

the flame

the newsletter of epilepsy queensland inc

Issue 1 – 2018

Get ready for
Purple Day

IT'S A WRAP

The Queensland
Epilepsy Symposium

Best
Day
Ever!

Emerging
technologies
and epilepsy

Beating the heat



Award for innovation and community contribution



Epilepsy Queensland has a dedicated volunteer board who contribute in many different ways to the organisation. Dr Andrew Barnes has been a familiar face to Epilepsy Queensland members for many years. We first remember Andrew from when he was competing in Epilepsy Queensland's annual school trivia challenges back in Primary School. Andrew along with two friends then won our high school website design challenge. Andrew and Vu Tran did work experience and volunteering at Epilepsy Queensland. From there an idea was born when Andrew and Vu formed their first website company when they were still at school.

In addition to his support on the board from 2013, Andrew and his online learning solutions company GO1 provide significant pro-bono assistance to Epilepsy Queensland, servicing our website to ensure Queenslanders living with epilepsy and their families are provided with an excellent information resource.

In 2016, GO1 secured \$4 million in funding from Shark Tank's Steve Baxter, Tank Stream Ventures and Blue Sky Ventures enabling them to continue to expand their offices across the world. The company has helped train more than 500,000 people and employs more than 130 staff internationally.

Andrew's innovation in the education sector also extends beyond Australia. He is the co-founder of Libromat, a social enterprise that combines access to laundry services for low-socioeconomic families, with early-education literacy programs in South Africa.

Andrew shares: "Education is one of those areas where a small amount of change can create a really big impact – particularly when addressing our world's biggest social challenges."

Andrew is a Rhodes Scholar and has received a number of awards over the years for his achievements and contributions. These include the Courier Mail's Top Ten Bright Young Things, AIM's Young Manager of the Year for Brisbane, B&T's 30 Under 30 and he was a finalist in B&T's Annual Awards. We were thrilled to be in attendance when Andrew received his latest award, the University of Queensland's Distinguished Young Alumni Award for 2017.

According to a UQ spokesperson: "Each year The University of Queensland celebrates the diverse achievements of our alumni with a suite of alumni awards. These awards recognise the achievements of alumni who have accomplished outstanding success in their fields and made exemplary contributions to their community."

Contents

- 2 Award for innovation and community contribution
- 3 It's a wrap: the Queensland Epilepsy Symposium
- 4-5 Emerging technologies and epilepsy
- 6-7 Our Annual Celebration and AGM
- 8-9 Get ready for Purple Day supporting epilepsy awareness worldwide

- 10 Melbourne Cup with a difference / Toowoomba swings into action for epilepsy
- 11 My epilepsy story: a cup of tea with Rosemary
- 12-13 30 minutes with Leonie Hogarth
- 14-15 Ask an educator - maintaining a healthy lifestyle this summer
- 16 Diary dates/memorial service



EDITORIAL DISCRETION

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It's a wrap: the Queensland Epilepsy Symposium

The Eight Annual Queensland Epilepsy Symposium was held at the Princess Alexandra Hospital on 26 October 2017.

A diverse group made up the audience, from people with epilepsy, our members, teachers to medical professionals and students, an interesting number of topics were covered.

Dr Piero Perucca, a consultant Neurologist from the Royal Melbourne Hospital led the day with his presentation on 'Genetic testing for focal epilepsy; ready for prime time?' Dr Perucca spoke about the current genetic research into the causes of focal epilepsy. It's an area where we look forward to further much needed research.

Associate Professor Lata Vadlamudi, a Senior Staff Specialist in Neurology at the Royal Brisbane and Women's Hospital and Principal Research Fellow, The University of Queensland Centre for Clinical Research, Faculty of Medicine also spoke about her current research which includes a particular focus on twin studies. Dr Vadlamudi spoke of the need for a deeper understanding of the mechanisms driving epilepsy with a focus on understanding contributing indicators allowing for earlier diagnosis and treatment choices and ultimately to treatments which modify epilepsy in the future.

Dr Sasha Dionisio, Director of the Advanced Epilepsy Unit at the Mater Centre for Neurosciences presented, 'Stereo-EEG: Finding hope in the depths of the brain' which highlighted the importance of surgery for some people living with non-lesional epilepsy. Dr Sasha took loads of questions about surgery from the audience, it seemed there certainly was hope presented in his talk!

A presentation by Ruth Blackburn, a psychologist working as a researcher with the Lambert Initiative focused on current issues surrounding Medicinal Cannabis and provided an update on the Paediatric Epilepsy (Lambert Initiative) Cannabinoid Analysis (PELICAN) Study. An important part of this study is speaking

with parents about their journey in/or experience with cannabis based products used in the treatment of childhood epilepsy. For parents currently using cannabis products, the PELICAN study can analyse their product for cannabinoid content with the option available to receive individualised feedback. To find out more about the PELICAN study email: lambert.initiative@sydney.edu.au

Associate Professor Cecilie Lander is no stranger to spirituality so her presentation on Epilepsy and Spirituality provided a fascinating perspective on health/spirituality research and the journey some people living with epilepsy have taken to find acceptance and resilience.

