



the flame

Issue 3 – 2016

the newsletter of epilepsy queensland inc



*Some of EQI's wonderful volunteers
with Chairman Steve Eltis*

inside...

Lendlease
Golf Day



Bridge
to
Brisbane



Spark
NeuroCare
Launch



Able X



Epilepsy Queensland is proud to have participated in QCIDD's "AbleX" initiative. This XSeries Program has been designed to influence, empower and educate a wider population to improve the health and healthcare of people with intellectual disability.

Worldwide, 60+ million people with intellectual disability experience poor health, die prematurely and receive inadequate healthcare. You will gain an understanding of the barriers and enablers for people with intellectual disability, their families, and their healthcare providers.

In the courses, you will learn about best practice in the field of intellectual disability healthcare and gain knowledge to improve health outcomes for this disadvantaged group.

Hear the voices of people with intellectual disability around the world, their families and healthcare practitioners:

- What is their experience – what barriers do they face and how do they overcome these?
- What are their healthcare needs and how can good health be promoted?
- What health conditions do they commonly experience and how can these be assessed and managed?
- What influence do other factors such as ageing and epilepsy have on their health?
- What mental health issues do they have and how can these be recognised and managed?
- What are some of the ethical and legal

issues that are of particular relevance to them?

What is an XSeries?

An XSeries is a group of courses that add up to a rich understanding of an area of study. Once you pass the entire series, receive a personalized XSeries Certificate that shows you put in the work, understand the material, and you have a shareable certificate to prove it!

More than 120 contributors from 22 countries have provided content for ABLE XSeries. The courses are self-paced and free. The courses are tiered to fit with Years 1, 2, 3 of any health, medical, or related degree. They can also be used for workforce education and can be accessed here: <https://www.edx.org/xseries/intellectual-disability-healthcare>.

ABLE XSeries

This online course series is free and open to anyone interested in improving healthcare for people with intellectual disability.

A certificate is offered on completion. If you need proof for an employer, school, or other institution that you have successfully completed the online course, you can purchase a verified certificate from edX (USD\$99).

ABLE101x – Through my Eyes focuses on the stories of people with intellectual disability around the world, and their families and supporters. Over four parts, students will look at the barriers and enablers to healthcare for people with intellectual disability, their experience of specific syndromes and communication difficulties, and how they stay healthy. Students will listen to family

members speaking about complex care, rare syndromes, early death, and planning for independence. The final component focuses on the history of treatment, the impact of rights' movements on healthcare delivery, common health conditions, and health promotion. <https://www.edx.org/course/through-eyes-intellectual-disability-uqx-able101x>

ABLE201x – Well and Able examines the specific physical health issues that affect people with an intellectual disability including, oral health, syndrome specific health issues, health communication, especially for non-verbal patients, sexual health, and interactions between tertiary and primary healthcare systems. There is a special section on complex care including issues associated with aging and spasticity, and the health impacts of epilepsy. <https://www.edx.org/course/well-able-improving-physical-health-uqx-able201x>

ABLE301x – Able-Minded focuses on the mental health issues of people with intellectual disability. Students learn about the complexities of diagnosing mental health issues in people with intellectual disabilities and the types of disorders, assessments, screenings, and treatments used. There is a special focus on the legal and ethical complexities in health practice with patients who often require substituted consent. <https://www.edx.org/course/able-minded-mental-health-people-uqx-able301x>

We loved working with the QCIDD team and would like to thank Miriam Taylor in particular.

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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

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, until a patient has been deemed suitable for screening, and the parents have signed the consent.

MEDADVISOR



A common scenario faced by QLD resident, Toni See, was losing her scripts or forgetting when she was due to fill her repeats.

In order to stay on track, she started keeping her scripts on file at her local pharmacy, Malouf Bundaberg at Southside Central. It was here that she was introduced to MedAdvisor by her pharmacist.

With MedAdvisor, Toni can view her medication records and pre-order medications so when she arrives at the pharmacy there's no waiting required. MedAdvisor is available free to all Australians on smart phone, tablet or PC.

Toni also receives useful reminders through MedAdvisor about when to take her medications, when to fill her scripts and when to see her doctor.

"I suffer short term memory loss so before this app, I was always losing scripts and had no idea when I was due to get a new one or how many. Now, I get sent reminders about my medications, ensuring I never forget."

Pharmacy partner, Wayne Stoff, at Southside Central in Bundaberg says MedAdvisor is an excellent tool for all. "Patients of all ages love using the program, especially those who are taking multiple medications or those caring for other family members. The Tap-To-Refill ordering feature is very popular amongst those who don't have time to wait around at the pharmacy. It also means scripts are never lost."

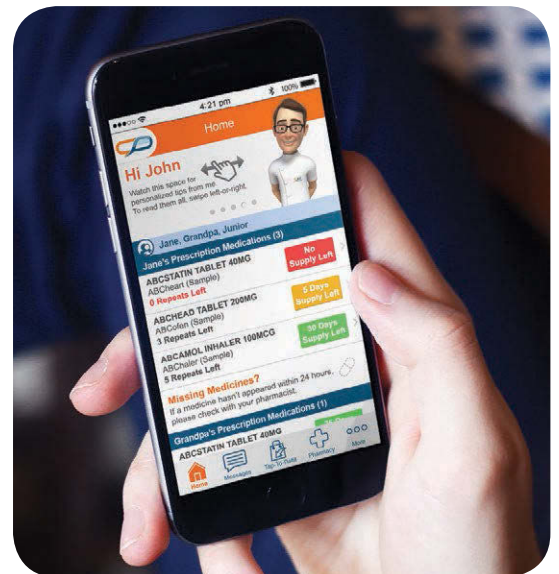
Toni says "I am able to go onto the app, order my medications and pick them up without having to wait. Malouf Bundaberg are really quick to process my order and send me a notification when it's ready to collect".

