

the flame

the newsletter of epilepsy queensland inc

Issue 2 – 2017

**getting NDIS ready
– carers**

medicinal cannabis update

Purple Ball

the urgent need for
new metabolic (dietary)
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never lose hope –

Gerrard Gaudiello's
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Taking control of medications, the easy way



Technology has revolutionised the way we manage our life. From a tiny computer in our pocket, we are just a few clicks away from managing our finances, ordering a taxi, booking a flight or having dinner delivered to our door. The smart phone has made it easier and faster to do just about anything, including now managing our medications.

At 71 years of age, Victorian resident Neil Ross, uses his smartphone to manage his medications and says he has never felt more in control about his health.

“Using technology to manage my medications has made an amazing difference. I have multiple medical issues, and I have to take several different medications a day. Keeping track of when I need to take them, how often and when I need to re-order is quite a complicated process.”

Since using a free app called MedAdvisor, Neil has been able to take the confusion and worry out of managing his medication. “I was told about MedAdvisor by my local pharmacy and I am so thankful. MedAdvisor is an incredibly useful and clever piece of technology.”

MedAdvisor connects users to their favourite pharmacy and provides a real-time list of medications that have been dispensed. Neil can easily view how many days' supply or repeats he has left and receives reminders when it's time to take his medications and if he's running low on tablets or prescriptions. He can also pre-order his medication with a simple tap so when he arrives at the pharmacy he doesn't need to wait.

“MedAdvisor gives me the ability and confidence to easily manage my medications. I travel a lot and I need ready access to what I am taking. I especially appreciate the ability to order and collect my medications at a time when it suits me.”

Since launching in 2014, over 650,000 Australians are now using MedAdvisor on their phones to track and order their medications. Users can also use the latest feature, GP Link, to connect with their regular doctor to order script renewals without an appointment.

MedAdvisor's CEO, Robert Read says, “Our goal is to put health back into the hands of Australians so they can feel in control. Through the MedAdvisor app we are helping users to manage their medications in a smarter, faster and simpler way compared to ever before.”

This is certainly true for Neil, who says, “It's a brilliant concept. I don't know what I would do without it and I don't know who wouldn't want to use it.”

MedAdvisor has partnered with Epilepsy Queensland to help more than 250,000 Australians living with epilepsy gain control over their medications. Join MedAdvisor today by going to <http://start.medadvisor.com.au/epilepsyqld> or download the app.

MedAdvisor will donate \$1 to Epilepsy Queensland per sign-up on this link.



Whilst the NDIS is client focused, it is recognised that family and carers play a vital role in providing informal supports to people living with epilepsy and other disabilities. These supports often fill the gaps where formal services and or paid workers cannot provide. Therefore, where possible and with the participants' permission (if the participant is an adult), family and carers should be included in the planning process. Their input is vital for helping the person accessing the NDIS to make decisions, set goals and comprehensively consider and participate in assessment of needs and future planning.

For many people transitioning to or entering the NDIS, the issue of supports for family and/or carers can be particularly confusing. Whilst the plan is focused on meeting the individual participants' goals and support needs, these supports may directly or indirectly benefit family and/or carers.

For example:

- personal care to support an individual in their home or the community
- supports to assist people with disability to enjoy social and community interaction without relying solely on you
- assistance with tasks of daily living, including help to improve a person's ability to do things
- supported employment services and help for people to move to work programs that prepare people with a disability for work
- training related to the caring role that may enhance your ability to provide care.

Epilepsy specific examples of formal support that also support family or carers may include things like:

- A support worker to accompany the person with epilepsy on public transport, to appointments etc. to improve confidence and encourage independence
- Epilepsy specific training for family and carers to assist with responding to seizures
- Support or counselling for family members impacted by the unpredictability of seizures and their associated support needs
- Behavioural management training to assist with behavioural disturbance related to, or following seizures.

