



the flame

Issue 2 – 2016

the newsletter of epilepsy queensland inc



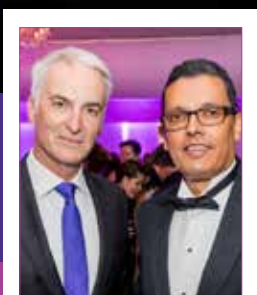
*Patron Wally Lewis with
Rupert McCall and Chairman Steve Eltis*

inside...

National
Awareness
Month



Purple
Ball



Medicinal
Cannabis
Update



in brief

THE TEA ROOM

A Friendly Space for Young People with Epilepsy



The TEA Room is a friendly social network and chat room for young people from the age of 13 to 19 years old who are undergoing diagnosis or living with epilepsy. TEA stands for Teenage Epilepsy Agenda.

If you have not signed up yet log onto www.thetea-room.com it only takes a minute!

- It's completely free to use and it's so easy to get set up.
- You can chat and make friends from all over the world.
- It's a fantastic space for you to talk about your experiences of living with epilepsy, get answers to your questions and talk about life in general.
- You can visit discussion forums, join groups, upload photos, or even tell us about your daily life by starting a blog.
- It's secure! NO ADULTS ALLOWED! The chat is only available to registered and approved users.
- The site is full of safety information and reminders to keep you right when using the discussion forums.

Sign up today at...

www.thetea-room.com

Clinical trial for fenfluramine for Dravet syndrome convulsive seizures

Lady Cilento Children's Hospital's Neurosciences is a site for a clinical trial for fenfluramine.

If you have a child with Dravet Syndrome convulsive seizures, and are interested in being considered for the trial, please email services@epilepsyqueensland.com.au. In the subject line say "Interest in the fenfluramine trial" with your contact details in the body of the email.

LCCH cannot discuss inclusion/exclusion criteria otherwise, until a patient has been deemed suitable for screening, and the parents have signed the consent.

Epilepsy in Adolescence Research

Epilepsy Queensland is commencing research into adolescents with epilepsy in Queensland. There will be a number of stages to this research over the coming years.

The first stage of this research will commence in the upcoming months, where Provisional Psychologist Dana Breadsell will be distributing a survey to gather information about the experiences of adolescents with epilepsy. Dana will also be conducting phone interviews and focus groups.

The aim of this research is to improve understanding of the experiences of adolescents with epilepsy, with the ultimate goal of identifying and providing effective support to adolescents in managing life with epilepsy and their transition from child to adult health care teams. If you would like to be notified once the research commences, please email Dana on dbreadsell@epilepsyqueensland.com.au or look for a notice in upcoming newsletters for more details.

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EDITORIAL DISCRETION

Epilepsy Queensland welcomes you to share your stories for inclusion in Flame. However, the Editor is responsible for the content of Flame and for ensuring the integrity of all work that is published in it.

The Editor is responsible for ensuring an appropriate balance of stories published and for taking reasonable care to ensure that no work is published that contains material that is unlawful, or otherwise objectionable, or that infringes any other person's copyright, right of privacy, or other rights.

The Editor reserves the right to edit or exclude stories from inclusion in Flame at his/her discretion.

The Flame is published quarterly by Epilepsy Queensland – www.epilepsyqueensland.com.au

APP CONFERENCE & MEDADVISOR LAUNCH

The Australian Pharmacy Professional Conference and Trade Exhibition was held from 17-20 March 2016 at the Gold Coast Convention and Exhibition Centre. Epilepsy Queensland was generously invited by the Pharmacy Guild of Australia to participate in the event which was attended by over 6,000 delegates.

Our sponsored session on Medicinal Cannabis was delivered by Dr Dan McLaughlin. Pharmacists filled every seat in the room, keen to learn about the topic. Following Dr McLaughlin's presentation, MedAdvisor and Epilepsy Queensland launched our partnership with a premiere of Pharmacist Phil's Purple Day message.

This is Australia's largest pharmacy conference and trade exhibition that provides a valuable platform for attendees to gain advice, information, opportunities and inspiration in the ever changing pharmacy landscape. Epilepsy Queensland was fortunate to be present to raise awareness about epilepsy and to celebrate Purple Day preparations with the pharmacist and store owners alike.

Sincere thanks to the Pharmacy Guild of Australia and MedAdvisor.



● Kos Sclavos (APP), Dr Dan McLaughlin, and Rob Read (MedAdvisor)

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Order medication in advance so they are ready to collect at the pharmacy

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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!

purple ball



What a fabulous night!

The Purple Ball launched our Epilepsy Awareness Campaign for the month of March and the big event wowed everyone again this year.

