



the flame

Issue 1 – 2016

the newsletter of epilepsy queensland inc

BMW ART UNION RAFFLE



*Patron Wally Lewis with
Deputy Chair of Epilepsy Queensland Elsewerth Ephraums
& Martin Roller of Brisbane BMW*

inside...

Annual
Celebration
& AGM



Book
Launch



2015
Charity
Golf Day



BMW Art Union Launch

Wally Lewis, Epilepsy Queensland's Patron and rugby league icon, returned to the home of rugby league in December last year to launch our 2016 Limited Edition #2 BMW Art Union.

Despite the searing heat bearing down on Suncorp Stadium's forecourt the ever professional Wally stood by as the new BMW 1 Series 5-door Sports Hatch took centre stage for the photoshoot. And don't they look fantastic!

Martin Roller, Managing Director of Brisbane BMW was there to give a guided tour of the magnificent new BMW 118i to Wally and Elsewerth Ephraums, Deputy Chairman of Epilepsy Queensland, before the three relaxed a little tossing a football around.

We would like to thank Brisbane BMW and everyone who has bought a ticket in the Art Union for making a difference and helping people with epilepsy live a full life without fear or prejudice. The Art Union will be drawn at Epilepsy Queensland's Purple Ball on Saturday 5 March 2016.

Only 750 tickets are available. The odds are in your favour!! To purchase a ticket securely online, go to www.epilepsyqueensland.com.au/car Or complete one of our order forms. Just don't delay - get your tickets today.



contents

2.....art union launch

3..... MedAdvisor

4.....adherence article

5-6..... our annual celebration & AGM

7.....chairman's report to AGM,
memorial service

8-11events & fundraising

12-13..... thinking outside the box symposium

14 30 minutes with Dr Lata Vadlamudi

15 diary dates, ask an educator

16 help epilepsy queensland

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

Your pocket pharmacist: MedAdvisor to help people with epilepsy manage their medications



Epilepsy Queensland is working with Australian software developer, MedAdvisor, to bring a patient-focused medication management system to people with epilepsy.

With adherence to common epilepsy medication hovering at just 50-60%, people with epilepsy and their carers can benefit from this simple, user-friendly system of reminders and handy functions such as Tap-to-Refill.

According to MedAdvisor, there are approximately 8,000 people with epilepsy using the MedAdvisor app to manage their medications, and those that do are up to 20% more adherent to the doses prescribed by their doctors.

Ms Helen Whitehead, CEO of Epilepsy Queensland, said: "We believe the MedAdvisor app is an important innovation that will help make a measurable difference to health outcomes for people with epilepsy. The app will facilitate some tailored information which will help bring epilepsy out of the shadows, and we look forward to promoting it to our community."

Brisbane resident, Mrs Beverley Pearce, has been using the MedAdvisor app since March

2014 to help manage up to seven medications on a regular basis, including Lamotrigine for epilepsy. The Malouf Pharmacy at Kenmore Village holds all Mrs Pearce's prescriptions

Mrs Pearce commented: "I think this is an excellent app and I often recommend it to friends and others that I meet. It is so simple to put an order through and it saves a lot of time being able to call and collect medication from the Pharmacy without having to wait for it to be dispensed.

"We all lead such busy lives and it is a great to receive a reminder when your medication is due to be ordered. It also helps to be notified when you need to see your General Practitioner for a new script. The information provided which explains about each medication you are taking is very helpful.

"I'm working very hard on my husband to change him over to ordering his medication this way."

MedAdvisor's CEO, Mr Robert Read, said he is proud to be working with Epilepsy Queensland. "MedAdvisor is a fantastic tool for people with epilepsy or their carers to remember doses and manage medication.

MedAdvisor users also save time at the pharmacy by pre-ordering their meds."

More than 330 pharmacies across Queensland are MedAdvisor-enabled, and around 25,000 Queenslanders are currently using the app to manage personal or family prescription medications. For more information, please visit www.medadvisor.com.au or speak to your local pharmacist today.



● Beverley Pearce

HELPING EPILEPSY QUEENSLAND

There are many ways that you can help us to help people with epilepsy and their families.

- ☒ Buy your art union tickets to win the brand new BMW118i
- ☒ Volunteer to help at Epilepsy Queensland's events – Brisbane Broncos match, Roar Game, Purple Day activities
- ☒ Get involved in Purple Day – organize an event and buy/sell merchandise
- ☒ Tell us that you're available to tell your story to local media
- ☒ Be part of our organisational review – tell us about your needs and what services you'd like see us provide more of.
- ☒ Buy from our online store
- ☒ Renew your membership if you haven't already

Want to find out more? Email epilepsy@epilepsyqueensland.com.au or phone 073435 5000

Medication Adherence

Appropriate use of medication is a key component of current gold standard therapy to help people with epilepsy live seizure-free. In Australia, medication adherence in epilepsy is typically quite low, with just 60% of medication doses taken as prescribed.

During his presentation at Epilepsy Queensland's 2014 Taking Charge Symposium Eminent Ambassador for Epilepsy, Professor Martin Brodie, addressed the issue of adherence and its importance in seizure management.

