the flame
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Cassidy Megan,
Founder of Purple Day with our Purple Pledge
Human-Type Epilepsy Discovered in Sea Lions

Eating fish exposed to toxin-laden algae harms the animals’ brains, study suggests.

WEDNESDAY, March 19, 2014 (HealthDay News) -- When exposed to a certain toxin in algae, sea lions develop a form of epilepsy similar to that in people, a new study says.

Domoic acid -- which can cause tremors, convulsions, memory loss and death -- is produced by algae blooms and accumulates in small fish that sea lions eat. Every year, hundreds of sea lions affected by domoic acid are washed up along the California coast.

Researchers examined the brains of 14 dead sea lions that had epilepsy caused by domoic acid and compared them to the brains of nine sea lions that died from other causes. The sea lions with epilepsy had about 50 percent fewer neurons in the hippocampus (the brain’s memory center) than the other sea lions.

“We found there was a loss of neurons in specific patterns that closely matched what is found in people. And there is synaptic reorganization -- a rewiring of surviving neurons. This also matches what is found in humans with temporal lobe epilepsy,” study lead author Paul Buckmaster, a professor of comparative medicine at Stanford University, said in a university news release.

The investigators also found that in most of the sea lions with epilepsy, the hippocampus on only one side of the brain was damaged.

“That was really surprising. That is what you find in people -- 80 percent of the time the damage is just on one side,” Buckmaster said.

The study appears online March 19 in the Journal of Comparative Neurology.

Further research in sea lions could lead to the development of better treatments for both sea lions and humans, according to Buckmaster.

Temporal lobe epilepsy is one of the most common types of epilepsy in people and has no cure.

More information
The American Academy of Family Physicians has more about epilepsy.
SOURCE: Stanford University, news release, March 18, 2014
-- Robert Preidt
Last Updated: Mar 19, 2014

Increased Risk of Epilepsy Among Autoimmune Disease Patients

Health Insurance Claim Data Suggests Value of Screening

BOSTON, March 31, 2014 /PRNewswire-USNewswire/ -- Patients with an autoimmune disease have a 3.8-fold increased risk of developing epilepsy, according to a new population-level study from Boston Children’s Hospital based on health insurance claim data. The study, published online March 31, 2014 in JAMA Neurology, is the largest to date to look at the association between autoimmune disease and epilepsy without a recognized neurological cause.

Epilepsy affects approximately 470,000 children and 2.3 million adults in the U.S. alone. While medical and surgical treatments can be effective in managing the disease, the results are mixed. A growing number of reports, based on small clinical or animal model studies, have begun to link specific autoimmune diseases to cases of epilepsy of previously
unknown cause. Epilepsy therapy is largely directed at the symptoms of disease and in about two-thirds of patients, the specific underlying cause of the condition is never found.

“Autoimmunity is strongly linked to seizures. We may be overlooking a treatable mechanism in epilepsy patients,” said the study’s lead author Kenneth Mandl, MD, MPH, who runs Boston Children’s Informatics Program (CHIP)’s Intelligent Health Laboratory. “We need to change how we think about clinical management of these conditions.”

Mandl and Mei-Sing Ong, PhD, first author of the study, looked at the autoimmunity-epilepsy connection at a population-level by analyzing de-identified claims data related to epilepsy and 12 autoimmune diseases from more than 2.5 million subscribers of a nationwide health insurance carrier.

The researchers found that there was a 3.8-fold increase in the risk of epilepsy for patients with an autoimmune disease and 17.5 percent of epilepsy patients also had an autoimmune disease. The increase in risk of epilepsy varied by form of autoimmunity, ranging from 1.9-fold for psoriasis to 9.4-fold for antiphospholipid syndrome. In addition, the increase in risk was greater among children (5.2-fold) than adults (4.3-fold).

Findings also revealed that autoimmunity patients on select immunosuppressing medications had a lower risk of developing epilepsy.

“These findings suggest a new approach to treating seizures, one based on quieting the immune system,” Mandl said.

According to Mandl and Mark Gorman, MD, a Boston Children’s neurologist involved with the study, the risk association between epilepsy and autoimmunity suggests that both rheumatologists and neurologists should consider screening their patients for signs of the associated condition.

“There are subtle signs of epilepsy that may suggest to an immunologist that a patient should be assessed by a neurologist,” said Gorman. “Similarly, if you are a neurologist, a referral to an immunologist may be warranted if a patient shows subtle signs of autoimmunity.”

The team’s data did not allow them to explore possible mechanisms behind the association, but they hope to work with collaborators to look for biological links.

“There are many ways in which autoimmunity can affect the brain and cause seizures,” said Gorman. “The next step is to find out what they are.”

The study was supported by the National Institute for General Medical Sciences (grant number R01GM104303), the National Center for Biomedical Computing (grant number U54LM008748), the Conte Center for Computational System Genomics of Neuropsychiatric Phenotypes (National Institute of Mental Health grant number P50MH94267) and the Australian National Health and Medical Research Council.

