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## WELCOME

Robyn Wakefield (Chairperson)

In the past 12 months all Epilepsy Australia member organisations across Australia have been working together to ensure that anyone living with, or impacted by, epilepsy is supported.

I would like to thank the following individuals for their invaluable contribution to achieving this goal. Graeme Shears Vice Chairman of Epilepsy Australia and CEO of Epilepsy Foundation (Victoria and New South Wales), Fiona Allardyce CEO of Epilepsy ACT, Wendy Groot CEO of Epilepsy Tasmania, Emma Buitendag CEO of Epilepsy Western Australia and Helen Whitehead CEO of Epilepsy Queensland.

This year our first national *Epilepsy Australia Purple Day* campaign was a fantastic success culminating with worldwide Epilepsy Awareness Day events held in all States and Territories on the 26th of March. This initiative plays a significant role in raising awareness of epilepsy; a condition which affects over 250,000 Australians.

Our *Epilepsy Smart Schools* program is currently being rolled out around Australia. This year up to 71,000 children and young people living with epilepsy will attend pre-schools, primary schools and secondary schools across Australia. Epilepsy Smart Schools is a program which aims to raise awareness of epilepsy and its effects on students' learning and wellbeing, and provide school communities with the resources they need.

If you would like to speak to someone about epilepsy the [Epilepsy Australia National Helpline](tel:1300852853) is just a phone call away - 1300 852 853. Our support staff are available to provide information and support to anyone living with epilepsy, as well as those around them.

Best wishes, Robyn

# EPILEPSY NEWS ACROSS THE STATES

## Epilepsy ACT

Epilepsy ACT has run its first ever **Kid's Cooking Class** in partnership with Nutrition Australia ACT. With lots of enthusiasm, children from across Canberra attended to learn some cooking skills and meets others in similar situations. The class was open to all children who have been touched by epilepsy including siblings and the children of parents who live with epilepsy.

Due to the success of the *Kids Cooking Class*, Epilepsy ACT will be running more activities for children with epilepsy. If you'd like to be involved email [epilepsy@epilepsyact.org.au](mailto:epilepsy@epilepsyact.org.au).

The Noodle Cakes were a great success and even the most sceptical children enjoyed them.



## Epilepsy NSW and Victoria

This year we are launching our very first **Walk for Epilepsy**. Join us on Sunday 21 October, 11:00am, Princes Park in Carlton for what promises to be a fun and wonderful event for people of all ages.

Together we can show our support for those we dearly love who have epilepsy and let them know they are not alone.

Just like Tracey who is walking for her children. *"I have three boys aged 8, 6 and 3 years. My middle son was diagnosed at 3 years old with epilepsy. My younger son has just started having seizures also at 3 years old.*

*Without the Epilepsy Foundation I would not know about half the assistance and contacts I needed. I will be forever grateful for their help in my time of need."*

So grab your best walking shoes, get your family and friends together, and join other caring Victorians like Tracey, who will be walking for those they love.

Whether you want to just walk or walk and raise funds visit [www.walkforepilepsy.com.au](http://www.walkforepilepsy.com.au) and follow the prompts. Together, let's show people with epilepsy they are not alone. Together, let's Walk for Epilepsy.

All funds raised will help provide support for people living with epilepsy and funding for research with the aim of finding a cure for epilepsy. Help for Today and Hope for the Future.

To register or for more information go to: <http://www.supportepilepsy.com.au/event/WalkForEpilepsy-2018>

# EPILEPSY NEWS ACROSS THE STATES

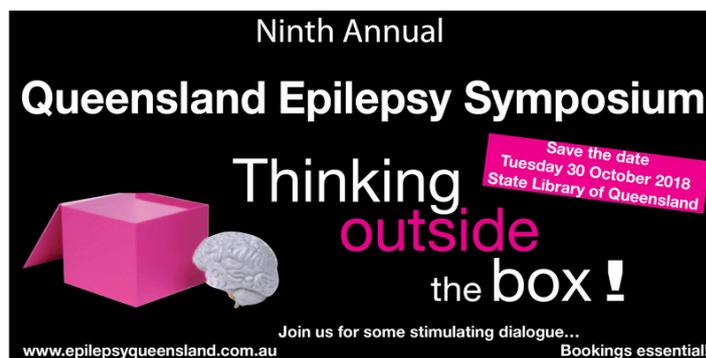
## Epilepsy Queensland

The Ninth Annual Queensland Epilepsy Symposium *Thinking outside the box – What's in the pipeline?* is planned for 30 October 2018.

