

the flame

the newsletter of epilepsy queensland inc

Issue 4 - 2020

MY EPILEPSY STORY

JULIA'S EEG STORY

Are you
Seizure Smart?

30 minutes with
Chris Dougherty

WHAT SHOULD SOMEONE LIVING WITH EPILEPSY
KNOW ABOUT EPILEPSY AND EMPLOYMENT?



MESSAGE FROM OUR CEO, CHRIS DOUGHERTY

To say this year has been a wild ride for all of us is an understatement. As I reach the two (2) month mark in the role of CEO I've been reflecting on the warm welcome and the brave sharing of your stories everywhere I go. I am humbled to be leading such a wonderful organisation that is having such a profound impact on people living with epilepsy.

Our hope is to do more. To reach more of the 28,000 people in Queensland currently diagnosed with epilepsy and to be there for the 3,000 people that will be diagnosed this year. Your stories are what motivate us to be better and your feedback helps us understand how.

As we consider where we will focus our energies of

the next few years I'd love to hear your feedback. So, whether you are living with epilepsy, are a parent or loved one of someone who is, a supporter or donor, researcher or other member of our epilepsy family please look out for opportunities to share your feedback and tell your stories.

This edition of Flame captures some great content including advancements in at-home EEG tools, being successful in small business and a wonderful acknowledgement to our previous CEO.

I've shared part of my story on page 8-9 so if you want to reach out to tell me yours please give the office a call on 07 3435 5000 – I would love to chat.

Contents

2 Message from our CEO	8-9 30 minutes with Chris Dougherty
3 'To Do' List	10-11 Are you Seizure Smart?
4-5 Julia's EEG story	12 Supporter Spotlight
6 Ask an educator - What should someone living with epilepsy know about epilepsy and employment?	13 Services Spotlight
7 Harry Finds Success Beyond the Daily Grind	14 SUDEP Action Day
		15 Research update
		16 Diary dates/Pharmacy Guild recognises former CEO



EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it.

The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights.

The Editor reserves the right to edit or exclude stories from inclusion in Flame at their discretion.

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



For information or help with any of the below please contact Epilepsy Queensland on 07 3435 5000

'TO DO' LIST

As we head toward the end of 2020 and school holidays, thoughts may eventually turn to 2021 and what needs to be completed to ensure a smooth return to school or work for your child living with epilepsy.

Here is a 'to do' list of things you might need to consider:

- Do you have an Epilepsy Management Plan? Epilepsy Queensland can help you with a new or updated epilepsy management plan. If a plan needs to be written, our team can work with your family and other care givers to complete a clear and comprehensive plan which includes individual seizure presentations and seizure first aid. If a plan needs updating for the new school year, the client services team are able to assist. The creation of a plan and plan updates can also be funded through the NDIS or independently.
- Midazolam Management Plans need to be written by the doctor who has prescribed the medication. Epilepsy Queensland can provide you with a Midazolam Management Plan template for you to take to your prescribing doctor for them to complete. It is always best to make several copies of this plan for your own record.
- Check Your Midazolam Kit:
 - ✓ Check the expiry date of the midazolam
 - ✓ Is the midazolam wrapped in the original foil packaging or aluminum foil?
 - ✓ Is the foil packaging labelled with the date the packaging was opened? (Midazolam expires within 8 months of opening the foil packaging and being exposed to light.)
 - ✓ Does the kit have your child's name clearly marked for easy identification?
- Does your Midazolam Kit Contain:
 - ✓ Plastic midazolam vials (5mg in 1ml)
 - ✓ 1ml syringes if required
 - ✓ An atomiser for intranasal administration if required
 - ✓ Disposable plastic gloves
 - ✓ Pencil and paper for documentation
 - ✓ The new Midazolam Management Plan (prescription) that is current
- Have You Considered the Following:
 - ✓ Are the contents of the kit stored in a container? (a small plastic lunchbox is suitable)
 - ✓ Is the container kept out of reach of children, both at home and school?



- ✓ Is the kit kept below 25 degrees celsius, and out of direct sunlight, both at home and at school? (Midazolam is not to be stored in the fridge or freezer)
- ✓ Have you provided an ice brick and cooler for the kit to be stored in during the hotter months when taking the kit outside?
- ✓ Do you have a separate kit for home and school? (This is to ensure the kit is never forgotten between destinations)

Midazolam is not to be kept on the child's person, in their school bag or desk. It is to be given to the school teacher or support worker for storage away from children, but it needs to remain accessible to staff in the event of a seizure occurring.

