



# the flame

Issue 1 – 2017

the newsletter of epilepsy queensland inc



*Paisley McLeod with Wally Lewis & Michael Walsh, Director-General of the Department of Health*

inside...

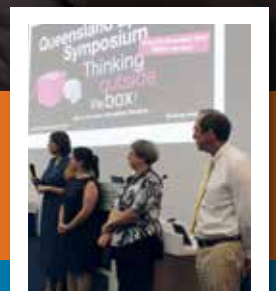
Toowoomba  
Golf Day



Purple  
Day



Symposium



## Art Union #3



Help support people  
living with epilepsy

DRAWN  
25 February 2017

# WIN

Mercedes-Benz  
A180 Hatch  
Prize valued at \$43,939

Tickets | \$100 ea.

**Only 500**  
tickets available

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## Epilepsy Queensland is thrilled to launch it's 2017 Limited Edition #3 Mercedes-Benz Art Union.

By purchasing a ticket, you are driving our services further, enabling us to help more people with epilepsy to live a full life without fear or prejudice.

This is your chance to win a magnificent Mercedes-Benz A180 Hatch – supplied by Mercedes-Benz Brisbane. With only 500 tickets on sale at just \$100 each, we are sure you will agree that the odds are fantastic.

This luxurious prize will be drawn at Epilepsy Queensland's Purple Ball on Saturday 25 February 2017 at Victoria Park Golf Complex. You do not need to attend to win, but how exciting if you are!

To purchase a ticket securely online today visit  
**[www.epilepsyqueensland.com.au/car](http://www.epilepsyqueensland.com.au/car)**

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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.

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## Seventh Annual Queensland Epilepsy Symposium 2016

On Friday 25 November 2016, Epilepsy Queensland held its 7th annual, Queensland Epilepsy Symposium, 'Thinking outside the box' at the Edwin Tooth Auditorium at the Royal Brisbane Women's Hospital Herston. This year's focus was 'Enhancing seizure control' succinctly defined by our highly regarded speakers throughout the day who engaged the audience with topics such as epilepsy surgery, medicinal cannabis, managing the impact of epilepsy and directions for future research in epilepsy. We appreciated our MCs Kos Sclavos and David Bunker who kept the day's program on track.

Professor David Reutens, Director of Epilepsy Services at the RBWH and the Director of the Centre for Advanced Imaging, discussed the multidisciplinary process by which neurologists and neurosurgeons determine candidates for epilepsy surgery, while Dr Lindy Jeffree (Neurosurgeon RBWH) demystified the procedure of epilepsy surgery itself. Dr Jeffree showed some wonderful, real images of brain surgeries which were fascinating! Another perspective followed, with a moving account from Joshua Marks, a young man who underwent focal epilepsy surgery after discovering he had epilepsy in his late twenties. Rounding off the morning session, Kate Thompson (Advanced Clinical Neuropsychologist) and Angela Spencer (CNC - RBWH) spoke about pre and post epilepsy surgery support. Yvette McMurtrie (project manager RBWH) gave us an insight on the new Comprehensive Epilepsy Centre at the RBWH.

Medicinal Cannabis was the hot topic after morning tea. Anastasia Suraev & Jordyn Stuart, research associates from The Lambert Initiative, The University of Sydney kicked off an educational and entertaining session on unlocking the therapeutic potential of cannabinoids,

with a focus on what we already know, what we still need to learn & the research that is currently or soon to be underway, as well as outlining the process for accessing medicinal cannabis under the new Queensland laws. Details of The Pelican Study & how you can be involved can be found below. Professor Reutens and Kimberley Irwin shared details on the Royal Brisbane Women's Hospital's participation in the topical medicinal cannabis trial in focal epilepsy. Dr Geoff Wallace (Lady Cilento Children's Hospital, Director of Paediatric Neurosciences) talked about their Epidiolex trial in children with Dravet syndrome, which is due to start in 2017. It was clear that this is an emerging area in terms of epilepsy research, that holds much hope for future treatment.

'Managing the impact of epilepsy' was a relevant and popular session also. Dr Paul Pun (neuropsychiatrist at the Statewide Epilepsy Network at the RBWH) addressed four different perspectives about the link between epilepsy and mood. Dr Pun gave us a better understanding of the complex link between epilepsy and mood/anxiety disorders and the treatment of anxiety and depression in the setting of epilepsy.

Dr Cecilie Lander adeptly managed to bridge the challenging gap between seizure control and enjoying life. Dr Sandra Petty specifically focussed on Epilepsy and bone health, an important topic that sometimes gets missed in the care of people with epilepsy. She also discussed her research which thus far has highlighted the need for baseline bone mineral densitometry tests for those on AEDs, with regular checks in this area plus supplements if necessary. Dr Karin Borges (researcher from UQ) enlightened us with her wonderful research on triheptanoin oil and its usefulness in seizure management. Karin's long term goal is to find new

treatments for epilepsy and other neurological disorders.