The symposium features speakers with an extensive knowledge of neurology; each widely renowned in their fields of expertise. This annual event is vital in sharing knowledge and information about the latest research, inspiring stimulating dialogue and thinking outside the box when it comes to epilepsy.

Each year the Symposium has presentations of interest to anyone with a connection to epilepsy; whether you are a person with epilepsy, a family member, a health professional or care worker.

For more information and to book [click here](#).



## Epilepsy South Australia & Northern Territory

The Epilepsy Centre has just over 3,000 active clients and averages 3-5 new clients per week. With no government funding, we rely heavily on our small but efficient call centre to sell Charity selling lottery tickets which are then invested into our service delivery. Tickets are \$60 each and the next lottery "In it to Win It" is drawn on 18th October. For your chance to win \$40,000 visit

[www.epilepsycentre.org.au/epilepsy-lottery/](http://www.epilepsycentre.org.au/epilepsy-lottery/).

The Epilepsy Centre also raises funds for Emfit Seizure Monitors which detect tonic-clonic seizures during sleep. We donate these Monitors to South Australian and Northern Territory children diagnosed with nocturnal seizures with families struggling financially. We are proud to have donated over 110 Seizure Monitors to protect our children in the three years we have been running this campaign.

The seizure monitors are made in Finland and detect tonic-clonic seizures once installed under a bed mattress. If a child has a seizure during sleep a loud alarm will be set off to warn family members, and the device will also detect weightlessness should a child fall off the bed. The Emfit costs \$1,000 each.

Our upcoming Quiz Night and Fundraising Event will be held at the Mawson Lakes Hotel Function Venue on Friday November 9th starting at 6.30pm. Tickets are \$70 each and include a sumptuous buffet dinner.

Be entertained by our Quiz Master MC Derrick McManus and dance the night away with 'Satisfaction – The Stones Show. The night has been created to honour and remember those who have passed away from SUDEP (Sudden Unexpected Death in Epilepsy).

# EPILEPSY NEWS ACROSS THE STATES

## Epilepsy Tasmania

Tasmania's *Epilepsy Connect* is the world's first, telephone-based peer support service for people affected by epilepsy.

Epilepsy Connect is a free and confidential telephone-based peer support service that connects Tasmanians affected by epilepsy with trained volunteers who have had similar experiences.

"We created Epilepsy Connect in 2016 in partnership with the University of Tasmania. Since then Epilepsy Connect has become a lifeline for many Tasmanians with epilepsy, especially the newly diagnosed and their close family members," said Epilepsy Tasmania CEO, Wendy Groot.



20,000 Tasmanians have epilepsy, but the condition also affects a further 80,000 family members, colleagues and carers.

"Epilepsy Connect gives each of these people a chance to access support, no matter where they live," said Ms Groot.

Skye Lee phoned the service after her young daughter was diagnosed with epilepsy, saying "I don't know how I would have coped without the support of my Epilepsy Connect peer volunteer".

With its ongoing success in Tasmania, *Epilepsy Connect* has the capacity to be rolled out across each state of Australia.

## Epilepsy Western Australia

Epilepsy WA has launched a monthly support group in Bunbury. This group joins the three existing regional groups that meet in Rockingham, Bunbury and Manjimup; and the four monthly groups that meet in the Perth metro areas.

The support groups are run in a peer support style, led by a facilitator representing Epilepsy WA. The groups are open to anyone whose life is impacted by epilepsy, whether it be as a parent, partner, family member or friend.

Lauren Buckels of Epilepsy WA said "support groups provide a safe space and an understanding environment, as people don't realise the profound impact epilepsy can have on families". For more information or to attend a support group email: [support@epilepsywa.asn.au](mailto:support@epilepsywa.asn.au).