Wayne tells his patients they can place a Tap-To-Refill order at any time. "Even if it is at 11pm at night and you suddenly remember you are running low, place the order and we will process it first thing in the morning. This eliminates the chance of forgetting later."

This is certainly true for Toni, who says "I can't fault MedAdvisor. It has greatly relieved my stress and confusion, keeping me organised and on track. I would be lost without it."

More than 195,000 + Australians use MedAdvisor to organise and order their medications. To join them, go to the website start.medadvisor.com.au/epilepsyqld

For every new sign-up through the above link, MedAdvisor will donate \$1 to Epilepsy Queensland



Status Epilepticus Research - The Townsville Hospital

Dr Jeremy Furyk, an Emergency department specialist and researcher at The Townsville Hospital is conducting a research project and we would like you to be involved.

The research aims to gain a consensus on research priorities from people who have been affected by status epilepticus. If either you or a family member has had an episode of Status Epilepticus, then we would like to know what your ideas are for prioritising research in this condition.

There will be two to three rounds of online surveys, each taking approximately 5-10 minutes and we would appreciate your participation. Your insight to this medical condition is extremely valuable to us and future research.

What do you need to do?

We would be grateful if you could complete the online survey, please go to <https://www.surveymonkey.com/r/39NKBRN>

Thank you for your time and commitment, it is greatly appreciated!



Medicinal Cannabis

The use of medicinal cannabis as an appropriate treatment in certain circumstances is currently being discussed in Queensland and the rest of Australia.

Public consultation, consideration and education are important factors in these discussions.

Currently there are two activities underway:

- Clinical trials (see the fact sheet)
- Proposed regulatory framework
 - A new Bill is being proposed to provide a formalised process for doctors to follow if they want approval to prescribe medicinal cannabis as part of their patient's overall treatment.
 - The proposed Public Health (Medicinal Cannabis) Bill 2016 was introduced into Parliament on 10 May 2016. It was referred to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee. A public departmental briefing was held on 15 June 2016. Submissions closed on 11 July and a hearing took place on 17 August 2016. The Committee's report is due by 30 September 2016.

Epilepsy Queensland has been involved in the consultation process and has representation on the Steering Committee for the clinical trials.

Although the Bill will allow people to seek approval to use medicinal cannabis, it's important to remember that access to medicinal cannabis products will still require additional approval from the TGA.

The Queensland initiatives ensure the foundations are in place to facilitate the improved access to medicinal cannabis treatment which may occur as a result of the Commonwealth Government's recently-passed legislation to allow domestic cultivation and manufacture of medicinal cannabis products.

The Commonwealth Government's role

Presently, no medicinal cannabis products are produced in Australia. This means to access a medicinal cannabis product, TGA

approval is required to import the product from overseas.

Australia has international obligations under the Single Convention on Narcotic Drugs 1961. To meet these obligations, the Commonwealth Government controls access to dangerous drugs through the TGA.

In February 2016, the Commonwealth Government passed legislation to allow domestic cultivation and manufacture of medicinal cannabis products. This means that in the future, the TGA could also approve access to Australian-produced medicinal cannabis products.

The regulatory framework for Queensland proposed in the proposed Public Health (Medicinal Cannabis) Bill 2016, provides robust controls around treatment with medicinal cannabis to prevent unauthorised use of these products. As such, the framework complements the Commonwealth Government's international obligations.

Making an application

There are currently no businesses licensed by the Commonwealth Government to cultivate or manufacture medicinal cannabis products within Queensland or elsewhere in Australia.

In order to legally access medicinal cannabis products they will need to be imported into Australia. These products are not on the PBS so all expenses are borne by the patient.

Legally imported medicinal cannabis requires approval from the Commonwealth Government's Therapeutic Goods Administration (TGA). If after consulting with your medical practitioner you determine that medicinal cannabis may be an appropriate treatment for you, your medical practitioner can make an application for legal importation of medicinal cannabis to the TGA under the Special Access Scheme.

If your medical practitioner holds a Special Access Scheme approval please have

them contact Queensland Health on 3328 9808 as both a State and Commonwealth approval will be required.

The Queensland Government is the only State Government to have enabled access to unregistered medicinal cannabis containing THC for therapeutic use so far in Australia. This was made possible by changes to the Health (Drugs and Poisons) Regulation 1996 in December 2015.

The GP or specialist involved in your care may apply for approval to supply medicinal cannabis if they determine there is significant scientific evidence for its effectiveness for your condition. Given that cannabis is an unapproved medicine, this requires both State and Commonwealth approval.

Source acknowledgement and for more information visit these Queensland Health web pages:

<https://www.qld.gov.au/health/conditions/all/medicinal-cannabis/queensland/>

<https://www.health.qld.gov.au/publications/system-governance/legislation/reviews/medicinal-cannabis/overview-medicinal-cannabis-2016.pdf>

<https://www.qld.gov.au/health/conditions/all/medicinal-cannabis/trials/index.html>

Medicinal Cannabis

Queensland clinical trials for children with severe epilepsy

The Queensland Government has established a partnership with GW Pharmaceuticals, a UK-based pharmaceutical company, for medicinal cannabis trials for children with severe treatment-resistant epilepsy.

The first of these trials will be using a pure cannabidiol product, Epidiolex®. Cannabidiol is a non-psychoactive cannabinoid. GW Pharmaceuticals has a number of other cannabis-derived pharmaceutical products in the development pipeline.

Clinical trial using Epidiolex®

The agreement with GW Pharmaceuticals allows for a clinical trial for compassionate access for a limited number of eligible children suffering from severe treatment-resistant epilepsy to use the medicine Epidiolex®.

