International
Epilepsy News
Newsletter of the International Bureau for Epilepsy Issue 1- 2010

Let's silence the *'E'* word!

The President's Message

Dear IBE Members and Supporters

It seems just a few weeks since I wrote the last message for IE News, when the year 2010 and a new decade were just beginning, and already the first quarter of the year has passed. It has been a busy, but at the same time rewarding, few months.

I have just returned from the 2nd Eastern Mediterranean Epilepsy Congress in Dubai, where the East Mediterranean report of the Global Campaign Against Epilepsy was launched by Dr Khalid Saaed, WHO's Regional Advisor for EMRO. I also had the pleasure of meeting Prince Bandzile of Swaziland, who was attending the congress accompanied by a representative of our Full Member, Mr Mbuso Mahlalela. The Prince spoke during a session which I was chairing in Dubai and his presence was very much appreciated by the delegates. You can read his presentation in this issue of IE News.

I also travelled to China, at the invitation of Dr Shichuo Li, to attend the 3rd International Forum on Epilepsy in Beijing. I met with several members of the China Association Against Epilepsy and I was particularly pleased to meet Dr Ding Ding who helps the Seahorse Clubs – which are support groups for people with epilepsy in China.

The meetings in both Dubai and Beijing were also important events for the Global Campaign Against Epilepsy, with the launch of the Eastern Mediterranean Epilepsy Report mentioned above and the Final Report on the Demonstration Project in China which was launched by the WHO's representative in China, Dr Mike O'Leary. You can read more about both of these special occasions in this issue.

We have also had the first meeting of the congress committee for Rome 2011, which is now just over a little more than a year away. The Golden Jubilee Task Force, chaired by Susanne Lund, is busy preparing special events to mark this milestone in the history of IBE and I will have more news for you on this in the next issue.

All the best until then!

Mike Glynn

President

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The Editor's Letter

Dear friends,

I am very enthusiastic about this issue of IE-News. We have a lot of articles and reports. We can mention a nice piece of work coming form India prepared by Vinod Saxena analysing epilepsy and divorce in India, a complex and touching history.

An article from the 2nd Eastern Mediterranean Epilepsy Congress in Dubai tells us about the important attendance of Prince Bandzile from the Kingdom of Swaziland.

Another interesting article comes from the American Epilepsy Meeting 2009 in Boston with a report on the treatment gap session dictated by Dr Steven Schachter, Dr Patrick Kwan and Eric Hargis.

Our President Mike Glynn writes about the anti epilepsy Stigma Campaign and the removal of the E Word. We also have news from the Global Campaign Against Epilepsy with a report of the Chinese Demonstration Project and the launch of the Eastern Mediterranean Regional Report on epilepsy.

Also in this issue of the magazine, Janet Mifsud has provided a report on the fourth EPICURE meeting, while Shunglon Lai tells us about a visit to Vietnam and how support will be provided in that country to encourage the creation of a new IBE member association.

Best wishes for everybody.

Dr Carlos Acevedo Sch.
IE News Editor

International Epilepsy News on the Web

IE News is now available on the IBE website
www.ibe-epilepsy.org
Previous issues can be found under the tab **IE News**, while the current issue is available to IBE Members on the **Members** section.

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Epilepsy and Divorce in India

Synopsis

The Hindu Marriage Act 1955 and Special Marriage Act 1958 specified that a marriage under these acts can be solemnized if, at the time of marriage, neither party suffered from insanity or epilepsy. This was incorrect medically and a travesty of natural justice since epilepsy is not a mental disorder. The anomaly had crept into the law as no specialist was consulted. The existence of such a law became known only in 1986 during a public seminar organized by the Indian Epilepsy Association (IEA).

This revelation set in motion activities on several planes. The law makers had little time for causes that seemed to affect only a small fraction of the population. The initiatives became running battles between IEA and activists as the governmental machinery moved slowly and ponderously as ever.

