


Epilepsy Report

Focussing on better community and health outcomes
for people living with epilepsy.

Issue No. 2, 2010



AUSTRALIA'S
Outstanding Person with Epilepsy
Michelle Bellon



Cassidy Megan &
the power of one!
Purple Day!

neuropsychologist
Robert Mittan

How to discuss SUDEP

SUDEP TASKFORCE
Rosey Panelli
reducing epilepsy death

Jack Packshaw
My life: before & after surgery

Meet Mike Glynn
President, International Bureau for Epilepsy

WELCOME

Welcome to the latest edition of *The Epilepsy Report*.

Firstly, the Australian epilepsy community congratulates Dr Michelle Bellon on being the inaugural Australian recipient of the IBE's *Outstanding Person with Epilepsy Award* for her ongoing commitment to improving the lives of people with epilepsy through her voluntary work with Epilepsy Australia and the Epilepsy Centre of SA & NT, and her professional work through Flinders University.

Commitment to improving the lives of people with epilepsy is a running theme through this issue. Commitment to research to better understand the vexing issue of epilepsy-related death, especially SUDEP, and the psychosocial issues that impact widely on well-being. Commitment of the specialist medical teams that enable the complex epilepsy surgery that can and does change lives. Commitment, as members of the Western Pacific region, to actively improve medical knowledge, treatment and community education among our developing neighbours and the commitment of the Global Campaign Against Epilepsy to bring 'epilepsy out of the shadows'.

We see it clearly demonstrated by our 'heroes' who challenge themselves while raising awareness of the impact epilepsy has on their lives and the lives of those they love, and by volunteers like Margaret Marshall who dedicated many years to helping her 'charities'.

On March 26, we can demonstrate our commitment to raising awareness of epilepsy and supporting Epilepsy Australia and its state-based member associations by embracing young Cassidy Megan's simple message "wear purple to raise awareness of epilepsy."

Are you committed? Help us make a difference.

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Editor

Denise Chapman

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Dr Michelle Bellon

Australia's inaugural recipient of the IBE's 'Outstanding Person with Epilepsy Award'

Every two years the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE) hold the Asian & Oceanian Epilepsy Congress (AOEC), with Melbourne hosting the 8th Congress this year.

The first combined Asian and Oceanian Epilepsy Congress (AOEC) representing both the medical and epilepsy support organizations of the regions was held in Korea in 1996. It was at the 4th AOEC in Nagano, Japan in 2002, under the guidance of Dr Park (Korea), Dr Marshall (Taiwan), Dr Kubota (Japan) and Dr Mehndiratta (India) the concept of the 'outstanding persons with epilepsy award' was developed to encourage people with epilepsy not to be ashamed of their condition and to overcome the heavy culturally defined stigma and discrimination that exists in the region. Since 2004, the "Outstanding Persons with Epilepsy Awards" have been awarded at a special ceremony during the Congress to recipients from countries across the regions in recognition of their significant contribution in raising the profile of epilepsy and helping to reduce the stigma of epilepsy in their country.

This award was presented to very worthy recipients, nominated by their respective IBE Chapters, at the subsequent congresses in Bangkok 2004, Kuala Lumpur 2006, and Xiamen 2008.

In 2005, the award came under the auspices of the IBE, and is now recognised as an international award.

The 8th Asian & Oceanian Epilepsy Congress will be the first time that Australia has participated in this award. The call for nominations along with nomination guidelines was widely publicised in June, and nominations were received from across the country.

The award recognises:

- Contribution to community service for people with epilepsy;
- Longstanding support for people with epilepsy;

- Longstanding advocate for people with epilepsy (community, disability, politics, media);
- Individual achievement that inspires others (personal, professional, educational, sporting, creative) regardless of their epilepsy;
- Distinguished service to a local epilepsy support organization.

After short listing six worthy applicants from the nominations received, the Joint Epilepsy Council of Australia, after lengthy deliberations, chose Dr Michelle Bellon of South Australia to receive this award.

Dr Bellon has lived with partial seizures since childhood.

"I have always been open about my seizures with friends, family, colleagues and my students, and try to explain them clearly to minimise people's misunderstanding and stigma. I consider myself fortunate in that epilepsy hasn't affected my study, career opportunities or other life decisions, however there are always times when it rises again to be an issue for example when demonstrating fitness to drive each year, planning pregnancy, managing stress and fatigue levels. My personal experiences have provided a positive opportunity to learn more about supporting people to live well with epilepsy through my study, research and community engagement," said Dr Bellon.

Dr Bellon's commitment to the epilepsy community includes volunteering her time as a director of Epilepsy Australia and, since 2003, as a board member of The Epilepsy Centre of SA & NT Inc, holding the position of Vice President since 2004. She is a regular contributor to the *Epilepsy Report* and speaks at conferences here and overseas. Her PhD was on the subject of Post Traumatic Epilepsy and her current research activities focus on community integration following acquired brain injury (ABI), mentoring programs in ABI and epilepsy and arts therapy. Currently a lecturer at Flinders



University SA in Disability Studies and Rehabilitation, she encourages her students to participate in on-going research on epilepsy and its impact whilst also supporting students to be involved in a hands-on commitment at camps and workshops. Recognising the importance of a holistic approach to the psychosocial needs of clients with epilepsy for a balanced working and social life, Dr Bellon has encouraged the expansion of The Epilepsy Centre's client services team.

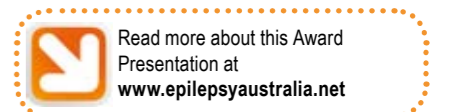
However she considers her most important achievement to date to be the birth of her son Jacob!

The Australian epilepsy movement could not be better represented by Dr Bellon and we congratulate her on receiving this award.

IBE President, Mike Glynn, will present the awards on Thursday, 21 October following the Epilepsy & Society Symposium.

The 2010 recipients from across the regions are:

Dr Michelle Bellon, Australia
Ms Cindy Li, China
Ms Li Ying Yi, Hong Kong
Ms Kavita D Shanbhag, India
Mrs Noriko Fukui, Japan
Mr T. Munkh-Aldar, Mongolia
Mr Mike Hills, New Zealand
Dr. Ronald Magbitang, Philippines
Ms Shih-Min Li, Taiwan



Read more about this Award
Presentation at
www.epilepsyaustralia.net

President's Report



A national disability insurance scheme: will it work for people with epilepsy?

In 2007, the Rudd Government's 2020 summit heard a proposal for a national disability insurance scheme. This scheme, along with a complete review of how services for people with severe disabilities are delivered, is now under review in an Inquiry by the Productivity Commission.

The review argues that the delivery of disability services and the way they are funded is outmoded and still reflects nineteenth century attitudes towards people with disabilities. People with disabilities and their carers are the most disadvantaged in Australia with low incomes and low employment rates. A national disability insurance scheme would assist in providing a more flexible funding model which in turn would create greater opportunities for both people with disabilities and their carers, thus leading to better quality of life and opportunities to contribute to the community.

A national disability insurance scheme would be a no-faults scheme similar to the Victorian Transport Accident Scheme (TAC). It would be based on need so that those with the greatest need would be ensured of having a liveable income and access to the services they needed. Needs would be judged across physical, intellectual and social impairment. Services would be coordinated rather than case managed and the emphasis would be on creating optimising people's well-being which in turn should lead to cost containments. Already, some of those who have looked at the financing behind such a scheme

have suggested that it would not cost as much as people think.

Given the Productivity Commission's focus on the most severe disabilities, including children who are born with a disability, and those arising from accidents in people under 65 years of age, there is a strong likelihood that many people with chronic illnesses are likely to miss out, once again. Amongst those will be people with epilepsy who are not so severely impaired they require full time care.

We would agree that those with the greatest impairment should be the greatest beneficiaries of such a scheme. We recognise that those who have severe uncontrolled epilepsy are likely to be part of this. However, the lack of understanding about epilepsy and the way stigma affects the ability of people with epilepsy to participate fully in their communities creates a level of impairment of its own. We know that people with epilepsy, even when their epilepsy is controlled, have trouble:

- attaining employment,
- having reasonable incomes,
- forming relationships and,
- participating in community activities.

This is a level of impairment that is socially bestowed and leads to unnecessary and humiliating dependence on family, carers, governments and not-for-profits.

When the Parliamentary Secretary for Disabilities and Children's Services, Bill Shorten spoke reviewing disability services including a national disability insurance scheme at the National Press Club in 2009, he said:

'Impairments are a fact of life. They arrive at birth through life's genetic lottery, they take hold of us in a car ride or a swim in the surf that goes devastatingly wrong, they slowly permeate us as we grow old.

'In a sense, impairments are not what disable people. What disables people is society's attitudes towards the impairment. An unrevised vision of the different.

'An unwillingness or inability to contemplate the different, to imagine its challenges and possibilities, and to recognise what is similar and humanly familiar.

'Australians with disability face a prejudice which is entrenched, systemic

and subtle, though still at times overt and openly abhorrent.'

All of this applies to the experience of having epilepsy, but people with epilepsy are 'in the shadows' and they will miss out on benefiting from these new initiatives unless we speak out. It is on this basis that Epilepsy Australia has made a submission to the inquiry by the Productivity Commission. By the time you read this, the call for submissions may have closed but I would suggest all concerned people need to take any opportunities that present themselves to address these issues.

For further information on the Productivity Commission Inquiry: <http://www.pc.gov.au/projects/inquiry/disability-support>

Even if you miss out on making a submission to the Productivity Commission Inquiry you might like to consider exploring the National Disability Insurance Scheme (NDIS) website: www.ndis.org.au

It is worth noting that during the recent Federal election campaign all three major parties endorsed a statement from the National Disability and Carers' Alliance to demonstrate they supported reform to both the delivery of services and the introduction of an insurance scheme. The Australian Labor Party, the Australian Greens and the Liberal/National Coalition considered that the issues were related to social justice and human rights. This statement of support however depends on the outcome of the Productivity Commission Inquiry in 2011.

During the election campaign, former NSW Parliamentarian John Della Bosca was appointed to head up future campaigns for the NDIS. When you visit the website there is the opportunity to contact him to put your point of view about including people with epilepsy in any new schemes.

Dr Christine Walker

New research project to examine epilepsy death in Australia

One of the very important challenges for epilepsy services in Australia is to raise awareness and understanding of possible risks related to living with epilepsy. While this is a difficult topic for all concerned it is essential that we use research and community education to clearly identify where risks exist and what strategies can be developed to reduce them. This includes the question of epilepsy-related death. While modest progress has been made in understanding epilepsy-related risks, there is still much work to be done, especially in the area of Sudden Unexpected Death in Epilepsy (SUDEP). Consequently Epilepsy Australia in partnership with the Epilepsy Foundation of Victoria has formed a taskforce to focus specifically on issues of risk and the challenge of reducing epilepsy deaths in Australia.

This project, *Reducing Epilepsy Death*, begins as a pilot project and is funded by Epilepsy Australia's *SUDEP Research and Education Fund* and supported by the Epilepsy Foundation of Victoria. Additional funding support will be sought, from a variety of sources, based on the outcomes of the pilot project.

Convened by Graeme Shears, Chair of the Joint Epilepsy Council of Australia, the taskforce includes representatives from forensic medicine, public health, epileptology and epilepsy support services. A reference group of key stakeholders has also been established with representation from the Epilepsy Society of Australia, Epilepsy Bereaved (UK), Department of Health and Ageing Australia, Department of Human Services Victoria – Disability & Health, the Joint Epilepsy Council of Australia, Royal College of General Practice, Traffic Accident Commission, and Vic Health.

Phase One of the project will be to establish a SUDEP bibliography; to pilot a survey of current knowledge and understanding of epilepsy-related death among health professionals, community services and people with epilepsy; to develop a key message document that promotes understanding of incidence, risk factors and management strategies; to liaise with the Victorian Institute of Forensic Medicine and comparable state bodies to document current death certification and death scene investigation processes across Australia; and, to explore the value of linking existing hospital, health, and research databases.

The project will be coordinated by Dr Rosey Panelli. Many of our readers will know Rosey through her past work with the Epilepsy Foundation of Victoria. Rosey has been at the forefront driving consumer information about SUDEP and epilepsy-related death in Australia since the late 1990s. Currently a member of the IBE Research Committee, a participant of the US NINDS Sudden Unexpected/Unexplained Death in Epilepsy Workshop (2008), Rosey co-authored with Jane Hanna (Epilepsy Bereaved) a chapter on SUDEP for an upcoming publication edited by Dr Paul Schraeder and Dr Claire Lathers (US), as well as co-editor of Epilepsy Australia's publication, *SUDEP: a global conversation*. Rosey is also engaged as a Research Consultant for Epilepsy Bereaved.