Various methods of measuring drug adherence including direct questioning, patient calendars, counting pills, electronic bottle tops and serum drug levels can be used. There is a Morisky Medication Adherence Scale used for some research¹. However, Brodie's preferred method is to look the patient straight in the eye at the clinic and asking sweetly "How often do you forget to take your tablets?"

Professor Brodie stated that adherence decreases with the number of antiepileptic drugs and drug doses prescribed each day, and that even a once daily dosage does not result in perfect adherence².

In a study of 33,658 patients, non-adherence was associated with:

- Increased risk of mortality
- More emergency department visits
- More hospital admissions
- More motor vehicle accidents
- Greater likelihood of fractures

This study was from a retrospective open cohort design using Medicaid claims data³.

There are also economic consequences of non-adherence, making epilepsy care much more expensive:

- Poorer work performance
- Higher disability payments
- More emergency department visits
- More hospital admissions
- More antiepileptic drugs at higher doses^{4,5}

Interestingly, non-adherence is sometimes overconsumption.

Professor Brodie discussed why don't people with epilepsy take their treatment?⁶

- They don't think they have epilepsy
- They don't want to have epilepsy

- They don't like taking pills in principle
- They don't like the prescribed medication
- They don't understand the need for treatment
- The drug schedule is too complicated
- They are disorganized, unfocussed, forgetful

Epilepsy Queensland recognises the vital importance of medication adherence in managing seizures and to promote adherence, has partnered with MedAdvisor. We strongly encourage you to register at www.medadvisor.com.au/start or visit your nearest participating pharmacy.

We have an information sheet about MedAdvisor which you can take to your pharmacist and are happy to discuss issues about medication adherence with you.

¹Morisky PE, DiMatteo MR. J. Clin Epidemiology 2011;64:255-7

²Cramer et al. Epilepsy and Behaviour 2002; 3: 338-42

³Faught E et al. Neurology 2008; 71: 472-8

⁴Zachry WM et al Epilepsy & Behavior 2009; 16:268-73

⁵Ivanova JI et al Pharmacoeconomics 2010; 28:678-85.

⁶Carpentier N et al Epilepsia 2013; 54:e20-23.

FREE

**Medication List**
Automatic list of all your scripts

**Take-My-Meds**
Set alerts to remind you when to take your medication

**Tap-To-Refill**
Order medication in advance so they are ready to collect at the pharmacy

**Automatic Reminders**
Useful reminders to fill repeat scripts and see your doctor for new scripts

**Carer Mode**
Manage medication for your children, partner or elderly family members

 + 



Pharmacist Phil is here to help you manage your epilepsy medications!

Register at www.medadvisor.com.au/start OR visit your nearest participating pharmacy to get started today!

Our Annual Celebration & AGM

Ebony Cavallaro from Channel 9 was a wonderful MC for our Awards Presentation and Annual General Meeting held on Monday 30 November 2015 at the Queensland Cricketer's Club.

Chairman Steve Eltis presented his report and paid tribute to longstanding Board member Alan Davidson who has stepped down.

The newly elected Board for 2016 is:

Chairman	Steve Eltis
Deputy Chairman	Elsewerth Ephraums
Secretary	Andrew Barnes
Treasurer	Jane Vidler

Board members

Charmaine Driver	David Bunker
Kim Davis	Kos Sclavos
Louise Foley	Noel Johns
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.

Patron Wally Lewis joined Ebony for the presentation of the following Awards:

DISABILITY AWARD – Community Respite Options South Burnett - *"It's amazing how they relate, train their staff and become involved in the local community. They provide 24 hour respite to people with many disabilities and epilepsy. They are a fabulous and welcoming group and they are especially impressive because of the way they diligently provide epilepsy training for their staff."*

YOUTH AWARD - Lewis Spriggs has worked hard, educating over 1000 staff and students at his school, Ignatius Park College. Delivering speeches, power points about epilepsy and bringing it out of the shadows. A story about

Lewis was published in the newspaper. Lewis also fundraises for Epilepsy Queensland. For the third year in a row, Lewis is organising a purple day fundraiser with the support of his Year 12 cohort. Lewis, who was diagnosed at age 2, says *"my main goal is to just make sure everyone is not scared of people with seizures"*.

ROLE MODEL AWARD - Haidee Costello George is a hero to many people, especially her Mum! She has had seizures from birth, not getting a positive diagnosis until she was 7, in year 3 at school. By this time she was struggling with seizures causing constant interruptions to her learning and with teachers thinking her seizures were behavioural. However her seizures have never slowed her down, despite many accidents caused by them. Haidee went from a happy kid who loved school, to one who didn't want to go. Thankfully a GP referred Haidee to Dr Kate Riney, who changed her life.

Haidee has persevered through medication changes, along with awful side effects but has never complained; she would tell other kids "I can do anything you can do, except swim without Mum and Dad". She has never ever let her epilepsy hold her back in anyway and has always been open to explaining it to new friends, advocated awareness of her epilepsy, and always is very positive about her future.

