

# the flame

**Ask an educator - What  
is the Patient Travel  
Subsidy Scheme (PTSS)?**

**MY EPILEPSY STORY**  
**MARIA'S ACCESS-ABILITY EXPERIENCE**

**30 minutes with ... Matt Butler**

the newsletter of epilepsy queensland inc

Issue 1 – 2020



# Audit – We would love your involvement

In February, Epilepsy Queensland undergoes its next independent quality audit of its services to assess how well we continue to meet the Human Services Quality Standards. This will help us to continue to deliver and improve our services to you. This is a regular audit and part of our grant funding requirements.

Part of this process is to gain valuable feedback from those who receive any service, assistance, information or referrals from us. You are invited to participate.

For those who may be interested in participating, your involvement would be approximately 10-15 minute discussion with an auditor, either face-to-face or over the phone or file review. Discussions are confidential and consent will be obtained before any action is taken.

If you'd like to be involved, please contact us on 07 3435 5000 or email [services@epilepsyqueensland.com.au](mailto:services@epilepsyqueensland.com.au).

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# GO PURPLE FOR EPILEPSY!

Purple Day (26 March) is just around the corner and we need your support! Part of a global campaign, it's an opportunity to help bring epilepsy out of the shadows and raise funds for Epilepsy Queensland's vital information and support services.

It's a time for people from around the globe to wear purple, help build an understanding of epilepsy and break down the common myths and misconceptions. Vital funds raised during the campaign ensure our services can continue across Queensland. Over 100,000 Queensland children and adults will acquire epilepsy during their lifetime.

This year our national theme for Purple Day is 'Go purple for epilepsy'. Throughout March, we encourage Queenslanders to 'Go purple' and show their support for Queenslanders living with epilepsy.

## How can I get involved?

**Anything is possible when you choose to go Purple**

### 1. Defy Yourself and Do Something Different

Be a Purple Day Hero for epilepsy and help to make the impossible possible. Choose from one of our experience events and fundraise to either soar like a bird at iFLY, or throw an axe at Lumber Punks.

2. **Wear the colour purple**, from your head down to your toes, your beard or nails and share your pictures and support on Facebook, Instagram, Twitter or LinkedIn with #GoPurpleForEpilepsy and tag Epilepsy Queensland.

3. **Host a purple event or activity** and go in the draw for great prizes! This can be as simple as a morning tea at work, host a dinner or a BBQ where your friends can make a donation.

4. **Become a Purple Day Hero** with your very own online Purple Day fundraising page. Simply share your epilepsy story or take on a challenge. Dare to be different, invite your friends to sponsor you in a sporting competition of your choosing, a walk or run. There are a number of events you can join and raise funds for EQI.

5. **Sign up and sell our retail range** – including our collectable cuddly turtles, our outdoor range that includes: caps, bucket hats, lip balm and cooler bags. Order using the enclosed flyer or visit our website. <http://bit.ly/PurpleStore>
6. **Share your story or our posts on social media** – add one of our frames to your profile picture, snap a selfie with a Purple Illumination or share our Purple Day Facebook, Instagram and Twitter posts.

## Go Purple in Brisbane

We listened to your feedback and will again host a Purple Day event at Southbank as Brisbane lights up purple. We will have entertainment and a twilight awareness walk around Southbank. Keep an eye on our website and social media for more details of this event.

### Purple Illuminations

On Purple Day 2020, we will have more purple illuminations and fountains across the State than ever before. Confirmed sites include Story Bridge, Brisbane City Hall, Victoria Bridge and Kurilpa Bridge (Brisbane) and Oxley Street fountain (Townsville). We will continue to keep you updated and post events where you can meet-up with other members of the epilepsy community via our Facebook page [www.facebook.com/EpilepsyQueensland](http://www.facebook.com/EpilepsyQueensland). If you would like to organise a Purple Day meet-up or illumination in your area please contact us on the details below.