The glitz and glamour of the 2nd Epilepsy Queensland Purple Ball was the place to be on Saturday 5 March. The Victoria Park Golf Complex marquee sparkled with purple as 350 guests danced the night away after a packed program of fundraising, fine dining and entertainment.

Big thanks go to the Deep Blue Orchestra and Rupert McCall for their enlivening entertainment. While once again Andrew Lofthouse and Chris Bombolas navigated us through the night including a live auction of fantastic prizes.

The Purple Ball was instigated and hosted by Elsewerth Ephraums. This year's Ball exceeded our expectations – raising awareness about epilepsy and Epilepsy Queensland, as well as raising much needed funds - \$80,000 - to help people with epilepsy and their families.

We could not have achieved this without our valued sponsors and a wonderful group of dedicated volunteers and supporters, thank you to everyone involved in making the night fabulous success!

Thank you to our Art Union Sponsor: **Brisbane BMW**



It was also very exciting to see the Limited Edition #2 BMW 118i Art Union drawn on the night with thanks to Brisbane BMW.

We are very thrilled to announce the winner is Jocelyn Schulte, with ticket number 384.

Ms Schulte, who is now driving the dream, says she is still on cloud nine and hasn't been able to wipe the smile off her face!

Thank you to everyone who purchased a ticket, through your tangible support, you have touched the lives of those in need of our services.



● Jocelyn with EQI's Deputy Chairman Elsewerth Ephraums



Thank you to our Sponsors:



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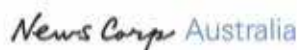
The Pharmacy
Guild of Australia



Bronze Sponsors



Our Valued Supporters



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- Rupert McCall • Helen Whitehead

Raffle and Additional Prizes kindly donated by

- Pulse Travel • Oaks Hotels & Resorts • Harbour Day Spa • Verve Portraits • Tognini's Hair • Perri Cutten • Terry White Pharmacies
- Fully Integrated Therapies • Sky High Coaching • Avon • Tree of Life Nutrition • Yellow Cabs • Sirianni's IGA Ascot • Victoria Park Golf Club
- Robin Aldophs • Goodlife Health Clubs • Cre8 Hair Salon • No More Knots • Stefan Hair Fashions • Perfect Potion
- Tracey Kunde Nutrimerics • Adorne • Deep Grey Photography • Christine Clarke • Jaspa Herington • Yeronga Park Fitness Centre
- Francis Whiting • Henry Coughlin Photography Studios • Bellabox • Obagi • Studio Pilates Ashgrove • Hypoxi Body Boutique Bulimba
- Runaway Room • Elysium Hair • Libertine Parfumerie

events & fundraising

BRISBANE BRONCOS



On Friday 11 March, the first home game for the Brisbane Broncos at Suncorp Stadium was dedicated to Epilepsy Queensland. At the match Little Poss took the field waving to all of his adoring fans along with Epilepsy Queensland Patron and Rugby League great Wally Lewis.

We also had our band of wonderful volunteers selling 50-50 Foundation Charity Raffle tickets of which we received a percentage of the jackpot. The atmosphere was exhilarating as the Broncos and Warriors supporters cheered on their teams and dug deep for charity. This was a fantastic opportunity for Epilepsy Queensland to raise awareness for epilepsy and also nearly \$4,000 from the night!

We are delighted to have been chosen as a NRMA Brisbane Broncos 2016 Charity Partner and look forward to working closely with them over the coming year.

Ipswich Bike Ride

As has been the case for 17 years now, Epilepsy Queensland was one of the beneficiaries of the Ipswich 100 Bike Ride held on Sunday 17 April. What an inspiring and uplifting event it was with over 900 entrants and some cycling as far as 170km over some pretty challenging countryside. Or should we say, **UP** considering one of the courses included Mount Walker. There were people on regular town bikes up for the challenge right through to the keenest of cyclists even travelling interstate for the event.

Each and every one deserved the big cheer and whoop whoop which they got from our Epilepsy Queensland team. A special thank you to the volunteers who were tireless in cheering with gusto. The look of pride on the cyclists faces when they heard the cheers was priceless and made our job all the more enjoyable.

A children's 5 km ride was part of the day's activities and it was wonderful to see their commitment, energy and delight in being included. They got some very special hoorahs from the cheer squad.

Thank you so very much to the Lions Club of Moggill-Mt Crosby for their donation of **\$2700**. Their ongoing inclusion of Epilepsy Queensland as a beneficiary in this wonderful event is deeply appreciated.



- EQ's Karen Lavin accepting a cheque from Michelle Kuskie, the Heritage Bank Ipswich branch Sales and Services Manager



BRISBANE ROAR



The Brisbane Roar and Newcastle Jets fans were big hearted as a team of volunteers and Epilepsy Queensland staff took up a collection outside of Suncorp Stadium before their game on Sunday 3 April.

