Epilepsy Australia congratulates

Dr Kim Powell

Inaugural recipient of the Cameron O’Brien Memorial Grant

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World Health Assembly passes Epilepsy Resolution

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

In this edition we celebrate a landmark decision by the World Health Assembly to pass the WHO resolution on the Global Burden of Epilepsy and “calling for Member States to strengthen their ongoing efforts in providing care for people with epilepsy”.

While here in Australia affordable treatment for epilepsy exists, up to 90% of people with the condition may not be properly diagnosed or treated in resource-poor settings. This resolution highlights the need for governments to formulate, strengthen and implement national policies and legislation to promote and protect the rights of people with epilepsy. It also stresses the need to reinforce health information and surveillance systems to get a clearer picture of the burden of disease and to measure progress in improving access to care.

The resolution calls on the WHO Secretariat to continue to lead and coordinate support to Member States in addressing the global burden of epilepsy so that people with epilepsy can receive timely treatment and can benefit from educational and occupational opportunities, free from stigma and discrimination.

Epilepsy Australia applauds Australia’s support of the resolution with the Australian delegation, under the leadership of Mr Martin Bowles, co-sponsoring the resolution at the General Assembly after speaking to it at Executive Meeting in January.

We also celebrate the international recognition of our new Ambassadors for Epilepsy. Personally, I am extremely humbled by this award as working on behalf of the international epilepsy community and getting to know so many inspiring people living with epilepsy has been reward enough.

I hope you enjoy reading this edition of *The Epilepsy Report*. 
Epilepsy Australia’s Executive Officer, Denise Chapman and highly respected epileptologist Professor Frank Vajda have been awarded the IBE/ILAE Ambassador for Epilepsy Award recognising their contribution to the epilepsy cause, internationally. They will be presented with their Ambassador for Epilepsy pin, along with 10 other winners, at the opening ceremony of the 31st International Epilepsy Congress to be held in Istanbul in September.

The Ambassador for Epilepsy Award is given biennially to a maximum of 12 individuals to recognise contributions to activities that advance the cause of epilepsy either at an international level or that have an international impact or significance and is given for the lifetime of the recipient.

Introduced by then IBE President Mrs Ellen Grass, in 1968, the Ambassador for Epilepsy Award celebrates 46 years of existence when they are presented in Istanbul. Now a joint IBE/ILAE award, to date 301 worthy recipients have been presented with the prestigious Ambassador pin.

Epilepsy Australia congratulates Prof Vajda and our Executive Officer Denise Chapman in joining a very elite group of Australians who have received this award over the past 46 years including Prof Ingrid Scheffer, Dr Rosey Panelli, Prof Sam Berkovic, Dr Peter Bladin, Dr Ernest Somerville, Mr Robert Gourley, Hon Mrs Ruby Hutchinson, and Mr Frank Burroughs.

The award acknowledges Denise’s involvement in the epilepsy fraternity for more than 21 years. As the current Chair of the IBE Western Pacific Region she has gained many friends and colleagues through her dedication in this role. She has helped countless people living with epilepsy and has a special interest in SUDEP, on which she has co-published. She has been involved in organising several successful Epilepsy & Society programmes held during the Asian & Oceanian congress, and in revitalising the Outstanding Person with Epilepsy Awards presented at regional congresses.

Born in Budapest, Prof Vajda emigrated to Australia, where he became a neurologist and epileptologist with a special interest in neuropharmacology. He is a leading figure in the clinical pharmacology of epilepsy. He contributed hugely to the development of epileptology globally and students include Sam Berkovic, Mark Cook and Terence O’Brien. His contribution to the literature on the clinical pharmacology of AEDs spans over 5 decades.

Prof Vajda has long been a supporter of Epilepsy Australia and is a contributing editor to The Epilepsy Report. Read more about the IBE/ILAE Awards at www.ibe-epilepsy.org

Members of EFNA include:
- European Multiple Sclerosis Platform
- European Headache Alliance
- Motor Neurone Disease Association
- Stroke Alliance Europe as well as associations representing rare neurological disorders.