Boston Children’s Hospital is home to the world’s largest research enterprise based at a pediatric medical center, where its discoveries have benefited both children and adults since 1869. More than 1,100 scientists, including seven members of the National Academy of Sciences, 14 members of the Institute of Medicine and 14 members of the Howard Hughes Medical Institute comprise Boston Children’s research community. Founded as a 20-bed hospital for children, Boston Children’s today is a 395-bed comprehensive center for pediatric and adolescent health care. Boston Children’s is also the primary pediatric teaching affiliate of Harvard Medical School. For more information about research and clinical innovation at Boston Children’s, visit: http://vectorblog.org.

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Use of the Modified Atkins Diet in Lennox Gastaut Syndrome

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Abstract

There is scanty data regarding the efficacy and tolerability of the modified Atkins diet in children with Lennox-Gastaut syndrome. This study was a retrospective review of children with Lennox-Gastaut syndrome treated with the modified Atkins diet from May 2009 and March 2011. The diet was initiated in those children who persisted to have daily seizures despite the use of at least 3 appropriate antiepileptic drugs. Twenty-five children were started on a modified Atkins diet, restricting carbohydrate intake to 10 g/d. After 3 months, 2 patients were seizure-free, and 10/25 children had >50% reduction in seizure frequency. At 6 months, of 11 patients on the diet, 3 were seizure free and 8 had >50% reduction in seizure frequency. At 1 year, all 9 children on diet had >50% reduction in seizure frequency. The side effects of the diet were mild. The modified Atkins diet was found to be effective and well tolerated in children with Lennox-Gastaut syndrome.

Journal of Child Neurology jcn.sagepub.com
My Epilepsy Story

by Jen Slaughter

Here I was again, starring in yet another movie which unfortunately always ended before Colin Firth came along to hold me in a sensuous embrace….I was never sure when I would be called on to play the starring role. These movie episodes happened at any time. Often happening when I was feeling overwhelmed, either at work, out and about-going into supermarkets for example-understandable when there are so far too many choices-do we really need a whole aisle of brekky cereals to choose from?

When I was at home with my 2 children, as a mum on my own, I found there were many interesting challenges never covered in all the “Bringing Children up the Easy Way” books. How do you manage to take one child to a soccer game that starts at 10am in Bribie Island and have the other start their soccer game at Noosa at 10.30? Or deal with “Mum, I need to have an ant costume for parade today” when you are just around the corner from school. Stress was never too far away...

These movies I was in had no pattern, time-wise. Some days I would have 3 movies to star in. Other times there were no starring roles for months. The movies were so brief, I could be talking to someone and they didn’t notice. (On some occasions I was talking to doctors while I was at work and they didn’t notice anything was happening). I often had feelings of déjà vu at these times and thought the episodes may have been a more dramatic form of déjà vu.

My family noticed and often told me I needed to have it investigated. The sand is often a great place to put your head when you are trying desperately to pretend something will go away. I rarely visited a doctor as I was otherwise very healthy. I had listened to so many people who did I feel like I was in a movie, I felt like I was going to faint (with no Leading Man’s arms around me). This episode scared me because it lasted over 2 minutes. By now I was starting to vomit after some of these episodes. When I mentioned to 3 different GPs that I kept having this weird feeling “like I was in a movie”, I am sure all these doctors thought the movie was “One Flew over the Cuckoo’s Nest”. The feeling of “being in a movie” can also be a symptom of Bipolar Disorder. The GP’s reaction was always the same - it was nothing to be concerned about - come back if it happens again. ECG and blood sugar was OK. No further questions to try and work out what was going on. There was another patient waiting….with all the advances in medical science there is still the 15 minute patient waiting….with all the advances in the reflection. Looking back am amazed I still worked and carried on life as normal.

When I finally did go to the GP the following week for a pap smear (which I thought I was overdue for) she laughed when she said I had had one 6 months ago and didn’t need one.

She didn’t laugh when I asked her for a referral for an EEG, as I had had 2 seizures just over a week ago. In fact she did a very good impersonation of the Headmistress in the movie “Matilda”. “SIT DOWN” she barked. I was the patient every GP dreads. First thing on Monday morning coming in for something simple and mentioning on the way out just a small referral for an EEG, as I had had 2 seizures just over a week ago. In fact she did a very good impersonation of the Headmistress in the movie “Matilda”. Under no circumstances was I to drive anywhere!!!! I had to ring my son to come to my rescue. He is now a Paramedic. I am very confident of his driving. At that time I felt very nervous as he had just passed his “P’s and wasn’t afraid of anything on the road. Within an hour I had blood tests, and was...
I didn’t take kindly to the emphasis he was putting on the issue of my not being able to drive until this had been sorted out, and the lack of emphasis helping me come to terms with the fact I mostly likely had epilepsy. During this appointment I had to have a healthy discussion with my husband who, when asked, advised that I did snore….I had stopped all that snoring! It was decided then that I had to see a sleep specialist and have a Sleep Study done, prior to a diagnosis of epilepsy being made. As always the process was a marvel of modern medicine, as due to delays in both being available, it took over 4 months, and we were paying to go privately!

