

## Feature 1: Raising Community Awareness

A vital part of our role at Epilepsy Action is to spread awareness of epilepsy. We often hear from our clients and supporters that there is just not enough awareness or information in the broader community. Due to this lack of knowledge, misconceptions abound. A crucial part of all our campaigns is to actively educate and inform. We believe that the only way to combat misunderstandings about epilepsy, seizures and treatments is to articulate the facts and spread awareness. This will in turn reduce misconceptions and foster understanding and acceptance amongst the wider community.



Our campaign Know Epilepsy. No Fear. has been widely promoted and shared among our followers and fundraisers. Simplicity often works best with messaging, from posters to t-shirts we are spreading awareness by showing off this slogan. You may have noticed that this slogan has attracted recent media coverage, helping further raise awareness of epilepsy in the community.

Three very talented and resilient individuals have also been raising awareness of epilepsy. Paul Wade a much sought after professional speaker and soccer master; Karley Miller a very talented young, up and coming photographer; and Stephanie Reggardo a gifted artist. All living with epilepsy and thriving.

### PAUL WADE

A talented soccer player from a young age, Paul put in the hard yards to secure a spot in the National team, playing a total of 118 games for Australia between 1986 and 1996 and playing in two FIFA World Cup qualifying campaigns (1990 and 1994).



Paul's experience and popularity as an Australian international allowed for an easy transition to a career as a sports presenter and Paul has worked with all major TV networks and Pay TV hosting or commentating on football shows covering the A League and World Cup Campaigns.

Paul has achieved all this whilst living with the unpredictable nature of epilepsy. "Don't get me wrong, it has not been an easy path but I just put in the hard work and never give up even when I wanted to."

Paul is passionate about raising awareness of epilepsy and bringing the best out in everybody no matter the age or level of ability. Starting Paul Wade Life Skills which is an inclusive programme visiting schools across Australia where Paul and his wife Val provide information and education about epilepsy while motivating and team building.

Paul is also a highly sought after entertaining and inspirational speaker, telling stories of his international experiences prompted by his collection of rare soccer jerseys interweaving the journey of life before and after brain surgery and the adjustments he and his family have made.

Paul's passion for epilepsy awareness, sport and life continues today and is clearly visible in his presentations to all and sundry from school and sporting clubs to the upper echelon of the business world.

To read more about Paul's life, Paul Wade Life Skills and his role as a Professional Speaker go to [www.paulwade.com.au](http://www.paulwade.com.au)

### KARLEY MILLER

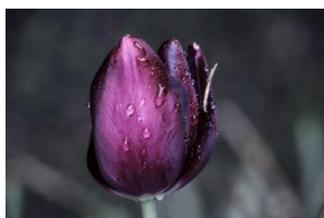
Talented up and coming photographer, Karley Miller from Central Western NSW has faced and overcome many challenges in her short life.

Karley, 19, was born with cerebral palsy and Sturge Weber Syndrome, a rare neurological condition involving a tangle of blood vessels in the brain leading to frequent severe seizures, headaches and for Karley a visual impairment. Classified as

legally blind this photographer has remarkable clarity in her vision for her photographic compositions.



In 2015, Karley faced the difficult decision to undergo a hemispherectomy to remove half of her brain with the support of her family and surgeon. Not only did the surgery relieve the disabling headaches, the seizures stopped the day after surgery.



With her new lease on life Karley ventured into photography, being given the opportunity by the Sebastian Foundation to travel to the United States for tutoring and work experience with award winning photographers. Upon her return she held her

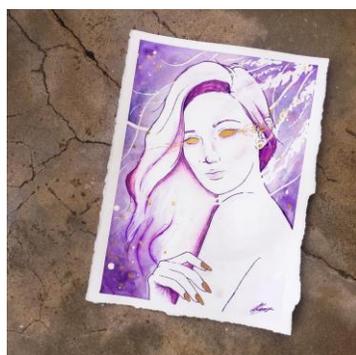
inaugural photography exhibition in Cowra.

A professional photographer with an impressive portfolio, Karley is giving back by composing enchanting portraits of children with special needs. Also donating a piece of her work for the Art For Epilepsy Auction helping to raise money for the cause Karley is passionate about raising awareness of epilepsy and those living with special needs. Karley believes "Through the lens of a camera we can change perceptions."

To view Karley's work go to [www.ArtForEpilepsy.com.au](http://www.ArtForEpilepsy.com.au) and Karley Miller Photography on Facebook.

