



ANNOUNCING OUR INAUGURAL EPILEPSY SYMPOSIUM 27 OCTOBER 2010

International and interstate speakers!

Professor Andres Kanner will be one of the visiting keynote speakers at our Epilepsy Symposium on 27 October in Brisbane. Anyone with an interest in epilepsy is invited. Look for the seminar details in this newsletter and register soon.

The article below is told by Professor Andres Kanner, one of the international speakers at the Symposium.

All invited!
Epilepsy Queensland
members may
register free of
charge!

INSIDE THIS ISSUE:

The Stigma of Epilepsy	4
Memorial Service	5
Michelle's Letter	6
Ask an Educator	7
Dr Sophie Calvert	8
Diary Dates	14

When an Epilepsy Doctor has an Epileptic Seizure

by **Andres M. Kanner, M.D.**

Professor of Neurological Sciences and Psychiatry,
Rush Medical College at Rush University
Director, Laboratory of EEG and Video-EEG-Telemetry,
Associate Director, Section of Epilepsy and Rush Epilepsy Center,
Rush University Medical Center, Chicago, IL



Editor's Note from Robert S. Fisher, M.D., Ph.D., Editor-in-Chief of epilepsy.com:
Dr. Andres Kanner, trained both as a neurologist and psychiatrist, was already one of the most empathetic epilepsy doctors. And then he had a seizure.

- *"You had an epileptic seizure?" my patient asked, totally incredulous.*
- *"Yes," I said.*
- *"But that's impossible! You are an epileptologist! You're not supposed to have seizures!" he insisted.*
- *"I wish you were right, but as you can see, epileptologists can have seizures as well."*

This brief exchange took place with one of my patients upon my return from a two-month absence that followed a neurosurgical procedure to remove a benign tumor of the coverings of the brain (meningioma), which was discovered after I had an epileptic seizure four years ago.

I have been an epileptologist (epilepsy doctor) for twenty-one years; during that time I have evaluated and treated thousands of patients and examined in detail the clinical manifestations of thousands of seizures in video-EEG recordings. And yet, the seizure I experienced four years ago has had one of the greatest impacts on my personal and professional life and has led to significant changes in my evaluation and treatment of patients. The purpose of this article

is to describe the symptoms I recall experiencing during and following my seizure. In addition, I write this article with the hope that patients and clinicians alike will start asking the questions that can make it easier for them to come to terms with a new diagnosis of epilepsy.

Having a seizure

I had been invited to give Neurology Grand Rounds, a weekly departmental lecture, at the Cleveland Clinic Foundation. Ironically, this was the institution where I trained as an epileptologist. I was connecting my computer to the slide projector when all of a sudden I started to move away from the podium. I was fully aware of what I was doing but did not know why and had no control over it. I could hear my hosts, Dr. Kotagal and Dr. Dinner, calling to me and telling me that my "brief case was next to the podium." I continued to walk at a faster pace away from the podium, towards the stairs of the auditorium, when I started to feel my left leg tripping. I could not stop myself from running up the stairs towards the back of the auditorium. At one point, I felt my head forcefully deviating to the left, after which I lost consciousness. I was told that from that point on the seizure evolved into a secondarily generalized tonic-clonic seizure.

continued page 2

When an Epilepsy Doctor has an Epileptic Seizure

continued from page 1

How many times have I heard patients describe the onset of their seizures or "auras" as "a strange feeling in my head with fully preserved awareness of what is going on around me?" Yet, since I experienced my seizure, I have come to understand that "full consciousness" must also include *total control of one's actions*. Failure to clarify this important point may lead to a false positive diagnosis of auras of seizures that are in fact disabling and can lead to self-harm, even if they do not evolve into a convulsion. (In other words, the potential harm of a seizure shouldn't be underestimated based on having a high level of awareness). In fact, I am sure that had I been driving, I would have had an accident even if my seizure had not evolved into a secondarily generalized tonic-clonic seizure.

The Immediate Postictal Period

I briefly regained awareness of my surroundings as the paramedics were placing me on the stretcher in the auditorium and then intermittently for short time periods while being transported in the ambulance to the emergency room and during the first thirty minutes of my arrival there. I became fully oriented only after I had undergone a brain computerized study (CT). In his usual calm manner, Dr. Kotagal came to my bedside and explained that I had had an epileptic seizure and that I would need to undergo a brain magnetic resonance imaging study of the brain (MRI).

I have had four MRI studies since the time of my surgery. Each time, I have had to take a low dose of lorazepam, lest I become overanxious and develop a claustrophobic feeling. Yet, while having the MRI study after my seizure, I was calm, or more accurately, I felt detached! In fact, I recall trying to distract my mind from the annoying noise of the MRI machine by considering the various diagnostic possibilities of the lesion found on my CT. It was as if I were trying to reach a diagnosis in a patient... without fear, even when considering the possibility of a malignant brain tumor or an abscess.

The Delayed Postictal Period

I was hospitalized for twenty-four hours for observation. My first call was to my wife, who had already been contacted by Dr. Kotagal and who was on her way to Cleveland. I wanted to give her the good news: "It's only a meningioma. I

will be okay." I did not consider that she had no idea what a meningioma was and the only thing occupying her mind was that her husband had a seizure and she was four-hundred miles away!

I do not recall being in any distress until around 8:00 p.m. that evening. While taking a walk on the medical floor, I noticed a set of computers for patients. "Let me check my e-mail," I told my wife. But I couldn't. I was not able to remember the password to access my e-mails. This was the first time the entire day that I felt scared and helpless. My wife immediately noticed my distress and insisted that I return to the room, where we turned on the TV. The feeling of helplessness was gone as soon as the television was turned on; clearly, the seizure had interfered not only with my memory functions, but also with the duration of my emotional response to a distressing event.



Reaction to Having Had an Epileptic Seizure

I returned to Chicago the next day and Dr. Richard Byrne, the epilepsy neurosurgeon from my institution, agreed to perform my surgery. Surgery is not usually urgent to control seizures, but my meningioma was causing edema (swelling) in the adjacent brain and that caused the neurosurgeon to recommend surgery the week after the seizure. I had worked with him for several years and had witnessed his incredible skills. My initial reaction to my impending surgery did not take place until my admission to the hospital. For the previous fifteen years, I had gone to the operating room with Dr. Byrne and his team to perform electrocorticography (EEG recordings from the surface of the brain) in our patients undergoing epilepsy surgery. Now, it was my turn to be the patient, and for the first time since my seizure, I was afraid. I was afraid for me and for my wife and two daughters.

For some reason, however, I did not feel the full impact of my epileptic seizure until one week after I was discharged from the hospital, when I went to see Dr. Byrne to get my stitches taken off.

"Everything looks great," I remember him saying. "I did not have to touch the brain during the surgery. However, I want you to have a brain MRI every six months for the first two years and then every year as there is a 10 percent chance that the meningioma can recur. However, if it does, we can take care of it with gamma knife (radiation) therapy without any problems."

