

the flame

the newsletter of epilepsy queensland inc

Issue 2 – 2019



Epilepsy Queensland

26 March at 5:00 pm - Purple Day Event

Going Purple to bring epilepsy out of the shadows!!
#PurpleDay #Ican #PurpleBomb #EpilepsyQueensland



**“Falls, faints and
‘funny-turns’ – could it
be epilepsy?”**

MY EPILEPSY STORY
SKATING ON THIN ICE, KNOW
YOUR TRIGGERS

100 Likes 10 Comments 3 Shares

THANK YOU FOR GOING PURPLE



30 minutes with ... Kylie Lodge



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 complimentary quarterly copy, we ask you to renew your membership by 30 June 2019.

As a valued member you will receive:

- Free (daytime in-house) workshops in Brisbane for members who have epilepsy and their immediate families
- Discounts on publications, regional workshops, seminars and special events

- An invitation to attend special events including the Annual General Meeting and Awards Ceremony
- Opportunity to contribute to 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

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

Contents

2	Is your membership due for renewal?
3	Know your triggers
4-5	My Epilepsy Story – Skating on Thin Ice
6	“Falls, faints and ‘funny-turns’ – could it be epilepsy?”
7	My brain map
8-10	Thank you for going purple

11	Celebrate with Little Poss
12	30 minutes with ... Kylie Lodge
13	Epilepsy training & Taxi subsidy extended
14	Who will you walk, run or wheel for?
15	Play for Purpose
16	Diary dates



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

KNOW YOUR TRIGGERS

Some people with epilepsy find that certain factors may induce seizures. You may not become aware of your trigger factors unless you keep a seizure diary for a period of time. A trigger usually occurs fairly consistently before seizures - not just once or twice. The following list of trigger factors is a guide but it is by no means an exhaustive list.

1 Missed Medication

Missing a dose of epilepsy medication can increase sensitivity to seizures

- The longer the break the greater your chance of having a seizure. This is the most common reason for breakthrough seizures. When medication is missed, seizures might become more frequent, longer, more intense, or more likely to cause injury. When it leads to status epilepticus, when seizures are prolonged, it's a medical emergency.
- Suggested ways to help take the right medicine in the right doses at the right time, include pill boxes, taking with meals, setting an alarm on your phone or using an app such as MedAdvisor: <http://bit.ly/EQMedAdvisor>

2 Stress

Extreme stress may lower your seizure threshold and trigger seizures

- Recognise the signs and symptoms
- Employ relaxation strategies that you find helpful in reducing stress.
- Monitor when you feel stressed. Can you let it go rather than letting it bother you?
- We recommend relaxation techniques such as yoga, or breathing exercises.
- Ask your doctor for a referral to a counsellor or psychologist to help with your stress management

3 Diet

Excess caffeine or very low blood sugar may trigger seizures

- Know your caffeine limits and practice moderation
- Maintain regular meals

4 Menstruation

Some women have more seizures around their menstrual cycle called catamenial epilepsy. This can be caused by increased fluid retention, altered hormonal levels or alteration in the blood levels of epilepsy

medication.

- Discuss it with your doctor
- Changes may need to be made to AED medication

5 Photosensitivity

Photosensitive epilepsy affects around 3% of people with epilepsy. Seizures can be triggered by sensory stimuli such as flickering sunlight, strobe lights and flickering television.

- Preventative measures include wearing wrap-around sunglasses to reduce glare and covering one eye to reduce the effects of flickering or flashing light

6 Alcohol

While some people with epilepsy have seizures that are very sensitive to even small amounts of alcohol, most are able to enjoy an occasional beer or two or a glass of wine with dinner.

- Know your limits
- Practice moderation
- Know the impact of alcohol on your medication

7 Lack of good sleep

One of the most common seizure triggers

- Understand the amount and quality of sleep you need each night
- Avoid fluctuations in the time you go to bed
- Your medications may affect your sleep (too sleepy or difficulty falling asleep). If you think this is happening, discuss this with your doctor.

8 Changes in temperature



Seizures may be triggered when the weather becomes very warm or rooms are overheated

- Try to avoid situations where you may become overheated
- On very hot days try to escape to places that are air-conditioned

9 Infections and illness

Children are particularly likely to have more seizures when they develop infections such as tonsillitis and earache. This could be due to higher temperature or epilepsy medication not absorbing if there is diarrhoea or vomiting.

- usually eases within a few days
- If you are concerned in any way please contact your GP or 000 for assistance.