Dr Dan McLaughlin, one of our frequent speakers superbly engrossed our audience until the last bell with his talk on 'Epilepsy in the life of men'. Some of the causes of reduced libido for men were the exposure to antiepileptic drugs (AEDs), changes in the brain due to seizures and possibly some psychological factors. He also spoke about how we might improve this problem, perhaps by a change of drug therapy, assessing testosterone levels, counselling and of course informing the treating doctor.

We look forward to another stimulating symposium in 2017.



● Dr Lindy Jeffree



● Kimberley Irwin



## Getting NDIS Ready – Planning

**NDIS is now up & running in the Townsville region, with expansion across the state underway. The following is the scheduled Queensland rollout plan:**

### **Between July 2016 to June 2017:**

- Townsville, Hinchinbrook, Burdekin, west to Mount Isa, and up to the gulf
- Mackay, Isaac and Whitsundays
- Toowoomba and west to the borders

### **Between July 2017 to June 2018:**

- Ipswich, Lockyer, Scenic Rim and Somerset
- Bundaberg
- Rockhampton, Gladstone and west to the borders

### **Between July 2018 to June 2019:**

- Logan and Redlands
- Cairns, Cassowary Coast, Tablelands, Croydon, Etheridge, Cape York and Torres Strait
- Brisbane suburbs north of Brisbane River
- Brisbane suburbs south of Brisbane River
- Fraser Coast, North Burnett, South Burnett and Cherbourg
- Gold Coast and Hinterland
- Moreton Bay including Strathpine and Caboolture
- Sunshine Coast, Noosa and Gympie

Whilst the rollout may still be sometime off in your region, early planning is said to be the key to getting the most out of the NDIS. So what can you do to get ready today?

### **ATTEND AN NDIS WORKSHOP**

Throughout the year we will be promoting workshops held in conjunction with Spark Neurocare and other partners in areas prior to roll-out. For more information follow Epilepsy Queensland on Facebook for upcoming events. The next workshop will be for anyone living in the Ipswich region.

#### **Springfield**

24 February 5:30 - 7:30 pm Springfield Lakes Community Centre, 63 Springfield Lakes Boulevard, Springfield Lakes

Phone MS Queensland on 1800 177 591 to book.

### **Check your eligibility by visiting the NDIS website:**

<https://www.ndis.gov.au/ndis-access-checklist>

### **START PLANNING**

The NDIS aims to provide participants with “reasonable” & “necessary” supports to improve day to day living & to achieve short & long term goals. For some people living with epilepsy, the NDIS may be your first time accessing

formal funded support & it may be overwhelming to know where to start. So we have put together a list of things to help get you started:

### **ASK QUESTIONS & RESEARCH**

There are heaps of resources available to help you navigate the NDIS. Whilst the NDIS website is great, the Epilepsy Queensland Facebook page also provides up to date information & dates for workshops happening across the state. If you still have questions or would like to talk specifically about developing your plan, Epilepsy Queensland staff can talk with you directly. This allows you to draw on our epilepsy specific knowledge & expertise to ensure you get the most out of your plan. Epilepsy Queensland will be a provider under NDIS and can assist with your epilepsy related needs.

### **BE CREATIVE**

The NDIS is an opportunity to be creative & think big! What are your dreams & aspirations, what barriers do you currently face that stop you from achieving these dreams? We’ve



put together some examples of goals & the funded supports that may help to achieve these goals. Whilst this list is not exhaustive, we hope that it will spark some ideas:

### Children living with epilepsy

- Goal:** To access therapies to support developmental delays & to help manage behaviours.
- Supports:** Speech Therapy, Occupational Therapy & Psychology
- Goal:** To attend school/social /sporting activities independently
- Supports:** Development of an Epilepsy Management Plan & Emergency Management Plan
- Understanding Epilepsy & Midazolam training for teachers, support workers, coaches, scout leaders, youth group leaders etc.
- Goal:** To attend sleep overs with friends & family
- Supports:** Understanding Epilepsy & Midazolam training for friends & family
- Goal:** To sleep independently & safely
- Supports:** Epilepsy Monitoring Equipment
- Goal:** To be able to play in the playground safely
- Supports:** Assistive devices eg. - Head gear, cooling vests etc\

### Adults living with epilepsy

- Goal:** To get a job
- Supports:** Job-readiness training
- Development of an Epilepsy Management Plan & Emergency Management Plan employer/ workplaces

- Goal:** To live independently
- Supports:** Epilepsy monitoring Devices eg. Falls detectors, emergency alert buttons
- Goal:** To be able to access social activities or to try a new hobby
- Supports:** Transport allowance
- Understanding Epilepsy & Midazolam training for support workers, friends & family, local club etc
- Goal:** To improve health & wellbeing
- Supports:** Access to a supervised exercise program
- Dietician

### KEEP A DIARY

Keep a diary of ideas as they come to you & examples of specific barriers that you face as they happen. This will help you to identify specific needs & help in formulating a plan to overcome.