The support and participation of the community is always crucial to epilepsy projects and we invite you to contact Rosey if you wish register your interest in this initiative and to receive ongoing updates on progress. You can email her at roseyunep@gmail.com or write to her C/O Epilepsy Foundation of Victoria, 818 Burke Road, Camberwell 3124.



With a history of advocating for improved communication on epilepsy-related risks, Dr Rosey Panelli has been appointed to drive the *Reducing Epilepsy Death Project*.

Epilepsy Australia's SUDEP Research & Education Fund

This fund was established in 2008 in response to donations received from families, friends and colleagues who have suffered the bereavement of an epilepsy-related death and who expressed a desire to see research conducted into SUDEP and avoidable death.

While scientific research still seeks to find the elusive cause of SUDEP, information regarding frequency, risk factors and possible causes is forming a considerable body of knowledge. Referencing, analyzing and distilling this information will provide the solid foundation on which the *Reducing Epilepsy Death Project* is based along with the collection of social research data which will assist in the development of a key message document for community dissemination.

This project is the first to be funded by the SUDEP Research & Education Fund. Progress updates will be available on the Epilepsy Australia website.

For more information or to support the SUDEP Research & Education Fund visit www.epilepsyaustralia.net

Sudden Unexpected Death in Epilepsy (SUDEP): Is there a link between the brain and heart?

Ms Emily Tu, Ms Louise Waterhouse, Dr Richard Bagnall, Professor Chris Semsarian
University of Sydney & Centenary Institute, Sydney, Australia

Epilepsy is a common neurological condition characterised by a tendency towards disruption of the normal electrochemical activity of the brain, resulting in recurrent seizures¹. Epilepsy affects approximately 50 million people globally². Every year approximately 1 in a 1000 patients who suffer from chronic epilepsy die suddenly, unexpectedly, and without pathological findings at post-mortem³. This phenomenon is termed sudden unexpected death in epilepsy (SUDEP).

What is SUDEP?

Sudden unexpected death in epilepsy (SUDEP) is defined as 'a sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in a patient with epilepsy, with or without evidence of a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicological or anatomical cause of death'⁴. Sudden death is much higher in patients with epilepsy than in normal populations, with mortality ratios up to 40:1^{5,6}. Sudden death accounts for 8-17% of all deaths in epilepsy^{3,7} and post-mortem examination of SUDEP cases often fails to find a pathological cause of death⁴. As cardiac electrical disorders also have a negative post-mortem, this leads to the hypothesis that there may be a connection between epilepsy and cardiac arrhythmogenic disorders. In support of this hypothesis, the incidence of SUDEP increases with increasing severity and intractability of epilepsy⁵.

What are the risk factors for SUDEP?

There is a well-documented correlation between severe, intractable epilepsy and a heightened risk of SUDEP^{4,5,7}. The risk factors most frequently associated with SUDEP are:

- poor seizure control
- a lack of compliance to prescribed anti-epileptic drugs (AEDs)
- polytherapy
- abrupt medication changes
- early-onset epilepsy.

The occurrence of frequent seizures, particularly generalised tonic-clonic seizures have been found to predispose patients to SUDEP⁴. However this association between SUDEP and epileptic seizures accounts for some of the evidence only, and there may be other environmental and genetic factors that contribute to SUDEP. SUDEP is significantly more common in males. Environmental factors such as alcohol abuse, vitamin D deficiency and prone sleeping position have also been shown to increase the risk of SUDEP^{3,7}. A seemingly protective effect is the presence of another person in the same room, especially during sleep⁴.

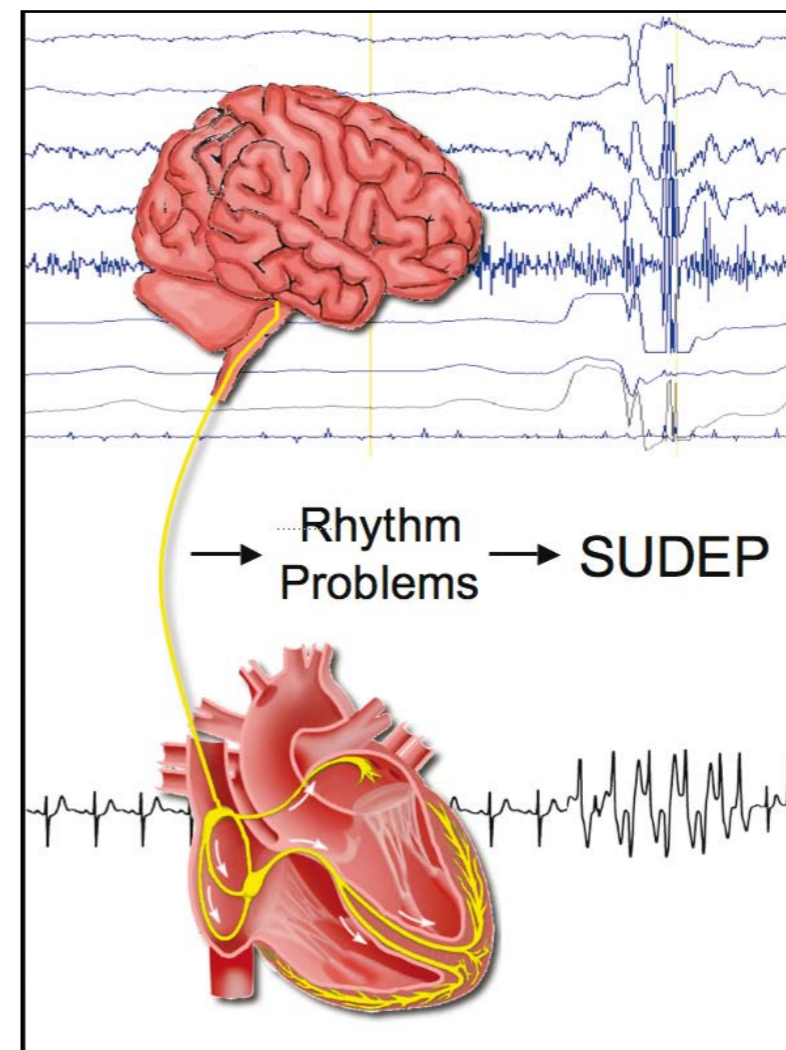
What are the clinical features of SUDEP?

Although the official definition permits diagnosis without evidence of a seizure, SUDEP is widely considered to be a seizure-related event⁴. Clinical and pathological findings indicate that most cases of SUDEP occur during, or shortly after a tonic-clonic seizure⁸ with most deaths believed to be triggered by such a seizure⁴. Thus, the risk of SUDEP increases with escalating frequency of

tonic-clonic seizures and occurs most frequently in chronic, uncontrolled epilepsy⁴. However, in support of the hypothesis that SUDEP is caused by a cardiac rhythm malfunction, at post-mortem there is no obvious cause of death. Diagnosis of SUDEP is not based on the presence of a pathological cause; rather it is diagnosed in the absence of any other cause of death. The patient must have suffered from epilepsy, and then based upon the knowledge gathered surrounding the death, a diagnosis can be given regarding the probability of SUDEP. Cases that fulfill all parts of the SUDEP definition are categorised as 'definite SUDEP'; sudden death in a person with epilepsy in which there is no post-mortem performed but there are no known competing causes for death are defined as 'probable SUDEP'; and cases in which SUDEP can not be excluded but there is limited information available are defined as 'possible SUDEP'⁵.

What is the underlying cause of SUDEP?

Although the pathogenic mechanisms behind SUDEP are unknown, respiratory and cardiac factors are often associated and death usually results just after a tonic-clonic seizure⁵. Also unknown is what causes one seizure to result in death when the epilepsy sufferer has had previous non-fatal seizures⁵. It has been hypothesised that cardiac arrhythmias during and between seizures or transmission of epileptic activity from the brain to the heart via the autonomic nervous system could potentially play a role in SUDEP³. Cardiac factors associated with SUDEP include alteration of cardiac repolarisation, bradyarrhythmias



(slow heart rate), asystole ('flatlining') and occasionally tachyarrhythmias (fast heart rate)⁴. It has been hypothesised that these abnormal rhythms could be caused by malfunctioning depolarisation or repolarization mechanisms within the voltage-gated ion channels of the heart⁹.¹⁰ or voltage-gated ion channels that are present in both the heart and brain and are encoded by the same gene⁷. This suggests a possible link between the brain and heart in SUDEP.

Management of Patients

As there is very little known about the causes and mechanisms of SUDEP there is no definitive preventative treatment available. However, as there is a strong correlation between severe, uncontrolled epilepsy and a high risk of SUDEP⁴ and as 70% of epilepsy sufferers become seizure-free with the use of anti-epileptic drugs (AEDs)¹, the correct use of AEDs could theoretically provide greater protection against SUDEP than leaving epilepsy untreated. In addition to good seizure control, avoiding potential seizure

triggers is important. This may include avoiding triggers such as alcohol, as well as taking precautions with activities such as swimming. Finally, education about epilepsy, and specifically SUDEP, amongst family friends and relatives, as well as raising awareness in the community, are important measures which could potentially improve the management and care of epilepsy sufferers at risk of SUDEP.

Current and Future Research

Generally speaking, very little is known about why SUDEP occurs, and how one can predict who is at risk of developing SUDEP. Our research team at the Centenary Institute and University of Sydney have a specific interest in all causes of sudden death in the young¹¹. We have recently begun a pilot study looking at the possibility that there may be a link between the brain and heart in people who die from SUDEP. We believe people who die from SUDEP ultimately have a terminal heart rhythm problem which leads to their death. We

already know that genetic faults in the ion channels (which allow sodium and potassium in and out of cells) can lead to heart diseases which can cause sudden death. One possibility is that some patients with epilepsy may have gene faults which affect these ion channels both in the heart and brain which could place those people at risk of SUDEP. We are currently reviewing SUDEP cases over the last 15 years in Sydney to determine whether such gene/DNA faults exist and whether these may be the underlying trigger for SUDEP. Our findings will most likely shed light on the mechanisms underlying SUDEP, with the ultimate goal to prevent this tragedy in epilepsy sufferers in the future.



<http://www.centenary.org.au/ourresearch/cardiovascular/molecularcardiology/>
<http://sydney.edu.au/medicine/people/academics/profiles/c.semsarian.php>

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Dr Kate Riney

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Dr Kate Riney is a Paediatric Neurologist and Epileptologist at the Mater Children's Hospital in Brisbane, co-chairing the Queensland Paediatric Epilepsy Network.

For more information on the Queensland Paediatric Epilepsy Network (QPEN) and activities currently being undertaken to improve health outcomes for young people with epilepsy in Queensland, please contact QPEN Network Manager Terry Lack, PO Box 128, Royal Brisbane & Women's Hospital Herston, QLD 4029.

SUDEP – seeing the full picture

Dr Damian Clark, Dr Kathryn Urankar and Dr Kate Riney

Introduction

Sudden unexpected death in epilepsy (SUDEP) is the main reason why people with epilepsy have an increased risk of death compared to the general population. Raising awareness of and working towards preventing SUDEP has been the common goal of doctors caring for people with epilepsy, and those who suffer from this condition. When tabling SUDEP with governments and health service leads, hard data on numbers of SUDEP deaths can be powerful information to help drive change towards reducing SUDEP. However, accurate determination of the number of SUDEP deaths is commonly hampered by a number of factors.

Background

Sudden death is a phenomenon that has been long recognized as occurring in people with epilepsy, with reference to this in medical literature from as early as the late nineteenth century. The term SUDEP was first coined to describe this phenomenon by Doctors Lina Nashef and Stephen Brown in 1996, at the first International Workshop on Epilepsy and Sudden Death in London,¹ with a definition for SUDEP proposed at that time: “the sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in an individual with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus where postmortem examination does not reveal a cause for death”.

Despite SUDEP being clearly defined, low rates of use of the term SUDEP on post-mortem reports have been noted in a number of studies.²⁻⁴ In a national survey of coroners and pathologists in the United States, with over 500 respondents, 84% of US pathologists who responded acknowledged that they considered SUDEP a valid diagnosis if no cause of death were found at autopsy, but only 23% of these actually used the term SUDEP in more than

half of cases where criteria for SUDEP were met.² Whilst the definition for SUDEP provides clarity around the circumstances that must be met in order for SUDEP to be diagnosed, the area of ambiguity that often arises is around the concept of the absence of an identifiable cause for death being revealed at post-mortem examination. SUDEP is not always a phenomenon that is unexplained, but rather unexpected. When the postmortem examination shows evidence of a recent seizure (such as tongue biting) or when there is evidence of asphyxia or suffocation (usually arising in the context of a seizure due to failure to correct body position in response to difficulties in breathing during or after the seizure), the death may certainly be explained as likely due to the adverse consequences of a seizure. Leading SUDEP authors argue that, although findings of asphyxia or suffocation or seizure may be noted at post-mortem, these deaths should still be considered as SUDEP deaths as the definition of SUDEP encompasses unexpected death in a seizure (which may be related to cardiac or respiratory factors in the peri-seizure phase) and that it is unhelpful to separate out deaths with post-mortem findings of seizure or asphyxia or suffocation (not least because the absence of these findings at post-mortem does not exclude these as having happened and caused death).⁵ It is for this reason that the term SUDEP includes the term ‘unexpected’ rather than ‘unexplained’, as it is likely that the major cause of SUDEP may be explained as being the consequence(s) of a seizure (especially of an unwitnessed and therefore an unattended nocturnal seizure). Nonetheless, it is this ambiguity that may lead to under-use of the term SUDEP as a post-mortem diagnosis.