Other speakers at the Symposium included Professor Harry McConnell (who also helped out as MC for the day along with David Bunker, one of EQI's board members) and Dr Rian Dob who both shared different aspects of Non-epileptic seizures. A topic close to many people's heart, one that is not often understood well.

Dr Dan McLaughlin insight is always welcome and his presentation *Why antiepileptic medication fails to work sometimes was very helpful.*

With the NDIS making its way across our state, Epilepsy Queensland's services development officer, Leonie Hogarth provided information helpful for those needing support accessing this scheme. EQI is able to work individually with people and their support networks and looks forward to making contact with anyone interested. A range of factsheets and other information about the NDIS is available. Please contact the services team at EQI on (07) 3435 5000 or 1300 852 853 for further information.

Planning is already underway for the Ninth Annual Queensland Epilepsy Symposium: Thinking outside the box scheduled for 30 October 2018. Stay tuned!

EMERGING TECHNOLOGIES AND EPILEPSY

Big Data Big Heart Hackathon

On the last weekend in October nearly 100 fantastic volunteers came together for the Big Data Big Heart Hackathon to create solutions for three charities making a difference in the lives of Queenslanders. Epilepsy Queensland was one of the lucky beneficiaries alongside Diabetes Queensland and RACQ Lifelight. We put forward five challenges faced by Queenslanders living with epilepsy and their families.

The challenges:

- a need for age appropriate resources for children and teenagers living with epilepsy
- the challenge of getting referrals so that we can help more Queenslanders to live well with epilepsy
- public awareness of epilepsy and seizure including the challenges that epilepsy brings to everyday life and what to do if someone has a seizure
- lack of a coordinated approach to sharing medical and wellness information across medical professionals who treat people living with epilepsy
- capturing seizure activity data in real time and the ability to predict seizures

Client Services Coordinator Jenny Ritchie was on hand in the lead up to the Hackathon and most of the weekend to give the teams an understanding of epilepsy and answer their questions. Consumer representative Chiara Wood spoke from the heart about what it's like to live with epilepsy, the challenges she faces and talked about some of the solutions that are desperately needed. Chiara was our representative on the judging panel assessing the solutions.

We were thrilled with the many innovative solutions presented and the passion of the participants to help people living with epilepsy.

The solutions:

The winners were: Medtech – they developed an app so that

people can take charge of their own medical records and have them available to share with emergency medical staff and members of their medical team.

Second prize went to: Epishare who were also looking at an app where people could store information about their children's medical condition, medications and treatments so that they could share with carers, support workers teachers and other people involved in the care of their child.

Third place went to a web based mapping and chat bot solution for Lifelight to help them with the logistics of scheduling their flights.

An honorable mention went to Reach Out who developed a chat bot for our website and Facebook messenger. It can be loaded with our most frequently asked questions and answers so that when people contact us electronically out of hours they can be engaged or redirected to call or email us. The team named the chat bot avatar 'The Legendary Jenny'.

A Health Challenge App for people with or at risk of Type 2 diabetes from Health U also received an honorable mention.

There were a range of other solutions for Queenslanders living with epilepsy including a high school video competition to raise awareness for epilepsy, a video monitoring system that could potentially detect absence seizures and an e-learning solution.

We are extremely grateful to the sponsors and organisers of the Hackathon Cloudtrek, Amazon Web Services, Trend Micro, Telstra, Fishburners, Youi and just digital people. Special thanks to Neil Hitz and Lyndon Swan from Cloudtrek, Elgin Lam from AWS and Josh Wolf for organising this amazing event. We look forward to working with Cloudtrek and many of the teams that are interested in giving more time to make these solutions a reality.

Technology forum

Following on from the inspiration of the Hackathon we were thrilled to hold a technology forum and expert panel at our annual celebration which was also streamed live on Facebook answering the question "Can technology provide new solutions for epilepsy". Dr Sasha Dionisio outlined advances in epilepsy surgery

including a surgical Robot, cortico-cortical evoked potential, Repetitive Neurostimulation, PRISMA, DBS and GAMMA knife.

He was joined by an expert panel including Dush Wimal, CEO of SmartCap and Elgin Wood from Amazon Web Services who discussed wearable EEG technology for advanced pre-emptive seizure detection. Neil Hitz from Cloud Trek and consumer representative Chiara Wood, plus Hackathon team members discussed technological solutions developed from the Big Data Big Heart Hackathon.