Epilepsy Queensland Chairman Steve Eltis and our energetic Little Poss mascot took to the field to start the game's proceedings with the coin toss before sharing a little bit about why the fans' donations mean so much to people across Queensland living with epilepsy. This was a brilliant opportunity for Epilepsy Queensland to raise awareness for epilepsy as Steve and Little Poss were beamed across the stadiums screens.

By all accounts it was a close thrilling match for those that attended and we thank Brisbane Roar for inviting us to participate in the day.



PURPLE DAY - National Awareness Month

A big thank you to everyone who got involved with Purple Day this year! You all have contributed immensely to epilepsy's National Awareness Month raising much needed funds for Epilepsy Queensland and bringing epilepsy out of the shadows.

Through your fundraising and awareness efforts during this important time of year, you are helping to ensure that Epilepsy Queensland will be able to continue to provide vital services and programs for the 94,000 Queensland children and adults who will be diagnosed with epilepsy.

It is heart-warming to see how you celebrated Purple Day through purple dress, purple hair, purple events, purple merchandise and more! Thank you to all the Pharmacies, workplaces, schools, shopping centres and individuals for your involvement.

Further spreading the purple, for two weeks in March, the Story Bridge in Brisbane illuminated the sky each night in a marvellous display of purple lights. The Brisbane City Council also displayed a banner across the bridge recognising Purple Day for Epilepsy.

Epilepsy Queensland also continued the Purple Pharmacy Promotion and photo competition. Through this, we encourage pharmacies to show the community that they support people living with epilepsy by decorating their pharmacy in purple. Congratulations to **Blooms the Chemist Bundaberg** who have been judged as the 2016 Purple Pharmacy of the Year.

Thank you so much to all the other pharmacies who participated in this year's promotion; it was stiff competition!



How can you help to cure epilepsy?

Last year, The Flame highlighted the growth of epilepsy surgery in Queensland, for example through the epilepsy surgery program at the Royal Brisbane and Women's Hospital Comprehensive Epilepsy Program. While a significant number of people with epilepsy will benefit from epilepsy surgery, many more suffer from types of epilepsy that cannot be cured by surgery. A question that is often asked is whether there are any new medications to help us achieve the goal of complete seizure control without side effects.

Many years of costly research and development to test safety and efficacy lie behind each new epilepsy drug that reaches your local chemist. To advance treatment, one of the crucial stages after extensive laboratory studies, is the performance of clinical trials that evaluate the effectiveness and side effects of new drugs. Clinical trials are also used to develop better ways of using existing treatments.

Clinical trials are a way of gathering together

the information from a group of people with epilepsy in standardised way that is more effective than individual doctors trying the drug in individual patients. This information allows others to benefit. Because the hope that both patients and doctors have that a new drug will be effective can introduce bias, trials are generally designed to minimise the risk of bias. Through the generous contribution of people with epilepsy participating in clinical trials, Australia has a strong tradition of contributing to the global epilepsy drug development effort, including the development of most of the drugs that are in use today.

Why can't we simply use the results of clinical trials from other countries?

Although results from other countries can give us important information, we know that the populations of different countries differ in aspects, like genetic makeup, that can influence the response to treatment. In fact, there is an entire discipline, pharmacogenomics, devoted to understanding this. Participation in clinical

trials also gives access to new treatment options that may otherwise not be obtainable for several years in this country.

In Australia, clinical trials are tightly governed by Commonwealth bodies such as the Therapeutic Goods Administration and the National Health and Medical Research Council. Before they can go ahead, trials are scrutinised by Human Research Ethics Committees to ensure that they comply with the highest scientific and ethical standards. Epileptologists from major centres around Australia, including the Royal Brisbane and Women's Hospital, have established an Australian Epilepsy Clinical Trials Network as the coordinating body for epilepsy trial centres in Australia and New Zealand.

You can help to drive the discovery of new effective therapies for epilepsy by talking to your specialist about any clinical studies s/he is involved in, if they are appropriate to your situation and what is required of participants.

PURPLE DAY in the community...

Kelly Dickett's Purple Run

Kelly Dicketts and her local running club, the Townsville Road Runners get together every Saturday in different locations around town to do what they enjoy, running.

With Purple Day falling on a Saturday this year, Kelly approached the club about raising funds and awareness for epilepsy by making it a Purple Run. Kelly was impressed by the support of her fellow runners as donations came in as well as and the offer of prizes for the raffle.

Members of the Townsville Road Runners were encouraged to wear purple on the day which attracted a lot of attention as they ran through the city. The support for the fundraiser was fantastic with about 130 people participating in the Purple Run, raising over \$230 throughout the day.