Other factors that impact on understanding the incidence of SUDEP include consistency of terminology in recording epilepsy related deaths on death certificates,⁴ subsequent

coding of cause of death by national statistics offices, practice in reporting of deaths to the coroner, actions of the coroner in deciding further examinations, completeness of post-mortem investigation, access to these sources of information retrospectively by those researching SUDEP and the availability of prospective data capture systems. In addition, variations in the laws of different countries may impact on the approach to investigation of sudden deaths in people with epilepsy. For example, in Queensland, mandatory reporting of sudden death per se is not required under the Coroners Act, 2003. However, in England and Wales, there is a particular emphasis in law on the coroner's legal duty to hold an inquest in the event of death being sudden and of unknown cause (United Kingdom Coroners Act, 1988 section 8(1)).

Review of SUDEP deaths in young people in Queensland

As part of the ongoing work of the Queensland Paediatric Epilepsy Network (QPEN) to improve health care outcomes for young people with epilepsy in Queensland, a retrospective review of epilepsy related deaths in young people (<18 years) was undertaken over a 5 year period to help understand the incidence and risk factors for SUDEP in the younger Queensland population. In Queensland, the Queensland Child Death Register (QCDR) was established under the Commission for Children and Young People and Child Guardian Act, 2000. The QCDR allows for the centralized collection and collating of mortality data from both coronial and non-coronial deaths of young people under the age of 18 years registered in Queensland. Through this process, data was captured on all deaths in young people under the age of 18 years in Queensland where epilepsy or seizure or a similar term was listed on the death certificate and/or post-mortem report.

In the 5-year period of this review, a search of the QCDR data identified over sixty young people with epilepsy who died, with reference to epilepsy or a similar term (e.g. seizures, convulsions etc) on the death certificate (two-thirds of deaths) or having the death referred to the coroner (one third of deaths). There was considerable inconsistency in the terminology used to record deaths from epilepsy on death certificates. Terms

used included ‘epilepsy’, ‘seizure’, ‘convulsion’ and a range of other terms that might refer to the seizure, the epilepsy type, the epilepsy syndrome or the underlying aetiology for the epilepsy. Whether epilepsy (or related term) was considered as the leading cause of death on the death certificate was also noted to be variable. Epilepsy (or related term) was listed as a causal factor in the death in 58% cases, and as a contributing factor to the death in 42% of cases. In a number of cases, epilepsy (or similar term) was listed several times on the death certificate e.g. 1(a) convulsion 1(b) epilepsy 1(c) epilepsy syndrome. Whereas in other cases ‘epilepsy’ was simply listed at 1(a) with no other entry made. In some instances, every condition the person had was listed randomly on the death certificate whether it had any relationship to the death or not. The epilepsy was determined to be the leading cause of death in approximately half of all deaths in young people with epilepsy in Queensland in the five year period of this review.

Although around a third of all deaths in young people with epilepsy were sudden, the term SUDEP was only used as the final post-mortem diagnosis in around a third of sudden deaths that had post-mortem diagnosis available. In the majority of sudden deaths, the circumstances of death would have met the criteria for SUDEP or ‘possible SUDEP’⁶ (where post-mortem investigations were not completed to allow criteria for SUDEP to be met, but all other factors were consistent). Instead of SUDEP, other diagnoses such as ‘epilepsy’, ‘aspiration due to epilepsy’ ‘seizure’ and ‘respiratory failure due to epilepsy’ were commonly found where SUDEP or ‘possible SUDEP’ would have been appropriate.

Conclusions

Data from this retrospective review indicates that we are a long way from being able to be clear that we can ascertain the number of SUDEP deaths currently occurring in Queensland (and by association in Australia), either from death certificate records or from post-mortem diagnosis records. In order to be able to identify SUDEP deaths, agreed standards for certification of deaths in people with epilepsy are essential as are standardized approaches

to reporting sudden deaths to coroners, standardized approaches to the post-mortem investigations of these cases and improved use of the term SUDEP on post-mortem reports when criteria for SUDEP are met. Central to this is collaboration amongst health professionals to agree such standards of care, education of the wider health community, and support for ongoing prospective data capture systems through funding resources. Accurate ascertainment of SUDEP deaths is essential to progress our understanding of SUDEP as without this it will always be more difficult to fully understand and study the risk factors that may predispose certain patients with epilepsy to SUDEP and ways in which SUDEP might be prevented.

Acknowledgements

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Robert J Mittan

Seizures and
Epilepsy Program (S.E.E.)
www.theseeprogram.com

For 22 years, Robert J Mittan, PhD, has been helping people with epilepsy and their families. A clinical psychologist, he is recognized as one of the foremost epilepsy educators in the world. His work helping others has earned many awards and his research on epilepsy has resulted in new and important discoveries.

The S.E.E. program is designed to give people with epilepsy, parents of children with epilepsy and family members the information and skills needed to get the best chance of becoming seizure free – without letting treatment become part of the problem.

Dr Mittan has presented this program to over 30,000 people with epilepsy and their families in Australia, Canada, New Zealand and the USA.

How to discuss SUDEP with patients and families

I must say I am surprised at the extent of controversy regarding whether or not physicians should discuss SUDEP with patients and families. Fear of dying from seizures is nearly universal among patients and families. Most patients and families are reluctant to bring the topic up. They don't ask their physicians because they are afraid their worst fears will be confirmed. These fears are substantial. In our original UCLA study (Mittan, 1986), two-thirds of patients were openly afraid they could die with their next seizure and nearly three-fourths were afraid seizures would cause further brain damage. The fact is that for the vast majority of persons with epilepsy and their families, raising the topic of SUDEP is not going to harmfully introduce fear that was not there to begin with.

For 27 years I have presented the Seizures & Epilepsy Education (S.E.E.) program. This has given me the opportunity to speak with nearly 40,000 patients and families with epilepsy in Australia, Canada, New Zealand, and the U.S. I have found patients and families are almost universally afraid of death from seizures. So is the general public. It makes sense – even non-convulsive seizures frighten people. In 27 years of asking, all but one parent thought that their child was going to die when they first witnessed the child's seizures. The one exception was an epilepsy nurse specialist whose daughter started having absence seizures.

When these universal patient and family fears are not discussed, these fears are left unchecked by the true facts of the risk. Each of us know from our own experience what is not said in a conversation can speak more loudly than what is said. When the doctor fails to discuss the potential death from epilepsy, patients and families naturally interpret the physician's behavior as confirmation that the risk of death is

real and too uncomfortable for him or her to discuss or for the family to hear. While physicians debate the wisdom of bringing up the topic of SUDEP and status epilepticus for fear of "unduly alarming" their patients, their behavior is actually confirming alarming fears in the minds of most patients and their families.

With the lack of facts and the apparent lack of "courage" to discuss death and epilepsy on the part of the physician, these fears can, and often do run rampant, to the serious ruin of quality of life. Fear is the force behind developmentally disabling overprotection and overcontrol of the person with epilepsy. Fear is the force leaving people afraid to be alone and afraid to go out by themselves because of seizures. Fear shrinks life to the house and social contact to the immediate family for far too many.

Rather than alarming families, discussing causes of death in epilepsy gives them a more realistic appreciation of the risk – which is often much to their relief! Just the fact that the physician feels comfortable in discussing the topic is comforting to the patient. If the physician can talk about the risk of death without alarm, patients and families see a real life human model that they can openly discuss this concern without alarm as well. For 27 years the S.E.E. program has taught patients and families about SUDEP, status epilepticus, and fatal accidents in epilepsy, including relative risk and circumstances for each. Two controlled outcome studies (Helgeson, et al, 1990, and Shore, et al, 2008) showed significantly reduced fear as a result – and equally important, significantly improved compliance. While there is much debate over the potential causes of SUDEP, there is virtually universal agreement on one prevention – seizure control (Hughes, 2009.) And seizure control is thought highly dependent upon compliance.

During every S.E.E. program I poll

the audience to find out how many have discontinued their medications on their own and have gone into status epilepticus. Consistently 10-15% will raise their hands. They protest they were "never warned" of the danger. Nearly all were angry with their physician about it. In fact, they undoubtedly were warned with "you should never stop taking your medications!" Some recall hearing this demand, but never recall hearing why.

However, telling people what to do is rarely effective in changing behavior. It is essential to tell people why to do it. Every prescription patients receive is accompanied with some version of "take this exactly as directed." Patients hear this so often it stops being meaningful. After all, how often have they failed to take all of their antibiotics or other medication and nothing bad happened? Why should it be any different with seizure medications? However, if the patient knew they risked status and possibly death by stopping their medication – that would get their attention. But to do this, the physician has to talk about status, SUDEP, and their lethal potential.

The benefits of talking about SUDEP, status epilepticus, and other risks in epilepsy not only fulfills patients' and families' right to know, but can significantly contribute to reducing fear. It may save a life. Rather than threatening the emotional wellbeing of patients and families (who already assumed a fear death), the discussion of SUDEP offers a therapeutic opportunity. It is a chance to significantly improve quality of life and reduce harm from seizures. The methods used in disclosing this information can strongly influence medical and psychosocial outcomes.

So how does one go about the process of talking about SUDEP, status epilepticus, accidents, and other potential sources of harm from seizures? Very often, how a message is given is more important than the content of the message itself. How many times have you been upset with someone, not for what they said, but how they said it? The same is true when talking about SUDEP. How it is discussed often has a greater impact on the result than hearing of SUDEP itself.

Let's say a man falls off a ferry into

The conversation can (and must) begin with specific positive steps persons with epilepsy and their families can take to improve their overall seizure control ...

the ocean. His life is at risk. He knows it and the ferry captain knows it. If the ferry captain frantically shouts to the man "Swim or you might drown!" the man is likely to become alarmed and thrash more violently out of fear he might die.

If instead the captain calmly yells, "People fall overboard sometimes. I'm going to tell you what you can do to keep yourself afloat. You don't need to drown when you can do things to prevent it. First, take off your shoes, jacket, and heavy clothing because those will weigh you down. Next, lie on your back and try to float on the water. Fighting against the water will only tire you out. I have stopped the boat. Just paddle gently to it. Take your time. That way you will reach the boat without spending yourself and getting into trouble."

Telling persons with epilepsy and their family members about SUDEP is similar to the wise ferry captain coaching the passenger. The captain does not avoid discussing death – the risk is obvious to everyone. What the captain does is reassuring and useful. He focuses his message upon providing the passenger with the practical skills the passenger needs to have the best opportunity to preserve his life.

We have advantage over the captain regarding SUDEP. The crisis has not occurred yet. The conversation can (and must) begin with specific positive steps persons with epilepsy and their families can take to improve their overall seizure control. These would include explaining how medications work, their behavior in the bloodstream, therapeutic ranges, and the challenges to be faced in maintaining proper blood levels day in and day out. These include talking about first aid, about how lifestyle habits can improve the chance of seizure control,

and the importance of identifying and avoiding seizure triggers. These include the unambiguous goal of good seizure control, with a clear plan for further diagnostic workups and / or treatment changes if current efforts are not successful. These include educating the person about medication side effects and how to recognize toxicity so these can be reported – and especially so these do not cause poor compliance.

Once patients and families possess the knowledge and skills they need to help protect life, then the physician is in the ideal position to introduce SUDEP as constructive therapy. SUDEP provides the physician with a compelling opportunity to illustrate why proper medical self-management skills are so valuable to the person and family. While these skills are designed to prevent seizures, they also afford important protections against more rare and serious complications in epilepsy, including SUDEP and status. The take home message, "Practicing these skills daily can reduce your risk of harm from epilepsy. That puts your future in your control."

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Research at Flinders

Epilepsy Research Group Flinders University and Medical Centre

Part 5: Curare-paralysis, thought processes and the EEG

In previous articles from our laboratory, we described our findings from experiments in humans with epilepsy and from animals in which we artificially induce seizures. This time the results come from experiments we have carried out on ourselves and our friends. They were undertaken to solve a problem we had in measuring fast EEG waves (gamma EEG, 30-100Hz), which we had previously identified as being involved in some forms of epilepsy.

The experiments involved some of us being injected with a curare-like drug (used initially by South American indigenous people to kill animals) causing complete paralysis of all muscles. The whole procedure was approved by our ethics committee and, of-course, we volunteered for this, even though we knew that we were going to experience total muscle paralysis.