### September was Purple Laces Month for Epilepsy WA!

Purple Laces are still available to buy and you can read more about this campaign and the accompanying #storiesofepilepsy movement, by visiting [www.purplelaces.com.au](http://www.purplelaces.com.au). Thanks to the fabulous student volunteers from the John Curtin Leadership Academy for all of their hard work with this campaign.

For more information visit: [www.purplelaces.com.au](http://www.purplelaces.com.au)



# EDUCATION SMART SCHOOLS

## *Epilepsy Smart Schools* is now national

We are very proud to announce that Epilepsy Australia is supporting the national launch of our ***Epilepsy Smart Schools*** program. This evidence-based program was developed to support schools to provide a safe and inclusive educational environment for students living with epilepsy.

Epilepsy is a very misunderstood condition in our community, and around 1 in 200 students are living with epilepsy. The *Epilepsy Smart Schools* program aims to positively support everyone in school communities and seeks to create generational change through better understanding of epilepsy.

To become a recognised *Epilepsy Smart School*, schools must complete three important steps:

1. Demonstrate that the school supports any known student living with epilepsy.
2. Ensure all teachers with a duty of care have received epilepsy specific training.
3. Educate students about epilepsy.

Parents and carers want to know that their child is in safe hands, getting the best education they can and are able to participate in all school and community activities. Teachers also want to be empowered to support all students within their class to participate fully. Training provided as part of the *Epilepsy Smart Schools* program allows these wants to be achieved.

A recognised *Epilepsy Smart School* is one that understands epilepsy and puts in place inclusive practices to support all students living with epilepsy achieve their learning potential and develop positive social relationships. All pre-schools, primary schools, secondary schools and special schools are eligible to become recognised as an *Epilepsy Smart School*.

If you would like to learn more about how your school can become a recognised Epilepsy Smart School, please visit the website - [www.epilepsysmartschools.org.au](http://www.epilepsysmartschools.org.au) or phone 1300 852 853 to speak to your local Epilepsy Australia organisation.



**Proud to be  
epilepsy smart**

[www.epilepsysmartschools.org.au](http://www.epilepsysmartschools.org.au)

epilepsy Learning

EPILEPSY  
✓ ✓ ✓  
SMART

# EPILEPSY TRAINING

## National Online Epilepsy Training - now available

All Epilepsy Australia member organisations are committed to raising awareness of epilepsy across Australia to ensure that no one with epilepsy goes it alone.

In 2018 we supported our member organisations to make nationally consistent online and face-to-face training programs available. The various training programs are relevant for people living with epilepsy, family members, carers, teachers, and staff in workplaces.

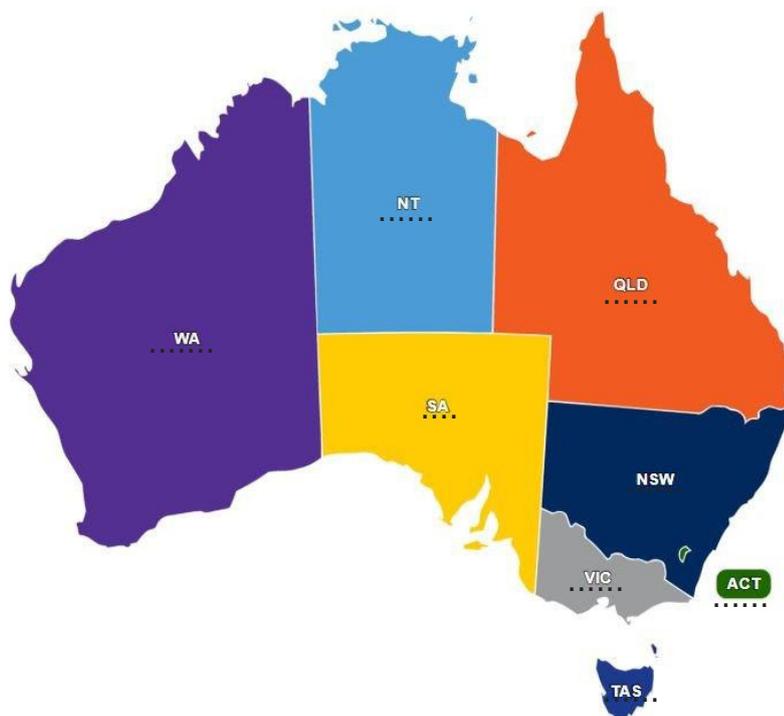
Providing training programs online helps to ensure that people can learn at a time which best suits them. Online training is available to individuals and teams in organisations.

