

the flame

the newsletter of epilepsy queensland inc

Issue 2 – 2020

MY EPILEPSY STORY ARTIST JESKA VALK

Epilepsy research

How did you Go purple
for epilepsy?

30 minutes with ... Gerard Benedet

GO FOR GOLD



YOU COULD WIN **\$250,000** IN CASHABLE GOLD TO
SPEND ON ANYTHING YOU LIKE!

EVERY TICKET SUPPORTS A GOOD CAUSE

PLAY FOR PURPOSE

Imagine how you could spend \$250,000. You could enjoy the security of having your bills paid up with a little left over to splurge on some home comforts or even upgrade the old car to that dream Mercedes-Benz you've always had your eye on. Perhaps home renovations are your thing. With \$250,000 the choice could be all yours.

Even better, your ticket purchases help provide vital funds in Epilepsy Queensland's work to provide services and programs supporting children and families living with epilepsy.

Just \$50 in tickets not only provides you with five chances to win thousands of dollars in prizes but provides information and counselling for someone newly diagnosed with epilepsy.

To purchase your tickets simply head online to playforpurpose.com.au/epilepsy-queensland and follow the prompts.

Your generosity in these uncertain times will help us maintain the vital funding we need to ensure our work continues across all of Queensland.

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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.

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EPILEPSY RESEARCH

Mater Epileptologist Dr Lisa Gillinder is looking for people aged 18 and over across Queensland with focal (partial) epilepsy who still have ongoing seizures after trying two or more anti-seizure medications

This study aims to identify features that can be used to accurately diagnose autoimmune epilepsy. These findings will ensure that patients with this condition are identified correctly and are receiving the appropriate therapy.

The study will be conducted at Mater Research over a period of three years with patient participation required for six months and will involve having some medical tests.

Participants in the study will have a blood test looking for any antibodies that are known to be associated with seizures. If this result is positive, participants will undergo other tests including MRI scan and memory testing. The study also requires a lumbar puncture if the antibody test in blood is positive, so the diagnosis can be confirmed.

If you are interested in participating or would like further information please contact epilepsy.research@mater.uq.edu.au



VALE ANNA FAIRLEIGH



We were deeply saddened to hear of the passing of Anna Fairleigh in October 2019 from SUDEP.

Anna was an active member of the Gold Coast sporting community, who enjoyed rowing and Rugby League. She was a huge Gold Coast Titans fan, who attended most matches. Anna is survived by her loving parents Tanya and Chris Fairleigh.

We are grateful to Anna's family, friends and the Gold Coast Titans for fundraising via a Go Fund Me page in her memory. Epilepsy Queensland ambassadors Anna and Jack Dalton, who both live with epilepsy, met with Chris Fairleigh and Gold Coast Titans Wellbeing Program Manager, Peter Smith to share some of their experiences of epilepsy and talk of their mutual love of Rugby League. Jack accepted a \$2,000 donation from the Fairleigh family on our behalf to assist us in our support services for families impacted by epilepsy.

The Gold Coast Titans had planned fundraising and awareness activities for Epilepsy Queensland during their first home game in March 2020. Unfortunately, due to the impact of COVID-19 on the NRL, this was postponed. Epilepsy Queensland looks forward to working with the Titans to raise funds and awareness of epilepsy on the Gold Coast. Thank you to Peter Smith and the Titans for arranging a very exciting trip to the Gold Coast for Jack and his Mum.



MY EPILEPSY STORY - WITH ARTIST JESKA VALK



Award winning Gold Coast portraiture artist, Jeska Valk, is passionate about sharing other people's inspiring stories. Jeska was inspired in the lead up to Purple Day 2020 to share her own story of living with epilepsy and how painting has helped her to cope with epilepsy.

Jeska was diagnosed with generalised onset absence seizures as a young child. In these early days the absence seizures were few and far between. It wasn't until Jeska was an adolescent that they became more frequent.

Jeska explains this difficult time: "I spent a lot of my early life trying to understand the effects it had on my emotional development. I would feel so self-conscious and nervous in social situations which was very frustrating to me because I was a social person."

"I would be calm and then when my absence seizures were triggered I would be extremely anxious at the drop of a hat. I would try to piece together what someone had said or try to hide my absence seizures, which was interpreted by others as being rude or misunderstanding me. I was unable to express how I was feeling and be part of the conversation."

From a young age, Jeska was encouraged by her mother to pursue art and this became a way to help her cope with her epilepsy.

"I've always loved to draw and over the years it became my comfort zone, I would always carry a sketch pad with me. Focusing solely on drawing would help deal with the anxiety when I could feel my absence seizures approaching, I could shut out the noise around me and just zone in."

Now because of that habit I'm able to pursue the career of my dreams." Jeska said

Her Mother's inspiration has been a key driving force for Jeska's recent success painting strong women.