### FOR MORE INFORMATION:

Epilepsy Queensland:  
Ph: (07) 3435 5000 or 1300 852 853  
(outside Brisbane)

Or visit the Epilepsy Queensland  
Facebook page

Spark Neurocare:  
[www.neurocarenetwork.com.au](http://www.neurocarenetwork.com.au)  
[www.ndis.gov.au](http://www.ndis.gov.au)  
[www.everyaustraliancounts.com.au](http://www.everyaustraliancounts.com.au)



# Epilepsy

## Talk About It

**Epilepsy Queensland can help with your questions and concerns about epilepsy**

- Information
- Support and counselling
- Inservice training
- Community awareness and education
- Advocacy



epilepsy  
queensland inc

**Visit**

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

**or call**

**1300 852 853**

## My recovery inspired by Wally Lewis



For anyone who has lived with the impact of epilepsy on their life or a family member's life, the wish is often to find a cure or an end to seizures. When John Manuel read Wally Lewis' book, 'Out of the Shadows', he thought, "This is me" and it started him on the path to surgery. The impact of our patron Wally Lewis publicly speaking about his battle with epilepsy and the surgery that gave him back his life can't be underestimated. John is one of many people that we hear from each week to be impacted by 'the King'.

While there are no guarantees when it comes to epilepsy surgery, the aim is to improve your quality of life. John could not be happier with the results. He has been seizure free for the last four years and feels like it saved his life.

John was first touched by epilepsy as a toddler. He began having tonic clonic seizures when he was just four years old. His primary school years were deeply affected with frequent seizures and a lack of understanding from other students and teachers. It compromised his learning and his ability to form friendships.

As his primary school days came to a close John and his family were relieved when his seizures stopped. His life was back to normal and they hoped that epilepsy was behind him. John had

always been handy and good with his hands so when he finished school, he got into carpentry. Life was good, until John reached his twenties and unfortunately the seizures were back.

"Man I'd get this horrible feeling; it was like confusions in my head. Coming all the time. It was the epilepsy on its way back. I'd just sit there and stare." John related. This time they were absence seizures and they were frequent.

John trialed a number of different medications and nothing helped. He was not responding to any treatments and the frustration was building. I remember I was on my way to the neurologist and I said to him "I've just had four seizures on the train. Nothing is working."

For many years John struggled with epilepsy. He hid the true impact even from his closest family members. He had a number of minor car accidents and now realizes that he was lucky not to cause any harm. John also had a number of accidents on the job and eventually he could no longer work. For John it got to the point where everything seemed hopeless. He was a proud man and didn't like depending on others. With the confusion caused by his seizures, John didn't feel comfortable socializing with others. At his darkest point John considered ending it all. He didn't share this with anyone.

One of John's biggest supporters was his sister, Koka. It was staying with her that helped John get back on track. As a librarian she has always believed in gaining as much knowledge as possible through books and the internet. When Wally's book 'Out of the Shadows' came into the library she read it cover to cover. Koka let us know. "It gave me a greater understanding of what John was going through and why he sometimes behaved as he did. I have always tried to support John but to gain that insight was so important. What Wally was describing rung so true for John. I told him 'You have to read this!'

She continued: "That's where it all began, the start of getting John back. Don't get me wrong it was a long journey from there to surgery. John had only ever seen GPs before so it was a matter of seeing a neurologist. They told me he couldn't get the surgery at the Austin because he was out of work and didn't have health insurance. This was in 2011 and at the time the Austin were at the forefront of this surgery."

There was the option of having surgery in Brisbane, but John wasn't sure. So he went into the office at Epilepsy Queensland to try and speak to someone who had already had the surgery.

John explained: "They connected me with Dale. We talked about his



experience which cemented in my mind the fact that it was the right thing to do and where I wanted to go. He told me all I needed was a referral to get started. So I went back to the neurologist and that's what I asked for."

Koka continued to advocate for her brother: "I started to have contact with epilepsy specialists on email and he arranged for John to go down to Melbourne for two weeks for the testing. That's when they discovered that they could do something. Another brother flew over from New Zealand and it was within the first couple of days that he had the seizures and it gave them all of the information they needed. Then they put together a letter and proposal and said they would like to go ahead with the operation."

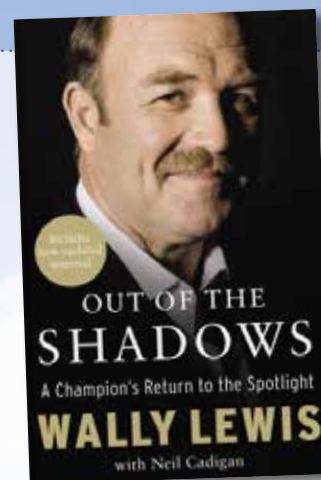
John talks about the lead-up to the operation. "I was not nervous. I just wanted to get it out. The book gave me comfort and before I had the surgery I went along to an event where Wally was speaking and we got to have a chat about it."

