

# the flame

the newsletter of epilepsy queensland inc

Issue 4 – 2017

**NDIS**  
get ready in  
five steps

*Queensland  
epilepsy  
symposium*

**Epilepsy  
Queensland  
awards**

**My Epilepsy Story**

From seizures to bubble wrap CEO





## Epilepsy Queensland can help you get NDIS - ready in five steps

### 1. Check your eligibility

Check out the NDIS Access Checklist to identify if you meet the access requirements to become a participant in the National Disability Insurance Scheme (NDIS). This can be found at: <https://www.ndis.gov.au/people-disability/access-requirements.html>. You can submit an access request from 6 months before the NDIS is rolled out in your area. For the rollout plan, visit: <https://www.ndis.gov.au/people-disability/access-requirements.html>

### 2. Think about your needs, strengths, barriers and goals

Think about what you need in your life, to enhance your independence and safety. What will it take for you/your loved one to be able to better access mainstream and community services? Or enhance your quality of life?

### 3. Start planning

EQI staff work closely with people with epilepsy and their supporters, to prepare for their first NDIS plan. This includes talking about what the NDIS may mean for their unique circumstances in plain language, removing all the jargon and complexities.

The pre-planning process is extremely important, as feedback from people in the trial sites have found that they are able to engage more effectively with the NDIA (National Disability Insurance Agency) if they have spent time doing pre-planning before their meeting with the NDIA or delegated Planner.

EQI have a workbook that can guide you through this pre-planning process, and you can choose to do this on your own or with the help of an EQI team member.

By completing this pre-planning work, you will be more prepared, knowledgeable and confident for when you do meet with the NDIA Planner.

### 4. Take your plan to the NDIA

Once the NDIS rolls out in your area, take your preparations to your NDIA meeting. EQI team members can also work with you to run through what other reports or evidence you may need to submit to inform your planning meeting.

### 5. Review your plan

Your NDIS Plan will usually be reviewed every 12 months. However, it is important to review your plan when necessary to make sure you are getting the right supports as your life and circumstances change.

For help to get ready for the NDIS contact Epilepsy Queensland on 07 3435 5000, 1300 852 853 or [ndis@epilepsyqueensland.com.au](mailto:ndis@epilepsyqueensland.com.au).

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#### EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it. The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights. The Editor reserves the right to edit or exclude stories from inclusion in Flame at his/her discretion.

*The Flame is published quarterly by Epilepsy Queensland – [www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au)*

# Eighth Annual Queensland Epilepsy Symposium



## Thinking outside the box !

Save the date  
Thursday 26 October 2017  
PA Hospital, Woolloongabba

Join us for some stimulating dialogue...

[www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au)

Bookings essential!

The eighth annual Queensland Epilepsy Symposium: Thinking outside the box, is being held on Thursday, 26 October 2017 at the Princess Alexandra Hospital in Brisbane.

The theme this year is "What's new in the epilepsy world?" with experts from throughout Australia presenting on a range of topics including genetic testing and research, emerging drugs, stereo-EEG, non-epileptic seizures, epilepsy and spirituality and where epilepsy fits within the NDIS.

This one day symposium will ensure members of the public including those living with epilepsy and their support networks, as well as medical and allied health staff have the opportunity to learn more about a range of topical issues.

We are thrilled to have Dr Piero Perucca from the Royal Melbourne Hospital and the University of Melbourne. Piero led one of the first genomics projects in the Melbourne Genomics Alliance. He recently published work, which used advances in next-generation genomic sequencing to understand the importance of genetic factors for people with focal epilepsy (which accounts for 60% of all epilepsies). The data from this study demonstrated that targeted gene analysis is an effective tool for patients with common focal epilepsies, and that it can be used to influence decision making, including anti-epileptic drug selection and consideration of epilepsy surgery. And hence, supporting its incorporation in the routine clinical care of this patient group.

A/Prof Lata Vadlamudi from Royal Brisbane and Women's Hospital and the University of Queensland Centre for Clinical Research will continue our exploration of genetics and epilepsy with "What is the cause of my epilepsy?"