In line with IBE’s own mission, EFNA aims to encourage the implementation of the necessary resource priorities in order to reduce stigma and improve the quality of lives of people with a neurological disorder.

Ann’s appointment recognizes the high esteem in which she is held by the EFNA.
Tuesday 26 May, 2015, will be remembered as a historical date for all those working to improve the quality of life of people with epilepsy and those who care for them. On that date, the World Health Assembly approved the WHO Resolution on the Global Burden of Epilepsy, which calls for UN Member States to:

1. strengthen effective leadership and governance to address the specific needs of people with epilepsy, and make resources available as necessary to implement evidence-based plans and actions;
2. introduce and implement national health care plans of action for epilepsy management, aiming to overcome inequalities and inequities in health, social and other related services;
3. integrate epilepsy management into primary health care where appropriate to reduce the treatment gap, by training non-specialist health care providers and by empowering people with epilepsy and their carers for greater use of specified self and home care programmes;
4. improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines;
5. ensure public awareness of and education about epilepsy, in particular in primary and secondary schools, to help to reduce the misconceptions, stigmatization and discrimination regarding people with epilepsy and their families;
6. promote actions to prevent causes of epilepsy, using evidence-based interventions;
7. improve investment in epilepsy research and increase research capacity;
8. engage with civil society and other partners in these actions.

How the resolution developed
Approval of the Resolution represents a major success for IBE, ILAE and their long-standing partnership with WHO. For some time, IBE, ILAE and their members have been working tirelessly to sensitize national governments about the need to set up a coordinated effort against epilepsy.

Responding to these calls, the People’s Republic of China took the lead in late 2014 by drafting a Resolution calling for a global action to be implemented under the umbrella of WHO and in partnership with ILAE and IBE.

The draft received early co-sponsorship by the Russian Federation, and many other countries soon joined in expressing their support.

In February 2015, the 136th Executive Board meeting of WHO voted unanimously to recommend that the Resolution be approved by the 68th World Health Assembly. The level of support that the Resolution received at the World Health Assembly was overwhelming.

Between the meeting of the Executive Board and at the World Health Assembly, a total of 43 countries made strong statements in favour of the Resolution and expressed commitment to step up actions against epilepsy. Remarkably, 19 countries requested to be named as co-sponsors of the Resolution. Further supportive statements were made by WHO itself and by civil organizations accredited with WHO, including, in addition to IBE and ILAE, the World Federation of Neurology and Health Action International.

Ensuring implementation of the Resolution?
The resolution provides a powerful tool to engage national governments into implementing effective actions to improve medical and social services for people with epilepsy, promote public awareness about epilepsy and allocate resources to epilepsy research. The Joint ILAE-IBE Global Outreach Task Force has already started drafting a
set of recommendations to assist all stakeholders, including IBE Members and ILAE Chapters, in ensuring that the Resolution translates into effective actions. Other planned activities include the organisation of meetings and workshops to facilitate the involvement of stakeholders, including policy makers, and the engagement of national and international institutions in order to achieve the goals of the Resolution.

All these activities will be conducted in close partnership with WHO.

Importantly, the Resolution calls for the WHO Director General to identify the relevant best practices to address the burden of epilepsy and to develop, in consultation with relevant stakeholders, a set of technical recommendations guiding Member States in the development and implementation of epilepsy programmes and services. The Resolution also requests WHO to provide technical support to Member States in actions for epilepsy management, especially in low and middle-income countries.

These are great times for all those who work towards ensuring better lives for people with epilepsy. The Resolution is just the beginning – it now our duty to exploit this unprecedented opportunity to its utmost potential. By working together, there are no limits to what we can achieve!