### STEPHANIE REGGARDO

An artist from East Gippsland in Victoria, Stephanie has been living with epilepsy since she was 16 years old. Now in her final year of a Bachelor of Arts at Federation University her creation, *Epileptic Vision* is based on her personal experience of epilepsy. Her pieces often feature jellyfish, depicting the muscle jerks and twitches she experiences from her Juvenile Myoclonic Epilepsy, much like shocks



without the electricity like those from a jellyfish sting.

Many people have little knowledge or awareness of epilepsy and through her art Stephanie is raising awareness of epilepsy and her lived experience of the unique sensation of her seizures.

To view more of Stephanie's art and her piece for the Art For Epilepsy Auction go to [www.ArtForEpilepsy.com.au](http://www.ArtForEpilepsy.com.au) and Stephanie Reggardo@\_stephreg\_Instagram

## Feature 2: Help is at hand



*Epilepsy Action Australia are proud to partner with Kindom. Find out more about this wonderful platform below.*

**When you have a family member with epilepsy or other serious health conditions the struggle to keep track of appointments, medical tests and reports can be almost overwhelming.**

Which is where the all in one online platform *Kindom* can help – it allows you to put every report, prescription, doctor's note, as well as your own observations, thoughts and photos into one easily accessible digital platform, with you in control of who you share it with.

For mum of three Valerie Wade whose husband and daughter have epilepsy, as well as another child with developmental challenges on top of the usual childhood illnesses and issues, it's exactly what she's been waiting for.

*"Simply being able to keep track and share vital health records and observations will be incredibly beneficial."*

*"Neurologists always want to know what happens, how long a seizure goes for, and asks you to describe it, this takes the pressure off as you're no longer relying on your memory."*

*"We've moved states three times since having children and each time we've had to find a new doctor and then try to*

remember each child's medical history and it's been very difficult," she said.



"Kindom also addresses one of the biggest challenges we faced at the start of every school year and that's having to go from teacher to teacher explaining each child's condition and treatment. To be able to simply hand them a printed health summary is amazing."

Kindom's founder and mum of six Cath Resnick knows all too well the challenges families face which is why she set about developing this platform.

**Mrs Resnick said *Kindom* helped families manage their health care by:**

- **Central, secure, storage of important data;** Whether it's medical records, blood tests, or even school reports
- **Shared care;** Enables easy access and sharing of records between everyone involved in the care circle

**Health summary;** *Kindom* automatically creates health and developmental summaries which you can be easily printed or emailed to give to clinicians, schools and carers.

**In-built journal;** Record key milestones, so you'll never forget.

- **Schedules, reminders, calendars** keep track of appointments, check-ups and key events.



Ms Wade said the app was invaluable.

"It's not just for families with special needs, I can see all families being able to use this to help them manage day to day life."

Kindom is available for free at [kindom.care](http://kindom.care)

## In the News – The latest on epilepsy



### New AEDs on PBS

A recent addition to the Pharmaceutical Benefits Fund, Brivaracetam is indicated for people with focal seizures who have failed three previous anti-epileptic drugs (AEDs) and currently taking a combination of two or more AEDs. While it is not to be prescribed concurrently with Keppra there are no identified drug to drug interactions between the two drugs and can be overlapped during a transition from one medication to the other. One of the benefits of Brivaracetam is the minimal to no interact with contraceptives and appears to be well tolerated in clinical studies. Find more information [here](https://www.healthdirect.gov.au/medicines/brand/amt,87639100,0168107/briviact) <https://www.healthdirect.gov.au/medicines/brand/amt,87639100,0168107/briviact> and [here](https://www.nps.org.au/australian-prescriber/articles/brivaracetam-for-epilepsy) <https://www.nps.org.au/australian-prescriber/articles/brivaracetam-for-epilepsy>

### Qantas Carer Concession Card

The Qantas Carer Concession Card is issued to people with disability and high level support needs who require the full-time assistance of a carer whilst they are on the aircraft. A person is eligible if they need to have one-on-one support when seated on the aircraft. A person is not eligible if they only need assistance boarding the aircraft, or when they arrive at their destination as these needs can be catered for by Qantas ground staff when pre-arranged. People with *Disability Australia* currently have an agreement with Qantas for discounted domestic companion flights. Find more information [here](http://www.pwd.org.au/what-we-do/qantas-carer-concession.html) <http://www.pwd.org.au/what-we-do/qantas-carer-concession.html>

