the flame

the newsletter of epilepsy queensland inc

AGM & Awards Night

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Issue 1–2015
One day he was drowning spiders in hair spray and vacuuming up their frozen bodies for quick disposal. The next, he was completely at peace with the eight-legged menaces. He has his seizures to thank.

The story of a man losing his arachnophobia overnight is the subject of a case study recently published in the journal Neurocase.

Forty-four years old and paralyzed with a fear of spiders, the man began experiencing seizures out of the blue. Brain scans showed his amygdala, the walnut-sized portion of the brain responsible in part for handling fear, had some abnormalities.

But, later tests showed it wasn’t anything to do with these fear centers but a rare disease affecting his central nervous system, known as granulomatous encephalitis. Relying on the same logic that calls for surgically removing cancerous tissue and treating epilepsy patients, the doctors decided the offending portions of his amygdala had to go.

The surgery was a success, if also an interesting look into how fear works. While the man did stop having seizures, he also lost some other sensations. Music, for one, lost its luster. What once sounded like a beautiful melody now made the man’s stomach lurch with revulsion. But while these feelings eventually subsided, his fear of spiders never returned.

Once apt to get immobilized with a quick aerosol spray and promptly sucked up, the bugs now drummed up no response — the man’s disgust turning to indifference and then eventually to full-on fascination. He reported total comfort with touching spiders and letting them crawl over his hands and arms. The effects prompted doctors to revisit the entire premise of fear and wonder whether they could knock out individual phobias in the future.

Scientists can only speculate as to what caused the man’s fear of spiders to fade but leave his other fears, like the fear of public speaking, intact. One theory implicates the different kinds of fear response. The first is the kneejerk reaction. It’s the snake-in-the-grass response. “It isn’t very accurate, but it’s necessary for basic survival,” said Nick Medford, the man’s observing physician, of the Brighton and Sussex Medical School. “And then there’s the more nuanced fear-appraisal, which takes longer to process but is more accurate.” These fears are slow to register and spark a more general unease. They include more social fears, like public speaking, parallel parking, and the fear of failure.

Medford submits the neural pathway associated with his subject’s arachnophobia must have resided somewhere in the portion of the amygdala that got removed. But it’s still anyone’s guess how, exactly, these specific fears are organized in the brain. Just because Medford may offer a ballpark doesn’t mean scientists can start zapping fears away one-by-one. There is, however, an interesting side note, Medford says.

“It’s not uncommon for people to have temporal lobe surgery for severe epilepsy,” he said. “And arachnophobia is supposed to be reasonably common. So we might be able to test people for that phobia, or any other kind, before and after surgery.”

The amygdala is already out as far as non-invasive techniques go — it’s simply too deep in the brain to get at — but other methods are currently in use. The most popular is exposure therapy. It argues placing a spider in the man’s hand may have yielded the same effect as cutting into his head, no incisions necessary.

Then there is the idea that fearful memories can be erased in full, although much of the science still needs to be established before Eternal Sunshine fans can begin to clamor. For now, you still have a better chance of suffering a seizure and having part of your brain removed than science does of recreating fiction. Score one for happy accidents.


Arachnophobia Gets Cut Out Of Man’s Brain After Surgery To End His Seizures  By Chris Weller, 31 Oct, 2014
Do you know the cause of your epilepsy?
No, the doctors were unable to determine the cause of my epilepsy. I do not have epilepsy in my family either.

How old were you when you had your first seizure?
I was 41 years old when I had my first tonic clonic seizure. Prior to that I used to experience focal seizures where I would experience an aura or déjà vu. I used to refer to them as a significant distortion or abstract experiences.

How frequently do you experience seizures?
I experience multiple seizure types: focal, focal dyscognitive, tonic clonic and muscle jerks.

I have been monitored previously in a sleep clinic so I know I have nocturnal seizures quite often; it is hard to say how many I would have a night though.

I have sudden muscle jerks every day, multiple times a day.

I also have tonic clonic seizures that tend to come in bursts either every 3 weeks or several months apart.

Have you ever sustained any injuries due to your seizures?
I have experienced lots of bruising and scratches in the past due to my seizures. However, fortunately I have not broken any bones or sustained any ongoing injuries.

Do you have any memory of the seizures?
Some of the seizures I have I remember as they stick clearly in my memory. Some I don’t even know I have had until someone tells me I have.

What medication do you take?
I have tried many different medications in the past however my seizures are still not well controlled. I now take Keppra and Zoloft.

Has epilepsy prevented you from doing anything in your life?
I do get frightened to go out as I am always fearful I will have a seizure in public which has happened to me many times.

Not being able to drive is a pain, however I know the consequences could be disastrous if I was to drive.

My short and long term memory are deteriorating over time. This can be frustrating.

My ability to concentrate is also affected.

How have you tried to overcome this?
I like to keep my mind active by writing, Sudoku and KenKen which is another form of Sudoku. I recommend it to everyone.

What is the best advice you can give someone living with epilepsy?
To go through all the channels you have available to you. Ask questions and explore all avenues.

How do you remain positive?
I keep my spirits up; I think I have a good life despite having epilepsy. I am glad I am alive.
On Monday 1 December 2014, Epilepsy Queensland held its Annual General Meeting and Awards Presentation with Tessa Scott from Channel 9 kindly hosting the event.