**Countries statements in support of the Resolution**

1. Albania
2. Argentina
3. Australia
4. Azerbaijan
5. Bahrain
6. Benin (on behalf of 47 Members of AFRO region)
7. Brazil
8. Canada
9. Czech Republic
10. Democratic Republic of Congo
11. Egypt
12. Georgia
13. Ghana
14. Greece
15. India
16. Islamic Republic of Iran
17. Iraq (on behalf of 21 Members of EMRO region)
18. Indonesia
19. Italy
20. Japan
21. Lebanon
22. Lithuania
23. Malaysia
24. Maldives
25. Malta
26. Nepal
27. Panama
28. Poland
29. People’s Republic of China
30. Republic of Korea
31. Romania
32. Russian Federation
33. Saudi Arabia
34. Suriname
35. Swaziland
36. Taiwan China
37. Tanzania
38. Thailand
39. Timor-Leste
40. United Kingdom
41. United States of America
42. Uruguay
43. Venezuela
Thirty riders participated in our 700 for SUDEP weekend ride this year, held in Jindabyne on the weekend of 21-22 March 2015.

Our riders elected which course they wished to take on the first day of riding, with two classic (albeit exceptionally tough) options:

A: 100km ride from Jindabyne, climbing up to the picturesque Charlotte Pass and back down to Jindabyne via Crackenback

B: 115km ride from Jindabyne, to the border of New South Wales and Victoria, and an unrelenting climb from Tom Groggin up Dead Horse Gap to Thredbo, and back into Jindabyne

And what a stellar day of riding it was…

The hills and aching muscles were soon forgotten at the Brumby Bar & Bistro where our team gathered for dinner and drinks. During the evening, one of our riders Ashley Ray addressed the room about his own personal journey and the circumstances that led him to sign up to join the ride. Ash was on the front end of an 830km ride back to his hometown in Melbourne, and had raised an exceptional amount of money for Epilepsy Australia - $12,491.48!

Ash blew the stigma that is so often attached to epilepsy to pieces, and while doing so gained the respect of every single person in the room. That respect was cemented even further when Ash completed his journey back to Melbourne, with thanks to his incredibly supportive family.

Our team were very forgiving when informed that “cops” had been riding amongst the pack, and that those who had broken Velominati’s Rules of Cycling would be “fined” accordingly. Although the riders had already generously purchased raffle tickets, and contributed money towards their participation in the ride, we were able to raise $500 for Epilepsy Australia with thanks to our “cops”.

The second day of riding brought 100km of rolling hills, and a terrible headwind. Although the team backed up a very tough Saturday ride with a perhaps equally tough Sunday ride, every single rider was able to finish the course with a smile on his or her face.

The heart and determination that our riders showed really is what the event is all about – riding for a good cause, raising some much needed funds, and remembering Cameron.

We also held a “Walk for Cam” along the Esplanade in Cronulla on the weekend following the ride, with the sunshine and around 70 people turning up for our morning walk and BBQ. Although it was understandably a difficult morning for the O’Brien family, it was incredibly encouraging to see so many people out in support of the cause and Cameron’s family, and raising awareness of SUDEP in the Sutherland Shire and beyond. A bunch of our Team SUDEP riders also joined us for the BBQ, having clocked up their 700 kilometres which was ridden throughout the month of March. It filled us with great pride to see the team in their jerseys and wrap up the 700km for such a great cause.
We also drew our raffle, with incredible prizes very generously donated by Two Monkeys Cycling (a bike!), ASICS (a $200 voucher) and Penshurst Physiotherapy Centre (a remedial massage voucher), and a bottle of Verve Clicquot thrown in for good measure. With thanks to their kindness, we were able to raise an additional $1,490 towards the cause.

Two Monkeys Cycling [www.twomonkeysycling.com.au] have been the driving force behind the ride, and have generously donated their time, money, resources and a tonne of prizes to allow the event to grow. We were all able to experience the sense of community that Two Monkeys Cycling has developed, and their commitment to the cause is second to none.