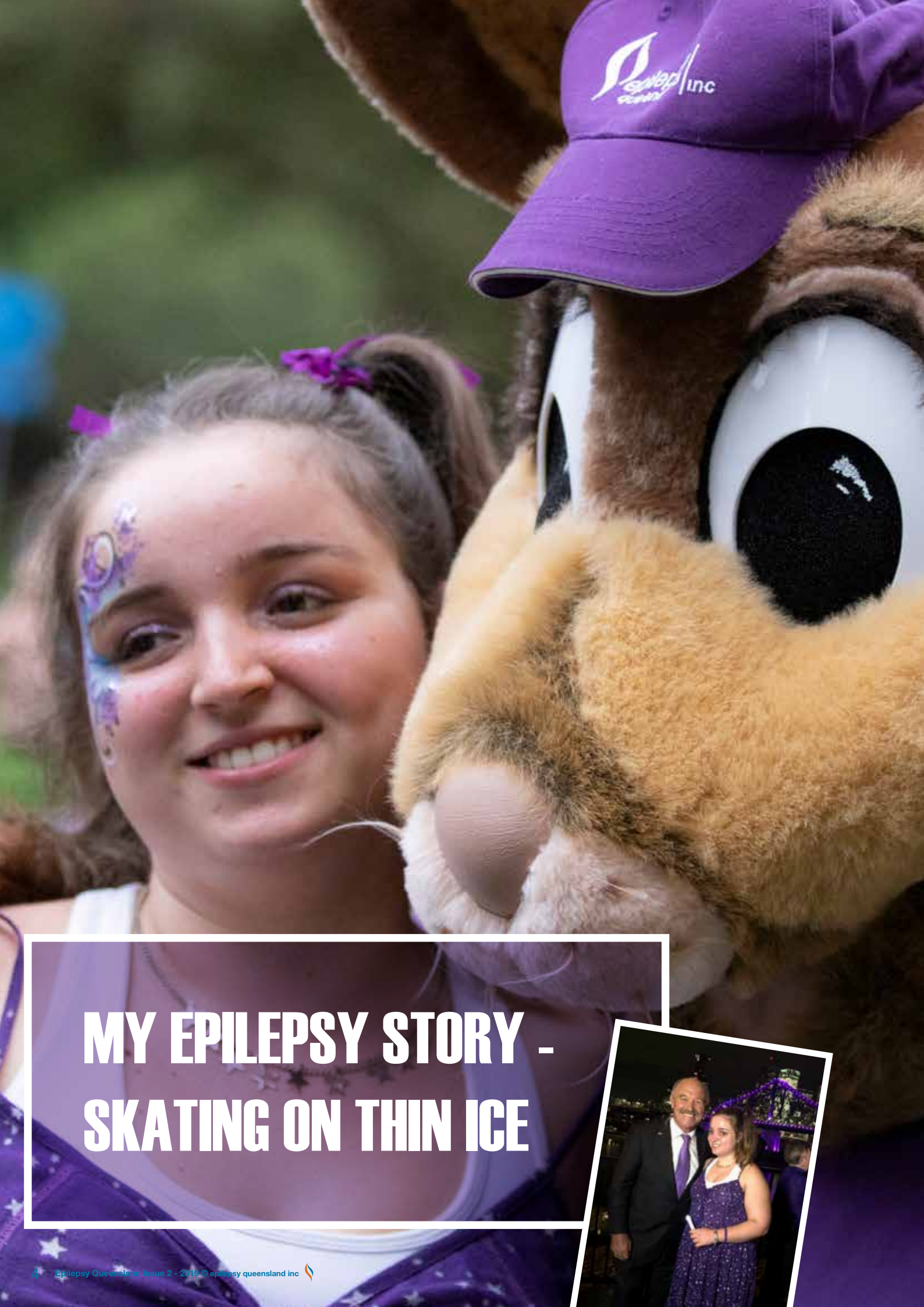
10 Other drugs

Withdrawal or combining some prescription, over the counter, herbal or illegal drugs with epilepsy medication can trigger seizures.

- If you are on epilepsy medication it is important to tell your GP, pharmacist, or specialist about any other medications you are taking or plan to take.

To find out more about seizure triggers and how to manage them visit: www.epilepsyqueensland.com.au/seizure-triggers-1 or contact our services team on 07 3435 5000.





MY EPILEPSY STORY - SKATING ON THIN ICE





Very few people have more interests and talents than 20-year-old Olivia Rowsell. She has participated in ice skating, ballet, tap, jazz, musical theatre, gymnastics, horse riding, karate, tennis, badminton, swimming, singing, piano, violin and Girl Scouts.

Olivia is up and out the door at 7:30am four days a week. She is dedicated to completing her courses at TAFE and Anglicare and also works three hours a week at Kmart.

This wasn't always the case for Olivia. As a person living with Tuberous Sclerosis Complex, a genetic form of epilepsy, Olivia experienced a great deal of isolation.

"These activities kept me busy and excited to try something new. Having all these experiences gave me confidence and the opportunity to meet new friends both in the community and at school."

Olivia's greatest talent lies in ice-skating, a sport not for the faint hearted. She talks about her first experience and how she became hooked on skating.