"My mother is my main support and hero. She has always been there for me, it's because of her that I'm inspired to paint strong, amazing women. She drew with me, encouraged me as an artist and always helped where she could."

Jeska was a finalist in the 2018 Portia Geach Memorial Award – Australia's most prestigious art prize for portraiture by female artists. In 2019, Valk entered the Archibald Prize, creating a portrait of Gold Coast-based Grace Loves Lace founder, Megan Ziems. Prints from this collection were recently featured on the 2020

season of House Rules.

Jeska explains why Megan is one of the favourite people she has painted "Megan Ziems is a fashion designer and the entrepreneurial founder of 'Grace Loves Lace', a company which specialises in creating beautifully elegant, unique and sophisticated designs in fine European lace and silk – designs that are redefining the bridal wear industry. Her influential and inspiring designs are empowering a new generation of women, by augmenting their natural beauty and celebrating their curves and femininity."

"She is courageous, inspiring, fearless and a game changer."

Like many of us, 2020 has brought highs and lows for Jeska and she has not been immune to the impacts of COVID-19.

"I have a new series about to be launched which is very exciting. I had planned to travel next year (which might be postponed) for a developing series exploring different cultures." Jeska said

"Financially it has been difficult, like for so many. I do usually work from home so my daily life is self-isolation but I miss being with the people I love."

Support from family and friends has been vital for Jeska and she looks forwards to reconnecting with them once the restrictions of COVID-19 are eased.

"I am truly thankful for the people in my life. My friends and family are kind and inspiring people. What they have taught me about love and respect for others and for myself has echoed through my work and my life. As a person living with epilepsy you can feel incredibly lonely, filled with shame and self-doubt and without them I would be a very different person today."

Jeska also believes that Epilepsy Queensland plays a vital role in educating the community and providing support and connection for people living with epilepsy and their support networks.

She shares: "I can only speak from my perspective but my advice would be to reach out, if you feel lonely and you're hiding away find someone you can talk to. It's the first step to making you feel safe and confident. To those who know someone with epilepsy, it varies so much from person to person, try to be patient and listen."



You can see more of Jeska's work on Art Lovers Australia <https://artloversaustralia.com.au/vendor/jeska-valk> or follow her journey on Instagram @jeska_valk.

If you would like to share your story please contact us on 1300 852 853 or pr@epilepsyqueensland.com.au.
To read more stories of people impacted by epilepsy follow Epilepsy Queensland on Facebook @EpilepsyQueensland, Instagram or Twitter @epilepsyqld.