Carer Statement:

As with all aspects of NDIS, pre-planning is essential and this also applies to carers and/or family considerations. Prior to starting the planning process with NDIS, carers and/or family

Getting NDIS ready – carers

must take the time to consider what role they currently play and what they will do into the future. As an informal part of the planning process, the NDIA (National Disability Insurance Agency) may talk to family and/or carers to gain further information. Carers and family members may choose to write a Carer Statement to be considered by the NDIA at this time.

How to prepare a Carer Statement?

A Carers Statement should outline:

- The support currently provided by you
- How these supports impact on you and/or your family
- What your support capabilities are currently and into the future
- Other responsibilities or life plans (job, other siblings etc.)
- And any other information that may be important for the planner to know.

Some example Carer statements can be found here:



<http://www.carersaustralia.com.au/storage/de-identified-carer-statement-1.pdf>



<http://www.carersaustralia.com.au/storage/de-identified-carer-statement-2.pdf>

To assist, a Carer Checklist has been developed and can be used to prompt you to consider all aspects of your caring role and ultimately help you to determine the most important information to include in your carer statement. This can be found here:



<http://www.carersaustralia.com.au/storage/carers-checklist-new-writable-sept-2016.pdf>

For those who live with or care for someone with epilepsy, there may be many day-to-day support needs. However, the episodic nature of seizures also means that some days these needs are greatly increased. Therefore, it is important to outline what a typical “good day” would look like, as well the acute impact that seizures have on family or carers.

For more information, contact:

Epilepsy Queensland:

Ph: (07) 3435 5000 or 1300 852 853 (outside Brisbane)

www.epilepsyqueensland.com.au/ndis

Or visit the Epilepsy Queensland Facebook page

www.ndis.gov.au ; <https://www.ndis.gov.au/families-carers/information-families-and-carers>

www.everyaustraliancounts.com.au

Carers Australia: <http://www.carersaustralia.com.au/ndis-and-carers/support-for-families-and-carers/>

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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





Kos Slavos is a board member of Epilepsy Queensland. In 2016 Kos was appointed to the Steering Committee to oversee the clinical trial of medicinal cannabis in Queensland. He is a pharmacist and pharmacy owner. Kos was the National President of the Pharmacy Guild of Australia from 2005 to 2013 and continues to serve on the Guild as Chairman of Australian Pharmacy Professional Conference.

Medicinal cannabis update

Patient access to medicinal cannabis

Medicinal cannabis may be approved if you have already tried the conventional treatments available for a reasonable period of time and these have failed, or if the effects of the conventional treatment proves to be intolerable for you. Your doctor will need to provide scientific evidence that the proposed type of medicinal cannabis is effective for your condition or symptoms.

There are three ways to access medicinal cannabis:

- specialist doctors can prescribe specific products to treat groups of patients with particular conditions (patient-class prescriber pathway) (<https://www.health.qld.gov.au/public-health/topics/medicinal-cannabis/clinicians/patient-class-prescribers>)
- your general practitioner or medical specialist applies for approval to prescribe medicinal cannabis treatment just to you (single-patient prescriber pathway) (<https://www.health.qld.gov.au/public-health/topics/medicinal-cannabis/clinicians/single-patient-prescribers>)
- if you meet the eligibility criteria for current clinical trials in Queensland (<https://www.health.qld.gov.au/public-health/topics/medicinal-cannabis/clinical-trials>)

As at 1 March 2017 there are currently no businesses licensed to manufacture medicinal cannabis in Australia, these products need to be imported.

You cannot legally produce your own cannabis for medicinal use. Queensland does not have an amnesty scheme (<https://www.health.qld.gov.au/public-health/topics/medicinal-cannabis/amnesty>)

Once Queensland Health and the Therapeutic Goods Administration (<https://www.tga.gov.au/>) (TGA) have approved the application to prescribe, your doctor can legally import medicinal cannabis under the Special Access Scheme (Category B). (<https://www.tga.gov.au/form/special-access-scheme>)

Medicinal cannabis is not on the Pharmaceutical Benefits Scheme (PBS) so you will need to pay for all expenses.