Tribute was paid to longstanding Board members Fergus Pollock and Louise Foley, who have stepped down, along with Steve Greenwood.

The newly elected Board for 2015 is:

**Chairman**  Steve Eltis  
**Deputy Chairman** Elsewerth Ephraums  
**Secretary** Andrew Barnes  
**Treasurer** Jane Vidler

**Board members**  
Jo Ahern  David Bunker  
Alan Davidson  Kim Davis  
Charmaine Driver  Lee Durant  
Vivienne Johnson  Kos Sclavos

Don Murray, Executive Director, Mater Private Hospitals, “Mater Neuroscience Centre of Excellence” was the guest speaker for the evening.


Patron, Wally Lewis, enjoyed presenting the Awards to the following recipients:

**Disability Award - Anglicare** exists to assist individuals, families and communities to live to their fullest potential. They work with people of all ages and from all backgrounds, to provide services from crisis intervention to long time support.

“The staff at Anglicare Lifestyle Support Options in Biloela are passionate, enthusiastic, dedicated, reliable and happy. These ‘long-time’ support people invest 150% into supporting their clients to have the best life that they can. We love them to bits!”

**Youth Award – Liam Warriner** acquired epilepsy in 2014. At first he was quite sad about it as he thought it meant that he would have to stop doing many things, such as kayaking. Liam was a champion and medal winner at a national level. He decided to be proactive about his epilepsy. He learnt what he could about his epilepsy and developed a plan to educate his school – Nudgee Junior College – about epilepsy. He made a presentation at his school assembly to 500 students as well as the teachers. Wally Lewis attended the presentation too. Epilepsy hasn’t stopped Liam from doing any of his sport or other pursuits. He continues to excel and is highly regarded by the Nudgee Junior College Community. He is a wonderful role model and also has helped other students with epilepsy.

**Education Award - Burpengary State Primary School** takes care of business when it comes to epilepsy.

“They update all their understanding epilepsy and midazolam trainings every year. They understand and co-operate in all areas of epilepsy management, from the condition itself and its impact on my son from seizures, to behavior and learning problems. This is a wonderful, caring and loving school and I believe they need acknowledgment for their epilepsy involvement.”

**Doris Kemp Memorial Award – Megan Massey and Sophie Kyriakides** joined Epilepsy Queensland in 2014 to complete their placement for their Nursing and Public Health degree.

Sophie and Megan very quickly became valued members of the EQI Services Team. Their communication skills and initiative have produced an excellent set of resources for teenagers. They were able to process a vast amount of new information in a short period of time and their warm, vibrant personalities have endeared them to everyone at Epilepsy Queensland, as well as our consumers whose calls they responded to. The ‘teenager’s resource’ they produced is a comprehensive set of fact sheets with information especially geared to teenagers and young adults with epilepsy.

**‘Fair Go’ Memorial Award - Virgin Australia ‘Information Services’** is a very close-knit and supportive team consisting of Melanie Jones, Simon Weldon, Tanya Schuhmacher, Llewellyn Jones and Chris Rosser.

“I have had three serious seizure events, multiple seizures lasting more than five minutes. I shared a management plan with my colleagues so that they could be prepared, but I never expected them to actually keep a close eye on me and to be able to see signs of seizure activity even before I noticed. My colleagues treat me no differently than they do anyone else, however they go above and beyond their contracted duties, showing the very best of caring. Melanie, Simon, Tanya, Llewellyn, and Chris, without you, I would not have the confidence to continue working, because you now provide an amazing structure which does not define me as someone who has epilepsy, but as a valued team member. The management at Virgin Australia have also been nothing but supportive, taking away any stress I might have had about job performance!”

**Carer Award – Mark Wood** is an exceptional carer and partner.

“It’s been a long journey for Mark, especially while waiting on my diagnosis. There were times when I couldn’t speak, couldn’t think, couldn’t stand – let alone sit up. I couldn’t make myself a cup of tea or even make toast. Mark took all of this in his stride and took over all of the tasks I would normally help out with. He was also my confidante and would put me at ease when I was distressed. He is always ‘on call’ should my workplace call him because of seizures and his calm and caring nature puts me and everyone around us at complete ease. I would not have blamed Mark if he had not stuck around, but instead he has treated me with compassion and love. Thank goodness. He is the best, a great carer!”

**Health Award – Dr Sophie Calvert** is a Paediatric Neurologist at the Royal Children’s and Mater Children’s Hospitals. Sophie’s expertise and professionalism is always outstanding with “great and ongoing support throughout all of 2014” and there is much appreciation for all the research she does in an effort to find new therapies to assist children with epilepsy.

**Media Award – Darren Klaassen from News Limited.**

“Once he heard about Adam and his condition, he has joined in with Epilepsy Queensland in helping spread the awareness. He has put advertisements in
the paper many times to promote Purple Day, and Epilepsy Queensland as well. A great guy, and always asks how my boy is doing.”

Marella Jenkins Award – Amy Murrell is one of those people who do fundraising in their local community for those affected by epilepsy and for us at Epilepsy Queensland. As well as raising much valued funds, her activities have also lead to an equally valuable increase in community awareness of epilepsy.