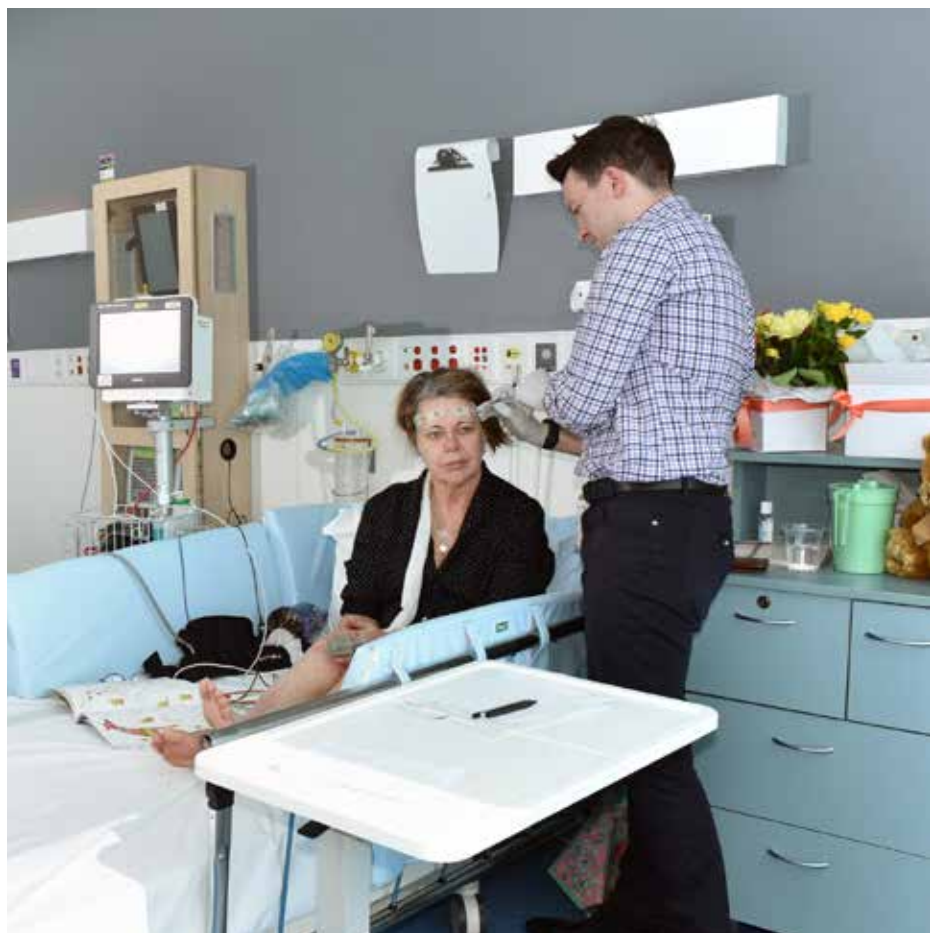
COMPREHENSIVE EPILEPSY PROGRAM MAKING A DIFFERENCE



Julie Grantham is about to sit her driving test again. She is 55 years old. “When I had to stop driving six years ago because of my epilepsy, I sold my car,” she states. “I never thought I would be in a position to use it. But now I am 12 months on from my epilepsy surgery at the RBWH, I am seizure-free and have recently been cleared for driving.”

Julie is a primary school teacher with two grown-up children and two grandchildren. She had lived with epilepsy for many years, but by her 50’s her epilepsy stopped her from working. She was having frequent seizures despite multiple antiepileptic drugs and living alone added another element of concern for her safety. When she was evaluated at the RBWH and found to be suitable for epilepsy surgery, she leapt at the chance. “The work-up was so thorough I didn’t actually feel too apprehensive. I felt great confidence in the team,” Julie said. She was also closely supported by the dedicated team of RBWH epilepsy nurses. “They were always accessible, by phone, email, or face to face if I needed. It was very reassuring to have them, from start to finish,” she recounts.

“Too few Queenslanders have been considered for epilepsy surgery in the past, due to an incorrect assumption about who is eligible and can benefit” said Prof David Reutens, Director of the RBWH Comprehensive Epilepsy Program. “All people with epilepsy in Queensland, including those from regional and remote areas, should have access to the



best options for complex epilepsy care. That's why a public state-wide service was set up." The RBWH program offers a full range of diagnostic tools including long term video EEG monitoring, intracranial EEG, and state of the art imaging, with high-resolution MRI, nuclear medicine scans such as SPECT, PET and functional MRI. The multidisciplinary team consists of professionals in many disciplines (including six epilepsy specialists). The team meets every week at a case conference to formulate an expert consensus opinion of the best management option available for candidates for surgery, carefully going through the test results. "International experience has shown that the combination of expertise from different specialists focusing on complex cases results in better patient outcomes," Prof Reutens states.

He also notes, "Not everybody will be suitable for epilepsy surgery, and not everyone will want to go down that road. That's why we also have an active Clinical Trials program, so that our patients can have access to the newest anti-epileptic drugs and other devices in development."

Kimberley Irwin has been coordinating the program since 2013. She remarks "What I like about coordinating the Clinical Trials is that it gives people with epilepsy hope. The program also has many research projects in imaging, genetics, neuropsychology and EEG, all trying to pave the way to a future where epilepsy's impact is diminished or eliminated altogether."

Other speciality clinics run by the Comprehensive Epilepsy Program focus on the optimum care of people with epilepsy at different stages of their life: First Seizure clinic for people who have had their first seizure, the Transition clinic for adolescents with epilepsy transitioning from paediatric to adult care, and the Women and Epilepsy clinic, which deals with specific issues relating to epilepsy management during the childbearing years. The Neuropsychiatry clinic is run by Dr. Chris Randall, a psychiatrist attached full-time to the Comprehensive Epilepsy Program. "The mental health care of people with epilepsy is as important as the care of their epilepsy. Studies have shown that improved management of conditions like depression improves their epilepsy as well, so it is vitally important we address these issues," he points out.

Sadly, Julie's father passed away in February. He left her his bronze Honda 4WD. Against all previous expectations, Julie will be able to drive it herself. As Julie lines up next to local teenagers in her suburban Department of Transport, waiting to sit her road rules test, she reflects on her journey and the team at the RBWH, "I am just grateful for all those who have got me to this point. Thanks for everything and keep up the good work!"



HOW DID YOU GO PURPLE FOR EPILEPSY?

March is our major National fundraising and awareness campaign for the year culminating in Purple Day on 26 March. Unfortunately Coronavirus (COVID-19) had a significant impact on our ability to host events, raise funds and awareness throughout the month of March. Thank you to everyone in our community who adapted, going purple for epilepsy at home and online.

Thank you to pharmacies and our sponsors

Thank you to our Purple Day sponsors the Pharmacy Guild of Australia (Queensland Branch) and Followmont Transport for your support. The Pharmacy Guild of Australia promote Purple Day to their members, asking them to support by selling our items. While our results have been severely impacted by Covid-19, these sponsors have been vital in assisting us in our merchandise campaign.