To everyone's surprise John felt no pain. It was an incredible recovery. These days he still gets the feeling like he did when the seizures were about to come on. But it goes away as soon as it arrives and nothing happens.

John feels like the results could not be better. "Everything is back to normal. I am able to hold down a full time job. Prior to the operation speaking was a major problem, but there are no more problems now."

"I went back to New Zealand after the operation and everyone was saying it was like I was finally back. I was like my old self again. I was smiling and happy and they hadn't seen that for years."

Now John wants to help others who are struggling with their epilepsy and don't know what to do. "People need to know what is out there and the possibilities. Go out and find it. Keep going till you get an answer. Get in contact with others and find out as much information as you can."



### **"Out of the Shadows"**

personally signed by Wally Lewis is available for purchase on the Epilepsy Queensland online store: [www.epilepsyqueensland.com.au/shop](http://www.epilepsyqueensland.com.au/shop) or from your local library. To speak to counsellors or nurses in our services team or to connect with others living with epilepsy phone 07 3435 5000 or 1300 852 853 (outside Brisbane). You can also find information about support groups on the back page of 'Flame'.



Epilepsy surgery is available for suitable patients in Brisbane through Royal Brisbane and Women's Hospital Comprehensive Epilepsy Surgical Program, the Mater Centre for Neurosciences and Lady Cilento Children's Hospital. Talk to your neurologist if you are wondering if you might be a candidate or contact our services team on 07 3435 5000 or 1300 852 853 to discuss.



**Purple Day** 26 March  
**for epilepsy** QLD

To find out how **YOU**  
can get involved call **1300 852 853**  
or register at **www.epilepsyqueensland.com.au**

**Join us**  
to raise funds  
and awareness during  
March

Supporting Epilepsy  
Purple Day - World's Most  
Around The World

epilepsy  
queensland inc

A photograph of a young girl in a purple dress and a man in a suit standing together.

### Get involved in **Purple Day** for epilepsy to support epilepsy awareness worldwide!

In 2008 a nine-year-old from Canada, Cassidy Megan created Purple Day to get people talking about epilepsy and to let people who are living with epilepsy know that they are not alone. In 2017 the lack of public awareness and stigma associated with epilepsy are still very real.

During March we need your support for our **Go Purple Campaign** to help bring epilepsy out of the shadows and raise funds for vital services. Your valued fundraising efforts will assist the 94,000 Queensland children and adults with epilepsy to live without fear and prejudice, while you spread awareness of the world's most common serious brain disorder.

How can you get involved to **GO PURPLE**?

Whether it is at home or work, with your local school, pharmacy or in your community, there are so many ways you can raise funds and awareness for **Purple Day**. Visit [www.epilepsyqueensland.com.au/purple-day](http://www.epilepsyqueensland.com.au/purple-day) for more information, to register today and **GO PURPLE**!

- Wear **purple** on 26 March and share your pictures on Facebook or Twitter with #PurpleDay
- **Host a Purple awareness/fundraising party/event/activity** and go in the draw for lots of great prizes! Can be as simple as a morning tea at work, BBQ with friends or challenge yourself and get your friends to sponsor you for a walk, run or colouring your hair purple! There is so much you can do to raise awareness, a few dollars and have fun at the same time
- **Become a Purple Day Hero** with your very own online **Purple Day** fundraising page. Please go to [www.epilepsyqueensland.com.au/purple-hero](http://www.epilepsyqueensland.com.au/purple-hero)
- **Buy or sell Purple Day Merchandise** – including our cute new Purple Lamb! Order the enclosed flyer or purchase online: [www.epilepsyqueensland.com.au/shop](http://www.epilepsyqueensland.com.au/shop)
- **Make a tax deductible donation** to Epilepsy Queensland.
- **Sign up** for the **Purple Pledge Project**
- **Order a Purple Day t-shirt!**

### CONTACT US NOW!

For further information about **Purple Day** and how you can get involved please contact our Fundraising Team on

**07 3435 5000** or email [purple@epilepsyqueensland.com.au](mailto:purple@epilepsyqueensland.com.au)

using







Look out for our banner flying proudly on Brisbane's Story Bridge from 20 to 26 March and also watch Brisbane's skyline turn purple on Sunday 26 March with the following landmarks shining a light on epilepsy – Brisbane Story Bridge, Brisbane City Hall, and for the first time the Wall of Water at Roma Street Parklands.

## Good Guys Doing Good



Epilepsy Queensland was thrilled to be a recipient of the 2016 Doing Good Week from our wonderful partners at The Good Guys Lutwyche. The award is in recognition of the work of our Patron, Wally Lewis, helping to bring epilepsy out of the shadows. Our mascot Little Poss was excited to meet staff and customers at the Lutwyche store.