Online training programs currently available are:

- Epilepsy: An introduction to understanding and managing epilepsy
- Epilepsy: Understanding the Epilepsy Management Plan
- Epilepsy: Administration of Emergency Medication (Part 1)
- Epilepsy: Administration of Emergency Medication (Part 2)

To learn more or to register for training click on your State or Territory below and you will then be taken to your local epilepsy organisation's booking site. Or alternatively contact your local epilepsy organisation to find out more.

Click on your State to find out more:





**The Hon. Greg Hunt MP**  
Minister for Health

### **MEDIA RELEASE**

26 March 2018

#### **\$2 million for medical research on epilepsy**

The Turnbull Government will invest \$2 million in new medical research to help find a cure for rare genetic epilepsy disorders.

I am pleased to make this announcement on Purple Day, a day dedicated to raising awareness about the impact of epilepsy.

Epilepsy is a chronic disorder of the brain that affects people of all ages, with around 250,000 Australians living with the condition.

This new funding will support our leading researchers to investigate genetic and other causes of epilepsy including the mutation of the Syngap gene, a rare neurological condition which can lead to epilepsy.

The SYNGAP-1 project will be the first project undertaken by the Australian Epilepsy Research Fund, and will be led by researchers from the respected Florey Institute of Neuroscience and Mental Health.

The Australian Epilepsy Research Fund has been established by the Epilepsy Foundation to provide Australians living with genetic and other types of epilepsy hope for the future through medical research.

The Epilepsy Foundation works with individuals and families, organisations and the community to increase people's understanding of epilepsy.

I want to thank the Epilepsy Foundation for their tireless commitment in supporting people living with epilepsy and their families, and for their work to establish a medical research fund to fight epilepsy.

It is my hope that this funding contributes to a medical breakthrough that will improve the lives of people living with this condition.

Since 2013 the Coalition Government has invested more than \$58 million for epilepsy research through the National Health and Medical Research Council (NHMRC).

The Turnbull Government spent more than \$71 million on the PBS for medicines to treat epilepsy in 2016-17.

All Australians benefit from the investment in health and medical research.

## Australian Pregnancy Register (APR)

The Australian Pregnancy Register (APR) is a national independent project that has been running for over 19 years nationally. The APR is an observational register which collects information about pregnant women with epilepsy, treated and untreated, to determine which anti-epileptic medications (AEDs) are safest for the baby while protecting the mother from seizures.

### Call for APR research participants

The APR would benefit from a boost to the number of women participating in the study and an increase in the length of the study to ensure enough evidence is collected for the findings to become treatment guidelines.

The APR is currently seeking to enrol women who are currently pregnant or who have given birth recently (infants up to 12 months of age) in the following categories:

- women with epilepsy taking AEDs
- women with epilepsy not taking AEDs
- women taking AEDs for other conditions.

Participation is voluntary. Once enrolled there are no appointments or visits required for this study. Information is gathered during four telephone interviews (or a combination of depending on point of enrolment):

1. On enrolment
2. 7 months gestation
3. 4 - 8 weeks post-delivery
4. 1 year post-delivery.

### To enrol in the research

Phone: 1800 069 722

Email: [apr@mh.org.au](mailto:apr@mh.org.au)

Website: [www.apr.org.au](http://www.apr.org.au)

(click on the 'Register Now' button)

### For assistance and further information

Janet and Alison, the Research Coordinators, are happy to discuss pre-pregnancy planning as well as respond to questions relevant to pregnancy, delivery, epilepsy and AEDs. In addition, they are able to provide current research-based information, and epilepsy and pregnancy resources.



“ All information is confidential and the APR team greatly appreciates the generosity of women who have shared their pregnancy journey so that they can continue to advise women in the future. The APR welcomes you contacting them.