Images supplied by Kristina Johnson Photography



Mia's Race Day

Following in the footsteps of Purple Day founder, then 9 year old Cassidy Megan of Canada, 10 year Mia Murrell of Toowoomba wants to encourage others to talk about epilepsy. With that in mind the Murrell family hold an annual event in their local community to raise awareness about the condition, the latest was a race day held 19 March at the Toowoomba Turf Club. Everyone dressed in vibrant shades of purple to celebrate the event which raised \$6,500 for Epilepsy Queensland.

After Mia's diagnosis at two years of age, her parents Brendan and Amy have always wanted to make sure she felt confident talking about her epilepsy and that those around her knew what epilepsy was, how to recognise a seizure and not to be frightened by it.

With five annual events now held, the Murrells are a wonderful inspiration of what a difference you can make in your local community raising awareness and funds for Purple Day. Whether you raise \$50 or \$500,000, it's all about raising awareness and every dollar will help us to reach more people living with epilepsy.



Anna Chesson spreading the purple message with merchandise

For over five years Anna Chesson has taken it upon herself to spread the awareness and raise funds for Epilepsy Queensland by selling merchandise outside of her local supermarket for Purple Day in March and the Little Poss Appeal in September.

This year was no different as Anna set up her purple display at Richlands Woolworths raising almost \$650 through merchandise sales and donations for the week leading up to Purple Day. As someone living with epilepsy herself, Anna describes selling merchandise, spreading awareness and chatting to the public as a rewarding experience.

PURPLE DAY in the community...

Freshwater Christian College awash with a sea of purple

Sally Morse knows all too well the ripple effects epilepsy has on a family and those within their support network. Sally's daughter Natalie was diagnosed with epilepsy at the young age of two and now attends prep at Freshwater Christian College with her older sister Lisa.

As a Teacher's Aide also at Freshwater Christian College, Sally found it to be a great opportunity to raise awareness and funds for epilepsy at the school for a second year in a row, and they had some amazing purple fun over 2 days!

Starting with a fantastic home baked morning tea; the staff came together, donated and shared a cuppa with friends. This was followed the next day by a free purple dress day; the entire primary school was awash with a sea of purple. Sally describes it as an amazing sight to see and wonderful to feel the love and support for her family by the school community! *"There were purple clothes, purple hair, purple face painting, purple nails; just an awesome amount of purple - everywhere!"* These combined events raised over \$500, a fantastic effort!

Sally took time to raise awareness sharing their epilepsy journey with the staff at the college as well as chatting with the school's year 5 and 6 classes, about what epilepsy is, what a seizure looks like, what they should do if someone is having a seizure, and how it can affect families. This was an inspiring experience for Sally as she openly answered questions from the kids at their level.

The college has been with the Morse family through the ups and downs of Natalie's journey with epilepsy, and while it was a challenging, emotional couple of days, Sally found it very overwhelming to feel the support from their school community. *"We, as a family are very blessed to belong to such a supportive school!"*



● Dad (Anthony), Mum (Sally), and Natalie Morse



● Meeka, Zahra, Natalie

Phil Pettifer's workplace fundraising

In the past Phil Pettifer has held small morning teas with his team at work to raise funds and awareness for epilepsy. However this year Phil sought to expand his little fundraiser and everyone at the Australian Tax Office (ATO) were enthusiastic to get involved to make this event bigger on a corporate scale.

In the foyer of the Brisbane ATO building, the Health team helped to run a Purple Day merchandise stand throughout the morning, providing information on seizures and Epilepsy Queensland for those wanting to know more.

While further up the high-rise Phil held a Purple morning tea for all ATO staff where purple cupcakes proved to be very popular.

In addition to donations and merchandise, Phil also set up his own online fundraising page through Epilepsy Queensland and Everyday Hero <https://everydayhero.com.au/event/purpleday>. Phil was impressed by how easy this was to set up and for his supporters to make tax deductible donations (something they certainly know about at the ATO!).

Phil found that many throughout his office building were keen to get involved as he received fantastic support from Managers and colleagues alike putting up posters and spreading awareness for the day.

Phil's corporate workplace fundraiser didn't require a huge amount of effort however raised close to \$800 for Epilepsy Queensland, raised awareness, and brought forward many who have had epilepsy touch their lives in some way.

ROSA the surgical robot

ROSA is a surgical assistant robot used for stereotactic EEG electrode insertion. It works with the neurosurgeon to ensure accurate and precise placement of depth electrodes used for epilepsy monitoring (invasive stereotactic EEG). ROSA guides the neurosurgeon to the surgical site—the surgeon still creates the opening (drill) and feeds the electrodes in, along the laser-guided pathway created by ROSA.