"By chance on a rainy and miserable day in October 2012, we saw an advertisement for Caloundra Rollerdrome On Ice. We went out of curiosity to see what it was about. I was a bit puzzled at what made people like this activity, sliding around with the rented penguin provided by the rink and by the end of the session I felt I had given it a good go but it wasn't for me."

"I was somehow roped in to another session with a family friend and it clicked. I grew more interested in learning and mastering ice and roller-skating. I have been a skating fanatic ever since. I even did roller derby for a year or two (non-contact of course). I joined my synchronised ice skating team last year and still continue to work at mastering roller skating."

Olivia's involvement with ice skating has helped her to meet and associate with people from all walks of life. As a person living with epilepsy, it is important being in a supportive environment that focuses on her ability.

"I have found there's a safety net that comes from relationships with a broad variety of people in my synchronised ice skating team, Evolution. There are paramedics, general practitioners, specialists, engineers, lawyers, teachers, researchers, pathologists and nurses! My coach and team see me as a skater that contributes to the overall success of the team. They acknowledge my disability but do not see it as limiting my contribution. They are always looking out for me and awaiting my return to skating after seizures and hospitalisations."

"In fact, eight months after one of these hospitalisations and having to learn to walk and talk again, I was competing at Nationals 2018 for the first time with the team."

Despite Olivia's success in ice-skating, she still struggles with TSC, epilepsy and the impact of seizures on her life.

"I present with all the 'hallmarks' of TSC. My physical traits include non-cancerous tumours on the brain, growths on the heart, kidneys, back of eyes and skin, and pitting of teeth. My symptoms include epilepsy and intellectual impairment. All these different aspects of TSC mean I have a lot of specialists and scans to keep an eye on the growths."

"Most people learn to walk and talk once in their life, I have had to learn a number of times."

Olivia is happy to credit her success to the many people that have helped and supported her throughout her journey with epilepsy.

"I believe that being connected to people is the best thing to get me through my bad days. I love my support team of doctors, Epilepsy Queensland, work colleagues at Kmart, skating team Evolution, family and friends. They help me realise that I have the strength to overcome challenges. It made it easier to face learning to regain the skills I lost due to a seizure by knowing that others have had to do the same. I also found inspiration in Ariana Berlin's story as told in "Full Out". We used the movie soundtrack to motivate me in my physiotherapy sessions as part of my rehabilitation following a seizure."

In recent years, Epilepsy Queensland has supported Olivia through her NDIS application and provided a support network.

"The brilliant Leonie has been instrumental in my NDIS plan helping me through the planning process, the plan meeting itself and with using my plan to access the supports I need."

"I had my first Purple Day this year and it was an awesome day. I loved the purple lights on Brisbane landmarks it made me feel recognised by my city. It was nice to meet new people and share stories. It is already in my calendar for next year. I'm hungry just thinking about the cupcakes with purple icing and lollies."

We hope that one day we can claim that we supported the great Olivia Roswell, professional skater through her journey with epilepsy.

"Skating is the joy of my life. I strive to be an amazing athlete and represent my country someday, which is why no matter what skating discipline I train for I give it everything I have."

If you would like to share your story to help raise awareness and understanding of epilepsy please contact us on 1300 852 853 or pr@epilepsyqueensland.com.au.

“Falls, faints and ‘funny-turns’ – could it be epilepsy?”

A pilot: Co-designing resources to improve the ability of seniors with epilepsy to access and be included in the community

Epilepsy Queensland is proud to have received a grant from the Brisbane City Council – Access and Inclusion Program 2018-2019, to address access and inclusion barriers for seniors living with epilepsy.

Recognizing that old age is one of the most common times to acquire epilepsy, Epilepsy Queensland is running a project to develop age-appropriate, factual, engaging and informative resources about epilepsy within the aging population. The overarching goal is to identify and break down barriers (perceived or real) of older people living with epilepsy to access and be included in what the community has to offer.

Epilepsy is not always the first possibility that comes to mind when an older adult has a seizure. Its clinical presentation can resemble other conditions common in the older population, such as stroke, head injury, brain tumors, cardiovascular disease, Alzheimer’s disease, or dementia.

Aging in itself can be challenging and sometimes isolating but older people with epilepsy have an added complication and this can have a profound impact on a person’s independence and capacity for economic and social inclusion.

The barriers (which this project aims to identify and overcome or minimise), may range from the person’s emotional and attitudinal state, their problem solving and coping mechanisms, to the strength and breadth of their family and support network and further, extending to the knowledge, empathy and understanding of clinical and community services staff and even further into workplaces and the general public.

A few of the barriers identified to date include:

- A lack of understanding and empathy that people with epilepsy can lead a normal life
- Misconceptions about what people (with epilepsy) can or can’t do at work
- A lack of understanding about what support services are available
- A need to overcome challenges to enable a person to engage in ‘normal’ activities such as swimming and travel;
- A lack of knowledge about what to do when someone is having a seizure

Through this project, information will be gathered from people over the age of 55 years with epilepsy and/or their families/carers.