The children will be able to use Epidiolex® as part of their treatment plan under a medically supervised trial that will take place at the Lady Cilento Children's Hospital (LCCH).

Key outcomes under the partnership for Queensland

1. A clinical trial using Epidiolex® for a maximum of 30 children with severe treatment-resistant epilepsy.
2. The establishment of a specialist centre to oversee the clinician-led trials into medicinal cannabis.

Substances for the trials

The GW Pharmaceutical product Epidiolex® will be used in the clinical trial. It is a recognised medicine, not a crude cannabis product, and has been manufactured to the highest specification. The product is pharmaceutical grade and made in a GMP (Good Manufacturing Process) accredited facility.

Epidiolex® a liquid formulation of pure plant-derived cannabidiol, or CBD, which is in development for the treatment of a number of rare paediatric epilepsy disorders. Epidiolex®

is taken orally and is currently being investigated overseas for the treatment of various rare childhood epilepsy syndromes, including Dravet syndrome and Lennox-Gastaut Syndrome. Epidiolex® has shown positive results in a compassionate use scheme in the United States and in Phase 3 trials in patients with Dravet syndrome and Lennox-Gastaut syndrome.

Research to date

A number of trials of the cannabinoid medicine, cannabidiol (Epidiolex®), in children with seizure disorders have shown promising results in certain sub-groups of children with epilepsy, including positive results in two Phase 3 clinical trials in the US and Europe in patients with Dravet syndrome and Lennox-Gastaut syndrome. Other cannabinoids, such as cannabidivarin (CBDV), have shown promise in animal models of epilepsy. Clinical evaluation has shown the possibility that cannabidiol may interact with other anti-epileptic medicines, and the precise nature of these potential interactions is being investigated in clinical trials. This means that children need to be carefully monitored for side effects and to ensure that their drug levels remain therapeutic and do not enter the toxic or harmful range.

Cannabis-derived medicines do not work for all children with epilepsy and some children do not tolerate the side effects and need to discontinue the treatment. However it is expected that some children will have a reduction in seizures and it is hoped that a smaller number may become seizure free. These trials will help clinicians understand who is most likely to benefit from using these medicines and what side effects they need to watch out for if these medicines become used more frequently.

Leading the trials

A team of researchers from Children's Health Queensland (CHQ) at the LCCH will develop the trials under the leadership of LCCH Director of Paediatric Neurosciences, Dr Geoff Wallace.

Purpose and Design of the clinical trials

In the first instance, the purpose of the trials will be determining if Epidiolex® is effective for the treatment of children suffering severe treatment-resistant childhood epilepsy.

The design of this initial trial will be almost the same as that of the compassionate access scheme being undertaken in NSW. This will allow collection of a large amount of data that will be used to inform ongoing trials or development of protocols for the use of this product in Australia.

Participating in the trials

Due to the limited quantity of GW Pharmaceuticals' product Epidiolex® that can be obtained at this time, a maximum of 30 children with severe treatment-resistant epilepsy, no co-existing conditions, and who are under the care of a paediatric neurologist, will be able to take part in the trial.

Not every child who takes part in the trial will obtain benefit, due to the complex nature of treating treatment-resistant epilepsy.

Anyone who thinks they are eligible and is interested in participating in the trial can call 13 HEALTH to register an expression of interest, or talk to your treating doctor.

Families will be advised if they meet the criteria and will be invited to take part in the trial.

Recruitment for the trials is likely to start on 1 November 2016, and pending approval, the trials should start by the end of 2016.

More information

Participants will need to meet specific criteria to participate in the trial:

Anyone who thinks they are eligible and is interested in participating in the trial can call 13 HEALTH to register an expression of interest, or talk to your treating doctor.

Queensland Health fact sheet. To read online go to <https://www.qld.gov.au/health/publications/conditions/all/medicinal-cannabis/trials/qldclinicaltrials-children.pdf>

Q: I don't really like the idea of taking medication, what are some ideas for taking medication safely and effectively?

A: Epilepsy is caused by a disruption in the electrical activity of the brain. The abnormal electrical impulses occur due to altered levels of some chemicals in the brain. Antiepileptic medication (AED's) can control brain chemicals which send signals to nerves so that seizures do not happen.

When you are prescribed a new medication, make sure you discuss with your doctor:

- If you've had an allergic reaction to similar medicines (ask your doctor to check your records).
- If you are pregnant or intend becoming pregnant.
- If you are taking an oral contraceptive as they may interact with antiepileptic medications, resulting in reduced effectiveness of the oral contraceptive pill. Your doctor will discuss with you the possible risks and benefits.
- If you are breastfeeding, or wish to breastfeed. Your doctor will discuss with you the possible risks and benefits.
- If you have liver disease, kidney disease or kidney stones.
- If you are taking any 'over the counter' medications or any complementary therapies.

Before you take your AED's it is a good idea to check:

- The expiry date (EXP) printed on the package. Do not take medication that has expired.
- Do not take capsules if the packaging is damaged or shows signs of tampering.

Can I substitute a cheaper brand?

Most neurologists advise that patients check with their neurologists if an alternative brand is suitable. Swapping and changing brands can affect the blood levels of your medication. All antiepileptic medication should be stored in a safe place where children cannot reach. A locked cupboard at least one-and-a-half metres above the ground is a good place to store medicines. Keep your medication in its packaging until it is time to take it. Most

antiepileptic medication should be stored below 25°C and kept away from light.

Do not leave your medication in the car or on window sills.

Do not store medicines in the bathroom or near a sink. Heat and dampness can destroy some medicines. If a package of medication has expired or is damaged, return it to your pharmacist for disposal.