The Good Guys have supported Epilepsy Queensland for the past eight years through the Local Giving Program. You can help support Epilepsy Queensland by placing your Local Giving token in the Epilepsy Queensland box when you make a purchase at the Lutwyche store. The Good Guys at Lutwyche have also assisted with fundraising barbecues and a number of in-kind gifts to support local children and adults living with epilepsy





● Wally Lewis and Peter Rookas

## Toowoomba Epilepsy Charity Golf Day

For Epilepsy Queensland supporter Peter Meyer, brain surgery and golf changed his life. It was the surgery that has meant that he has now been seizure free for 3 ½ years, but it was golf that helped him avoid post-surgery depression and get his life back.

Now Peter is a passionate advocate for epilepsy, hosting the second annual Toowoomba Epilepsy Charity Golf Day at Middle Ridge Golf Club along with wife, Susan. The event is now a highlight of the Toowoomba golfing calendar with a host of sporting heroes sharing their stories and teeing off with local supporters.

Brian Lara widely acknowledged as one of the best cricketers of all time, took to the greens along with former Australian Cricketer Greg Ritchie who was a junior member at Middle Ridge Golf. They were joined by Rugby League legend and Epilepsy Queensland patron Wally Lewis.

As the golf wound up and the 100 golfers made their way to the 19th hole, the charity auction got underway. A variety of sporting memorabilia, and experiences including some genuinely 'one-of-a-kind' items such as a 1948 team sheet signed by Don Bradman, Captains Lounge Tickets donated by The Melbourne Storm with flights to Melbourne donated by Airnorth, Southcares Experience, donated by the Sydney Rabbitohs including an opportunity to meet the players and a Brian Lara and Sir Garfield Sobers signed bat.

Susan Meyer said "Without our sponsors who continue to support us each year, this day would not be possible. We would like to thank Darren Simmons of Acer computers Australia for his continued support and generosity, Chris Sheath and Associates Solicitor's, Tilly Crawler parts and Horizon Accounting to name just a few."

The day was not just a fantastic experience for all who attended, but also a very important fundraiser for Epilepsy Queensland. We are extremely grateful to Peter and Susan Meyer and their supporters for raising \$60,000 to support vital epilepsy services in regional Queensland.

If you would like to host your own event for Epilepsy Queensland or volunteer your time or a prize for one of our current events, please contact Leigh Gilbert on 07 3435 5000 or 1300 852 853 (outside Brisbane).



● Paul and Gabby Hanlon with Jason Smith



# Our Annual Celebration & AGM

The Epilepsy Queensland Annual Celebration and AGM is always a highlight on our events calendar. It is an opportunity to celebrate our achievements and outcomes for people living with epilepsy and also to recognize those people in the community who have made a difference through the Epilepsy Queensland awards. Emily Prain from Channel 9 was a wonderful MC for the event held on Monday 5 December 2016 at the Queensland Cricketer's Club.

We were pleased to have two speakers who shared their connection to Epilepsy Queensland and their appreciation of our services. Firstly, Michelle King revealed her experience as a parent and carer of Daelle, who is a high needs disabled young adult with uncontrolled epilepsy. Michelle talked about the journey that she and her family have had with epilepsy, the complications and the small victories. The wonderful pictures and stories she told brought tears and smiles to many attendees faces.

It was also a pleasure to hear from Michael Walsh, Director-General of the Department of Health. For many years Epilepsy Queensland has been the recipient of vital funding from the Department of Health. Director-General Walsh spoke about the importance of not for profit organisations in the delivery of services and support of people living with epilepsy and other chronic conditions. He shared his personal connection to epilepsy with his grandson living with the condition and reiterated the support of the Department of Health. He also gave information about the medicinal cannabis trials at the Lady Cilento Hospital and about the cooperation between

federal and state governments to enable access to medicinal cannabis.

For the formal part of the evening, Chairman Steve Eltis presented his report and paid tribute to longstanding Board members Louise Foley and Noel Johns who stepped down. He also acknowledged staff member Jenny Ritchie for her ten years of service to the organisation and the contribution of CEO Helen Whitehead over the year who was not able to be present due to an ongoing illness.

The newly elected Board for 2017 is:

<b>Chairman</b>	Steve Eltis
<b>Deputy Chairman</b>	Elsewerth Ephraums
<b>Secretary</b>	Andrew Barnes
<b>Treasurer</b>	Jane Vidler
<b>Board members</b>	Charmaine Driver David Bunker Kim Davis Kos Sclavos Vivienne Johnson

A copy of our Annual Report can be found on our website. If you would like a paper copy of the report or our financial statements, please contact our office on 07 3435 5000.

## Award winners are:

**'Fair Go' Memorial Award** – Grant Barrie is a Branch manager for Pickles Auctions (Archerfield) and the direct supervisor of Jason, who has epilepsy. Grant has consistently provided avenues for Jason to feel safe in his workplace, following his recent epilepsy diagnosis. Grant organised a workplace visit and has liaised with the

EQI team and Jason to develop a workable Management plan. He continually encourages Jason's care through medication management, keeping a seizure diary and making healthy lifestyle choices. He understands that Jason wants to return to full time employment and former duties and is working with him to realize his potential.