- Does your child's schoolteacher, day care teacher, support worker, grandparent or other family or friends caring for your child at any time need training in 'Understanding Epilepsy' or the 'Administration of Midazolam'? Epilepsy Queensland can provide training in these areas both during the day and after hours. Please contact the team for a training request form.
- Will your child be participating in any school based or personal swimming programs, hydrotherapy, horse riding, sailing or school camps? If yes, you will need a letter from your doctor giving your child permission to participate in one or all of these activities. All schools now request these letters before the child is allowed to participate, and they do not always give you a lot of notice. Considering how difficult it can be to get an appointment with your doctor, it is advisable you have all the required letters written prior to the start of the New Year. If you would like more information on how your child can swim safely with epilepsy, please contact Epilepsy Queensland for our fact sheet on epilepsy and swimming.
- Does your school, day care centre, respite facility or home need resources to assist in understanding epilepsy? Epilepsy Queensland has a range of children's storybooks available to help both children and adults understand epilepsy. Please buy from our website: www.epilepsyqueensland.com.au or contact 07 3435 5000 for information on the children's books and resources available.



YOU CAN DO ANYTHING YOU PUT YOUR MIND TO, NO MATTER HOW MANY OBSTACLES

JULIA'S EEG STORY

To connect with others impacted by epilepsy
or share your story contact Epilepsy
Queensland on 1300 852 853 or
epilepsy@epilepsyqueensland.com.au.

Julia Scott is a 24-year-old primary school teacher, living in rural Central Queensland, jumping over obstacles to follow her dreams.

Julia experienced her first seizure in 2012 at the age of 16. She was diagnosed with epilepsy in 2013 and prescribed her first medication (Carbamazepine) by her GP after her second seizure. Julia was not told her type of epilepsy until years later when she saw her first neurologist and was diagnosed with generalised epilepsy with tonic-clonic seizures.

Recently, Julia's neurologist requested an at-home EEG (electroencephalogram) to see if she was having epileptic and non-epileptic seizures. We thought this may be of interest to our community, particularly in the time of COVID-19 and Julia has generously shared her experience.

For Julia, the connection time was approximately one hour including a brief run down, wire connection for EEG and ECG (electrocardiogram) and explanation about the battery change over and camera operation. This took place in-person at Seer Medical in Brisbane. Julia stayed with her parents in Brisbane for the duration of the testing. She was required to complete the EEG over an eight-day period and states that she found the only restricting part was being confined to the one room. Julia found the positives for her was to be able to stay at home and that it was easy to manage, just requiring the battery to be replaced daily and to check the wires remain connected.



She says: "I hardly noticed the wires after the first day. I could still sleep normally and the bag that holds the wires is just like a front pack or hangs over your shoulder like a handbag."

There were, however, some challenges Julia reported. The EEG limited what activities she could do including not being able to shower, the need to unplug and move the camera (see photo) if she wanted to sit in another room for a long period and not being able to do her regular daily/weekly routine. This meant no seizure activity during the recording. It was necessary for Julia to have a seizure in the time period, so her neurologist could identify whether the seizure activity was epileptic or non-epileptic.

Despite this, Julia says she would definitely recommend an at-home EEG if these issues will not affect you or your results.

"Removal was simple and took no more than 30 minutes. They cut off the wires then used acetone to scrub at the glue to remove the rest of the wire (it doesn't hurt) then a fine tooth comb to pull the left over glue off the scalp. I went straight to the car and smothered my hair in coconut oil and combed it multiple times with a fine tooth comb and just kept going until I could feel and see that most of it was out. I left it in for about an hour (they suggest longer, about two hours but I had a flight to catch) washed it all out and it was fine with no glue left," she said.

Julia shares: "Before this, I'd only ever had the short one in hospital which is just hook up, flash lights and make you hyperventilate then they come off. Not the one where you stay in hospital. I have been stuck in a hospital bed for a week without an EEG connected in the hope I would have a seizure so that they could see it to somewhat figure out what type of seizure I was having. My seizures had slightly changed and they wanted to see if I had both generalised and focal epilepsy. That was just as much fun as I didn't have a seizure that time around either."

"With the at-home EEG, this was WAY better even though I was still limited to a bed. I was able to see my family more often as they didn't have to visit a hospital, eat whenever and better food than hospital food, had access to my own TV, internet, computer, books and generally being in your own bedroom is better than a hospital bed," she said.

Julia is now back at school, doing what she loves. As a teacher, Julia feels it is important to educate people when they are as young as possible about seizures, so that all people with epilepsy are included in everyday life. She showed her students videos, so that they would understand and be able to identify the different types of seizures. Julia also taught them the basics of seizure first aid and has Epilepsy Queensland's resources at her school.

Julia's epilepsy motto is: "You can do anything you put your mind to, no matter how many obstacles" and says her partner's favourite is "it is what it is".

"I have zero control of what happens," she says, "but I choose not to let it define my life and what I want to do with my life."