How to access

1. Talk to your doctor about whether medicinal cannabis may be suitable for your condition or symptoms. You will need to give informed consent.
2. If your doctor believes that it would be effective, they can contact Queensland Health for approval to prescribe.
3. If Queensland Health approves the application, your doctor then applies to the TGA for approval to allow supply of the product.
4. Once the TGA has approved, your doctor arranges for a pharmacist to dispense the medication for you.

Conditions that may benefit

Current limited evidence suggests that medicinal cannabis may be suitable to treat:

- severe muscular spasms and other symptoms of multiple sclerosis
- chemotherapy-induced nausea and vomiting
- some types of epilepsy with severe seizures
- palliative care (loss of appetite, nausea, vomiting, pain).

There is no evidence that medicinal cannabis is an effective treatment for cancer. You should not:

- consider medicinal cannabis as an alternative treatment for cancer
- defer the standard treatment in favour of using medicinal cannabis.

Rural and remote patients

If you live in a rural or remote area, access to medicinal cannabis will be through either your GP or a specialist. You may be able to access specialist consultations through a telehealth service. Generally, your GP will prescribe medicinal cannabis in consultation with the specialist.

You cannot drive while taking medicinal cannabis.

Research has shown that cannabis use has an effect on a person's driving ability. Unlike alcohol, there is generally no applicable concentration of cannabis that can be identified as an indicator of impairment. It is illegal for any patient being treated with medicinal cannabis containing THC to drive while undergoing treatment. THC (Tetrahydrocannabinol) is the main psychoactive component of cannabis.

Queensland Health is working with the Department of Transport and Main Roads to ensure that the regulation of medicinal cannabis is consistent with relevant transport legislation.

Clinical trials

Clinical trials are running to test a medicinal cannabis product (Epidiolex) as a treatment for children with severe treatment-resistant epilepsy: <http://conditions.health.qld.gov.au/HealthCondition/condition/8/60/810/medicinal>



30 minutes with...

Ruth Blackburn



Parents don't take the decision to treat their child's epilepsy with cannabis products lightly, but for many, they have tried countless conventional treatments with no success. Parents will do whatever it takes to improve their child's quality of life, so if using a cannabis product is the only thing working, they may feel like they have no other choice. The fact that using cannabis-based products from the community is illegal may leave families feeling uncertain and worried. The PELICAN study can provide answers to parents about what is in their product, while working towards informing better treatment options for children with epilepsy that isn't responding to drugs currently on the market. It also gives parents a chance to share their perspective about medicinal cannabis in a way that may have some bearing on governments and policy-makers.

Have you seen significant changes in the area of medicinal cannabis and epilepsy since you started working in this area?

Absolutely! It is a very dynamic time in the field of medicinal cannabis in Queensland. We are leading the rest of Australia in some respects and the struggle that those who have been using cannabis products to treat their medical conditions illegally have been going through is beginning to be recognized by the government and the wider community. I can see the culture around using cannabis as a medicine changing as more and more people speak out about their personal experiences. Parent's using cannabis oils or tinctures to treat their child with epilepsy is a common story. The Medicinal Cannabis Act that came into effect on the 1st of March has helped with this culture shift but also now makes it possible for cannabis products to be prescribed to treat both paediatric and adult epilepsy. Although cannabis is still not an entirely accessible treatment option for patients in Queensland, I think people with epilepsy that is not responsive to traditional anti-epileptic drugs (25-30% of people with epilepsy) have a lot to gain from further research into cannabinoids as a treatment.

Where else have you worked in your life?

I have worked for The Benevolent Society in family support and with children and adults who experience learning difficulties as well as Life Without Barriers, supporting foster children and their carers. After finishing my Masters in Psychology, specialising in educational and developmental psychology, I have become really interested in how research can benefit the lives of children and their families.

What do you love about your job?

I love that I will have the opportunity to meet real families, hear their stories and learn about a range of perspectives to do with using cannabis products to treat paediatric epilepsy. I am also excited about the opportunity to contribute new information to the area of medicinal cannabis which will

hopefully be used by governments and pharmaceutical companies to improve outcomes for children with epilepsy that isn't controlled by existing anti-epileptic drugs.