This year, our partner Two Monkeys Cycling was able to secure a number of businesses and organisations as corporate sponsors of the event. These businesses and organisations provided a significant donation to 700 for SUDEP.

Gold sponsor
BR International Logistics
Silver sponsors
NRMA
St George and Sutherland Regional Law Society
Bronze sponsor
Frank Nolan & Associates

Our foundation sponsor Vitamin King also joined us for the second year running, fuelling and hydrating our team with thanks to Horleys and Endura.

We would like to express our heartfelt gratitude to our corporate sponsors for supporting us in our second year, with their support a true display of the sense of community and charity embodying those businesses and organisations.

A wonderful part of our ride is the fact that riders are able to really challenge themselves by tackling some of the toughest climbs in New South Wales with a group of people who soon become friends, whilst knowing that a support car isn’t too far behind the pack. Our roadies and foodies kept everyone’s hunger at bay, and ensured that our riders were safe on the road. Without their support, the event wouldn’t have been as successful as it was and we are incredibly thankful to you all.

We managed to raise over $30,000 this year, which wouldn’t have been possible without those sponsors and individuals who generously donated money, those who so generously donated their time in fundraising, those who purchased raffle tickets, and last but certainly not least our exceptional support crew and team of riders.

The funds raised in the last 2 years in excess of $45,000 have gone directly into funding the Cameron O’Brien Memorial Grant, which seeks to assist those with a SUDEP-related purpose in undertaking their research, education or awareness raising endeavours.

We are looking forward to growing the event, with a number of sponsors already locked in for next year – BR International Logistics, NRMA, Frank Nolan & Associates, Belle Property at Lugarno, Endura Sports Nutrition, and Toby’s Estate with more to come on board in the very near future.

Why don’t you dust off your bike and join Team SUDEP next year on 2–3 April 2016 in Jindabyne? For updates follow 700forSudep on Facebook. It’s set to be an amazing ride…
Dr Kim Powell awarded Cameron O’Brien Memorial Grant 2015

Epilepsy Australia congratulates SUDEP researcher, Dr Kim Powell, on being the inaugural recipient of the Cameron O’Brien Memorial Grant.

The $2,500 grant will enable Dr Powell to travel to the American Epilepsy Society in Philadelphia in December to present her research to an international epilepsy audience.

Dr Powell’s research, published in Epilepsia in 2014, investigates cardiac dysfunction and molecular changes in the heart in animal models of chronic epilepsy.

Summary of Dr Powell’s research

Epilepsy, characterised by spontaneous, recurrent seizures, is one of the most prevalent chronic neurological disorders worldwide. Cardiac electrophysiological and structural dysfunction is common in people with epilepsy; particularly in those with a longer duration of epilepsy. As a result people with epilepsy can suffer from serious cardiac arrhythmias, often precipitated by a seizure, which could contribute to their substantially increased risk of sudden death. Such deaths are termed Sudden Unexpected Death in Epilepsy (SUDEP), and this is a major clinical problem facing epilepsy patients, accounting for 17-38% of all epilepsy related deaths.

The incidence of SUDEP is probably underestimated, because it often goes unrecognised by clinicians and coroners. Despite the high level of concern in the epilepsy community regarding cardiac dysfunction and SUDEP, and growing scientific attention into the problem, knowledge about the underlying causal mechanisms remains limited.

Recent research from our laboratory has shown that heart function is detrimentally altered and the expression of ion channels critical for controlling cardiac rhythm, HCN channels, is reduced in animal models of chronic genetic and acquired epilepsy. This suggests that epilepsy itself causes changes in the heart that may predispose patients to the development of serious heart conditions, and potentially SUDEP.

This research has the potential to motivate new thinking regarding the pathophysiological mechanisms, and prevention strategies, for this devastating consequence of this common neurological condition.