We also have Dr Sasha Dionisio from the Mater Centre for Neurosciences. He will be talking about how Stereo-EEGs have been transforming the lives of Queensland patients with focal epilepsy. This revolutionary technique enables patients to have epilepsy surgery, most of whom were previously told that they could not have surgery as their brain scan was normal.

Don't forget, if you are an up to date financial member of Epilepsy Queensland, you get a \$40 discount on the cost of registration.

As a not for profit, charitable organisation Epilepsy Queensland Inc. is grateful for the support of experts from universities and hospitals throughout Australia. Register online today, fill in the enclosed registration form or phone 07 3435 5000 or 1300 852 853 (Regional Queensland) to be a part of this important event. For details of the full program and information on registering for the Symposium: <https://queenslandepilepsysymposium2017.eventbrite.com.au>.

Sponsored by:



Epilepsy Queensland thanks the  
Princess Alexandra Hospital for

use of their venue

Metro South  
Health







# Epilepsy Queensland Awards

## Nominate your epilepsy hero

Epilepsy Queensland are committed to bringing epilepsy 'out of the shadows' and helping to demystify the condition. In addition to providing assistance with NDIS navigation, counselling, support programs, advocacy and research, we are focused on educating the broader community so that people with epilepsy can lead fulfilling and satisfying lives. Our annual awards recognise the support demonstrated by individuals and groups towards achieving this goal.

We get very excited about celebrating the commitment of people who support us, as they give so much of their time and resources. The Awards evening is a way we can acknowledge those people and organisations whose efforts have been significant. We want to salute you - those of you who deal with epilepsy on a personal level, work in the wider community or it might be that you've made a special effort to understand and support people with epilepsy. We welcome your nominations!

The following are the descriptions of our Awards -

### Nominated by Epilepsy Queensland:

**Our Flame Award** is special as the flame is the symbol of epilepsy throughout the world. It stands for bringing light to epilepsy. This award is only awarded in special circumstances for services and support to Epilepsy Queensland.

**Marella Jenkins Fundraising Award** is presented to people who fundraise for Epilepsy Queensland in their local communities. The award is named after Marella Jenkins who worked tirelessly to financially assist Epilepsy Queensland.

### Nominated by members of Epilepsy Queensland and the general community

**The Health Award** is presented to those who contribute significantly to the medical care of people with epilepsy such as nurses, doctors, neurologists, EEG technicians, pharmacists and therapists.

**The Disability Award** is given to individuals or organisations whose support is vital for those with disabilities. This could include services such as respite or supported employment.

**John Wellings Memorial Education Award** is awarded to teachers and other personnel in schools, preschools/day care facilities or tertiary institutions who have provided assistance to people with epilepsy. It may also be awarded to those who raise awareness in the teaching and training industry. John Wellings was a longstanding President of Epilepsy Queensland and a passionate educator.

**Our Carer's Award** is presented to those who care for someone with epilepsy. It is always a difficult one to allocate as all carers are deserving of an award.

**The Role Model Award** is given to an individual who has been a role model for others that is not covered by another category.

**The Media Award** is awarded to individuals, journalists or organisations whose published or broadcasted work has significantly contributed to the awareness of the challenges and achievements of people living with epilepsy, the treatment of epilepsy, or Epilepsy Queensland.

**Our Youth Award** awarded to a young adult or teenager who helped someone with epilepsy, or the epilepsy community in general. It may also be awarded to a young person with epilepsy who has been a role model for others.

**The Doris Kemp Memorial Award** is awarded to a tertiary student who has completed a project, assignment or thesis in the field of epilepsy. This award is in memory of Doris Kemp OAM, the founder of Epilepsy Queensland.

**The Pam Wellings Memorial Award** - Pam Wellings was the wife of John Wellings, a past President of Epilepsy Queensland. This award is dedicated to a volunteer or supporter of Epilepsy Queensland.