During the effects of the paralyzing drug (about 1 hour), we were provided with artificial respiration via an airway-tube placed in our throat connected to a ventilator. While paralysed, we had our EEG recorded and undertook a number of mental tasks: these included learning a list of words, detecting high-pitched tones amongst lots of low-pitched tones and discriminating between similarly sounding or identical pairs of words. Just before being paralysed, we did the same mental tasks so that we could compare the EEGs recorded first without, then during, paralysis. Throughout, we were looked-after by expert anaesthetists, so the experience of full muscular paralysis was not frightening: it was pleasant, very relaxing in fact!

Now, returning to the motivation for our unusual study, we need to explain that normal EEG can be quite different from person to person. Even worse, differences between high frequency EEG (gamma EEG) as measured during a normal EEG procedure are extremely different between different people. Because our Epilepsy Research group is particularly interested in measuring gamma EEG, we needed to understand what the differences in gamma EEG in different people might be due to. After all, our results in animals and in patients with epilepsy had suggested to us that gamma EEG is important in understanding epilepsy (see earlier Epilepsy Reports). But it seemed from our own recently completed study of

over 600 people that natural differences in gamma EEG between people might overshadow changes in gamma EEG due to having epilepsy. We thought it possible that variability in gamma EEG between people might be because EEG is swamped by electrical signals arising from muscles around the head and jaw (active muscles produce electrical signals known as electromyogram, EMG). The only way we could directly test this idea experimentally was to fully paralyze awake humans and compare the EEG before and during paralysis.

The planning and procedures for paralyzing awake humans were organized like a military exercise. Thirteen personnel were involved in the process (the volunteer subject, two intensive care specialists, an anaesthetic technician, an anaesthetic nurse, a neurologist, an EEG technician, a computer operator, an electronic engineer, two EEG analysts, an official recordist of all procedures and a video-camera recordist! All procedures were practised to ensure they worked as planned. We have now performed the experiment with 6 volunteers, one of whom was female (Figure 1).

The results of our experiments were striking. They indicated that, even compared with a quiet resting normal state, there was a remarkable reduction in apparent gamma EEG activity after we were paralysed. Put another way, even when we seemed to be completely at rest, our facial, jaw and neck muscles continued to be active: they produced electrical signals (EMG) at similar frequencies as gamma EEG and, therefore, interfered with its measurement. Around the scalp, muscle signals overshadow the brain signal by approximately 10-fold in amplitude (Figure 2).

The results of our study also made it clear that much of what neurologists see in clinical EEGs (the low frequency activity in the EEG) is not affected by muscle contamination. Importantly for us and for our future work, the very central area of the scalp is relatively free from high frequency contamination, so we will focus our analyses on gamma EEG from this area. Already we have confirmed an increase in gamma EEG in individuals with inherited forms of epilepsy, though it is not a large increase.

The recordings we have made during paralysis in these studies provide us with



Figure 1. Anne-Louise Smith (Biomedical Engineer), awake on the respirator, while paralysed with a curare-like drug and doing mental tasks

'gold standard' muscle-free EEG. We will use these records to assist us in the development of mathematical techniques for removing EMG from scalp recordings, so leaving us with EEG that can be analyzed reliably. By improving our detection of gamma EEG we hope it can be used to improve diagnosis and management of some common forms of epilepsy.

For individuals interested in any of these articles, you may email the researchers via the Epilepsy Report editorial staff.

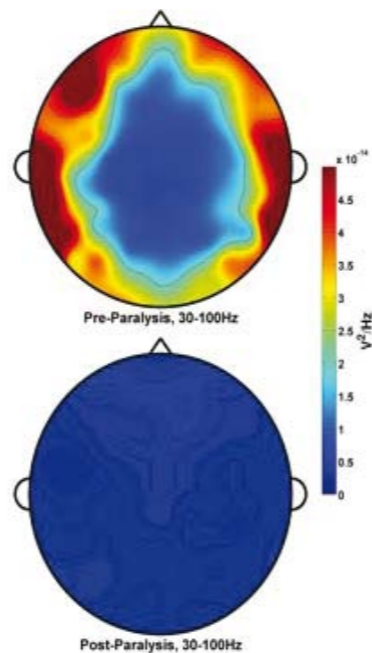


Figure 2. This colour-coded picture shows how much gamma EEG is due to active scalp muscles even when individuals are at rest. The figure depicts the head viewed from above with the nose in front. Colours except for the darkest blue depict EMG activity that disappears completely when subjects are paralysed with a curare-like drug. (Reproduced with permission from Clinical Neurophysiology, 119: 1166-1175 (2008)).

The lottery of life! Tuberous Sclerosis Complex

Elizabeth Pinkerton had a seizure the day she was born. "She gagged and twitched for about 10 seconds" reports her mother Sue. Unfortunately the seizures which followed on a daily basis were so subtle and quick that her parents didn't become alarmed at her behaviour until she was three months old. It was another few months before a diagnosis of Tuberous Sclerosis Complex changed their world.

Tuberous Sclerosis Complex (TSC) is a genetic disorder occurring 1 in 6000; however, over 70% of new diagnoses result from sporadic mutations on either chromosome 9 or 16, and are not inherited from the parents. TSC is a multisystem disorder which can affect many organs of the body including the brain, heart, kidneys, skin, lungs, eyes and other organs. The range and severity of symptoms can vary from person to person.

Benign tumours in the brain cause electrical activity- seizures-which are often the first symptom of TSC in individuals. These may include muscle spasms (myoclonic jerks) as was Elizabeth's case. About 80% of people with TSC experience epileptic seizures.

Up to 90% of individuals with TSC have brain lesions or tumours which are detected by MRI (magnetic resonance imaging). Lesions in the kidney are found in 60% of TSC individuals and usually develop by adolescence. Cardiac tumours (rhabdomyomas) may also be present in infancy but tend to disappear in the following few years.

TSC causes a range of skin involvement: white patches on the torso and limbs, facial lesions (angiofibroma) usually occur between the ages of 3 and 5 or prior to adolescence and require painful and intrusive laser treatment for removal. Small benign growths can occur around or under finger and toe nails. While the skin signs are harmless they can cause social and emotional concerns for the child and family.

The greater challenge for a family with a TSC affected child is control of their epilepsy. The seizures associated

with TSC are wide ranging and typically difficult to control. While some TSC affected children experience early control of epilepsy with minimal use of antiepileptic drugs, there are many who, despite the best endeavours of the medical profession have years of uncontrolled seizures. Epilepsy surgery is not suitable for all TSC candidates as it can be difficult to isolate and remove the tumours causing the seizures. However there are increasing numbers of TSC affected families who are choosing epilepsy surgery for their young children. Other epilepsy treatments used for TSC affected children include the ketogenic diet and the vagal nerve stimulator.

Early control of the seizures is important as it improves the outcome for children to develop normal intelligence. However, nearly 50% TSC people have intellectual impairment and autism despite the best efforts to control seizures. Early intervention programs providing speech therapy, occupational therapy and physiotherapy should be accessed so that child development can be assisted and monitored.

There are also many people with TSC living normal productive lives. Tuberous Sclerosis Complex does not always cause life changing disabilities. The diagnosis of TSC isn't always like you've lost the Lottery of Life!

When a diagnosis of TSC is made, that person then has 50% chance of having a child affected by TSC. Two different genes are known to cause TSC. It is essential that the family consult a Geneticist or Genetic Counsellor for further advice. A blood test can provide valuable genetic information, allowing TSC affected families to plan and make informed decisions about their future.

Following a diagnosis of TSC the child or adult should receive monitoring of brain involvement, kidneys and heart at the recommended intervals and ideally should consult a neurologist or paediatrician on a regular basis.



The Australasian Tuberous Sclerosis Society was established in 1981 to support families with this diagnosis and also to raise awareness of TSC amongst the medical professions and the community. The ATSS is a dynamic group of volunteers who have worked steadily to achieve collaboratively:

- The establishment of a TSC Genetics Diagnostic Laboratory at SEALS at Prince of Wales Hospital Randwick.
- Medical Meetings with international TSC experts sharing their knowledge to improve the care and management of TSC patients in Australia and New Zealand.
- Annual Seminar Days for families affected by TSC, a National Family Event Day.
- Production of a variety of resources providing information and support for families and professionals including a biannual journal, a DVD, ATSS website, Facebook page, phone and email contact.

The Australasian Tuberous Sclerosis Society is a registered charity with tax deductibility for donations over \$2.

The Australasian Tuberous Sclerosis Society
1300 733 435
Email: info@atss.org.au



For more information visit
www.atss.org.au

Sue Pinkerton, President

My life: before and after surgery

Jack Packshaw

On the evening of April 14th, 1999 Sydney experienced a huge hail storm. People still remember that night and the incredible electrical activity and the storm damage caused to properties throughout the city. My family and I remember that night for a different reason. I was eight and a half years old and I was watching a movie at home curled up on the sofa with my sister and auntie. The next thing I remember is everyone standing around me and panicking. I had experienced my first epileptic seizure. I felt exhausted and scared. I was having trouble speaking and felt very strange and my family were all in shock. The paramedics arrived, tested my blood sugar levels and told us that it was probably just a “one off” occurrence, perhaps to do with the extreme electrical storm. My parents put me to bed in their room, to keep an eye on me, and then at 4am, I had my second seizure. We then went straight to the hospital. The doctors commenced a range of tests and we were informed that I either had a brain tumour or epilepsy and we were all strangely relieved when I was diagnosed with generalised epilepsy.

Here began a huge journey for my family and me. Learning to live with this totally unpredictable, scary thing. Adjusting to taking twice daily medications, missing school because I was either exhausted after having a seizure, or because I felt terrible nausea from my medication, more blood tests, another MRI or EEG and a specialist or alternative therapist. During the past eleven years I have experienced a myriad of different types of seizures or episodes. Tonic clonic seizures, partial seizures, absences, recurring seizures every few minutes, flickering eyes and even a couple where I got stuck in a partial seizure for hours.

The impact of this on my life has been major. I have struggled against

the stigma of my condition. My family have encouraged me to share with my friends because there were issues around my safety. School camps were a negotiation with the teachers and my Dad used to come too. If I had a seizure while staying over at a friends’ place, they needed to know not to freak out – although they usually did! As I became a teenager and enjoyed a little more freedom, I had to implement some basic safety strategies: wearing medic alert dog tags around my neck, carrying a card in my wallet and entering ICE (In Case of Emergency) into my mobile phone.

Just over two years ago, with my seizures still uncontrolled, something showed up on an MRI scan that had my neurologist excited. He wanted to explore it more and referred me to the Epilepsy Unit at Westmead Hospital. I spent a week in the unit undergoing telemetry and video monitoring with the amazing crew there. At the end of the week, the specialists there thought that they may be able to help me and that I might be a candidate for surgery. As I was only seventeen at the time and studying for my HSC, my parents agreed that it would be better to wait until I had completed school and was also an adult and therefore able to give my consent to the operation. Three weeks in hospital, two operations and the possibility of finally gaining control – bring it on!

March 2010

It is now four weeks since my surgery – which involved removing a portion of my left lobe the size of a redheads matchbox! I had a weakness in the right side of my body after the surgery and I have been doing physiotherapy exercises to regain my strength. I have had no seizures to date – not even an aura! It is early days to say whether it has been a success or not. However, I can report that I feel great – calmer, clearer and



Jack Packshaw is thankful that surgery to stop his seizures was an option for him

more focused. My thoughts and speech are more aligned and one of the things I love to do is write and perform hip hop. I have noticed that “my flow” has improved and it is now much easier for me to read straight off the page, rap and stay with the beat. I live near Byron Bay on the beautiful north coast of NSW and I am excited to think that I may one day soon be able to learn to drive and not rely on my mates and my family to chauffeur me around.

September 2010

It has now been almost 7 months since my operation and I’m powering on! There have been a couple of “bumps in the road” – I have had 2 fitting episodes, both times after very late nights and very busy weeks. I have found that I need to be very focused on my health and wellbeing and to also make sure that I get plenty of sleep – no late night partying, alcohol or recreational drugs (which is hard as all my friends go out and enjoy themselves and I am an outgoing 20 year old). I have just recently finished an Electronic Music Production course at SAE Institute, Byron Bay and am currently studying Media at the Byron Region Community College (similar to TAFE and other tertiary education facilities).

Since recovering from the operation my memory is much better and I am more confident and less nervous when performing my hip hop songs on stage. I can now think and process quicker, you could say I’ve got a new quick wit (ha ha!). I’m very excited about going to get my drivers’ licence next July and then hopefully soon after moving down to Sydney and getting a job or an internship in a recording studio. Overall, I am so much happier and everyday I wake up with a big smile on my face, knowing how fortunate I have been to have this surgery option. If I continue to take care and look after myself I hope to be fit-free forever!!