## Research Project – ‘Body image and epilepsy’

A research project is currently being undertaken by The University of Melbourne in collaboration with the Florey Institute of Neuroscience and Mental Health and the Epilepsy Foundation, looking at the impact of epilepsy on body image. In particular, this study is looking at body dissatisfaction and whether it might contribute to depressive symptoms in people with and without epilepsy.

Ultimately, the aim of this research is to help improve the quality of care provided to people with epilepsy, through better awareness and the development of effective treatment strategies for body dissatisfaction.

### Volunteers wanted

The investigators are searching for volunteers, between the ages of 18 and 65, who have a diagnosis of epilepsy or know someone with epilepsy, as well as those without epilepsy.

Involvement includes completing an online questionnaire asking about body image, mood and medical history, which takes approximately 30 minutes to complete.

### Contact information

If you would like any further information concerning this project please feel free to contact Dr Genevieve Rayner or Ms Honor Coleman, on the below information:

Dr Genevieve Rayner  
Email: [raynerg@unimelb.edu.au](mailto:raynerg@unimelb.edu.au)

Ms Honor Coleman  
Telephone: (03) 8809 0654 (Tues & Wed)  
Email: [hcoleman@epilepsyfoundation.org.au](mailto:hcoleman@epilepsyfoundation.org.au)  
[research@epilepsyfoundation.org.au](mailto:research@epilepsyfoundation.org.au)



## Rhythms and Patterns in Epilepsy

An article was recently published in Lancet Neurology about natural rhythms or patterns of seizures in people with epilepsy. By looking at patterns in seizures experienced by over 1,000 participants, the study found that seizure cycles are more common than researchers previously thought.

The study found that a circadian pattern was the most common pattern for seizures, experienced by over 80% of participants, while weekly or longer patterns were less common.

About two-thirds of people in the study had more than one type of pattern evident for their seizures. These findings could help people living with epilepsy better predict and manage their seizures. For example, Senior Author Professor Mark Cook suggested that researchers may begin to investigate the possibility of adapting the timing of medication doses to suit weekly or monthly cycles.

Article: Karoly et al. (2018). Circadian and circaseptan rhythms in human epilepsy: a retrospective cohort study. Lancet Neurology. [http://dx.doi.org/10.1016/S1474-4422\(18\)30274-6](http://dx.doi.org/10.1016/S1474-4422(18)30274-6)

## Fady and Dalia's Story

The last years of school are a busy time when young people are becoming more independent, learning new skills and considering what the future holds.

For Fady, a 16 year old from Melbourne, that time is now. Fady is currently in Year 11 undertaking his Victorian Certificate of Applied Learning (VCAL) and enjoying his senior years at school. Part of this program involves attending TAFE and he recently completed a community services placement to gain on-the-job retail experience and other important skills for the future. Fady also happens to have been diagnosed with epilepsy as an infant.

Talking with Dalia, Fady's mother, it was clear she is very proud of Fady's achievements, "especially after what he has been through to get control over the seizures that started when he was a baby". Fady has had three neurosurgical procedures to treat his epilepsy - at nine years, 12 years and the final one when he was 15 years old. Since his final surgery, Fady no longer experiences the seizures that were a daily occurrence in his childhood.

At one and a half years of age, while living in Egypt, Fady had his first tonic-clonic seizure at home. The experience was terrifying for Dalia, and she did not know what was happening. "Initially our GP in Egypt thought the seizure was as a result of a high fever. But when we immigrated to Australia in 2008 Fady started having a range of different seizures which led to a referral to Royal Children's Hospital in Melbourne. After testing, Fady was diagnosed with epilepsy," recounted Dalia. "I didn't know what epilepsy was, so it came as a shock to my husband and I when the doctors said that was the cause of his seizures."

After diagnosis, Fady continued to experience a range of different seizure types, including ongoing tonic-clonic, absence and focal impaired awareness seizures. Despite the best efforts of Fady's paediatric neurologist, the prescribed anti-epileptic medications (AEDs) were not controlling the seizures and Fady was experiencing side-effects that impacted his ability to learn and participate at school. "So the doctors thought surgery might help Fady and they began lots of testing to check if he was a good candidate," explained Dalia.