In 2015, with the opening of the Mater Centre of Neurosciences, the Advanced Epilepsy Unit (under the direction of Epileptologist, Dr Sasha Dionisio, and Neurosurgeon, Dr Jason Papacostas) undertook the first SEEG case in Queensland (September 2015)—becoming one of three centres country-wide credentialed in this procedure. By December 2015, three cases had been successfully implanted and monitored.

The purchase of the robot was to improve surgical times (the time in the operating theatre under general anaesthetic) to reduce clinical risk and to improve on the accuracy of electrode placement.

Now, by April 2016, a further 3 cases have been undertaken and successfully implanted, using the ROSA.

Rosa Robotic Surgical Assistant

The Rosa Robotic Surgical Assistant is the latest generation in robotics to work alongside neurosurgeons to provide guaranteed accuracy that is ergonomically superior to a standard navigation system.



● Team photo with the epilepsy service, neurosurgeon, engineers and ROSA staff from France

Benefits

- Procedural safety is increased as the instruments are guided into position based on the planned trajectory inputs
- Application accuracy is the best available on the market today. It combines robotic accuracy with patented laser technology.
- Patient comfort is increased
- Operating time is reduced
- There are no limitations with planned trajectories and they can be easily modified.
- There is a seamless integration between surgical planning and actual execution, thus providing the surgeon with increased confidence in their surgery.

Clinical advantages

- access to a larger area of the brain (including posterior electrodes), allowing for a more detailed and accurate implantation and subsequent diagnosis and treatment (Medtech, 2015)
- the ability to quickly and accurately modify the trajectories intraoperatively to within a fraction of a millimetre, promoting patient safety (Medtech, 2015)
- decreased anaesthesia for the patient with a more rapid recovery
- an increase in clinical confidence in electrode placement.

The Mater Centre for Neurosciences is the only centre in the southern hemisphere with a Rosa Robotic Surgical Assistant.

Story provided by Mater Centre for Neurosciences

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
or to RSVP on 07 3435 5000 or rsvp@epilepsyqueensland.com.au**

PATIENT CASE REPORT

From epilepsy clinic review to video EEG, SEEG and surgery

Clinic review

PU presents to the Mater Advanced Epilepsy Unit in May 2015 with refractory epilepsy.

He is a 59 year old right handed married gentleman, retired from the Water Police service due to his seizures.

PU and his wife are foster parents to 5 young children, with grown families of their own. They live remotely in north Queensland.

PU reports his first seizure was while out hiking 4yrs ago. His wife reports that he stood still, looked vacant and started staring. He was unresponsive at this time, and has no memory of the event.

A second event occurred a week later when he became blank and started smacking his lips, becoming vague and irrational. He was also involved in an accident at work where he drove the boat into a pontoon, damaging the hull. PU was totally unaware of this accident when informed by a colleague. PU also reports an unpleasant gastric sensation.

PU reported on his clinic visit to the mater that he has a significant decline in his memory, forgetting familiar people's names. He additionally reported that he had lost all self-confidence and was diagnosed with depression and commenced on antidepressants. PU stated that the epilepsy had 'destroyed everything' sapped him of energy, and taken all his independence. PU avoided going out in public.

The seizure frequency was high, and PU had failed multiple AEDS.

On the first clinic review, PU was with his wife. He struggled to engage, sitting while constantly staring at his feet. He looked broken.

A hypothesis of a limbic network epilepsy was tabled, given the semiology. No imaging was available, so MRI and FDG-PET were organised. A video EEG was scheduled for July 2015.

Video EEG

A 5 day admission was undertaken using the standard 10:20 electrode placement. Full carer support was requested as best practice, with 24hr nursing support dedicated to the telemetry. Neurophysiologists were located in the epilepsy monitoring room to real time analyse the recordings. The nursing staffs are trained to spot electrographic changes and then attend to the patient to undertake an

ictal interview, to assist in seizure localisation.

10 seizures were recorded that were suggestive of a left temporal or left fronto-temporal onset. Radiology was negative, making him a good candidate for stereotactic EEG. PU was referred to neuropsychology for language evaluation as the seizures were in his dominant hemisphere, and neuropsychiatry for and management of depression.

SEEG

Stereotactic EEG involves close collaboration between neurosurgery and neurology, with both disciplines needing to be trained in the technique. SEEG is an advanced monitoring and diagnostic procedure that involves mapping of the brain and localisation of areas of potential epileptic activity-areas of onset of seizure, and areas that it may propagate to. Once identified, these areas are located in a 3 dimensional plane and plotted graphically. In the operating theatre, a neurosurgeon, with the assistance and guidance of the neurologist, implant deep brain electrodes through strategically drilled holes in the skull. The electrodes have many contacts that record very small areas of brain tissue for activity.