Amy is from Toowoomba. During each of the last two Purple Day Campaigns, Amy hosted highly successful fundraising events – Mia’s Walk for Epilepsy in 2013 and Mia’s Race Day for Epilepsy this year. Both were named in honour of Amy’s young daughter, Mia, and Epilepsy Queensland gained over $15,500 as a result of the events – a wonderful outcome.

Amy has made a significant and much appreciated contribution to Epilepsy Queensland. We consider ourselves very fortunate to have supporters like her.
As Chairman of Epilepsy Queensland Inc (EQI) it gives me great pleasure to present the 45th annual report of the organisation.

This year has been a year of great contrasts. In late 2013 we were advised that the Department of Health was going to place one of our operating grants out to tender. EQI, along with other small providers duly submitted a tender only to subsequently find that all of us were not successful. This grant represented approximately 23% of EQI’s income and was used to provide education and training as well as to support service delivery. To assist the organisations to ‘de-fund’, the Department of Health subsequently advised transitional funding to December 2015.

The loss of funding and the potentially devastating impact it might have on the organisation in 2016 has initiated substantial reflection by your Board. Reflection about how services can continue during this time, how staff can be supported and more fundamentally, how services like those provided by EQI can be maintained when NDIS is rolled out from 2016. Front and centre of these deliberations has always been meeting the needs of people with epilepsy and their families now and into the future.

The net result from this challenge is a renewed sense of commitment to the cause and a renewed sense of commitment to our members.

I mentioned a year of contrasts. At the same time the Department of Communities, Child Safety and Disability Services renewed their commitment to keep funding us through to 2016. Something for which we are extremely grateful and we hope reflects, in part, the quality of the services we provide.

Other positives during the year that I would like to draw your attention to include Purple Day and the Spring Challenge. Both generated significant income and provided an opportunity for our members and clients to become actively engaged with EQI. Former Origin Greats donated a car to help our work in the community.

I have been on EQI’s Board for nearly two decades, for some time as Treasurer and subsequently, Chairman. The pace of change in the not-for-profit sector has accelerated rapidly. The challenges faced by the Board have become increasingly complex, drawing heavily on the skills and expertise of Board members. During this time there have been many developments in the diagnosis and treatment of epilepsy. However, people with epilepsy and their families still need our support services. EQI’s operations have developed, meeting stakeholder needs via an evidence-based and quality accredited service. A game changer for EQI occurred when Wally Lewis became our Patron, lifting our profile considerably.

I would like to pay tribute to the Board, staff and volunteers for their continued dedication and enthusiastic efforts.

Finally, I am very pleased to advise that the process to renew the Board has continued this year and I would like to thank outgoing Board members Louise Foley and Stephen Greenwood for their outstanding contribution to the organisation. As always, I would also like to thank our Chief Executive Officer, Helen Whitehead, for her unstinting leadership of the organisation during this unsettling time and for all the support she has provided me and the Board. I know Helen has carried an enormous load and the organisation is better positioned and better able to tackle the challenges of next year due to her efforts.

Fergus Pollock
Chairman
Steve Eltis is a senior executive in a local Queensland-based bank and leads their Human Resources function. He has over 15 years of management experience and has worked with Epilepsy Queensland over the last few years, initially as a volunteer and more recently as Board Chairman. Steve’s father and daughter have epilepsy and Steve is very motivated to enhance the lives of all those touched by epilepsy.

What inspired you to join the board of Epilepsy Queensland? I first became involved with Epilepsy Queensland when our daughter Sophie was first diagnosed with epilepsy. We received so much support in what was a really hard time. We wanted to give something back so we started volunteering and fundraising. When we broke the world record for three-legged walking in 2008, we got to know the team at EQI. We also told our story at a few events and after a while Helen asked if I would be interested in joining the board.

What is your background? I am a career banker (with a Capital B)! I have a background in Human Resources and a degree in HR from Newcastle University (my home town). I first joined NAB in 1993 as a teller and had a variety of roles there as I worked my way into management. I then had a financial planning business for a short time before joining my current employer, QT Mutual Bank, in 2008 where I am the Head of Human Resources.

If I had not gone into HR and Banking I would have liked to be... A sports commentator. I love watching all sport but especially cricket and rugby league. It would be a dream come true to get paid to watch sport all day long.

My greatest achievement... I would have to say breaking the Guinness world record for three legged walking! Not just the physical effort of the walk but the whole event. It was a massive project. The logistics, the publicity and awareness. Although it was huge effort it was so worth it, despite the blisters!

I would most like to travel... to Europe. My son went last year on a choir tour and I am very jealous. I would like to go to Europe for the culture but for relaxation there is nowhere better than Fiji!

My favourite food is... Ice Cream. I love it! All types but especially Cookies and Cream. Ben & Jerry’s is a huge treat!


My most embarrassing moment... There have been thousands of them! I once sent a work email to all users and left the R out of the word shirt. I have never lived it down.

The person I would most like to meet or have met is... Wally Lewis. (one of the perks of being involved with EQI). I first met Wally at an event where we were both telling our personal experiences of epilepsy. I was awestruck and so excited that I got to have lunch with him. It was quite funny really as having grown up in NSW I used to hate how he led the Qld Origin team to so many victories but was pleasantly surprised at what a great bloke he is and his amazing dedication to improving the lives of those with epilepsy. I would really like to meet author Matthew Reilly. Not just because I love his books but I feel he is such a role model of positive leadership. He lost his wife to suicide, such a challenging thing to have to deal with. I am not sure I could.