Failure to achieve headway with some dispatch was hardly expected but the law-makers insulated themselves to the point that they appeared insensitive. More surprise awaited us as we were stone-walled everywhere. The selective and callous choice of issues by the governing politicians was seemingly limited to protection of own turf for their next elections. Political instability of three short-lasting governments during this phase may have been some excuse as IEA stood waiting for twelve long years.

An almost unplanned lead came from the courts opening another avenue of Public Interest Litigation. Driven to desperation and hoping to cope with the rigors of the legal system, IEA approached the Supreme Court of India on 9 September 1996. Though a Bill was introduced by the Government on 13 August 1997 after much prevarication, help on the home lap came from a socially committed journalist.

The positive result came with passage of an Amendment to the quoted Acts on 30 November 1999 in the Upper House and on 20 December 1999 in the Lower House of the Parliament.

The Amendment disconnected insanity from epilepsy.

A great amount of ink, sweat and toil by all concerned finally removed the offensive statute and freed many of the sufferers of ill-fated matrimony from this ever hanging Sword of Damocles above their heads.

A Special Report by Dr Vinod Saxena IBE Vice President South East Asia

The Law before 1999

India was the only country, up to 1999, where epilepsy was equated with insanity under Hindu Marriage Act 1955 and Special Marriages Act 1958. These acts specified that the marriage can be solemnized “if at the time of the marriage *neither* party suffers from recurrent attacks of insanity or epilepsy”. This blatantly unmeritorious and unscientific situation crept in as an amendment to the law as late as 1976. No opinion was sought from any professional organization. This law gave unfair advantage to some dissatisfied spouses, almost always male. It was like taking away a legitimate right of the female population, exposing them for exploitation under the mischief of such a law. The law is termed blind, but what else?

How did IEA get involved?

In a seminar organized by IEA on medico-social aspects of epilepsy, held in Bangalore on 18-19 October, 1986 this law came under discussion. The participants in this symposium had extensive and, at times, acrimonious discussions with the medics, social activists, lawyers and a sole jurist. Dr KS Mani led the discussion and Dr Harry Meinardi also present discussed the incongruity of this law while the world had become more socially conscious.

IEA takes steps

It was a fact that the legal empathisers understood our objective clearly and early and were prepared to fight our battles. We did not, however, take into account that the lawmakers and bureaucrats protected their ‘*status-quo*-ism’ firmly and resolutely enough to thwart all counter efforts to rectify the situation. Our letters, representations and petitions did more merry-go-rounds than those in amusement parks (except that we did not find it amusing). It was much more than IEA had ever bargained for.

During the long years of battles unequally waged there were at least three successive governments as Prime Ministers/Health/Law/Social Welfare Ministers passed though political revolving doors. All our missives elicited either silence or a polite acknowledgement from an underling protecting his master with arduous zeal. And some even carried a fork-tongued message that the matter was ‘under consideration’.

Needless to add, the period between 1987 and 1999 was full of infructuous follow up by our tallest leaders - Drs EP Bharucha, KS Mani, G Arjundas and B Ramamurthy. In December 1992, Dr Bharucha and Bombay Chapter of IEA collected over 1500 signatures in a campaign, which he and Dr VS Saxena presented to the Speaker of the Lok Sabha. Dr Saxena also worked with a Member of Parliament to introduce a private members bill, but all in vain, as our successive governments were always dealing with seemingly other matters of state to which they accorded higher priority. Dr Saxena had several sessions with the bill drafters, wasting precious breath on innocuous phraseology. (The biggest surprise was kept for last as the Bill was eventually passed without any discussion or even a whimper).

Exasperated, but still unwilling to concede, IEA took recourse to the new legal provision of Public Interest Litigation. We risked borrowed funds and took an adversarial position to file a case against the Government in the Supreme Court of India on 9 September 1996. The Government was represented by the Solicitor-general of India Mr Soli Sorabjee who assured that the Government had drafted a Bill on 13 August 1997.

The next thirty months were another bout of coma. Dr Saxena met Ms Mohua Chatterjee, a committed journalist of the largest circulated English daily, *Times of India (TOI)*. She was convinced of the true nature of our campaign and promised help. She, however, cautioned about the reading habits of politicos which may not venture beyond headlines or the front page. She could only assure her best attempts as the editorial departments determined placements.