Where would you most like to travel?

I would love to visit the Great Lakes and explore the northern border of the US and Canada.

What is your favourite food?

I love Vietnamese food, especially Banh Mi!

Describe your most embarrassing moment?

I was shown a red card during a soccer match for committing a foul (I swear it was an accident!). To add to my shame, a photo of me receiving it appeared on the internet.

What is your favourite book/author?

I am a big fan of Norman Doidge's 'The Brain that changes itself'. It tells some great stories about how meaningful changes can occur despite people, even medical professionals, ruling it out.

Who is the most famous person you have ever met? Who would you like to meet?

I met Kevin Rudd (if you count politicians as 'famous'). If I

could meet anyone it would be Beyoncé – I think she's a great role model and a powerful woman.

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

I am a secret RnB fan and love anything from the 90's and 00's, the golden era!

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

I have recently been learning to skateboard. I highly recommend wearing a helmet and elbow pads!

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

I think that a lot of medical advancement in epilepsy treatment is needed if the prescription anti-epileptic drugs currently available don't work to control seizures for up to 1/3 of people with epilepsy. That leaves a lot of people whose quality of life is affected and future opportunities may be limited due to uncontrolled seizures. I would like to see these patients and the families of people with epilepsy listened to- if there is currently nothing available to help these people, it is important to listen to them as the experts on what works for them and what is providing them relief.

What is the exact title of your role?

I am the Research Officer for the Paediatric Epilepsy (Lambert Initiative) Cannabinoid Analysis – PELICAN Study in Queensland.

How long have you been working on the Pelican Study?

I started with the University of Sydney's Lambert Initiative for Cannabinoid Therapeutics a month ago and have working on getting the study set up in Queensland from the Centre for Children's Health Research (CCHR) next to the Lady Cilento Children's Hospital since then.

I hope to be starting the project with Queensland families in April.

Can you tell us about some of the early results of the study?

The PELICAN study has been running in New South Wales since August last year, headed by Anastasia Suraev, so this is not a new project, it's just new to Queensland. Anastasia has interviewed and taken cannabis samples for analysis from a group of families who use cannabis to treat their child's epilepsy. She has also heard the experiences of families who have used cannabis to treat their child in the past, or have never used cannabis to treat their child's uncontrolled seizures.

We are finding that there are lots of different cannabinoids (the therapeutic elements in cannabis) present in the products families are using to improve epilepsy symptoms in their child. CBD is one cannabinoid linked to anti-epileptic effects but the low amounts of this compound found in Australian cannabis suggests that it is likely that other cannabinoids also work to control seizures.

What impact do you think opening up the study in Queensland will have on families?

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 our trained researchers, or at the Centre for Children's Health Research.

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-QLD.pelican@sydney.edu.au
☎: (07) 3069 7014
http://www.sydney.edu.au/science/lambert/get_involved/pelican.shtml



Purple Ball

Epilepsy Queensland's Purple Ball launched our Epilepsy Awareness Campaign for the month of March, with a fantastic evening of purple glitz, glamour, fundraising, fine dining and entertainment.

Guests were treated to a wonderful night of entertainment from our MC Andrew Lofthouse, Auctioneer Chris Bombolas, the magical comedy stylings of Anthony Laffan, the Musicians Hub for pre-dinner music and many danced the night away to the very funky RedTie Band. The highlight for many people was a heartfelt speech from 10-year-old Purple Day Ambassador Nickayla Winter. Nickayla left everyone feeling that you can't let epilepsy get in the way of living a happy, fulfilling life.

Once again, our Purple Ball raised awareness about epilepsy and vital funds in excess of \$35,000 to help people with epilepsy and their families. Our heartfelt thanks go out to our sponsors, supporters, donors, volunteers, staff, board and the initiator of the Purple Ball, Elsewerth Ephraums.

An update on the fantastic efforts of all our Purple Day fundraisers and activities will be included in the next issue of Flame.