At-home EEG quick facts

- More than 750 people in Queensland have been through monitoring by Seer in 2020, this is more than double the number of people with seizures that were monitored in 2019 (2019: 309)
- Seer has maintained access to monitoring through COVID-19 with enhanced clinical safety measures being implemented (more information here: www.seermedical.com/coronavirus)
- Seer offers at-home EEGs as a 100% Medicare bulk billed service
- Seer currently has 3 locations in QLD & will be expanding their services to Townsville in October
 - Brisbane - Fortitude Valley
 - Gold Coast – Bundall
 - Sunshine Coast – Birtinya
- Stay tuned for more announcements on Epilepsy Queensland's social media pages and in Flame about new technology developments about this service and other devices.
- Epilepsy Queensland would like to thank Seer for donating \$50 for every monitored patient that was referred to Seer between 19 February and 26 March 2020 to Epilepsy Australia affiliates to celebrate Purple Day. Epilepsy Queensland was grateful to receive a donation of \$1867.
- Speak to your Doctor or Neurologist if you would like to be considered for an at-home EEG



EMPLOYMENT OPPORTUNITY

ASK AN EDUCATOR WHAT SHOULD SOMEONE LIVING WITH EPILEPSY KNOW ABOUT EPILEPSY AND EMPLOYMENT?

Employment is very much in the news at present with a range of initiatives in place during the pandemic.

For people with epilepsy, employment is often an important focus. Many people with epilepsy can and do find and maintain work. People with epilepsy can work in a range of occupations and generally epilepsy is not a factor in a person's ability to do a job well.

Unfortunately, there are some vocations not available to anyone with epilepsy, even where seizure control has been achieved. These include pilot, air traffic controller, commercial driver and jobs involving high voltage electricity, heights, heavy machinery or water.

Who should I tell?

Even when you have a job, misconceptions about epilepsy and fear of stigma can make people reluctant to tell employers about their diagnosis. Ultimately, your health is a personal and private issue and whether or not you disclose your epilepsy is up to you.

While there is not usually a legal requirement for an employee to disclose their epilepsy to their employer or colleagues, if people in your workplace are aware of your condition, it may reduce risks associated with a seizure. It also means they can be prepared to assist you if required, and will be aware of safety issues that may apply to you. If your direct supervisor/s are informed, they can then make reasonable accommodations for you should they be required.

Can I get any help finding employment?

In Australia, there are a range of Disability Employment Services (DES) established to assist people find employment. Usually an intake officer will go through the registration process and conduct an informal discussion face to face or by phone to determine which program is the best fit moving forward.

Anyone living with a disability, health condition or injury can directly register with a service they believe best suits their needs or can be referred by Centrelink or referred/recommended by a community organisations/services.

Usually proof of disability can be provided through a medical verification form or letter from a medical specialist or via an Employment Services Assessment conducted by an independent medical professional appointed by Centrelink who can then make a referral to a DES.

People seeking assistance from a DES do not necessarily need to be in receipt of payments from Centrelink, however an individual will be required to apply for a CRN (Customer Reference Number) through Centrelink.

More information about the range of DES providers and the services they offer can be found on the Job Access website. Through this website people can find out more about the service they think would best serve their individual needs. www.jobaccess.gov.au

Some general tips and hints on looking for employment:

- Having an up to date resume.
- Draft a cover letter with help from your provider but tailor this to suit the job/employer and do your homework (quality over quantity).
- Keep your provider up to date with jobs you have applied for.
- Jobs opportunities are not always advertised online. The face to face approach still works.
- Be open about other job choices.
- Ask your provider about opportunities they are working on - it's a shared effort.

Disclosure about disability, health conditions and injury is very personal and completely one's choice on how this should be dealt with. A strengths-based approach is a great way to tell an employer (with support of a provider where required) that one has overcome some personal barriers with self-determination to get to a stage where they are motivated and ready to work.

Employment rights for people with epilepsy

Federal and State anti-discrimination laws legally protect people with epilepsy from discrimination. You are entitled to take legal action if you believe you have been discriminated against because of your epilepsy.

If you believe you have been unfairly treated in the workplace due to your epilepsy status and would like to speak confidentially with someone, you can contact our Services team on 07 3435 5000 (metro) or 1300 852 853 (outside Brisbane).

Workplace advocacy and training

Epilepsy Queensland can assist with conversations with employers to help build an understanding of epilepsy or provide you with wording should you wish to disclose epilepsy to your employer. We also offer in-house or on-site training for Understanding Epilepsy and Seizure First Aid to help build understanding in the workplace and help employees feel comfortable in assisting someone who has a seizure. You can find out more on our website www.epilepsyqueensland.com.au/living-well/epilepsy-and-employment.



Harry Finds Success Beyond the Daily Grind

Harrison Hedges, 26, knows what it is like to battle the exhaustion that epilepsy can bring. He also knows what it means to hustle. The qualified personal trainer, exercise physiology student and expert barista has recently added another accomplishment to his repertoire- entrepreneur and small business owner.

The Sunshine Coast resident, who lives with epilepsy and mild cerebral palsy, opened Whatcha Brewing Speciality Coffee Co in the Big Top Shopping Centre, Maroochydore in May of this year. Harry made the decision to strike out on his own after becoming increasingly frustrated with the limitations of previous job roles.