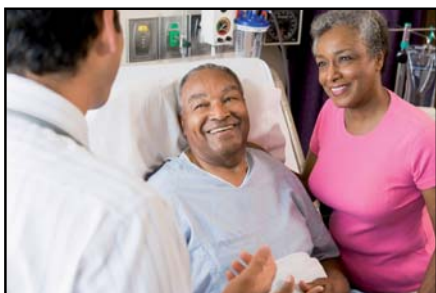
Dr. Byrne looked happy since he had given me wonderful news. And why not? A 90 percent probability of cure was pretty good! In fact, how many times did I give the "good news" to my patients with idiopathic generalized epilepsy: "The good news of suffering from this type of epilepsy is that it has an 80 percent to 90 percent chance of total seizure remission." And yet, for the first time, a 90 percent probability of cure did not look so good to me; after all, it was not 100 percent. I had a 10 percent chance of recurrence of the meningioma and maybe of my seizures! For the first time since my seizure I did not feel as confident. I spent that afternoon researching statistics on recurrence rates of meningiomas. And even though I was well acquainted with the neuroepidemiologic data of seizure recurrence I could not help myself from looking it up again and again.

I soon realized that I was not the only one feeling uneasy. I noticed that my wife and daughters would not leave me alone in the house. Indeed, if my wife had to go out, she would always make sure that one of my daughters (both of whom were in summer recess from college) stayed home until her return.

I tried to explain that it was safe for me to be left alone. And it was not as if seizures were foreign to my wife! She worked with me as a research assistant and was well versed on all aspects of epilepsy. In the end, I failed to convince them. They gave multiple excuses not to leave me alone, until the real reason came out: "What if you have another seizure and you are alone?" My attempts to reassure them of the unlikely possibility of seizure recurrence were unsuccessful, much like the 90 percent probability of total cure failed to put me at ease. All of a sudden I understood where their fear and my own uneasiness for the last two days came from: the day I had my seizure, I lost the predictability of my physical integrity and well-being. I could not be 100 percent sure that the next day I would not have another seizure while waiting for the train or while

making rounds with my residents and fellows. And my family was experiencing the same loss, which became apparent in their “overprotective” behavior towards me.

The significance of this loss became clearer one week later, when I was working on a manuscript and had to check some statistics on the prevalence of Sudden Unexpected Death in Epilepsy (SUDEP). I remember starting to read the chapter when I suddenly experienced a feeling of panic, which prompted me to close the textbook. I was unable to return to it for the following six weeks.



It took me a few weeks to come to terms with this feeling of loss of predictability. Thankfully, I learned not to fight it, and soon I discovered that accepting this loss was no different from losing a loved one...you had to allow yourself to mourn. Fighting it only caused anxiety. I knew that eventually, I would regain my sense of inner security.

New-onset seizures have an impact on people’s lives at multiple levels. I have made it a point to discuss these issues with my patients at the time of their first visit. Yet, the loss of predictability of their physical and emotional well-being was one issue I had never raised before my surgery.

I did not assume that all patients react to having seizures in the same manner as I did. Yet, I decided to alert them and their family members to the possibility of such a reaction. Thus, in each consultation for new onset epilepsy, I would review as usual my diagnostic impression, treatment recommendations, and seizure precautions and then I would make the following statement: “Having a seizure can cause great insecurity in people since no one can predict when and if another seizure will occur. This loss of predictability of your physical integrity and well-being can be very scary to the patient and to family members.”

In most (but not all) patients, this statement was followed by tears, either of the patient, a family member, or both. And the immediate and “automatic” attempt of the family member or patient to reassure the other by saying, “Don’t cry, everything is okay!” was a predictable reaction. At that point, it was

essential to remind them that they were reacting in a completely normal manner and that they should allow themselves to cry and feel sad, as they had suffered a significant loss. I would add: “Everything at this time is not okay.” Over time, I would conclude, the sense of confidence would return, but for now they should not fight that sense of loss.

Over the last four years, I have come to the conclusion that a patient’s failure to face the diagnosis of epilepsy might be partly an expression and consequence of difficulty accepting the loss of predictability of his or her physical and emotional safety. Thus, helping the patient and family members become aware of such loss may facilitate their adjustment to the diagnosis.

In the case of family members, overprotection may be a natural consequence of the same phenomenon, particularly in the parents of children with newly-diagnosed epilepsy.

A word on my patients’ reactions to my seizure: most were surprised to learn that their epileptologist had a seizure. Some were almost incredulous. All showed great concern about my health and wanted reassurance that I was feeling well. In fact, some patients continue to be concerned about my health, as they always make sure that I am feeling well at each visit.

Reaction to having seizures is complex and varies from one person to another. Some people adjust very quickly, while others do not. And this difference may stem from each person’s previous medical and psychiatric histories. Healthy people who develop a new seizure disorder may have greater difficulty coming to terms with their new disorder than patients who have suffered from a variety of medical conditions. In fact, facing the loss of predictability of one’s life is not unique to epilepsy, but applies to many medical disorders. On the other hand, comorbid psychiatric disorders, in particular depressive and anxiety disorders, can pose significant obstacles to adjusting to a new diagnosis of epilepsy. In fact, recent population-based studies have demonstrated the existence of depressive and anxiety disorders preceding the first recognized seizure in both adults and children. Thus, clinicians need to factor in all of these variables when helping patients come to terms with their newly diagnosed seizure disorder.

Concluding remarks

Four years have gone by since I had my seizure and surgery. So far, I remain seizure-free and have had no

recurrences of the meningioma. For the first twelve to eighteen months after my seizure, my wife insisted on coming with me on every work-related trip I took. Now, her concerns have waned but have not totally disappeared, as she always asks before I go away, “Who is going to be there who knows you?”

My feeling of loss of predictability lessened over the following months, and the confidence in my health returned over time. Am I scared of a recurrence of the meningioma or my seizures? You bet! But I have come to terms with the feeling that it is okay to be scared.

Andres M. Kanner, MD, is a senior attending physician in neurology. He has been director of Laboratory of Electroencephalography and Video-EEG-Telemetry at Rush University Medical Center in Chicago, Illinois, since 1991, when he joined the staff at the Rush Epilepsy Center. He also holds the positions of associate director of the Section of Epilepsy and Clinical Neurophysiology and of the Rush Epilepsy Center. He is also professor of neurological sciences and psychiatry at Rush Medical College.

Source: Epilepsy: Insights & Strategies (Epilepsy Therapy Project) January 2010
Reprinted with kind permission
Copyright © [2010] epilepsys.com
All Rights Reserved



Late night dashes across town tracking down the medications you need are now a thing of the past with the Pharmacy Guild of Australia’s free online “findapharmacy.com.au” tool.

This free service allows you to search for the closest open pharmacy to your location. All you have to do is fill in your current location and choose how far you would like to travel to get to a pharmacy. You can choose from as close as 250 metres to over 5 kilometres away.

Using technology enabled by Googlemaps, the website also provides a graphical map of the pharmacy locations and directions from where you are, to the closest pharmacy, which makes this service an invaluable tool for when you are planning trips around Australia, so that you are still able to find a pharmacy, wherever you are.