Thank you to our generous sponsors and valued supporters:

Epilepsy Queensland's 2017 Purple Ball
proudly sponsored by



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In Memory

Heartfelt thanks to the Connors family for their generous donation of \$3,000 in loving memory of David Connors.

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Thank you to everyone who purchased tickets in our recent Limited Edition #3 Art Union. We are happy to announce the winner is Tim Schofield, with ticket number 406 drawn at Epilepsy Queensland's Purple Ball on Saturday 25 February.

Tim's smile couldn't get any bigger as he was presented with the keys from Matthew Christie from Mercedes-Benz Brisbane. Congratulations Tim!



The urgent need for new metabolic (dietary) treatments of epilepsy

Dr Karin Borges is Senior Lecturer at the School of Biomedical Sciences, University of Queensland. She heads the neurological disorders and metabolism lab.

Metabolic therapies such as the ketogenic diet and various versions thereof are promising approaches, as they do not dampen neuronal activity and thus do not slow thinking processes or make people with epilepsy tired. These therapies have improved remarkably over the last 30 years and have been shown to be effective in multiple clinical trials in drug-resistant patients, mostly children but also some adults¹.

However, these dietary regimens are not free of side effects. They require medical and dietary supervision, restrict food choices and intake. They are also costly. Thus, many people with epilepsy are unable to follow the strict dietary treatment regimens. Therefore, I suggest that new improved metabolic therapies are urgently needed, which should be more effective in drug-resistant epilepsy than drugs that just dampen the excitability of the brain. To develop such new therapeutics, it is important to understand the mechanisms that initiate and propagate seizures.

Metabolic impairments in brain can promote epileptic seizures

The processes that lead to spontaneous seizures are complicated. Many physiological processes can be out of balance and can promote seizures, such as the levels of excitation vs. inhibition, but also inflammation and impairments in energy metabolism. This article attempts to explain the changes found in brain metabolism in between seizures compared to a "healthy" brain.

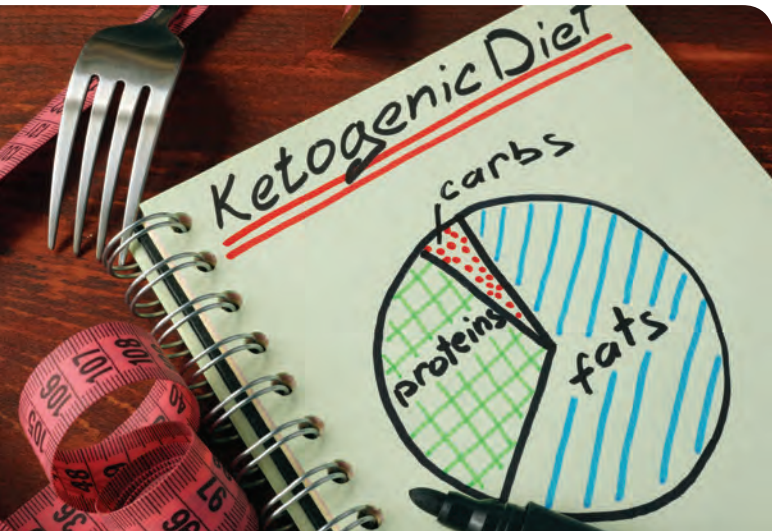
Most living cells and especially brain cells rely on ATP, a powerful fuel that supports processes in cells that require energy. For example, cells need energy to survive, to communicate with each other, to fight against injury and regenerate. In simple terms when the membrane potential is lost, neurones become excited and start firing. If this happens in certain groups of neurones, this overexcitation can initiate an epileptic seizure, which can spread to other areas of the brain and in some cases involve the whole brain. Because ATP is vital to maintain membrane potentials, it is thought by many researchers, including myself, that providing sufficient ATP to the brain is crucial in people with epilepsy to prevent seizures.