So that’s where I am at today and I wanted to share my story. To give some hope to other teenagers out there battling to control their epilepsy. To encourage discussion and openness, to increase public awareness of this condition and the strategies on how to support someone during and after a seizure.



clockwise top left: tracking Jack’s recovery

How the team at Westmead prepared for Jack’s surgery

At the Epilepsy Unit at Westmead, staff specialist Andrew Bleasel and his specialised team conduct the highly technical scans and tests required when planning for all epilepsy surgery.

In reviewing Jack’s case, Dr Bleasel describes how these investigations provided the information necessary to determine if surgery was possible.

“There were a number of neuroimaging studies that did show a very definite abnormality in the region that was eventually removed.

“The first very helpful scan was the PET scan in 2007 that showed a clear defect in the mesial aspect of the left frontal lobe.

“Jack came into hospital for video EEG monitoring on two occasions, one in 2007 and one in 2009. The video EEG studies confirmed that he was experiencing frontal lobe seizures.

“One of the most valuable tests during Jack’s assessment was the ictal SPECT scan. This involves injecting the patient with a radioisotope as soon as the seizure begins which then maps the area of increased blood flow.”

SPECT scans require careful planning to ensure that the isotope is ready for injecting as soon as a seizure occurs. For

Jack this meant having a nurse sitting at his bedside with the ready-mixed isotope ready to inject at the onset of a seizure. Sleep deprivation is a well known provocation for seizures and Jack was kept up at night so that he would sleep once the isotope was available in the morning. He had a seizure shortly after falling asleep and the nurse was able to immediately inject the radioisotope. The resulting scan again showed an abnormality in the left frontal lobe.

The next step was for the EEG technician to co-register the PET scan and the SPECT scans (functional neuroimaging studies) with the MRI scan (a structural neuroimaging study). With these studies and the EEG studies, which included an intracranial EEG evaluation (where electrodes are placed on the surface of the brain) the team was able to plan Jack’s surgery.

Yet surgery is not without risks and when asked about the risks associated with Jack’s surgery, Dr Bleasel said, “Perhaps the most likely problem would be that we would fail to cure his epilepsy. There is always about a 30 – 40% chance of this happening with the non-lesional extra temporal epilepsy cases. Other possible bad outcomes are

much less common, but it is possible to get an infection, a stroke, a hemorrhage or even to die with intracranial EEG evaluations. We would usually quote these complications as being less than 2 – 3%,” he said.

Understandably, Jack and his parents asked a lot of very important questions and Jack spent a lot of time considering whether to go ahead with the surgery. However once the decision was made, the relationship that Jack had developed with the team during his stays at the Epilepsy Unit in 2007 and 2009, gave him and his family the confidence to go ahead with the surgery in February 2010.

For Jack the cause of his seizures was indeed a malformation of cortical development as had been predicted by his referring neurologist.

Dr Bleasel explains, “The pathology showed a focal cortical dysplasia where neurones had not matured normally and were in abnormal spots within the microscopic architecture of the brain.”

Through the skills of the Dr Bleasel’s Westmead team and the neurosurgeon, Dr Mark Dexter, Jack’s surgery was successful and he is now looking forward to a future without seizures.

Our inspiring 'everyday' heroes

Once again Sydney put on a beautiful spring day for the annual City2Surf fun run. This year a record number of runners elected to support Epilepsy Australia and raised valuable funds to support our work. **Denise Chapman** speaks to two runners – **Kathy Wilson** and **Melanie Hipkiss** – on why they chose Epilepsy Australia as their charity of choice.

When **Kathy Wilson** from Newcastle crossed the finish line of this year's City2Surf, she was running not just for herself, but for her daughter Amy, who suffered brain damage arising from a car accident twenty years ago.

When asked how she felt when she crossed that finish line, Kathy reflected on the journey that got her there.

Head injuries caused by that car accident, left Amy with epilepsy and learning difficulties. While her seizures ceased around the age of six, they returned with the onset of puberty, and now challenge Amy on a daily basis.

For Kathy, her local gym provided her with the time out she needed over the years as she and husband Jim coped with the devastating realization that Amy was not going to recover fully from her injuries. Added to this was the tiring and demanding litigation process that has been part of their lives for the past twenty years.

Not daunted by Amy's disabilities, Kathy and Jim ensured that Amy acquired a mainstream education, attending school until year 12. Since leaving school Amy volunteers for Red Cross, helps out in the reading program at her local school, and more recently has begun attending art classes.

Amy also participated in the social programs run by Castle Personnel, a highly regarded disability services provider in the Hunter region of NSW. It was through this program that Amy began attending her local gym. Through her injuries Amy's right side was damaged resulting in limited use of her right arm and weakened right leg. Going to the gym is great therapy for Amy and it was here that she met Corey, a personal trainer, who offered to help her with her training. Not long after her

older sister Katie and her mum Kathy, joined them.

While not having any experience working with a person with a disability, Corey happily took on the challenge. Learning from each other, they have developed a shared understanding of managing exercise around Amy's seizure activity enabling her to strengthen her body while building her confidence in her ability to achieve goals, and enjoying the pure pleasure of physical activity.

It was Corey who also took Kathy from someone who, last December, couldn't run 'round the block' to considering running the 14 kilometre Sydney City2Surf fun run. Finally deciding in April Kathy, under Corey's guidance, began serious training for the event. It certainly paid off! Kathy at the age of 49, ran the event in an amazing time of 1.22.40, finishing 20,745 in a record field of 80,000 runners! Along the way Kathy has met some fantastic people only too willing to support her cause, raising \$800 for Epilepsy Australia.

While the past can't be changed, Kathy admits there are times that she travels down the 'what if' road, but as she says, 'that's a dead end. While the road we're on has its twists and turns, travelling down it has shaped our lives in so many positive ways that I know we're heading in the right direction. You never know what's around the next bend, but that can be exciting as well.'

"I never imagined that I would compete in the City2Surf, yet here I am already training for next year's event. The spin off has been a more active family, and a heightened interest in nutrition and exercise. I always believed in Amy's potential and to see her confidence grow as she achieves her goals encourages us all."



Kathy nearing the finish line.



Amy with constant companion Ms Maggie May.

You can be a hero for Epilepsy Australia by building your own personal fundraising page. It only takes a few minutes to build and email to all of your contacts and you're on your way!



To become an Everyday Hero for Epilepsy Australia just go to www.everydayhero.com.au

Running for Emily

For 27 year old **Melanie Hipkiss**, the desire to rise to the challenge and enter the City2Surf run was three-fold. Firstly to improve her own fitness, secondly to be part of something historic and tremendous in Sydney's history, and finally to raise money for a cause that has affected her family.

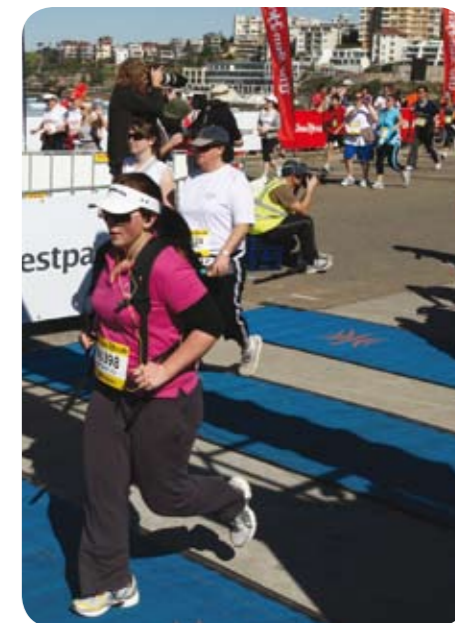
"Completing the race was very satisfying – not only was I rewarded with the picturesque panoramic postcard views of Sydney over the route", said Melanie, "I achieved my personal goals."

"Supporting Epilepsy Australia was one way I could show my young niece, Emily, how much I admired her. Emily's mum lives with epilepsy, and as such Emily has had to grow up very quickly. Emily has no siblings and lives with her mum. While both Emily and her mum always have the support of Emily's mum's parents and immediate family, Emily has still had to bear a heavy load on such small shoulders. I wish they both had more support and certainty in order

to deal with Gillian's epilepsy.

"I have witnessed seizures and the emotional stress on the person and those who suffer along side – and I can tell you it is not pleasant for a young child to witness their mother suffering in such a way. It is not only the emotional stress that Emily endures, but it has also resulted in time missed from school over several years, more chores than what an average child may have of the same age, and a responsibility to notice and act when her mother may be having an attack and look to prevent its severity by applying what first aid she can.

"Unbelievably but not surprisingly – Emily is one smart cookie! Having being named dux when in year 6 she continues to receive A+++ grades now that she is in secondary school. She is the most responsible, respectful, generous, thoughtful, smart young girl I have ever met and it is all thanks to her mother Gillian and her grandparents – John and Sophie, and her favourite Aunty and



Melanie crossing the finish line.

Uncle, Alison and John.

"Although only 13, my niece Emily is my inspiration and role model in order to run this race as she has had to triumph over adversity and still managed to come out on top."

Melanie completed the course in 3.24.40, raising in excess of \$300 for Epilepsy Australia.

Value your volunteers when they are with you ...

Last month we farewelled Margaret Marshall who had been with Epilepsy ACT for over 10 years. At 82 Margaret still kept the books in immaculate order. She had a strong work ethic and a strong commitment to volunteering.

Margaret was one of the silent ones, one of those true treasures who contributed her talents to charities in the community. Margaret had been both a treasurer and a rock to Epilepsy ACT, National Seniors and Canberra Seniors. She was always first to volunteer, always happy to do her share and more. She cut sandwiches, made cakes, sold Christmas Cards and was always on the look-out for further opportunities for all her "charities".

Margaret was never one to stand behind the door when a party was mentioned – indeed her password was

"Party Girl". She was always first in and loved a good time. Margaret spent her early childhood in Broken Hill where her father was a mining manager.

Margaret formed great friendships with those who helped us at Epilepsy ACT. Our auditor always had time for her and they did "coffee" and held meaningful conversations about the books. Our insurance broker visited on a regular basis and always brought a cake for Margaret. She was an astute business woman who always drove a hard bargain.

To the end Margaret was a true friend a professional who promised to get the books ready for the audit. She died two days prior and they were perfect.

We will miss the laughter, jokes and the professionalism that Margaret contributed.



MARGARET JOAN MARSHALL

6 September 2010

Much loved mother and mother-in-law of David and Chris. Cherished Gran of Nicole, Claire, Daniel, Becky and Douglas. Loved sister of Don and Marlene and their families.

Remembered with love.



Purple Day for Epilepsy –26 March

An International Day for Epilepsy Awareness

Epilepsy Australia - official Australian partner purpleday.org

Purple Day is a grassroots effort dedicated to increasing awareness about epilepsy worldwide. On Friday 26 March people from around the globe are asked to wear purple and spread the word about epilepsy.

Founded in 2008, by then 9 year-old Cassidy Megan from Nova Scotia, Purple Day has achieved international recognition through the internet, and in particular social networking sites including Facebook, YouTube and Twitter. Since Purple Day exploded around the world, children, businesses, organisations, politicians and celebrities have embraced Cassidy's simple message: wear purple and spread the word about epilepsy!

Why Purple Day

Cassidy started Purple Day because she wanted to tell everyone about epilepsy, especially that all seizures are not the same and that people with epilepsy are ordinary people just like everyone else. She also wanted kids with epilepsy to know that they are not alone.

Before starting Purple Day, Cassidy said "I was afraid to tell people about my epilepsy because I thought they would make fun of me. After the Epilepsy Association of Nova Scotia did a presentation in my class, I started to talk with the other kids about my seizures. That is when I decided to become a spokesperson for kids with epilepsy. I called it Purple Day after the international colour for epilepsy – lavender."

Since 2008 Purple Day celebrations across the world have included Niagra Falls turning purple after dark, as well as the lights on the CN Tower in Toronto. With support from the Anita Kaufmann Foundation in the US, a Purple Day USA launch party was held in New York along with a Purple Day fashion parade. In June this year, Cassidy was chosen to present flowers to Her Majesty, Queen Elizabeth II at the end of her official tour of Nova Scotia. This honour followed on

I wanted kids with epilepsy to know that they are not alone ...



© Michael Thompkins

Cassidy Megan

from Cassidy being awarded the 2009 inaugural Power of Positive Change Award from the Province of Nova Scotia.

www.purpleday.org.au

Epilepsy Australia and its state-based member organisations are the official Australian partners of Purple Day, joining up with other epilepsy organisations from across the globe including Canada, USA, UK and South Africa to make Purple Day even bigger.

In 2010, over 100,000 students, worldwide wore purple on 26 March with hundreds of workplaces and organisations (including Epilepsy Australia) joining the campaign, wearing purple to work and hosting Purple Day events and promotions.