Please phone the office on 07 3435 5000 or 1300 852 853, or email [jritchie@epilepsyqueensland.com.au](mailto:jritchie@epilepsyqueensland.com.au) to receive a nomination form. Alternatively, you may wish to visit our website <http://www.epilepsyqueensland.com.au/awards> and download a registration form.

**Our “Fair Go” Memorial Award** is in memory of long time active member Fred White. This award is dedicated to someone who has given a person with epilepsy a ‘fair go’. This could include an employer, sporting or community group.

If you would like to nominate someone who you believe has made a contribution towards improving quality of life for people with epilepsy, you may do so by contacting us at Epilepsy Queensland for a nomination form or downloading from our website. The nominee may also have ongoing contact with different people with epilepsy, or they may be involved specifically with one person with epilepsy.

#### **How will the winner be selected?**

We make the difficult decision of selecting the winners through a subcommittee, who forward their recommendations to Epilepsy Queensland’s Board for review and endorsement.

The winners will be announced at our Special Awards Ceremony held in conjunction with the Annual General Meeting and celebration on 4 December.

If you would like to support these awards you can do that as an Epilepsy Queensland member or supporter in either of the following ways. Firstly, by nominating someone who helps

or assists you. Secondly, you may wish to sponsor a specific award, or make a donation for these awards generally. Video nominations are also accepted.

A couple of things to keep in mind:

- Nominees must be Queensland residents.
- A person can be nominated more than once, but can only win a category once.
- Epilepsy Queensland takes no responsibility for receipt of applications.  
All nominations received will be acknowledged. If you do not receive acknowledgement, please contact us.
- The judges’ decision is final and correspondence will not be entered into.
- Nominations must be for actions occurring in the previous 12 months.
- Epilepsy Queensland may elect not to award a particular category.
- From time to time, Epilepsy Queensland will introduce additional awards. Nominations for these are generated within Epilepsy Queensland.

*You are invited to:*

## **Epilepsy Queensland Annual Celebration**

*including*  
**AWARDS CEREMONY, CHRISTMAS  
FESTIVITIES and AGM**

**When: Mon 4 December - 6:30pm**

**Where: Queensland Cricketers' Club**

**RSVP: <https://eqiannualcelebration17.eventbrite.com.au>**







# My Epilepsy Story

## From seizures to bubble wrap CEO

For Dion and Tara Van Leent the diagnosis of epilepsy for their daughter Amelia at the age of 18 months was a huge emotional challenge. Amelia has Jeavons Syndrome and Eyelid Myoclonia with absence seizures. This means she has absences, confusion and anxiety. She has troubles opening her eyes in the morning and evenings due to Eyelid Myoclonia. By the age of four, Amelia's seizures escalated and she was dealing with 100 to 200 seizures a day.

Amelia's condition had a big impact on the family. Dion explains: "It affected us deeply in good and bad ways. Coming to realisations that she has a syndrome that's incurable has been challenging as a family. We both work part time now to support each other, our family and Amelia."

Now aged ten Amelia's seizures are controlled during the middle of the day, but she still struggles most mornings and evening with seizures. With a little help from Epilepsy Queensland and support from Amelia's medical team and school, Dion and Tara have set Amelia on a path to success.

Dion told us how they got Amelia started as a young Bubble Wrap CEO: "We moved from Brisbane to the Gold Coast