The music I most like to listen to is... I love classic Australian rock like Cold Chisel, Midnight Oil, Silverchair and the Hoodoo Gurus but more recently I have been getting into musical theatre as my son has become involved in this and I find myself listening to songs from “Oliver” and “Wicked!”

Any interesting hobbies? I play indoor cricket every Tuesday night and a few years back was selected for the Queensland squad for my age group.

The thing I feel would most improve the epilepsy care in Queensland... More funding! It would be great if we could better service the needs of rural and regional Queensland.

My hope for the future for people with epilepsy... Is that Epilepsy Queensland is sustainable for long into the future. People rely on the support they receive from EQI and I would hate for the service we received as a family not to be available into the future.
During the national epilepsy awareness campaign (1 March to 26 March – Purple Day) we are asking people, families, groups, workplaces, schools, retailers, companies and organisations to help increase awareness and understanding of epilepsy – plus raise much needed funds for Epilepsy Queensland.

There are a number of ways YOU can help us... including:

• Buy and/or sell Epilepsy Queensland merchandise including pens; badges; wristbands; keyrings; USB cards; bracelets; and plush bears, mammoths and gorillas. Check out our Merchandise Order Form – there is something for everyone!

• Hold an event or fundraising activity at home, work, park, gym, club/hotel or local shopping centre. There is still plenty of time to organise something and we are happy to help with suggestions. Even a morning tea at work with purple cupcakes or a sausage sizzle at the local shopping centre – the list of possibilities is endless – be creative and think purple!

• Tell others what Purple Day means to you and ask them to help too. Speak to your local Golf or Bowls Club to see if they would put on a day for epilepsy or your local Service Club (Lions, Rotary etc.); Pharmacy; Gym; Shopping Centre; Medical Centre or Corner Store to enquire if they would sell merchandise or make a tax deductible donation.

• Become a Purple Hero for Epilepsy by easily creating your own online fundraising page and asking your friends, family and colleagues via email or Facebook to make a tax deductible donation. This is simply the best and easiest way for you to raise funds and awareness – you will be surprised how many people will want to join your campaign.

• Share your story! The media is always looking for people and families living with epilepsy to interview and/or photo for a story in the local newspaper. Let us know if you are interested.

• Encourage others to sign the Purple Pledge! It’s a fantastic way to spread the word via social media by taking a photo of someone holding the Pledge Sign.

• Join us on Purple Day for our annual Purple Procession through South Bank (or beyond) to watch the city’s skyline turn purple.

• OR... you can help enormously by making a tax deductible donation yourself.

For further information visit our website or call us on - 07 3435 5000 / 1300 852 853 for regional Queenslanders.

What does Purple Day mean to you?

Don’t forget to ask your children’s school to GO PURPLE too!

More about Purple Day...

Purple Day is a grassroots effort dedicated to increasing awareness about epilepsy worldwide. On 26 March people from around the globe are asked to wear purple and spread the word about epilepsy. Purple Day was founded in 2008 by 9 year old Cassidy Megan of Canada. Motivated by her own struggles with epilepsy, Cassidy started Purple Day in an effort to get people talking about the condition and inform others they are not alone. She named the day Purple Day after the internationally recognised colour for epilepsy – lavender.

Since then, hundreds of schools, workplaces and organisations (including Epilepsy Queensland) have also joined the campaign, wearing purple and hosting Purple Day events and promotions.

Epilepsy Queensland is proud to have the official role of fundraising, selling merchandise and promoting Purple Day throughout Queensland.

McCullough Robertson – Spring Challenge

Spring is well and truly behind us and so is Epilepsy Queensland’s Spring Challenge. A huge THANK YOU to the many individuals and teams who participated.

McCullough Robertson Lawyers was one of these teams. Elissa O’Donohoe – whose young daughter has epilepsy - encouraged her colleagues at McCullough Robertson to show their support for Epilepsy Queensland and they did this in a big way. EQI had the privilege of being the beneficiary of their Community Partnership Program’s inaugural dress down day – held in support of our Spring Challenge. Many thanks to Elissa and the team at McCullough Robertson.
School Holiday Fun!

To kick start the New Year we were very excited to be the chosen charity for the 2015 Crazy Kid’s School Holiday Fun program held in January. The 2 day event offered families an opportunity to come together and enjoy a day in the great outdoors experiencing the sunshine & natural setting the Botanic Gardens has to offer. Although a tad hot, Little Poss made an appearance and joined in the fun of a martial arts display whilst making some new friends. We are very grateful to the team at the Botanical Café Functions & Events for this wonderful opportunity to help bring epilepsy out of the shadows.

- Brisbane’s Story Bridge will once again light up purple for epilepsy awareness from 16 to 29 March 2015. Keep an eye out for our new Purple Day awareness banner up there too!
As with many not for profit organisations, Epilepsy Queensland functions as a team effort through the hard work of its staff members, supporters and volunteers. To recognise that effort, we would like to shine a spotlight on our volunteer program, guided by Karen Piekarski Community Fundraising Officer. Additionally, we are sharing the stories of three of our very own volunteers: Lindsey, Gus, and Lachlan.