Tell your doctor or pharmacist if you are taking any other medicines, including medicines you buy without a prescription from your pharmacy, supermarket or health food shop (including vitamins). Some medicines may affect the way other medicines work or absorbed.

Always follow your doctor's instructions about how to take antiepileptic medication. Keep taking your antiepileptic medication for as long as your doctor tells you. Antiepileptic medication helps to control your condition, but does not cure it. Therefore, it is important to keep taking your medication every day. Your doctor will check your progress to make sure the medicine is working and will discuss with you how long your treatment should continue. Antiepileptic medication is meant to be taken as a long-term medicine. Do not reduce your dose or stop your medication unless your doctor tells you to.

If you forget to take your medication

If it is almost time for your next dose, skip the dose you missed and take your next dose when you are meant to. Otherwise, take it as soon as you remember, and then go back to taking your medication as you would normally. Do not try and make up for the dose that you missed by taking more than one dose at a time. This may increase the chance of you experiencing an unwanted side effect. If you are not sure what to do, ask your doctor or pharmacist. Make sure you are honest with your doctor so the dose is not unnecessarily increased.

If you have trouble remembering to take your medicine, speak to the services team at Epilepsy Queensland to find out some hints on how to remember.

If you have taken too much, you need to immediately telephone your doctor or the Poisons Information Centre (telephone 13 11 26) for advice, or go to Accident and Emergency at your nearest hospital, if you think that you or anyone else may have taken too much of their antiepileptic medication. Do this, even if there are no signs of discomfort or poisoning. You may need urgent medical attention. If you are not sure what to do, contact your doctor or pharmacist. Keep telephone numbers for these places handy.

Signs of overdose include drowsiness and sleepiness. You should not drive at this time.

While you are taking antiepileptic medication, there are things you must do:

- Tell your doctor if, for any reason, you have not taken your medicine exactly as directed. Otherwise, your doctor may think that it is not working as it should and change your treatment unnecessarily.
- Tell your doctor immediately if you become pregnant.
- Tell any other doctors, dentists, and pharmacists who are treating you that you are taking antiepileptic medication.

There are things you must not do:

- Do not give your medicine to anyone else, even if their symptoms seem similar to yours.
- Do not use your epilepsy medication to treat any other complaints unless your doctor directs you.
- Do not stop taking your medication, or lower the dosage, even if you are feeling better without checking with your doctor. If you stop taking your epilepsy medication suddenly, your condition may worsen and your chance of experiencing an unwanted side effect may increase.

To prevent this, your doctor may gradually reduce the amount of medication you take each day before stopping the medicine completely.

There are things to be careful of:

- Be careful driving or operating machinery until you know how the new medication



affects you. Antiepileptic medication may cause drowsiness in some people. Make sure you know how you react to your medication before you drive a car, operate machinery, or do anything else that could be dangerous.

- Make sure you keep cool in hot weather and drink plenty of water.
- When starting a new medication, avoid alcohol. Once you have been taking the new medication for a few weeks it is safe for many patients to drink in moderation. (see 'Epilepsy and alcohol' fact sheet for more information)

Like other medicines, antiepileptic medication can sometimes cause unwanted side effects. Sometimes they are serious, though most of the time they are not. You may need medical treatment if you experience some of the side effects. If you do experience any unwanted side effects, tell your doctor or pharmacist.

MILD Side Effects:

Tell your doctor if you notice any of the following that are troublesome or ongoing:

- drowsiness or sedation (especially early on in the treatment)
- loss of appetite
- loss of weight
- dizziness
- loss of concentration
- nausea
- agitation or irritability
- double vision
- depression
- poor muscle coordination

- confusion
- poor memory
- stomach pains
- diarrhoea
- speech abnormalities
- skin rashes, fever and allergic reactions
- anxiety or nervousness
- tremor
- sounds in one ear or both ears
- constipation
- dry mouth
- changes in taste
- joint pain
- flu symptoms
- headaches
- shortness of breath

These are the more common side effects of antiepileptic medications. They are usually mild and in some cases short-lived. They tend to be at their worst in the beginning but go away as your body gets used to the medication. Side effects also tend to be lessened if the medication is introduced gradually.

SERIOUS Side Effects:

Tell your doctor immediately if you notice any of the following:

- strange or unusual thoughts
- sharp abdominal pain
- prolonged respiratory and urinary tract infections
- an increase in seizures
- skin rashes
- change in gait (walking style)

- loss of balance
- impaired sensation
- change in vision

Tell your doctor immediately or go to Accident and Emergency at your nearest hospital if you notice any of the following:

- sudden signs of allergy such as a rash, itching or hives on the skin
- swelling of the face, lips, tongue or other parts of the body
- wheezing or troubled breathing
- swollen glands
- hallucinations
- memory loss
- insomnia
- thoughts of suicide
- decreased sweating and heatstroke
- muscle pain or weakness

These are very serious side effects. You may need urgent medical attention or hospitalisation. Life threatening reactions can include coma and even death. These side effects are rare and you may not experience any of them.

Where to go for further information?

If you have any further queries regarding your medication, please don't hesitate to contact the services team at Epilepsy Queensland or discuss this with your doctor or pharmacist. You may also like to call the Medicines line on 1300 633 424.

References: National Prescribing Service Limited

www.nps.org.au



Little Poss Appeal

State Epilepsy Awareness Campaign - September Epilepsy Queensland needs your support!

Help us create positive change for children living with epilepsy by raising awareness and much needed funds. Let's make September the month we bring epilepsy out of the shadows by participating in the Little Poss Appeal at your school, workplace, business or home.

September is a special month at Epilepsy Queensland because it is our mascot - Little Poss' birthday. Little Poss has epilepsy as some possums do. He helps children learn about epilepsy and how to deal with seizures, medication, teasing and schoolwork.