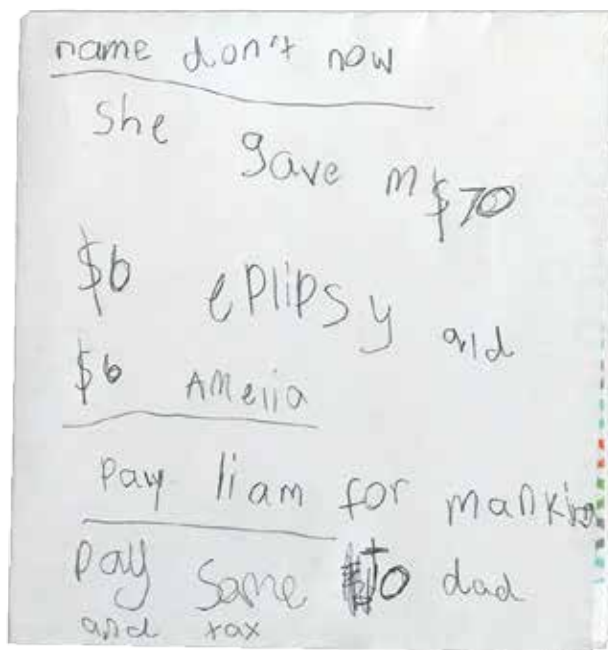
as Amelia was accepted into a very special school called Silkwood. During the move, I had an opportunity to start a little business with her in tow. We have come to the realisation that due to her learning disabilities, for her to be successful, she may need to do it outside the normal avenue of working for someone. If she can learn how to run a small business, she will be able to control her own future."

This was where Gold Coast Bubble Wrap was born as an opportunity for Amelia to learn practically how money works and gain confidence. As many people and organisations along the way had helped Amelia and the family, Dion and Tara wanted her to understand the importance of giving back to the community. The business has also been fortunate enough to have had a lot of support from their supplier Brisbane Bubble Wrap.

Amelia donates a minimum of five percent of all sales through Gold Coast Bubble Wrap to Epilepsy Queensland. In just over a year this has come to more than \$1,200 donated to help provide more services for Queenslanders living with epilepsy.



**Dion and Amelia posted  
this image on Facebook of  
Amelia's order calculations**



Always humble in what she is doing Amelia sends handwritten notes of thanks to her customers and when we asked her about how she felt about the impact she was having through her donations she answered with one word "proud".

Amelia and Dad Dion have managed to work the business around Amelia's epilepsy and the rest of her day.

He explains: "A usual day is seizures for the first 40 minutes of day until her medicine kicks in. In winter, we put her to bed in school uniform to make it easier in the mornings for her. She loves school and has learning disabilities but has a lot of support. She rests after school and after that spends a while with her latest hobby... which this month is being a contortionist. As the business has grown, Amelia now looks after the smaller retail customers and Dad fits the wholesale deliveries and managing the orders around his day."

Amelia does the retail deliveries with her Dad and her favourite part of the business is meeting customer's dogs. In fact, Amelia loves animals so much that her hope for the future is to one day run her own business with animals.

Dion said: "She is very connected to animals. When she gets home from school, neighbourhood dogs come to greet her. It's not uncommon for her to have three dogs on her bed with her as she rests after school. Dogs calm her when she is feeling 'yucky'. We are fortunate as well to have support from Arundel Park Riding for Disabled where she rides and learns about horses once a week."

Dion talked about the support they received from Epilepsy Queensland: "When Amelia was first diagnosed about eight years ago, the support given to our family was so comforting in a very difficult time. Although we were given the medical support by the health system, emotional support isn't always given, so services like Epilepsy Queensland are critical. The family retreat we attended in 2011 was so special for us and we have never forgotten what your team did for our family."

Epilepsy Queensland Services Coordinator Jenny Ritchie commented: "It's always a privilege for staff to go on camps with families and help them to deal with new diagnosis of epilepsy and create strategies to not only care for their child living with epilepsy but also for themselves."

"We are really thrilled when families we have assisted continue to stay in touch and let us know of their successes such as Amelia's. I think it's important to share these stories and great ideas about how parents can help their children with epilepsy to live fulfilling lives."



**Gold Coast Bubble Wrap**

29 June · Gold Coast · 🌐

Our last donation to Epilepsy Qld for this financial year! \$342.00 😊 thank you to all our customers who have helped raise money for this great cause BUT still get their Bubble Wrap cheaper than anywhere else...makes good business sense to me!