More than 100 pharmacies across the state stocked our purple awareness merchandise during challenging times. Transport of our precious cargo was kindly provided by Followmont Transport free of charge. Myrtle the turtle (named by our members through voting on our Facebook and Instagram pages) was a big hit selling out before Purple Day.

We are pleased to announce that the winner of our Purple Pharmacy of the year is Agnes Water Pharmacy. This wonderful local pharmacy not only sold our merchandise, but also held an Easter colouring-in competition and staff dressed in purple.

Purple Heroes

Thank you to our Purple heroes who were still able to raise awareness and funds for our epilepsy services. Some managed to get in their events before social distancing measures started to come into full force and others adapted to host virtual and online events.

We also still had some wonderful schools who went purple, shopping centre stalls, Everyday Hero pages, people who shared their stories, or hosted BBQs, morning teas and even a virtual online art auction. While we can't share all of their stories, here are just a few.



Townsville fountain



Epilepsy Queensland volunteer Anna Chesson



Agnes Water Pharmacy



Cameron Asher Art Show





Ed Barker and
Wilson State School



Sponsor Followmont
Transpot



Ollie and Codie
Sheppard

Ed Barker - Toowoomba

Ed Barker, of Toowoomba, is a wonderful human and true purple hero. For Purple Day this year, Ed, who lives with epilepsy, organised a range of activities in support of our organisation and Queenslanders living with epilepsy.

Accompanied by his son, Bailey, Ed organised two class talks at Wilson State School which was met with lots of interest, questions and learning about epilepsy. This was complemented by class activities and worksheets.

With the support of Miss Orvain, Wilson State School went purple for epilepsy and had a free dress day, raising approximately \$700 for Epilepsy Queensland.

Big W Clifford Gardens, where Ed is employed, was also a huge support, selling purple merchandise and featuring Epilepsy Awareness Day on their community notice board.

Overall, Ed's efforts for Purple Day have resulted in over \$1,800 raised so Epilepsy Queensland can continue to deliver our specialist services to Queenslanders living with epilepsy.

Cameron Asher art show

A huge shout-out to Cameron Asher for his support of Epilepsy Queensland and people living with epilepsy. Cameron lives with epilepsy and after undergoing brain surgery, wanted to do something to assist others with epilepsy. Cameron decided he would like to host an art auction and epilepsy awareness event on Purple Day and set about painting amazing works of art.

When COVID-19 came along and impacted all of our lives, Cameron decided to move his art auction to a Facebook live event, raising an amazing \$670. Thank you to everyone who supported Cameron and Epilepsy Queensland by purchasing a piece of his artwork.

Our sincere thanks go out to Wandering Cooks, South Brisbane, who provided the venue and support for Cameron and Epilepsy Queensland in these incredibly challenging times for the hospitality industry.

Codie and Ollie Sheppard

Ollie Sheppard is four and a half years old and you would never know it from that great smile, but he has been through a lot, along with his devoted Mum, Codie.

Ollie was just 14 months old when he experienced his first seizure and was diagnosed with epilepsy soon after. Two years ago he had brain surgery to help with his seizures and currently he is on two forms of medication to provide daily relief. Now three months seizure-free, Ollie is enjoying his first year of kindergarten.

"It's the same school and staff as his daycare, which has made it really easy," says Codie. "It means they already have the

training in what to look out for and do if Ollie has a seizure so that is a huge relief. I trust them with him."

This Purple Day, Codie had a home barbecue and went "purple crazy." Ollie's kindergarten also showed their support by hosting a bake sale.

When asked what Purple Day means to them, Codie responds "raising awareness and educating."

"There is a big misunderstanding as to what epilepsy is," she says. "This is a day where we can educate people. A lot of people still go around thinking epilepsy just means that you have large fits, which is not true. It is important to educate people on the different forms and side effects of epilepsy."

Codie sums up what it is like being a Mum to a gorgeous young man living with epilepsy with this poem.

*A child is like a
butterfly in the wind.
Some can fly higher than others,
But each one flies the best it can.
Why compare one against the other?
Each one is different.
Each one is special.
Each one is beautiful.
I love you Ollie*

Thanks to their tireless efforts raising awareness of epilepsy through social media, we are pleased to announce Codie and Ollie as the winners of the Epilepsy Australia's purple iPhone 11 competition. Thank you to everyone who took a purple selfie, tagged @epilepsyqueensland and #GoPurpleForEpilepsy to go into the draw.

If you had to cancel your Purple Day event, get in touch with our fundraising team on 1300 852 853 if you would like to host your event later in the year.