We hit pay dirt when on 22 November 1999 we saw her large and impassioned exhortation on the front page of TOI quoting extensively on IEA’s long fight for a just and humane cause which was languishing under Government’s red tape.

Some people took notice. From there on, for us, what followed was at breakneck speed. The Upper House, Rajya Sabha, took it up and passed the long pending Bill on 1 December 1997, the Lower House, Lok Sabha, took it up and passed it on 20 December 1997. All the national newspapers gave us extensive coverage, some under social but most under Parliament news. It was the most desired outcome of our struggle of years just before everyone seemed to have given up to the futility of standing up for a cause not so popular with the political class.

How did we use the new law?

The legal unshackling was duly celebrated by all the Chapters of IEA as we disseminated information to them and to those afflicted patients who were on our files. We organized special sessions to broadcast the changed legal scenario. Some of our physician members used their patient list to counsel them on the new provision. To this day, we continue to guide and counsel through our state Chapters and regional meetings.

What we learned

1. All laws once they come into existence in the statute book are very hard to challenge. All arms of the government protect their past actions energetically and different wings act in a incestuous manner when their authority is challenged.

2. For health issues, it is often the medical colleagues who turn into hard core bureaucrats. We came to learn that the first irregularity in the enactment of law took place in 1976 when a medical man in the health ministry chose to hoist his individual and whimsical view. Once enshrined as a legal statute, not only was reversal difficult, few were willing to take up something ‘not fashionable’ with the current government’s political thinking. Almost all very ponderously pronounced ‘how many people does it affect anyway compared to the other pressing medical issues facing the country’.

3. We need to be pro-active rather than reactive as many laws are passed without much ado.

4. The right connections, whether in government, bureaucracy or in the press, seem to matter and one needs to spread the net far and wide.

African Prince attends Dubai Congress

> **"I feel humbled and honoured to address this august body, which is the pillar of hope for those of our people who have epilepsy."**
> ***HRH Prince Bandzile***

The recent joint IBE/ILAE epilepsy congress in Dubai, the 2nd East Mediterranean Epilepsy Congress, was honoured to welcome His Royal Highness Prince Bandzile of the Kingdom of Swaziland, as a delegate to the congress. Accompanying the Prince and his entourage was Mbusomuni Mahlalela from IBE's Full Member, the Swaziland Epilepsy Association. Prince Bandzile is a Patron of the association.

Prince Banzile spoke during the session *Controversies in Epilepsy*, which was chaired by IBE President Mike Glynn and Hassan AL Hail (Qatar). Other speakers in the session were Hassan Hosny (Egypt) and Nahida Al Assi (Lebanon).

The following is the full text of His Royal Highness Prince Bandzile's address to delegates:

– Director of Ceremonies
– President of IBE
– IBE Eastern Mediterranean Regional Committee
– ILAE Commission on Eastern Mediterranean Affairs
– Chairman of IBE Africa Region
– Distinguished Guests
– Ladies and Gentlemen

I feel humbled and honoured to address this august body, which is the pillar of hope for those of our people who have epilepsy.

I bring with me greetings from His Majesty the King, Mswati III and the people of the Kingdom of Swaziland, especially those who have epilepsy. For those of you who are not familiar with the Kingdom of Swaziland, our country is a landlocked country, situated in the southern part of Africa, to be precise, between South Africa and Mozambique.

We pride ourselves for being the oasis of peace and stability. This has continued to bind us as a nation. I am cognizant of the fact that our country is attending this great congress for the first time, and I hope we shall benefit a lot from the congress. This forum will also present an opportunity to share experiences, discuss pertinent issues, present challenges that we meet, and also map out survival techniques and a way forward for the benefit of our membership.