Despite “falling in love” with hospitality work and attaining 11 years of work experience in the sector, Harry felt he “never really got anywhere” in the jobs he worked for employers, due to them underestimating his true abilities. “I worked in roles I could do with my eyes shut,” he states. “I knew I could do better.”

Employment Challenges Left Bad Taste

Harry was diagnosed with epilepsy at six months old, after experiencing tonic-clonic and absence seizures. He continues to take low doses of anti-seizure medications, which fortunately has allowed Harry to achieve seizure control for the past 15 years.

Harry is keen for people to understand however, medications are not a cure for epilepsy and the side effects of medications, such as fatigue, can still impact a person's day-to-day life. However, Harry remains hopeful- “There's no cure for epilepsy- YET,” he says.

Harry recalls one experience with a previous employer in which he experienced discrimination related to his perceived abilities.

“I wasn't hitting the minimum required job hours and was performing tasks outside of my job description, such as washing dishes. I felt really ripped off and as though this employer was not listening to me,” he recounts.

Harry engaged with the employment service that secured him the job role to set up a mediation meeting with his then-employer, but the experience left Harry fed-up and strengthened his resolve to do better.

A Cup Half Full

Like many people working in the hospitality industry, Harry lost his coffee consultant job when the COVID-19 restrictions came into place earlier in the year. For a period of three months, Harry struggled with a lack of purpose and had to move back in with his parents for a short period.

Then, when a coffee supplier contact informed Harry of the shop available for lease, Harry recognised the opportunity and grabbed it.

Harry acknowledges that those close to him had some reservations about his ambitions to start the business. Regardless, Harry pressed on with his plans, bolstered by determination and strong self-belief:

“I knew I could do it. I knew with my networking skills, that I could grow this business.”

Sharing a Coffee and an Opportunity

Recently, Harry accomplished one of the goals that he envisioned for

his business from the outset, employing a second person to work in the busy cafe.

It is important to Harry that he creates meaningful employment opportunities with supportive training- not just another job with limited opportunities for growth, which he personally felt of many of his own previous employment experiences.

“I'm giving someone a go. It's nice to know that I'm helping make a difference,” he says.

Harry used Mylestones Employment to recruit his new team member and intends to continue to use the disability employment services provider as his business continues to expand.

Brewing up Diversity

While Harry admits in the past to not disclosing his medical conditions to employers and even in personal relationships, he believes that things with respect to disability employment are now headed in a more positive direction:

“We live in a diverse world, with an increasingly diverse economy. I'm setting the tone for what disability employment should look like.”

When asked what his message to other people that might be experiencing challenges with employment, Harry responds: “Don't be afraid to share challenges you might be facing.”

The Perks of Self-employment

For Harry, the most exciting part of being self-employed is seeing his business grow and creating opportunities for others in the community.

“In living outside my comfort zone, I'm achieving growth within myself also,” he states. “I knew I could do it. Now I have the privilege of hiring people who NEED work.”

Harry concedes the long hours and high energy required in working in your own business can be challenging, but is clear he neither wants or needs sympathy:

“This is something I wanted to do for myself. I wanted to do it, so I'm gonna do it.”

He describes a transformation in energy when he took on the business and says he loves what he does. A quote from American entrepreneur, Erin Dubs resonates:

“Do what you love and you'll work harder than ever before.”

Harry held a fundraising and awareness #CoffeeForEpilepsy event during #SeizureSmartSeptember. He donated \$1 per beverage sold on Friday, 25 September and raised \$1,000 to support Epilepsy Queensland's seizure first aid training and awareness programs. We are incredibly grateful to Harry, Whatcha Brewing Specialty Coffee, Holey Moley Golf Club and Strike Bowling Maroochydore, Big Top Maroochydore Shopping Centre, Tim Adams Specialty Coffee, Junk Asian Fusion Restaurant, Heritage Bank, Malouf Pharmacies, Magic Massage, Mr Ink Tattoo and Barber Lounge and Alternative Dairy Co who supported the event.

30 minutes with...

Chris

Dougherty



About your role

What is the title of your role?

Chief Executive

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

As this edition goes to print I will have had eight weeks at Epilepsy Queensland – still a newbie.

Where else have you worked in your life?

I have worked in Aged Care, Disability, Multicultural Health and Mental Health. I have also been very lucky to have lived and worked in Ireland and Canada.

What is your personal connection to epilepsy?

When I decided I wanted this job it was because I saw a great organisation doing amazing work and I wanted to bring my experience in other areas of health to help us be better. I have been overwhelmed by people's stories from those I don't know at all, and those that are close that I should know better. Epilepsy does not discriminate.

What do you love about your job/working in the profit for purpose space?

In my job, I get to empower the work of others. I get to get up every day and know that almost everything I do will have an impact on someone today, tomorrow and into the future.

How do you think Epilepsy Queensland can have the biggest impact for people living with epilepsy?