Once inserted, PU was recovered in the ICU and then returned to the ward for monitoring. The electrodes are covered with dressings and padded with bandages (like a turban) and connected to the wall mounted EEG amplifier. UP to 256 channels of activity are able to now be monitored (video EEG allows approximately 20 channel recording).

PU's SEEG evaluation was over 2 weeks. The evaluation provided strong evidence of left mesial temporal onset epilepsy.

Cortical stimulation (localisation of function of specific areas of the brain through direct electrical stimulation) and CCEP studies (a technique to map networks within the brain using the implanted electrodes) were also undertaken-this provided further evidence of this being the epileptogenic zone and network.

Surgery

Based on the evaluation, PU was referred to neurosurgery where the decision was made to undergo a left anterior temporal lobectomy. This surgery was performed 17th November 2015.



● Intraoperative photo demonstrating electrode placements

Post operatively, PU recovered well, but with moderate deficits in naming-he found it difficult to remember well known person's names, including extended family. He was referred to rehab for a short inpatient stay to work with the speech therapists and occupational therapists. This was frustrating for PU as he felt physically well and out of place, as he saw individuals around him who were, in his mind, significantly more in need of assistance (physically disabled from injury such as stroke). He discharged home to his family, where he continued to recuperate over Christmas. This continued to be frustrating for PU as he struggled with the number of people he was seeing during this holiday period.

PU has recently presented for outpatient review. His report:

"I have my life back"

"I have energy to burn, I no longer sleep all day"

"I go out walking with friends"

His wife reports that she does not know what to do with him, he has so much energy. He reports that he is fixing things around the house (renovated the bathroom) and the garden (fixed the fence).

PU is seizure free.

PU is scheduled for follow up routine EEG as an outpatient at 6 months. He will continue to see the Mater advanced epilepsy service for a minimum of 2 years while continuing on medications. After 2 years, if PU remains seizure free, he will be weaned of his meds and discharged from the service.

PU is a charming man with a wonderful caring family. It was so rewarding to see the change and outcome.

Story provided by Mater Centre for Neurosciences

What are the educational implications for children with epilepsy?

Children with epilepsy have the same range of intelligence and ability as other children. However, repeated seizures which affect consciousness (tonic clonic, focal dyscognitive and to a lesser extent absence seizures) are associated with cognitive impairment. Some of the learning difficulties are directly related to epilepsy, while others are related to treatment (eg medications) and psychosocial factors.

It is helpful to be aware that epilepsy can lead to changes in ability from day to day for your child. For example, they may know something one day and may have forgotten it the next. If a child is doing well in school, there is no reason to worry about the effects of epilepsy on learning. If the teacher reports problems, or if parents become aware that their child's performance is slipping, other strategies – both medical and educational may be necessary.

Absence seizures may not always be apparent, or they may be misinterpreted as day dreaming, inattentiveness, and poor concentration or even as hearing problems. These seizures may account for inconsistency in the pattern of a child's learning and performance and they may have considerable difficulty in learning. As a result they may withdraw, become frustrated, aggressive and lose confidence.

Missed schooling due to increased seizure activity, doctor's appointments etc can impact on learning and important peer socializing.

Sometimes confusion and exhaustion after a seizure can be quite prolonged, from minutes up to several hours and children may need a quiet place to rest or sleep or go home. Children may have no memory of the seizure.

Short term memory problems are one of the main concerns for many children with epilepsy. This will affect learning and has implications for teaching. Children with short term memory problems may have difficulty remembering instructions or tasks.

Some suggested strategies that may help:

- Providing written instructions or a tick list of tasks for all pupils
- It's important to make sure that the child has a written record of homework activities
- Reducing the rate at which information is presented
- Practicing new information daily
- Allowing for processing time when requesting a response from the child
- Focusing on one type of information at a time
- Using diagrams, graphs and pictures to illustrate information
- Monitoring the child's attending behaviour and refocus if necessary
- Providing immediate and frequent feedback
- Additional adult support may be necessary

In order to encourage a healthy self esteem for the child with epilepsy, it's good to encourage active participation in all school activities in accordance with parental and medical advice. Providing help and information for other children, teachers and parents to understand epilepsy will encourage social acceptance. Having a matter of fact approach will help to normalize the condition. Encouraging the child to deal with new or difficult situations may help to build confidence.

Act quickly on any teasing or bullying! We might find that the child may feel angry and resentful about their epilepsy at times. It might be good to recognize and record any changes of behaviour, mood, energy and performance as a way of monitoring. Avoid letting the child use their epilepsy as an excuse.

With sports and activities, the child should be encouraged to participate in sport and extra-curricular activities ensuring there is adequate supervision. A student with epilepsy should never swim alone and consideration should be given to playground equipment such as climbing frames which may pose a danger if the child has a seizure. The student who is denied the opportunity to participate may develop feelings of social isolation and rejection can be reinforced. Restrictions ideally, should be discussed with the student and family.