Follow the journey of researchers, clinicians, families, and organisations working together to tackle epilepsy deaths

The Cameron O’Brien Memorial Grant

This Grant, established in 2015, is funded through the activities of the 700 for SUDEP: Cameron O’Brien Memorial Ride which to date has raised in excess of $45,000.

The aim of the Grant is to award $2,500 annually to support activities that advance research, education, and awareness of sudden unexpected death in epilepsy (SUDEP) and epilepsy-related death.

Types of activities eligible for funding:

- **Travel grant**
  - Australian researchers* conducting research into SUDEP and epilepsy-related deaths to national or international epilepsy specific conferences to present on their research findings.
  - Australian Epilepsy organisation staff to attend SUDEP/epilepsy-related death meetings – national or international
  - Individual advocates* e.g. bereaved family member to attend SUDEP/epilepsy-related death meeting – national or international

Research projects examining sudden unexpected death in epilepsy and epilepsy-related deaths

Community activities raising awareness of sudden unexpected death in epilepsy (SUDEP) and epilepsy-related deaths

Closing dates for applications: 30 April each year.

For further information about the Cameron O’Brien Memorial Grant please visit our SUDEP page at www.epilepsyaustralia.net
Epilepsy & Employment

Monica Wo Chen Mun & Kheng-Seang Lim
University of Malaya

Employment is one of the important pieces of the puzzle that completes adulthood, leading to a good quality of life. Clinically, the ultimate goal for a person with epilepsy is to achieve seizure freedom. However, 40% of people with epilepsy continue to have seizures despite optimal treatment. People with epilepsy are commonly perceived to have greater challenges in obtaining or sustaining a job, and the worse scenario may be expected in those with uncontrolled seizures. (Chaplin et al. 1998) Does this mean that people with uncontrolled seizures could not work?

A study in Malaysia (Lim et al. 2013) revealed that as high as 50% of people with epilepsy who had full-time employment were having at least one seizure a year. A multinational study revealed that a large percentage of people with epilepsy were able to retain a successful career in the open labour market (Baker et al. 1997). The adjusted employment rate of people with uncontrolled seizures, excluding students, housewives and those with learning disability, were as high as 82% in Europe, 76% in Africa and 73% in Asia, with only slight difference (6-16%) from people with well-controlled seizures. In comparison with age-matched normal population, the employment rate of people with epilepsy was only 22-24% less.

We are currently studying the factors affecting employability in Malaysia by interviewing 21 people with uncontrolled seizure (11 employed and 10 unemployed). Ability to work is one of the emerging key themes, in which the participants viewed that having adequate training, cognitive and physical function, ability to continue working after a seizure, ability to travel to work and to cope with stress, all important elements in successful employment. Besides challenges related to seizures, people with epilepsy need to face the similar challenges in employment as in those without epilepsy. However, this also indicates that employment is possible if people with epilepsy learn to equip themselves with these abilities.

Most studies focused on negative factors affecting employability in people with epilepsy such as stigmatization, low self-esteem, high seizure frequency, high injury risk and so on. Aside of repeatedly focusing on the reasons of employment failure, it might be more meaningful to study the positive factors leading to successful careers in people with epilepsy, particularly those who were still having seizures. In our study, positive factors were more commonly found among participants in full-time employment at time of interview than those unemployed.

When they are asked “Why work is important for you?”, those employed tended to work for a “future goal” and “self-satisfaction”. This indicates that self-determined motivation is an important factor affecting the employability among people with uncontrolled seizures. (Figure 1) This is supported by a study by Tremblay (2009), based on a self-determination theory by Deci & Ryan (1980), that showed that those with self-determined motivation had higher job satisfaction and organizational commitment.

A previous study in public attitude towards people with epilepsy by our group (2013) showed that the public tend to have a more positive attitude towards people with epilepsy when a general statement is asked (e.g. People with epilepsy have the same rights as all people) but not when the statement involved personal consideration (e.g. If I am an employer, I would give equal employment opportunities to someone with epilepsy). In fact, during the interviews, the participants were more concerned about the attitudes of
their closely related persons such as family members, the employers and the colleagues, rather than the public. Support given by these people was a great motivator for some of them to pursue their career.