Epilepsy Australia would like to thank all those who participated this year increasing awareness of epilepsy within their communities.

2011 promises to be an even bigger year. Epilepsy Australia will be widely promoting this event. Promotional materials and Purple Day merchandise will soon be available from:

- Epilepsy Australia
- Epilepsy Foundation of Victoria
- Epilepsy Queensland
- The Epilepsy Centre SA & NT
- Epilepsy ACT
- Epilepsy Tasmania

If you would like to register to participate in Purple Day 2011 in your state just call 1800 852 853.

Get involved It's easy!

- Wear purple on 26 March and encourage others to do the same.
- Hold a Purple Day awareness party or fundraising event on or before Purple Day.
- Become a Purple Day 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 Purple Day webpage. Each donation is recorded on your page along with any message of support from your donors. Please go to www.everydayhero.com.au
- Buy and/or sell Purple Day merchandise including purple pens and purple awareness ribbons and badges in the shape of an 'e' for epilepsy.
- Encourage your local community, schools and businesses to get involved by holding a free (purple) dress day in return for a gold coin donation.
- Donate your Facebook status by changing your status in March to read: "On March 26, I'm wearing PURPLE to support EPILEPSY AWARENESS. Help spread the word - just copy this message to your status!"
- Deck out your Twitter and Facebook accounts by adding a Purple Day Twibbon (support ribbon) to your social networking accounts. Sign up - it's free! Just go to <http://twibbon.com/join/Purple-Day-purpleday>



For more information visit www.purpleday.org.au

China's International Epilepsy Caring Day

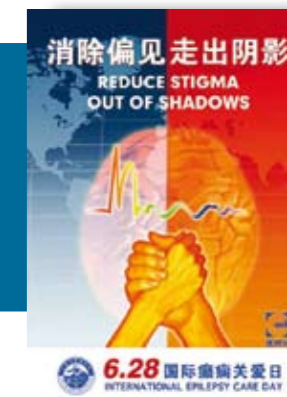
Dr Shichou Li, President, China Association Against Epilepsy (CAAE)

On June 28 2010, China celebrated its 4th International Epilepsy Caring Day (IECD).

Acknowledging the fact that people with epilepsy and their family members are vulnerable groups in society, especially in developing countries, suffer from discrimination, stigma and sometimes neglect, in 2007 the China Association Against Epilepsy (CAAE) established June 28 as International Epilepsy Caring Day.

Motivated by the need to create social awareness and care for people with epilepsy and their families, to protect and improve social welfare benefits for people with epilepsy, and to overcome prejudice and stigma people living with epilepsy experience in relation to education, employment, marriage and pregnancy, the CAAE with support from UCB Pharma has conducted awareness raising and epilepsy education activities in most of the provinces of China. These have included public education meetings on epilepsy awareness, voluntary diagnosis and treatment by senior epileptologists, multi-mass media publicity and visits to patients in hospital.

At the 7th AOEC in Xiamen, a lively discussion was held on whether the name of epilepsy in some Asian languages caused misconceptions and stigma and Dr Wang Wenzhi (China) and Anchor Hung (Hong Kong) provided information and insights into stigma research. This thought provoking session canvassed the possibility of changing the Chinese name for epilepsy which causes a negative view of the condition and of persons with epilepsy. Contributing to this discussion, renaming of the Chinese character for epilepsy is under investigation in China and as part of the IECD activities, new names were collected from people living with epilepsy for consideration.



Public education meetings held as part of International Epilepsy Caring Day activities were well attended

Hong Kong officially changes Chinese name for epilepsy

Following on from the meeting in Xiamen in 2008, representatives from Hong Kong including persons with epilepsy and health care professionals expressed their difficulties encountered due to misunderstanding and stigmatisation arising from the Chinese wording of epilepsy. It is because epilepsy is known as '癲癇' (*din1 gaan2*) with the word '癲' (*din1*) being associated with 'crazy' and 'insane' in the Chinese language, particularly used in Hong Kong. A special Task Force was set up under convenor Dr Shichou Li with representatives from countries that may use Chinese to investigate the possibility of changing the Chinese name for epilepsy.

Ms Anchor Hung, Manager for the Hong Kong Society for Rehabilitation and Hong Kong's representative on the Task Force reports that over the past two years they have worked hard on this issue, especially with China, for a name change.

"On the 27th June 2010, we have officially promulgated a new Chinese name for epilepsy as '腦癇'. The words '腦' (*nou5*) means 'brain' and '癇' (*gaan2*) means 'seizure' respectively. The name change has been adopted by the Hong Kong Government especially the Food and Health Bureau and the Hospital Authority," said Anchor.

"It has truly been a valuable experience showing how persons with epilepsy, health care professionals and the Government work together to tackle epilepsy and stigma."

Anchor went on to say that "The progress in Hong Kong is only part of the renaming movement. We will continue to pursue if a common name will be used in the future for all Chinese speaking regions with further discussion and effort. This start off in Hong Kong will be an important step."

It is estimated that more than 40,000 people live with epilepsy in Hong Kong.



Epilepsy in Vietnam Medical and Psychosocial Issues

Report by Shunglon Lai, Vice President
Western Pacific Region, IBE

a platform where health care workers taking care of people with epilepsy can exchange information and experiences with each other, as well as with other international organisations, in order to improve the quality of medical services for people with epilepsy.

It was based on this background that the Asian Epilepsy Academy (ASEPA) and the IBE Regional Committee Western Pacific formed a strategic plan to help in the creation of a new IBE Member in Vietnam and, to this end, meetings were arranged in Hanoi and Ho Chi Minh City, taking place from 27 to 29 November, 2009.

The main theme and objective of the meeting was: “Approach to Coping with the Medical and Psychological Issues of Epilepsy in Vietnam.” Sponsors for the meeting were

- Asian Epilepsy Academy
- ILAE Commission n Asian and Oceanian Affairs
- IBE Regional Committee Western Pacific

The goal of the initiative was to promote epilepsy care and the formation of support groups for persons with epilepsy in Vietnam. The objectives of the meeting were:

- To introduce the diagnostic aspect of medical care in epilepsy
- To identify the scope of psychosocial problems among persons with epilepsy
- To enhance the perception among physicians caring for people with epilepsy of the psychosocial problems involved
- To introduce the concept, model and implementation of support groups or self-help organisations
- To discuss the solution of coping with psychosocial care for persons with epilepsy in Vietnam

The population of Vietnam is about 86 million people. It is the 4th most densely populated country in the Western Pacific region, following China, Japan and the Philippines. The prevalence rate of epilepsy is between 4.4% (95% CI 3.8–5.0) and 5.5%; higher among males (5.1) than females (3.7).

In some areas, due to those who have developed epilepsy because of cysticercosis (an infection which results from the ingestion of the eggs of the pork tapeworm), the prevalence could be as high as 7.9%.

Due to the lack of accurate educational information on epilepsy, the awareness level of people about the condition is very low. Consequently, stigma towards people with epilepsy is still very high, which prevents them integrating into the community and causes many difficulties for the management of epilepsy.

The treatment gap remains very wide. According to the results of another epidemiological research project, which was conducted on a population number of 8,000 people in 2003, only 22% of people with epilepsy were treated, and most of those who did receive treatment were treated inappropriately. There are many reasons for such a low level of awareness in the population about epilepsy, including poverty, inability to access proper medical services, incorrect diagnosis or omission, etc.

The Vietnam chapter of the International League Against Epilepsy was formed in 2009, however there is not a support association addressing the social needs of people with epilepsy in Vietnam. Therefore they do not have

Organisation of the Workshop

Academic Program

- Professor Jing-Jane Tsai Associate Dean for the Faculty Development Affairs; Professor, Department of Neurology; Chief, Division of Epileptology. National Cheng Kung University, Medical College, Taiwan.

Administrative issues (venue, accommodation and promotion)

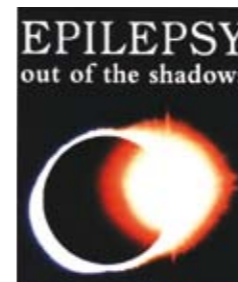
- Associate Professor Le Quang Cuong MD, Ph.D. Head of Department of Neurology, Hanoi Medical University, Vietnam
- Dr Luc Tran Viet

The meetings were held in Hanoi and Ho Chi Minh City with more than 100 doctors attending the workshop in each city. The main scientific topics discussed were diagnosis and psychosocial issues, while the social issues were experience of China and other IBE Members in the Western Pacific region.

It was concluded that the future direction for the care of people with epilepsy in Vietnam was as follows:

- Promote education and increase awareness of epilepsy
- Organise retraining courses for doctors to reinforce the basic knowledge of epilepsy in order to improve quality of treatment.
- Develop the etiology diagnosis of epilepsy, especially of genetic disorders.
- Undertake research and apply other therapies, such as surgery therapy, ketogenic diet, vagus nerve stimulation, in addition to pharmaceutical therapy for the treatment of epilepsy.
- Organise an IBE member association to promote comprehensive care for

IBE News Issue 1, 2010
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Global Campaign Against Epilepsy – European Report

The aim of the ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE) is to assist governments worldwide to ensure that the diagnosis, treatment, prevention and social acceptability of epilepsy are improved. The strategy has two parallel tracks: raising general awareness and understanding of epilepsy; and supporting national Ministries of Health to identify the needs and to promote education, research, training, prevention, treatment and care services.

Activities of the GCAE included the gathering of epilepsy data from the regions in the form of regional reports to inform policy-makers.

It has taken six years for reports from the six regions to be finalised, with the two final reports for the Eastern Mediterranean region and the European region completing the global picture in 2010.

Launching the European Report at the recent Epilepsy & Society Congress in Porto, Dr Matt Muijen, Regional Advisor for Mental Health and Brain Disorders of the World Health Organization in the WHO European Region, said “We believe that the recommendations will help countries to develop activities to combat stigma, restore dignity and reduce the treatment gap for people with epilepsy in Europe. This Report is an advocacy tool and an instrument for dialogue with governments, healthcare providers, consumer associations, non-governmental organisations, academic institutions and development partners.”

Dr Muijen noted how ‘supply and demand’ in epilepsy treatment – access to drugs, staff, quality of staff and services – varied across Europe. He cited the key factors for such variations as idiopathy, comorbidities, risk groups, cultures, stigma and varying social determinants across Europe.

In examining the effect of stigma on mental health generally, he drew on the following statistics: 44% of people with mental health problems had experienced discrimination from GPs; 32% from other health services; 47% in the workplace; 37% in looking for work; 56% in the family; 51% from friends; and 40% from personal relationships. This stigma has consequences for well-being because it affects employment, education, family status, and relative income.

He drew attention to the fact that in his role as WHO advisor, epilepsy is never raised in discussion with Ministers of Health because it was too small and too specialist. This ‘lack of priority’ carries with it a ‘lack of power and influence’. He emphasised that because of this it was important the IBE partner with other mental health and disability organisations to get its messages across. Collaboration, ‘power in numbers’, would improve services for all these people, including people with epilepsy.

Yet the treatment gap in Europe is as concerning as it is in other parts of the world. Epilepsy affects more than six million people in Europe but up to 40% of people with the condition may still be untreated.

“Epilepsy is a highly treatable condition but the existing gaps in epilepsy care and the level of stigmatisation faced by people with epilepsy are simply unacceptable,” said Hanneke M. de Boer, Coordinator of the Global Campaign Against Epilepsy.



Dr Matt Muijen, WHO, (third from left) with delegates after the launch of the European Report in Porto.

In addressing the meeting Hanneke went on to say, “When it comes to epilepsy every country is a developing country. Developed countries in the European Union still have a long way to go to improve the conditions of people with epilepsy.”

IBE President, Mike Glynn captured everyone’s attention with his words “Epilepsy: today the killer, tomorrow the cure”, shining a light on the vexing issue of epilepsy-related death.

“Mortality rates among people with epilepsy are two to three times higher than in the general population,” said Mike.

“An estimated 40% of all epilepsy-related deaths are as a result of a phenomenon called Sudden Unexpected Death in Epilepsy (SUDEP), yet the mechanism behind SUDEP remains unknown and awareness of risk factors is very low. Research into this and other aspects of epilepsy is vital in order to improve our understanding and ultimately improve patient care”.

The new Global Campaign Against Epilepsy website was also announced at this meeting. The history of the GCAE can be found here, along with the latest news, updates on the Demonstration Projects, and Regional Activities. The European Report can also be found here.

www.globalcampaignagainstepilepsy.org



A national longitudinal survey on epilepsy is underway

Dr Jaya Pinikahana, Longitudinal Survey Coordinator

Australia's first longitudinal study of epilepsy looking at needs, perceptions and experiences of people living with epilepsy is underway with the generous support of the Epilepsy Foundation of Victoria. This project has been made possible through the innovative direction undertaken by the Epilepsy Foundation in 2006 in establishing a psychosocial research program aimed at providing an evidence base to argue for improved policies and services at the government and community levels.