### Without your support, we can't make a difference

Contact our team on 07 3435 5000, 1300 852 853 or email [purple@epilepsyqueensland.com.au](mailto:purple@epilepsyqueensland.com.au), visit [www.epilepsyqueensland.com.au/purple-day](http://www.epilepsyqueensland.com.au/purple-day) or [www.facebook.com/EpilepsyQueensland](https://www.facebook.com/EpilepsyQueensland), [www.instagram.com/epilepsyqld/](https://www.instagram.com/epilepsyqld/) <https://twitter.com/epilepsyqld> for more information, to register today and **GO PURPLE!**



# MY EPILEPSY STORY - MARIA'S ACCESS-ABILITY EXPERIENCE

If you have had difficulty finding or keeping employment due to epilepsy and would like support, contact our services team on 1300 852 853 or [services@epilepsyqueensland.com.au](mailto:services@epilepsyqueensland.com.au).



“

*The more we get to know about people with disabilities, the less likely we are to make assumptions. It's a great way to break down barriers*

”

Late last year, the Motor Accident Insurance Commission hosted jobseeker, Maria Rawson (pictured), for a day as part of the AccessAbility initiative, which connects people with disability and employers, so they can experience what each other has to offer.

Maria, who has epilepsy, explained that she was interested in connecting with Treasury because she wanted to play her part in helping the community.

“I really enjoy working with people in the community, particularly those in need. So, having the opportunity to come in to Treasury was great, and everyone was really friendly and inclusive,” she explained.

“My epilepsy doesn't affect my intelligence or my ability to work. However, I do worry about how others are affected when I have a seizure, as it tends to upset other people more than me.

“There's still a lot of stigma associated with disability in the workforce. Employers are fearful about health and safety issues, how much time off work I'll need, whether I'll need modifications in the workplace and whether my colleagues will accept me.

“I put it down to fear of the unknown.

“My seizures can happen at any time, any day, so I get on with living my life; I keep going.”

Claims Specialist Krystal Grace was Maria's mentor for the day.

“We put our hand up for the AccessAbility initiative because, as a team, we felt it was something we could do to contribute to and encourage diversity in Treasury and MAIC,” she explained.

“Meeting Maria highlighted that recruitment and ‘team fit’ should be about the person, their experience, qualifications and skills, not their disability.

“There are steps we can all take – as managers or co-workers – to ensure that Treasury is accessible and inclusive to people with disability. The first being to educate ourselves.

“I would encourage as many teams as possible to participate in the AccessAbility initiative.

“The more we get to know about people with disabilities, the less likely we are to make assumptions. It's a great way to break down barriers.”

The Queensland Government is committed to increasing employment opportunities for Queenslanders with disability and has set a foundational target that people with disability will make up at least eight percent of the Queensland Public Sector workforce by 2022.

### **International Day of People with Disability**

Every year on 3 December, people around the world come together to celebrate the understanding and acceptance in the community.

Now is the time to break down barriers and build awareness and understanding of the people with disability. Learn more and build your confidence in your interactions with people with disability by completing Treasury's Disability Awareness eLearning.

The commission is part of Queensland Treasury, and Treasury shared Maria's story with its employees through their online newsletter.

## **Are you free on Sunday the 22 March and have a love of Rugby League?**

The Gold Coast Titans have their first home game of the season against the Eels at CBUS Stadium with kick-off at 5pm.

We need volunteers to help us collect funds on match day through 50-50 charity raffle.

You must be able to travel down to the Gold Coast and be willing to collect funds on Epilepsy Queensland's behalf.

The game will also be a great opportunity for us to raise awareness of epilepsy on the Gold Coast during our National Awareness month.

All volunteers get to enjoy the second half of the game. For more information, please call the fundraising team on 3435 5000





#### References:

Queensland Ombudsman, June 2017, The Patient Travel Subsidy Scheme Report.  
Queensland Health website: <https://www.qld.gov.au/health/services/travel/subsidies>

# ASK AN EDUCATOR

## WHAT IS THE PATIENT TRAVEL SUBSIDY SCHEME (PTSS)?

Financial assistance for patients is provided by the Queensland Government by way of Queensland Health's (QH) Patient Travel Subsidy Scheme (PTSS). The PTSS provides travel and accommodation subsidies for patients who need to travel more than 50 kilometres from their nearest hospital to attend approved specialist medical appointments.

Many regional, rural and remote Queensland residents rely on the subsidy provided through the PTSS to access specialist healthcare that is not available locally.

The PTSS is decentralised, with applications assessed and managed by individual hospitals. Consequently, the nature of a patient's experience with the PTSS often depends on where their application is made.