Wearable seizure detection technology

Dr Dionisio as part of his presentation discussed the 'Fitbit' for the brain developed by Melbourne scientists and currently being trialed. The technology detects brain waves via a small eeg device implanted behind the ear with a string of electrodes running beneath the scalp. The information is then sent via a smart phone or computer. By analysing this information, the technology learns how to predict seizures and can send an alert to the person living with epilepsy, their emergency contact or doctor. The device also has applications for mapping of seizures prior to epilepsy surgery. Potentially this will enable more people to have the source of their seizures mapped and more candidates for surgery that can put an end to seizures.

SmartCap currently markets wearable eeg technology to measure fatigue and microsleeps in the mining and transport industry. It can be worn as a head band or as part of a hard hat or cap, connecting via Bluetooth to an app on a smart device. Mr Dush Wimal outlined how the device has the future capability for warning of pending seizures for people with epilepsy. The technology uses algorithms based on eeg.

Elgin Wood is the Technical Account Manager at Amazon Web Services and also lives with epilepsy. He believes that eeg headsets could be utilised to capture brainwaves so they can be

analysed to predict seizure patterns. Using a smartphone, the data could be uploaded to the cloud in realtime. The objective is to then analyse the data and predict when medical problems occur so that actions and alerts can be performed. An IoT (Internet of Things) button could also be pushed to indicate when a seizure has occurred.

The objective is to find a brainwave pattern for each patient, which can signal the onset of a seizure. Once the patient's "seizure pattern" has been established, the incoming data can be continually analysed for patterns and if a seizure pattern is predicted, notifications can be sent via SMS. Once you can predict, you can pre-emptively act. Push notifications (Including GPS location) could be sent to family members or persons physically near the patient (ie in a workplace) so that first aid measures can be performed.

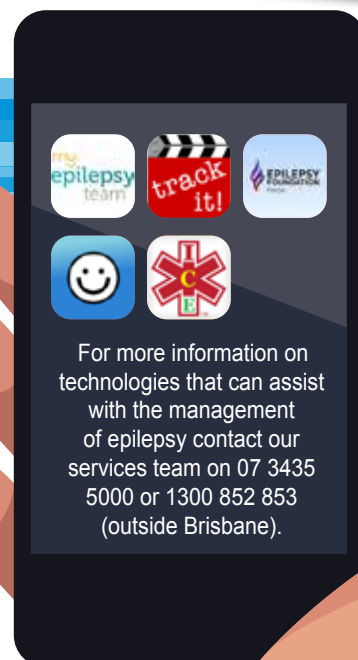


5 OF THE BEST EPILEPSY APPS

While these advanced seizure detection technologies may be some distance away for everyday use, there are a number of free apps currently available that can assist with the management of epilepsy.

1. My Epilepsy team (www.myepilepsyteam.com) is a social network for people living with epilepsy. You can connect with others near you (or around the world) with a similar diagnosis, share your experience with epilepsy, how you are feeling as well as access resources.
2. Seizure Tracker (www.seizuretracker.com) – Keep track of seizure length, type, potential triggers and associated symptoms to assist with the management of epilepsy.
3. Seizure First Aide (www.epilepsyfoundationmn.org/app) – This app developed by the Epilepsy Foundation of Minnesota gives the four steps of seizure first aid that could save a life. There is also a handy seizure timer and videos of the most common seizure types to assist with seizure identification.
4. Snug Safety (<http://snugsafe.com/>) – For anyone who lives alone this is a daily check-in service that will notify your emergency contact if you don't respond by a designated time. This app includes free and paid plans.
5. ICE Medical Standard (www.icestandardtech.com) – This app allows you to input and share your medical and emergency contact information with first responders on your phone's lock screen.

Nichols. (15 September 2017) *The 10 best epilepsy apps*, Healthline Media UK Ltd, *Medical News Today*, Retrieved from <https://www.medicalnewstoday.com/articles/319430.php>.



For more information on technologies that can assist with the management of epilepsy contact our services team on 07 3435 5000 or 1300 852 853 (outside Brisbane).

Our Annual Celebration and 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 4 December 2017 at the Queensland Cricketer's Club.

We were thrilled to hold a technology forum which was also streamed live on Facebook answering the question "Can technology provide new solutions for epilepsy". More information on this part of the night can be found in our Epilepsy and technology article on pages 4 and 5.

For the formal part of the evening, Chairman Steve Eltis presented his report and paid tribute to Board members Elsewerth Ephraums and Vivienne Johnson who stepped down for their outstanding contributions. The efforts of Steve Eltis were also recognized as he stepped down from the position of Chairman.

The newly elected Board for 2018 is:

Chairman	David Bunker
Deputy Chairman	Kristin Ramsey
Secretary	Andrew Barnes
Treasurer	Jane Vidler
Board Members	Charmaine Driver Kim Davis Kos Sclavos

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.