### New implantable device for seizures

A new device, developed at St Vincent's Hospital and the Graeme Clark Institute, is like a "fit bit for the brain" and has the potential to predict and prevent epileptic seizures. *The Minder*,

is fitted under the skin on the scalp and records brainwaves. Find more information [here. http://www.abc.net.au/news/2017-07-08/new-device-to-track-epileptic-seizures-like-fit-bit-for-brain/8690646](http://www.abc.net.au/news/2017-07-08/new-device-to-track-epileptic-seizures-like-fit-bit-for-brain/8690646)

### **New hope for treatment of poorly controlled seizures**

A significant number of people with epilepsy will not respond satisfactorily to any current treatment. Researchers from Lund University in Sweden have shown they were able to reduce seizures using a method known as ‘chemogenetics’ focussing precisely on the region of the brain affected by the epileptic seizures, leaving other areas of the brain unaffected. Find more information [here. https://www.epilepsyresearch.org.uk/new-hope-for-the-treatment-of-intractable-epilepsy/](https://www.epilepsyresearch.org.uk/new-hope-for-the-treatment-of-intractable-epilepsy/)

### **Effective epilepsy medication without the side effects?**

Approximately 60-70% of people with epilepsy will have their seizures controlled with medication. But even then, the drugs used may have unpleasant, unwanted side effects. New research from the Australian National University aims to look at the molecular level to find a way of reducing negative side effects without reducing the drug’s efficacy. Find more information [here. https://www.sciencedaily.com/releases/2018/02/180227090739.htm?utm\\_source=feedburner&utm\\_medium=email&utm\\_campaign=Feed%3A+sciencedaily%2Fmind\\_brain%2Fepilepsy+%28Epilepsy+News+---+ScienceDaily%29](https://www.sciencedaily.com/releases/2018/02/180227090739.htm?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+sciencedaily%2Fmind_brain%2Fepilepsy+%28Epilepsy+News+---+ScienceDaily%29)

## **Q&As – Our service providers answer your questions**



***Q: I’ve been experiencing anxiety attacks since my first seizure a couple of months ago. Is that normal?***

A: Anxiety is a core emotion that many people experience at certain points in life. Anxiety is quite normal when we sense something bad is going to happen, but it can become problematic if it gets out of hand, causing a constant feeling of nervousness, distress and unease for no apparent reason. With any medical condition, people may become anxious after diagnosis, but anxiety is also related to epilepsy in more specific ways, not only as a reaction to the diagnosis, but also as a symptom of the epilepsy. In some cases, it’s a side-effect of seizure medicines. For many, knowing a seizure can occur at any time without much or any warning is a major point of anxiety. Relaxation, meditation and yoga will help if done on

a regular basis. There are a number of online sites and apps that can help with anxiety such as Headspace (link: [www.headspace.org.au](http://www.headspace.org.au)), Smiling Mind (link: [www.smilingmind.com.au](http://www.smilingmind.com.au)), CALM (link: [www.calm.com](http://www.calm.com)) and MindSpot (link: [www.mindspot.org.au](http://www.mindspot.org.au)) a free virtual clinic offering initial assessment and psychological well-being treatment courses. If your anxiety is severe please seek the assistance and guidance of your doctor for potential referral.

***Q: Apart from a few dollars in price, what’s the difference between branded and non-branded medications from chemists?***

A: Generic medications are generally less expensive copies of the original, branded medication. Neurologists can spend years titrating their patient’s antiepileptic drugs for optimal seizure control while minimising adverse effects. Due to the narrow therapeutic range of antiepileptic drugs, switching from innovator (original drug) to generic (copy drug), generic to innovator or generic to another generic drug isn’t recommended. Innovator and generic drugs almost contain identical active ingredients and must meet the same standards in quantity, purity and quality.

However, some variation in bioequivalence is permitted, and the inactive ingredients (such as fillers and colours) may differ. The difference in the inactive ingredients may change the bioavailability of the active ingredient. This is especially important for drugs with a narrow therapeutic range, as it can lead to subtherapeutic or toxic doses.

If your pharmacist offers a different brand of the same medication, don’t accept it. It is important to stick with the same brand. Speak with the prescribing doctor before switching between generics and innovator drugs.