Illuminations

Did you see Brisbane light up purple from a different angle and take the FREE City Hopper along the Brisbane River? For those not in Brisbane on Purple Day 2020 we had purple illuminations and fountains across the State including Ayr Fountain, Brisbane City Hall, Forgan Smith Building – UQ, King George Square, Kurilpa Bridge, Newstead Gasometer, Parliament House, QPAC, Story Bridge, Victoria Bridge (Brisbane), Munro Martin Parklands (Cairns), Graincorp Dalby West Silos, Ipswich Civic Centre, Mackay fountain, Graincorp Carrington Port silos (Newcastle) Oxley Street fountain (Townsville).

Thank you to Nine News Queensland who did a live weather cross with a view of the Story Bridge lit up purple, to our Patron Wally Lewis and the news team for sharing a special Purple Day message.

30 minutes with...

Gerard

Benedet



What is the exact title of your role?

Branch Director – Pharmacy Guild of Australia Queensland. It sounds fancy but it's Pharmacy's way of saying CEO.

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

Pharmacy House is located in Spring Hill on the edge of the Brisbane CBD. I've been the Branch Director for just over six months. I was privileged to take on the role after the very successful tenure of Ms Robyn Ede after twenty-five years of dedicated service.

Where else have you worked in your life?

I've made a very conscious decision in my career to try different things, to continuously learn and to transfer skills and knowledge between industries. I've worked in Parliament House, Canberra for several Cabinet Ministers, at the National Rugby League in Sydney, been a Chief of Staff to a State Treasurer, worked for News Corporation and managed Government, Public Affairs and Marketing for a National VET training provider. I've consulted on different projects to the Business Council of Australia and Medicines Australia and most recently set up an organisation called Advance Australia, which I successfully moved out of its initial start up phase when the Guild approached me to take on the Branch Director role, that I am currently enjoying.

What do you love about your job?

The diversity. I love roles which cover a range of tasks, skills and expertise – I like to be challenged and enjoy learning new things. At any one moment I could be dealing with a training matter, stock shortages from wholesalers, a member concern or the delivery of our conferences and events. The broader the role the better for me – I like to be kept on my toes.

How do community pharmacies support people living with epilepsy?

Community pharmacies are a great source of information and guidance about different medications, how to take, prepare and use medicines safely, especially when people have complex conditions or are on multiple medications.

What is your personal connection to epilepsy?

My son was diagnosed with focal epilepsy when he was six months of age. My wife noticed a muscle tic above his right eye and took him to see our GP. I, of course, thought nothing of it. The GP said we should take him straight to the Lady Cilento Children's Hospital, so we did. He was admitted immediately and the doctors (all very excited to be capturing an EEG on a six-month-old), were brilliant and very understanding of two parents who had never had to deal with or had given much thought to epilepsy.

Our son was indeed having seizures and underwent numerous tests which revealed a small dysplasia of cells in his right frontal lobe. We decided to medicate him and for two years the treatment worked to limit the number and severity of seizures.

Actually, I'd just started a new job (with long hours and increased responsibility) when the medicated options ceased to work. We sought second, third and fourth opinions and they all led to surgery. So, on our son's third birthday, after undergoing more scans, tests and a blessing he underwent five hours of brain surgery.

I am elated to report that since the surgery our son has been seizure free. For us, it's been our little miracle.

I know that our (because it was really my wife and I – a true team effort) journey is so different to that of so many other families. Despite our trials, our experience was relatively straight forward compared to that of other families, who continue to see loved ones suffer.

Special mention goes to Dr Kate Riney, who was spectacular through our consultations, decision making, surgery, post op and discharge. A woman I will never forget and could never thank enough.



Where would you most like to travel?

I'd love to go back to America, get a hire car and drive across the country, taking in the various sights and sounds. America is maligned by some, but I've always found the people polite and interesting. Call me a studier of sociology or people watcher but I enjoy being able to engage with different people and understand their perspectives on the great events that form American history. I'd also love to be in Santa Clara, California for a 49ers home game!

What is your favourite food?

Has to be creamy boysenberry ice-cream! A good steak finishes a very close second. I am easy to please!

Describe your most embarrassing moment?

We are all human! My most embarrassing moment was getting a golden duck (zero runs) as an opening batsman in my final game of first grade cricket in year twelve – it just happened to be the final as well. I was clean bowled, with all three stumps cartwheeling – not a good look or feeling!

What is your favourite book/author?

At the moment, it would be 'Start with Why' by Simon Sinek. For leaders it's a great way to drive clarity in complex and fast paced environments.

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

Former Prime Minister the Hon John Howard. I would love to have met Winston Churchill and Captain James Cook – two men whose unique yet very different styles had an enormous impact on our livelihoods and western civilization.