Therefore, based on the findings in our studies, we proposed a model on how people with uncontrolled seizures can achieve a successful employment. (Figure 2)

In this model, it is stressed that a person with epilepsy must be first assessed for their ability to work according to the type of employment they are looking for. Second step is to identify and create positive factors of employment.

People with epilepsy should be encouraged to develop self-determined motivation by finding the meaning and goal of having a job. Family members and employers should be involved in the job seeking process, by providing them adequate clinical information, and emphasizing how their supports help in making the employment of people with epilepsy a success.

Figure 1: Self-determined motivation is essential

Figure 2: An approach for people with uncontrolled seizures to achieve successful employment

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Subjective Well-Being in Men following Neurosurgery

Martin Raffaele PhD, Faculty of Health Sciences, University of Sydney

A recent research study, conducted at the University of Sydney looked at the way men judge themselves following neurosurgery for adult onset epileptic seizures (AOES). The term 'onset' in this study refers to the time or age at which seizure activity commenced. As I am an individual with epilepsy, who has experienced this surgery to reduce my seizure activity, I felt it was important that I undertook a research project on this topic in order to offer greater understanding from a perspective that often only those who experience a medical condition can provide.

The study reports on how poor understanding about epilepsy and how the individual judges himself affects him when he is present in the different social environments of Family, Professional / Consultant and Social Networks (including peer-groups and the workplace). Subjective Well-Being (SWB), or how a person sees himself, can often be understood when looking at their feelings of happiness, peace, fulfilment, and self-perception (Diener, Oishi & Lucas, 2003). SWB is often influenced by the coping skills the individual uses or what they understand the problem to be (Krause & Broderick, 2004).

This research is important because SWB is sensitive to anguish in several environments of living (Ohaeri, Awadalla & Gado, 2009). A series of five cases focused on individual men who began to experience seizure activity in their adult years. Although the participants were not living in the same social environments, each of the men were asked how they felt about themselves following surgery and the reactions of others in similar social groups: the family, healthcare and social networks.

The Study

One-on-one interviews took place with the men who participated in the study. A small number of questions were asked to encourage general conversation about their social experiences following surgery. By doing so, further questions relevant to each individual’s experiences became clearer. This allowed for better understanding on how men with adult onset seizures perceived their roles in different social environments, including the family, following surgery. Table 1 provides a personal outline of those who took part in this study.

The age of the five male participants varied from 34-years to 59-years. Each of these men had experienced complex partial seizures that commenced in a single region on the brain, the temporal lobe, before experiencing this surgery. All the participants were in strong personal relationships before the operation, and only three of those men, Chris, David and Eden remained in these relationships.

Cost of Social Stigma Post-Surgery

The study found that poor social stigma was caused predominantly by a lack of understanding of epilepsy. Most people fear epilepsy because they don’t know what to do when watching someone having a seizure. In reality, members of most social environments find it more difficult to deal with epilepsy than many other illnesses (Myers, 2004).

Studies have found that the general community’s knowledge of epilepsy is
very limited, resulting in the person with epilepsy experiencing a large weight of negative emotions (Hasan, et al., 2010), however, more studies are needed to better understand how to address these issues (Austin, 2011). More time needs to be allocated by health professionals to provide education on epilepsy for people with the condition in most societies. Better understanding is needed on how seizures, that start in adulthood affects the way people judge themselves, and also how others judge them.

It is often felt that soon after a man has undergone surgery to reduce seizure activity, most of the difficulties he faced before the operation will no longer affect him, and he is ready to return to all normal duties, including employment. However, this is not necessarily so, and returning to all normal duties can take longer than most people realise and often influence the person to think negatively when he does not perform these tasks well.