The longitudinal project aims to help us better understand the impact of living with epilepsy and is a unique opportunity to collect crucial information with regard to issues like stigma, education, employment, social support, quality of life, mental health status, physical health cost and treatments. This longitudinal study is expected to continue for at least 10 years, on an annual basis, to establish the changing pattern of the true impact of living with epilepsy. The project has received human research ethics approval from Deakin University in Victoria.

What has been done?

The Epilepsy Foundation of Victoria established a *Research Participant Register (RPR)* in 2006 with the aim of gathering valuable information on living with epilepsy. This register invites people with epilepsy and their carers who are interested in participating in psychosocial research, to register their names on a separate and confidential database.

This is an exciting development and it is important to realise that the register is a first for Australians with epilepsy.

The register now numbers more than 700 people after less than four years. We are pleased with this take-up rate and expect the register to grow steadily over the next few years. The registry has the support of all agencies around Australia who are now promoting recruitment.

About the survey

The longitudinal survey instrument was constructed by combining a number of different elements of the existing literature to be a comprehensive assessment tool for long term use. Following ethics approval 702 people who registered were sent a package, in February 2010, containing an introductory letter, newsletter, plain language statement, the survey and a reply paid envelope. In April and June, two reminder letters were sent to those who were yet to respond, with further encouragement to join the survey online.

Of the 702 people initially contacted, 37 were not able to be contacted because they had left the address, six were deceased, 27 asked to be removed from the register and 11 people declined participation in the current study. Of the remaining 621 people who received the survey, 346 responded, giving us 55.7% response rate. Out of these 346 people, 246 (71.1%) were people with epilepsy and the rest were those who completed the questionnaire on behalf of a person with epilepsy, or were carers or family members. Data entry and analysis is being carried out and it is expected that a final report will be produced before the end of the year.

Use of the research

With the information gathered from the study, we will be better armed

to assist service providers to make decisions about education, support and health care for people living with epilepsy. We also hope it will help to raise awareness of the challenges people with epilepsy face. The great advantage of launching this longitudinal study is that it becomes possible to research what happens in the lives of people with epilepsy over time. This provides us with valuable data about the impact of epilepsy on a person's life as they grow and mature and their life circumstances change.

In the meantime, we have developed a new webpage detailing our research initiatives with a specific link to our longitudinal study.

The page can be found at:

http://www.epinet.org.au/articles/social_research_projects/the_longitudinal_survey

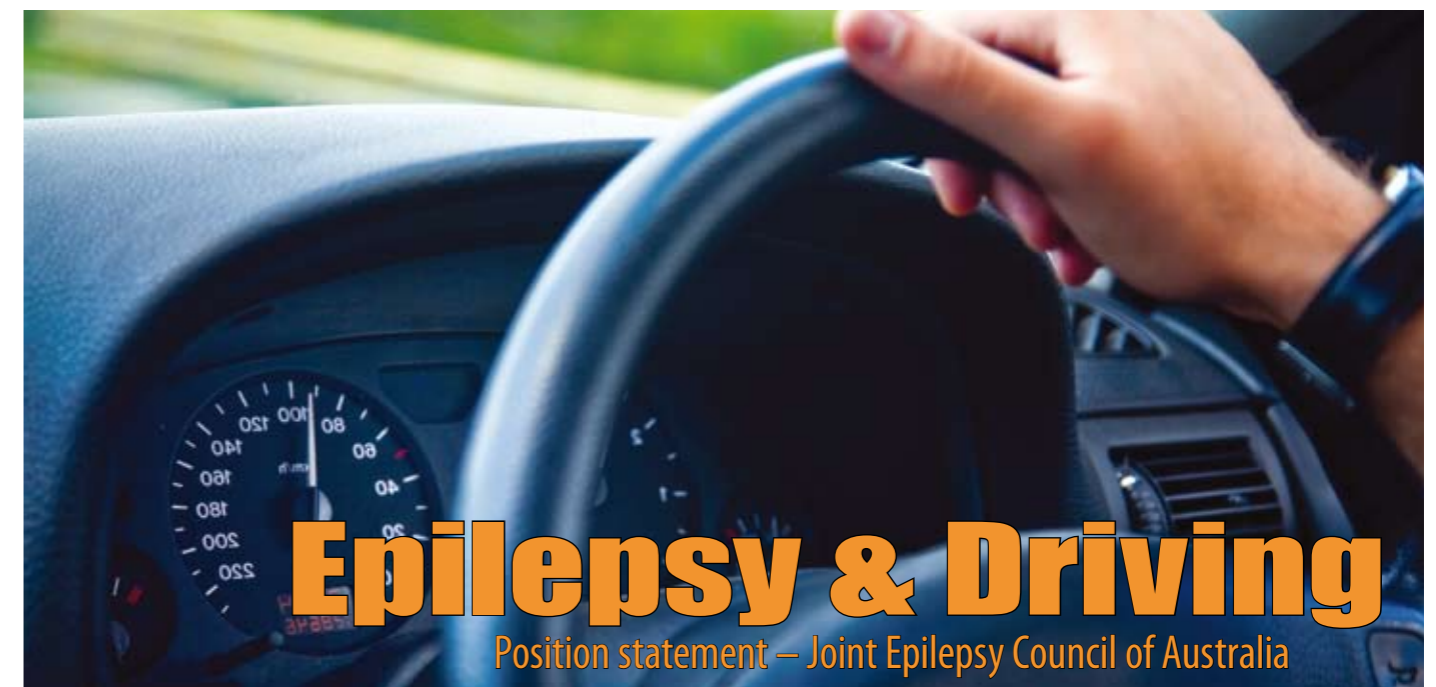
Participation

Participation in the Epilepsy Foundation of Victoria's Research Participants Register does not obligate people in any way.

To join the register online, go to

http://www.epinet.org.au/articles/social_research_projects/

Or contact the coordinator on 03 9805 9125 for a RPR form to be sent to you. Please help us make a difference by joining the research register.



Epilepsy and driving is a serious and sensitive community issue. Epilepsy affects 1–2% of the population and those with well-controlled epilepsy are legally able to drive.

The Joint Epilepsy Council of Australia acknowledges that for many adults, the sudden loss or suspension of a driving licence for a significant period of time can adversely affect employment, education, and social participation. Driving restrictions impact on quality of life and independence.

The challenge for the Australian Transport Council was to develop driving regulations and guidelines that balance the interests of public health and safety, and the promotion of optimal quality of life for people living with epilepsy.

It is well understood that driving carries the risk of accident. The level of risk tolerated by the community is reflected in our regulations and legislation, and population variables.

In comparison, the relative accident risk of drivers with epilepsy compared with other drivers is estimated to be between 1.0 and 1.95, (far below the accident rate of young males), while the contribution of seizures to accident statistics is only 0.025–0.053%.¹

For example, risks that the community finds acceptable or unavoidable are:

- a) driving within the legal alcohol limit of .05 – an accepted increased accident rate of 2.0;
- b) young males under 25 – an unavoidable increased accident rate of 7.0;

c) drivers 75 years and over – an unavoidable increased accident rate of 3.2.²

Based on these statistics, Austroads and the National Transport Commission, with the contribution of the Epilepsy Society of Australia, developed management guidelines and medical standards for licensing drivers with epilepsy. The Joint Epilepsy Council of Australia supports these guidelines and their consistent application across all jurisdictions.

The Joint Epilepsy Council of Australia supports the position taken by the Epilepsy Society of Australia, that:

- determining fitness to drive and the subsequent granting of a driver licence lies ultimately with the Driver Licensing Authority (DLA);
- that decisions are based on a full consideration of relevant factors relating to health and driving performance, including medical reports provided by a treating practitioner; and
- such a system should be supported by a review process consisting of an expert panel of neurologists indemnified by the driver licensing authority.³

The Joint Epilepsy Council of Australia acknowledges that drivers with epilepsy who are assessed fit to drive are personally accountable for management of their condition in conjunction with support of their medical practitioner.

It is a legal requirement in all Australian states and territories for the driver to notify the DLA of the onset of epilepsy or recurrence of seizures.

The Joint Epilepsy Council of Australia is firmly opposed to mandatory reporting to the DLA by the treating doctor as it will encourage non-reporting of seizures to the treating doctor. The withholding of information interferes with treatment and has the potential for possible fatal consequences. Mandatory reporting breaches doctor-patient confidentiality, has the potential to erode the doctor-patient relationship, and serves neither patient nor public safety.

The Joint Epilepsy Council of Australia advocates self-reporting with the individual taking responsibility for the condition and the limitations it presents. Consequences, for example, may be the inability to get to work, loss of employment resulting in financial hardship, or difficulties in meeting family commitments. The Joint Epilepsy Council of Australia strongly advocates for government transport assistance to support the person with epilepsy during the suspension period until driving rights are restored.

References

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2. Epilepsy and Driving in Europe. A report of the Second European Working Group on Epilepsy and Driving, an advisory board to the Driving Licence Committee of the European Union. 2005
3. Somerville ER, Black AB, Dunne JW. Driving to distraction – certification of fitness to drive with epilepsy. MJA 2010; 192: 342–344

New AED joins Pharmaceutical Benefits Scheme

Lacosamide (Vimpat®) is the latest antiepileptic drug to be added to the Pharmaceutical Benefits Scheme (PBS).

Approved by the Therapeutic Goods Administration (TGA) in 2009, lacosamide tablets are indicated as add-on therapy, in the treatment of partial seizures with or without secondary generalisation in patients with epilepsy aged 16 years and older.

For those Australians who had not responded to other medicines, access to lacosamide tablets is now available under the PBS.

In announcing the subsidy, Health Minister Nicola Roxon said, "Lacosamide tablets (Vimpat®), provide an additional option in the management of epilepsy when the condition is not adequately controlled by other medications.

"Subsidised access to lacosamide tablets will be initiated by a neurologist for patients who have not responded to other therapies, as an authority-required benefit."

The cost of subsidising lacosamide through the PBS would amount to about \$16 million dollars over the next 5 years.

Improved support for carers

Are you caring for a child under 16 with a severe disability or severe medical condition?

Changes have been made for qualification for Carer Payment. From 1 July 2009, the assessment process changed from a narrow medical model to one that recognises the total care load of people caring for children with severe disability or severe medical condition.

Other changes include:

- more circumstances in which carers may qualify for Carer Payment:
 - one child with severe disability or severe medical condition
 - two or more children with disability or medical condition
 - an adult and one or more children with disability or medical condition
- access to Carer Payment for short term or episodic care for periods of at least three months but less than six months
- more sensitive and generous arrangements for carers of children in hospital
- automatic qualification for Carer Allowance based on qualification for Carer Payment
- provision for a wider range of treating health professionals to complete medical forms.

Need further information? visit the payment page on Centrelink's website www.centrelink.gov.au; telephone Centrelink on 13 27 17 or visit your nearest Centrelink office.

Single Assessment Process

Qualification for Carer Allowance (child) from 1 July 2010 will now be 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 from Carer Allowance (Child) 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.

Extending the list for treating health professionals

From 1 July 2010, speech pathologists are included on the list of treating health professional who can complete the medical assessment for children.



Australian Pregnancy Register

This voluntary, nationwide study that is enrolling women who are currently pregnant or who have given birth recently (infants up to 6-9 months of age) in the following categories:

- Women with epilepsy taking antiepileptic medication (AEDs).
- Women with epilepsy not taking AEDs.
- Women taking AEDs for allied conditions.

From previous research it is believed that women who are taking an AED may have a slightly higher incidence (4-6%) of having babies with birth defects than the general population (2-3%).

After ten years of data collection and analysis, there is now some evidence available to determine whether this small increase is related directly to the drugs, the epilepsy itself, or other factors.

Breast feeding information

Of 1114 women analysed so far it has shown that 857 did successfully breast feed their babies and 257 women didn't breast feed.

Of those that didn't feed, 145 chose not due to the medication and the remaining 112 chose not to for other reasons relating to breast feeding (anatomical reasons, poor supply etc.)

To participate in this study call
1800 069 722



For more information about the Australian Pregnancy Register visit www.apr.org.au



Workplace rights

One of the biggest legal issues for people with epilepsy who are in the workforce is whether they have a right to reduce their hours of work or take time off work. **Josh Mennen** from Maurice Blackburn Lawyers discusses your rights at work.

Seizures may affect people with epilepsy in the workplace. Many have great difficulty maintaining full-time work and would benefit by a reduction in working hours or taking some time off work.

The transition may be relatively smooth with the cooperation of treating doctors and a supportive employer. However, this is not always the case.

Some employers are unable or unwilling to accommodate people with epilepsy with requests to reduce their work hours or take time off, sometimes with the result that workers have to leave their jobs.