How you can help?

Help us sell our range of cute merchandise including pens, Poss badges, keyrings and awareness wristbands - plus gorgeous plush possums. This year we have a new cute possum finger puppet! This is a simple yet meaningful and fun way to not only raise funds but also increases community awareness, both of which are of enormous benefit to people living with epilepsy.

Each order comes with a compact counter display box, Little Poss stickers for retail staff to wear and promotional posters. It's easy to do your bit! As the merchandise is sent on consignment - there is no cost to you.

Other ways to help?

- 1 Arrange a Little Poss Theme Day** or Morning/Afternoon Tea in exchange for a gold coin donation to Epilepsy Queensland at work, school or your home – a "P" party perhaps or serve "possum patty cakes"? Nothing is imPOSSible!
- 2 Be a Little Poss Hero** - set up your own online fundraising challenge page on Everyday Hero. Walk, run, shave your head or give up something you love for the month of September. www.everydayhero.com.au/event/littleposs
- 3 Celebrate Little Poss' birthday or yours** – Are you celebrating your birthday or a special event in September? Ask your family and friends to donate to Little Poss and Epilepsy Queensland in lieu of gifts. Set up your celebration page at: www.everydayhero.com.au/event/celebrateforepilepsy
- 4 Buy Merchandise** - visit our online shop, download and return an order form or purchase from a participating pharmacy or location near you. www.epilepsyqueensland.com.au/shop
- 5 Donate online** - make a secure **online** tax deductible donation. Visit www.epilepsyqueensland.com.au/donate.
- 6 Promote on Facebook** – Participate in our "Where is Little Poss?" Facebook challenge. Print the Little cutout Poss and post a picture of yourself and Little Poss in a fun or unusual place. Share on your own Facebook page tagging us @EpilepsyQueensland or emailing pr@epilepsyqueensland.com.au. We'll be sharing the best photos and the winner will receive a great prize.



Contact Us

So what are you waiting for?

Register today for the Little Poss Appeal activity of your choice or contact us for further information.

Phone: 07 3435 5000 or 1300 852 853 (Regional Queensland)

Email: pr@epilepsyqueensland.com.au

Epilepsy Queensland would like to thank the following for their kind and valued ongoing support:



Little Poss launches the Appeal at Nashville Pharmacy

Each year a number of community minded pharmacies put up their hand to help raise awareness and funds for the Little Poss Appeal. One of our most dedicated is the Nashville Pharmacy at Brighton on the Northside of Brisbane. To launch the campaign Little Poss delivered the first awareness and merchandise kit. He was also joined by Christine and little Chloe Clarke who lives with Dravet Syndrome, a rare form of childhood epilepsy.

Pharmacist Zarina Scholz says: "As a local pharmacy we are always happy to support community health projects. There are a number of people living in the Bayside area with epilepsy and it is so important that they continue to have the support of Epilepsy Queensland. We are proud to be supporters of the Little Poss Appeal for the 9th year and hope the community will show their support for Epilepsy Queensland by visiting their local participating pharmacy to pick up their very own Little Poss badge, pen, or plush possum."

Our sincere thanks go out to the Pharmacy Guild of Australia (Queensland) for their ongoing support of Epilepsy Queensland and the Little Poss Appeal.



Chloe Clarke meeting Little Poss as he delivers the first box of merchandise to Nashville Pharmacy

Celebrating 20 years of walking to make a difference

It was a beautiful, sunny August morning for 30,000 runners and walkers out for Queensland's biggest fun run. This year's Bridge to Brisbane event was a celebration of 20 years raising funds for charity and getting Queenslanders out of bed early on a Sunday morning.

For a number of our wonderful Epilepsy Queensland supporters this was a chance to raise funds for essential services for Queenslanders living with epilepsy and/or pay tribute to a loved one. We are pleased to report that 49 teams and individuals registered to raise funds and awareness of epilepsy whilst they challenged themselves on the 5km or 10km routes. In total the Epilepsy Queensland heroes raised nearly \$26,000 and we thank every single one of them for helping to bring epilepsy out of the shadows.

Special thanks go out to Team Sammy Milne for raising an amazing \$19,822 (and still counting!). The 106 strong team were raising funds in honour of their much loved family member and friend who sadly passed away recently. Their fantastic island shirts made them stand out from the crowd and were a wonderful tribute to Sammy's vibrant personality.

We also wish to thank the Purple Power Walkers led by our own passionate staff member Karen Lavin. Her team of walkers dressed lavishly in all kinds of purple gear were a favourite with other walkers who stopped them to get selfies along the way.

If you would like to join our Purple Power Walkers team for next year's Bridge to Brisbane or are interested in participating in one of a number of other similar challenge events throughout the year we would love to hear from you!



Record was broken at the Lendlease Charity Golf Day

It was an early start for 144 keen golfers at Indooroopilly Golf Club, out in support of Epilepsy Queensland and Legacy for the annual Lendlease Charity Golf Day. After their spirited round of golf the very generous participants were whipped into a frenzy of giving by the always entertaining Rupert McCall, Epilepsy Queensland's Patron Wally Lewis and auctioneer extraordinaire Scott Gemmell from LJ Hooker New Farm.

We are pleased to report that the event raised a record breaking \$86,000 to be shared equally between the two charities. Now in its seventh year, the event has raised an amazing \$492,000 for Queensland charities and Epilepsy Queensland is honoured to be one of the beneficiaries each year since 2010.

Epilepsy Queensland's CEO, Helen Whitehead, is thrilled with the result - thanks to the dedication of Lendlease's Maria Bran and the Golf Day Committee. "The past seven year's contributions have been a very important part of our fundraising income - ensuring our epilepsy helpline is available for Queenslanders desperately in need of support and information. We are touched by the generosity of all involved particularly the inspiring team at Lendlease and the wonderful sponsors. The golf day is a wonderful opportunity for workmates to express their competitive side or just have a fun round of golf in support of Queenslanders in need."