I found out there was a good reason for my “gasp for air” during the night when severe Sleep Apnoea was diagnosed. Once I started using my Sleep Machine (thanks so much to the Aussie team who developed it!) I felt fantastic, was no longer so tired. (Must work out a way to dress up the sleep machine’s hose and mask set up in something beckoning and sexy. Let me know if you already have!)

Incredible how you don’t realise how bad things are until you feel better. It was amazing - I felt like my brain had returned! It was able to think more clearly. My memory was still a concern. I had great difficulty remembering so many occasions. My family have become used to me saying “I don’t remember”.

It was always a little unnerving however, when I met someone who obviously knew me well “Hi Jen How are you? What’s Craig up to?” and I had no recollection of ever meeting them. Especially as I had always prided myself on never forgetting a face.

Bluffing my way through it worked sometimes but, when it didn’t, I found some people couldn’t understand how I could forget them! As always most people were very understanding. I just put it down to old age, never mentioned the “E” word. In the meantime I had an EEG. As the neurologist was going on holidays he left it in his receptionist’s capable hands to tell me the result.

When it came back as normal she had no hesitation in putting on her neurologist’s hat, telling me I didn’t need to come back - everything was normal. I didn’t agree with her diagnosis and requested she discuss it with the neurologist when he returned. She still insisted everything was normal and no further appointment was needed.

She was the Berlin Wall of receptionists. A kerfuffle when the neurologist returned resulted in my being on the other side of his desk shortly afterwards. The end result was - yes I did have epilepsy and that I was not able to drive until I had been seizure free for 3 months (under certain conditions) - always the neurologists main concern.

I finally started on the first of 3 medications that all had adverse reactions - the last caused me to become very aggressive! Worse than a bad case of PMT - I even frightened myself! So that was it ! I didn’t have epilepsy. I put the “D” in denial. It was all a huge mistake.

These 3 medications didn’t work because I didn’t need them. The neurologist was so concerned with telling me not to drive he didn’t know what he was talking about. I even put together a huge file to show him why he didn’t know what he was talking about. I wasn’t afraid to let him know my feelings. I was going to get a second opinion which would prove me right! My inner monster really took hold in his office (I am normally very quiet and subdued).

He said under his breath loudly enough for me to hear - Who’d be a neurologist?” He gave me a funny look when I left. At the time I thought it was because he realised he had misdiagnosed me.

Of course I was proved wrong, after a huge family wedding, which ended in loads of tears (not the happy ones) from several family members, and the usual massive family Christmas kerfuffle.

I had 2 more seizures one night when some outrageous family members had an overnight stay. They thought they heard a big bump in the night. After I went back to the neurologist with my neurones in tatters, he finally told me about Epilepsy Queensland, and showed some compassion. The next medication proved to be the one that suited me, thankfully. I am so grateful to the doctors and scientists who developed the medication.

Even more grateful to the volunteers who were brave enough to take part in the trials. Even starting on a low dose made me wonder how those volunteers felt when they had to take large doses of the medication at one time!

Still no more driving though…I would have been more impressed if I had been told no more washing up or housework as well! Finally after being seizure free for 3 months I went to see the neurologist who had to give me the bad news the law had now been changed to being seizure free for 6 months!!! The original law, “Jet’s Law”, had come about because of an unfortunate 2 year old boy who died as a result of a driver having a seizure causing an accident. There was a change to the law to provide a safer exclusion time after seizures. If you like a good mystery novel - read through the current Austroads Guidelines for licensing...
laws pertaining to driving after seizures. As much as I found it difficult not being able to drive there was no way I was going to cause harm to anyone in an accident.

Just when I was about up to the 6 month mark, there was still one more movie to star in…. for the first time since I had started medication. So no driving for another 6 months! By this time I was used to not being able to drive. In all this time I didn’t tell many people about having epilepsy. It’s definitely not a trendy disease to have (if there is such a thing). I never discussed it unless I asked friends for a lift.

No one thinks twice if they have diabetes or high blood pressure. There is no need to keep it a secret. Often it can be a subject of a lengthy discussion. However if you mention epilepsy you can cut the air with a knife. You can see the look of terror “OMG!!!! What do I do if you have a seizure?” - Just make sure I am in a safe spot, or make it safe. If it doesn’t stop in 5 mins, don’t run out the back door, ring 000 instead. Remember it will be worse for you looking on as I will have no recollection of it. “Are you still normal?” (As normal as ever- whatever that means) “Can you still work?” (Yes - epilepsy doesn’t come with a winning Lotto ticket unfortunately). I found it very difficult when I had to tell people I had to wait even longer to be able to drive. “Oh well 6 months isn’t long!” Isn’t long!!!! Just see how you feel if you can’t drive for 6 HOURS!!!