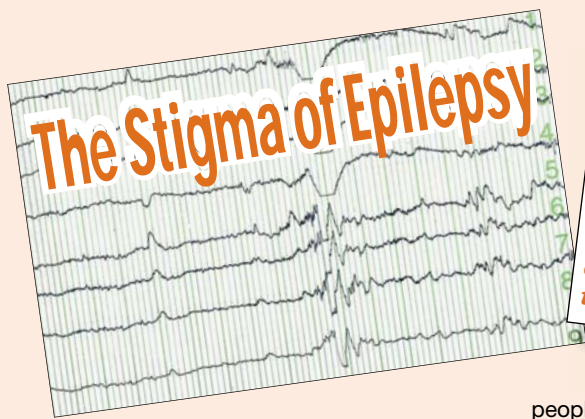
Need to find a pharmacy? Why not search for one on –

www.findapharmacy.com.au

(See the link on Epilepsy Queensland’s homepage)



The Pharmacy Guild of Australia



“People with epilepsy not only have to contend with the actual seizures, but also with a set of attitudes, feelings and ideas about the condition, their own, other people’s and those of the society in which they live....”

Epilepsy

Epilepsy is the most common serious brain disorder in the world and is perhaps one of the most universal of all medical disorders. Despite its prevalence, epilepsy is still widely misunderstood. In our society, as with other parts of the world, people with epilepsy are subject to broad stigmatization and a range of social and legal penalties. In fact the World Health Organisation states that “epilepsy is

Dr Orrin Devinsky has said “There is an ongoing, significant embarrassment level about it...It carries a stigma a lot worse than cancer or HIV. At some level, it’s society that needs to wake up and realise it is just another neurological disorder.”

What is stigma?

Stigma is a word with a multitude of connotations. By definition, it means “a mark or token of disgrace or infamy”. In practice in our society, stigma focuses on the differences in people and then labels them according to those differences. Once labeled, a person is then assigned undesirable characteristics. “Stigma exists when a person is identified by a label that sets the person apart and links the person to undesirable stereotypes that result in unfair treatment and discrimination which leads to unequal outcomes.” As is so commonly the case for people with epilepsy, the labeled persons are placed in distinct “us” versus “them” categories. Dr Tim Betts adds to this, saying, “People with epilepsy not only have to contend with the actual seizures, but also with a set of attitudes, feelings and ideas about the condition, their own, other people’s and those of the society in which they live....”

Graham Scambler is well known for his research on stigma and has differentiated between “felt stigma” and “enacted stigma”. Enacted stigma refers to instances of discrimination against the person with epilepsy. Felt stigma is more to do with the fear of enacted stigma and may be associated with feelings of shame and that epilepsy should be concealed.

Living with Stigma

Living with uncontrolled epilepsy can have a devastating impact on a person’s life. It brings with it enormous physical and medical issues that may be further compounded by psychological difficulties such as depression and anxiety. Some of the depression and anxiety experienced by

people with epilepsy has been attributed to the effects of on-going social isolation, discrimination, relationship problems as well as employment and education limitations. These lifestyle inhibitors are not the direct result of a person’s seizure activity, but rather, they are the result of society’s preconceived notions of who a person with epilepsy is and what they are capable of.

Epilepsy Queensland’s 1993 statewide survey of the needs of and issues experienced by people with epilepsy reported that 81% of study participants reported facing some degree of prejudice in the community. In relation to employment, 26% who had been in paid employment in the past five years said that they had lost jobs due to epilepsy.

In the “Life with Epilepsy” Report which is currently Australia’s largest ever nationwide survey of people with epilepsy, 53% of people with epilepsy reported experiencing discrimination in key areas of their life such as their workplace and educational institutions, stating that the biggest impact of epilepsy related to their ability to participate in the workplace, with only 12% of respondents working full time. Epilepsy Queensland’s membership surveys in the last five years indicate that our members and supporters feel that while stigma still exists, things are getting better as a consequence of our efforts to inform the community and change community attitudes.



In addition to this, the vast majority of people with epilepsy (70%) felt uncomfortable telling new friends about their epilepsy for fear of being shunned socially or stigmatised. Participants in the survey felt that by revealing their epilepsy they would risk being rejected or lose acceptance and opportunities.

In **Australia** we are not alone with our prejudices towards people with epilepsy. Worldwide, people with epilepsy live with antiquated social and legislated rules that

govern their day to day lives—

- In both **China and India**, epilepsy is commonly viewed as a reason for prohibiting or annulling marriages.
- In the **United Kingdom**, a law forbidding people with epilepsy to marry was repealed only in 1970.
- In the **United States of America (USA)**, many individual States prohibited people with epilepsy from marrying. The last State to repeal this law did so in 1980. In addition, in the USA, 18 States provided eugenic sterilization of people with epilepsy until 1956. Until the 1970s, it was also legal to deny people with seizures access to restaurants, theatres, recreational centres and other public buildings.
- Data from **Germany, Italy and USA** indicates that of people with epilepsy of working age, 40%-60% are employed (although these jobs are often below their potential), 15%-20% are unemployed and about 20% retire early.

What can be done?

Perhaps the best weapon in combating stigma is education. In the case of people with epilepsy, there needs to be a raising of public and professional awareness of epilepsy. As well, legislation which reinforces fear and discrimination must also be changed. This includes—

- Be aware that psychosocial issues, employment, driving, independence & relationships can all be affected by epilepsy.
- Health Practitioners take patients’ fears of discrimination seriously.
- Encourage people to not be limited by their epilepsy.
- Stress what the person with epilepsy can do, rather than things they cannot do.
- Secrecy breeds more stigma-fear-guilt & embarrassment.
- Use correct terminology.
- Refer to appropriate support agencies, such as Epilepsy Queensland.

References—

Joint Epilepsy Council of Australia – Life with Epilepsy Report 2006.

World Health Organisation.

Oxford Dictionary definition of stigma.

www.2betrhealth.com/EpilepsyStigma.html.

Scambler, G & Hopkins, A (2008) Being Epileptic—Coming to terms with stigma. *Sociology of Health and Illness*, 8(1) 26-43.

Spencer, A & Ray, L (1993) *Shadows of Discrimination. A study of Epilepsy in Queensland, Epilepsy Queensland.*

Study explores mechanisms of epilepsy



Melbourne researchers have used EEG-functional MRI to explore the mechanisms of absence epilepsy in children and defined a core network of structures that are involved.

Eleven children with absence seizures confirmed on video-EEG underwent functional MRI after having been weaned off antiepileptic medication. The technique assessed blood oxygen level-dependent (BOLD) signals prior to and immediately after events of interest.

The study, led by Dr Graeme Jackson from Austin Health, identified positive BOLD signals in the thalamus and negative BOLD signals in the lateral and mesial parietal lobe, caudate nucleus and brainstem reticular formation.

In the subcortical structures, the change in the BOLD signal occurred at, or immediately after, the onset of EEG changes. However, in the parietal cortex there was a subtle BOLD signal increase for about 10 seconds before the onset of epileptiform activity.



Dr Graeme Jackson

“We have confirmed a core network of structures involved in generalised epileptiform activity that includes the reticular structures of the brainstem,” the researchers concluded.

The prior changes in the parietal cortex suggested that this region was involved in initiating epileptiform activity.

Findings in previous EEG-MRI studies had been variable, perhaps reflecting the refractory or mixed cohorts of patients, the confounding effects of medication, and genetic variability between individuals, the researchers said.