Awards

Epilepsy Queensland recognised 11 outstanding Queenslanders and organisations for making a difference in the lives of people with epilepsy. The 2017 awards were presented by founding and Life Member, Marella Jenkins.

The Award winners:

'Fair Go' Memorial Award – Melissa Worrad is from the "Eating in Café" Myer and has been a tremendous support to Lindsay Carter who has intractable epilepsy. Mel and her team have taken time to learn more about epilepsy and do online training to understand epilepsy first aid. As an employer she has allowed Lindsay the opportunity to work in a meaningful role despite the challenges faced by seizures and long periods of speech loss. The team have learned to identify Lindsay's signals which indicate he's having a focal seizure, make him feel at ease and encourage her team to be observant, caring and monitor his safety.

Pam Wellings Memorial Award – Cassandra D'Arcy has many talents including providing excellent music tuition, however it is her generosity of time and spirit that earns her this award. She volunteers her time at the Epilepsy Queensland's office, whether it be stuffing envelopes for mail outs, making phone calls to our members, entering data, or just being a wonderful peer support to those wanting to join the Adult Support Group.

Marella Jenkins Award - Samantha Rowles "has been an avid supporter of my son Levi and Epilepsy Queensland since day one of our diagnosis."

Sam owns and runs pharmacies in Gayndah and Mundubbera and through her business raises awareness and funds during Purple Day in March and through the year. This includes her businesses and staff going purple, selling purple cupcakes and pancakes and raising awareness in a small town by reaching out to all media. She dresses as a purple epi-ape coming to Levi's school for Purple Day and on other days such as walking the Bridge to Brisbane to raise funds.

John Wellings Memorial Education Award – Somerville House, was nominated by a parent. She says "we are overwhelmed with the support our Jemma receives from staff and students alike". She is a boarder there, she has intractable epilepsy, and can have many seizures each day. Everyone involved with Somerville House contributes to the care and support of this young lady and they are very worthy recipients of this award.

Youth Award – Nickayla Winter has helped to raise awareness and funds for Epilepsy Queensland several times in 2017. She

has been the ambassador for Purple Day, allowing us to use her photo with Patron Wally Lewis for posters and promotion. Nickayla spoke at the Purple Ball about not letting epilepsy beat her and received a standing ovation. A piece of art she created and donated for the auction sold for \$1200. Her parents also gave permission for us to use her speech for a Regular Giving and Flame appeal and she's appeared in short videos.

Carer Award – Louise Martin and Hazel Lloyd

1. Louise Martin is a dedicated carer of her son William, aged 15 years. She has cared for him as a single parent with the help of her younger son, Toby. William has Lennox Gastaut Syndrome, he is nonverbal and can't feed or bathe himself and she cares for him 24/7. Despite the challenges, Louise is William's strongest advocate and fights to ensure he has the best quality of life. She recently shared their story in *Flame*, eager to point out the beauty of William and the joy of truly knowing him.
2. Hazel Lloyd provides outstanding care and support of her young son Taylor who suffers from a form of epilepsy known as ESES. She goes above and beyond to support him in having the best learning outcomes and future despite the challenges of acquired brain injury and epilepsy. She is a prolific researcher and is always learning and attending conferences to keep up to date with emerging treatment options and support for Taylor. She is an incredible carer and mother and has been extremely hands on in ensuring that he gets inclusive educational opportunities. Hazel has been active in positive roles in the community, such as the family advisory council at the Lady Cilento Children's Hospital.

Role Model Award – Renee Williams is a true purple hero for epilepsy. She set herself the challenge of raising awareness and funds for epilepsy during Purple Day 2017 and exceeded all of her expectations. She collected over 300 signatures on the Purple Pledge in Bundaberg, collected donations, organised the Bundaberg fountain to go purple, and appeared on TV, radio and newspaper. At the time she was only 18 and hadn't previously told many of her friends about her epilepsy, making this a very brave move.

Health Award – Associate Professor Lata Vadlamudi and Peter Jones

1. Associate Professor Lata Vadlamudi is the Senior Staff Specialist at RBWH Neurology and is Principal Research Fellow, UQ Centre for Clinical Research. One of her patients said "She is an amazing doctor who has really helped me through a very difficult journey of pregnancy and epilepsy. I have been scared and anxious and she has taken so much time to explain things to me and make sure I (and soon to be born baby) are getting the best possible care. She also encourages me to communicate my concerns and questions and never fails to get back to me."
2. Peter Jones is part of the team at the Mater Centre for Neurosciences. This is a selection of quotes from his nomination: "Peter is an incredible person, fully dedicated to patients, always committed and supportive. He has just become Australia's first Epilepsy Nurse Practitioner. Peter's amazing clinical and emotional intelligence has been a guide for patients and fellow staff throughout surgical work-ups and is key to excellent patient outcomes."