Karen was charged with coordinating the work as the volunteering program grew in 2011 – matching the talents of volunteers with the needs of EQI. Today, there are between five and ten volunteers who come to the office in Brisbane on a weekly basis to help with a wide variety of tasks. Laughing, Karen said that the volunteers come to the office to assemble mailings and sort through merchandise but they turn the tasks into a social event. This “social event” is invaluable – it allows staff members to turn their attention to some of their many other pressing duties.

When asked what the most rewarding part of working with volunteers was, Karen said that it was “relating to them. Most of them have some connection with a person who has epilepsy or they have epilepsy…They enjoy working here and being able to talk freely. One gentleman mentioned that he even feels physically better after working here.” It also helps that she gets much needed help with time consuming tasks!

Recently we were joined by Lindsey, a student at Bond University pursuing a Master’s degree in Communication. Diagnosed with juvenile myoclonic epilepsy at age 14, Lindsey realises, “I have the good fortune to have very well-controlled epilepsy – but I know that can change at any time. Working with an organisation that is dedicated to education and support for such a complicated condition gives me confidence that I too will have support should I need it in the future. Through my volunteering, I’m paying it forward and learning at the same time.” Growing up she was often worried about telling her friends about her condition; would it scare them? There was very little information available to educate and no vocal organisations that made it apparent how common the condition truly was. “Now that I am a bit older and wiser (I think!), I’ve chosen to take a completely different approach.” Through a work experience program, Lindsey assists Epilepsy Queensland with their media and public relations. It provides an opportunity for Lindsey to contribute her time and further her education by spreading awareness of events and communicating with media outlets.

Gus has been a volunteer with Epilepsy Queensland for about four and a half years. “If you want it, I put my hand up!” he responds with vigour, when asked what inspired him to volunteer. He has been involved with epilepsy awareness in other aspects of his life in addition to volunteering with EQI. Through petitions to the government on behalf of patients and work to raise money for related organisations, Gus recognises and pushes for education across communities. At EQI he helps staff members with community outreach by organising brochures, leaflets and mailings. Diagnosed with epilepsy at 7 years old, Gus moved to Australia from New Zealand in 1987. A man of many talents, he worked mainly as a painter and a decorator. While he is no longer able to work, he has fond memories of working at Royal Brisbane Hospital “because people were understanding” of his condition. Now that he receives a disability support pension, volunteering with EQI is one way for Gus to see, meet and work with new people – it’s quite fulfilling for him! It’s an opportunity for Gus to “get a better understanding of people from all walks of life – people who have had surgery or been put out of work, or being unable to drive.”

Another frequent volunteer is Lachlan, a student at Queensland University of Technology. Before heading off to university he would volunteer fortnightly with EQI – now he returns on holidays for work experience. He was born with a brain tumour in the left temporal lobe; after 2 neurological operations Lachlan experienced absence, focal dyscognitive, and tonic clonic seizures which are now mostly controlled with medication. When asked what some of the best parts of volunteering with EQI are, he begins a list: “broadened network of friends, boosted social skills, provided work experience”. He was exposed to people who shared some of his experiences of epilepsy and it also broadened his own awareness of the condition.

As well as the volunteers whom we regularly welcome in the office, we also enjoy the support of many others who engage in a variety of fundraising and awareness-raising activities in their own communities or help us with special events such as the Purple Procession. Regardless of the type of work they’re doing, EQI volunteers all share a desire to make a positive difference to the lives of people affected by epilepsy.

If you are feeling inspired and wish to become a volunteer with Epilepsy Queensland please contact Karen on 07 3435 5000 or karen@epilepsyqueensland.com.au. It would not be possible for our organisation to reach as many people with epilepsy, their families, carers, and the community without the support of our volunteers. Thank you to all of our volunteers both in our office and those doing work in your own communities.
Fish oil (n-3 fatty acids) in drug resistant epilepsy: a randomised placebo-controlled crossover study

Christopher M DeGiorgio, Patrick R Miller, Ronald Harper, Jeffrey Gornbein, Lara Schrader, Jason Soss, Sheba Meymandi

INTRODUCTION

Drug resistant epilepsy is a serious disease, defined as failure of a patient with epilepsy to respond to two or more appropriate antiepileptic drugs at a therapeutic dose. Treatment options include adding new antiepileptic drugs, followed by consideration of epilepsy surgery, neuro modulation or dietary therapy (Ketogenic diet or the modified Atkins diet). Fish oil, which contains ω-3 fatty acids (n-3 fatty acids), is of particular interest because it may improve cardiac health, reduce sudden cardiac death after myocardial infarction and delay the onset of seizures in a pentylentetrazole model of acute seizures. n-3 fatty acids, especially docosahexaenoic acid (DHA), cross the blood brain barrier and become incorporated into the cell membrane’s lipid bi-layer. There, n-3 fatty acids are believed to modify calcium and sodium channels, reducing membrane excitability in heart myocytes and neurons. Randomised controlled clinical trials of high-dose fish oil have been performed with promising, yet inconclusive results. The purpose of this clinical trial is to evaluate high dose and low-dose fish oil in a phase II randomised placebo-controlled crossover trial in participants with drug resistant epilepsy.