*Source: Article by Tony James, Neurology Update (Monday 23 August 2010)
Reprinted with kind permission
re Neurology 2010 published online ahead of print*

Inaugural Memorial Service



“Their Light Still Shines”

As the Epilepsy Queensland candle was carried into the room at Riverglenn Center on Saturday 4 September, the light that radiated from it was a poignant reminder of the lives that have been lost to epilepsy and its sometimes unknown causes. That light still shines in our lives.

Families gathered with many memories, both treasured and unique. Epilepsy Queensland invited Epilepsy Grief and medical specialists to join them beside these families as they courageously shared their journeys of grief.

It was through prayer, reflection and song that we all were able to remember some important people who shared our lives.

Names specifically mentioned during the service included:

Nathan Britton
Anita Callebaut
Ian HOFFIE
Brendan Krause
Daniel Landrigan
Craig Leech
Tayla Michelle McErlane
Bronwyn McInnis
Michael Milburn
Nicholas Stapleton
James Rasmussen
Amanda Webber
Glenn White

A sapling tree was a small expression that each family was able to take away as a symbol of hope and growth.

After the service, everyone gathered over afternoon tea bringing the afternoon to a gentle close. Special thanks must go to Rev Dr Cecillie Lander who respectfully facilitated our ceremony. Many thanks also to Rev Tom Britton and his wife Diana for their participation in planning the service, and Mr Michael Wright who gave us the gift of music and song; it added a wonderful dimension to the reflections on the day.

HOW YOUR \$\$\$ HELP US TO HELP OTHERS



With the support of those who generously donate, organise and/or sponsor events, we are able to reach out and help more people and families living with epilepsy in various ways. From getaways for mothers and siblings to our popular mascot Little Poss – every dollar is wisely spent on maximising the benefits for those who come to us for advice and support or just to meet others in a similar situation.

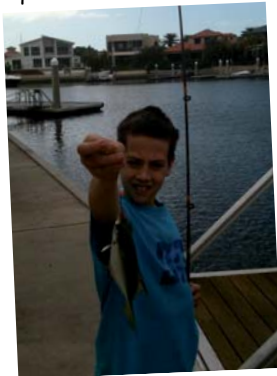
One family who has benefited from the generosity of others is the Cunninghams. Michelle is the mother of three boys – the youngest, Rheece, has epilepsy and loves Little Poss (as you can see from the picture). Rheece's older brothers enjoyed time out on the Sunshine Coast with other siblings last year at our inaugural "Camp E", funded by Airen Youhanna The Good Guys at Loganholme.

Mum Michelle was able to take a rare day out of her busy and stressful life for herself by attending the recent Pamper Day that was kindly funded by Alf Said and his team at the Good Guys Lutwyche, in conjunction with United Way Queensland. This really was an opportunity for Michelle to put herself first for a change and meet and chat with other Mums who also have a child with debilitating epilepsy.

Please read Michelle's letter to get a better understanding of how epilepsy can have an effect on the whole family and how Epilepsy Queensland is always here to help – from home visits by one of our dedicated staff, giving advice, support and a shoulder to cry on when the days seem tougher than others, to being able to provide training to Rheece's school teachers and carers.

This is how you make a difference to the lives of just one family.....

My son Rheece was 17 months old when he had his first seizure. He had been unwell that weekend and had high temperatures. I had put him to bed and heard him cry and knew something didn't sound right. I walked into his room to find him convulsing and called an ambulance. We were taken to the hospital where at first we thought it was febrile convulsions. After bringing down his temperature we thought all would be okay and stayed overnight at the hospital. The next morning he had another seizure and then another, they were getting more frequent and I started to cry as



I didn't know what was wrong. After putting him through various tests Rheece was hooked up to a video EEG. Even though the doctors had seen him convulsing they needed to know what part of the brain it was coming from. The EEG captured him having a convulsion and the doctors looked at it and said he has Myoclonic Epilepsy. This was a very scary and stressful time and the doctors had to find what medication would best suit Rheece. After 10 days in hospital it was time to go home and the doctors explained to me how to administer the medication, I was very overwhelmed and thought

what if I get it wrong. The doctors were very supportive and told me to call if I had any concerns.

Initially Rheece had a severe reaction to one of the medications and is no longer taking it. We have had to try many different medications to find the best combination. Rheece went for many years without having a seizure and all of a sudden a few years ago, they started again and he now also has absence seizures. It took a while to figure out what his triggers were but we discovered it would happen if he was stressed or tired. He now finishes school a little earlier so he can come home to have a sleep as he won't sleep at school because he doesn't want to miss out on any of the activities. Rheece is now 12 years old, and attends a special school as he has an intellectual impairment as well as ASD. The school has a special health plan in place for Rheece which details what to do in case he has a seizure and the staff have all been trained and have attended many courses held by Epilepsy Queensland. The plan also covers information about his shunt and what to look for in the case of it malfunctioning. The school has a nurse and I feel very comfortable knowing that he is well cared for when at school.

Over the years, Rheece's health has deteriorated and we spend a lot of time attending appointments at the hospital. People often ask me "How do you do it?" and I say "I just do". It's just a natural instinct and you want to stay strong for your child. We may not show our pain on the outside but inside my heart is breaking. I often worry about what the future holds for Rheece, but I have to stay positive and I know that I will always be there for him no matter what. Rheece enjoys fishing and cooking and is

always keen to help at dinner time.

When Rheece's seizures had started again I felt overwhelmed and needed someone to talk to for advice, I contacted Epilepsy Queensland and became a member. They have always been there to support me whenever things get a little tough. They also do home visits which is something I have needed and appreciate as I do not have a car so it is comforting to know that they will come to me. My two older boys sometimes feel left out as a lot of my attention can be focused on Rheece. Last year, Epilepsy Queensland held a siblings of children with epilepsy camp. My two boys went and had such a great time that they didn't want to come back! A few months ago they held a Mother's Pamper Day at Apollo's Day Spa which I was lucky enough to attend. This included massages, pedicures and manicures and was topped off by a beautiful lunch. This was a great opportunity to meet other mothers and exchange stories. It was a very relaxing day and some well deserved time out for the mums who don't get the opportunity to be pampered like we were on the day.

Without your help, Epilepsy Queensland would not be able to provide opportunities for the families of children with epilepsy, so please give generously.

Michelle





ASK AN EDUCATOR

Q. I recently saw the ABC 7.30 Report on SUDEP. Can you tell me more about it?

What is SUDEP?

A. SUDEP refers to the unexpected death of an individual with a diagnosis of epilepsy, who dies suddenly, in benign circumstances, without a structural or toxicological cause for death being found.

What is the cause?

The precise mechanism, or cause of death is, as yet, not understood. Most sudden deaths of people with epilepsy are unwitnessed and this makes it difficult to determine what exactly occurs in the last moments of life. Most frequently, but not always, there is evidence for seizure activity prior to death and recent studies strongly support a close relationship between seizure episodes (especially generalised tonic-clonic seizures) and SUDEP. Various potential mechanisms have been proposed and these mainly involve the cardiac and/or respiratory systems.

How common is it?

Around 300 Australians die from epilepsy related causes each year. Of these, about half are attributed to SUDEP. A recent paper by Riney (2010) analysing "Epilepsy-related Deaths in Queensland from 2004-2008", estimated that there were an average of 45 deaths per year from epilepsy in Queensland.