But I decided in the interests of public safety - best to say nothing, go away and have a quiet tantrum on my own. However I am happy to say I am now seizure free, can go to the movies without having them come to me, and am grateful to have the Best Leading Man after all. (Sorry Colin)

My husband stuck to the “In Sickness” part through all of this, drove me everywhere I needed to go when he could. Gave me loads of support and love, even when I was less than my loveable self. Although we did have a moment at home when I was finding the novelty of not being able to drive getting all a bit much. He kindly informed me that he needed some “time out” and promptly drove off in the car. When he finally returned he did gain an understanding of the issue I was having in no uncertain terms!! Very difficult to understand unless it happens to you…. What did I learn through all of this…..

Never neglect any health issues until they get to the point of no return. Keep trying to find a GP who you are confident in and makes time to listen. (My GP and I are “good friends” now when I have to see her. We had a laugh when my Pap smear finally was due). Most receptionists do a wonderful job, but for those who aren’t aware the Berlin Wall was torn down years ago, just keep making your request polite but persistent.

Hang in there while you are trying to get your medications sorted out, there will be one that suits - just like trying to find Mr/ Mrs Right. Drink loads of water especially in summer. I always carry a water bottle just in case I get caught out (in a traffic snarl for example). Keep that grey matter hydrated, aim for juicy peach effect not dried prune. Avoid getting hot or being out in the sun. I find now I am more prone to heatstroke. Make sure you get as much sleep as possible. I eat at least every 2 hours to make sure my blood sugar doesn’t get down to my toes. I always carry a snack of nuts, dried fruit or piece of fruit with me just in case.

Find ways of dealing with stressful situations - especially the unavoidable ones. I try as much as I can to prepare myself beforehand. If a curly problem comes up, I grab a cuppa and have a walk outside. A Tim Tam might also be needed if it’s serious. If that doesn’t go a long way to solving the problem, time to pack up toys and go home. Trying to see the lighter side also helps.

The biggest lesson I learned was to do with the Not Being Able to Drive issue. I amazed myself by riding my pushbike (fantastic find at a tip shop for $45) to work - something I never would have dreamt of in my wildest dreams. I live out in the country, up a gravel road, 9 kms from the nearest town, where I work. No public transport within Cooee. I learnt that you see a lot more when you travel slowly, people are able to say hello. I took lost dogs home, helped put fallen bumpers back on cars. Gave directions, and realised there is so much we miss by racing past in our car. Met new people every day, and best of all felt fantastic when I had all my endorphins whizzing around.

I could ask for a lift home. I realised that having our own cars is isolating and doesn’t provide many opportunities to get to know people.

I developed a new appreciation for public transport. The secret was to get organised with timetables. It may take longer but is so much more relaxing. Especially compared to trying to find a park in a shopping centre at Christmas, or heading off to Brisbane in peak hour. Family and friends find it difficult to understand why even now I would much prefer to use public transport on occasions. I met so many helpful bus drivers.

One even went just off the bus route so that I didn’t have to walk in the rain to an appointment at a hospital. I also enjoyed being driven around without having to worry, although when I was driven by a “P” plater on the odd occasion - worry was never too far away. I realise I am one of the very lucky ones whose epilepsy is very well controlled. I feel for all the people, their family and friends who are not so fortunate. I also discovered that staying home, once I got used to it, wasn’t all bad. I made myself a list of what I could do with my time, and now have no difficulty staying home.

I hope this is of some help to you. I found it helpful to know I wasn’t the only person dealing with epilepsy.

All the Best

Jen

Won’t it be a great day when we can say “Actually epilepsy is all around” and accepted.
Thank you to everyone who got into the purple spirit this year and either wore purple, signed the Purple Pledge, donated, bought/sold/packed merchandise, held or attended an event, shared their story with the media, and/or became a Purple Hero for Epilepsy. We are delighted with the response and the funds are still rolling in from businesses, individuals and schools - making it a record breaking year!

Events hosted by our valued supporters around Queensland increased the understanding and awareness of epilepsy in local communities, as well as raising funds for Epilepsy Queensland. They included cupcake selling, dyeing hair, Movie Night, sausage sizzles, stalls in shopping centres and local Shows, Race Day, Dinners, Purple Ball, Fashion Parades and many morning teas. We are truly appreciative of every single event and activity (and there were a lot of them!) - no matter the size of the event or the financial outcome. What is important is that everyone had fun and, from all reports, that was certainly achieved.

We have already heard from a few people who have started planning their events for March 2015. If you have an idea for an event or want to get involved more next year, please contact Leigh Gilbert at Epilepsy Queensland on 07 3435 5000 or pr@epilepsyqueensland.com.au.

It literally “rained on our parade”! But the spirits of those who braved the wet weather conditions weren’t dampened as they participated in Epilepsy Queensland’s third annual Purple Procession through South Bank Parklands on Purple Day. Channel Nine’s Garry Youngberry did his weather report live (including facts about epilepsy) from our Purple Party at QPAC afterwards. The following message from Cassidy Megan (founder of Purple Day) was read out on the night by Sharni Ephraums –

Hi Everyone at Epilepsy Queensland,

I hope you are all having fun with your Purple Day celebrations! I want to thank you all for all your support and hard work with Purple Day. I love seeing all your pictures and hearing all of your stories.