Under normal circumstances the brain relies on glucose and its metabolism to produce ATP. Most of the cellular ATP is generated by mitochondria, which are found in most cells. Growing evidence shows that dysfunction of metabolic processes in the brain can contribute to epileptic seizures. This includes impairments in glucose uptake into the brain and energy metabolism in mitochondria. This is supported by the fact that epileptic seizures can occur in people with genetic defects that result in insufficient uptake of glucose into the brain or deficiencies in mitochondria. Ultimately these defects lead to an inability to produce ATP, the main fuel needed in cells for survival and stabilisation of membrane potentials which is needed to avoid the generation of seizures.

Continue Next Page →

These genetic imperfections can be passed to offspring. Moreover, in people and animals who developed epilepsy in response to brain injuries, problems in brain metabolism have been repeatedly described. Using modern brain imaging techniques many studies have shown that local glucose uptake is decreased in “epileptic hotspot brain areas” in between seizure activity ^{2,3}. Thus, there is reason to believe that therapies aimed at increasing brain energy can be effective in people with epilepsy who do not get relief from seizures from the current medications available ⁴.

What are the options to boost brain energy metabolism?



Current ketogenic therapies

Current metabolic dietary approaches to treat epilepsy include the ketogenic diet, the modified Atkins diet and various versions thereof ¹. In some ketogenic diets, 50-60% of calories are from **medium chain triglycerides** (MCTs). These are oils that contain mostly triglycerides of eight or 10 carbon fatty acids, octanoate and decanoate. These MCTs, are more ketogenic (meaning they produce more ketones) than the long-chain triglycerides that are typically found in our food ⁵. Another alternative is the low glycemic index diet, in which higher amounts of carbohydrates with low glycemic index are allowed. Several controlled studies show that these high fat/low carbohydrate diets are effective in many children with epilepsy and some of the children remain seizure-free after stopping dietary treatment ¹. Some adults also experience reduction in seizures.

Ketogenic diets and their variations are thought to be anticonvulsant through various mechanisms. Importantly, due to the low carbohydrate intake with these diets, blood glucose levels constantly remain in the lower end of the normal range. This appears to help prevent seizures, because the inhibition of glucose metabolism in rodent seizure models can also block seizures, while high blood sugar levels promote seizures ⁶. Moreover, when glucose is in short supply, the

liver turns fats into ketones, which are then excreted into the blood. When blood ketone levels are high, human and rodent brains use substantial amounts of ketones instead of using only glucose ⁷. ATP can be produced from ketones and can provide the energy needed for normal brain function. This demonstrates that alternative fuels, such as ketones, can be effective fuels and prevent seizures when glucose metabolism is impaired, such as in an “epileptic” brain.

Even medium chain fats as anticonvulsants?

In patients on the MCT ketogenic diet the blood levels of the medium chain fatty acids octanoate and decanoate, reach near millimolar amounts. Moreover, medium chain fatty acids can diffuse directly into the brain and can be metabolised (references in ⁸). Thus, while taking MCTs, the production of ketones by the liver should not necessarily be needed to provide the brain with alternative fuels. Interestingly, several studies have demonstrated that specific medium chain fats can be anticonvulsant in various models in vitro and in vivo ^{9,10}, such as octanoate and decanoate. In addition, our laboratory has employed the oils (triglycerides) of these fats as a suitable formulation to avoid acid overload in patients and animals. My laboratory found that the triglyceride of decanoate effectively inhibited seizure generation in two different mouse models. This raises the hope that it may also block seizures in people with certain types of epilepsy ⁸.

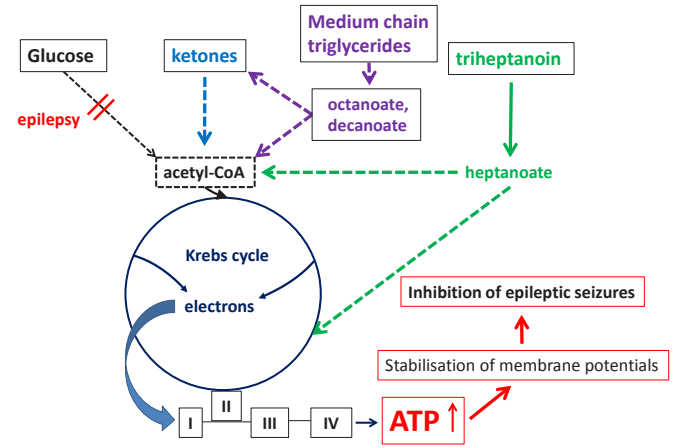
The anticonvulsant mechanisms of medium chain fats are likely due to the provision of alternative fuel to glucose and potentially reduced glucose metabolism. Indeed, we published evidence that the MCT of octanoate reduces the metabolism of glucose. In addition, the MCT of decanoate can fight oxidative stress and it improves mitochondrial function, which can further support the synthesis of ATP ⁸.

