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QUEENSLAND EPILEPSY SYMPOSIUM 2016



On Friday 25th November, Epilepsy Queensland joined with the Royal Brisbane Women's Hospital to deliver the 7th Annual Queensland Epilepsy Symposium. It was a fantastic day, with interesting & informative talks from a range of respected speakers, covering topics like epilepsy surgery, medicinal cannabis, managing the impact of epilepsy & dietary therapy research. Of most interest to parents of children with epilepsy, was the session on medicinal cannabis. Anastasia Suraev & Jordyn Stuart from The Lambert Initiative kicked off the session with an informative talk on unlocking the therapeutic potential of cannabinoids, with a focus on what we already know, what we still need to learn & the research that is currently or soon to be underway, as well as outlining the process for accessing medicinal cannabis under the new Qld laws. Details of the The Pelican Study & how you can be involved can be found below. Professor Reutens shared details on the RBWH participation in the topical medicinal cannabis trial in focal epilepsy. Dr Wallace talked about Lady Cilento Children's Hospital's Epidiolex trial in children with Dravet, which is due to start in 2017. It was clear that this is an emerging area in terms of epilepsy research, that holds much hope for future treatment. For more information, please feel free to talk to one of our friendly Service team members.

EPILEPSY SOCIETY OF AUSTRALIA MEDICINAL CANNABIS POSITION STATEMENT:

The Epilepsy Society of Australia is a professional organisation for clinicians, scientists and technologists involved in the diagnosis, treatment and research of epilepsy in Australia. In November 2016, they released the following statement:

Marijuana and Medicinal Cannabis in the treatment of epilepsy

Patients, families, carers and doctors recognise the need, sometimes a desperate need, for additional, more effective and better tolerated therapies for epilepsy. Medical treatment decisions should always be based on knowledge of potential risks and proven benefits of the therapy.

Anecdotal reports of patients with epilepsy experiencing dramatically beneficial responses to treatment with derivatives of marijuana, "medical marijuana" or "medicinal cannabis" as it is often known, have brought renewed attention to its potential as an anti-epileptic therapy¹. Importantly, there are also many reports of people who experience worsening of seizure control with the use of marijuana.

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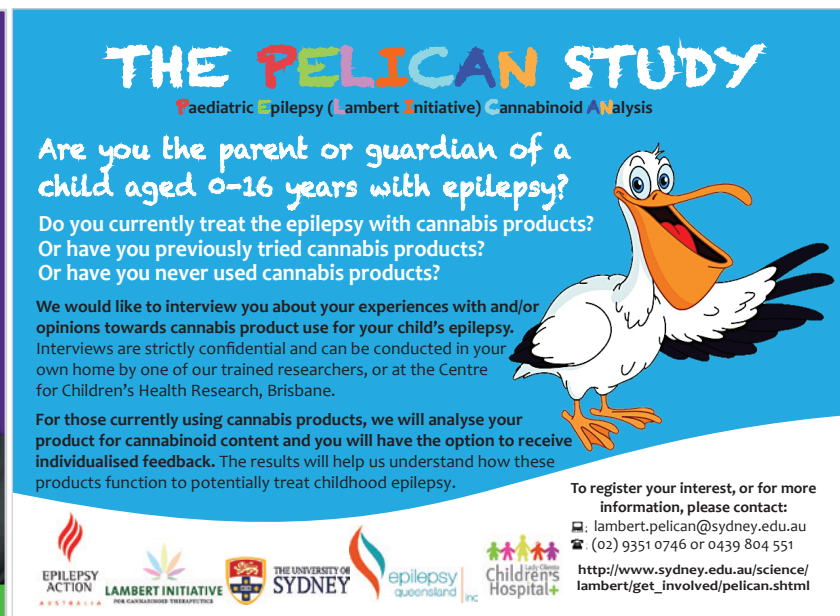


Purple Day 26 March
for epilepsy QLD

Join us
to raise funds and awareness during March

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

1300 852 853 | www.epilepsyqueensland.com.au



THE PELICAN STUDY
Paediatric Epilepsy (Lambert Initiative) Cannabinoid Analysis

Are you the parent or guardian of a child aged 0-16 years with epilepsy?
Do you currently treat the epilepsy with cannabis products?
Or have you previously tried cannabis products?
Or have you never used cannabis products?

We would like to interview you about your experiences with and/or opinions towards cannabis product use for your child's epilepsy. Interviews are strictly confidential and can be conducted in your own home by one of our trained researchers, or at the Centre for Children's Health Research, Brisbane.

For those currently using cannabis products, we will analyse your product for cannabinoid content and you will have the option to receive individualised feedback. The results will help us understand how these products function to potentially treat childhood epilepsy.

To register your interest, or for more information, please contact:
lambert.pelican@sydney.edu.au
(02) 9351 0746 or 0439 804 551
http://www.sydney.edu.au/science/lambert/get_involved/pelican.shtml

EPILEPSY SOCIETY OF AUSTRALIA MEDICINAL CANNABIS POSITION STATEMENT (CONTINUED)

Marijuana contains many different compounds. The most active compounds are the cannabinoids, which include THC (9-tetrahydrocannabinol) and CBD (cannabidiol). THC is the main cannabinoid responsible for the psychoactive and addictive effects of marijuana. THC may be harmful for people with epilepsy and put them at increased risk of psychiatric problems such as psychosis.