Randomisation

Participants were randomised in blocks of four to a crossover sequence of low dose, high dose and placebo. All participants were randomised once they met inclusion criteria at visit 1, and entered the initial 10-week treatment period. Entry into the study was followed by a 6-week washout period, and again a 10-week treatment period, followed by a second 6-week washout period, and then a final 10-week treatment period. Participants were randomised to six possible sequences. The entire duration of the study was 42 weeks.

Adverse events

Fish oil was well tolerated, with no serious adverse events encountered during the study. One participant died during the study due to autopsy-confirmed sudden death in epilepsy (SUDEP). This participant was in the high-dose fish oil treatment period when SUDEP occurred. At the same time, the participant was on multiple antiepileptic drugs and aripiprazole, an antipsychotic also associated with an increase in cardiac mortality. The patient had failed epilepsy surgery, vagal nerve stimulation, had frequent tonic–clonic seizures and was found after a seizure next to his bed in the prone position. The cause of death was thought by the investigator to be unrelated to the treatment with fish oil.

Discussion

The primary finding is that low-dose fish oil (3 capsules/day, 1080 mg of EPA+DHA) was associated with a reduction in seizure frequency of −33.6% compared with placebo. Low-dose fish oil was associated with a responder rate of 25% and a seizure-free rate of 10%. Though the size of the trial will require confirmation, the magnitude of the effect on seizure frequency is similar to many randomised trials of anti epileptic drugs. Low-dose fish oil was also associated with a modest reduction in blood pressure, but this finding was significant only when compared with high-dose fish oil. The reduction in blood pressure indicates that low-dose fish oil may exert a positive cardiovascular benefit in this cohort with drug resistant epilepsy, a finding of some importance, given the recent data that the risk of death due to myocardial infarction is significantly higher in people with epilepsy.

It is important that the results from this trial be confirmed in a large multi centre trial. Limitations include the relatively short duration of exposure; participants were only exposed to each treatment for 10 weeks. It is unknown whether the improvement in seizures for the low-dose group is sustained over time. Second, due to the crossover design, a pretreatment baseline was not incorporated. This was designed to minimise the time where participants were held captive in the study without treatment, due to the already long duration of the study (42 weeks). However, since the study was a double-blind placebo-controlled crossover design, all comparisons were made to a true placebo. A large confirmatory study will likely use a traditional parallel group design with a pretreatment baseline. Finally, the study did include three participants who had exclusively simple partial seizures. Inclusion of participants with partial seizures is common in antiepileptic drug studies.

Low-dose fish oil is a safe and low-cost intervention that may reduce seizures...

However, these participants were highly drug resistant, and their response did not contribute to efficacy demonstrated by fish oil, as none experienced more than a 17% reduction in seizures.

In summary, we report that low-dose fish oil (3 capsules/day, total of 1080 mg EPA+DHA) was associated with a 33.6% reduction in seizure frequency compared with placebo in a cohort with drug resistant epilepsy, and a mild but significant reduction in blood pressure. A large randomised controlled trial of fish oil is warranted to confirm or refute the findings of this study. Low-dose fish oil is a safe and low-cost intervention that may reduce seizures and improve cardiovascular health in people with epilepsy.

References


If you would like a full copy of this research paper please contact Epilepsy Queensland or a full copy can also be found on our website at www.epilepsyqueensland.com.au
For his whole life Peter has suffered from focal dyscognitive and absence seizures. At 18 months of age Peter was diagnosed with epilepsy, and as a child was always aware of his seizures and when they would occur. Over time Peter identified his own triggers and adapted his life to avoid them. As Peter became more aware of his seizures and was able to “feel them coming on” he would become an expert at removing himself from situations and have his seizures away from people so no one would know about them. Peter said, “For 45 years no one knew I was having seizures, let alone had epilepsy.”

Peter is an avid golfer and actually lives behind a golf course, and even his good friend from early childhood with whom he plays golf on a weekly basis was unaware of his epilepsy. Peter said when he felt a turn coming on he would walk into the trees, hide away, have his seizure and return to playing golf without a sign of distress.

Before surgery Peter was on daily medications to manage his epilepsy. However, he was still experiencing seizures at least every 4-6 weeks. During those periods Peter would have 10-15 seizures per day for 3–4 days. Peter said he had never made plans in his life as he never knew when the seizures would begin. This was the norm up until 2012 when Peter said, “something changed” and he was having seizures every day. He couldn’t function, was in bed exhausted and was unable to move. On the days that he could function he would try to manage some work or take some walks to the golf course and hit some balls.

Peter recalls the moment in time when he finally decided ‘enough is enough’, something had to change. It was when he was playing golf with his regular round of friends who had no idea Peter had epilepsy. He was waiting to tee-off on the 7th hole and suddenly felt a seizure come on. He had nowhere to hide, and when he recovered from his seizure the question on everyone’s lips was “What just happened?” In a way it was Peter’s ‘coming out’ about his epilepsy. After this experience, he slowly told his closest friends about his epilepsy and his decision to have surgery. Many reacted the same way: shocked and speechless.