Based on evidence from the National Health Survey 2007/2008, the incidence of

SUDEP in Queensland was calculated as 0.7 per 1000 with epilepsy per year. Males were noted to be of higher risk. Those under 5 years of age and those in their 30's were also most at risk of SUDEP.

Risk factors for SUDEP

Without a known cause, it is not feasible to accurately determine whether or not an individual may be predisposed to SUDEP. However, investigations of SUDEP circumstances have identified several associated factors that indicate some individuals are higher risk.

The factors most consistently identified in case studies include those which are deemed unmodifiable, such as: being male, early onset of epilepsy and young adult age, and those which are deemed modifiable with the potential to lower SUDEP risk. These include, but are not limited to, frequent generalised tonic-clonic seizures (especially unattended nocturnal seizures), poor compliance with the anti-epileptic drug (AED) regime and the number of different types of AEDs used.

Can I reduce the chance of this happening to me or my child?

With what we presently know, it is not feasible to accurately determine the exact risk factors and some of them are out of your control. However, as 60% of SUDEP deaths indicate a recent seizure, reducing seizure frequency could reduce your risk of SUDEP.

Work with your doctor or specialist to try to achieve the best seizure control possible—

- seek regular medical consultation to re-evaluate epilepsy diagnosis, review medication and the possibility of new treatments

- discuss implications of lifestyle changes
- maintain good adherence/compliance with medication regime (this is particularly important as 70% of all SUDEP deaths had below therapeutic levels of their anti-epileptic medications in their blood)
- identify possible triggers for seizures and determine an effective strategy for keeping these to a minimum, for example, by maintaining regular and adequate sleep patterns.

It is also prudent for family, friends and caregivers to be informed of what to do during and following a seizure. This includes knowledge of the recovery position and cardiopulmonary resuscitation techniques. In addition, the necessity of calling an ambulance if the seizure lasts for more than 5 minutes or repeats without full recovery, and of staying with a person for 15-20 minutes after the seizure to ensure that recovery continues.

Reference—

Riney, K (2010) *Epilepsy-related deaths in Queensland 2004-2008.*

WE WOULD LIKE YOUR OPINION!



Epilepsy Queensland has been working with QPEN (Queensland Paediatric Epilepsy Network).

We are keen to gather feedback from families about their experience of the paediatric epilepsy services in Queensland. What your ideal service would be like, what's working well and how it could be made better? If you would like to provide some feedback please email services@epilepsyqueensland.com.au or call 3435 5000 or 1300 852 853 (outside Brisbane).

SEIZURE FIRST AID

Tonic Clonic Seizure
Convulsive seizure with loss of consciousness, muscle stiffening, falling, followed by jerking movements.

- 1 Note the time the seizure started. Quickly remove any hard objects that could cause injury. Do not attempt to restrain the person, or to stop the jerking. Do not put anything in the mouth. Protect the head as best you can. If available use a pillow or cushion.
- 2 Gently roll the person onto their side as soon as the active movements of the seizure have ceased so that you know the person has regained consciousness. The reasoning and let the person know where they are, that they are safe and that you will stay with them while they recover.

Complex Partial Seizure
Non-convulsive seizure with partial motor activity, consciousness or attention impaired. Can be mistaken for alcohol or drug intoxication.

- During a complex partial seizure you may need to guide the person to safe places, and away from dangerous places.
- As the seizure finishes, establish responsive communication and call a first aid officer.
- Call an ambulance if the person is not returning to recover after 15 minutes.

Absence Seizure
Usually affects children, non-convulsive and consists of brief periods of loss of awareness. Can be mistaken for day dreaming.

- Recognise that a seizure has occurred.
- Recognise the person and request any identification that may have been issued during the seizure.

When to call an ambulance – 000

- ✓ When the seizure activity more than 5 minutes or second seizure quickly
- ✓ If the person is not responsive
- ✓ If the person is not breathing
- ✓ If the person is not recovering
- ✓ If the person is injured
- ✓ If the person is pregnant
- ✓ If the person is on medication
- ✓ If the person is on medication
- ✓ If the person is on medication

Would you know what to do if you saw someone have a seizure?

Learn what to do

Contact Epilepsy Queensland for a free copy of the Seizure First Aid Poster on

07 3435 5000 or admin@epilepsyqueensland.com.au or

download a copy from our website www.epilepsyqueensland.com.au

30 minutes with Dr Sophie Galvert



Sophie is a Paediatric Neurologist with an interest in epilepsy. Originally from New Zealand, Sophie moved to Adelaide when she was seven.

1. What inspired you to become a neurologist? I decided to do Medicine as I wanted to do something interesting. My father is a doctor but that is not the main reason I chose this career. I chose Neurology because I enjoyed my first rotation in the Paediatric Neurology at the Women's and Children's Hospital when I was undergoing my paediatric training.

2. Where did you do your training? I did my basic medical degree through Flinders University in Adelaide and my paediatric training at the Women's and Children's Hospital and Flinders Medical Centre in Adelaide. I then did further paediatric neurology training at children's hospitals in Bristol and London in the UK.

3. If I had not become a doctor? I would most likely have studied Arts Law with the hope of combining my interest in languages and travel and becoming a diplomat.

4. The biggest change in epilepsy care I have noticed since I started working in the field? Would probably be an increased recognition of the impact epilepsy has on people's lives. There has also been an increase in non-drug treatment options such as Vagal Nerve Stimulation and the Ketogenic Diet.

5. I would most like to travel to? Mmm, that is a hard one. I have travelled quite a bit but I have not been to Canada, South America or Africa. I would like to go to Botswana. In Australia, I would like to see the Great Ocean Road and the Kimberley region.

6. My favourite food? Chocolate! But I try not to have it too often. I also enjoy good wine.

7. The book I am reading at the moment? "The No. 1 Ladies' Detective Agency" by Alexandra McCall Smith although I have a few on the go.

8. My most embarrassing moment? Well one I can think of is when I knocked a whole jug of icy water onto a prominent adult neurologist at the Annual Epilepsy Conference in Perth last year.

9. The person I would most like to meet? At the moment it would be Julia Gillard. I would like to urge her on to greater things. She is an inspiration to young women and girls.

10. The music I most like to listen to? Classical. I used to play the flute but that was a while ago.

11. When I am not working I like to? Go to the movies and try to get into shape with my personal trainer. Recent movie? I just recently enjoyed Robin Hood. Historically inaccurate, but entertaining.

12. The thing I feel would most improve the epilepsy care in Queensland? Would be to have an epilepsy nurse in every region and more regional paediatricians with an interest in epilepsy.

13. My hope for the future for people with epilepsy? More accurate diagnosis of epilepsy, less grey areas and hence a lower rate of misdiagnosis.



YOU can make a difference to the lives of people touched by epilepsy!

Epilepsy Queensland relies on support from many areas of the community. It is usually the busiest people who find time to assist others.

There are easy ways that you can support our vital work.