The main cannabinoid that is promising as a treatment for epilepsy is CBD. Many reviews emphasise that the current data for CBD in epilepsy are limited, and no definite conclusions can be drawn until further formal clinical trials are published 2-5. The clinical trials reported thus far are for the severe epilepsies of childhood (in particular Dravet and Lennox-Gastaut syndromes), rather than more common types of epilepsy. Further, the safety profile of long term treatment with cannabinoids is not established.

One pharmaceutical CBD (Epidiolex™) has been given Orphan Drug status by the Food and Drug Agency of the United States as an investigational drug therapy for patients with Dravet and Lennox-Gastaut syndromes. A recent open-label non-randomised study in 214 children and young adults with severe uncontrolled epilepsies reported a mean 34% reduction in monthly seizure rate over a 12 week study period⁶. Serious adverse effects were reported in 12% of patients possibly related to CBD intake. The most common severe adverse event reported was status epilepticus, affecting 6% of individuals.

More recently GW Pharmaceuticals announced (by media release) positive results of the first randomised, double blinded, placebo controlled Phase III clinical trial of Epidiolex for the treatment of Lennox Gastaut Syndrome. Epidiolex was added as an adjunct to the patient's current treatment resulting in a significant reduction in seizure frequency over a 14 week period in the treatment group compared patients in whom placebo treatment was added ($p=0.0135$). This trial follows a media announcement in March this year of a positive result for the same agent in a Phase III, double blind, placebo controlled study for Dravet's Syndrome. Formal publication of the results is awaited in a peer-reviewed journal.

More broadly, the adverse effects on health from marijuana intake include effects on brain development, risk of addiction, cognitive impairment during times of intoxication, subsequent psychiatric illness and increased risk of motor vehicle accidents⁴. Currently, we have limited understanding of the long term effects of marijuana intake, including whether it is teratogenic (effects on the unborn baby). Further, the increase in the THC concentration of marijuana in the United States is estimated to have risen from 3% to 12% over the last 30 years. This may lead to increased toxicity⁷.

How should neurologists and other medical practitioners advise patients regarding "medical marijuana" (medicinal cannabis) for the treatment of epilepsy until there is sufficient, good quality evidence from clinical trials to allow informed decisions for best management?

Firstly, the extent of uncertainty regarding efficacy (whether it works in people with epilepsy) and safety of CBD should be explained to patients and families. Secondly, the patient or family should be encouraged to inform a treating doctor if this alternative therapy is being commenced (and the lack of legal implications in doing so emphasised). This means that if a significant change in the patient's health occurs, it can be properly assessed. Thirdly, definitive answers regarding efficacy and safety of marijuana and specific cannabinoids to treat people with epilepsy needs to be obtained from properly constructed and ethically approved double-blind randomized placebo-controlled trials, in both children and adults, in different types of epilepsy. Finally, individual doctors should determine their position on how the use of an illicit substance to obtain a therapeutic benefit should be appropriately managed.

In summary, the Epilepsy Society of Australia has the following position:

- In general, the use of CBD and related agents in epilepsy should be in the context of a human ethics committee approved research trial, as efficacy and safety are still being evaluated. These agents are at a stage of development of an investigational drug.
- There may be select cases of severe drug resistant epilepsies (eg. epileptic encephalopathies) where prescription outside of a clinical trial may be considered, where a suitable compound meeting consistent concentration, bioavailability and stability standards as applicable by the Therapeutic Goods Administration approved medicines is available.
- Recommendations regarding use will likely change with information obtained from clinical trials of these drugs.

References:

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- Detyniecki, K, Hirsch, L. *Marijuana use in epilepsy: The myth and the reality.* *Curr Neurol Neurosci Rep* 2015; 15: 65.
- Friedman, D, Devinsky, O. *Cannabinoids in the treatment of epilepsy.* *N Engl J Med* 2015; 373: 1048-1058.
- Gloss, D, Vickrey B. *Cannabinoids for epilepsy.* *Cochrane Database Syst Rev* 2014; DOI: 10.1002/14651858.CD009270.pub3.
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- Adverse Health Effects of Marijuana Use.* Volkow ND et al. *N Engl J Med* 2014;370: 2219-2227

THE TEA ROOM

A Friendly Space for Young People with Epilepsy

www.thetea-room.com





Before the start of the new school year have you thought about the following:

- Do you have an **Epilepsy Management Plan?** Epilepsy Queensland can help you with a new epilepsy management plan template or we can help complete the plan for you, making it easier for you to update at any time or obtain a new copy at any time. It is always best to make several copies of this plan for your own record.

- **Midazolam Management Plans** need to be written by the doctor who has prescribed the medication. Epilepsy Queensland can provide you with a Midazolam management plan template for you to take to your prescribing doctor for them to complete. It is always best to make several copies of this plan for your own record.