Disability Award – Darling Point Special School nomination read "What jumps out for me is the supportive and constant way the whole team respond to their students' needs, not only in a crisis or seizure but in the every "moment" kind of way. The team take special efforts to keep a calm environment in which the students feel a sense of comfort and increased resilience in an often unpredictable environment. There is always open communication from the Darling Point team with parents and caregivers on any issue."

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



A nighttime photograph of a city skyline reflected in water. A large bridge, likely the Sydney Harbour Bridge, is illuminated with bright purple lights. The city lights are visible in the background, and the purple light reflects on the water in the foreground.

GET READY FOR

Purple Day

for epilepsy 

SUPPORTING EPILEPSY AWARENESS WORLDWIDE

Purple Day (26 March) each year is an opportunity for anyone living with epilepsy and the people who support them, to help bring epilepsy out of the shadows. People from around the globe wear purple, help build understanding of epilepsy and break down the myths and misconceptions.

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. Epilepsy Queensland proudly introduced Purple Day to Australia a year later. In 2018 the lack of public awareness and stigma associated with epilepsy is still unfortunately very real. Now in its exciting 10th year, we hope to make Purple Day the biggest ever, but we can't do it without your help.

Your valued fundraising and awareness efforts will assist the 100,000 Queensland children and adults with epilepsy to live without fear and prejudice, while you spread awareness of one of the world's most common serious brain disorders.

How can I get involved and GO PURPLE?

Whether it is at home or work, with your local school, pharmacy, club or in your community, there are so many ways you can raise funds and awareness for Purple Day. In the lead-up to Purple Day we will be promoting 26 Ways in 26 Days you can get involved. We've included a small sample to get you started.

1. **Wear purple** on 26 March and share your pictures on Facebook or Twitter with #PurpleDay. **Order your own Purple Day t-shirt!** <http://bit.ly/eqtshirt>
2. **Host a Purple event or activity** and go in the draw for great prizes! This can be as simple as a morning tea at work or a BBQ with friends. There is so much you can do to raise awareness and a few dollars plus have fun at the same time.
3. **Become a Purple Day Hero** with your very own online Purple Day fundraising page. Challenge yourself and get your friends to sponsor you for a walk, run or colouring your hair purple!
4. **Buy or sell Purple Day Merchandise** – including our cute new Purple rabbit just in time for Easter! Purchase online or call 07 3435 5000.
5. **Share #MyWhy on social media** – change your cover photo to let others know why you Go Purple, add one of our frames to your profile picture or share our Purple Day Facebook posts.

Contact Us Now!

Contact our Fundraising Team on 07 3435 5000 or email purple@epilepsyqueensland.com.au, visit www.epilepsyqueensland.com.au/purple-day or www.facebook.com/EpilepsyQueensland for more information, to register today and **GO PURPLE!**



Join our Purple Climb or Twilight Walk

This year we have options for everyone, whether you are a thrill seeker looking to climb the Story Bridge as it goes purple, attend our Purple Day celebration in Brisbane or take the City Hopper to see Brisbane light up purple. We have great incentives for Purple Heroes willing to join the Climb on Purple Day and fundraise for our essential services and programs. To find out more about the Purple Climb or Twilight Walk visit www.epilepsyqueensland.com.au/purple-climb-celebration or phone 07 3435 5000.

Purple Illuminations

On Purple Day 2018 we will have more purple illuminations and fountains across the State than ever before. Confirmed sites include Story Bridge, Brisbane City Hall, Treasury Casino, Wheel of Brisbane, Brisbane sign at Southbank, Suncorp Stadium, Queensland Parliament House, Victoria Bridge, Sir Leo Hielscher Bridges and Kurilpa Bridge (Brisbane), City Hall and Victoria Street Bridge (Toowoomba), Civic Centre (Ipswich). We will continue to keep you updated via our Facebook page www.facebook.com/EpilepsyQueensland with more sites.



Queensland Cricketers' Club hosted a gorgeous Melbourne Cup Day of Decadence in their newly renovated QC Club.

Ladies and gents dressed in their finest spring race wear, generously supported Epilepsy Queensland through a raffle and sweeps as they indulged in a long table lunch overlooking the magnificent Gabba Cricket Grounds.

Two very special guests spoke at the event about their personal journeys with epilepsy. Rozanne Burley shared her son Adam's story of living with Dravet Syndrome, a severe form of epilepsy. Everyone was moved by Rozanne's story, her family's strength and love for her son.

Before the main race, guests enjoyed a chat with Epilepsy Queensland's Patron Wally Lewis who shared his journey living in the shadows with epilepsy, the surgery that changed his life

as well as some great laughs from his Rugby League career.

We sincerely thank Rozanne, Wally, Queensland Cricketers' Club, their guests and our prize donors for all of their support and help to spread awareness, raise vital funds and bring epilepsy out of the shadows. It was a wonderful day for everyone involved.