***Q: My 11-year-old has gained weight on Epilim despite healthy eating. Which medications don’t have this effect?***

A: Side-effects of any medication are a concern for parents, especially when they impact a child’s health, self-esteem and social interactions. Ask the prescribing doctor to consider the impact of these side-effects versus the benefits gained, namely seizure control, before considering other therapies. Many drugs can cause weight gain including Valproate (or Epilim). Others have no impact on weight or suppress the appetite and cause weight loss. Clinical trials indicate a dose dependant weight gain in 4-9% of people who are only taking Valproate. This gain

does not appear to plateau as it does with other drugs. The mechanism of Valproate induced weight gain remains unclear, but recent evidence suggests a relationship between the drug and levels of ghrelin and leptin – hormones that play a major role in appetite control and long-term weight regulation. Speak to your doctor about this side effect and medications that may be a better choice for your child.

**Q: Is it a legal requirement to disclose epilepsy when applying for work?**

A: The nature of the work involved and period of seizure freedom will influence your decision to inform any potential employer when applying for work. Some occupations require mandatory periods of seizure freedom such as professional truck, bus or emergency vehicle drivers whilst other occupations may be hazardous if a seizure occurs such as working around water, fire and at heights. In those instances, you will need to inform a potential employer. It is important for you to consider the consequences of experiencing a seizure in the potential workplace and if it poses any risk to yourself or others around you such as working near the frying vats in a commercial kitchen. People with epilepsy can work in commercial kitchens however reasonable adjustments will need to be made to ensure a safe workplace.



The general rule of thumb is, if you have been deemed fit to drive a motor vehicle, your seizures are considered well controlled and there is no real need to inform a potential employer of your epilepsy. If you choose to inform a potential employer it is best to time it after you have received a job offer in writing and before you accept the position. It is at this point any work place accommodations can be negotiated. Under the Work Health & Safety Act, employers need to know about a condition, or they can't be held responsible for failing to adopt safety measures. If you choose not to inform your employer of your epilepsy, you may choose to let a co-worker know so if you do experience a seizure in the workplace they will have some idea what is happening and how to assist you. When completing an application form you can leave sections blank however it is important not to say you do not have a health condition when you do as this can lead to instant dismissal.

**Q: My seven-year-old son was diagnosed with epilepsy four years ago. Recently the GP mentioned that he had cortical dysplasia. What is cortical dysplasia?**

A: Cortical dysplasia refers to a disorganisation of the neurones (nerve cells) in the grey matter of the brain (cerebral cortex) and is classified within the group of 'Malformations of Cortical Development.' The cerebral cortex is a 2-4 mm thick outer layer of the brain made up of nerve cells often referred to as grey matter. As the brain develops in utero, nerve cells migrate to different parts of the surface of the brain. If this migration is altered or disrupted, the structure of the cerebral cortex can become disorganised and hyper-excitable nerve cells can develop. These nerve cells may misfire giving rise to abnormal signals. Focal (localised) cortical dysplasia is the most common cause of intractable epilepsy in children and is a frequent cause of epilepsy in adults. It would be important to have contact with an epilepsy specialist for assessment and ongoing management.

## Taking Action – What's happening at Epilepsy Action

### ANOTHER SUCCESSFUL PURPLE DAY!



What a huge Purple Day we've had! This year we had more fundraising and school events registered than ever before. We've also had a record number of people spreading awareness for epilepsy through our "Know Epilepsy. No Fear" and we received a tremendous amount of media coverage in print, online and broadcast media. Thank you to everyone who got involved and helped to raise funds and awareness of epilepsy throughout Australia. Every event, donation, purchase and conversation made a difference to the work we do for those impacted by epilepsy.

Can't wait for 2019! Let us know if you'd like to be involved to keep the momentum going, simply email the team at [epilepsy@epilepsy.org.au](mailto:epilepsy@epilepsy.org.au).

### *MyEpilepsyTeam*

**MyEpilepsyTeam.com** is the social network for those living with epilepsy. We believe that if you have been diagnosed with epilepsy, it should be easy to connect with others who can share their daily experiences, provide emotional support, and even practical insights like how to afford a co-pay for certain drug, which hospital to choose, or what to expect during particular treatments. Visit <https://www.myepilepsyteam.com/> to join.



### *MedAdvisor*

MedAdvisor is a medication management app that connects Australians to their local pharmacy or doctor to provide them with real-time visibility of their medications. Available free on mobile and internet devices, MedAdvisor simplifies the complex job of managing multiple medications through a variety of features including reminders and pre-ordering of medications. Visit <http://start.medadvisor.com.au/epilepsy/> to get started.