**'Pam Wellings' Memorial Award** – Epilepsy Queensland has been privileged to be one of The Good Guys – at Lutwyche, cause partners. Alf Said and his wonderful team have been supporting Epilepsy Queensland for the past seven years. With quarterly donations from the 'Good Guys Doing Good' tokens collected in store, selling Little Poss and Purple Day merchandise and donating a number of items to local people with epilepsy and Epilepsy Queensland – they certainly have done good!

**Youth Award** – Paisley McLeod is a special person in the eyes of her family. They are very proud of her continued efforts, resilience and overall care of her brother Noah, and also for her drive to raise epilepsy awareness & support and care for others like Noah. Paisley has promoted Purple Day and Little Poss Appeal at her school – she was particularly thrilled when Kelvin Grove College came on board this year. Like most siblings Paisley is proud of her brother and proud to be out and about in the public raising awareness. Paisley is always explaining to people she meets about Noah's epilepsy. This little person makes a huge difference, not only in her brother's life, but the epilepsy community itself.



● Wally, Emily Prain & Steve Eltis



● Michelle King presentation



# Our Annual Celebration & AGM *cont...*

## **Carer Award –**

Alana Lundin and Leigh Blackman

1. Alana Lundin is a quietly spoken woman whose dedication to her son's wellbeing and education is evidenced by her selfless attention to his safety and needs. She has networked and advocated for him to be enrolled in a specialist school where his achievements can be maximized whilst his frequent seizures are addressed. Her partnership alongside medical specialists is exemplary. Alana is always available for her boy, as well as putting her career on hold for him. She's a testament to the good that comes from the power and focus of a special needs mother.

2. Leigh Blackman is an absolutely devoted mother to Gabby who, because of Aicardi Syndrome and other medical conditions, has uncontrolled seizures. Leigh tirelessly searches for options to assist Gabby, ensuring interventions such as ketogenic diet, medication, physiotherapy is rigorously implemented. She has adjusted her work responsibilities, putting her sole parenting of Gabby and her sister first. Leigh is resilient, smiles all the time and always takes time to support other families as well as the school. Leigh is a role model of quality parenting and optimism.

**Role Model Award** – Elizabeth Kelly is a someone her Mum thinks is a great role model for others with epilepsy. She has 'survived 2 frontal lobe surgeries', plus all the testing that goes along with that, she has suffered awful discrimination in the workplace, often receiving little or no acceptance, yet she has managed the courage to pick herself up and move on.

She has lived independently for years and is an example for others in similar situations.

**Doris Kemp Memorial Award** - Tristan Francis is a young man who spent his 13-week placement as part of his Bachelor of Health Science degree with us. It was time well spent as he did some great research into epilepsy and children's programs and gathered stakeholder feedback and analysis. With this wonderful information we will be able to reshape our children's program with updated resources. We were so impressed with this quiet young person, as we watched him tackle new challenges.

**Allied Health Award** - Sandra Gurr is an Advanced Neurophysiology Scientist at the Lady Cilento Children's Hospital where she spends her days reviewing the squiggly lines of brainwaves, performing PET and SPECT procedures for surgery work ups and playing games and singing silly songs with children! She is an expert at dodging and weaving with electrodes and leads and capturing seizures, and she is a favourite with kids, parents and staff. She was nominated by a top paediatric neurologist who informed us that Sandra is world-class and that the Lady Cilento has the best EEG team in the country!

**Disability Award** – Jenelle Whittaker from Mackay District Special School was nominated because she goes the extra mile. She is calm, and kind, and her very efficient management of seizures at her school is inspirational. "She looks after the child concerned, their classmates, her co-workers, and their families and she teaches us all by her example. She goes above and beyond."

**Education Award** – Jane Hindmarsh

from Townsville Community Learning Centre has been a pivotal person in providing support to remotely located students, their families and schools. Jane worked tirelessly and with passion to set up a regular 'fly in fly out' service from Townsville to schools in and around Mount Isa and Mornington Island. Many of these families are indigenous which brings extra complexities and an extra need for good networking. Many hours of prep go into these visits to ensure all goes as smoothly as possible. Jane often works in her hotel room at night to complete tasks and prepare for the next day. When Jane leaves the school, they all have individual and Emergency Health Plans organised, the staff are trained in the safe management of complex epilepsy and seizures, they have access to resources, tools and advice through Jane and the team via phone, I/Connect as well as visits.

**Health Award** – Dr Sasha Dionisio was nominated because: "He is the most caring neurologist that I've ever dealt with. He has helped my daughter with her epilepsy when no other doctor could. He has given her hope. He treats his patients with respect and care, this also includes their families. He will not stop until he gets answers for the patient. He has been our saviour, we are in debt to him for helping our daughter, Sasha is very deserving of this award."