Prizes for the Melbourne Cup were generously donated by:

The Point Brisbane – Hotel, PandaPearls Australia Pty Ltd, Pilates Unlimited, Lorna Jane, Senator Claire Moore, Seafood at Home, Lucia's Place Hair and Beauty, TerryWhite Chemmart Myer Centre, Urban Climb West End, Bacchus South Bank, Heritage Bank, Blue Room Cinebar, The 400 Co, Palace Cinemas, Merlo Coffee, Nak, Veuve Clicquot

TOOWOOMBA SWINGS INTO ACTION FOR EPILEPSY

On an overcast Toowoomba morning, around 100 golfers joined Peter and Susan Meyer for a round of golf to make a difference in the lives of Queenslanders living with epilepsy. For the third year Epilepsy Queensland has been the beneficiary of the Toowoomba Epilepsy Charity Golf Day, which is a highlight of the Toowoomba golfing calendar.

Corporate teams from across Toowoomba had the opportunity to tee off with sporting legends including Epilepsy Queensland Patron Wally Lewis, Australian cricketing great Andy Bichel and Rugby League international Wally Fullerton Smith. The post-golf lunch didn't disappoint, with guests regaled with stories from the three legends as well as the ever entertaining and inspiring poetry of MC Rupert McCall.

Epilepsy Queensland CEO Helen Whitehead said: "We would like to thank Peter and Susan Meyer for their unwavering dedication to raising funds for Queenslanders affected by epilepsy. The event inspires generosity in everyone who attends and supports via the auction and raffle on the day and those who donate the fantastic prizes. The event raised \$45,385 which will enable us to help more people living with epilepsy in regional areas through our helpline, counselling and training services."



With Purple Day not far away it is the perfect time to put your hand up 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 lgilbert@epilepsyqueensland.com.au or 07 3435 5000.



My Epilepsy Story:

A cup of tea with Rosemary

When people come to visit Rosemary Borg they are encouraged to donate when they have a cup of tea, not to cover the cost of the tea but to support Epilepsy Queensland.

"I believe all donations made to Epilepsy Queensland both big and small are put to good use. I have an Epilepsy Queensland donation tin on my dining room table and I encourage everyone who comes to visit to have a chat, a cuppa and donate."

Rosemary, 62, was initially diagnosed with epilepsy when she was 28. After further investigation she was diagnosed with Rasmussen's encephalitis, also known as chronic focal encephalitis (CFE), a rare inflammatory neurological disease, characterized by frequent and severe seizures, loss of motor skills and speech.

In 2002 Rosemary had a Vagus Nerve Stimulator (VNS) surgically inserted at the Princess Alexandra Hospital. She has found this a great help but continues on a complex regime of medications. Rosemary has a port-a-cath (a central access port for timely administration of intravenous drugs). Every four weeks Rosemary is administered a drug to support her immune system.

She has required a wheelchair at times throughout her life following status events, but this has not stopped Rosemary.

"I manage to enjoy my life and to have a social life despite my disability. I am currently experiencing a good period in my life because I am not experiencing such severe seizure activity."

"I have been involved in Purple Day and the Epilepsy Brisbane Adult Support Group since they started. I enjoy being involved in activities with other people living with epilepsy. We can discuss matters only other people with epilepsy can relate to."

"I would describe the Adult Support Group as becoming like extended family to me and I would recommend people join a support group if they have the opportunity."

Rosemary transitioned to the National Disability Support Scheme (NDIS) in July 2017 and has found it a very positive

experience. Epilepsy Queensland is one of Rosemary's care providers and she has found dealing with Leonie Hogarth, Services Development Officer at Epilepsy Queensland encouraging.

"Leonie is a very approachable, helpful person. We can ring or make an appointment and come into Epilepsy Queensland and talk with staff about any matter regarding my epilepsy."

If you would like more information on Epilepsy and the NDIS contact Leonie Hogarth on ndis@epilepsyqueensland.com.au or 1300 852 853.



30 minutes with...

**Leonie
Hogarth**



What is the exact title of your role?

Services Development Officer

Where do you currently work & how long have you been working there?

I started working with the wonderful team at Epilepsy Queensland in June 2017.

I am sure you have seen a great deal of change in the disability sector. What do you think is the most exciting change & why?

I think one thing to recognize and appreciate is that change is constant. I have worked in the Community Services sector for 12 years, so I have seen many changes. Ultimately, any change that enables flexible and personalized life enhancing options and opportunities for people is welcomed.

Over the years, there has been greater focus on person centred supports – ensuring that the person is at the centre of all decisions about their life; strength based methodologies – focusing on the inherent strengths of the person – and more broadly their families and community; and more recently – the principle of co-design – that is, working with people to design policies, programs and solutions that work for them. For me, these are core frameworks that guide my work.