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

Honestly, it depends on my mood. When I am on my road bike, I love to listen to Australian Rock and sing along every so often. When I am writing board papers or finalising documents I enjoy listening to classical music, baroque is best. My favourite song at the moment is Tucker's Daughter – the Ian Moss version.

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

Nothing out of the ordinary, I like poking around in the vegetable garden. With four kids, I am kept plenty busy around the house or playing sport, hide and seek or the latest game that comes home from school. I do enjoy getting on my road bike to clear my mind.

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

Firstly, I'd like to know more, what are the challenges that need to be solved, before offering advice. But in the quick little piece of research I did, greater support for families and Epilepsy Queensland could be a great starting point. I am a big fan of active industry or community organisations, it's what helps build and maintain a caring society.

During the COVID-19 pandemic, pharmacies are very much on the frontline. Do you have any helpful messages for people living with epilepsy during this time?

It's true, our members have been on the front line of the COVID-19 pandemic. Be it the run on prescriptions, the demand for masks, hand sanitizer and flu vaccinations, our members have been open and accessible. While, we've had a few scares in Qld, pharmacies have been hugely successful at putting in place infection control measures and continued to serve the community.

Social distancing is here to help you. Studies from overseas clearly show that people with complex conditions or comorbidities are at greater risk if they contract COVID-19. The intensive care statistics out of places like New York and London are frightening. In New York, one study had the mortality of patients placed on a ventilator at over 70%, in Australia it's under 25%, so we must be doing something right. I would strongly urge you to continue to follow the social distancing rule, despite the hardship that comes with them, they are saving lives.

Ask, don't guess. It's a simple message but its power is in knowing. Medicines and medications can take on very different behaviours under different circumstances. Community pharmacy is here to help, if you have a question, ask and your local Community Pharmacist will be able to provide you with the answer.





CORONAVIRUS

AND EPILEPSY

The coronavirus (COVID-19) is impacting on many countries including Australia and is occupying a lot of time in the news. On 11 March, the World Health Organisation declared the outbreak to be a pandemic. You're not alone if you're feeling worried about it and what it means for you and your family.

The coronavirus attacks the respiratory system. Most people infected with the viral illness will only have mild to moderate symptoms, however it can be severe and life threatening, particularly for the elderly with an underlying health condition.

We are receiving calls from people who are understandably worried that epilepsy may place them at higher risk of developing coronavirus.

Epilepsy is a term given to many different disorders that lead to seizures. Some people will have easily controlled seizures, have no other health problems, and become seizure-free on medication. Or they may have epilepsy with occasional seizures but no other health problems. For these people the available data suggests that just having epilepsy alone:

- Does not increase the risk of getting coronavirus and
- Does not increase the severity of coronavirus

They may be taking medicines to control seizures that also affect their immune system (for example, ACTH, steroids, immunotherapies). Or they may have other neurological or developmental issues that affect their immunity. People in these situations are at greater risk of developing more severe symptoms with viral illnesses.

People with epilepsy may have other medical problems that could place them at higher risk of developing more severe symptoms with coronavirus.

For example, people who have problems swallowing or frequently inhale food or liquid into their lungs (aspiration) are at higher risk for pneumonia.

People with diabetes or underlying heart or lung problems also appear to be at higher risk for severe coronavirus.

Regardless of your situation, it is important for anyone with epilepsy to talk to their treating doctor about their individual risks and if any specific medical precautions are needed. Take precautions to avoid getting sick too.

Can coronavirus increase seizures if a person gets the virus?

When a person with epilepsy gets sick with another illness, especially with a high temperature, they may notice a change or increase in their seizures.

The illness is a physical and emotional stressor to the body that could make seizures more likely. The same happens with coronavirus.

Other triggers may include:

- Not eating or drinking normally
- Not being able to take medications regularly (for example, if vomiting is a problem)
- Not being able to sleep well
- Worry and anxiety about seizures and coronavirus may affect people.

Preliminary information from countries where outbreaks have occurred suggests that the risk of worsening seizures with coronavirus appears to be low for most people with epilepsy.

What should be done if seizures change or increase?

If you or a loved one develop coronavirus and notice changes in seizures, contact your GP and neurologist.

Just like any other time, if you or a loved one have an emergency such as seizures lasting too long or more seizures than usual, seek emergency help.

What to do to avoid catching coronavirus?

- Wash your hands often for at least 20 seconds
- When you can't wash your hands, use a sanitizer
- Avoid touching your eyes, nose and mouth
- Avoid close contact with people who are sick
- Stay home if you are sick and call your doctor first, before going into their clinic
- Cover your cough or sneeze with a tissue and then throw the tissue in the bin
- Clean and disinfect frequently touched objects and surfaces

Preparing for any emergency


Preparing for potential emergencies is part of life for all of us.