I started Purple Day because when I found out I had epilepsy I thought I was the only one. I was afraid, embarrassed and felt so alone and scared, I wanted to see if there was anyone else out there with epilepsy and I wanted them to know that they weren’t alone.

Since I started Purple Day in 2008 I have seen March 26th, Purple Day grow bigger and bigger every year.

I have seen it become a day that is celebrated by people with epilepsy and people without epilepsy all over the world. It has become a day where people learn more about epilepsy. A day, where people with epilepsy don’t feel alone or afraid.

A day, that all of us, from all over the world can call our own. A day for all of us to be proud and stand together. I see more people talking about epilepsy. I see people from all over the world no matter how old they are, what race or religion they are or where they are from, coming together as one to stand together and help each other grow braver in themselves and educating the world about epilepsy.

I am so happy and proud to be working with all you to make Purple Day bigger and better every year. Visit www.purpleday.org to learn more :) 

Thank you again so much for everything that you are doing and have done for supporting Purple Day and epilepsy awareness.

Thank you for asking me to send you something you can read at your event and thank you Sharni for reading it for me.

I hope that one year soon I will be able to come to Australia and visit you guys and celebrate Purple Day with you all.

Remember to never give up on your dreams, anything is possible if you just believe.

Love Cassidy Megan

Founder of Purple Day
Epilepsy Queensland’s inaugural Purple Pledge Campaign was a great success with Members of Federal, State and Local Governments amongst those who signed the Pledge after reading the Ten Facts about Epilepsy and pledging to wear purple on Purple Day to acknowledge and support people with epilepsy.

Mayor Paul Pisasale & Councillors from Ipswich City Council

George Christensen MP, member for Dawson made a speech about Purple Day in Federal Parliament

Mayor Deirdre Comerford & Councillors from Mackay Regional Council

For the second consecutive year Coral Coast Pharmacies – Burrum Street Pharmacy (Bundaberg) has taken out the Purple Pharmacy Award. We truly appreciate the support of the Pharmacy Guild of Australia (Queensland Branch) and also the many wonderful pharmacies around the State that turned their pharmacies purple in support of epilepsy awareness this year.

140 Guests attended Mackay’s second Purple Day Ball organised by Beryl Nielsen (pictured right with Desperate Housewives duo). With a charity auction, entertainment, comedy hosts and key note speakers the event celebrated the courage of those living with epilepsy and was a night full of merriment and awareness. We sincerely thank Beryl who raised nearly $5,000 for Epilepsy Queensland through the Ball and her kind and generous supporters.
Amid howls of laughter, some very serious fundraising happened in Pittsworth at the second Epilepsy Awareness Evening which was hosted by Anne Thompson, whose daughter sadly lost her young life to epilepsy.

Following on from the success of 2012’s evening which featured Wally Lewis as a guest speaker, Anne chose a different format for the event, an intended smaller gathering but one which still attracted around 200 supporters and raised $24,000. Held at the Pittsworth Bowls Club with no room to spare, supporters were treated to an abundance of entertainment, tinged with some reality and education as special guest speaker was neurologist, Dr Cecilie Lander.

The highlight of the night however was the much anticipated fashion parade, which included ‘models all the way from Las Vegas’. The models were something to behold and the parade featured a new model for each month of the year, Miss January right through to Miss December. The fact that the models were some of the town’s more masculine members only proved to cause even more of a stir as the men played up to the crowd with their new found anonymity under the guise of a female supermodel. A 2014/2015 calendar featuring the ‘girls’ was launched on the night with all proceeds donated to Epilepsy Queensland. There are still a limited number of copies available to purchase at $15.00 from Epilepsy Queensland.

Thank you to The Pittsworth Sentinel for the photos and your excellent front page story!

A number of buildings, bridges and fountains lit up on Purple Day including QPAC; Mackay’s Civic Precinct Fountain; Gold Coast’s Ormeau Youth and Community Centre; Townsville’s Oxley Street Fountain and, for the first time, Brisbane’s Story Bridge – which looked amazing. If you know of any other landmarks that regularly change colour, let us know for next year!
Taking Charge was held on Thursday 13 March at the Des O’Callaghan Auditorium, Kelly Building, Mater Hospital, South Brisbane. It was a ‘sold out’ event!

Our keynote speaker, Martin Brodie, Professor of Medicine and Clinical Pharmacology and Ambassador for Epilepsy from the University of Glasgow Scotland presented “Adherence to medication in epilepsy”. He examined some of the reasons people don’t take their medicine and the impact it can have on their epilepsy. We are grateful to UCB for bringing Prof Brodie to Australia.

Professor Harry McConnell, Clinical Subdean at Gold Coast District Health Services and Griffith University School of Medicine and director of Neurosciences at St Vincent’s Hospital Brisbane presented “Neuroplasticity and epilepsy, implications for learning, memory and seizures”. It is great to know we can retrain our brain to a certain extent and there is always hope of improvement and recovery.