I would encourage everyone to donate to a good cause before the year ends...remember it's all tax deductible....but you only have 2 days!  
[www.givenow.com.au](http://www.givenow.com.au)



**If you would like to support Epilepsy Queensland by purchasing supplies via Gold Coast Bubble Wrap call 0466 558 288 or visit [www.goldcoastbubblewrap.com.au](http://www.goldcoastbubblewrap.com.au). For more information on support offered for families with a child living with epilepsy contact 07 3435 5000 or email [services@epilepsyqueensland.com.au](mailto:services@epilepsyqueensland.com.au).**





# Wally Lewis shares his story at Lendlease Charity Golf Day



It was a beautiful Autumn morning for 144 keen golfers and 186 lunchers at Brookwater Golf Club, out in support of Epilepsy Queensland and Legacy for the annual Lendlease Charity Golf Day. They got to spend time with our Patron Wally Lewis who shared his story of living in the shadows with epilepsy and how surgery changed his life. After a fun round of golf featuring speed tests and other competitions for golfers of varying skill, the very generous participants dug deep for some fantastic prizes spurred on by MC Josh Holt from Channel 10 and auctioneer extraordinaire Scott Gemmell from LJ Hooker New Farm.

We are pleased to report that the event raised \$73,330, shared equally between the two charities. Now in its eighth year, the event has raised an amazing \$284,419 towards Epilepsy Queensland's services for children and adults living with epilepsy.

Epilepsy Queensland's patron, Wally Lewis, is thrilled with the

result. "I really enjoy a good game of golf and the Lendlease Charity Golf Day is one that I always look forward to. It's not just a fun day, but a wonderful way to get our message out to corporates each year and help to bring epilepsy out of the shadows. One in 26 people will develop epilepsy at some stage in their life, so this is something that will affect a person or their family in most workplaces."

"It's fantastic to see the generosity of the sponsors of the event and everyone who digs deep on the day in support of Epilepsy Queensland and Legacy. Special thanks to Lendlease, Maria Bran and the Golf Day Committee plus Legacy and their band of Australian Defence Force volunteers."

If you would like to raise funds by hosting or supporting an event for Epilepsy Queensland please contact Leigh Gilbert on 07 3435 5000 or email [fundraising@epilepsyqueensland.com.au](mailto:fundraising@epilepsyqueensland.com.au). Together we can make a very real difference for Queensland children and adults living with epilepsy.



# Inaugural Platinum Sponsor: **RPS**

## Silver Sponsors:

- Bosform
- Allroads

## Bronze Sponsors:

- Glascott Landscape & Civil
- BVN
- A.G. Coombs
- Shamrock Civil
- Fredon
- Arcadis Australia Pacific
- Shadforths Civil Contractors
- FIP Electrical
- Hurst Concepts







Team Sammy Milne

# Purple Power conquers Bridge to Brisbane



Congratulations to everyone who got up early on a chilly Sunday morning in August to walk or run the Bridge to Brisbane for Epilepsy Queensland.

While the 10km enthusiasts were already underway, Epilepsy Queensland's Purple Power Walkers gathered under the Story Bridge for some warm-up exercises. The team included EpiApe (aka Samantha Rowles from Gayndah and Munduberra Guardian Pharmacies) and Jaimie Roth with their daughters from Gayndah, plus a group of tutu wearing gals from Dalby called Chelsea's Cheerers.

EpiApe and Jaimie graciously took the stage to share their story with the growing number of walkers at the starting line. Jaimie spoke about her son Levi who lives with epilepsy, and the wonderful support they receive from Epilepsy Queensland.

The team walked the 5km towards the back of the pack in just over an hour, with EpiApe stopping occasionally for photos, getting a lot of attention for Epilepsy Queensland along the way.

Team Sammy, also walking for Epilepsy Queensland, were spread across the course with over 40 family and friends proudly wearing colourful Hawaiian shirts in memory of Sammy Milne.

The day finished with the Best Dressed Team competition, and to our surprise, we won - bringing in another \$500 for our fundraising! This gave Jaimie another great opportunity again to speak on stage, bringing epilepsy out of the shadows.

Thank you to everyone who participated in or supported Epilepsy Queensland in this year's Bridge to Brisbane. We had a fantastic day, and also surpassed our fundraising goal raising an amazing \$20,000 across all of our teams! This will enable Epilepsy Queensland to assist more people living across Queensland with epilepsy. We couldn't do it without you, THANK YOU!