Our biggest impact will come from understanding the needs of our members and those living with or impacted by epilepsy. With this information, we can better reimagine the services we offer and deliver.

What are your top priorities/aims in your new role?

Right now it's to do just that. Listen and hear what our members, people living with epilepsy, their families and all of our other stakeholders have to say so that we can tailor our strategy for the next few years to be better for them.

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

I think the development of a national plan to support the work of organisations like Epilepsy Queensland to translate and apply current research into their services in the communities they know best will take a big step in the right direction.

About you

Where would you most like to travel?

My favourite country in the world is Denmark. I love Copenhagen.

What is your favourite food?

A difficult choice – I think it would be equal first for Indian or Thai cuisine.

Describe your most embarrassing moment?

Thankfully, this wasn't witnessed, but it's embarrassing enough to tell people. At home I use smart lights and can control them using voice via Google Home. So I should be able to be carrying a lot of things, yell out to Google to turn on lights and then find my way through the apartment. One day I came home with things in my hand and my bedroom door had blown closed – this happened to be the day the voice command for the lights decided to delay activating and I slammed into the door and fall backwards onto the ground. Just as I hit the ground, the lights turned on.





What is your favourite book/author?

Currently my favourite book is a book of little short stories called 'All I Really Need to Know I learned in Kindergarten' by Robert Fulghum.

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

Hugh Jackman would probably be up there. It's cheating a little because he is married to my Dad's cousin but still!

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

I listen to a wide variety of music. I believe music heals the soul so you listen to whatever it is you need at the time! Right now, annoyingly, the song that gets me grooving is Watermelon Sugar by Harry Styles. Admitting that may have just become my most embarrassing moment!

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

I have a board game addiction. Like geeky, nerdy, prize winning board games. At last count we had 167 in our collection and running out of space.



Are you Seizure Smart?

Seizure First Aid



TIME the seizure

PROTECT from injury

ROLL onto side if unconscious
SUPPORT head if seated
REDIRECT if confused

REASSURE and re-orientate
STAY with the person

DO NOT restrain
DO NOT put anything in mouth
DO NOT give any food or drink until recovered

**CALL AN
AMBULANCE
000**
or 112 for mobile phones

- As per management plan
- Seizure longer than 5 minutes
- Second seizure follows
- Seizure occurs in water
- Person is eating or drinking
- Person's first seizure



epilepsyqueensland.com.au | 1300 852 853

This information is a guide only. Epilepsy Queensland Inc shall have no liability arising by reason of any person using or relying on the information.

What is Seizure Smart September?

Did you know one in 10 people will have a seizure during their lifetime regardless of whether they have epilepsy. With this in mind, our aim is for one person in every household, office and classroom to know seizure first aid.

Throughout September, Epilepsy Queensland shared new seizure first aid resources and ran a digital campaign to educate as many people as possible on how to respond to a seizure situation and be #SeizureSmart.

"Many people know basic first aid, but they don't know what to do if someone is having a seizure," says Epilepsy Queensland Services Coordinator Jenny Ritchie. "Your knowledge could help save a life".

The campaign also focuses on how to recognise different types of seizures as not all seizures are the same and can present very differently from one individual to the next.

What is a seizure?

Seizures are caused by sudden and increased electrical activity in the brain – up to 500 times per second – which is more than six times the normal rate. Essentially the brain controls everything that we do – when these electrical pathways get mixed up – it can cause a seizure. For a brief period this can cause abnormal activity such as strange sensations; unusual behaviours; convulsions and spasms through to loss of consciousness.

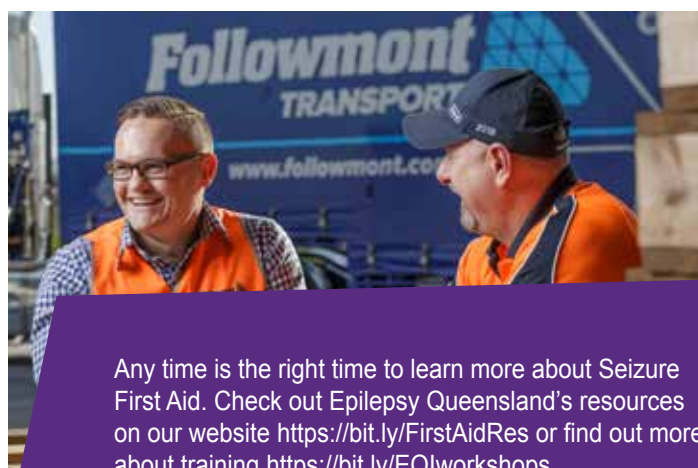
What to do if someone has a seizure?

Our downloadable seizure first aid poster (above) is an excellent resource for managing seizures in four key steps. For more information on how to recognise different types of seizures, the specific first aid for each, and the first aid steps for a seizure occurring in water or in a chair, visit our website: <https://www.epilepsyqueensland.com.au/about-epilepsy-epilepsy-queensland/seizure-first-aid>

Thank you to sponsors

Thank you to our Seizure Smart September sponsors the Pharmacy Guild of Australia (Queensland Branch) and Followmont Transport for your support. The Pharmacy Guild of Australia promoted Seizure Smart September to their members, asking them to support by selling our seizure first aid awareness tokens.