Our epilepsy organisation is pretty new and it was established in 2004 and, ever since, it has continued to work tirelessly to promote the welfare of our membership. We have successfully embarked on a campaign for raising awareness and sensitizing the nation on issues of epilepsy. Our aim is to create awareness and ensure that the nation is kept abreast on the plight of our membership.

The main focus of our epilepsy organisation in Swaziland is on children where we advocate for the wellbeing of the child with epilepsy both at home and at school. This does not mean that we have forgotten about adults.

We applaud the assistance we received from UNICEF, particularly for providing our members with financial help. The joint advocacy project, between our members and UNICEF was a huge success. We were able to reach out to many of our citizens under this programme. You will all agree with me that people living with epilepsy are suffering from stigmatization from members of society, hence the need to work tirelessly so that our members are given the dignity that they deserve. Society has to embrace people living with epilepsy.

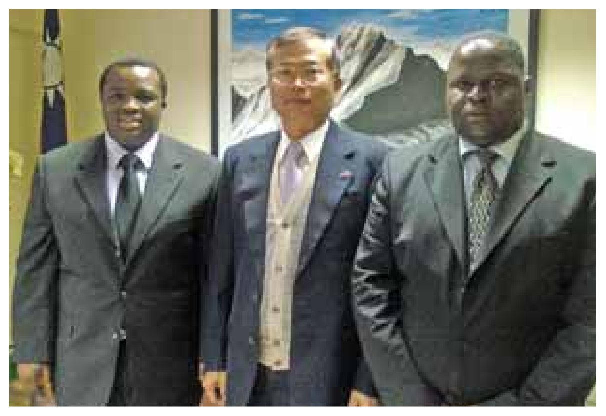
Indeed we have come a long way, and I am happy to report that the message is positively accepted in my country. The nation now is aware of epilepsy, and we will continue to push our agenda forward. Hurdles and challenges will always be evident, but in unison we shall conquer.

We are very pleased to point out that, through networking and strong advocacy, the Swaziland Epilepsy Association has established partnerships with different institutions in the Kingdom.

This includes, *inter alia*, the National Children's Coordination Unit (NCCU), the Social Welfare Department, under the Deputy Prime Minister's Office, and non commutable diseases under the Ministry of Health.

We believe that our collaboration with these stakeholders will make our work trouble-free and we will

Attending a presentation on epilepsy, which took place in recent weeks at the Swaziland Epilepsy Association are, from left, His Royal Highness Prince Bandzile, Taiwan Ambassador to Swaziland His Excellency Peter Tsai and Mr Mbusomuni Mahlalela



achieve our desired objectives. As an organisation we are determined to create an environment conducive for those who are affected.

I have no doubt that our participation in this congress will benefit us in many ways, especially the following:

- Information gathering in raising awareness and campaigns to help our people affected by epilepsy
- Driving regulations for people with epilepsy
- Safety and monitoring of anti epileptic drugs
- Practical approach to genetic testing and clinical presentation to the testing decision
- Networking.

On another note, I see the epilepsy congress as a conduit to bringing their plight to the public domain.

Our organisation comes a long way. May I also state that we have an ambitious programme, but resources always limit us to achieve our desired goals. One of the major challenges that we face is care and support. At the moment we do not have enough medical specialists trained in the field. However, His Majesty's government is doing everything possible to get specialist treatment for our membership.

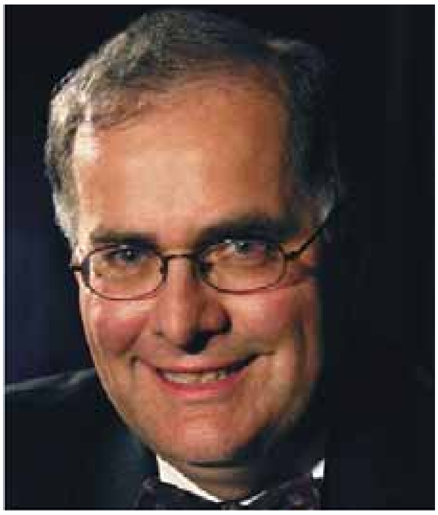
As I alluded to earlier, the stigmatization is another challenge which continues to humiliate our people. I would like to assure this congress that our advocacy programmes will be vigorous in this regard. We shall continue telling the nation, and the world at large, that people living with epilepsy should have equal opportunities like all human beings. We need to accept that a seizure is one of the conditions that could be addressed.