If you would like to raise funds by hosting or supporting an event for Epilepsy Queensland please contact Leigh Gilbert on 07 3435 5000. Together we can make a very real difference for Queensland children and adults living with epilepsy.



GOLD SPONSORS:



Civil Contractors

SILVER SPONSORS:



FIP ELECTRICAL



BRONZE SPONSORS:



Giving Back to Bring Epilepsy out of the Shadows

When Michelle and Michael Hiller's youngest son Ned was diagnosed with epilepsy at the age of three, they were adrift in a frightening new world of hospital visits and uncontrolled seizures. They had many misconceptions and a myriad of information thrown at them. One of the first calls they made was to Epilepsy Queensland. The practical information and support provided by the team during that early time has never been forgotten. Michelle and Michael have spent the last nine years paying that support forward and five years ago they became regular givers of Epilepsy Queensland donating \$50 per month. Their aim is to help bring epilepsy out of the shadows.

"Our youngest son Ned was diagnosed in 2007 with (uncontrolled) epilepsy. Ned had his first seizure just before he turned three. We didn't know what was happening.

We were given a lot of information by the hospital, but we still felt very naive with regards to what was involved. We had always thought that epilepsy was manageable with medication but what we found with Ned was very different. He is in the third of the epilepsy population that have uncontrolled epilepsy.

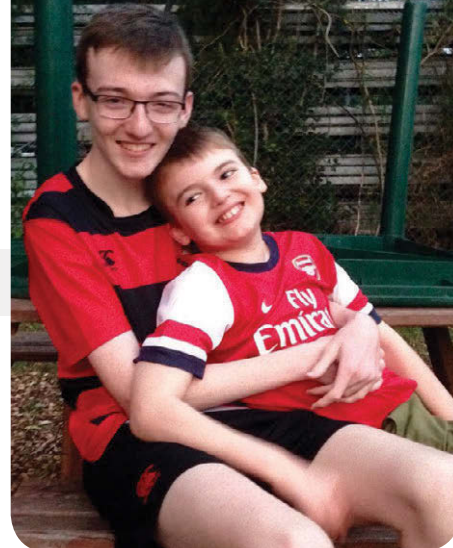
Ned has tonic clonic seizures and absence

seizures mostly at night. It has really affected his development and he was so bright before it all started. For some people epilepsy has a huge effect for others it doesn't and that can be hard to explain to people.

Unfortunately nine years down the track and Ned is still the same. He has been on a real journey trying 12 different medications, surgery and the ketogenic diet. We are currently trying Vagus nerve stimulation (VNS Therapy®). We have had wonderful support from Ned's Paediatric Neurologists Dr Geoff Wallace and Dr Kate Riney. EQI has also been with us all the way and has connected us with others who were going through the same thing. It's been a long journey and it's still going. We rely on EQI to keep up to date with future solutions and treatments that are coming. We always read any information on research and treatments through the Flame magazines.

EQI is one of the major charities we support. If we can do that on a regular basis EQI knows what is coming in and can budget for it. We don't receive appeal letters anymore so feel that is the most efficient use of our contribution.

We also help in other ways where we can. We take a table for the Purple Ball and take our



● Nick and Ned

friends along which we really enjoy. Michael's work (KPMG) also recently held a morning tea to raise money for EQI. When we show our support for EQI we feel that it is helping to get the message out there. We can all do something to help.

Epilepsy Queensland is such an important charity to support and yet the impact and prevalence of the condition is not recognised by most people. With our personal connection we know that it is statistically one of the most common serious brain disorders in the world. There are more people living with epilepsy than with muscular dystrophy, cerebral palsy, Parkinson's disease and motor neurone disease combined and yet epilepsy remains in the background. That's why we feel it is important the work Epilepsy Queensland does to raise awareness and bring it out of the shadows.

We are proud to be Epilepsy Queensland regular givers because we know that our monthly donations will help to ensure they are there for more families faced with a diagnosis of uncontrolled epilepsy into the future."

Michelle and Michael Hiller –

Regular Givers and committed epilepsy advocates

If you would like to support Epilepsy Queensland by becoming a regular giver

– please visit our website

www.epilepsyqueensland.com.au/

regular-giving-program,

call our office on 07 3435 5000

or email

pr@epilepsyqueensland.com.au.



● Ned's Family - Michael, Nathan, Michelle, Nick - back row, Ned - front row

Spark NeuroCare Launch

The *NeuroCare* Network is an innovative alliance of not-for-profit organisations helping people live with progressive neurological disease in Queensland.

On Tuesday 2 August 2016, Epilepsy Queensland joined partner organisations for the official launch of the Spark *NeuroCare* project at James Cook University (JCU), Townsville. The launch brought together representatives from each of the seven specialist care providers, including MS Queensland, Epilepsy Queensland, Motor Neurone Disease Association of Queensland, MND and Me Foundation, Huntingtons Queensland, Parkinson's Queensland and Youngcare. Special guests at the launch included the Honourable Coralee O'Rourke MP, Minister for Disability Services, Minister for Seniors and Minister Assisting the Premier on North Queensland and Cr Jenny Hill Mayor of Townsville.

Epilepsy Queensland is excited to be a partner in this flagship enterprise and the launch was a wonderful event, well attended with a combination of 83 individuals and organisations. Attendees included local services providers, practitioners, the Spark *NeuroCare* Staff, doctors and health practitioners specialising in epilepsy and other neurological conditions, James Cook University representatives; and importantly consumers of the Spark Service and partner organisations.