Below is some general information about the PTSS which explains some of the more frequently asked questions:

- Patients approved for PTSS will receive a subsidy to attend the closest public hospital or health facility where the specialist medical treatment is available.
- Patients travelling to access private specialist services may be eligible for a subsidy if the service is not available within 50 kilometres of the patient's closest public hospital or health facility.

Eligible patients can apply for the following subsidies:

- » Travel subsidy
- » Accommodation subsidy
- » Escort subsidy

- To be considered for a travel subsidy patients need to register with the PTSS. Patients who are already registered do not need to register again unless their details have changed.
  - The PTSS process involves:
    - o Register
    - o Provide Travel Referral
    - o Assessment process
    - o Book travel
    - o Confirm attendance
    - o Claim subsidy payment
- Forms and paperwork need to be submitted for this process. Relevant forms are available on the PTSS website: <https://www.qld.gov.au/health/services/travel/subsidies/ptss-forms>
- The initial Patient Registration form can be submitted at any Queensland public hospital or health facility—in person or via email, fax or post. Patient travel offices have different opening hours depending on their location. Patients should check the office hours of their local patient travel office before visiting.
  - Patients can submit their registration form at the same time as their Travel Referral.
  - Patients who have travelled for specialist medical treatment within the last 12 months are able to submit a retrospective application – the process and forms are the same.
  - Patients applying for a PTSS should submit documents as early as possible to allow sufficient time for processing and travel bookings. A user guide to assist in completing this paperwork is available at: [https://www.qld.gov.au/\\_data/assets/pdf\\_file/0026/56258/ptss-patient-reg-form-a-user-guide-new.pdf](https://www.qld.gov.au/_data/assets/pdf_file/0026/56258/ptss-patient-reg-form-a-user-guide-new.pdf)
- Once an application has been received, it will be assessed against the PTSS Guideline (PDF) to determine the patient's eligibility for a subsidy. Patients will be notified of the outcome of their application approximately five working days after it is received by the approving hospital or health facility. Processing times can vary by location and are dependent on patients providing all necessary information.
  - If the application is approved, the local hospital or health facility will offer to assist the patient to arrange and book their travel. If the patient's application cannot be approved, they will be given the reason and advised of the process for lodging an appeal.
  - Patients who have been approved for a travel subsidy and have the date(s) of their appointment should contact their local public hospital or health service to organise travel. The health facility will either book travel and accommodation on behalf of the patient or provide information to assist them to make their own bookings.
  - Travel and accommodation subsidies are paid at the approved amount only and patients will be required to pay any additional costs.
  - Patients who book their own travel or accommodation need to submit their tax invoices to their local hospital or health facility, after their appointment, to start the claim process.
  - Return travel: if return travel has not been arranged, patients should speak to someone at the treating facility (such as ward or clinic staff, or a social worker) about contacting their local hospital or health facility to arrange this. Patients will need the approval of a doctor or clinician before they can travel home.

For more information on the PTSS please visit: <https://www.qld.gov.au/health/services/travel/subsidies>

## Funding to continue supporting members living with a disability

We are incredibly grateful to the Queensland Government for their ongoing support of Epilepsy Queensland and our community through our funding from the Department of Health and Disability Services. In past years, Epilepsy Queensland has received funding from the State Government's Disability Services to assist with service provision for people living with a disability. With the advent of the NDIS, it was anticipated that people with epilepsy would receive services within the NDIS framework and that some of Epilepsy Queensland's services would be funded through NDIS funding, however this hasn't eventuated. The Hon Jackie Trad MP, The Deputy Premier the Hon Jackie Trad and Minister for Communities and Disability Services the Hon Coralee O'Rourke listened to our concerns and ensured there were provisions in the budget to help Epilepsy Queensland to operate during the transition to the NDIS until the end of this financial year. This helps us to continue to support all Queenslanders living with epilepsy, whether or not they are able to access the NDIS.

Our local MP Jackie Trad met with some of our staff, volunteers, board and ambassadors to hear more about the impact of epilepsy on their lives and how the support of Epilepsy Queensland makes a difference. She listened to the challenges of accessing NDIS funding for people living with epilepsy.



# SYMPOSIUM 'THINKING OUTSIDE THE BOX'

Epilepsy Queensland hosted its Tenth Annual Queensland Epilepsy Symposium, Thinking outside the box – 'Where are we now?' in October 2019. Sourcing a high calibre of speakers is always the goal of a great symposium. This one, however, was a great testament to the preceding 10 years of seminars.