A week before the surgery in Melbourne Peter was playing championship golf and had a $50 bet with his mate that he’d win. After the first round of four Peter had won, but for the following week his mate nagged him continuously, wanting to regain his position on the ranks. Three days before the major surgery, Peter told his mate about his epilepsy. His mate let Peter keep his winning place in the ranks and never nagged him about it again.

When Peter had decided to go forward with the surgery there were several things that he still had to consider. First were his two children aged 7 and 9 at the time, second was his IT business and his 12 employees and partner, and third was himself. Peter was given an 80% chance of having a stroke after the surgery and 90% chance of major depression alongside several life threatening complications. “People thought I was mad” said Peter when I asked him about what his friends and family thought. Even Peter seemed to have his doubts. As he explained “I needed to do it, even if I didn’t think I was going to live.”

Peter’s surgery was scheduled for 26 March 2013: Epilepsy Queensland’s Purple Day.

After a successful surgery Peter decided to return to a neurologist he had seen in 1998 about his epilepsy. Ironically Peter told me the neurologist actually recommended the surgery to him in 1998 but Peter didn’t feel ready to proceed. He said, “I wouldn’t have been able to do it then, I’ve grown up now. I haven’t had a drink since the surgery and before that I was the sort of man who enjoyed his beers.” He says if there was anything he would have done differently it would have been to do it sooner. “But you have to be ready within yourself to do it.” Peter knew when he was in Melbourne for the video monitoring he had to have the surgery then; “It’s NOW or NEVER,” he said.

Peter says he remembers his first thought and feelings as he was waking up from surgery in the recovery room. He said “I remember the first thing I thought as I came out of surgery was that I could feel my legs. I thought ‘I CAN WALK!’” From then on he knew he was alive and had survived the surgery.

To top it off, Peter hasn’t experienced a single seizure since the surgery. He remembers he was told he wouldn’t be able to play golf for 6 months after the surgery but by 2 months his best mate was dragging him to the green and they were driving about on the buggies. Peter says without his friends’ daily calls and golf course trips and continual support from the team in Melbourne, he would have fallen into a deep depression. Peter explains he would have post surgery jitters around 4:30–5:30pm every day, but when he was out on the green they disappeared.

Peter says he will feel forever in debt to the people in Melbourne who helped in the process of his surgery and recovery, especially Professor Gavin Fabinyi.

“Every day I feel frightened that I’ll have another seizure, it’s like I’m waiting for it to happen. But I’m excited too, I push myself to do things I would never have done before, because I knew I would have a seizure if I did. It’s amazing!”

After 45 years of hiding in the shadows about his epilepsy and even his closest friends being unaware of his condition, Peter is slowly opening up about his experience, not only about his epilepsy but his surgery as well, and how it has changed his life. Peter still hasn’t seen the footage of him having the seizure used for the surgery, and he says he will never watch it. Peter claims he wouldn’t have done anything differently and recommends surgery to anyone who has the option.
Q. I have noticed that my little boy has more seizures in summer. Is that usual?
A. It is not uncommon for people with epilepsy to have more seizures in the hotter weather. Hot days and sudden changes in temperature can trigger seizures. Living in Australia, exposure to extreme high or low temperatures can be difficult to avoid. Side effects of certain anti-epileptic medication can make it difficult to regulate body temperature in some people with epilepsy. However, being aware of this and having simple strategies in place to regulate body temperature can help.

**Strategies to help...**
- **Keeping cool:**
  - Arctic Heat is an Australian company that manufactures heating and cooling vests and other temperature regulating products. This can be effective when needing to cool down quickly.
  - Placing a water bottle in the freezer overnight and bringing it with you the next day can be an easy way to cool down. You can either drink the chilled water or place the water bottle on the back of your neck to help bring down body temperature.
- **Exercising and outdoor activities:** When you are exercising or doing outdoor activities, it can be difficult to keep cool, especially if you're doing vigorous activity or sport.
  - If you are outside, try to keep in the shade whenever possible. The hottest part of the day is between 10am and 2pm, so planning outdoor activities outside of this time period can help. Also, you could consider indoor sports or joining an air-conditioned gym.
  - Remember to drink water whilst exercising or doing physical activity, to replace lost water from sweating and to help prevent dehydration.
  - It is important to always assess your safety and the associated risks before participating in exercise. You can contact your doctor or Epilepsy Queensland on 07 3435 5000 for help in assessing the risks.

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### Midazolam - New School Year To Do List

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

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

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

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

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

- **Have You Considered the Following:**
  - Are the contents of the kit stored in a container? (a small plastic lunchbox is suitable)
  - Is the container kept out of reach of children, both at home and school?
  - Is the kit kept below 25 degrees Celsius, and out of direct sunlight, both at home and at school? (Midazolam is not to be stored in the fridge or freezer)

- **Have you provided an ice brick and cooler for the kit to be stored in during the hotter months when taking the kit outside?**
- **Do you have a separate kit for home and school?** (This is to ensure the kit is never forgotten between destinations)

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

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

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

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

For more information or help with any of the above please contact Epilepsy Queensland on 07 3435 5000.
Hearing about the use of marijuana in the treatment of epilepsy and other conditions always brings up a little anxiety, hesitancy and speculation. How can this be a useful medicine when it is an illegal substance? Will it help or harm my child or family member when nothing else seems to be working? Will I be judged for trying anything that might stop seizures and increase their quality of life?