Her mum says *"We are so proud of her, she is doing amazingly well. Haidee's seizures are well controlled currently with medication, she has become very good at understanding her triggers and adjusting her life accordingly. She manages her own medications, 'by being responsible'!"*

At 'School Presentation' night, she received a 'Vocational Excellence Award and Medal' for Tourism, as well as an 'Academic Merit Award' for excellent effort and behaviour across all subjects.

EDUCATION AWARD – Redlands College – the team from the Junior School lead by Janet Kohlmannuber; learning enrichment coordinator Anne Luthy; and Steve Lowther who takes care of behaviour management. There are also teacher aides, Beth Cooper, Sam Mangleson, Rachel Iedema, Kathryn Kerridge and Ruth Smith. This group all work well together to optimise educational outcomes through an effective collaborative approach to education, always considering epilepsy and its effect on cognition, behaviour and on mood!

DORIS KEMP MEMORIAL AWARD - Lindsey Navin was looking to begin a career within the field of communications and advocacy after completing her Master of Communications at Bond University when she came to Epilepsy Queensland for a semester of work experience followed by her final internship. Lindsey was a wonderful asset to the Fundraising and PR Team and during her time with Epilepsy Queensland developed a number of media strategies for the annual Purple Day/National Awareness Campaign.

'FAIR GO' MEMORIAL AWARD – Ostwald Brothers - Alex is 19 years of age and in his second year of a Diesel Fitting apprenticeship with Ostwald Brothers. During this time, Alex has suffered many seizures at work. The management and staff offer concern and care and have implemented procedures to protect Alex. Ostwald Brothers are a family run organisation with strong community values, and have certainly offered Alex a Fair Go!

PAM WELLINGS AWARD - Followmont Transport is Queensland's largest family-owned transport company with an excellent reputation for service and going the extra mile. Epilepsy Queensland has been extremely fortunate to have the support of Followmont

During the evening, Robyn Adolphs launched her new children's book "Lucy's First Disco" - a touching story about a young girl's first seizure and how her friends support her when she returns to school.

After a long career as a primary school teacher and living with epilepsy herself, Robin set out to write a children's book that would help those living with epilepsy and their school friends understand what it is all about. Robin has developed teacher resources, free activities, and downloads on her website www.robinadolphs.com to accompany the book and is generously donating a portion of her sales to Epilepsy Queensland.

If you would like to purchase a copy for your child and their school or daycare please contact us on 07 3435 5000 (regional Queensland phone 1300 852 853) or email pr@epilepsyqueensland.com.au or go to our shop at <http://www.epilepsyqueensland.com.au/shop>



Our Annual Celebration & AGM

for not just years, but verging on decades. They deliver the Little Poss Appeal and Purple Day Campaign merchandise boxes far and wide throughout Queensland, free of charge. Every badge, every ribbon, every pen and wristband gets to a supporter through the generosity of Followmont. Without their support our merchandise campaigns would certainly not be viable and we thank them sincerely for this incredible support.

CARER AWARD – Linda Powell has devoted herself since the early years of her son Jamie's life, when he was diagnosed with Dravet Syndrome. Giving up her professional careers, and then coming to Australia for her husband's work, meant that Linda had to make new friendships far away from her family. She provides exceptional care for Jamie who has many seizures daily, she diligently sees to his every need and does so with total selflessness. Linda continues to research options for Jamie, in partnership with his medical team, and has linked in with international experts in Melbourne and constructively shares her knowledge. Linda is always joyful and accepting whilst reciprocating appreciation of others. Linda is a role model for us as well.

HEALTH AWARD - Dr Kate Riney has been described as a brilliant paediatric neurologist. *"She works tirelessly to ensure accurate diagnosis for her patients and best treatment options. Her epilepsy knowledge and her willingness to educate those around her are unparalleled. She is a saint! Her devotion and dedication to making sure our kids have the brightest future is amazing. I think she should be Australian of the Year, every year! Her patients and their parents appreciate her caring approach, and her special ability to work with the child's goals and aspirations to achieve the best possible outcome."*

MARELLA JENKINS AWARD - Mother of two from Toowoomba, **Angela McNamee**, is one of Epilepsy Queensland's highest individual fundraisers in 2015, raising an astonishing \$10,352.74 by participating in the Cairns half ironman triathlon. Yes she travelled from Toowoomba to Cairns to compete!

Angela was already signed up to the half ironman but after her daughter was diagnosed with epilepsy she considered dropping the challenge. However, she then saw an opportunity to increase awareness of epilepsy and also give others an opportunity to help families like hers by fundraising for Epilepsy Queensland. Angela started her fundraising through an online Everyday Hero

fundraising page that she shared on her personal Facebook page as well as emailing some of her friends. Overnight she gained a huge following and support for her cause. Thanks to her amazing effort and remarkable backing from the community including family, friends and businesses she raised more than she thought was possible. She described this moment as *"blown away, empowering, exciting and truly inspiring"*. This also gave her motivation to complete the epic physical challenge which lasted six and a half hours!

FLAME AWARD – The Epilepsy Team at the Royal Brisbane and Women's Hospital in recognition of their outstanding contribution to epilepsy services in Queensland.