1. Arrange to make an automatic monthly/quarterly/annual donation.
2. Allow for Epilepsy Queensland in your Will.
3. Volunteer your time to help - tasks range from packing information mailings and educational kits (either on a flexible or regular basis) to utilising your professional skills.
4. Conduct a FUNdraising event and make Epilepsy Queensland the beneficiary.
5. Assist with finding avenues for us to sell Little Poss and Purple Day merchandise ie shops, offices or door to door.
6. Donate through your workplace and ask your employer to match the donation.
7. Become an Epilepsy Queensland Hero! In just minutes you can build your own online fundraising page and approach your supporters for a tax deductible donation by emailing a unique link to your own Hero webpage. Each donation is recorded on your page along with any message of support from your donors. Please go to www.everydayhero.com.au/charity/view?charity=240.

If you would like to discuss any of these ways of helping, or discover other ways, phone 1300 852 853 and ask for Leigh or email lgilbert@epilepsyqueensland.com.au.

VALE

Nicholas Stapleton

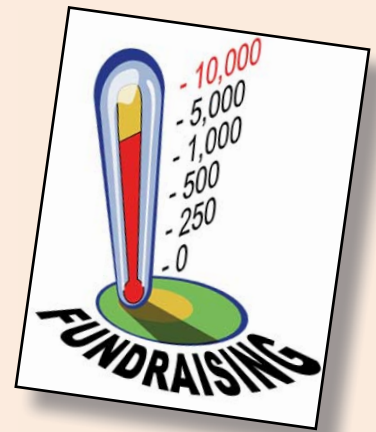
Brenda Treasure

Betty Ritchie





WHAT'S BEEN HAPPENING . . .



June was an extremely busy month for Epilepsy Queensland with a number of events held by loyal and new supporters alike. In addition, our Little Poss Appeal was widely supported by individuals, businesses, pharmacies, newsagents and Westpac branches.

The events included those mentioned in our last edition of the Flame - Boulderstone Charity Golf Day, Skate for Epilepsy and Ride for Luke and Epilepsy. Another event that we have been fortunate to be the beneficiary of is Darren's Day.

For the fifth year, the Caloundra Bowls Club hosted this day of bowls, raffles, auctions and fun in memory of Darren Elms, the son of Les and Kathy. Each year these two special people work tirelessly collecting donations of raffle and unique auction items including framed autographed footy jerseys - which the members and supporters on the day certainly enjoyed outbidding each other for. Friends of Les, Kathy and Darren come from far and wide including Melbourne, Sydney and Lithgow to attend plus a special group from Woy Woy come up every year too.



Kevin Bertwistle (Caloundra Bowls Club Manager), Les and Kathy Elms and Leigh Gilbert (EQI's Fundraising & PR Manager) with the big cheque!

Darren sadly lost his life due to seizure related causes two days prior to Christmas in 2005 whilst living in Canada. He developed his epilepsy through an unprovoked attack on his way home from work 10 years earlier in Ireland. The onset of Darren's epilepsy did not deter his love of travelling and life to which his loving Mum says he lived to the fullest.

We were over the moon to hear that the day broke all previous records raising an amazing \$17,000. This makes a total of \$60,000 raised over the five years!!! Well done to the management, staff and members of the Caloundra Bowls Club along with Les and Kathy and their team of wonderful helpers and all those who bought raffle tickets, auction items and enjoyed a game of bowls on the day - we are sincerely grateful for your continuous and generous support. Darren would be proud of what his parents have and continue to achieve for those affected by epilepsy and their families.

This year was no different with the exception of the sad passing of Les' mother the day before in Lithgow which meant that he was unable to be there to join his many mates on the day. However, the staff and supporters at the Club rallied behind Kathy to ensure a great day was had by all in memory of Darren - the day falling on his 37th birthday.



Darren's mates having a great time with Darren's brother Chad.

A TRIVIAL FACT

Did you know . . .

- ? The number of dimples on a golf ball is 336
- ? When leaving a cave, bats always turn left
- ? If you refrigerate rubber bands, they last longer
- ? During World War 2, Oscars were made of wood because metal was scarce
- ? Forests cover one quarter of Russia
- ? A pregnant goldfish is called a "Twit"



REGISTER NOW!

for the

2010 Trivia Challenge

Visit

www.epilepsyqueensland.com.au/trivia

or phone Judy on

3435 5000

EPILEPSY QUEENSLAND'S SEMINAR

EPILEPSY – GIVING HOPE

We would like to thank our speakers, Professor Harry McConnell, Professor David Reutens, Associate Professor Cecilie Lander and Dr Steve Malone for taking the time to share their immense knowledge and expertise.

Professor Harry McConnell started the day speaking about the complex relationship between epilepsy and behaviour. He gave the audience an insight into why so many people with epilepsy experience behavioural or psychiatric difficulties and how these difficulties can be affected by some of the more commonly prescribed anti-epileptic drugs. We look more closely at Professor Harry McConnell's discussion on Epilepsy and Behaviour in a future edition of *The Flame*.

After morning tea, Professor David Reutens spoke about the extraordinary progress that is currently being made in epilepsy research here in Brisbane. Professor Reutens is the Foundation Professor of Experimental Neurology and Director of the newly established Centre for Advanced Imaging at The University of Queensland. He was able to discuss advancements in neuroimaging with MRI and PET and related how in the future this will benefit people with epilepsy enormously in both diagnosis and treatment of epilepsy.

Professor Cecilie Lander discussed finding the balance between managing epilepsy and lifestyle. Her presentation covered practical aspects of life such

as reducing seizure triggers as well as looking at specific aspects of lifestyle such as alcohol and employment. She advocated a moderation but, most of all, a positive mental attitude towards living with epilepsy.

Finally, Dr Stephen Malone spoke about the role of paediatric epilepsy surgery. Dr Malone discussed the options for surgery in children and gave the audience an understanding of when surgery may be an option and what surgical procedures are currently being done for children with uncontrolled epilepsy.



Dr Stephen Malone

We would also like to thank Mirtha Barboza (Carers Australia) and Paul Watson (Maurice Blackburn Lawyers) who also gave presentations on supporting people with epilepsy and their carers. Mirtha spoke about the extensive support Carers Australia provides for carers and how to access their many services. Paul was able

to shed light onto the many complex legal issues that face people with epilepsy and advise on how best to deal with these.

Special thanks goes, as well, to Stephanie O'Halloran, who gave a moving and inspiring account of her son Braydon's experience with epilepsy. It would be fair to say that there was not a dry eye in the house! Louise Ryan also shared her personal journey with brain surgery—Louise you are an inspiration! Thank you for sharing.

It was a wonderful day of giving and sharing knowledge made possible by the generosity of our speakers as well as the individuals who came to learn. Participants were certainly enthusiastic in their praise for the day. Cathie wrote *"Thank you, just great and very empowering!"* This was echoed by another participant who wrote, *"Thank you again EQI while sometimes find these day emotional, I always learn something new. Looking forward to future events and catching up soon."*

You can be kept up to date about the details of future seminars through our newsletters or by visiting our website www.epilepsyqueensland.com.au.



Louise Ryan and Stephanie O'Halloran—who shared their personal experiences

DATE CLAIMER



THE CELEBRATION THAT STOPS A NATION

Come and join the EQI team
for all the fun and excitement
of the 2010 Melbourne Cup

on

Tuesday 2 November 2010

at

Diana Plaza Hotel
12 Annerley Road
Woolloongabba

Register your interest now on 3435 5000 or
email rsvp@epilepsyqueensland.com.au

Epilepsy Queensland 2010 Awards

NOMINATE NOW!