Our presenters delivered engaging sessions on a wide range of epilepsy topics and related research. These included genetics, early intervention, medical bionics, sleep, fitness to drive, anxiety and depression, social cognition research, valproate and pregnancy, midazolam, functional neurological disorders, epilepsy diets and executive functioning skills.



Laureate Professor Ingrid Scheffer started the day discussing 'How genetics is transforming epilepsy care'. Her work has resulted in identification of the first epilepsy gene and many more genes subsequently. Her research is translational, meaning more patients are referred for genetic testing and new treatments are applied to help improve quality of life. Professor Scheffer outlined the importance of this testing, particularly for people living with developmental and Epileptic Encephalopathies.

The State Library of Queensland hosted our Symposium again this year and to celebrate our tenth year we were fortunate to offer two streams of presentations in the afternoon. The second stream was tailored for Nurses and Allied Health professionals and attracted a full house. Excellent presentations were delivered on Midazolam guidelines, FND (Functional Neurological Disorder) as well as the best diets for epilepsy and some new skills around 'organising the body and brain to improve learning performance and mental wellbeing'. We were fortunate to have Dr Kate Sinclair, Vince Cheah, Katie Barwick and Dr Carina Capra as presenters for these afternoon sessions.



The symposium benefited from a range of experts including Dr Ubaid Shah, Associate Professor Lata Vadlamudi, Robert Klupacs, Associate Professor Bruno van Swinderen, Dr Dan McLaughlin, Ray Kopeshke, Peter Jones, Krystina Wallis, Dr Maryam Ziaei and Associate Professor Cecilie Lander.



We sincerely thank our presenters for their time and wisdom. We also are grateful to our sponsors UCB, Eisai and Terri Butler MP who support us each year. Lastly but very importantly, thanks to the symposium attendees who made the symposium such a success. We look forward to welcoming everyone along in October 2020 to another event of stimulating dialogue.

## SPONSORS







# EPILEPSY QUEENSLAND ANNUAL CELEBRATION



Our annual celebration, AGM and awards is an opportunity to recognise the advances we have made in our mission to bring epilepsy out of the shadows in Queensland and optimise life for people affected by epilepsy. The 2019 celebration brought our 50th-anniversary celebrations to a close as we honoured members of our community who have contributed to Queenslanders living with epilepsy. The Hon Jackie Trad MP (Deputy Premier, Treasurer, Minister for Aboriginal and Torres Strait Partnerships, Member for South Brisbane) hosted our celebration at the Parliamentary Annexe, Brisbane.



Sophie Upcroft from Nine News Queensland was our engaging master of ceremonies. We were inspired by 20-year-old Paralympic Swimmer Lakeisha Patterson who shared her epilepsy story, the challenges she has faced, how she lives her best life with epilepsy and other disabilities and her hopes for a more inclusive and aware future. This was followed by a forum as our young ambassadors looked to the future of epilepsy. They shared their stories and lived experiences around managing the challenges that come with living with epilepsy. Thank you to Charlie Harms, Georgia Sherry, Ivy McAllister, Jack Dalton for your candid insights and to Leonie Hogarth who facilitated the panel.



Each year, a highlight of our Annual General Meeting is our annual awards. We get very excited about celebrating the generosity of many important people who support us at Epilepsy Queensland and Queenslanders living with epilepsy. They give their time and resources and our Annual Awards event is a way we can acknowledge those generous people and organisations whose efforts are significant.



Congratulations to our award winners:

Youth Award - Jack Dalton

Role Model Award – Billy Dyer

John Wellings Memorial Education Award – St Gerard Majella Primary

Fair Go Award – Rackley Swim School and Haymans Electrical

Pam Wellings Memorial Award – Sandi Unnasch

Carers Award – Laura Rowsell

Disability Award – Flexi Queensland

Corporate Partnerships Award – Lendlease

Health Award – Dr Ubaid Shah

Doris Kemp Award – Shannon Bullen and Krystina Wallis

Marella Jenkins Award – Simon Watt

## Epilepsy Queensland's current board members

**Chairman** - Sam Bryce

**Deputy Chair** - Kim Davis

**Treasurer** - Kalvin Booth

**Secretary** - Andrew Barnes

## Board members

Charmaine Driver

Murray Fairgrieve

Lousie Prychidczuk

William Tuffley

Katrina Tune

Simon Watt

Thank you to our sponsors of the event

Travel Partner/Education Partner

Accommodation Partner

## Sponsors:



[ THE JOHNSON ]



Art Series Hotels

To read more about our impact on the epilepsy community in our Impact Report visit:  
<http://bit.ly/EQlimpact2019>

# SUPPORTER SPOTLIGHT

## Lendlease Charity Golf Day

In 2019, Epilepsy Queensland (EQI) celebrated 50 years of supporting Queenslanders living with epilepsy. We couldn't do it without the support of amazing companies like Lendlease who care about the communities where they live and work.