Cost of Discrimination

Discrimination often results following the ability to distinguish between how a person is different from others (VadenBros, 2007). Few other chronic illnesses arouse more discriminative reactions in social networks than epilepsy. This being second only to that incurred by leprosy (Engel, et al., 2007). Individuals might experience discrimination in many social environments when choosing to experience elective neurosurgery. This will often influence the level of stigma and isolation shown towards the participant, further lowering their self-perception (Buelow, et al., 2003), however there is still opportunity for changing the attitude of others towards the participant.

Results

Through the use of one-on-one interviews, a better understanding on what factors influence the Subjective Well Being in men following surgery for adult onset epileptic seizures (AOES) was revealed. The results showed that men with AOES see relationships with their family having the strongest impact on happiness, fulfilment, self-perception and life-satisfaction following surgery. Health Professional / Consultant relationships were the second most influential factor on how they judged themselves. Their relationships with social networks, including friends and work colleagues also influenced how they saw themselves after the surgery. However, it was found that these men often spent a lesser amount of time outside of their home after surgery, demonstrating that social network relationships have the least influence on SWB.

The study found within a small number of years following the surgery, only three of the participants, Chris, David and Eden remained in the same personal relationship. All five men felt poor understanding of epilepsy in their family and the need for the surgery caused emotional difficulties to occur. Adam and Brian also felt poor rehabilitation following the surgery contributed to problems that lead to the ending of their personal relationships.

Adam said that prior to experiencing epilepsy, he owned and ran a small carpet cleaning business, but the onset of seizures made it no-longer possible. This resulted in bankruptcy and the need to apply for a pension. Adam claimed these changes caused instability to arise in his personal relationship. Adam said: “It was something that was never discussed in front of her family or her friends because being with someone who is on a pension is embarrassing.” He said that although his desire was to return to the workforce and establish a new business following surgery, it was his inability to do so immediately that caused the relationship to end.

One of the participants, Brian continued to experience seizures after surgery. Brian claimed his partner now perceived him as being a less than adequate husband. “She emotionally deserted me first.” Brian then felt
surprised by the speed at which the relationship ended. He said, “I was living with my wife and my three children. She seemed happy about this, but before I realised it, she was gone. We both knew that I needed the operation, but I was unaware of what would result after surgery.”

However, more positive results were experienced by the men and their partners when they turned to the same family members for support.

Each case study highlights the post-surgery issues the participant faced in relation to important social environments. Participants spoke about their recovery process and how different activities influenced the way they judged themselves at that time. In most cases, the participants felt that not enough support was offered after the surgery and hence this lack of understanding of the impact of the surgery and the recovery process, made it difficult for them in most social environments.

Participants found themselves feeling more positive following surgery when practising activities to improve skills, including co-ordination and memory recall. Positive effects were evident in the life-satisfaction of participants when they felt comfortable talking about how their experiences after surgery emotionally affected confidence. Some of the men in this study said it was easier to cope after making a mistake as a result of their surgery by making a joke out of it. The study found that many of these men felt negatively about themselves when they were unable to gain the information that could help them understand why they were experiencing difficulties fitting into societies. As a result, many chose to enter environments where there were a lot of people only when necessary to do so, such as shopping for groceries.

The study also found many men with AOES experienced lower self-belief following this surgery as they found it difficult to set new goals or achieve goals they may have set before surgery. As in most cases, a limited amount of rehabilitation was available following the surgery, often leading many of these men blaming themselves for a lack of understanding and achievement.

Happiness, fulfilment, self-perception and life-satisfaction were most strongly influenced by education and understanding. The participants felt it was easier to see themselves in a more positive way when others accepted how the surgery affected their everyday life. The study found that to improve how people with epilepsy feel about themselves following surgery, better education is needed in most societies about epilepsy and why an operation is, at times, needed. Better education of the impact of surgery is needed to improve how men with AOES see themselves following surgery for epilepsy.