Epilepsy touches the lives of many people in different ways. There are many individuals and organisations who help people with epilepsy and their families, often in their own quiet way. Every year Epilepsy Queensland presents awards to acknowledge these wonderful people.

If you would like to nominate someone who you believe has made a contribution towards improving quality of life for people with epilepsy, please contact Epilepsy Queensland on 3435 5000.



Australian Government



ARE YOU CARING FOR A CHILD UNDER 16 WITH A SEVERE DISABILITY OR SEVERE MEDICAL CONDITION?

Changes to the assessment
for qualification for Carer
Allowance (child) commenced
on 1 July 2010 and include:

- **Single assessment tool**— qualification for Carer Allowance (child) is now assessed and scored using the same process and scoring as used for Carer Payment (child). This makes it easier for carers. All carers qualified for Carer Allowance (child) on 30 June 2010 remain qualified for payment.
- **Easier transition to Carer Allowance (adult)**—it is now easier for carers to move between Carer Allowance (child) and Carer Allowance (adult) when their child turns 16. The carer may remain qualified for Carer Allowance (child) for up to three months after the child turns 16 years. This transition period is already available for Carer Payment.

Do you require further information?

Further information is available from the payment page on Centrelink's website www.centrelink.gov.au, telephone Centrelink on 13 27 17 or for TTY service 1800 810 586, the Indigenous Call Centre 13 6380 and assistance in languages other than English on 13 1202, or visit your nearest **Centrelink office**.

MEET THE EQI TEAM

Here's a list of who's who at Epilepsy Queensland—

Chief Executive Officer

Helen Whitehead

Client Services Team

Yvette McMurtrie (*Client Services Coordinator*)

Jenny Ritchie

Jodie Derriman

Lois Trudinger

Kate Marley

Accounts

Natalie Lee

Administration

Jo Moran (*Office & Communications Manager*)

Amanda Roberts

Carolyn Anderson

Fundraising

Leigh Gilbert (*Fundraising & PR Manager*)

Ruth Tyssen-Day

Sue Wagner

Judy Vorster

Karen Piekarski

Debra York (*Quality Coordinator*)



is now on

facebook

Want to keep up to date with the latest news and information from Epilepsy Queensland? Look for our page— Epilepsy Queensland Inc. Join us now and never miss another event.

Thank You
for sharing and connecting

THANK YOU thank you merci danke takk grazie
GRACIAS 謝謝 謝謝 謝謝 謝謝 謝謝 謝謝 謝謝 謝謝 謝謝 謝謝

facebook

You can contact us on **3435 5000** or **1300 852 853** (outside Brisbane) services@epilepsyqueensland.com.au www.epilepsyqueensland.com.au www.talkpilepsy.com.au



VNS Therapy is now on the Prosthesis List!

VNS therapy has once again been included on the latest Government Prosthesis List effective 14 August 2010, and valid until February 2011.

VNS Therapy has two entries:

1. RA001—VNS Therapy Generator (102 or 102R) Amount Covered \$12,670 (ex GST)

2. RA002—VNS Therapy Lead (302.2) Amount Covered \$3,400 (ex GST)

These can be seen by either downloading the Excel Spreadsheet— Part A at the following webpage www.health.gov.au/internet/main/publishing.nsf/Content/prostheses-list-excel.htm.

It is confirmed that the price charge by Aurora BioScience is identical to those listed above.



EQI's CHRISTMAS PARTY!

When: Saturday 4 December 2010 (11am - 2pm)

Where: Orleigh Park, Orleigh St, Hill End

Sausage Sizzle lunch provided
Please BYO drinks, nibbles & picnic blankets

BOOKINGS ARE ESSENTIAL
Ph: 3435 5000 or 1300 852 853



ADVERTISEMENT

RED ALERT

EMERGENCY CARDS
BE SAFE, BE READY, BE RED ALERT

Red Alert has been produced by Colin Furphy. Colin would have an extraordinary number of severe seizures anywhere at anytime. After continuously going to hospital Colin designed Red Alert Cards. As a result the cards reduced the need to repeat the same information over and over again when admitted to hospital.

Not only was Red Alert Cards useful for Colin in hospital but also work, travelling and social occasions. Red Alert Cards became a stress-free communication tool that Colin used to inform necessary people of his condition.

Red Alert Cards gave Colin a strong sense of security. If something was to happen in public Colin would show someone his Red Alert Card and ask them to call family and emergency personnel.

RED ALERT CARDS **HELP ME**

RED ALERT CARDS CAN **HELP YOU**



"Now that I carry a Red Alert Card I feel safer when I'm in public. If something is to happen my Red Alert Card can help others help me."



"We've been looking for something like a Red Alert Card for a long time. Now we have one to give to our friends so they are prepared for an emergency (if it is to happen)."



"I have Epilepsy. My Red Alert Card has helped me out of many awkward situations. I give a copy to my employer and friends so they know what to do if something happens."



HELP OTHERS HELP YOU

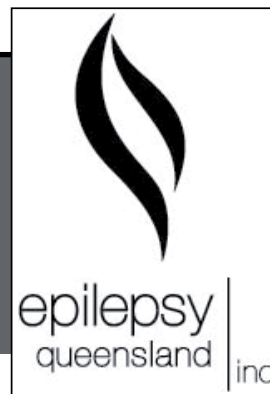
0422 712 717

RED ALERT CARDS **HELP ME**
RED ALERT CARDS CAN **HELP YOU**

HEADS UP!

Inaugural Epilepsy Symposium

Presented by Griffith University and Epilepsy Queensland



You are receiving an advanced invitation to an epilepsy seminar with expert speakers giving you the 'heads up' on epilepsy and the mind!

This is a unique opportunity to hear PROFESSOR ANDRES KANNER from the USA, ASSOC. PROFESSOR MAL HOPWOOD from Victoria, PROFESSOR HARRY MCCONNELL from Queensland and PROFESSOR GRAHAM SCAMBLER from the United Kingdom.

Where? Princess Alexandra Hospital Auditorium Ipswich Rd, Woolloongabba

**When? Wednesday 27 October 2010
2pm – 6pm**

FREE FOR ALL FINANCIAL MEMBERS!

SEMINAR FOLLOWED BY EPILEPSY QUEENSLAND'S AWARDS CEREMONY AND ANNUAL GENERAL MEETING

You may choose to attend just the seminar, or just the Awards Ceremony and AGM, or all components of this event.



PROGRAM

1.45 - 2.10pm	Registration with light refreshments on arrival
2.10 - 2.15pm	Welcome
2.15 - 3.00pm	Professor Harry McConnell
3.00 - 3.45pm	Professor Andres Kanner
3.45 - 3.55pm	The Hon. Paul Lucas MP Deputy Premier and Minister for Health
3.55 - 4.05pm	BREAK
4.05 - 4.50pm	Assoc. Professor Mal Hopwood
4.50 - 5.40pm	Professor Graham Scambler
5.40 - 6.00pm	Panel Forum
6.00 - 6.30pm	REFRESHMENTS
6.30 - 7.00pm	Awards Ceremony
7.00 - 7.20pm	Annual General Meeting

This event is designed for people with epilepsy and their families, allied health workers, disability support workers, teachers and education specialists, counselors, psychologists, and medical practitioners.