Fady was nine when he had his first right temporal lobe neurosurgery and 12 when he had his second surgery. Initially the surgeries led to better seizure control but, as can be the case with any epilepsy surgery, Fady's seizures returned a few months after each. When Fady was 15 the medical team felt that use of intracranial grids and electrodes prior to his third surgery could optimise success. "Although it was a big decision, we thought another surgery really could be the answer to our prayers, and because Fady was a little bit older we made sure he was part of the discussions so he knew what was going to happen," recounted Dalia.

Any epilepsy-related surgery is assessed by a medical team in terms of benefits and risks, and explained to patients and families to assist them in making an informed decision. Not all people living with epilepsy are suitable candidates for surgery. The risks vary according to each person, the type of surgery and the area of the brain that's involved.

Fady was part of the pre-surgery conversations, the pre-surgical testing and even recalls the benefits and risks being explained to him.

## Fady and Dalia's Story

"I was told I might have memory problems and that my eyesight could be affected, but I didn't want to have seizures anymore so I wasn't too worried," said Fady.

Fady's surgery was a great success and now, almost two years on, he is still seizure free; an outcome he describes as "amazing and a big relief". The surgery did end up affecting Fady's peripheral vision, which may impact his ability to drive in the future.

Fady and Dalia have been connected to the Epilepsy Foundation for many years and through this connection they have been able to attend events and meet other families. Connecting with others has been an important part of their journey, and talking to other families living with epilepsy means they don't feel alone. Through support from Epilepsy Foundation staff, teachers at Fady's school have received epilepsy training based on his 'Epilepsy Management Plan' should he ever experience a seizure at school. "We want teachers to know what to do," explained Dalia.

As part of his VCAL studies Fady is now undertaking a Certificate II in Community Services, which involved a weekly placement at a local Op Shop connected to a disability services organisation. "I loved working at the Op Shop as I was getting lots of support from my supervisor to know what to do and assist people who come into the shop," said Fady. Although Fady is not yet sure what pathway he would like to take when he finishes school he is seriously considering more training and a career in community services, so that he can continue to help other people.

Fady and Dalia's lived experience with epilepsy has made them adamant that more people in the community need to understand epilepsy.

"Primary school was a bit hard for me as I had a lot of seizures, so I really want everyone to understand that just because you have epilepsy you aren't different to other people. You just have seizures," emphasised Fady.

Dalia is a firm believer in ensuring that teachers gain an understanding about how epilepsy affects students. "A lot of teachers don't know about epilepsy, which means they don't always understand how tiring seizures and medications can be for a child. So, I think it's important that all teachers learn about epilepsy and give students who have epilepsy all the support they need to learn and make friends," stated Dalia.

We are grateful to Fady and Dalia for sharing their story and for being passionate advocates for people living with epilepsy. We look forward to being part of Fady's ongoing journey to independence and desire to ensure that others living with epilepsy are understood in the community.



# OTHER NEWS

## MyEpilepsyTeam

Like many members of MyEpilepsyTeam the daily burden of epilepsy can feel unrelenting even when we're surrounded by loving friends and family.

MyEpilepsyTeam is the social network for those diagnosed with epilepsy, or the parent or spouse of someone who is living with epilepsy. It's the one place where the burden of epilepsy is let go.

MyEpilepsyTeam is a safe place completely dedicated to those diagnosed with epilepsy and their primary caregivers, and is not for researchers or health providers, and it is not a medical site. It's available 24/7 to members who share similar experiences. But the conversation goes beyond medication. It extends to every day ups and downs. The small wins, the hard days, the big achievements of daily life.

Click on the links below for some of what you can find here:

[Driving and Epilepsy](#)

[Relationships and Epilepsy](#)

[Working and Epilepsy](#)

Meet others like you when you join [MyEpilepsyTeam](#). It's free and password protected. Also available on iTunes and GooglePlay.



Epilepsy Australia, October 2018. The information contained in this publication provides general information about epilepsy. It does not provide specific advice. Specific health and medical advice should always be obtained from a qualified health professional.