Although there are some teething problems, the National Disability Insurance Scheme's (NDIS) core principles about greater choice and control over the supports people with disability or functional impairment require to live the life they choose and be more connected to other people and the wider community, is exciting. Given that the NDIS is the largest

social reform since Medicare, speaks volumes as to the change that is upon us.

What do you love about your job?

I am privileged that I get to work across various aspects of the job – being part of the Services team, means I get to engage with people with epilepsy, their families, service providers, workplaces etc. all at a time of need or support. Providing information, referrals, support or just being a listening ear on the other end of the phone – is very humbling.

I am also excited to be part of the team that is looking towards the future, and really getting to know what supports and services people are seeking. With the NDIS live in some regions, and on our doorstep in others, this will create opportunities for some people with epilepsy that haven't had this before. I am able to be part of their journey from starting to consider their eligibility through to having additional supports in services available to them to use in ways that they haven't been able to in the past. We recognize that not everyone will be eligible for the NDIS, so we are also focused on providing information and support through other pathways to meet need.

What is the most challenging part of your job?

At this point in time, epilepsy is considered by some people within the National Disability Insurance Scheme (NDIS) as a health condition, and hence, not eligible under the NDIS, as it would be the responsibility of the health sector. Whilst epilepsy does require interventions from the health sector, such as appointments with Neurologists, medication management etc.; the focus of the NDIS is on providing supports and services to people with disability or functional impairment – so we are working hard to reframe this thinking to – what is the impact that epilepsy has on the person's life. This may be in relation to mobility, communication, social interaction, self care, self management, or learning.



We want to know what you think!

Please complete our survey to tell us about your needs, what you think our priorities should be, and how Epilepsy Queensland can help you better.

www.surveymonkey.com.au/r/letterfromheleneq

For inquiries about the survey or to obtain a paper version or be interviewed by phone, please contact us on 07 3435 5000

Where would you most like to travel?

I have been lucky in that I have done some travel over my life, I have been to the UK, Fiji, Vanuatu and quite a few road trips to Victoria, where I was born. Whilst, I would love to go back to Ireland – I just love the feel of this country; my next trip I would love to go to Japan. I have always been interested in going to places with different cultures and way of life that I have grown up with, so this is on the list.

What is your favourite food?

My background is Italian, so it would have to be anything Italian, but gnocchi is definitely a favourite.

What/who is your favourite book/author?

Quite embarrassingly, I haven't really made enough time to read a lot of books for pleasure. However, reading the Power of One many years ago – has definitely been a stand out for me.

Who would you like to meet?

Tough call – it would have to be a toss up between the Queen and Barak Obama – both powerful leaders who have endured many difficult times, whilst having the ability to connect positively with so many people on various levels.

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

I would say my music taste is very eccentric – I love anything from Green Day, P!nk, Evanescence, The Beatles, The Carpenters – I think it depends a lot on my mood. I am loving Post Modern JukeBox at the moment – singing mostly modern songs with a vintage filter. If you haven't heard them, I would strongly recommend checking them out.

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

In addition to a social netball team that I am part of and loving, the other hobby I like to do with my husband is visit Antique Centres, or garage sales – with my mum. I love old antiques, and pondering what history or story is behind the piece. We also had a classic 1950's wedding, and were able to incorporate quite a few of our pieces in the reception centre, which was very personalized for us.

What do you feel would greatly improve epilepsy care currently in Queensland?

There are a number of things that come to mind – advancements in technology to detect, monitor and treat epilepsy, improvements in medications available to reduce negative side effects, etc., however, perhaps one of the most powerful ways to improve the care and support to people with epilepsy is to raise awareness and understanding of the condition, and truly 'help bring Epilepsy out of the Shadows.'

Leonie is available for appointments over the phone or in person (depending on location) to speak about the NDIS and epilepsy.

**Contact Leonie Hogarth on
ndis@epilepsyqueensland.com.au
or 1300 852 853.**

ASK AN EDUCATOR



Q: What tips do you have for maintaining a healthy lifestyle this summer?

A: A long summer can be a challenge for many people with the heat. With a little forward thought and planning, summer can be a positive experience for people living with epilepsy.



Drinking:

While some people with epilepsy have seizures that are very sensitive to even small amounts of alcohol, most are able to enjoy an occasional beer or two or a glass of wine with dinner. The key is to ensure the principle of moderation. Moderate alcohol intake is having no more than 2 standard drinks in a day and preferably not every day.