Spark *NeuroCare* is a collaboration igniting the power of coordinated care for people living with progressive neurological disease in Townsville. Epilepsy Queensland along with the other six not for profit organisations have joined forces to establish the Spark *NeuroCare* Service providing free coordinated care services for hundreds of local customers with progressive neurological diseases (PND).

Of the 130,000 people living with PND in Queensland a significant proportion are unable to access the necessary information, support and care they require to manage their daily lives. This is particularly prevalent in regional areas, such as Townsville.

During the formal addresses at the Launch, the key individuals from the seven organisations were acknowledged including our CEO Helen Whitehead. Lincoln Hopper, Chair of Spark *NeuroCare* and CEO of MS QLD stated "Not for profits are under enormous strain to deliver services state-wide. ... the Spark collaboration was instigated to share resources across Queensland". Mr Hopper went on to provide an overview of the the Spark initiative; highlighting the history, hopes and aspirations for the Pilot. Furthermore Mr Hopper said that "By working together, we can support more customers and deliver efficient services with our combined PND expertise. We can also address the significant unmet need for people living with PND. Customers will benefit from advice, referrals, assistance with preparing for the NDIS, links to other service providers, education events and centralised equipment loans".

Minister O'Rourke spoke of her interest in the Pilot, and the work had been done to realise the evolution of Spark, and presented key Members of the consortium with a plaque. The event included a tour of the facility, which provides state of the art purpose built and resourced therapeutic rooms.

In a first for Queensland the initial project site based in Townsville is funded by members of Spark *NeuroCare*, the Queensland Government and from philanthropy and provides the combined expertise of the seven partners, who together have more than 220 years' combined experience working with



● Spark Launch address by the Honourable Coralee O'Rourke MP, Minister for Disability Services, Minister for Seniors and Minister Assisting the Premier on North Queensland



● Spark Launch address by Lincoln Hopper

people living with progressive neurological disease. With the intended success of this proof of concept project site, the initiative will address significant unmet need for coordinated care for people with progressive neurological diseases and may pave the way to expand the service across the state in line with the NDIS implementation rollout. Spark *NeuroCare* will not replace the services offered by Epilepsy Queensland. The aim is to deliver more coordinated solutions of care while maintaining the unique specialist and background knowledge of each representative organisation. The strength of NeuroCare is from being a vibrant network of individuals working together to help Queenslanders with common neurological challenges.

To get in touch with Spark *NeuroCare* either contact Epilepsy Queensland on 07 3435 5000 or call them direct on 07 4412 7700.



● Spark Launch Partner Organisation Reps and Minister O'Rourke

Memorial Service

Reverend Cecilie Lander joined us again on Saturday 3 September to celebrate with us and remember the lives of those lost to epilepsy. We are grateful to her and those who attended for providing a special space for each of us to remember, to reflect and to celebrate those who have left us. The service was special, the readings and poems just wonderful and the music added to the sacred space that was created. Heartfelt and emotional, yet refreshingly peaceful to come together, were some of the responses from attendees.

We wish to thank Dr Lander for her presence and guidance.

We also would like to thank Mr Lawrie Knott for his prayerful music.

Thank you to everyone who gathered for the Memorial Service. We treasure the opportunity to join together with the community, the medical profession and service providers, in memory of people who have died from epilepsy.

*May the road rise up to meet you,
May the wind always be at your back,
May the sun shine warm upon your face;
The rains fall soft upon your fields
And until we meet again,
May God hold you in the palm of His hand.*



Queensland Specialist Immunisation Service

The Specialist Immunisation Clinic offers Queensland children and young people with complex immunisation needs, access to greater protection against life-threatening vaccine-preventable diseases.

Children who may need to see an immunisation specialist at the Lady Cilento Children's Hospital include those who have underlying complex medical health problems, complex immunisation needs and those who have previously experienced a significant adverse event following immunisation. The team of immunisation specialists include senior medical, nursing and allied health staff.

If you are concerned about your child's immunisation status you should discuss this with your local GP or specialist for a referral to the Specialist Immunisation Clinic. For general immunisation advice call 13HEALTH.

Read More:

QSI services: <http://www.childrens.health.qld.gov.au/home/lcch/patients-families-visitors/queensland-specialist-immunisation-service/>

Vaccination Matters: <http://vaccinate.initiatives.qld.gov.au/>



SAVE THE DATE...

Epilepsy Queensland will be holding its Annual General Meeting and Award's Ceremony on Monday 5 December at the Queensland Cricketer's Club, Woolloongabba.

More information will follow closer to the date.

30 minutes with *Little Poss*

Little Poss is Epilepsy Queensland's Mascot. He is a baby Brushtail Possum and lives in a place called Ningaloo in Australia.

How did you come to be Epilepsy Queensland's Mascot?

When I started to grow too big to be in my Mum's pouch, I ventured out into the big wide world. It was a wonderful thing. I was able to see so much more of the world, the big yellow sun, the fluffy clouds and all these trees. Well I really wanted to climb higher up these trees, so one day I did, I went higher and higher! But then, I fell and landed on the ground! I was taken to see an animal doctor, and after a while he told me I had epilepsy. I was a young possum still and I didn't know what epilepsy was. Do you know what epilepsy is? The doctor explained that it means sometimes I go wobbly and I begin to shake all over. When you have epilepsy the brain sends out mixed messages, so you can't do things quite right for a while. There are many kinds of epilepsy. Some kinds make you fall down and shake all over, others make you stop what you're doing and stare. But by taking my medication, I can be just like all the other possums.... and kids!

Who is your most special friend?

I have lots of friends. Ruby Rosella, Miss Red Roo, Eddie Emu, Gertie Goanna and Kerry Koala!

What is your favourite food?