A special mention goes to Hayman's Electrical Supplies for their generous donation to Team Sammy. As well as The Print Bar for the stunning work they did on our purple shirts and caps, and Skechers Australasia for sponsoring the final fundraising incentive prize.

**We're keen to do it all again in 2018, if you would like to join us please email or call Lisa now to receive your personal invitation next year.**

**e: [fundraising@epilepsyqueensland.com.au](mailto:fundraising@epilepsyqueensland.com.au)  
p: 07 3435 5000 or 1300 852 853**

Chelsea's Cheerers







SAVE THE DATE

TUES **7** NOV

# MELBOURNE CUP

DAY OF DECADENCE  
LONG TABLE LUNCH

AFTER A SELL-OUT EVENT LAST YEAR, WE'RE SADDLING UP AGAIN FOR OUR MELBOURNE CUP DAY OF DECADENCE AT THE NEW-LOOK QC CLUB OVERLOOKING THE MAGNIFICENT GABBA!

Begin your day with a complimentary pre-luncheon drink in the Glasshouse then settle in to the long table three-course luncheon soirée with free flowing wine and bubbles. Keep the celebrations going at the fun-filled garden after-party! Throughout the day enjoy live music, be pampered at make-up stations and spoil yourself at an array of pop-up shops. Plus, have a little flutter on the sweeps and raffles for a chance to win some fabulous prizes. Part of the proceeds from the day will be donated to Epilepsy Queensland.

**FROM \$135 PER PERSON** • CELEBRATION STARTS FROM 11AM  
LONG TABLE LUNCH AT 12NOON • AFTER PARTY FROM 2.30PM

Join us and watch the nation's ultimate race at the QC Club.  
For more information email [events@qcclub.com.au](mailto:events@qcclub.com.au)

411 VULTURE STREET • THE GABBA



[qcclub.com.au](http://qcclub.com.au)   



# 30 minutes with...

## Peter Meyer

*Peter and Susan Meyer  
with Rupert McCall*



### ***What inspires you to raise funds for Epilepsy Queensland?***

Raising funds for epilepsy creates awareness, I had epilepsy for 46 years and in all that time I told no one and confided in no one, this insidious disease needs to be discussed. My family was embarrassed that I had epilepsy and they lived in fear of others finding out. All this taboo behind epilepsy has to go. I think the fastest way to educate people is to have them part with their money. People tend to listen to you more when you have their money.

### ***What do you enjoy about hosting an event for Epilepsy Queensland?***

That every cent raised goes back to helping families and educating the public. Epilepsy Queensland do excellent work to assist families across Queensland. The helpline is a vital service providing support and information for people who are newly diagnosed and anyone with uncontrolled epilepsy. The staff have also done a number of training sessions at local schools and businesses in Toowoomba where I am based.

### ***Why golf days?***

I love the game and it allows people to have some fun, with 18 holes of golf taking around four to five hours. I get to educate people a little more about epilepsy every three or four holes.

### ***You are Epilepsy Queensland's highest individual fundraiser. What is your secret to raising more money for epilepsy support?***

I would encourage everyone to have ago at a fundraiser. Don't underestimate the generosity of people, they will support you. I don't think how much you raise matters just getting the word out about epilepsy is refreshing.

### ***How did epilepsy affect your life prior to surgery?***

Epilepsy is a debilitating chronic disease. I would get struck down with seizures every two to three weeks. Everything I did before surgery required a lot more thought.

### ***What was your greatest fear prior to surgery and now?***

That the operation would not be successful. I still worry every day that I am going to have a seizure at any moment . They were such a big part of my life. It's the most incredible feeling not to have to deal with seizures, so much so I cannot put it into words.

### ***How long have you been seizure free?***

At the time of answering this 52 months 3weeks 6 days 3 hours 51 minutes and 12 seconds not counting though.