**Congratulations to all of the award recipients for the inspiration you provide to your local communities and to others living with or caring for someone with epilepsy.**



● Award winners and nominees



● Good Guys and their award

## 30 minutes with

### Allied Health Award Winner... Sandra Gurr

**What is the exact title of your role?** Advanced Neurophysiology Scientist, Lady Cilento Children's Hospital (LCCH).

**How long have you been working in the neurosciences department in LCCH and Royal Children's Hospital Brisbane?** I joined the team at RCH in 2004 and transferred to LCCH when we moved in December 2014.

**Many families would know you from the time you spend attaching little electrodes on scalps for electroencephalographs (EEG's). What other roles do you perform in your job?** I work in the Epilepsy Monitoring Unit (EMU) where we mainly look after inpatients having long term EEG monitoring, usually with the aim to capture events. If a patient is a potential surgical candidate, we perform a range of tests. SPECTs can be challenging as it involves injecting a small dose of radiation during an actual seizure. If patients proceed to surgery here at LCCH we go into theatre and perform intra-operative monitoring which helps the doctors tailor the surgical approach.

**I am sure you have seen a great deal of change in Children's Health services. How has the field of neurosciences developed since you first started working?** Here's where you'll find out how old I am... I'm from the era when we used to do our EEGs on old pen and ink machines which would produce reams and reams of paper. We'd have to fill the inkwells in the mornings and sit and scribble on the EEG to mark all annotations... and learn to dodge flying ink when you had a particularly active patient or sudden seizure activity! With the digitalisation of EEGs we have been able to co-record video and have the ability to manipulate the data, apply filters and change settings as required. This has proved invaluable for more accurate reviewing and reporting purposes. Digitalisation has also meant we can perform long term EEGs which allows us to capture actual seizures which helps with diagnosis and treatment.

**Where else have you worked in your life?** I started my Neurophysiology training at the RBWH where I worked for several years. After that I worked for quite a few years at a very busy private practice in Orange NSW. I then took up a position as a senior scientist in Riyadh, Saudi Arabia for several more years. I

met my husband in Saudi and subsequently lived for short periods in several other Middle Eastern countries. We were eventually transferred to Belgium where we lived for more than 5 years. There I worked for the European Organisation for the Research and Treatment of Cancer (EORTC) where I helped to co-ordinate clinical pharmaceutical trials across Europe. I had my children in Belgium but returned to Australia in 2000. I worked at the Greenslopes Private Hospital performing overnight sleep studies for some years before easing my way back into Neurophysiology at RCH in 2004.

**What do you love about your job?** I love working in paediatrics and can't imagine ever going back to the world of adults. In paediatrics we get to have fun, play games and sing silly songs with our patients. I can get a great sense of achievement even with something as simple as finally getting a full set of electrodes on a challenging two-year-old. In the long term monitoring unit, I get to interact with both the patient and with their family over an extended period. We really get to know our families, particularly those that are on the surgical work-up path as that often involves multiple admissions. It is wonderful to be able to share the journey with these families. I am privileged to work with a wonderful team of dedicated doctors and scientists.

**Where would you most like to travel?** I travelled a lot in my younger years and have seen quite a lot of the world. My retirement plan is to do Canada and Alaska which has long been on my bucket list.

**What is your favourite food?** Italian and pasta and Italian and more pasta.... Yum ☺

**Describe your most embarrassing moment?** When working in Europe I met a very distinguished visiting professor/physician. As he introduced himself he mentioned he was from Sweden. I replied, "Oh Sweden..." and automatically launched into my very best impression of the Swedish chef from the Muppets. His stunned expression registered before I realised what I was doing. What can you say after something like that??? I imagine I presented a memorable (though not exactly professional) first impression.

**What is your favourite book/author?** I've had a few favourites over the years but my



latest craze is for David Baldacci. He's about the only author these days that I must buy the week of a new release.

**Who is the most famous person you have ever met? Who would you like to meet?** I apparently don't get out much. I can't think of any famous people I have actually met. I've seen a few famous people visit the ward but generally don't get to speak to them personally. Chris Hemsworth visited the ward recently but I sadly missed his visit. I probably would have swooned at his feet if I had met him personally and would have taken much delight in endlessly bragging about it to my teenage daughters.

**What genres of music do you like listening to/favourite song?** I have two daughters in their late teens so I sadly lost control of the music selection in both my house and car at about the time we started enjoying the likes of "The wheels on the bus", Hi5 and other such "favourites". My music taste has probably evolved with them and so I listen to whatever they like to play. I did however go to a 70's/80's revival concert recently and felt most sentimental when the old Jimmy Barnes and Cold Chisel songs were played. I was pretty chuffed I could still remember all the words!

**Do you have any interesting hobbies you would like to tell us?** I tend to work long hours so don't have much time for hobbies unless you count washing, ironing and generally playing Mum's Taxi. I took a course in mosaics a couple of years ago in an attempt to release some creative juices but haven't done any for a while now. I tinker with the idea of taking up painting someday.