Epilepsy specialists have diligently worked at the Royal Brisbane Women's Hospital to provide the best epilepsy care possible, often

with extremely limited resources. Dr Cecilie Lander has clearly demonstrated her resilience with tenure of about 34 years. Dr Lander is well known for her specialization in epilepsy and pregnancy. The current epilepsy team are not only involved in the diagnosis and treatment of epilepsy, but are well credentialed in terms of epilepsy research.

Since 1992, the team has been lobbying for a Comprehensive Epilepsy Program. Epilepsy Queensland has supported these advocacy efforts. Queensland has been the only mainland state without such a program, putting people with refractory epilepsy at considerable disadvantage.

Epilepsy Queensland also applauds the Minister for Health, the Hon Cameron Dick, for supporting this initiative.



● Haidee Costello - Role Model Award Recipient



● Oswald Brothers - 'Fair Go' Memorial Award Recipient



● Epilepsy Team, Royal Brisbane & Women's Hospital

Chairman's Report to AGM

As Chairman of Epilepsy Queensland Inc (EQI) it gives me great pleasure in presenting the 46th annual report of the organisation.

This year has been another year of great change in the operating environment for EQI. Earlier in the year we conducted our inaugural Purple Ball which was an outstanding success. The team of EQI staff, Board members and volunteers under the leadership of Elsewerth Ephraums and Leigh Gilbert pulled together an enormous set of logistical challenges to make the event truly memorable and rewarding in so many ways.

EQI has been heavily involved in the debate and discussion around the Medicinal Cannabis trials that have been announced by the State Government. One of our Board members represents Epilepsy Queensland on the government Steering Committee for the trials. EQI has also advocated for the funding for and implementation of Queensland's first Comprehensive Epilepsy Service (CES). We are very pleased to confirm that funding has been approved and work is well underway to establish the CES. Both initiatives are of critical importance to Queenslanders with epilepsy and their families.

We are planning for the upcoming rollout of the National Disability Insurance Scheme (NDIS) into Queensland. The NDIS has the scope to be a tremendous opportunity for EQI to reach out to and assist more families in need of our services in Queensland and so we approach this with some excitement but also with the expected resourcing, funding and logistical challenges that are associated with being a small diagnosis specific nongovernment organisation.

As you may have read in the most recent issue of our newsletter "The Flame", we were very pleased to hear recently from the Palaszczuk Government that our recurrent government funding has been reinstated. While this funding is most welcome and provides us with some short-term certainty around our financial status, we need to continue to look at new and innovative ways to raise funds outside of government funding. Significant effort has been undertaken this year with the Board and Management of EQI to devise or enhance our fundraising efforts and this will continue into 2016.

Finding ways to raise funds will be vital to ensure EQI continues to be able to provide the valued services currently undertaken, as well as look at further opportunities to provide more services as part of the NDIS rollout. I appeal to all the stakeholders and friends of EQI to continue to assist us as we strive to continually improve the quality and quantity of our service delivery.

At this time, I would like to pay tribute to the Board, staff and volunteers for their continued dedication and enthusiastic efforts.

Finally, I am very pleased to advise that the process to renew the Board has continued this year and I would like to thank outgoing Board member Alan Davidson for his outstanding contribution to the organisation. As always, I would also like to thank our Chief Executive Officer, Helen Whitehead, for her unstinting leadership of the organisation during this tumultuous time and for the all the support she has provided me and the Board. I know Helen and the EQI staff work very hard to deal with the multiple challenges of client service delivery and fundraising and on behalf of the Board I'd like to finish by paying tribute to their efforts.

Steve Eltis

Chairman



2016 Memorial Service

16 July 2016, 2.00 pm

Mercy Place, 371 Simpsons Road, Bardon Q 4065

This is a nondenominational service where all are welcome...

to all those bereaved... whether a family member or friend of someone who has died from epilepsy-related causes...

whether an Epilepsy Queensland supporter, or your work brings you in contact with people with epilepsy.

Please join as we remember and celebrate those lives.

Contact Jenny Ritchie at Epilepsy Queensland for more information.



Purple Day 26 March
for epilepsy QLD

Join us to raise funds and awareness during March

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

epilepsy queensland inc

Supporting Epilepsy Around the World

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 during March to support epilepsy awareness worldwide!

Register your involvement in **Purple Day** to help us to increase awareness of epilepsy and raise much needed funds for Epilepsy Queensland. By doing so, 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 for more information, to register today and **GO PURPLE!**

- Wear **purple** on 26 March
- Host a **Purple** awareness/fundraising party/event/activity and go in the draw for lots of great prizes!
- Become a **Purple Day Hero** with your very own online **Purple Day** fundraising page. Please go to www.everydayhero.com.au/event/purpleday
- Buy or sell **Purple Day** Merchandise – including our cute new Purple Puppy!
- 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



NEWSFLASH!

Our new online shop is open!!

You can now buy your Purple Day merchandise securely and quickly by visiting www.epilepsyqueensland.com.au - Lots of other merchandise is also available including Little Poss, Wally Lewis and Lucy's First Disco books – plus lots more to come.





Look out for our banner flying proudly on Brisbane's Story Bridge which will be lit up purple to celebrate **Purple Day** from 14 to 27 March.

Bronco's Partnership & Game

We are delighted to announce that we have been chosen as a **NRMA Brisbane Broncos 2016 Charity Partner**.