I love to eat leaves and berries but my most favourite food is bananas.

Do you have a favourite book?

I am still learning to read, but my Mum reads to me often. Because Possums are active at night, I find it is very soothing listening to my stories as I go off to sleep when the sun

comes up. One of my most treasured is the story of my first seizure and how my family, friends and I learnt about epilepsy. This book is called 'And down went Poss'. It is a wonderful published book now, helping kids all over Australia understand epilepsy. I also really love the book 'Possum Magic' by Mem Fox. I just adore how Grandma Poss and Hush travel all over our beautiful country trying to undo the invisibility magic. My Mum also tells me stories of the Australian bush from long ago.

Do you like music? Do you have a favourite song or a favourite band?

Lolling about in my trees I really enjoy listening to the dreamy beats of a corroboree. The song 'Old Man Emu' makes me laugh and laugh, and I also like 'Waltzing Matilda'. I would have to say, I am a music lover!

Who is the most famous person you would like to hang out with?

I would love to meet Dr Chris Brown from that television show, 'Bondi Vet'!! He sounds fantastic.

What is your most favourite hobby?

Ooh, this is a good question! I love to swing and race through the trees at night, because I am nocturnal. It is so much fun! Sometimes I do this all by myself and I am very, very careful not to fall. Having epilepsy makes me think that bit extra about how I should take care of myself, and in particular my brain. But I don't let it stop me too much. I still have lots of fun. Sometimes I hang out with my cousins and we talk to each other in possum language, which would probably sound like clicks and



screeches to humans. We talk about all sorts of interesting things, like where to find the berry tree.

What do you think would be the best thing to happen for everyone who has epilepsy?

Oh, a cure would be the best thing of course! But there are so many different types of seizures and causes of epilepsy that it is a really hard thing to figure out. I hear from my doctor that new brain scanning machines and equipment are being invented all the time though. If the doctors can work out where a seizure is coming from in the brain and maybe why it happens, then people and animals just like me can be on the best medicine for our type of seizure, or even have surgery!

If we could help the whole world understand about epilepsy and what it means to someone who has it and their family, it would make a huge difference. When I talk about it with my friends, they are really surprised and say they didn't know anything about epilepsy at all. Talking about epilepsy in a really positive way has helped me and I have learnt so much.



CREATING ARTISTIC WAVES!

**Put yourself in the frame for
International Epilepsy Day**

Monday 13th February 2017

Do you like to draw or paint using traditional or digital tools?

Do you sculpt, make pottery, or create multimedia works of art?

Do you make videos or even compose music?

Announcing an international art competition, for all ages and all abilities, to celebrate International Epilepsy Day.

More information on how to get involved, categories and prizes will be announced very soon.



diary dates

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

September	Little Poss Appeal and State Epilepsy Awareness Campaign
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.
30 November	Understanding Epilepsy Workshops (Gold Coast) For families, people with epilepsy, carers, child care workers, teachers, nurses and allied health professionals
5 November	Brisbane Adult Support Group Meeting
11 November	Northside Brisbane Support Group
25 November	7th Annual Queensland Epilepsy Symposium – Thinking Outside the Box!
5 December	AGM & Awards Ceremony
13 February 2017	International Epilepsy Day
26 March 2017	Purple Day

VOLUNTEERS TAKE A BOW

Epilepsy Queensland benefits greatly from the many volunteers who donate their time and skills to help people with epilepsy and their families.

Volunteers play an important role in administration, fundraising, communications, Board membership, raising awareness about epilepsy, and supporting our services team.

We absolutely couldn't do what we do without volunteers and on Tuesday 24 May 2016, an Epilepsy Queensland volunteer thank you evening was held to show our appreciation.

Chairman Steve Eltis and Deputy Chairman Elsewerth Ephraums expressed sincere thanks on behalf of the organisation in their speeches.

We're always keen to hear from people who would like to become a volunteer. Please contact us by emailing volunteering@epilepsyqueensland.com.au or phoning 07 3435 5000.



Seventh Annual Queensland Epilepsy Symposium

www.epilepsyqueensland.com.au



Bookings essential!

Thinking
outside
the box!

Join us for some stimulating dialogue...

Friday 25 November 2016
RBWH, Herston



I would like to help Epilepsy Queensland!



I would like to join Epilepsy Queensland

☐ \$35.00 Ordinary membership

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

☐ \$90.00 Organisation membership

☐ \$50.00 Family membership

Please find enclosed my Tax Deductible Donation of:

☐ \$25

☐ \$50

☐ \$100

☐ My Choice \$ _____

OR Please charge \$ _____ monthly to my credit card until otherwise advised

PAYMENT AND ADDRESS DETAILS

DONATIONS OF \$2 OR MORE TO EPILEPSY QUEENSLAND INC ARE TAX DEDUCTIBLE

☐ Please find enclosed my cheque / money order made payable to Epilepsy Queensland Inc

☐ Please debit my:

☐ Visa

☐ Mastercard

Card number: _____

Expiry date: _____

Cardholder's name: _____

Signature: _____

Mr/Mrs/Ms/Miss/Dr: _____

Company: _____

Address: _____

Suburb: _____ Postcode: _____

Phone: _____ Email: _____

Please return this slip with your method of payment to—

Epilepsy Queensland Inc, PO Box 1457, Coorparoo BC Qld 4151

☐ I am interested in volunteering.

☐ Please send me information about remembering Epilepsy Queensland in my will.

☐ Please send me information about 'In Memoriam' or 'Celebratory' gifts.

☐ Please add me to your e-News and e-Bulletins Lists (my email address is listed above).

Or to join online visit www.epilepsyqueensland.com.au/member-form

Thank you for your contribution!

A Tax Invoice will be issued on receipt of fee and approval of membership



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