Their experiences commencing from initial symptoms through to diagnosis, treatment and management of epilepsy will form the foundations of the project. The aim is to understand what the barriers are to accessing and being included in, the community. Once the barriers are identified and understood, then the project’s aim is to identify ways to break those barriers down.

We are thankful to those people who were able to join us on 4 April for a workshop to explore the topic. This was a very productive morning, with participants able to connect with each other and share their stories in a welcoming and supportive environment.

Next steps:

We are currently seeking input from two different groups within the Greater Brisbane Region:

- A: People who received a diagnosis of epilepsy after the age of 55 or later in life and/or their families/carers;
- B: Any person/s who work in the clinical or community service sector who have supported older people with epilepsy and are able to share their experiences, information and ideas.

Options available for providing your information is via a paper survey, an online survey or phone call with the Project Facilitator, Janet Pond.

For more information, please contact Janet Pond, Project Facilitator, on 0410 596 133.





“My Brain Map” – Bringing a Systems Approach to Personalized Health

We were fascinated to read about this research initiative of the Epilepsy Foundation of America

In 2017, the Epilepsy Innovation Institute, a research program of the Epilepsy Foundation of America, released an online survey asking where the scientific community should be focusing their efforts in epilepsy. Over six hundred individuals impacted by epilepsy responded from across the United States and abroad. Understanding the causes of epilepsy was selected as a top priority for researchers. We know people living with epilepsy are not having seizures one hundred percent of the time, so why are the seizures happening when they do? What is it about the pathways in the brain in the moments before a seizure starts? What is it about the brain activity that activates those pathways in that specific area of that brain in that specific moment? And what causes the seizure to then spread or not spread when the initiation occurs? Although researchers have been studying seizures for over a century, we still cannot answer the questions of why seizures start, how seizures spread and why they stop when they do for those impacted by epilepsy.

The Epilepsy Innovation Institute (Epilepsy Foundation of America) will be leading an effort to better define an individual's brain network. “We aim to create a Google Map for your brain that highlights your unique brain traffic pattern. With this map, we can better identify the routes your seizure could take, where the potential traffic jams might be, and how activity can get re-routed in the brain during those situations. Our purpose is to better define an individual's brain network to enhance diagnosis and care.”

This will lay the groundwork to:

- Identify key brain regions unique to the individual that could be critical for seizure control
- Improve our abilities to pinpoint where a seizure originates, which may improve surgical options and outcomes
- Optimize neurostimulation therapies to the individual
- Better understand the biological profiles of epilepsy syndromes, which in turn could improve diagnosis and address why seizures occur

Request for Proposals

The Epilepsy Innovation Institute has announced a Request for Proposals for the My Brain Map initiative to fund pilot studies (up to US\$200,000) that would propose novel exploratory ways to model seizure propagation in a personalized brain network model.

Submissions opened on March 15, 2019, and are due by June 21, 2019.

<http://bit.ly/MyBrainMap>

We want to better understand how a seizure begins and how it spreads throughout the brain network in particular moments in time.

THANK YOU FOR GOING PURPLE

This year, the theme for Purple Day was #ICan. Purple Day is an important day for people living with epilepsy, their family and friends, but it means different things to different people. During the month of March we asked people to share what #ICan means to them and why they went purple. For many people it was to show support for someone they love, decrease the stigma or to help build understanding of epilepsy.

Thank you to all of our supporters who helped to raise funds. We are extremely grateful to everyone who went purple across Queensland, held morning teas, purple free dress days, sold merchandise or helped to bring awareness via social media or sharing their story. We also appreciate all of the support and good wishes that we received from our MPs, Senators and Councillors from across Queensland.

Purple Celebration

Epilepsy Queensland's Purple Day Celebration had an amazing turn out, with 90 people dressed in purple, faces painted and ready to celebrate. There was plenty of entertainment throughout the night with balloon animals, a raffle and a visit from Little Poss.

A number of celebration attendees also hopped onto a bus and joined the live 9 News sports broadcast with Epilepsy Queensland Patron, Wally Lewis. The broadcast overlooked the Story Bridge, which was lit purple for epilepsy awareness. We are sincerely grateful of the time Wally spends listening to the stories of our members and his ongoing support to bring epilepsy out of the shadows.

Throughout the night people were also able to visit all of the many purple illuminations happening across the city. There was a total of 24 landmarks illuminated or dyed purple, captivating the city and regional towns across Queensland.

Our wonderful supporters held over 70 events for Purple Day. We were thrilled to see increased involvement in regional areas across the State. This includes schools, workplaces, councils, hospitals, pharmacies and even more individuals that have supported the campaign throughout 2019. The incredible support from the Purple Day Hero's friends and family shows that together, everyone can rise above the challenges that epilepsy can bring.