Altogether these new findings raises the hope that MTCs may also block seizures in some people with epilepsy ⁸. Please note, that it remains to be investigated in controlled clinical trials whether MCTs can provide seizure control in people. Until such results are produced it cannot be recommended to add MCTs to a normal diet, as this can cause weight gain, diarrhoea and other side effects, including increases in seizures frequencies and severity.



Uneven medium chain triglycerides: Triheptanoin as an anticonvulsant

Triheptanoin is a synthetic MCT, namely the triglyceride of the seven carbon fatty acid heptanoate. It provides fuel (acetyl-CoA) directly to the mitochondrial Krebs cycle. In addition, it is also highly effective in boosting the Krebs cycle and the production of ATP within the brain (Fig 1). Triheptanoin is already in clinical trials to treat rare metabolic disorders, such as long-chain fatty acid metabolism disorders ¹¹ and



various diseases affecting the brain. It is also used to provide fuel to the brain in disorders where glucose cannot be taken up (glucose transporter1 deficiency) resulting in seizures and sudden odd movements ¹². My laboratory discovered that triheptanoin protected mice against seizures in different epilepsy models. Along with other researchers, we also showed that triheptanoin improved brain metabolism in models of epilepsy, in which glucose metabolism was perturbed. Based on the mouse seizure models, effects against medication-resistant seizures in humans are possible. My team is about to finish three controlled clinical trials with triheptanoin in adults and children with epilepsy in Australia. Some results are promising (data unpublished).

Conclusion:

Different variations of dietary or metabolic therapies can be effective in people with epilepsy. Although much improved, the current strict dietary regimes remain difficult. Work in several laboratories worldwide raises the hope that novel simple metabolic therapies become available within the next 5-10 years. To develop such new therapeutics, it is important to support further research in the laboratory as well as in clinics.

Note: This article has been edited for publication. The full article can be found at:
<http://www.epilepsyqueensland.com.au/dietary-therapy>.

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Never lose hope

Gerrard Gaudiello's epilepsy story

There are important milestones in everyone's life and we were thrilled to celebrate four years' seizure free with Gerrard Gaudiello during our Purple Day 2017 awareness month. Gerrard is another surgery success story. Gerrard believes that "if he can get through epilepsy surgery he can get through anything".

It wasn't always smooth sailing for Gerrard and he shared what it was like for him living with epilepsy prior to the operation.

"Nothing was helping me. I was drowsy all of the time and my weight was constantly fluctuating with the medications. It got to the point where Dad was checking on me every time I had a shower to make sure I was alright."

"People I didn't know thought I was drunk when I was having a seizure. I was just completely unaware. I was having instances when I was coming out of tonic clonics and I was violent. There is just so much stigma and a lack of awareness associated with epilepsy. I can remember that it made me feel terrible and so insecure. I hope that through sharing our stories of living with epilepsy this can change."

Gerrard first had signs of epilepsy with deja vu feelings at the age of 16, but he wasn't officially diagnosed until the age of 17. Despite the difficulties, he completed high school and a Diploma of Tourism as well. His graduation photo is an ongoing reminder of what life was like pre-surgery as it captured him having an absence seizure.

When his neurologist proposed epilepsy surgery, he felt he had no choice. A meeting with Epilepsy Queensland Patron Wally Lewis helped him to feel reassured that he was doing the right thing.

