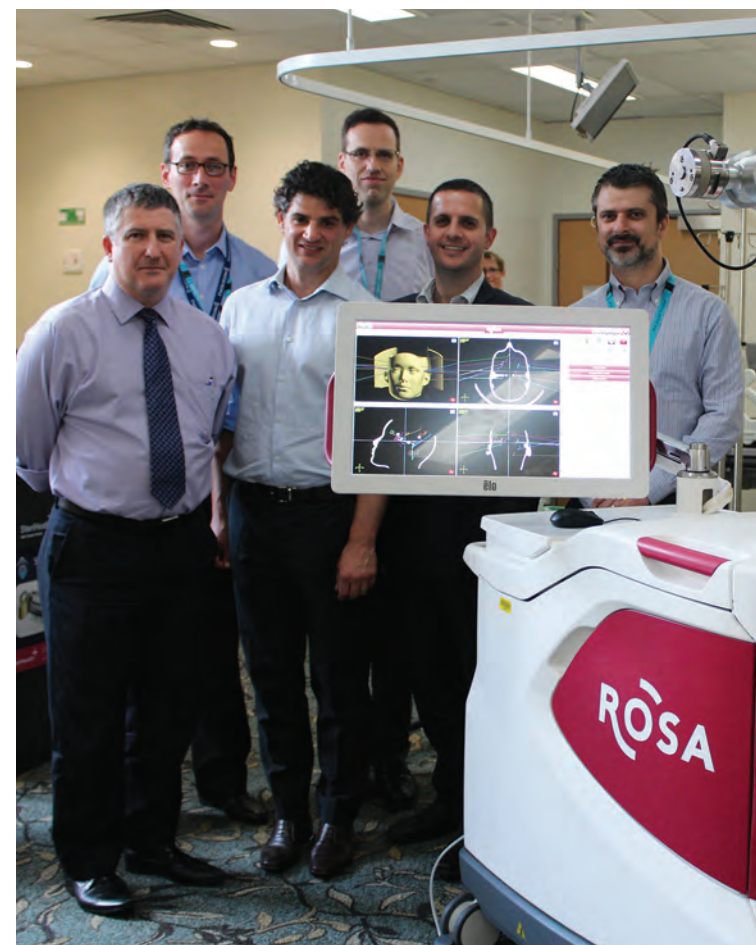
There are too many works of art to name just one. So for now, I am reading Andre Vltchek's "Exposing lies."

Who would you like to meet?

Can I choose 5 people (alive or passed)? David Attenborough, Fidel Castro, Robert Fisk, Mike Tyson, Nikola Tesla, Jean Bancaud...also Russel Brand, Jose Marti, Jeremy Corbyn...wait that's more than 5 now...

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

My playlist right now for the bus ride is this: Evidence- throw it all away, Midnight express- Danger zone, Pharoahe monch- time 2, Chino XL- fathers day, Brother ali- stop the press, Stevie wonder- As, Marvin Gaye- What's going on, Jackson 5- I wanna be where you are, MJ- Sunset Driver, Dilated Peoples- LA river drive.



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

I used to have tons from martial arts, diving, DJing to breakdancing (!) but now my life is more about changing nappies, making food and washing clothes for my little daughter and I would not change this for the world!

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

There needs to be changes on multiple levels. Firstly, the neurology community need to be better at teaching their trainees about epilepsy. We definitely need more epilepsy specialists around both in the adult and pediatric communities and encouraging and inspiring the younger generation of neurologists is imperative.

There needs to be far more recognition and resources invested into epilepsy care from a government level including funding for epilepsy services, local and statewide epilepsy support services and improved social services (Centrelink assistance for example as well as graduated return to work programs). Government programs also need to especially be supportive of the growth of higher end epilepsy units offering complex surgeries and treatments and this is especially critical in the pediatric epilepsy community, where seizure freedom is absolutely transforming.

Most importantly there is the ultimate need to recognize that illness comes in all forms and that the stigmatization and discrimination that people face, has no place in society and benefits no one. We really do need to "bring epilepsy out of the shadows". Thank you for having me.

Thank you to the Community Benefit Fund

Epilepsy Queensland wishes to acknowledge and express appreciation to the Queensland Government Community Benefit Fund for the \$17,740.91 grant provided to upgrade our IT System. The equipment purchased through the grant enables staff to work more efficiently and helps ensure money donated by our supporters is utilised for our vital services for Queenslanders living with epilepsy.



**Queensland
Government**

Did you know that you can challenge yourself in events and support Epilepsy Queensland?



Step up for Epilepsy

Getting involved is easy!

1. Choose your challenge, there are plenty of events for all fitness levels
2. Select **Epilepsy Queensland** as your charity of choice when you register for an event
3. Follow their steps to set up your own online fundraising page, or call us to find out how
4. Spread the word, share your inspiration and send your fundraising page to your friends, family and colleagues via email, facebook, twitter etc.
5. Dress the part in your own Epilepsy Queensland t-Shirt, purchase online at www.epilepsyqueensland.printup.com.au

Upcoming events in Queensland include:



Be a HERO for Epilepsy and start fundraising today!
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