Purple Bridge Climb

One of the highlights of the night was the Purple Bridge Climb of Brisbane's Story Bridge. This was an extraordinary experience for a group of our supporters to climb the bridge, whilst illuminated purple, to raise funds and awareness for people living with epilepsy.

Larissa Winter climbed the bridge on behalf of her daughter, Nickayla, who lives with epilepsy. "I was petrified!" said Larissa, "This was something that Nickayla really wanted to do, but couldn't because of her seizures, so I did this to show my daughter, and others who struggle with epilepsy, that I can face my fears and so can you."

"I had a few rocky moments but I finished and Nickayla was so pleased to see me at the end that it made it all worthwhile."

When asked what Purple Day means to her, Larissa said that "It is

so important to have a day that raises awareness of what epilepsy is." She went on to say that when Nickayla was younger, she would not be invited to birthday parties as the children's parents were afraid that their children could "catch" this disease. "There is just not enough education around the fact that someone with epilepsy is not a risk to anyone around them, which leads to them feeling alone."

Joanne Scott

Every year on Purple Day, people come together to support members within their community living with epilepsy. It is a day where people acknowledge the challenges and show how people have risen above and accomplished so much. These purple heroes are inspirational as they have not been beaten by epilepsy however, they continue to fight.

Joanne Scott from Mackay was diagnosed with epilepsy when she was 18 months old. Today, Joanne is 45 and still has approximately four to six seizures a month. "The last six months have been particularly hard for me," says Joanne "but I just have to remember to take it one day at a time."

"Even though I have my friends and family, being able to call Epilepsy Queensland and have their support when I am going through a tough time and get some information is always extremely helpful."

Joanne said one of the biggest problems of dealing with epilepsy is that there is not enough awareness of what it is and how to handle it. "People still ask if they need to hold my tongue when I am seizing, which is actually one of the worst things you can do. I am really glad that Epilepsy Queensland and people like Wally Lewis are out there spreading awareness as people really need to have the correct information when talking about this."

Joanne embraced this year's "I Can" theme with her motto: I can think positive and be strong.

Cairns Neurology Clinic does it again

Cairns Neurology Clinic went purple this March in support of Epilepsy Queensland. They had a 53% increase in their efforts. "I am really happy with our total, everyone worked really hard."

"We had a morning tea on Wednesday after our Epilepsy Clinic, where we spend the morning treating only epileptic patients," says Neurology Administration Officer, Teresia Lallemand. Along with their morning tea, the clinic also sold purple merchandise and encouraged their patients to get involved.

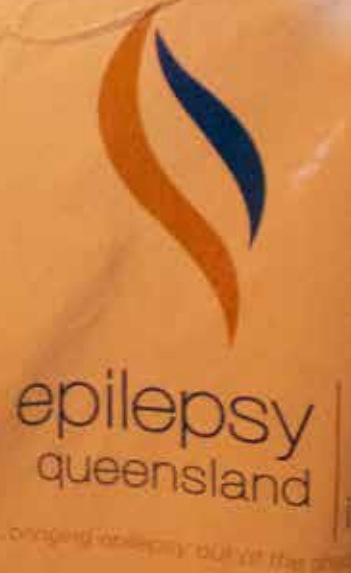
"We make sure that all of our patients know about the services that Epilepsy Queensland provides as they are a major source of support for so many people," says Teresia.

"Our offices were purple for all of March and we also fundraised at the local shopping centre. This year we started handing out a seizure first aid guide to the shoppers as many people think that just because they don't have a family member with epilepsy, they don't need to know this. But what happens if you are at the shops and someone starts seizing? This is a very important skill that everyone should know."



Purple Day for Epilepsy

26 March



Thank you to our Purple Day supporters:

Purple Illuminations supporters: Brisbane City Council, City of Gold Coast, Fraser Coast Regional Council, Gasworks ULA group, Gladstone Port Authority, Graincorp, Ipswich City Council, Logan City Council, Mackay Regional Council, Office of Speaker of the House (Queensland Parliament), QPAC, Queensland Department of Housing and Works, Suncorp Stadium, Toowoomba Regional Council, Townsville City Council, Transurban

Teresia has been an amazing Purple Day ambassador for Epilepsy Queensland and works tirelessly to help support the cause from contacting the local council about getting involved in Purple Day, to sending merchandise to her sister in France. "I am always happy to help," Teresia says.

Queensland's Purple Pharmacy of the Year

Congratulations to Buderim Pharmacy for winning the 2019 Purple Pharmacy! Buderim Pharmacy celebrated and raised funds throughout March and had a big Purple Day on 26 March. "We had a selfie frame that staff and customers could pose in and our boss donated a dollar per selfie towards Epilepsy Queensland," said staff member, Mel. "I also made a cake for gold coin donations and we all wore our purple shirts."