### ***What is your greatest achievement or your proudest moment?***

Adopting our two boys from Taiwan, travelling to Taiwan, walking up the stairs looking at our son in his cot, to do that twice, it is just mind blowing. It will never be beaten.

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

Scotland to play St Andrews Links course.

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

Chocolate.





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

Buying our second house applying for the loan, telling our banking officer that I wasn't sure I wanted it, because when we looked through it the neighbour didn't shut up and I sure as hell didn't want that every time I came and went. It turned out to be her husband. He was very quiet for the first 6 months.

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

Three men in a boat by Jerome K Jerome.

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

Adam Scott: I'd love to meet Will Ferrell.

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

Anything 80's or 90's.

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

I work pretty long hours, and with two young active boys you don't have time for hobbies, except for the odd game of golf.

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

Better education for GPs and a more targeted specialist approach. Greater education and awareness about this chronic illness that doesn't just affect the life of the sufferer but everyone around them as well. More funding.



*West Indian cricketing great Brian Lara at the 2016 Toowoomba Golf Day*



# Little Poss Club

One of the special things we do for our little people with epilepsy is to introduce them to Little Poss. Little Poss is one of Epilepsy Queensland's mascots. He has been around here for a long time, and has a club called the Little Poss Club.

Little Poss is a brushtail possum, with epilepsy, who lives in Ningaloo with his friends Ruby Rosella, Kerry Koala, Eddie Emu, Wally Wombat and Gertie Goanna. He goes to school in Ningaloo and his teacher's name is Miss Roo.

Epilepsy Queensland has two books, written by Anne Little, that tell children about Little Poss' journey with epilepsy. 'And Down Went Poss' and 'Poss's School Days' tell a delightful story that helps children understand their own epilepsy. They are wonderful books, especially designed to show how to be a friend to someone with epilepsy and how to help someone who is having a seizure.

Children with epilepsy are able to join him in adventures and birthday celebrations. Every year he has a birthday party where he invites all his club members to join him to help him celebrate. He usually has some entertainment, some food and always a birthday cake. He loves meeting his friends this way.

Little Poss manages to send out to his members and friends a birthday card and bi-monthly newsletter full of puzzles, brainteasers and other activities. The newsletter lets them know of any upcoming events like Purple Day. Little Poss has his own website and email address. He loves getting letters and messages from his friends. When Little Poss is available, he visits schools and childcare centres and often attends Epilepsy Queensland's events such as Purple Day.

If you would like your child to become a member of the Little Poss Club, please contact the team at Epilepsy Queensland on 07 3435 5000 or email for a Little Poss membership form to [services@epilepsyqueensland.com.au](mailto:services@epilepsyqueensland.com.au)

You might like to visit Little Poss at his website [www.littleposs.com](http://www.littleposs.com)





# ASK THE EDUCATOR

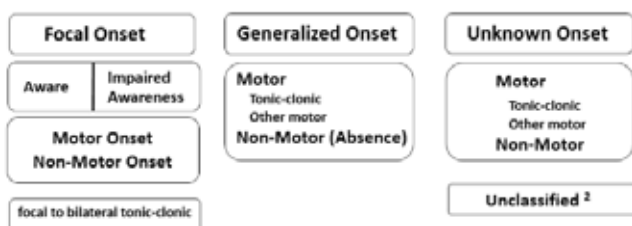
**Q: My Neurologist has again changed the name of my seizure type. It was changed not so long ago, and now I am confused. Can you explain?**

A: The International League Against Epilepsy (ILAE), the world's main scientific body devoted to the study of epilepsy, recently updated its classification of seizures. Modern research has improved our understanding of epilepsy and seizures, leading to the development of a classification system, which in turn helps doctors choose seizure medications, alternative treatment options and clinical investigations.

Dr Robert S Fischer, who led the Seizure Classification Task Force, notes that whilst there are multiple benefits clinically for the changes, 'a classification provides words to patients to describe their disease'. Notably, it aims to reduce confusion by removing terminology that was difficult for non-medical people to understand, including terms such as "dyscognitive", "psychic", "partial", "simple partial" and "complex partial" and using terms that are more descriptive of what is happening during the seizure.