We also celebrate our 10th year of partnership with Lendlease in Queensland through the Lendlease Charity Golf Day. Lendlease has worked with us to raise significant funds and awareness of epilepsy with their employees, contractors and members of the construction industry.

Many months go into the detailed planning with Lendlease and their team, headed by General Manager Brad Protheroe, ensuring all partners of Lendlease participate. This year the event attracted 33 teams and over 160 players to support EQI. Lendlease were able to recruit a number of amazing event sponsors including Stowe Australia who were the Gold Sponsor.

The event raised over \$77,000 divided equally between charity partners Epilepsy Queensland and Legacy Brisbane. Funds raised will enable us to support more Queenslanders living with epilepsy and their families through information, education and support services.

## St Columba's Mothers' Lunch

When a school community comes together for a good cause, wonderful things can happen. In October 300 guests were invited to The Calile Hotel to enjoy a special St Columba's Primary School Mothers' Lunch. Epilepsy Queensland was the nominated beneficiary and we are extremely grateful to be chosen.

The day included a number of fun activities and raffles raising a generous sum of over \$17,500 for Queenslanders affected by epilepsy. We would like to thank Katrina Tune, Carla Di Fabio, John O'Connor, Michelle Kneen, Melissa Bates and Damon Tune for their tireless efforts to make this event a huge success. A special mention goes to Pikos and Brisbane Screenprinting and Displays with a full list of sponsors available on our website. <http://bit.ly/EQIpartners>

## Insurance Advisernet Foundation show support

Our patron Wally Lewis recently accepted a generous \$10,000 donation made by the Insurance Advisernet Foundation. Their collective goal is to leave an important social legacy for generations to come.

Mr Ian Carr (pictured with Wally) said 'We are delighted to have Wally Lewis attend our 2019 conference and accept this cheque on behalf of Epilepsy Queensland. We are proud to support such an excellent charity and cause'.

Thank you Insurance Advisernet Foundation.

For more information on Insurance Advisernet, visit [www.insuranceadviser.net](http://www.insuranceadviser.net). Insurance Advisernet are one of the largest and most respected general insurance businesses in Australia, with over 210 advice practices throughout Australia and New Zealand.

## Cycle for epilepsy across the Australian Alps

Congratulations to Michael, Yowie and Karl on completing their amazing cycle from Canberra to Melbourne over the Australian Alps. The team has raised over \$2,000 for support services for people affected by epilepsy.

"We made it, over 1000k mountain bike ride from Canberra to Melbourne over the Australian Alps with my great mates Big Karl and Yowie. Finished at Heidi Museum of Modern Art. Today we battled 38-degree heat, ferocious head winds, trees down, and a storm where the temperature dropped 12 degrees in minutes as we took shelter in a random open garage. We would like to thank everybody for their encouragement and support - it certainly was a bit of journey!" - Michael, Yowie and Karl

Thank you to Terry for organising the fundraising side. When Terry's daughter, Eleanor was diagnosed with epilepsy at the age of 26, the family was faced with a range of challenges. Eleanor lives in remote Exmouth in WA. She is a talented artist and works as a Park Ranger coordinator. One of the greatest challenges was losing her driver's license. Her Brisbane-based parents, Terry and Elaine, recently attended the Queensland Epilepsy Symposium to learn as much as possible about epilepsy and how they can help. They were inspired to do more to raise awareness and funds to help others living with epilepsy.

When Terry found out one of his friends, Michael, wanted to take on a cycling challenge, he asked if he would use the opportunity to raise awareness and funds for epilepsy at the same time. Michael's cycled from Canberra to Melbourne crossing the Australian Alps - 1100km cross country and climbing some 26,000 m of elevation along the way.