- Talk to your pharmacist about creating an emergency supply of prescription medicines
- Don't leave it until the last minute to get a new prescription from your doctor
- If you will need a new prescription in a few weeks, get it early
- Keep your Epilepsy Management Plan up to date – you can ask Epilepsy Queensland to help you with this
- Keep a phone and any electronic devices charged that you may need for medication reminders or for calling family or emergency responders.
- Call our friendly Services team if you have more questions on 07 3435 5000. Keep up to date with the advice from the Department of Health www.qld.gov.au/health/conditions/health-alerts/coronavirus-covid-19

The primary source of this information is www.epilepsy.com/article/2020/3/concerns-about-coronavirus-and-epilepsy

COVID-19 and Mental health

In these uncertain times, it's easy to feel overwhelmed. One in five people will experience a mental health condition even in "normal" circumstances, and we know that people with epilepsy experience higher rates of anxiety and depression. This can be especially difficult if you are already isolated, which is the case for some people with epilepsy. Just as we're looking after our physical health, we need to be proactive and look after our emotional and mental health.

 Call us on 1300 852 853.

During this time it is important to access CREDIBLE information about COVID-19. We have included some helpful links:

- Australian Government Department of Health www.health.gov.au
- Australian Government Department of Health www.headtohealth.gov.au
- Queensland Government COVID-19 latest information and available support www.covid19.qld.gov.au
- Queensland Health COVID-19 alerts www.qld.gov.au/health/conditions/health-alerts/coronavirus-covid-19

- Australian Government WhatsApp <http://aus.gov.au/whatsapp>
- Beyond Blue www.beyondblue.org.au/the-facts/looking-after-your-mental-health-during-...
- Coronavirus Australia government app in the Apple App Store or Google Play
- Coronavirus news and information in 63 languages www.sbs.com.au/language/coronavirus
- Health Direct Symptoms Checker www.healthdirect.gov.au/coronavirus
- Queensland Health Facebook Page www.facebook.com/QLDHealth

 Beyond Blue 1300 22 4636

 COVID-19 information line 1800 020 080

 Kids Helpline 1800 55 1800

 Community Recovery Hotline 1800 173 349


COVID-19 update- hospital neurology services

Things are changing every day at present. For Epilepsy Queensland members, supporters, volunteers and stakeholders this can be challenging.

Neurology services in hospitals in Queensland are still operating but clinic appointments are being impacted. In some cases, reviews are available via phone.

Staff in Neurology departments may be reassigned in the near future to assist onwards and in other front line services so they may not be able to provide you with all the services they have previously. Contacting your GP in those instances may get you quicker responses.

Staff have been in touch with EQI and send their thoughts and best wishes and look forward to seeing you in the future.

 If you do not have family/friends to assist in filling scripts assist may be available from the Community Recovery Hotline on 1800 173 349 (also known as the Care Army)

If you would like to chat with one of the Client Services Team at Epilepsy Queensland call us on 1300 852 853 or send us a message.

Keep up your usual medical appointments and checks

Don't cancel your usual medical appointments. It's vital to keep them up, to ensure you maintain best possible management of your seizures.



NEW EPILEPSY QUEENSLAND WEBSITE IS NOW LIVE!

We are excited to announce our new Epilepsy Queensland website is now live!

Epilepsy Queensland's mission is to optimise life for people living with epilepsy and bring epilepsy out of the shadows. Access to credible and up-to-date information online is vital. Our new website has a range of new and updated information to help you or your loved one to manage your epilepsy.

We can also assist you along different stages of your epilepsy journey including a new diagnosis of epilepsy, people facing challenges in the workplace, pregnancy and fitness to drive.

With current restrictions related to COVID-19 we have a range of online training and support opportunities available. Our website allows you to register for these securely online.

Our online store has also been updated and we have stock available if you missed out on epilepsy awareness items during Purple Month.

Access our new website at: epilepsyqueensland.com.au

Go social

Don't forget to like us on your preferred social media channels. We are active on Facebook, Instagram, Twitter and LinkedIn! This is the quickest way to get the most up to date information and news on epilepsy research, treatments, issues, training, local events and to connect with other members of our epilepsy community.

If you have feedback contact us on 1300 852 853 or epilepsy@epilepsyqueensland.com.au. We look forward to hearing from you.

Zoom online training available

Whilst we are not able to deliver face-to-face training at this time due to COVID-19 restrictions, our amazing Services team CAN still provide "Understanding epilepsy" and "Administration of Midazolam" training via web conferencing platform Zoom. <http://bit.ly/eqitraining>

We also offer online training through Epilepsy Australia's Epilepsy Smart program <http://bit.ly/EpilepsyTraining>

We understand the need for specialist epilepsy training and support is still very important and our organisation is committed to working in innovative ways to continue to provide this service.