More than 70 pharmacies across the State stocked our tokens. Transport of our precious cargo was kindly provided by Followmont Transport free of charge.



Any time is the right time to learn more about Seizure First Aid. Check out Epilepsy Queensland's resources on our website <https://bit.ly/FirstAidRes> or find out more about training <https://bit.ly/EQIworkshops>.

#1in10Heroes

Amie's uphill challenge for seizure awareness

Brisbane #1in10hero Amie Wilcox battled a local hill 10 times a day for 10 days to raise awareness of seizure first aid. She took on the challenge in honour of her daughter, Lucy, who is eight years old and lives with epilepsy. Lucy has focal seizures and Amie wanted to raise awareness that not all seizures are the same.

Amie's family and friends were a huge support of her challenge donating, encouraging her on Facebook, joining in on the walk or cheering her on. By day eight Amie's calf muscles were starting to yell at her and by day 10 the climb was getting a little slower.

Amie shares: "I signed up for the challenge because I read about it around the same time Lucy had a recurrence of seizures and we ended up back at the hospital. So took it as a bit of a sign and thought why not? It's been a very positive experience and it has been great for my mental health as much as my physical health. It has certainly got me talking more about epilepsy with my friends and family. I was really blown away by the support I received from everyone."

Support Amie's challenge <http://bit.ly/amie1in10>



Get ready for Purple Day 2021

Spread a little purple cheer in support of people living with epilepsy, register your interest now for Purple Day, 26 March 2021. www.epilepsyqueensland.com.au/get-involved/purple-day



Crunchtime for #1in10 heroes Kat and Warner!

Super Mum Kat completed 10 sets of 10 crunches to raise funds and awareness as part of our October #1in10challenge. This was to help raise vital funds and awareness of seizures and seizure first aid for #SeizureSmartSeptember.

Kat's little boy Warner, who is five years old, is one of the 1 in 10 people who will experience a seizure in their lifetime.

You can still support Warner and Kat's efforts here: <http://bit.ly/Warner1in10>



Naomi and Emmett climb mountains for epilepsy

1in10 hero and epilepsy warrior Emmett and amazing Mum, Naomi, never shy away from a challenge. This year the duo from Townsville, stepped up to undertake our #1in10challenge in October.

Naomi's goal was to take 10 000 steps each day for 10 days to raise vital funds and awareness of seizures and seizure first aid. This was in solidarity with the 1 in 10 people who will experience a seizure in their lifetime.

Naomi and Emmett even conquered the mountain near where they live in Purple Day shirts on a couple of occasions to contribute to their challenge.

Support Naomi and Emmett's challenge here: <http://bit.ly/Emmett1in10>



SUPPORTER SPOTLIGHT

iFLY Warriors

Congratulations and a very BIG THANK YOU to our fearless flyers who took part in our iFLY for epilepsy indoor skydiving challenge on Saturday 5 September.

An incredible \$11,610 was raised which will go towards Epilepsy Queensland's vital services such as our helpline to support Queenslanders impacted by epilepsy.

You truly are all warriors and we are deeply grateful for your support- we hope you had a blast and soared beyond your own expectations.

Thank you: Melony Boadle, Nickayla Winter, Larissa Winter, Anthony Winter, Charlotte Whitlock, Jade Whitlock, Mia Whittall, Bonnie Fairbanks, Lance Nash and Chloe Bradford.



Odd jobs help Natalie make a difference

Guess how much money is in this jar? We were blown away by the generosity of teenager Natalie Lorimer, when she and her Dad, long time EQI member and supporter Paul, stopped by our office recently.

Natalie, who is 14 years old and lives with epilepsy, had been saving six months doing extra odd jobs around home. She wanted to donate her collection to Epilepsy Queensland as her family fundraiser for Purple Day each year, but unfortunately this year their usual activities were impacted by COVID-19.

Thank you Natalie for such a thoughtful gesture and to you and your Dad for taking the time to drop this off in-person- it was wonderful to see you both.

The final amount was \$571.15. Thanks for an amazing effort Natalie.



Bronwyn's cards for epilepsy

Bronwyn is on a mission to raise funds and awareness for epilepsy, so others receive the support they need. Using her talent for creating hand-made cards, Bronwyn has already raised over \$2,000 for Epilepsy Queensland's support services. Bronwyn has also shared her epilepsy story and gives encouragement to others living with epilepsy through Epilepsy Queensland and her own Facebook and Instagram pages.

She is forever grateful for the support she has received from Epilepsy Queensland and our social media community.