**What do you feel would greatly improve the care of epilepsy currently in Queensland?** More funding for staff in Queensland Health!! Our Neurologists work exceptionally long hours. I am sure it's the same across many hospitals. We need more Neurologists, Fellows and Neurophysiology staff.

# Epilepsy Queensland's Understanding Epilepsy and Administration of Midazolam training

*Epilepsy Queensland proudly conducts monthly in-house Understanding Epilepsy and Administration of Midazolam workshops at our Woolloongabba office and bi-monthly at the Gold Coast. Did you also know that we frequently deliver these training sessions to a range of different organisations, schools, kindergartens and child care centres around Queensland and northern NSW?*

## Come along...

...to our in-house Understanding epilepsy and Administration of Midazolam training at Woolloongabba or the Gold Coast. In 2017 we will also be offering three after -hours in-house sessions.

These workshops cover -

- seizure first aid
- known causes of epilepsy
- recognition of seizure triggers
- current treatments for epilepsy
- administration of midazolam

Download a flyer from our website

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

or call to register. We would love to see your family, friends and colleagues there or come along to meet new people.

## Hint!

Schools love our 1.5-hour Seizure recognition, first aid and Administration of Midazolam training.

Encourage your school to get in quick as training dates for early 2017 are booking out fast!

## What we offer...

Understanding Epilepsy  
Administration of Midazolam  
Epilepsy awareness  
(tailored to individual needs)  
Length – 1.5 hours to 4 hours

## How to organise an education session

It's easy! Simply download a 'training request' form from our website ([www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au)) or call us on 07 3435 5000 or 1300 852 853 (toll free) to discuss a training package and a suitable date and time.

## Need after hours training?

No problem! Contact us to arrange a training package to suit your needs.

Please note, after hours training incurs a 25% surcharge.

## Testimonials

'Trish was an excellent and knowledgeable presenter. She listened to all questions and addressed our concerns kindly and professionally. I now feel confident to administer Midazolam if my daughter has a prolonged seizure.'

'Jenny travelled two hours to train my staff in Epilepsy awareness. The session was engaging and interesting. Our clients will be much better supported. I will be recommending this training to others.'



## diary dates

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

25 February 26 March	Purple Ball and Art Union Draw Purple Day
6 February (9.30am + 5.30pm) 16 March 13 April 18 May (9.30am + 5.30pm) 15 June 20 July 17 August 14 September (9.30am + 5.30pm) 19 October 16 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
March 15 May 17 July 19 September 13 November 15	<b>Understanding Epilepsy Workshops (Gold Coast)</b> For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
March 4 June 3 November 4	<b>Brisbane Adult Support Group Meeting</b> - Also Informally 1st Saturday of each month
Feb 10 May 5 Sept 1	<b>Carer Support group – Friday at Bracken Ridge Library 10.30am</b>
March 23 June 8 October 12	<b>Carer Support Group – Thursday at Bulimba Library 10.30am</b>

### Brisbane Adult Support Group

On the first Saturday of each month the Adult Support Group hold an informal gathering at the Coffee Club Brisbane Square, 244 George Street, Brisbane City at 1pm. It's a fun social get together to which everyone is very welcome.

The Adult Support Group also meets more formally at the Brisbane Community Library in the Community Meeting Room, 266 George Street Brisbane.

The dates for this year's meetings are as follows:

Saturday 4 March, 3 June and 4 November from 1 – 4pm.

For more information, please contact:

Rosemary Borg on 0400 141 393 or stressed\_mum@hotmail.com

or

Robin Green E: robin\_green79@yahoo.com.au

Cassandra D'Arcy: cassie\_babe@bigpond.com or 0429 163 550



po box 1457, coorparoo bc qld 4151  
phone 07 3435 5000 1300 852 853 (outside brisbane)  
fax 07 3435 5025  
email [epilepsy@epilepsyqueensland.com.au](mailto:epilepsy@epilepsyqueensland.com.au)  
[www.epilepsyqueensland.com.au](http://www.epilepsyqueensland.com.au)  
ABN 42 025 269 961

Opinions expressed in this publication are not necessarily those of Epilepsy Queensland. Questions and concerns about your condition, its treatment and management should be directed to your doctor.

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epilepsy  
queensland | inc

# Purple Ball

*bringing epilepsy out of the shadows*

Saturday 25 February 2017, 6:30 pm  
Victoria Park Golf Complex, Herston

You are invited to join us for an exciting night of  
unforgettable entertainment and help support  
children and adults living with epilepsy

TABLE OF 12

**\$2,400**

INC. GST

TICKET

**\$209**

INC. GST

Tickets include a three course dinner and premium beverages

**Book online now!**

For bookings, sponsorship opportunities and further information

Please contact Epilepsy Queensland

E [purple@epilepsyqueensland.com.au](mailto:purple@epilepsyqueensland.com.au) | T 07 3435 5000

**[www.epilepsyqueensland.com.au/purple-ball](http://www.epilepsyqueensland.com.au/purple-ball)**