On Friday 11 March, the first home game for the Brisbane Broncos at Suncorp Stadium has been dedicated to Epilepsy Queensland.

If you are attending the game, keep an eye out for Little Poss and our band of wonderful volunteers who will be selling raffle tickets. If you are watching from home, you may see Little Poss playing around on the field with the Bronco's Buck.

The Brisbane Broncos have an ongoing commitment to assisting the Queensland community. In an effort to give back, the Brisbane Broncos Charity Partner Program was established to assist Queensland charities whose values are aligned with those of the Brisbane Broncos. There are currently 12 charities supported through financial, merchandise and ticket donations, player appearances, and the allocation of one home game each to promote their charity. Charity partners provide voluntary support to the 50/50 Charity Raffle at each Broncos home game and in return, will receive a percentage of the 50/50 Charity Raffle jackpot from their corresponding home game.

"We are pleased to be aligned with Epilepsy Queensland in 2016 and are looking forward to working closely with their team to not only raise funds for a worthy cause, but to raise their profile within the Broncos community and Queensland."

PLEASE HELP!

Roar Game

Epilepsy Queensland is very excited to be involved in an upcoming **Brisbane Roar** game when they play Newcastle Jets on Sunday 3 April. We have been invited to do a collection prior to the game at Suncorp Stadium and we need your help!

If you love getting in, lending a hand and meeting new people while helping others we'd love to hear from you! To register your interest in volunteering your time for this event or others and/or for further information please call 07 3435 5000 or email klavin@epilepsyqueensland.com.au.

PLEASE HELP!

Melbourne Cup

Once again RUSH CBD hosted a fantastic day for Melbourne Cup on the Green last year and Epilepsy Queensland was honoured to be the sole beneficiary. Held at Post Office Square, the sun shone brightly as the event came alive with jazz music, premium seafood buffet, Fashions on the Green and a huge screen televising all the action live from Flemington.

Wally Lewis graced us with his presence to share some of his experiences living with epilepsy as well as some footy talk. While Epilepsy Queensland blessed some lucky winners in our deluxe raffle that included luxurious prizes with thanks to Carla Zampatti, The New Inchcolm Hotel, QPAC, Park Regis Brisbane, T2, T.M.Lewin, Studio Star Gold Coast, Rebel Sport, TFE Hotels, Mitchell Ogilvie Menswear, Stefan Hair Fashions, Palace Barracks Cinemas and Max Brenner.

A big thank you goes out to Donna and the team at RUSH CBD for choosing Epilepsy Queensland to be involved and we look forward to doing it all again this year!



Epilepsy Queensland was honoured to be a charity beneficiary alongside Guide Dogs Queensland for the prestigious Brisbane BMW and Westside BMW Ride for Life Challenge on 8 November last year.

The ride was non-competitive and saw over 800 cycling enthusiasts cover a distance of 87kms starting and finishing at Northside Riverside Park via Redcliffe.

It was a very early start for all involved and we are very appreciative of the efforts our volunteers who were up before the crack of dawn to help at the event. Thankfully the rain was very light and didn't dampen any spirits; both riders and volunteers had a fantastic morning.

Epilepsy Queensland is grateful to Brisbane BMW and Westside BMW for the wonderful opportunity to be a part of The Ride for Life Challenge - and the wonderful donation of \$7,500 - which is not just a cycling challenge but a great opportunity for cycling enthusiasts to give back to local charities.

Thank you to all involved! www.rideforlifechallenge.com.au



2015 Epilepsy Queensland

Charity Golf Day, Toowoomba

Toowoomba Golf Club played host to the Epilepsy Charity Golf Day with thanks to our new supporter and friend Peter Meyer.

This was a larger than life event with sporting heroes, former Australian Cricketer Greg Ritchie, and Epilepsy Queensland Patron and Rugby League great Wally Lewis involved on the day.

Some highlights of the event included the Audi Hole-in-One competition which was missed by only 5cms, Greg Ritchie wowed the crowd as MC for the day, and there were great raffle prizes and giveaways, while Wally Lewis met with some families with children doing it tough with epilepsy. Oh and there was even a round of golf played!

Peter was inspired to do something in the name of epilepsy after living with and hiding the condition for 45 years. Having been seizure free for 2 ½ years, after undergoing successful surgery, he now wants to raise not only funds, but also awareness of epilepsy and the support and services that Epilepsy Queensland offers to all Queenslanders.

By all accounts, it was a very successful day raising \$40,000 for Epilepsy Queensland. We appreciate the fantastic efforts Peter and his supporters went to in making this day happen, including major sponsors Tilly's Crawlerparts, Wippells Auto and Acer Computers.

Peter hopes to hold the event again this year so watch this space!



● Greg Ritchie & Charlie



● Wally Lewis & Greg Ritchie



Tuberous Sclerosis Australia

Epilepsy Queensland along with Lady Cilento Children's hospital, combined with Tuber Sclerosis Australia (TSA) for an Information Day on Sunday 21 February at Lady Cilento Children's Hospital. We enjoyed coming together to collaborate with TSA about the management of these specific conditions.