## Motorbike Ride for Epilepsy

Thank you to everyone who participated in our inaugural Motorbike Ride 4 Epilepsy in August. It was a fantastic ride from Revolution Rider Training at Archerfield to the Barn and Scotty's Garage at Flagstone. Your support will help us reach out to more Queenslanders living with epilepsy.

Special thanks to our volunteers and ride organisers Mark and Sandi Unnasch and our sponsors Revolution Rider Training, Trident Trades and Labour Hire, Action Formwork, Mount Franklin, AEG Powertools and The Mad Hueys.

**To discuss hosting an event or taking on a challenge to raise funds to support Epilepsy Queensland services contact our fundraising team on 1300 852 853.**





Lendlease Charity Golf Day



St Columba's Mothers' Lunch



Insurance Advisernet Chairman and Patron Wally Lewis



Lendlease cheque presentation to Epilepsy Queensland and Legacy



Michael, Yowie and Karl finish their epic cycle



Our fantastic riders In August in Flagstone





# 30 minutes with...

## Matt Butler



### ***What is the exact title of your role?***

Fundraising and Donor Development Officer. It essentially means I have the pleasure of raising funds for Epilepsy Queensland.

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

I'm working in the fundraising department of Epilepsy Queensland and I've been in this position now for over seven months.

### ***Where else have you worked in your life?***

I've worked in the Not for Profit sector for five different charities spanning over 24 years.

### ***What do you love about your job?***

It is a cliché but I've remained in the not for profit sector including working at Epilepsy Queensland and I actually like giving back to the community and trying to make a difference for people in need. I am an extrovert so I love meeting all of the amazing people who host events and fundraise for Epilepsy Queensland.

### ***Where would you most like to travel?***

I have Scottish heritage so one day I'd like to visit Scotland, Ireland and England. Some of my family members went to the effort of developing a family tree and produced a book of our lineage back to land owners from Scotland, which is very cool to read. Being able to trace my ancestry to a particular part of Scotland and then visit this area would be brilliant.

### ***What is your favourite food?***

I just love Thai food. However, a good old-fashioned roast dinner has always been a love for me too.

### ***Describe your most embarrassing moment?***

My girlfriend and I were swimming in a pool on an inflatable tyre tube. I thought we had floated into the very deep end and panicked when we both fell off the tube into the water. My first thoughts were that my girlfriend couldn't swim so I burst into action. I swam down beneath her and tried to push her to the surface. I was having no success and lungs near bursting point I had to surface. My girlfriend wondering what I was doing was casually standing on the pool bottom. We had drifted into the shallow end and she was in no fear of drowning. How embarrassing!

### ***What is your favourite book/author?***

I'm a fan of Dean R Koontz. His book "lightning" is my favourite.

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

I've been lucky enough to meet a number of famous people including Wally Lewis, Craig Lowndes, Jamie Wincup, Allan Langer, Allan Border, Trevor Gillmeister to name a few.

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

I'm not a big music listener but I do like a bit of Bryan Adams and Bon Jovi. I am acquiring a taste for jazz.

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

Nothing too exciting, I enjoy volleyball, cricket and am delving into photography.

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

I believe that it would be beneficial to have a larger presence in regional Queensland. Our funding only stretches so far and to be able to provide support for more remote areas of our state would be fantastic. Perhaps having the capability of utilising remote counselling via video hook-up would be a future option.





# IMAGINE HAVING THE ENVIABLE CHOICE OF A \$250,000 1ST PRIZE PACKAGE

**Which option would you choose?**

Option 1- A home makeover package. You could renovate the kitchen or bathroom perhaps or...

Option 2- A travel package. Take that much-needed holiday and get away from the everyday!

The choice could be all yours. Plus there are \$500,000 in total prizes to be won. That's a 1 in 34 chance to win a prize!

Did you know that \$5 from every ticket purchase goes directly to Epilepsy Queensland? You are making a difference in providing vital services to families and individuals who are living with epilepsy.

**Visit [playforpurpose.com.au/epilepsy-queensland](https://playforpurpose.com.au/epilepsy-queensland) to order your tickets today.**

## Our Donors are our lifeblood

Thank you to each of you who made a gift to our Christmas Appeal in December.

We have raised over \$14,000. You are ensuring we can continue to assist families and individuals across Queensland.