The topic of medical marijuana was discussed at length with a panel at Epilepsy Queensland’s ‘Thinking Outside the Box’ Symposium that was held on 20 November 2014. Michelle and Rozanne, parents of children with severe epilepsies, Professor Roy Beran, Dr Dan McLaughlin, Professor Terry O’Brien and Dr Jenny Jones spoke honestly and openly about the benefits, challenges, ethics and legalities of using medical marijuana.

At this point, Epilepsy Queensland supports the JECA (Joint Epilepsy Council of Australia) Statement (published in the last Flame) and are advocating for further clinical trials. We would love it to be an available treatment option for families and hope that it is not too far off.

Thanks to modern technology Dr Chris DeGiorgio, a Professor of Neurology at UCLA School of Medicine, along with colleague Dr Colin Kealy, was able to join the symposium via Skype. His presentation on his trials and use of the Vagal Nerve and Trigeminal Nerve Stimulation was an eye opener for many in the room. For those who have drug resistant epilepsy especially, surgery, vagal nerve stimulation and trigeminal nerve stimulation may now be more of an option. The vagal nerve stimulation has been and continues to be an established and effective therapy and now, along with continuing trials, the Trigeminal Nerve Stimulation, it seems, is an emerging platform that is now approved in Australia.

Professor Terry O’Brien has particular expertise in epilepsy, neurotrauma and related conditions. He currently leads a large research team who study these, and other neuropsychiatric disorders. Professor O’Brien joined the symposium, speaking of the new and future treatments for people with epilepsy. He took us on a journey, from the old to the new medications and their efficacy, to being able to make choices, to having options to find the right drug for ‘my’ epilepsy. Professor O’Brien and his research team have us enthusiastically looking forward to developments in epilepsy therapies such as surgery, the nerve stimulations and dietary therapies.

Overall the ‘Thinking Outside of the Box’ Symposium was filled with experts, looking at Epilepsy – on the Horizon. Professor Christian Gericke, Director and CEO of The Wesley-

St Andrew’s Research Institute took time to demonstrate that the way forward from any deficit in anti-epileptic medication is effective care research.

Roy Beran, Professor of Medicine with a keen interest in law and ethics, as well as a healthy sense of humour, led a very useful discussion about the benefits, challenges and the legal considerations of generic medications in the future.

Professors Peter Silburn and Harry McConnell also joined in with their experience of new medication and deep brain stimulation. Those who attended were certainly brought up to date with the latest in epilepsy therapies. Epilepsy Queensland is again grateful to Griffith University and St Vincent’s Hospital. With their continued collaboration we can bring our consumers the latest information and support.

We could also not host these events without the support from UCB, SciGen, Aurora Bioscience, TabTimer, Epi-Assist and QUT. Don’t miss this year’s event!
<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>12 February</td>
<td>2015 Understanding Epilepsy Workshops (Woolloongabba)</td>
<td>For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families.</td>
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<tr>
<td>18 February</td>
<td>2015 Understanding Epilepsy Workshops (Gold Coast)</td>
<td>For Families, People with Epilepsy, Carers, Child Care Workers, Teachers, Nurses and Allied Health Professionals</td>
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<tr>
<td>28 February</td>
<td>Brisbane’s Purple Ball (Victoria Park Golf Club)</td>
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<td>7 March 16 May</td>
<td>Brisbane Adult Support Group Meeting</td>
<td>For further information please contact the Services Team at Epilepsy Queensland</td>
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<tr>
<td>19 February 22 May</td>
<td>Carers of Children with Uncontrolled Epilepsy Support Group</td>
<td>For further information please contact Charlene Mundy at Epilepsy Queensland</td>
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<tr>
<td>Regular</td>
<td>Other Support Group Meetings</td>
<td>For further information please contact the Services Team at Epilepsy Queensland</td>
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### Introducing Jack Packshaw...

Jack Packshaw recently took part exhibiting his 2014 artworks at the Graduate Exhibition at the Gold Coast City Gallery, creating awareness of epilepsy. He has been very focused on incorporating epilepsy and aspects of epilepsy into his artworks to give them layers of depth.

**Artist Profile:**

My name is Jack Packshaw and I am a QCA studio artist who mostly works within the digital realm. I have a fascination with the human mind, how it works and our consciousness.

My artwork concepts surround mental illness, more specifically Epilepsy. As a person with epilepsy myself, I have personal experience with the issue and embrace it in my art. I explore a broad spectrum of mediums in my practice, varying from illustration to sound-art utilising a range of software including Photoshop, InDesign, After Effects and Logic Pro 9.

I like to convey my ideas and concepts through methods that can be interpreted by audiences of all ages, in many different ways. Employing a variety of self-discovered techniques in my creative process, I develop artworks that are unique and aim to educate, immerse and involve interaction with the audience.
I would like to help Epilepsy Queensland!

I would like to join Epilepsy Queensland

☐ $35.00 Ordinary membership  ☐ $28.00 Concession membership

☐ $90.00 Organisation membership  ☐ $50.00 Family membership

(must provide copies of concession card with form)

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☐ 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).

Thank you for your contribution!

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