Speakers included Clare Stuart from TSA, Dr Kate Riney (Paediatric Neurologist, Lady Cilento Children's Hospital), Alison Alsop, (Epilepsy educator, Epilepsy Queensland), Dr Honey Heussler (Developmental Paediatrician, Lady Cilento Children's Hospital), Dr Hope Northrup (Geneticist & TSC Clinic Director, University of Texas), Dr. Peter Trnka (Paediatric Nephrologist, Lady Cilento Children's Hospital) and Dr. Andrew Mallett (Nephrologist, Royal Brisbane and Women's Hospital). We are pleased to say that the audience and participants enjoyed varied and meaningful information day sessions.

Tuber Sclerosis Complex (TSC) is a genetic disorder that may affect nearly every organs system. It affects many people in many different ways and with varying degrees of severity. Signs and symptoms of TSC can also progress at different rates in different individuals. The diversity and variation make it challenging to determine what healthcare is needed to achieve the best quality of life for a person with TSC.

About Tuber Sclerosis Australia

TSA is the only organization dedicated to TSC in Australia. We help in the following ways:

- Provide phone and email support for TSC affected families
- Publish Reach Out, a regular magazine
- Maintain a detailed website of TSC related information and resources
- Connect a network of TSC families across Australia, including an online discussion group
- Hold conferences and seminars for families and health professionals
- Manage the TSC Professionals Network for health professionals experienced in managing TSC
- Advocate to improve access to best practice care
- Fund and stimulate TSC research in Australia.

Find out more at www.tsa.org.au

20 November 2015 invited 'Epilepsy – Through the lifespan, our sixth Annual Queensland Epilepsy Symposium, Thinking outside the box' to inspire us. We were joined by heavy duty professionals such as Professor Helen Cross from the UK. Helen is The Prince of Wales Chair of Childhood Epilepsy and Honorary Consultant in Paediatric Neurology at UCL Institute of Child Health, Great Ormond Street Hospital for Children.

Professor Helen Cross stimulated some dialogue around epilepsy and the developing brain in specifically improving outcomes for early onset epilepsy in children. This once again highlighted the importance of seizure control in improving cognitive, neuropsychiatric and behavioural outcomes for children.

Helen later continued the conversation about Medicinal Cannabis, by asking 'is it a miracle or a fairy tale?' Cannabis is one of the most widely used recreational and medicinal drugs worldwide and is best known for its psychoactive constituent 'THC'. However, despite some anecdotal evidence, little is known about its long term medicinal value. With limited studies so far, involving small numbers, poor follow-up and issues of placebo bias, Helen acknowledged the need for quality, long term research. This will require (a reliable source) access to (a consistent source) medicinal grade cannabis (currently unavailable in Australia), careful selection of trial participants (free of bias), long term studies, as well as collaborative research (for example, health economics studies) to determine its overall viability as an epilepsy treatment. So whilst the question 'miracle or fairy tale?' remains, she left us with hope that processes are in place for seeing this being answered once and for all.

A student of Professor Helen Cross and a noted epileptologist at the Lady Cilento Hospital, **Dr Kate Riney** keenly spoke about developing independent health management skills in our teens with epilepsy. Often it's a difficult step transitioning from childhood to adulthood, even more challenging when their epilepsy needs to be managed by themselves, rather than their carers. In building a capacity for their health advocacy, Kate highlighted the need for developing confidence in

communication, confidence in patient-doctor relationships and understanding the adult health care system. This requires input from the teen to engage, the doctor to redirect and involve the teen and the parents/carers to "let go" and support the teen's involvement. She described building capacity as a process that needed to commence in the pre-teen stage and continue right through the teenage years. She gave practical examples of allowing pre-teens to participate in appointments through asking questions, contributing to health decision making and by encouraging supervised independence with regards to taking medications and being aware of when prescriptions needed to be filled etc. At the teen stage, she suggested providing health education opportunities about epilepsy and lifestyle as well as legal/social obligations, linking teens to non-parent support networks and increasing the focus of consultations to the teens and away from the parents/carers. She described the importance of establishing new health care contacts in order to empower both the teen and the parent. An effective transition from the paediatric to the adult health system is imperative as it can increase treatment adherence, reduce health related anxiety and reduce the risk of seizures or worse, SUDEP.

Professor David Reutens shared his research and wonderful work in imaging and its advances, particularly the implications for clinical practice. With respect to epilepsy, these images help to answer questions like...Where is it in the brain? What is the pathology? What is the function of the brain in that area? and What is its relationship to other brain networks? Therefore doctors are able to use this information to help individualise treatment choices. He also outlined the movement towards MRI

increasing resolution through increased strength of signal, further improving its clinical application into the future. And finally, he spoke of the unpredictable nature of seizures and the obvious problems it presents for those with epilepsy. He outlined research into seizure prediction and in particular a recent competition which saw the winner being able to accurately predict seizures in 81-85% of cases. He highlighted the continued need for collaboration between medical professionals and those outside the medical field (mathematicians, scientists, technology experts etc) and the key role that a number of Australians are playing in this much needed research.