## Help us deliver our services...



# AT-HOME EPILEPSY DIAGNOSTICS

*Short waitlists  
Comprehensive report  
Fully Medicare bulk-billed*

**medicare**  
BULK-BILLING

Seer is solving the problems of accessibility for gold-standard epilepsy diagnostics.

Seer Medical is committed to making diagnosis and management of epilepsy easy. We started providing ambulatory at home video-EEG-ECG monitoring in 2017 to address issues of accessibility and long wait times. Since then we have received well over 1800 referrals to our fully bulk-billed service, helping people with epilepsy and their doctors reach conclusive diagnoses. With clinics now in VIC, NSW, TAS, QLD, SA - and over 14 satellite clinics, we are lowering the barriers to world class diagnostics.

Seer was formed in 2017 following a series of research engagements with medical device companies conducting clinical trials. What linked these technologies was the generation of huge amounts of data from electrodes on or within the brain. Yet none of these trials had given much consideration as to how this data would be stored or shared among the project teams distributed around the world.

From this shortcoming the Seer Cloud was born. Capable of housing vast amounts of data and sharing this in very specific ways between different users, it was quickly determined that an immediate use for the Seer Cloud would be to allow for long-term diagnostic monitoring of people with epilepsy to be performed outside of the hospital environment. Following an intensive 6-month period of developing the required hardware and ensuring that all aspects of safety and comfort had been considered, Seer began accepting referrals for Australia's first at-home, gold-standard diagnostic monitoring service.

"For a lot of these people, the hospital environment is just an unnecessarily stressful step in getting a diagnosis", says Seer's co-founder and CEO Dean Freestone, "when it can take upwards of six months for people and their families to access reliable diagnostic monitoring then there must be a better way of doing things". With each study usually occurring over 5-7 days' duration, the shift to home-based monitoring has also resulted in a downward pressure on hospital wait times for in-patient monitoring of more complicated or high dependency cases.

By enabling people to undergo the monitoring process in the comfort of their own homes, they typically find the experience significantly more comfortable and less disruptive than when they are restricted to a hospital bed or telemetry unit.

"We really do appreciate that the monitoring could be done in the comfort of our home and not have to go to hospital", commented a user of the service, Michelle.

Accessing Seer's at-home monitoring is easy. The first step is to get a referral from either a neurologist or GP. Referrals can be sent to Seer via our website, fax, email or directly through the Seer Cloud, whatever works best for the referring doctor. After receiving a referral we will contact the person to arrange booking times for their connection and disconnection appointments. During the first of these sessions at our clinic we will go through the process of connecting the 25 electrodes which will record the brain and heart activity during the monitoring session. At this appointment they will also be given the basic instructions required to ensure they get the maximum benefit and comfort over the coming days.

Once all of the connections have been made, we will provide the monitoring hub for the system that handles data storage and video recording and we'll ensure everything is working as it should. Once this is all done, they are ready to head home and get settled. We recommend that there are some additional movies, books or games on hand to keep things entertaining. To make sure everyone is comfortable and feeling supported, our staff will check-in regularly, confirm the system is functioning correctly and see if there's anything else that is needed to make the process as comfortable as possible.

On the last day of the requested monitoring period, we remove the electrodes during a short appointment in our clinic. The additional hardware is disconnected and returned to our team member who begins uploading the study data onto the Seer Cloud. From here it is available to any of the specialist neurophysiology staff that Seer has on its team around Australia for review.

Leading specialists in adult and paediatric neurology review these findings and formulate a comprehensive report which is promptly shared with the referring doctor.

All of this is achieved with no out-of-pocket costs to the family, within a timeframe that is much shorter than currently available approaches and in the comfort of the person's own home.

If you'd like to learn more about Seer Medical's epilepsy diagnostic service, please visit our website ([www.seermedical.com](http://www.seermedical.com)), call one of our friendly staff on 1300 495 047.

Seer Medical's Brisbane office is at 15 Green Square Close, Fortitude Valley.





# BRISBANE SCIENTIST SAMANTHA NIXON WANTS YOUR SPIDERS — THE BIGGER AND HAIRIER THE BETTER.

Brisbane researchers have been studying spider venom to create medications that could treat childhood epilepsies and other neurological conditions. The University of Queensland Venom Lab is led by Professor Glenn King, who spoke at our 2018 Queensland Epilepsy Symposium on tarantula venom and Dravet Syndrome.