A standard drink is equal to:

- One small glass of wine (100ml)
- One middy of full strength beer (285ml)
- One nip of spirits (30ml)

Be aware of the quantity of alcohol you drink and don't let anyone persuade you to drink more. Alcohol and epilepsy medications interact in specific ways. Epilepsy medications can make you more sensitive to the sedating effects of alcohol while alcohol reduces the effectiveness of epilepsy medication making seizures more likely. Excessive drinking can result in poor seizure control due to late nights, missed meals, or forgotten doses, while 'hangover' seizures are likely to occur as the alcohol level in the blood falls.

Binge drinking can cause a seizure, even in people who do not have epilepsy. Such seizures can be due to the toxic effects of alcohol, too much fluid, alcohol withdrawal and metabolic changes in the body and can occur within four to 72 hours of stopping drinking.

Ask your doctor about the effects of drinking alcohol with the medication you have been prescribed.



Travel:

Having a regular supply of medication is very important for anyone travelling away home for any period of time. Always carry a copy of your prescription with you. If something unforeseen happens to your medication you can have it replaced immediately.

- Travelling overseas requires some extra planning:
- Take enough of your medication in its original packaging to last your holiday.
- If you are going for less than six months, you should take enough medication to last the whole time.
- Pharmacists are able to dispense the full amount of the script, including all the repeats at once if the script is endorsed by the doctor with the words Regulation 24.
- Carry a letter from your doctor listing your medications, including their chemical names, since brand names may vary between countries. This is useful for customs and in case you need to get tablets while you are away.
- If your seizures are not fully controlled and/or you are travelling alone, ask your doctor for a brief letter about your condition in case you need to see a doctor while you are away.
- Always carry extra medication in your hand luggage in case your main luggage is lost or delayed.
- Find out if vaccinations are recommended for the country or countries you intend to visit. Most vaccines are safe for people with epilepsy with the exception of malaria. Your doctor will be able to discuss your options with you.
- Avoid excessive alcohol during the flight.
- Take out travel insurance for the duration of your trip. While epilepsy is considered a pre-existing condition, seizure control can be taken into account. Even if a higher premium is charged, it will be far less than paying for medical treatment overseas.

Heat:

In some people, seizures may be triggered when the weather becomes very warm or rooms are overheated.

The Queensland Government operates the Medical Cooling and Heating Electricity Concession Scheme which can assist with the costs of cooling and heating your home. To find out more visit: <https://www.qld.gov.au/community/cost-of-living-support/medical-cooling-heating-electricity-concession-scheme#Eligibility>

Epilepsy and swimming:

Most people living with epilepsy can take part in activities like swimming. It is important to assess individual risk which includes considering the age of the person, their epilepsy, the swimming location and other support around to assist in the event of a seizure.

Even for people with well controlled epilepsy it is recommended you always swim with a companion who:

- is aware of your seizures and what they look like
- is able to maintain frequent eye contact
- stays close at all times
- is a strong swimmer
- knows what to do in the event of a seizure occurring in and out of the water

Some key points to consider before swimming:

- Always seek advice from your doctor before swimming
- Inform the life guard (if available) of the potential risk of a seizure occurring
- A brightly covered swimming cap or swimming costume can help ensure quick and easy identification
- Avoid resting on the edge of a body of water
- If flickering or reflective light is a potential trigger for your seizures try wearing tinted goggles or sunglasses
- If you have had brain surgery check with your doctor before diving
- People with epilepsy should not swim or continue to swim if he/she is fatigued, feeling unwell, has missed medication or is experiencing warning signs that a seizure may occur
- People with epilepsy should avoid swimming under water for long periods of time as this can cause hyperventilation which has been identified as a trigger for seizures.

If a seizure occurs in water an ambulance should always be called, even if the person's breathing appears to have returned to normal and the person appears to have recovered, water may have been inhaled into the lungs.

For more information on managing epilepsy during hot weather contact our services team on 1300 852 853.

2018

DIARY DATES

26 March	Purple Day Purple Day is a grassroots effort dedicated to increasing awareness about epilepsy worldwide. On 26 March each year, people from around the globe are asked to wear purple and spread the word about epilepsy. See enclosed flyer for more information on Purple Day activities.
14 April	Memorial Service
15 March, 19 April, 17 May, 14 June (9:30am and 6pm), 19 July, 16 August, 13 September, 18 October (9:30am and 6pm), 15 November	Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families
7 March, 16 May, 25 July 5 September, 14 November	Understanding Epilepsy Workshops (Gold Coast) For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals
6 March, 20 March	MyTime Social and Support Group (Woolloongabba)
Informally First Saturday of the Month Formally – 3 March, 2 June, 1 September, 3 November	Brisbane Adult Support Group Meeting
7 March, 18 April, 30 May, 27 June, 25 July, 29 August, 26 September, 24 October, 28 November, 19 December	Adult Social Group Ipswich
Please call 07 3435 5000 for further information on any of the above events	

MEMORIAL SERVICE 2018

14 April - 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 on services@epilepsyqueensland.com.au or 07 3435 5000 for more information.