"Wally said to me that he always urges anyone who is a candidate for surgery to do it while they are still young. He felt like he wasted so many years because of fear and denial."

"He gave me advice on what to expect after the surgery. He told me to expect to wake up with a massive headache and don't be afraid to ask for pain medication. You're going to need it. He was right. I woke up with the worst pain and a great scar with 20 staples in my head. A couple of days later I had a black eye."

"While the pain eventually subsided, it took me about six months to fully recover. I didn't drink and was so relieved to get through the first 12 months' seizure free. Now I'm four years' seizure free and I know every bit of pain was worth it."

Gerrard also shared the need for support post-surgery. "It's not just the physical recovery but depression is also normal for people after epilepsy surgery. Wally Lewis spoke to me about it when we met up before my surgery and it really helped because I was aware of it and was able to deal with it when it came up. Anyone with signs of depression should seek help and be open about it."



Like Wally, Gerrard's aim in life is now to help others, whether they have epilepsy or other conditions. The time spent in hospital recovering from his surgery gave him a huge appreciation for the nurses that care for everyone. It also gave him time to reflect on his future life direction and he came out determined to pursue a career in nursing.

Two years after his surgery Gerrard commenced his Nursing Degree and he is now getting close to completing it. Gerrard said: "It was the best choice I have made other than surgery. The job they did was just marvelous and I want to help people in tough situations."

Gerrard also wants to help others considering surgery. "Sometimes what you need is someone to talk to who is in the same situation to put your mind at ease. When I spoke to Wally Lewis it helped me with the fear. I want to be able to do that for others. I would urge anyone considering surgery who is scared to get in touch with Epilepsy Queensland and they can connect you with someone who has been through it."

Gerrard's message for anyone struggling with their epilepsy is: "Anything is possible. Don't let it be a setback, let it be a challenge. Even if you can't control your seizures seek help from Epilepsy Queensland or your medical team to manage them. Medications improve all the time and with research that will continue and a cure will come. So never lose hope."

If you are considering surgery, would like to speak to someone about managing epilepsy or need support contact Epilepsy Queensland on **07 3435 5000** or **1300 852 853** (outside Brisbane) or email services@epilepsyqueensland.com.au.

2017

DIARY DATES

10 June

Little Poss' Birthday Party

13 April

Understanding Epilepsy Workshops (Woolloongabba)

18 May (9:30am + 6:00pm)

For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families

15 June

20 July

17 August

14 September

19 October (9:30am + 6:00pm)

16 November

17 May

Understanding Epilepsy Workshops (Gold Coast)

26 July

For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals

6 September

15 November

3 June

Brisbane Adult Support Group Meeting –

4 November

Also informally 1st Saturday of each month

5 May

Carer Support group – Friday at Bracken Ridge Library

1 Sept

8 June

Carer Support Group – Thursday at Bulimba Library

12 October

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

Membership renewals due 30 June 2017

The end of the financial year is a reminder that your membership with Epilepsy Queensland may be due for renewal.

As a membership based organisation, we rely greatly on the support of our members to help us achieve our mission to bring epilepsy out of the shadows and to optimise life for people touched by epilepsy.

Your membership helps us to...

- empower and create a supportive environment for people with epilepsy and their families
- contribute to the scientific understanding of epilepsy through research, education and its application
- ensure health, welfare and other services respond appropriately to the needs of people with epilepsy and their families
- ensure appropriate policies for people with epilepsy are included in public policies in all sectors
- ensure the long-term sustainability of Epilepsy Queensland

Your support is important to us - Together we CAN make a difference!



As a valued member and important part of our family of loyal supporters, in return you receive:

- Discounts on publications, workshops, seminars and events
- Complimentary Epilepsy Queensland magazine "The Flame"
- An invitation to attend special events including the Annual General Meeting and Awards Ceremony

To join or renew your membership today return the enclosed form or contact us on:

Phone: 07 3435 5000 or 1300 852 853
(outside Brisbane)

Email: member@epilepsyqueensland.com.au

Online: <http://www.epilepsyqueensland.com.au/member-form>