Parents should be notified of school excursions and camps well in advance to enable planning for:

- Seizure management training for the teaching staff attending the camp/excursion
- Parents to supply medication
- Contact to be made with medical facilities local to the camp and the availability of emergency services
- Development of a camp plan in collaboration with the treating medical team if needed
- Parents to attend camp/excursion to manage the students' epilepsy if necessary

Epilepsy and behaviour has its complications also. Possible causes could include stress in response to epilepsy and its challenges, some underlying brain damage; anticonvulsant medication often causes dose related or idiosyncratic behavioural side effects and aggressive behaviour that occurs during and immediately after a seizure may reflect confusion. This behaviour can be increased or induced by attempts to restrain the person.

Common types of behavioural problems may include; difficulty with attention and concentration, aggressive verbal or physical behaviour, lack of motivation and energy, inability to plan and organize behaviour, motor hyperactivity, depression, anxiety, irritability, poor social skills, impulsiveness, and mood swings. People with epilepsy may be less responsive to the traditional methods of behaviour management. This does not mean that these methods should be disregarded. However, they may need to be adapted and altered. Finding a strategy that works is often a matter of trial and error.

Some strategies to try include making environmental compensations to reduce stress, avoiding situations which are known to cause stress, reorganizing less structured times of the day, separating goals into small sequential steps, using frequent repetition, modeling calm, controlled, predictable behaviour, redirecting rather than confronting organically based behaviours such as compulsions, using visual cues, having a consistent routine, keeping rules simple and straight forward.

Medicinal Cannabis update

The Hon Cameron Dick, Minister for Health and Minister for Ambulance Services, recently tabled a historic Bill – the Public Health (Medicinal Cannabis) Bill 2016. He said:

“There is a growing body of evidence that demonstrates the possible therapeutic benefits of medicinal cannabis products for a range of conditions. The evidence shows that medicinal cannabis may be an appropriate treatment option, particularly when used to complement traditional treatments. We know that there are Queensland patients out there right now who could benefit from having access to medicinal cannabis products. We know this because the Palaszczuk government has consulted extensively and widely with the community and with health industry stakeholders about the reforms proposed in this bill. More than 96 per cent of respondents to a recent government survey on the Get Involved website regarding the draft bill supported treatment with medicinal cannabis products.

Some who responded to the survey or who have contributed to community debate, particularly on social media, have advocated for the right to grow their own products or for cannabis use to be decriminalised. However, I wish to be clear:

The evidence shows that medicinal cannabis may be an appropriate treatment option...

medicinal cannabis, regardless of its form, is a dangerous drug. When used improperly or as an alternative to proven conventional treatments without close medical supervision it is potentially harmful. When obtained illicitly, whether from a criminal supplier or grown in the back garden, patients have little certainty about the concentrations of active ingredients in the products they are consuming or knowledge about the contaminants to which plant products may have been exposed. For this reason, the use of medicinal cannabis must be regulated properly.

On 11 December 2015, Queensland became the first state in Australia to legalise the use of restricted medicinal cannabis products. On that date the Health (Drugs and Poisons) Regulation 1996 was amended to give the chief executive of Queensland Health discretion to approve the use of medicinal cannabis products for the treatment of a person where an approval to access the product has been given by the Commonwealth Therapeutic Goods Administration. While this was an important first step to permit the lawful use of medicinal cannabis products, a more comprehensive and robust regulatory framework is required. The bill before the House provides this framework.

A draft of this bill was released for community consultation from 1 March 2016 to 1 April 2016. Members of the public made submissions by completing a survey on the Get Involved website. There is strong community interest in this bill. As I noted, an overwhelming majority of respondents supported allowing lawful access to medicinal cannabis products. Targeted consultation was also conducted with key health industry stakeholders including medical professionals in speciality areas for which medicinal cannabis treatment may be sought. These stakeholders strongly supported the framework in the bill, particularly the controls around who can prescribe, dispense and possess medicinal cannabis products.

The framework in the bill provides two pathways for Queensland patients to obtain medicinal cannabis treatment. The first pathway involves patient-class prescribers. Under the patient-class prescriber pathway, a regulation will give certain specialist doctors an as-of-right authority to prescribe medicinal cannabis products to patients suffering specific conditions without the need to obtain any further state approval.

The regulation of all medicines, including medicinal cannabis, involves the application of both state and Commonwealth laws. The TGA schedules all medicines according to the level of regulatory control required to protect public health and safety, and states and territories give effect to these scheduling decisions in their own legislation.