• Check Your Midazolam Kit:

- ✓ Check the expiry date of the Midazolam
- ✓ Is the Midazolam wrapped in the original foil packaging or aluminium foil?
- ✓ Is the foil packaging labelled with the date the packaging was opened? (Midazolam expires within 8 months of opening the foil packaging)
- ✓ Does the kit have your child's name clearly marked for easy identification?

• Does Your Midazolam Kit Contain:

- ✓ Plastic Midazolam vials 5mg in 1ml
- ✓ Syringes if required
- ✓ An atomiser for intranasal administration if required
- ✓ Disposable plastic gloves
- ✓ Pencil and paper for documentation
- ✓ The new Midazolam Management Plan

• Have You Considered the Following:

- ✓ Are the contents of the kit stored in a container? (a small plastic lunchbox is suitable)
- ✓ Is the container kept out of reach of children, both at home and school?
- ✓ Is the kit kept below 25 degrees Celsius, and out of direct sunlight, both at home and at school? (Midazolam is not to be stored in the fridge or freezer)
- ✓ Have you provided an ice brick and cooler for the kit to be stored in during the hotter months when taking the kit outside?
- ✓ Do you have a separate kit for home and school? (This is to ensure the kit is never forgotten between destinations)

Midazolam is not to be kept on the child's person, in their school bag or desk. It is to be given to the school teacher or support worker for storage away from children, but it needs to remain accessible to staff in the event of a seizure occurring.

- Does your child's school teacher, day care teacher, support worker, grandparent or other family or friends caring for your child at any time need **training in Understanding Epilepsy or the Administration of Midazolam?** Epilepsy Queensland can provide training in these areas both during the day and after hours. Please contact Epilepsy Queensland for a training request form.

- **Will your child be participating in any school based or personal swimming programs, hydrotherapy, horse riding, sailing or school camps?** If yes, you will need a letter from your doctor giving your child permission to participate in one or all of these activities. All schools now request these letters before the child is allowed to participate, and they do not always give you a lot of notice. Considering how difficult it can be to get an appointment with your doctor, it is advisable that you have all the required letters written in one go prior to the start of the New Year. It is one less thing you will have to worry about. If you would like more information on how your child can swim safely with epilepsy, please contact Epilepsy Queensland for our fact sheet on epilepsy and swimming.

- Does your school, day care centre, respite facility or your home need resources to assist in understanding epilepsy? Epilepsy Queensland has a range of **children's story books available** to help both children and adults understand epilepsy. Please contact the office for information on the children's books and resources available.

For more information or help with any of the above please contact Epilepsy Queensland on

07 3435 5000

Status Epilepticus Study

We would like to say a huge THANK YOU to everyone who participated in our online survey for the status epilepticus research project that is being conducted at The Townsville Hospital.

We had such a fantastic response, which gave us a really valuable insight into people's ideas for prioritising research in this condition. This stage of the study is now complete and we will inform you when we have results available. Again, thank you for your support, it is greatly appreciated!

From The Research Team
Townsville Hospital

WHAT'S ON...



'UNDERSTANDING EPILEPSY' WORKSHOPS BRISBANE

Epilepsy Queensland is holding monthly workshops in our Woolloongabba office on:

16 February (9.30am & 5.30pm)
16 March

'UNDERSTANDING EPILEPSY' WORKSHOPS GOLD COAST

Epilepsy Queensland holds bi-monthly workshops at Benowa:

8 March

CARER & PARENT SUPPORT GROUPS

Bracken Ridge Library

10 February

Bulimba Library

23 March

EVENTS

13 February 2017 • International Epilepsy Day

25 February 2017 • Purple Ball

26 March 2017 • Purple Day

For further information on any of the above events please contact Epilepsy Queensland on 07 3435 5000 or 1300 852 853 (Regional Queensland) or email epilepsy@epilepsyqueensland.com.au.

Do we need to update our mailing list?

We hope you enjoy reading the Livewires newsletter. However, if you no longer wish to receive Livewires, please let us know by calling 07 3435 5000 or 1300 852 853 (Regional Queensland) or emailing pr@epilepsyqueensland.com.au.

We would also greatly appreciate being advised if you have received multiple copies at the same household, so we can update our records accordingly. Thank You!



Telling your story is a great way to raise awareness about epilepsy. We are keen to raise the profile of epilepsy and increase community understanding and acceptance of epilepsy every single day. You can help so much by volunteering to tell your story in our publications and the media.

Please contact pr@epilepsyqueensland.com.au if you're interested in assisting or just want to have a conversation about what may be involved.

EPILEPSY QUEENSLAND'S UNDERSTANDING EPILEPSY AND ADMINISTRATION OF MIDAZOLAM TRAINING

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

Come along...

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

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

Download a flyer from our website (www.epilepsyqueensland.com.au) or call to register. We would love to see your family, friends and colleagues there or come along to meet new people.

Hint... !

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

Encourage your school to get in quick as training dates for early 2017 are booking out fast! Contact us for more information.

What we offer...

Understanding Epilepsy

Administration of Midazolam

Epilepsy awareness (tailored to individual needs)

Length - 1.5 hours to 4 hours

How to organise an education session

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

Need after hours training?

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

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

Testimonials

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

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

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