Associate Professor Cecilie Lander, a clinical neurologist and epileptologist from Brisbane presented “Epilepsy and lifestyle: no need to push the limits”. This was a very practical presentation that focused on ways we can try to reduce the number of seizures we have by modifying our daily life.

Feedback from participants was exceptionally positive and we hope we can continue to bring you more of these events in the future. We are also grateful for the assistance of QCCID to secure the venue.
The Changing Face of Epilepsy seminar was specifically targeted at improving the epilepsy knowledge of medical professionals. It was exciting to see so many doctors and health professionals turn out to the Cricketer’s Club, Woolloongabba on Saturday 29 March.

Topics such as epilepsy diagnosis and management, Medication and side effects, Depression and anxiety, and Driving and epilepsy were covered by fantastic local and interstate speakers. We would like to thank Dr Kate Riney, Dr Dan McLaughlin, Prof Harry McConnell and Prof Roy Beran for their time and expertise. We are also grateful for the support of Dr Brian Benson and SciGen for assistance in the organisation and generously sponsoring the event.

We really appreciate your feedback!

Epilepsy Queensland continually strives to improve our service to you and so we value your feedback. If you have any comments, suggestions or complaints, we encourage you to contact us.

Please email quality@epilepsyqueensland.com.au or phone 1300 852 853.

Don’t forget to let us know what we do well too!

Privacy Policy

On 12 March 2014 the laws regulating how organisations collect, hold, use and disclose personal information changed. The Privacy Act 1988 was amended by the Privacy Amendment (Enhancing Privacy Protection) Act 2012.

You can find our new policy statement online at our website www.epilepsyqueensland.com.au. We will be working to ensure that we comply with the new laws.

If you have any queries about the personal information that we collect, store, and use, please do not hesitate to contact us on 3435 5000 or 1300 852 853, or email epilepsy@epilepsyqueensland.com.au.
Drug Adherence in Epilepsy

Eminent Ambassador for Epilepsy, Professor Martin Brodie came to Brisbane as our keynote speaker at the Taking Charge Seminar

While 70-75% of people with epilepsy will get full seizure freedom on medication, 25-30% remain refractory despite treatment. Is it that we are refractory to treatment or are we not taking the medication properly? Prof Brodie addressed the issues of Drug Adherence in Epilepsy, why we might not take the medication and the risks associated with skipping or missing doses.

Prof Brodie defined drug-resistant epilepsy as the “Failure of adequate trial of two tolerated, appropriately chosen and used antiepileptic drug schedules (whether as monotherapies or in combination) to achieve seizure freedom.”\(^1\) (Drug adherence is defined as “taking the exact amount of medication at the precise times of every day for an extended period of time”).

Various methods of measuring drug adherence including direct questioning, patient calendars, counting pills, electronic bottle tops and serum drug levels can be used. There is a Morisky Medication Adherence Scale used for some research\(^2\) however, Brodie’s preferred method is to look the patient straight in the eye at the clinic and asking sweetly “How often do you forget to take your tablets?”

Prof Brodie stated that adherence decreases with the number of antiepileptic drugs and drug doses prescribed each day, and that even a once daily dosage does not result in perfect adherence.\(^3\)

In a study of 33,658 patients, non-adherence was associated with:

- Increased risk of mortality
- More emergency department visits
- More hospital admissions
- More motor vehicle accidents
- Greater likelihood of fractures

This study was from a retrospective open cohort design using Medicaid claims data.\(^4\)

There are also economic consequences of non-adherence, making epilepsy care much more expensive:

- Poorer work performance
- Higher disability payments
- More emergency department visits
- More hospital admissions
- More antiepileptic drugs at higher doses\(^5,6\)

Interestingly, non-adherence is sometimes overconsumption.

If a person with epilepsy dies suddenly and no obvious cause can be found after a post mortem examination, it is called SUDEP. The actual cause of SUDEP is not known. There is some suggestion, however, that some people may be more at risk than others. These may include people who:

- Have uncontrolled seizures
- Have generalized seizures in their sleep
- Are not taking their prescribed antiepileptic medication
- Are having frequent or sudden changes to their antiepileptic medication.

The risk of SUDEP for an adult with epilepsy is low, at one in 3000 persons over a one year period. However, for people with poorly controlled seizures, the risk is one in 100 persons over a year.

There are measures you can take to try to reduce the risk of SUDEP. These include maximizing seizure control, sound drug adherence, and avoiding known seizure triggers, especially sleep deprivation. It is also important to eat well and have adequate rest and exercise.

Epilepsy Queensland encourages you to initiate a discussion with your specialist if he/she hasn’t raised it, to discuss why seizure control is important and how you can reduce the risks of SUDEP.

You can also obtain further information on medication and tips for taking it correctly and SUDEP by contacting the client services team at Epilepsy Queensland on 3435 5000 or outside Brisbane 1300 852 853.