We thank Buderim Pharmacy and all the Pharmacies across Queensland that participated in Purple Day. The funds raised through the sale of our purple merchandise is vital and will help us continue to provide services to Queenslanders living with epilepsy and their families across the State. We loved seeing the pictures of staff dressed in purple and pharmacies decorated purple. Every conversation you had throughout the month helps to raise awareness and let people living with epilepsy know that they are not alone. Thank you to the Pharmacy Guild of Australia (Queensland Branch) for their ongoing support promoting Purple Day to their members.



PURPLE DAY 2020

We would love to hear your thoughts on how you would like to celebrate Purple Day in 2020.

Our survey should only take five minutes to complete. If you'd prefer you can phone us on 07 3435 5000 or email with your feedback.

Find our survey online <http://bit.ly/PD20survey>



CELEBRATE WITH LITTLE POSS



Do you have a child or grandchild living with epilepsy? Join the Little Poss Club and come along to Little Poss' Birthday Party at the Community Place at Stafford to celebrate and meet other families affected by epilepsy.

There will be activities for the kids, a chance to give Little Poss a cuddle, face painting, balloon art, fun games, a light lunch and birthday cupcakes! Meet and share a coffee with other parents.

Get the kids to dress up as their favourite superhero, book or movie character and have your look finished by our face painter Jazzy J! Be in the running for great prizes for the best dressed!

If your child is a member of the Little Poss Club, your invitation should already be in the mail for the birthday celebrations.

If you haven't met Little Poss yet, he is Epilepsy Queensland's mascot. He is a loveable brush tail possum who comes from in Ningaloo in Western Australia. He developed epilepsy after he fell out of his tree.

Members also receive a newsletter every two months with loads of fun things to read and activities to do as well as some information about epilepsy. You may even like to enter some of the competitions.

Your child will receive a certificate that shows you are a proud member and Little Poss will send you a birthday card for your birthday!

Remember that if you have any questions about your epilepsy or a friend or relative's epilepsy, Little Poss and his friends will answer them for you. All you have to do is write him a letter and he will try to help with some answers.

To register for the Little Poss Club (membership is free) or his birthday party visit our website www.epilepsyqueensland.com.au/little-poss-0 or call 1300 852 853.



30 minutes with...

Kylie

Lodge



What is the exact title of your role?

Neurology Clinical Nurse Consultant

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

I work at the Gold Coast Hospital and have been here for 13 years in a variety of roles, most of my time has been in the Emergency Department. I have acted in the Stroke Coordinator role and now in the Neurology role relieving maternity backfill.

What is your special interest in epilepsy and how did it develop?

I find all of epilepsy fascinating and am very privileged to work with epilepsy patients in the outpatient setting currently, aiming to be a point of contact for them if they develop side effects or further seizures but also aiming to prevent hospitalisation.

Obviously prior to my appointment, I would be part of the team managing patients in the acute setting when they present with a seizure.

I have a special interest in improving the transition for paediatric epilepsy patients to the adult setting and the management of epilepsy and pregnancy.

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

I think the current cannabis trials are exciting with the current results and the potential for improving patient's quality of life without multiple antiepileptic medications.

Where else have you worked in your life?

I have worked in the public and private setting for 22 years in a range of specialties such as plastics, ENT, cardiology, orthopaedics, paediatrics and emergency and critical care.

What about your work brings you joy?

The patient contact and the feeling that I am making a difference to my patients.

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

More research studies and trials.

What is the best part of being a nurse?

The satisfaction that it brings.

Where would you most like to travel?

South America.

What is your favourite food?

Any Thai food.

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

I love my garden and get a lot of peace from being in it and I love pilates.

SEIZURE FIRST AID

We want to hear about your experiences of people providing first aid for seizures. We want to know the good and the bad.

Email your experiences to
pr@epilepsyqueensland.com.au.



Is your epilepsy and emergency medication training up to date?

Do you have a family member, student, client or staff member living with epilepsy? One in every 50 people will develop epilepsy at some time in their life and one in 10 will have a seizure.

Ensure training in Understanding Epilepsy and Administration of Emergency Medication is up to date, so you are confident and prepared for any event.

We have a new location at the Gold Coast University Hospital, for epilepsy training and workshops delivered on a bi-monthly basis. Workshops are \$60 per person.

Location: Gold Coast University Hospital, Block A, level 6, Room 027, 1 Hospital Blvd, Southport

Upcoming Dates: 12 June, 14 Aug, 13 Nov

Time: 10am - 12pm

Topics covered

- Recognising seizures types
- Minimising triggers
- First aid and emergency situations
- Intranasal and Buccal Midazolam administration

If you have any questions about the above or to book, visit our website epilepsyqueensland.com.au/our-training, phone 07 3435 5000 or services@epilepsyqueensland.com.au.

Taxi subsidies to continue

We've had feedback from a number of our members concerned about the Taxi Subsidy Scheme which was due to end 30 June 2019. The cost of transport remains an issue for many Queenslanders living with epilepsy, whether they have access to the NDIS or not.