Recommendations

This study shows that it is very important to understand how relationships in all societies can affect the way a man sees himself following surgery for adult onset epileptic seizures (AOES). This understanding may help to improve emotional scarring caused by how society judges this individual, as well as providing a better opportunity to successfully participate in all social atmospheres, including the home, workplace, and other environments.

Health professionals need to conduct stronger investigations into each individual’s personal and medical history, which may include the experience of physical and psychological injury. Additionally, ongoing post-surgery counselling assessments should be completed and evaluated. To improve post-surgery rehabilitation, it is also important to continue regular discussions with family members, such as partners, children, and siblings. Observations of the individual during formal assessment and/or therapy should be noted and addressed to improve their overall SWB.

Men and women with uncontrolled AOES spend most of their life in the home environment. I strongly recommend that individuals within the family environment be provided with community learning about epilepsy. A further recommendation is that government funding be allocated to registered epilepsy support groups to ensure greater education on this chronic illness is available to members of all relevant social environments.

Summary and Conclusion

In summary, the desire of this study was to gain greater understanding of how the Subjective Well-Being (SWB) of men who underwent neurosurgery as a means to control Adult Onset Epileptic Seizures (AOES) is affected post-surgery. The findings identified that SWB was influenced by the nature of social reaction in the family, health care, and social network environments. The study found that the quality of communication about AOES post-surgery can influence SWB in family, consultative, and community participation. It is important that individuals with AOES following elective neurosurgery attain a preferred quality of life with adequate education available for members of all relevant social environments.

References

Austin, J.K. (2011) Personal communication. email, February, 12, 2011


WINNER:
“My name is Zac Clarke. I am 14. The first photo is me happy with the calm water behind me. I have my sunglasses on and my music so I don’t see or hear what’s coming behind me. The middle photo is the seizure. It comes at me from behind and spins me upside down. I don’t like it but I can’t stop it. It changes the way I feel and see things. The last photo is after the seizure. I’m in the same place but my surrounding has changed. Things are going on behind me that I can’t see or control. Even though I’m in the same place things have changed. This is how seizures and epilepsy is for me.”

2015 Facebook photo competition

This year’s Facebook Competition to celebrate National Epilepsy Awareness Month was a photo competition based on the theme “What epilepsy means to me”.

Conducted in March, the competition drew some very creative entries, each portraying a visual image of what epilepsy meant to them.

Judges this year were: The Hon Sussan Ley MP, Federal Health Minister; Cassidy Megan, Founder of Purple Day and Kelly Moffat from Medic Alert Foundation. While they were impressed with all the final entries, Zac Clarke’s entry was chosen as the winner for 2015, with entries from Zoe Gow and Kelly Clohessy close runners-up.

Epilepsy Australia thanks the following sponsors for their continued support.

• Medic Alert Foundation www.medicalert.org.au for 2 Gift Vouchers to the value of $150 for the winning entry and 1st runner up.
• Five Souls Designs www.facebook.com/five5souls for generously donating vouchers, and
• Medical Action Bag www.medicalactionbag.com) for donating 2 Medical Action Bags.

All the images received are collated in an album on Epilepsy Australia’s Facebook page - www.facebook.com/epilepsyaustralia. Please visit our page, check out all the images and learn more about epilepsy and how it impacts on people’s lives. Their courage and determination will inspire you.

RUNNERS UP 1 & 2:

The above photos represent what epilepsy means to Lizzy. The wolf has been her main visual hallucination. The one of her laying down was taken during a hallucination seizure and it shows what effect they have on her she shuts down and deals with them from anywhere from 15 minutes to 45 minutes. Zoe Gow

Epilepsy - Through the Lifespan

Friday 20 November 2015
9:00am – 5:00pm
(Registration from 8:30am)

Venue: Edwin Tooth Auditorium
RBWH Education Centre, Herston

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Queensland Epilepsy Symposium

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