Now they need your help! Recently Brisbane scientist Samantha Nixon, Big Bessie the golden orb spider and Maurice the tarantula put out a call on ABC radio saying, "More spiders are needed to get enough venom to study".

From Twitter -Samantha Nixon @SamNScience · Jan 15

Early spider gets the worm! Tune in to @abcbisbane at 6:20 am Thurs to catch Big Bessie & I chatting to @zonca & @Loretta\_Ryan about spider #science! @VenomsLab are looking for more spiders to study venom for medical research! Can you help us find spiders?  
@IMBatUQ @UQ\_News #scicomm

Ms Nixon said, "If you have big hairy eight legged friends running around your yard give us a call because we're interested in using spider venoms to make new medicines and new technologies."

"We're definitely chasing tarantulas especially. Tarantulas are great because their bigger size means we can get more venom from them."

"We're also interested in huntsman, orb weavers, trapdoors, funnel-webs, you name it."

Ms Nixon tells us why spider venoms could make precision medication. "The great thing about spider venoms is they have evolved over millions of years to become these complex cocktails of different molecules. And we're harnessing the molecules for example that shut down the parts of the brain that are too active in epilepsy to make new anti-epileptic medications or using venoms that cause pain to understand pain pathways."

The venom lab needs many spiders to get the amount of venom required as sadly they had seven spiders pass away last year.

"We have to collect from a lot of spiders to get the one little droplet we can use," Ms Nixon said.

If you live in the Brisbane area and would like to make an eight-legged contribution to the research, you can send a photo to Samantha on Twitter @SamNScience or via email at samantha.nixon@uq.net.au. If you're confident catching the spider yourself you can catch it, put it in a container and someone from the venom team will come and collect it. If the thought of catching a spider makes you squeamish, the team will also collect the spiders for you.

Reproduced from Samantha Nixon speaking with Loretta Ryan and Craig Zonca on ABC Radio Brisbane Breakfast Thu 16 Jan 2020. [www.abc.net.au/radio/brisbane/programs/breakfast/breakfast/11856812](http://www.abc.net.au/radio/brisbane/programs/breakfast/breakfast/11856812)

For more information on the venom lab at the Institute for Molecular Bioscience at UQ visit: <https://imb.uq.edu.au/venom>

2020

## DIARY DATES

26 March	<b>Purple Day</b> Purple Day is a grassroots effort dedicated to increasing awareness about epilepsy worldwide. On 26 March each year, people from around the globe are asked to wear purple and spread the word about epilepsy. See enclosed flyer for more information on Purple Day activities.
6 February 12 March 9 April 14 May 11 June 16 July 13 August 10 September 15 October 19 November	<b>Understanding Epilepsy Workshops (Woolloongabba)</b> For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with epilepsy and their families
11 March 13 May 24 June 12 August 11 November	<b>Understanding Epilepsy Workshops (Gold Coast)</b> For families, People with epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
20 & 21 February	<b>Understanding Epilepsy &amp; Administration of Midazolam Workshops (Cairns)</b>
Informally First Saturday of the Month 1 February, 7 March, 4 April, 2 May, 6 June, 4 July, 1 August, 5 September, 3 October, 7 November	<b>Brisbane Adult Support Group Meeting</b>
19 February, 18 March, 15 April, 20 May, 17 June, 15 July, 19 August, 16 September, 21 October, 18 November, 16 December	<b>Adult Social Group Ipswich</b>
21 February	<b>Cairns Epilepsy Meet-Up</b>
<b>Please call 07 3435 5000 for further information on any of the above events</b>	

## TELL US WHAT MATTERS TO YOU – MEMBER SURVEY 2020

We conduct a survey every alternate year to find out what our members are thinking about our services and how we can improve.

Your feedback helps us improve services we are delivering now and plan how we can support you into the future.

Please complete the enclosed survey or take the survey online: [www.surveymonkey.com/r/K2BBKLN](http://www.surveymonkey.com/r/K2BBKLN)

## MATER EPILEPSY CLINIC

Do you have an appointment coming up at the Mater Neurosciences Clinic? We'd love you to come and say hello to our services team member Trish. Trish will be available at the Clinic every second Monday to talk about our services and how we can assist. Thank you to Dr Sasha Dionisio, Jade Vince, Peter Jones and all of the team at the Mater Clinic.