The question that is often asked is whether employers can be forced to agree to workers reducing their hours or taking time off because of epilepsy.

Until recently, the answer was probably 'no'. However, several Court decisions and some recent changes in the law mean that workers with disabilities may be able to reduce their work hours or take time off.

Generally speaking, under anti-discrimination laws it is unlawful for an employer to discriminate against an employee because of a disability. It is also unlawful for an employer to indirectly discriminate against a person with a disability by having in place a policy or practice that affects a person with a disability more than other workers. However, employers will usually be excused if their conduct was reasonable.

In the past few years some Court cases have accepted that it may be unlawful

sex discrimination for employers not to allow women to return to work part-time from maternity leave. For the same reasons, it may be unlawful disability discrimination to refuse reasonable requests from people with epilepsy to work part-time.

The most important changes have been the introduction of the Fair Work Act 2009 and the amendments to the Disability Discrimination Act in 2009 which make it unlawful for an employer to take detrimental action against an employee because of a disability and legally requiring employers to make reasonable adjustments to accommodate people with disabilities.

Accordingly, if you want to reduce your hours of work because of your epilepsy or even if you need to take some time off work, in most cases your employer will have to take reasonable steps to accommodate you.

If they don't, you may have a claim for compensation or perhaps for an order to force your employer to offer you appropriate work.

If you are considering ceasing work or reducing your work hours, speak to your doctor, get a certificate and then approach your employer to try to negotiate.

Warning

However, before you take any steps to alter your work, it is important to

consider whether going part-time or stopping work will have any affect on your superannuation and insurance rights.

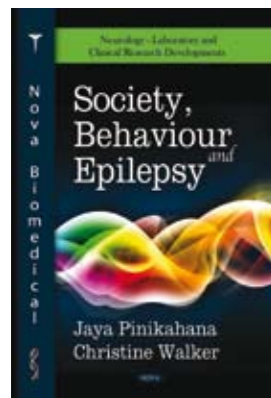
Most workers are covered for lump sum disability benefits (called TPD) in their employment superannuation and many also have income protection insurance (called TTD). Sometimes those benefits can be reduced or even lost if you reduce your work below a minimum number of hours a week or stop work altogether for a period of time.

If you have to stop work because of your epilepsy or any other health problems, you may be eligible for a TPD lump sum or income protection monthly payments which can 'top-up' your superannuation to give you a retirement benefit. You might also be able to continue with your insurance cover, even if you start another job and get new superannuation disability cover.

It's really important that you protect your workplace rights and your superannuation and insurance rights, so get advice before you decide to go part-time or stop work altogether.

Help

Maurice Blackburn Lawyers has set up a disability help line (toll free 1800 196 050) which is a free service for people with epilepsy, their families and friends to find out what their rights and entitlements are.



SOCIETY, BEHAVIOUR and EPILEPSY

eds. Jaya Pinikahana & Christine Walker

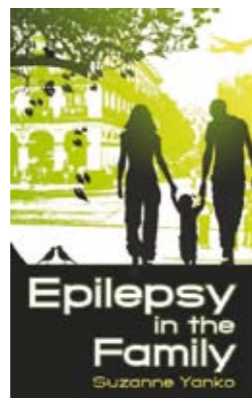
Nova Science Publishers (NY)

Although clinical, neurological, biological, psychiatric and even therapeutic aspects of epilepsy have been fairly consistently reviewed, relatively little is known about the psychosocial aspects of this condition, the consequences of which are, arguably, often more severe than the epilepsy itself.

Studies show that the rates of social exclusion, fear, anxiety, stress, suicide, unemployment and homelessness among people with epilepsy are higher than the general population. Although there are no viable eclectic theories of bio-psychosocial aspects of epilepsy, there are several current psychological and sociological perspectives of this disorder. This book fills a gap in the literature on the psychosocial context of epilepsy.

Seventeen international authors, including some world authorities on the psychosocial aspects of epilepsy, such as Gus Baker, Coleen Dilorio, Penny Rhodes, Lisa Andermann, Malachy Bishop and Ramon Bautista have contributed to this volume.

Topics covered include: the lived experience of seizures; social consequences of epilepsy; the treatment gap in epilepsy; sociology and epilepsy; mind-body medicalisation; and psychosocial adjustment in children with epilepsy and their families, among others. This book is due for release by the end of the year. For more information please contact Dr Jaya Pinikahana at jpinikahana@epilepsy.asn.au



EPILEPSY in the FAMILY

Suzanne Yanko

www.bookpal.com.au

RRP: \$33.50

e-book available from author

'This marvellous book intertwines the author's personal story of epilepsy, and that of other sufferers, with practical and up-to-date information on the evolving knowledge of epilepsy, how it can be treated and above all how to live a normal life with it ...

– Samuel F Berkovic AM, MD, FAA, FRACP, FRS

And so begins the preface of this new book, *Epilepsy in the Family*, by Suzanne Yanko. Writing from her own experience with epilepsy, and of epilepsy in her family, the book covers many aspects of epilepsy from diagnosis to living with this condition. Interspersed with the factual and the practical are personal accounts of the real experience of living with epilepsy. It is these personal insights that engages the reader and helps in understanding just how complex epilepsy can be.

Suzanne's personal triumph over epilepsy through surgery carries with it a profound sadness in losing her son Daniel to epilepsy. As she says in the book's foreword, "My own family has experienced the very best and the very worst than can happen for people with epilepsy."

This book carries with it a message of hope. The future holds exciting developments in the treatment of epilepsy and with the knowledge and support of the medical and community agencies – as Suzanne says, "You are not alone."

Novel involving epilepsy wins Pulitzer Prize for fiction

father's seizures, and the chemical electricity that surrounded him before each sudden violent seizure, is beautifully written. Indeed, throughout the book, the language used by Harding is the real star of the narrative. Published in January 2009, the novel has received rave reviews.

Bellevue Literary Press is a small US publisher connected to the School of Medicine of NYU.

Harding, formerly the drummer for rock band Cold Water Flat, now teaches creative writing at Harvard. Having previously published short stories, this is his first novel.



TINKERS

Paul Harding

Bellevue Literary Press (US)

ISBN 978-1-934137-12-3

Author Paul Harding has won the Pulitzer Prize for fiction 2010 with his debut novel *Tinkers* which has

been described by critics as 'a powerful celebration of life'.

George Washington Crosby, the main character of the book, is a grandfather who, lying on his deathbed and surrounded by family, looks back on his life.

Central to his reminiscing are memories of his father Howard, who had epilepsy. Harding's description of the

Mike Glynn is the current President of the International Bureau for Epilepsy (IBE). As CEO of Brainwave, the Irish Epilepsy Association, Mike's involvement with the international epilepsy movement spans sixteen years. A keen rugby union man and father of three sons, Mike reflects on his involvement with IBE, and the challenges and highlights of his first year in office.

We welcome Mike to Melbourne for the 8th Asian & Oceanian Epilepsy Congress.



I first became involved with Brainwave when I came in to help out as a financial advisor at a time when I was self employed. Coming from a banking / financial services background, the intention had been that I should just stay for a short while, write a report and make suggestions that would straighten things out and then move on. These situations are never as straight forward as one hopes and I stayed for several months. Then, Dublin was awarded the 22nd International Epilepsy Congress when problems arose over Florence's candidacy. With very little time available to organise the 22nd IEC, Brainwave and the Irish Epilepsy League (ILAE chapter) needed Richard Holmes, then CEO of Brainwave, to work full time on the congress. I was appointed to deputise for him for this period.

Sixteen years on this November, Richard continues to organise congresses for the ILAE/IBE and I am still here and much happier here than anywhere else even if the financial rewards are not quite the same in the voluntary sector!

My reasons for staying on with Brainwave were determined in no small part by the fact that my mother has had epilepsy, developed during childbirth, for many years. She continues to have nocturnal seizures but resists all efforts to convince her to attend an epilepsy specialist and have her treatment reviewed. As far as she is concerned, she is dealing with it in her way and myself and my siblings have to accept this.

I have been involved with the International Bureau for Epilepsy (IBE) for most of the sixteen years that I have been in the epilepsy movement.

When I joined, Richard Holmes was Treasurer of IBE and I was appointed as Finance Manager of IBE. This was considered a "staff" position and Brainwave was paid a small amount by IBE for my services. During this time though I was also active as a volunteer in IBE, first as a member of the IBE Regions Commission which was tasked with developing a regional structure for IBE. When the Regional Committee for Europe was founded, I was elected as vice-chair and was always regretful that I never became chair. This was because I then was elected as Treasurer for the period 2005–2009. I remain immensely proud of the fact that IBE is now a very solid financial citizen when compared to the very fragile state of its finances when I was first involved.

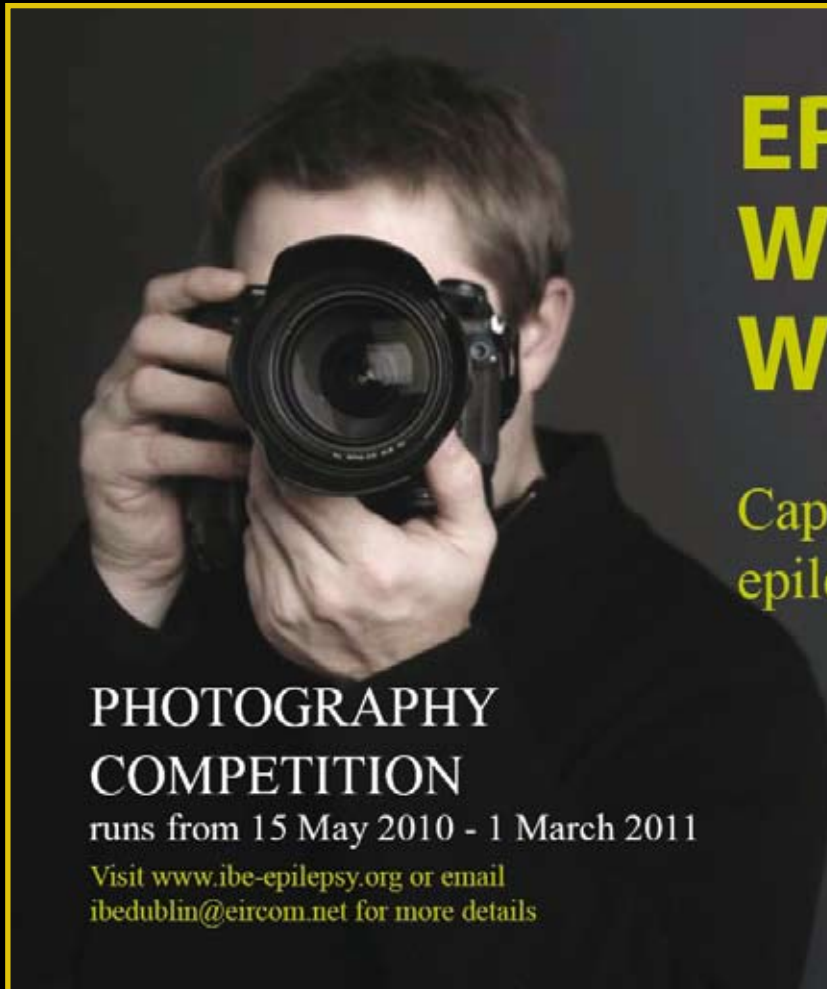
The role of the President of IBE has always been to act as a sort of executive company chairperson to the international epilepsy charity, and represents a balancing act between the day job, reduced family time due to travel commitments and trying to achieve as much as possible in the four years term.

I must admit that when I put my name forward for the IBE Presidency, I thought that I would be able to divest myself of much of the work associated with my Brainwave role with my colleagues, spreading it amongst them. However, the recession has hit harder in Ireland than most countries and Brainwave's funding, both public and statutory, has taken a battering and I have had to spend much more time on local matters than I anticipated. This

has meant that I have become very frustrated in terms of my hopes for IBE. Combined with this, there have been some real messy problems for IBE mainly caused by people with no mandate from anyone who believe they know better than anybody elected to IBE Regional or International Executive committees by the membership all around the world.

However putting that aside, the highlight of my first year has been the launch of the Chinese report of the Global Campaign against Epilepsy (GCAE) in Beijing last November. I thought I had a better idea than most of what the GCAE had achieved in China but it was only when I was there and heard about the activities on the ground, saw how many people were helped in this vast country and saw the presence of so many top Government ministers and WHO dignitaries attend, did I realize what has been done. I believe the situation in Brazil is similarly successful and these two vast countries represent a huge swathe of the developing world. During the year too, Nico Moshie, President ILAE, and I put in train the setting up of a new Global Campaign Taskforce and this is now almost ready to begin its work.

As the second year of my term commences, I am more determined than ever to achieve the goals I have set myself to improve the lives of people with epilepsy everywhere over the remainder of my presidency.



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