As seen below, the new basic classification breaks down seizures according to:

## ILAE 2017 Classification of Seizure Types Basic Version <sup>1</sup>



<sup>1</sup> Definitions, other seizure types and descriptors are listed in the accompanying paper & glossary of terms

<sup>2</sup> Due to inadequate information or inability to place in other categories

- Where the seizure start in the brain
  - Focal Onset Seizures – start in an area or network on one side of the brain (previously called partial seizures)
  - Generalised Onset Seizures – start and involve networks on both sides of the brain

- Level of awareness experienced during the seizure
  - Focal Aware – if awareness remains intact, even if the person is unable to talk/respond (previously called simple partial)
  - Focal Impaired Awareness – if awareness is altered, meaning the person loses awareness of what's going on around them or becomes confused, even if the person has a vague recollection of the event afterwards (previously called complex partial or focal dyscognitive)
  - Generalised Onset Seizures – awareness is not used as a classifier, as the person will always have an altered level of awareness or be unconscious
- Symptoms experienced at the beginning of the seizure
  - Motor - changes to movement during the seizure, for example: twitching, jerking, stiffening, loss of muscle tone, automatisms – i.e. action performed unconsciously or involuntarily
  - Non-motor – all other symptoms, for example: changes in sensation, emotions, thinking, behaviour and autonomic functions like flushing, sweating, increased heart rate

So what does this mean for you? If you have been given a new name for your seizure, it is simply a name more descriptive of what is happening when your seizure occurs. It does not mean that you are having a different type of seizure. The new classification also reconfirms the importance of eyewitness accounts of what happens during your seizures. Noting a person's level of awareness and other symptoms, particularly at the onset of the seizure, is important information, used by your doctor to classify your seizure type and in turn optimize your treatment.

## References

Fisher RS, Cross JH, French JA, et al., Operational classification of seizure types by the International League Against Epilepsy: position paper of the ILAE Commission for Classification and Terminology, *Epilepsia*, 2017;58:522–30.



2017

## DIARY DATES

26 October

### Queensland Epilepsy Symposium

Sourcing speakers with extensive knowledge of neurology, widely renowned in their fields of expertise, this annual event is vital in sharing knowledge and information, stimulating dialogue and thinking outside the box when it comes to epilepsy. Register online today! <https://queenslandepilepsysymposium2017.eventbrite.com.au>

7 November

### MELBOURNE CUP - LONG TABLE LUNCH

Looking to celebrate Melbourne Cup with a day of decadence? The QC Club overlooking the magnificent Gabba cricket grounds is a fantastic venue to enjoy fine food and wine while also supporting Epilepsy Queensland through the sweeps and raffle at the event. We'd love to see you there! Book at [www.qcclub.com.au](http://www.qcclub.com.au) today.

19 October (5.30pm + 6.00pm)  
16 November

### Understanding Epilepsy Workshops (Woolloongabba)

For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families

15 November

### Understanding Epilepsy Workshops (Gold Coast)

For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals

4 November

**Brisbane Adult Support Group Meeting** – Also informally first Saturday of each month

15 November

**Ipswich Social Meet Up for Adults** – QRI Banjo's Bar 11:30am

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

# SEIZURE FIRST AID NEWS

What a fantastic month of sizzling! Thank you to everyone that hosted or supported a September Sizzle to raise funds and awareness of seizure first aid. One in 10 people will have a seizure during their lifetime. Together we are helping more people to become familiar with seizure first aid.

It's not too late to download or order your seizure first aid resources. We have a posters, wallet cards and fridge magnets available for your home, work or school. Visit: [www.epilepsyqueensland.com.au/first-aid](http://www.epilepsyqueensland.com.au/first-aid)

Do you know what to do if someone has a seizure? Take the Epilepsy Queensland seizure first aid quiz and test your knowledge. <https://apps.facebook.com/fb-quizzes/seizure-first-aid-quiz>



**Dale Blyth, Woolworths Beenleigh**