Our training can be tailored to suit individuals, community organisations, health and welfare groups, disability services, businesses, education providers, students, state institutions and other groups.

We can also provide personalised training for people under the NDIS, who require training for their support team – contact us today for a quote of services.

To express interest or for further information, please contact services@epilepsyqueensland.com.au or give us a call on 3435 5000 (Brisbane metro) or 1300 852 853 (outside Brisbane).

Our support groups are still running via Zoom and Facebook.

Whilst face-to-face meetings are suspended due to COVID-19, our support groups continue, now available via video conferencing platform, Zoom.

During this difficult time, our community is more important than ever. Our weekly Zoom catch-ups will include a mix of activities based on interests of the group, conversations about different aspects of living with epilepsy and a chance to share your experiences.

There is no cost to attend- you just need an internet connection and computer or mobile device.

Upcoming dates and times

Adult Social Group (South-East Queensland):
Fridays from 1 May (weekly basis): 1.00 pm - 2.30 pm

Adult Social Group (Regional Queensland):
Fridays from 1 May (weekly basis): 4.00 pm - 5.00 pm

We also have Facebook support groups to help you connect.

Regional Facebook Group: <https://www.facebook.com/groups/623976604683092>

Epilepsy Adult Support Group of South East Queensland, Australia Facebook Group: <https://www.facebook.com/groups/917169625299578/>

Find out more <http://bit.ly/EQISupportGroups> or register your interest via email Leonie: lhogarth@epilepsyqueensland.com.au



RECRUITMENT 24/7 IPSWICH100 CHARITY BIKE RIDE

On Sunday 15 March just short of 500 keen cyclists came together for the 25th Ipswich 100. Epilepsy Queensland was again one of the beneficiaries of this fantastic event. Cyclists enjoy a picturesque ride through the Scenic Rim and Ipswich region on undulating roads. This fantastic event offers a 100 Mile, 100KM, 50KM, 25KM and Kids Capar ride suitable for all levels of interest and ability.

Thank you to all of the cyclists, organisers and to the various Lions Clubs who work to make this event a success especially the Moggill Mt Crosby Lions Club who has been running it for 21 years.

Gordon Brown from Lions Club of Moggil Mt Crosby said "The 21st running of the ride was held in challenging circumstances on Sunday March 15.

Fears of a Covid-19 pandemic, and pending government restrictions on public events dominated the lead up. In addition, it rained on 8 of the 14 days before the ride, limiting rider training.

Consequently, numbers were well down and so were funds raised from entries, but we were pleased to raise around \$40,000 in total for our beneficiaries and Lions projects."

DONATE YOUR COMMUTE

March is usually our major fundraising and awareness campaign for the year.

Unfortunately, Coronavirus hit us hard in March and is continuing to have a significant impact on our ability to raise funds. We understand everyone is struggling and for this reason, our epilepsy community in Queensland needs your support now more than ever.

If you are now working from home and finding you are saving a few dollars through not commuting, buying your lunch or that take-away coffee, we would love your support as we participate in the Everyday Hero #donatemycommute initiative.

Any support you can provide is greatly appreciated and will help Epilepsy Queensland to adapt and continue to provide our vital services in this difficult time.

- Keep our Epilepsy Helpline available with information and support from our trained counsellors and nurses.
- Ensure training of educators and disability support worker continues through online platforms.
- Help us provide support and community through our social media pages and Facebook support groups.
- Help keep our advocacy with employers, service providers and policymakers on track.

If you are in a position to help and be an everyday hero, please head to <https://bit.ly/DonateCommute>



2020

DIARY DATES

11 June 16 July 13 August 10 September 15 October 19 November	Understanding Epilepsy & Admin of Midazolam Workshops - via web conferencing platform Zoom For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
6 June 4 July 1 August 5 September 3 October 7 November	Brisbane Adult Support Group Meeting (Online via Zoom)
22 May 29 May 5 June 12 June 19 June 26 June	Adult Social Group (Online via Zoom) South East Queensland – 1pm Regional Queensland – 4pm

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

SUCCESSFUL QUALITY AUDIT

Epilepsy Queensland is pleased to share that it has undergone another successful independent quality audit of our services, continuing our Certification to the Human Services Quality Standards. This audit helps us to continue to deliver and improve our services to you. A big thank you, again, to our clients who spoke to the auditor about the services we offer and how we continue to meet the needs of people affected by epilepsy.

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 please renew your membership by 30 June 2020.

As a valued member you will receive:

- Complimentary access to our monthly “Understanding epilepsy” and “Administration of Midazolam” training sessions currently via web conferencing platform Zoom
- 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 visit our website <http://bit.ly/eqmember>, return the enclosed form or contact us on:

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

Email: member@epilepsyqueensland.com.au