We are pleased to report that the Palaszczuk Government has stepped in to ensure the Taxi Subsidy Scheme for National Disability Insurance Scheme (NDIS) participants continues over the coming year.

Deputy Premier and Treasurer, Jackie Trad, said a further \$6 million would be committed in 2019-20 to continue the subsidy payment.

"Taxi subsidies were expected to transition to the NDIS funding arrangement by now but under the Morrison Government this hasn't happened," Ms Trad said.

"We will not allow thousands of Queenslanders to be left stranded – so we will step in to ensure that doesn't happen.

"We want to ensure that people with special needs continue to receive this support so they can undertake everyday activities and stay connected with family and friends.

"We understand how important it is for all Queenslanders have access to transport."

"We will continue to work over the coming year to ensure the NDIS agreement delivers proper affordable transport options for Queenslanders in the longer term."

The Taxi Subsidy Scheme (TSS) provides a co-contribution of up to \$25 per trip for people with severe disabilities who are unable to use other forms of subsidised public passenger transport.

Transport and Main Roads Minister Mark Bailey said the budget commitment continues the same level of investment in the TSS as 2018-19.

This is in addition to \$15.7 million to continue TSS for non-NDIS eligible members.

"We have listened to the concerns of Queensland NDIS participants, their families and carers, disability advocacy organisations and transport providers," Minister for Disability Services and Seniors Coralee O'Rourke said.

"I will continue to push the Federal Government to fund plans fairly by providing adequate transport."

Who will you walk, run or wheel for?



Epilepsy Queensland is excited to be entering a team in Bridge to Brisbane for our third year in a row. We are inviting everyone touched by epilepsy and enjoys either a challenge, or a leisurely stroll along the scenic Brisbane River, to join Team EpilepsyQLD for this iconic day.

Whether it is personal, or in honour of someone you love, there is so much to gain from participating in this event while raising funds and awareness to help Queenslanders living with epilepsy.

With 5km or 10km options, Bridge to Brisbane is for all ages, abilities and fitness levels, for those serious about achieving their fitness goals or those out to have fun!

Lauren McCallum has participated in the Bridge to Brisbane for the last decade and has spent the past three years doing it with Epilepsy Queensland. "I lost my sister unexpectedly in 2015 due to complications due to epilepsy," said Lauren. "So I joined the Epilepsy Queensland team to raise awareness and funds for people living with epilepsy." This year Lauren will be walking the 5km with Epilepsy Queensland. To join the team please visit the link below

Step up for epilepsy and start fundraising today. We'll be with you every step of the way!

A dedicated Fundraising Coach will be available to offer you tips and suggestions on how to maximise your fundraising. Raise over \$100 to receive a Team EpilepsyQLD B2B-19 Cap.

To register or for more information visit www.epilepsyqueensland.com.au/team-epilepsyqld today!

Get your organisation/company involved!

In addition to the above fantastic benefits, your organisation/company's participation will see your brand shared in Epilepsy Queensland's communications and all the goodness that comes from team bonding.

Increase your team's fundraising impact:

- Encourage friendly department competition
- Match \$ for \$ what your team raises
- Sponsor your team by paying their Bridge to Brisbane registration
- Share Epilepsy Queensland's message with your clients and customers.