"I'm always mindful that a seizure can occur at any time. When first diagnosed, my first thought was "why me?" but then I came to realise that I'm not the only one who has epilepsy. There were times after I was diagnosed that I had enough and wanted to give up and felt like I couldn't cope. After feeling that way, I realised I had friends and family who could help me. Having met many online epilepsy friends through Facebook support groups, I am able to reach out and chat with others in similar situations and with similar struggles."



Winnin walking warriors

Shout out to Renee Winnin and daughter Maliyah, who lives with epilepsy, and their family who walked 5.6km for epilepsy on Sunday 27 September, raising \$1,040 for Epilepsy Queensland. THANK YOU!

They shared: "Epilepsy QLD has been a great resource for us and where we get our epilepsy training, so we want to give back to this amazing charity."





SERVICES SPOTLIGHT

New seniors resources launched

Epilepsy is very common in people over the age of 60. In fact, epilepsy affects children under the age of five, and people over 60, more than any other age groups.

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 tumours, cardiovascular disease, or dementia.

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

An older person with epilepsy may experience further confounding factors, such as:

- higher sensitivity to the toxicity of anti-seizure medications
- medication side effects of confusion, disorientation and tiredness
- adverse interactions between anti-seizure medications and other medications
- increased problems with memory due to medication
- increased risk of falls and injury dependent on seizure type
- increased home safety requirements

As part of Seniors Week celebrations, Epilepsy Queensland launched a suite of new resources for seniors living with epilepsy, their families, carers, and health and care professionals that work alongside them. Thank you to the Brisbane City Council for funding this project through the Access and Inclusion Program.

Special guests included Minister for Communities and Minister for Disability Services and Seniors, the Honorable Coralee O'Rourke MP and

Neurologist Associate Professor Cecilie Lander who gave a fantastic presentation about epilepsy in later life. Carol Barrett also shared her experiences of living with epilepsy.

We would like to recognise the hard work and contributions that went into delivering this valuable project and resources including Project Co-ordinator Janet Pond and the forum participants who helped co-design the resources.

If you weren't able to make our Zoom eTea launch, you can access all of the presentations and find out more on our YouTube Channel <http://bit.ly/EpilepsyYouTube>. You can find the new resources on our website: <https://bit.ly/EpiSenior>.

Connecting teens with epilepsy

The tunes were pumping, the smarties and balloons were plentiful and no button was left unglued when we welcomed teens and young adults living with epilepsy to our E-Connect sessions during the September school holidays.

These self-care and wellness workshops are welcoming, age-appropriate and held in a supportive environment where participants can come together to:

- ✓ Meet other people living with epilepsy
- ✓ Engage in activities to better understand seizures and epilepsy
- ✓ Learn about and try techniques to help manage emotions
- ✓ Try new activities – such as arts, creative writing, music
- ✓ Join in the cooking activities - and share the final product

All this while learning new skills to build independence, with a focus on FUN! We think these smiles tell the story.

To access Epilepsy Queensland's resources for teenagers visit: <http://bit.ly/EQl teens>.

If you would like to register an expression of interest for future events tailored to children, teenagers, seniors, parents, women or men living with epilepsy, contact our services team on services@epilepsyqueensland.com.au.



SUDEP Action Day

What is SUDEP Action Day?

SUDEP Action Day is a special day which brings organisations and people together to raise awareness of SUDEP worldwide.

Launched by SUDEP Action on 23 October 2014 (as SUDEP Awareness Day), it shines a light on the largest cause of death in people with epilepsy, helping empower people through increased awareness and raise funds for SUDEP research.

What are the Goals of SUDEP Action Day?

- Encourage people with epilepsy to learn about SUDEP and their individual risk
- Show what is currently being done to tackle SUDEP
- Promote ways people can manage their epilepsy to reduce their risk
- Highlight the need for more research into SUDEP to help save lives
- Raise public awareness about SUDEP
- Honour the lives of those we have lost

What is SUDEP?

SUDEP (Sudden Unexpected Death in Epilepsy) is defined as the sudden unexpected, witnessed or unwitnessed death of a person with epilepsy, where no clear cause of death is determinable after a postmortem examination. This may be with or without evidence of a seizure.

What causes SUDEP?

The cause of SUDEP is unclear and not well understood. Research is ongoing with some studies suggesting the part of the brain that controls breathing may have a role. Other studies suggest the possibility of problems with the function of the heart and brain. It may be that there is no single cause, but a combination of factors.

Who is at risk?

Presently, it is not possible to predict who may be affected by SUDEP. Many people with epilepsy live full life spans, although it is known that people with epilepsy have an increased risk of death compared to the general population. Without a known cause, it is not possible to accurately determine whether a person may be predisposed to SUDEP, however, it seems some people may be more at risk than others.

This may include people who:

- have uncontrolled seizures;
- have generalised seizures during their sleep;
- have frequent tonic-clonic seizures;
- are not taking their prescribed antiepileptic medication;
- are having frequent or sudden changes to their antiepileptic medication.