The TGA recently made an interim decision to reschedule medicinal cannabis products from a schedule 9 prohibited poison to a schedule 8 medicine. If this interim decision is made final, appropriately qualified medical practitioners may be authorised under Queensland law to prescribe schedule 8 medicinal cannabis products.

Provided rescheduling occurs, a regulation will be made under the bill to make specialists in paediatric neurology, oncology and palliative care medicine the first medical practitioners authorised to prescribe medicinal cannabis to patients in their care. There is an increasing trend towards national uniformity in the controls implemented between states and territories, and other jurisdictions will be consulted before this list of patient-class prescribers is finalised. However, the Palaszczuk government will ultimately make a decision which best addresses the concerns of both patients and medical practitioners in Queensland.

It is anticipated that the TGA will finalise the rescheduling decision by the end of May. If this happens, the expected implementation date for the rescheduling will be 1 June 2016. As this bill will not be debated until later in the year, I propose to make urgent amendments to the Health (Drugs and Poisons) Regulation 1996 to insert a similar patient-class prescriber pathway. This will allow Queensland patients to take immediate advantage of the final rescheduling decision, without having to wait for passage of the bill. Once the bill commences, the regulation amendments will be repealed.

The second pathway in the bill will be used where a patient is ineligible to be treated by a patient class prescriber. Under the single-patient prescriber pathway, a patient's medical practitioner may make an application to the chief executive of Queensland Health for approval to treat the patient with medicinal cannabis. Applications made under this pathway will be decided on a case-by-case basis.

An expert advisory panel will assist the chief executive to decide whether applications should be approved and what conditions should be imposed. For example, the panel

may provide advice on the appropriateness and safety of treatment based on medical evidence about the patient's conditions and symptoms. Individual patients will still need to seek authority from the Therapeutic Goods Administration to allow for the legal import of medicinal cannabis into Australia. This is done under the special access scheme. The expert panel will also undertake ongoing monitoring of the use of medicinal cannabis in Queensland and may make recommendations to the chief executive about research activities, including targeted clinical trials, to refine the safety and efficacy of these products. A medicinal cannabis approval granted under the single-patient prescriber pathway may be subject to conditions, including general conditions detailed in the regulation or specific conditions imposed by the chief executive. One likely approval condition will be for the prescriber to report back on the clinical outcomes of their patient's treatment. This clinical feedback will assist the chief executive to decide whether suspension or cessation of the approval should be considered and will also add to the knowledge base of the expert advisory panel.

The bill does not authorise people to grow their own cannabis, even if intended for their own therapeutic use, nor does it authorise

any recreational use of cannabis. These activities will remain offences under the Drugs Misuse Act 1986. The bill also contains strong penalties for unauthorised use of prescribed medicinal cannabis products. During implementation of the regulatory framework, the Department of Health will develop a public awareness campaign to highlight that any unauthorised use of cannabis remains illegal. To combat the risk of prescribed medicinal cannabis products being diverted for unlawful purposes, the regulatory framework will limit the amount of medicinal cannabis that can be dispensed to a patient at any one time. The framework will also track the type and amount of medicinal cannabis dispensed to patients through pharmacies. The bill does not regulate the cultivation or manufacture of medicinal cannabis products in Queensland. However, my department is working closely with the Department of Agriculture and Fisheries about how Queensland industries can participate in the new Commonwealth licensing scheme for local cultivation and manufacture of medicinal cannabis. These opportunities will also be discussed with relevant Queensland industry representatives over the next few months in a series of roundtable meetings being jointly chaired by Queensland Health and the Department of Agriculture and Fisheries.

In closing, the regulatory framework in the bill establishes arrangements so that people who need access to medicinal cannabis products can obtain and use them in Queensland. Queensland patients who are able to use medicinal cannabis products under the proposed framework will be carefully monitored by appropriately qualified medical practitioners. The two pathways in the bill will accommodate patients with conditions for which medicinal cannabis is a proven treatment and also those patients for whom medicinal cannabis treatment may be considered more experimental but which offers real hope of effective treatment. The bill also manages the risk of unlawful diversion and provides serious penalties for any misuse of prescribed medicinal cannabis products. This bill is proof that the Palaszczuk Labor government listens to Queenslanders and is leading the way in providing those most in need with comprehensive treatment options to improve their quality of life".

This is an extract from Hansard –see <http://www.parliament.qld.gov.au/documents/tableOffice/BillMaterial/160510/Cannabis.pdf>

diary dates

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

16 July	Memorial Service
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.
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
9 July 5 November	Brisbane Adult Support Group Meeting
11 August 11 November	Northside Brisbane Support Group
7 June 6 September 6 December	Parents/Carers of Children with Uncontrolled Epilepsy Support Group
4 August 18 October Longreach Charleville	2016 Regional Trips For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families



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