****RSVP ESSENTIAL****

by phone 07 3435 5000 or
email rsvp@epilepsyqueensland.com.au

NB – Article by Kanner and article on Stigma in THIS newsletter!!

We really value your feedback!



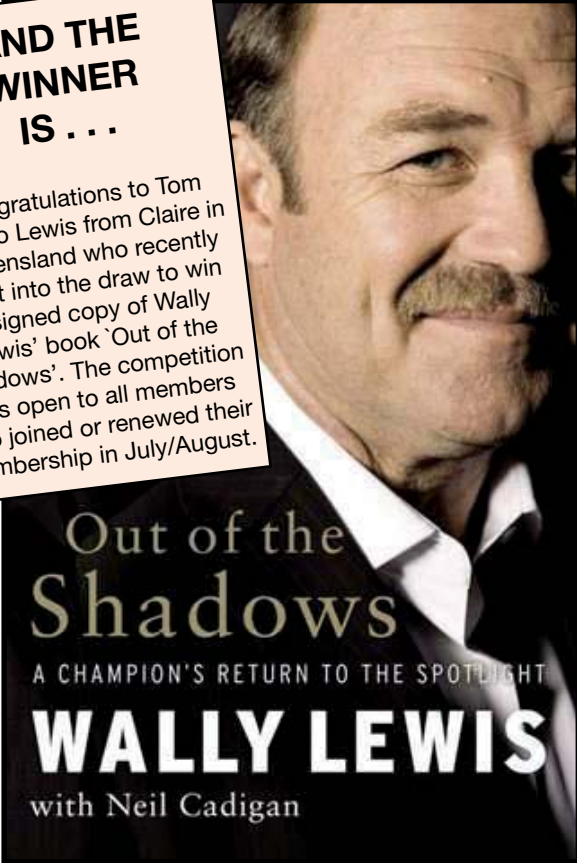
Epilepsy Queensland continually strives to improve our service to you and so we value your feedback. If you have any comments, suggestions or complaints, we encourage you to contact us.

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

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

AND THE WINNER IS . . .

Congratulations to Tom and Jo Lewis from Claire in Queensland who recently went into the draw to win a signed copy of Wally Lewis' book 'Out of the Shadows'. The competition was open to all members who joined or renewed their membership in July/August.



Out of the
Shadows
A CHAMPION'S RETURN TO THE SPOTLIGHT
WALLY LEWIS
with Neil Cadigan

DIARY DATES

Thursday 21 October Monday 22 November	Understanding Epilepsy Workshops (Woolloongabba) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families.
Sunday 10 October	Trivia Challenge State Final (Griffith University, Nathan Campus, Mt Gravatt)
Monday 18 October	Understanding Epilepsy Workshops (Dalby) For Disability Support Workers, Child Care Workers, Nurses, Allied Health Professionals, Volunteers, People with Epilepsy and their Families.
21 - 24 October	Asian and Oceania Epilepsy Congress (Melbourne)
Wednesday 27 October	Inaugural Epilepsy Symposium, AGM and Awards Ceremony (PA Hospital Auditorium) A not to be missed epilepsy seminar with expert speakers.
Tuesday 2 November	Melbourne Cup Luncheon (Diana Plaza Hotel, 12 Annerley Road, Woolloongabba) Register your interest in joining the Epilepsy Queensland team to celebrate the 2010 Melbourne Cup!
Sunday 7 November	Epilepsy: Top of Mind Symposium (Brisbane Convention & Exhibition Centre) A one day symposium for parents/carers of an infant, child or teenager with epilepsy.
Monday 15 November Tuesday 16 November	Understanding Epilepsy Workshops (Maryborough and Bundaberg) Epilepsy Queensland is coming to Maryborough and Bundaberg in November and extends an invitation to Disability Health Workers, Child Care Workers, Teachers, Nurses, Allied Health Professionals, People with Epilepsy and their Families.
Saturday 4 December	Christmas Picnic (Orleigh Park, Hill End) For Epilepsy Queensland families and volunteers. Register your interest now!!
Monthly	Gold Coast Support Group meets on the last Wednesday of each month Toowoomba Support Group meets on the fourth Tuesday of each month Dalby Support Group meets on the third Wednesday of each month

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



EPILEPSY & MENTAL HEALTH

If you or someone you care for with epilepsy has experienced depression, anxiety, or other mental health conditions, we would like to hear from you. We are keen to find out—

- What type of service/doctor helped with the mental health aspects of your care?
- Did you find it helpful? What would have made it easier?

Please email us at services@epilepsyqueensland.com.au or phone **3435 5000** and ask for Helen Whitehead.

Opinions expressed in this publication are not necessarily those of Epilepsy Queensland. Concerns about your condition, its treatment and management should be directed to your doctor.

Information on products should not be regarded as an endorsement or recommendation of this product.



I would like to help Epilepsy Queensland!



I would like to join Epilepsy Queensland

- | | |
|--|---|
| <input type="checkbox"/> \$27.50 Ordinary membership | <input type="checkbox"/> \$20.60 Pension membership |
| <input type="checkbox"/> \$55.00 Community/School membership | <input type="checkbox"/> \$68.75 Corporate membership |

Please find enclosed my Tax Deductible Donation of:

- \$30
 \$50
 \$100
 My Choice \$ _____

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/Miss/Dr: _____ Company: _____

Address: _____

Suburb: _____ Postcode: _____

Phone: _____ Email: _____

Please return this slip with your method of payment to:

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

- I am interested in volunteering.
- Please send me information about remembering Epilepsy Queensland in my will.
- Please send me information about 'In Memoriam' gifts.
- Please add me to your ENews Bulletins List (my email address is listed above).

Thank you for your contribution!

TOWNSVILLE & CAIRNS 2010 REGIONAL TRIP



A very warm August day found the Services Team arriving in Townsville to deliver an updated "Understanding Epilepsy" Workshop. Carers, support workers, teachers, people with epilepsy and their family members attended the training at the Robert Douglas Auditorium at Townsville Hospital and it was great to catch up with so many friends. The following morning a small gathering joined the team for a social get-together over coffee and cake. It was good to connect with those who live with epilepsy, also those who work hard to support and to raise awareness of epilepsy. They support their children and other people with epilepsy. The Services Team hope to be of service to the group as they gather to support each other on a regular basis.

Cairns was the next stop on this latest regional trip. It also provided very warm weather as the team offered another "Understanding Epilepsy" Workshop to Cairns and its surrounds. Sixty support workers, carers, teachers and those who live with epilepsy attended the training and enjoyed a break over afternoon tea at the Holiday Inn in Cairns. It's a rewarding time for the EQI team to visit these areas and connect with so many people.

Over morning tea the next day, people with epilepsy and their family members met to share with us, their lives, their journeys and often their frustrations. It is hopeful that a new support group will be formed where many people can continue to be of support to each other and others in the Cairns area, also its hopeful that they can celebrate socially as well. It was another rewarding trip up to North Queensland again for Epilepsy Queensland.


 po box 1457
 coorparoo bc qld 4151
 phone 07 3435 5000
 1300 852 853 (outside brisbane)
 fax 07 3435 5025
 email epilepsy@epilepsyqueensland.com.au
www.epilepsyqueensland.com.au