Reducing risk

There are measures you can take to try and reduce your risk of SUDEP. Maximising seizure control if possible, is very important. You should also:

- Ensure you never run out of seizure medication;
- Never make changes to, or stop medication without speaking to your doctor first;
- Avoid known seizure triggers- especially sleep deprivation;
- Look after yourself: eat well, have adequate rest and exercise;
- Talk with your family and friends about SUDEP, and consider telling colleagues about your epilepsy.

Want more info?

Visit our website <http://bit.ly/EqiSUDEP> or contact our team on 1300 852 853. If you would like to honour a family member by sharing their story please contact us on pr@epilepsyqueensland.com.au.





RESEARCH UPDATE

Epilepsy Queensland works collaboratively with medical and academic institutions to promote research, new technology and clinical trials for people living with epilepsy. We provide updates from around the globe of research bringing hope for a future where everyone has access to effective treatments and deaths are preventable until a cure is found.

Epilepsy Care in the Genomic Era

Queensland Genomics has funded a clinical project Integrating Epilepsy Genomics into Clinical Care aimed at patients with refractory epilepsy; where the seizures are not able to be controlled by medications.

The project will seek to find answers to two crucial questions for patients: 'What is the cause of my epilepsy?' and 'How can my epilepsy be treated?' Led by neurologist Associate Professor Lata Vadlamudi, the project team will work to incorporate genomic testing into the healthcare for eligible patients with refractory epilepsy at Royal Brisbane and Women's Hospital, Queensland Children's Hospital and Cairns Base Hospital.

With this new technology and the discovery of new genes associated with epilepsy, studies like this will enable a deeper understanding of the causes of epilepsy, which will ultimately drive the search for more effective drug treatments for patients.

The goal of including genomics in epilepsy healthcare is to improve the quality of care for patients and their families, and improve efficiencies in healthcare.

For more information if you are interested in participating, please see our website <http://bit.ly/EQIresearch>.

Impact of earlier diagnosis in focal epilepsy goes beyond timely treatment

Having focal epilepsy with subtle symptoms can go without a diagnosis for long enough to cause unexpected seizures that contribute to car accidents, a recent study published in *Epilepsia* Journal has found.

Researchers say the study is among the first to outline failure to recognise symptoms of subtle seizures as a main reason for the delay in diagnosis.

Led by researchers at NYU School of Medicine, the study shows that it can take on average two years for physicians to recognise the early signs of focal epilepsy, particularly for patients with seizures that do not involve uncontrolled movements of their arms and legs.

Among the study's other findings, a number of patients reported having one or multiple car accidents before their diagnosis.

The research team next plans to study patients who go to the emergency room (ER) after a car accident with early signs of epilepsy to see whether they are asked about their seizure history, or subsequently evaluated by a neurologist.

Because an ER visit can be the first time undiagnosed epilepsy patients are seeing a doctor, it offers a critical opportunity to intervene and prevent subsequent harm, the researchers say.

Read the full research summary: <http://bit.ly/ImpactEarlyDiagnosisFocalEpilepsy>

For more about focal epilepsy: <https://bit.ly/TypesofSeizure>

2020

DIARY DATES

25 November	Epilepsy Queensland AGM You're invited to Epilepsy Queensland's AGM. Our Annual General Meeting and Awards night is usually held each year in December. After much consideration the Board of Epilepsy Queensland has made a decision to hold the formal components of the Annual General Meeting (AGM) separate to our awards / celebration evening this year to ensure we can keep our members safe. All financial members are invited to attend or nominate proxy for the formal AGM.
5 November	Understanding Epilepsy & Administration of Midazolam Workshops (Gympie)
19 November	Understanding Epilepsy & Administration of Midazolam Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
11 November	Understanding Epilepsy & Administration of Midazolam Workshops (Gold Coast)
7 November	Brisbane Adult Support Group Meeting (The Coffee Club Brisbane Square)
6 November, 13 November, 20 November, 27 November	Social Group – epilepsy crew (Online via Zoom) South East Queensland – 1pm Regional Queensland – 4pm
Please call 07 3435 5000 for further information on any of the above events	



Former Epilepsy Queensland CEO recognised with community contribution award

The Pharmacy Guild of Australia, Queensland Branch held its annual dinner at Parliament House in Brisbane recently.

Helen Whitehead, former Epilepsy Queensland CEO, was recognised with an award for her outstanding contribution to the community. For 28 years, Helen assisted Queenslanders living with epilepsy by helping to reduce stigma and discrimination by raising community awareness and promoting understanding.

The Pharmacy Guild of Australia, Queensland, has been a supporter of Epilepsy Queensland for most of this time.

We are thrilled for the acknowledgement of Helen and the wonderful relationship Helen has helped to build with The Pharmacy Guild (Queensland). Their support of our recent #SeizureSmartSeptember campaign is invaluable.

Read the full Australian Journal of Pharmacy - AJP article here:
<https://bit.ly/2Fz0Gem>