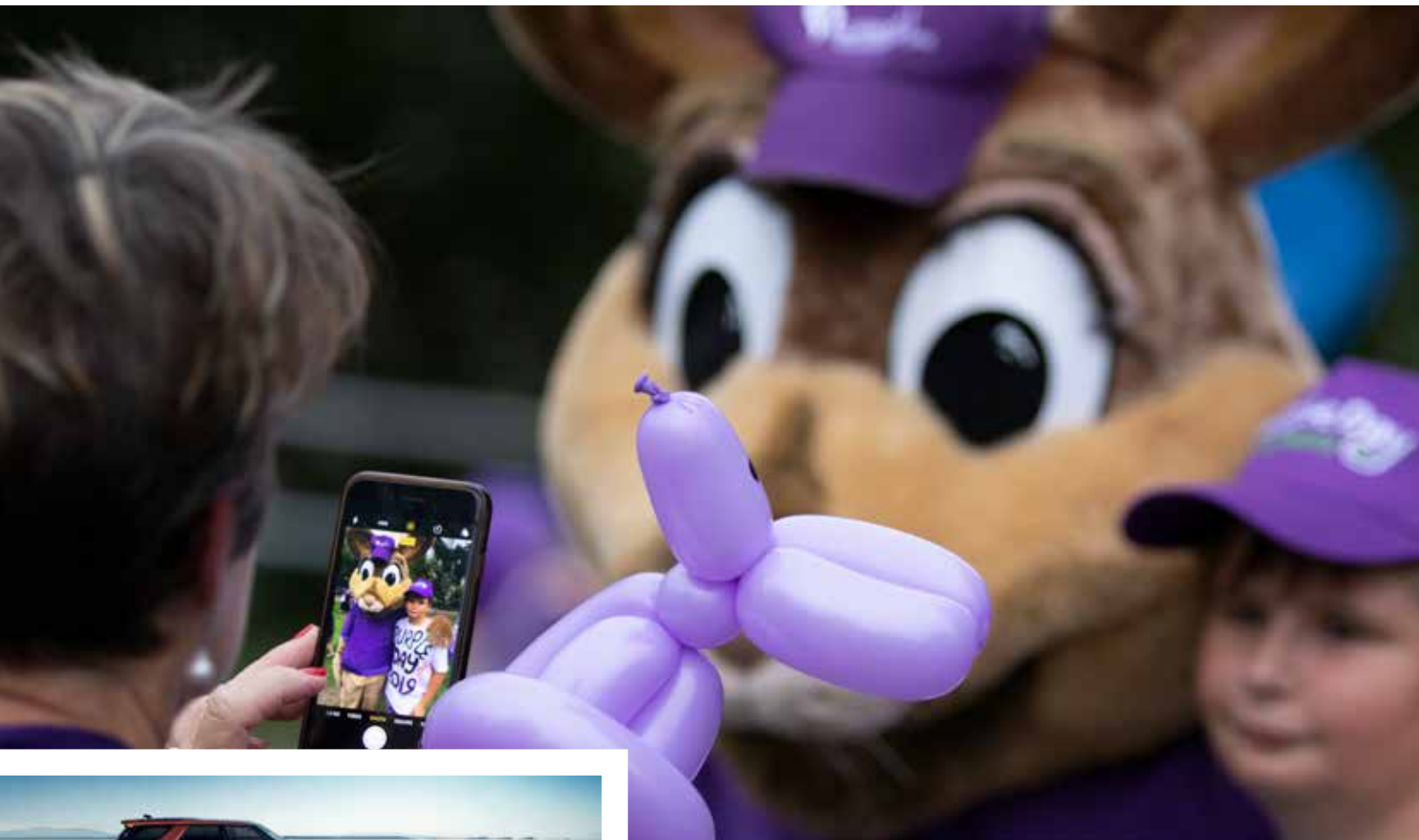
Alternatively, your organisation/company can be involved by sponsoring Team EpilepsyQLD.

Can't make it to Brisbane?

What about joining Team EpilepsyQLD in our Virtual Run/Walk for Epilepsy? Challenge yourself to run, walk, wheel or ride the 5-10km distance of the Bridge to Brisbane from the comfort of your hometown, in your own time, while raising funds for Epilepsy Queensland.

For more information on fundraising or joining Team EpilepsyQLD email Lisa at fundraising@epilepsyqueensland.com.au or phone 07 3435 5000.

Show your support and donate to TeamEpilepsyQLD online <https://b2b2019.everydayhero.com/au/epilepsy-queensland-purple-power-1>



Play for Purpose is a charity lottery where you can support your favourite charity. By joining together Play for Purpose are able to offer a 1 in 34 chance of winning over 7,500 prizes including gold bullion, a luxury car, fantastic holiday packages and gift cards. Tickets are just \$10 and \$5 from each ticket sold using the below link will go to Epilepsy Queensland for services for people with epilepsy.

Why not play for purpose today?

Visit: <http://bit.ly/eqraffle>

Buy \$10 ticket
\$5 from each ticket goes
to Epilepsy Queensland

2019

DIARY DATES

9 June	Little Poss' Birthday There will be activities for the kids, a chance to give Little Poss a cuddle, face painting, a light lunch and birthday cake! Each year Epilepsy Queensland's mascot Little Poss celebrates his birthday with members of the Little Poss Club. If you have a child living with epilepsy, Little Poss would love for them and their brothers and sisters to join his club. Register today or for more information contact services@epilepsyqueensland.com.au or 07 3435 5000.
22 & 29 June 3 & 5 July	E-connect (Stafford) The self-care and wellness workshops are welcoming, age-appropriate, fun and in a supportive environment where people aged 12-15 years living with epilepsy can come together.
13 June (9:30am and 6pm), 18 July 15 August 12 September 17 October (9:30am and 6pm) 14 November	Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
12 June, 14 Aug, 13 Nov	Understanding Epilepsy Workshops (Gold Coast) For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
Informally First Saturday of the Month Formally – 1 June, 7 September, 2 November	Brisbane Adult Support Group Meeting
19 June, 17 July, 21 August, 18 September, 16 October, 20 November, 18 December	Adult Social Group Ipswich

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

Contact EQI for information about:

- Eligibility and access for becoming a participant of the NDIS;
- Support for NDIS plan reviews
- Assistive technology assessments; developing epilepsy management plans or staff/carers training