We all can struggle a little with memory throughout our lifespan. **Dr Kate Thompson**, a neuropsychologist from the RWBH shared with the audience some of the cognitive impacts to the brain from epilepsy, such as foggy thinking, difficulties concentrating, losing train of thought, and needing extra time to process information. She stressed that these symptoms can be raised with your specialist and a plan of action can be developed. Early identification of seizures certainly can assist.

Women's health and epilepsy is always a great topic of conversation and **Dr Cecilie Lander** is always on hand to share her expert knowledge with regards to pregnancy, lactation and the effects of epilepsy medication. Cecilie spent time discussing the importance of pre-planning pregnancy and in particular medication choice with regards to the teratogenic and cognitive risks to the baby. She also outlined, the need to modify AED dosing during and after pregnancy due to changes in metabolism, correct dosing of folate before and during pregnancy, AED's and breastfeeding and most importantly, pre-pregnancy planning should involve good

seizure management for Mum; equals healthy mum and healthy baby. Overall, she suggested that managing expectations and risks, coupled with developing good support networks after birth were key to improving outcomes for mum and baby.

The challenges for teenagers with epilepsy are many and varied. **Dr Dan McLaughlin** continued this conversation highlighting some of the syndromes that have an onset in adolescence. Juvenile myoclonic epilepsy, Juvenile absence epilepsy, photosensitive epilepsies and non-epileptic seizures, were just a few. He described others that may have childhood onset that can persist into adolescence such as childhood absence epilepsy, benign childhood epilepsy, Lennox-Gastaut syndrome.

Our adolescents with epilepsy can be prone to emotional, mental, physical, and social developmental difficulties, which can lead to stigma and poor psychosocial and socioeconomic outcome in the long term. Dan described some of our teenagers' typical behavior as they transition into adulthood that may assist us to understand their changing view of the world around them. They begin to question rules and adult decisions often, without seeing too much gray. They can develop strong belief in individual rights which may explain their need for 'justice'. It was a very worthwhile presentation that carried on from Kate Riney's earlier discussion.

Our journey through the lifespan continued with **Professor Harry McConnell** as he reflected about the relationships between anxiety, depression and epilepsy. He highlighted the need for proper management of each and that when anxiety attacks are refractory to medications, epilepsy must be considered as a cause.

Our older and wiser generation benefited from **Professor Christian Gericke's** presentation 'Epilepsy in older patients'. This would be the snapshot of people who are the most likely to be diagnosed with epilepsy at the moment. He discussed common seizures and highlighted the fact that presentation of these seizures can be very different in the older age group. He also

spoke about possible causes, in particular poly-pharmacy, as well as the difficulties with anti-epileptic drug tolerability but the favourable remission rates in comparison to that in younger populations.

Last but not least, **Dr Ichhya Shrestha** from the QIMR Berghofer Medical Research Institute joined us to speak about clinical trials of new medications in the treatment of epilepsy, especially the clinical trial

investigating topical cannabidiol as a novel anti-epileptic for treatment resistant epilepsy.

Epilepsy Queensland is again grateful to many who assisted in bringing this symposium together, especially the University of Queensland, to RWBH for their auditorium. Special thanks to our sponsors UCB, SciGen, Aurora Biosciences, MedTel and EpiAssist.



● Professor Helen Cross with Helen Whitehead (CEO Epilepsy Queensland)



● Professor Harry McConnell with Dr Kate Thompson

30 minutes with *Dr Lata Vadlamudi*

Associate Professor Lata Vadlamudi is a Senior Staff Specialist in Neurology at the Royal Brisbane and Women's Hospital; Acting Head of the Royal Brisbane Clinical School; Visiting Scientist QIMR Berghofer; and has an Affiliate Appointment at the Queensland Brain Institute.

What inspired you to become a neurologist? During my medical training, I enjoyed working with the Neurology team. I found that there was never a dull day and no two patients were the same. They suffer from such a variety of conditions and illnesses. I also enjoy working with Dr Ric Boyle.

Where did you do your training? I obtained my medical degree in 1989 from UQ School of Medicine and in 2000 completed physician training in the field of Neurology at the PA with Dr Boyle. I then did further training with Professor Sam Berkovic at the Austin Hospital in Melbourne. I then worked at both Westmead in Sydney and the Mayo Clinic, USA before returning to the RBWH. I obtained my PhD in 2006 from the University of Melbourne, which was entitled "The Genetics of Epilepsy: The Testimony of Twins".

If you had not become a neurologist, what would you have most likely become? I have an interest in Geriatrics, taking a multi-disciplinary approach. Otherwise, I may have worked in Pharmacy, I find drug interactions interesting.

What is your greatest achievement? Having two healthy children was a big achievement for me. They are now aged 4 and 8 and very well now but they were both very high risk pregnancies and I spent many months in hospital prior to the birth of both children.

What do you see has been the biggest change in epilepsy care since you starting working in Neurology? There have been many advances in both imaging and genetics that have allowed us to understand the underlying causes of the epilepsy. However, there is still a long way to go.

Where would I most like to travel?

Anywhere would be nice! My favorite place to visit is Hawaii - I love the people, the culture and the beautiful beaches. I would also love to go back to France, in particular Paris. My husband and I had a lovely trip there pre-kids. I dream of a trip like that again!