\(^1\)Kwan P et al. Epilepsia 2010; 51: 1069-1077
\(^2\)Faught E.Epilepsy and Behaviour 2012; 25:297-302
\(^3\)Morisky PE, DiMatteo MR J. Clin Epidemiology 2011;64:255-7
\(^4\)Cramer et al. Epilepsy and Behaviour 2002; 3: 338-42
\(^5\)Faught E et al. Neurology 2008; 71: 472-8
\(^6\)Zachry WM et al Epilepsia & Behaviour 2009; 16:268-73
\(^7\)Ivanova JI et al Pharmacoeconomics 2010; 28:678-85.
\(^8\)Carpentier N et al Epilepsia 2013; 54:e20-23.

Disclaimer:
This presentation reflects the presenter’s personal views and practice. The presentation or discussion may include information relating to products not approved or inconsistent with their approved use in Australia. Please refer to the approved product information before administering any medication. We are grateful for the support from UCB in Bringing Professor Brodie to Australia.
The Mozart Effect and Epilepsy

The term ‘the Mozart effect’ was first coined by Alfred A. Tomatis who used Mozart’s music as the listening stimulus in his work attempting to cure a variety of disorders. The approach has been popularised in a book by Don Campbell, and is based on an experiment published in the scientific journal Nature, suggesting that listening to Mozart temporarily boosted scores on one portion of the IQ test.

Other scientific studies suggest that classical music increases brain activity more positively than other kinds of music, and that listening to certain kinds of complex music may induce an improvement in the performance of certain kinds of mental tasks known as spatio-temporal reasoning. These studies are currently being disputed but may have some merit.

Two pieces of Mozart’s music, Sonata for Two Pianos in D Major (K. 448) and Piano Concerto No. 23 (K. 488), were found to have this effect.

Studies found that rats negotiated a maze faster and more accurately after hearing K.448 than rats who were played white noise, silence, or minimalist music. Elsewhere, children taught a keyboard instrument for six months, learning simple melodies of Mozart, did better on spatial-temporal tests than children who spent the time working with computers.

Later research by John Jenkins also suggested that K.448 can reduce the number of seizures and the severity of the seizures in people with epilepsy. A closer look shows that Mozart’s music does have a profound effect on the brain, though no one yet knows why.

The Mozart effect on seizures

Mozart Music has been evaluated to see if it has other properties. The April 2001 edition of Journal of the Royal Society of Medicine assessed the possible health benefits of the music of Mozart. John Jenkins played Sonata K.448 to patients with epilepsy and found a decrease in epilepticiform activity.

The research looked at 29 people with severe epilepsy. Their brainwaves were measured as they listened to the music and 23 people showed reduced epilepticiform activity. In one patient the epileptic activity dropped from being present two thirds of the time, to just one fifth of the time. In two other patients who experience epilepticiform activity 90% of the time, this dropped to 50%. Whatever the effect of the music is, it isn’t simply related to enjoying the music, because many of the people were asleep during these tests.

The effect stopped when the music stopped, so in order to assess the longer term effect, an eight year old girl was played music for 10 minutes in every hour. Her seizures fell from nine in the first hour to one in the last hour. On the second day she had just two seizures in eight hours. Professor John Jenkins from the University of London, author of the paper “The Mozart Effect”, thinks the music in some way affects the electrical impulses of the brain.

The Mozart effect can also refer to:

• Popularised versions of the hypothesis, which suggest that “listening to Mozart makes you smarter”, or that early childhood exposure to classical music has a beneficial effect on mental development;

• A US trademark for a set of commercial recordings and related materials, which are claimed to harness the effect for a variety of purposes. The trademark owner, Don Campbell Inc., claims benefits far beyond improving spatio-temporal reasoning or raising intelligence, defining the mark as “an inclusive term signifying the transformational powers of music in health, education, and well-being.”

While the clinical research into the Mozart effect is limited, the studies are encouraging. At the end of the day, listening to music is a soothing way of relaxing the body and reducing any emotional stress for us all. For people with epilepsy there may be the additional benefits of reduced seizures.

References


Teenagers and The TEA Room

Prof Brodie discussed drug adherence being particularly difficult for teenagers to maintain. There are many reasons for this which include:

• Stigma - “if I don’t take my pills regularly I won’t need to tell people I have epilepsy. Many teens avoid social activities and are afraid to tell others about their epilepsy due to their perception that epilepsy is stigmatized.

• Remembering to take medication.

• Feeling worse when medication is taken, or conversely, when feeling better, stopping taking medication.

Prof Brodie stated that it is particularly difficult for teenagers prescribed three antiepileptic drugs to adhere to their treatment schedule. In a study of 385 Brazilians at a tertiary centre, non-adherence was highest in young males with uncontrolled epilepsy taking a complex schedule (the non-adherence rate was 66.2)%.

Prof Brodie’s Charity, The Scottish Epilepsy Initiative, was responsible for establishing the ‘tea room’. The TEA stands for Teenage Epilepsy Queensland has, until recently, been a friendly space to talk with other teenagers aged 13 to 19 years. The forum provided a forum, specifically for teenagers with epilepsy the ‘tea room’. The TEA made it easier for teenagers prescribed complex medication to communicate their experience of epilepsy. The TEA was successful in encouraging teenagers to develop a stronger sense of community with each other.

Q - I recently read in the paper that the jockey, Nathan Berry died from NORSE syndrome. What is NORSE and should I be worried about it happening to me?

Nathan Berry contracted viral encephalitis and later was diagnosed with Norse syndrome. NORSE is defined as new onset refractory status epilepticus. It usually occurs in previously healthy adults, is highly refractory (will not respond) to treatment, and has no clear etiology or cause.

Super-refractory status epilepticus (which refers to status that will not stop despite treatment) is usually due to a severe brain insult (e.g. trauma, infection and stroke), and the cause is readily apparent from the history and neuroimaging. However, there are also a range of less common causes, which in the great majority of cases could be assigned to one of five categories: immunological disorders; mitochondrial disorders; uncommon infectious diseases; drugs or toxins; and uncommon genetic diseases (Shorvon et al., 2011).

This disorder has received several names, including FIRES, DESC, AERRPS, or NORSE. No effective therapy has been reported yet. NORSE is a catastrophic epileptic syndrome with high mortality but the incidence is very rare. It is also not significantly more common in people who already have a diagnosis of epilepsy than in the general population.

References


Australian Pharmacy Professional Conference
“Towards 2020: Priming Pharmacy for Patient Focused Care”

It was a privilege to participate in this conference at the invitation of the Pharmacy Guild of Australia.

CEO of Epilepsy Queensland, Helen Whitehead, was involved in a plenary panel discussion on “Pharmacy viability at risk – is anyone listening?”. Community Pharmacy is experiencing viability challenges in the changing health landscape.

The information booth in the exhibition area provided us with the opportunity to speak with many pharmacists about epilepsy.

Zonegran® Press Release for Consumer

Zonisamide (Zonegran®) is a new-generation, broad-spectrum antiepileptic drug currently approved in Australia for adjunctive therapy in the treatment of adult patients with partial seizures, with or without secondary generalisation1. It is available on the PBS in capsule form in 25mg, 50mg and 100mg strengths.

Zonegran® has an extensive history of use in Japan and the United States having accumulated nearly 20 years of clinical experience in these countries. Zonegran® has been shown to reduce the frequency of seizures by up to 51% and due to its long half-life may be taken once a day following the titration phase. Zonegran® has a unique mode of action, minimal interactions with other drugs including oral contraceptives.2

The adverse event profile demonstrates an excellent tolerability and safety profile, adverse events are generally mild-moderate with few leading to discontinuation of Zonegran®.3

You should discuss with your Physician whether Zonegran® may be suitable for you.
1. Zonegran Approved Product Information
**2014 diary dates**

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<tr>
<th>Date</th>
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<td>18 September</td>
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<td><strong>2014 Understanding Epilepsy Workshops (Woolloongabba)</strong> For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families.</td>
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<td><strong>2014 Regional Trips</strong> For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families.</td>
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<td><strong>Memorial Service (Riverglenn Conference Centre)</strong></td>
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<td>September</td>
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<td><strong>State Epilepsy Awareness Campaign / 2014 Little Poss Appeal / Spring Challange</strong></td>
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<td>Regular</td>
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<td><strong>Support Group Meetings</strong> For further information please contact Charlene Mundy at Epilepsy Queensland</td>
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Please call 07 3435 5000 for further information on any of the above events

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**I would like to help Epilepsy Queensland!**

I would like to join Epilepsy Queensland

- $35.00 Ordinary membership
- $70.00 Community/School membership
- $50.00 Family membership
- $85.00 Corporate membership
- $28.00 Concession membership (must provide copies of concession card with form)

Please find enclosed my Tax Deductible Donation of:

- $25
- $50
- $100
- My Choice $ __________________

**OR** Please charge $ __________________ monthly to my credit card until otherwise advised

**PAYMENT AND ADDRESS DETAILS**

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

- Please find enclosed my cheque / money order made payable to Epilepsy Queensland Inc
- Please debit my: □ Visa  □ Mastercard

Card number: ___________________  Expiry date: ___________________

Cardholder’s name: ___________________  Signature: ___________________

Mr/Mrs/Ms/Miss/Dr: ___________________  Company: ___________________

Address: ___________________

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Please return this slip with your method of payment to—

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

□ I am interested in volunteering.
□ Please send me information about remembering Epilepsy Queensland in my will.
□ Please send me information about ‘In Memoriam’ or ‘Celebratory’ gifts.
□ Please add me to your ENews Bulletins List (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

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ABN: 42 025 269 961

Epilepsy Queensland Issue 2 – 2014 © epilepsy queensland inc
Brisbane's Story Bridge goes purple for Epilepsy Queensland

Purple fairies

Purple Hero visits statue of our Patron at Suncorp

WE RESPECT YOUR PRIVACY

We hope you enjoy reading the enclosed Flame Newsletter. However, if you do not wish to receive the Flame any further, please let us know by calling 07 3435 5000 / 1300 852 853 (Regional Queensland)
or emailing pr@epilepsyqueensland.com.au

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

Thank You!