My favourite food is? Japanese - I have recently discovered Edamame beans and I love them. I also love Thai food.

Describe your most embarrassing moment? There are so many it is hard to pick just one however, seeing one of my patients in the Women and Epilepsy Clinic and saying she was looking bigger at her clinic appointment, but in fact she had delivered her baby about one month prior was very embarrassing!

What is your favourite book or who is your favourite author? It has been a while since I have had time to read. My life is full of epilepsy papers. As a child I loved to read Jane Austen. I also have a favourite children's book called "Beautiful Oops" by Barney Saltzberg. It is about when you have made a mistake; think of how to make something beautiful - inspiring to any age group and so relevant to our daily life.

Who is the most famous person you have met or would like to meet? I don't get out enough to meet famous people. The person I would most like to meet would be Mother Teresa. She was so inspirational - so small, yet so huge in her impact and achievements.

What style of music do you like to listen to? I like listening to Michael ???- my children find that very funny! I'd love to see him in concert. He seems to be a nice person too.



Do you have any interesting hobbies or pastimes you would like to tell us about?

It always feels like there is never enough time! I am trying to get back into fitness, particularly working out at the gym and trying Pilates. I also love spending time with my children and they love cooking with me. As a young child I learned ballet.

Name one thing that you feel would improve the epilepsy care in Queensland

Queensland needs a Comprehensive Epilepsy Centre. It is exciting that the funding has finally come through for this. This will help to alleviate the wait times for people waiting to see a neurologist. It will also mean that people in Queensland can access current and appropriate treatments here without having to travel interstate. This has been a long time coming.

What is your hope for the future of epilepsy care? I hope there will be more treatment options in the future. I also hope for further development of devices that give people with epilepsy greater predictability of when they are going to have a seizure and therefore give them greater freedom in their lives.

diary dates

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

5 March		Purple Ball and BMW Art Union draw
11 March		Brisbane Broncos home game (Epilepsy Queensland is the Charity Partner)
26 March		Purple Day
4 April		Brisbane Roar home game (Epilepsy Queensland is the Charity Partner)
16 July		Memorial Service
10 March 14 April 19 May 16 June 14 July	25 August 15 September 20 October 24 November	Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families.
9 March 18 May 20 June 7 September 30 November		2015 Understanding Epilepsy Workshops (Gold Coast) For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
12 March 9 July 5 November		Brisbane Adult Support Group Meeting
11 May 11 August 11 November		Northside Brisbane Support Group
8 March 7 June 6 September 6 December		Parents/Carers of Children with Uncontrolled Epilepsy Support Group
21 April 17 May 2 June 4 August 18 October	Gladstone Mackay Mt Isa Longreach Charleville	2016 Regional Trips For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families

ask an educator

Q: How prevalent is epilepsy in older people?

A: Epilepsy is very prominent in people over the age of 65. Having said that, epilepsy often goes undiagnosed and untreated in the older age group. Other medical conditions can make diagnosis more difficult such as kidney failure, strokes (including mild strokes), diabetes, cardiac conditions, migraines, vertigo and blocked arteries leading to the brain. Sometimes seizures begin for no known reason.

The more common seizure type seen in older people is a discognitive focal seizure (complex partial seizure). These arise in one area of the brain, often the temporal lobe, and appear to the observer as a blank stare, often accompanied by automatisms. Automatisms are repetitive pointless movements, such as hand wringing; picking at clothes; fiddling with buttons, pens or other objects; repeating a phrase or words, which make no sense, over and over again; smacking the lips or making chewing

movements with the mouth. The person will have no memory of the event and will often appear confused and tired when the seizure is over.

Sometimes there may be focal seizures where the person is awake and aware of something happening, such as pins and needles or tingling down one side of the body; an odd feeling in the stomach or chest; sensory hallucinations such as a strange taste in the mouth, or an odd smell, or sound. It may also present as a strange emotional feeling like fear, apprehension, déjà vu or problems with speech, not being able to get the right words out during the seizure.

If a generalised tonic clonic seizure occurs, in a frail elderly person, it can lead to broken bones and painful strains and sprains. It is also more stressful on the heart in elderly people.

Seizures can be well controlled in older people; however, as they are much more sensitive to the toxicity of anti-convulsants,

the side effects of confusion, disorientation and tiredness are much more frequent. There is also a greater likelihood of adverse interactions between anti-convulsants and other medications. Memory can be affected with epilepsy and sometimes the medication may increase this problem. It is important that epilepsy medication is taken correctly, so a Webster pack may be helpful, as well as diaries and calendars to help keep track of appointments. Regular medication reviews are also important.

It can be difficult adjusting to epilepsy later in life. Concerns about safety at home and in the community can be managed with alarms and monitors. Injuries such as falling may take time to recover from when you are elderly and can contribute to isolation concerns. Friends and family are necessary and important connections to maintain for this reason. Relationships also with community services, doctors and family members are the basis of strong ongoing care for the elderly with epilepsy.



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☐ \$28.00 Concession membership
(must provide copies of concession card with form)

☐ \$90.00 Organisation membership

☐ \$50.00 Family membership

Please find enclosed my Tax Deductible Donation of:

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