In conclusion, let me take this opportunity once again to thank this august body for allowing us to share with you distinguished delegates our experiences and activities from the Kingdom of Swaziland. As an organisation we have established a programme that will address the plight of people living with epilepsy. I believe, together, we can make a difference and empower people with epilepsy around the world.

Thanking you for your kind attention. May God bless you!

Epilepsy attracts major research grants

NHMRC grants announced for 2010



Professor Sam Berkovic

The Australian National Health and Research Council (NHMRC) Program Grants have been announced, with the big winners being researchers in neurobiology and epilepsy, aging, malaria control and melanoma research.

Professor Sam Berkovic, from the University of Melbourne, has been awarded a 2010 NHMRC Program Grant of AU$16,450,000 for research on *Neurobiology of human epilepsy: Genes, cellular mechanisms, networks and whole brain.*

Professor Berkovic's team is comprised of neurologists, molecular geneticists, physiologists and brain imaging specialists and leads the world in the discovery of the genetic causes of epilepsy.

They will continue to identify genes underlying epilepsy and study how genetic variations result in development of seizures. Advanced brain imaging will be used to understand the effects of genetic variation on brain structure and function. This study may lead to new diagnostic methods and treatments for epilepsy.

The NHMRC-EU scheme supports Australian participation in leading international collaborative research under the EU Seventh Framework Programme.

Epilepsy Patients Caught In Treatment Gap

Much progress has been made over the last 15 years in the healthcare community's ability to diagnose and treat epilepsy and its complications. Yet this progress has not reached most of the 50 million people around the world, who have the disorder.

According to Dr Steven Schachter, President of the American Epilepsy Society (AES), there is an enormous gap between what is currently being done and what is now possible to reduce the burden of epilepsy globally. Patrick Kwan, of the Chinese University of Hong Kong, and Eric Hargis, IBE Secretary General and President and CEO of the Epilepsy Foundation, also spoke to the treatment gap in epilepsy at the annual AES meeting in December 2009.

Using data from the WHO, Steve Schachter explained that three-quarters of those who have epilepsy in the world today get no treatment whatsoever for their seizures. Researchers in a US study found that there continues to be a major gap, averaging seventeen years, between the diagnosis of epilepsy and pre-surgical evaluation at a specialized epilepsy centre in the United States. Professional guidelines recommend that patients be evaluated as potential surgery candidates after failing appropriate trials of first-line antiepileptic drugs, trials typically taking less than two years.

“Complete freedom from seizures is not a possibility for everyone who has epilepsy. But it is important for patients with continuing seizures and their healthcare providers to make every effort toward that goal.”

Seizures are not benign. Mounting evidence suggests that they can lead directly to brain injury, permanent disability and death. Animal research suggests the injury may be due to seizures affecting the structure and function of dendrites, neuronal branches that connect brain cells. Epilepsy experts that recommend early aggressive treatment to prevent these possible severe consequences.

Patrick Kwan noted that this recommendation is followed less often in practice than actually observed. The care that is provided is further complicated by a variety of standards for defining refractory epilepsy which can contribute to the sub-optimal care that some patients are getting.

Dr Kwan participated in the ILAE Commission on Classification and Terminology, a committee of epilepsy experts that developed the first ever global, consensus definition of refractory epilepsy.

“The new consensus definition represents, for the first time, a common language in recognizing refractory epilepsy that can be applied by clinicians at all healthcare levels,” Patrick Kwan said, adding. “We believe its general adoption into clinical practice can have a significant impact in improving patient care by providing clinicians a framework to recognize and refer patients fulfilling the definition to specialist centres promptly for further assessment and management. Perhaps equally important, it will improve the interpretation of research results, which, in itself, can help in raising the level of epilepsy care.”

The new definition of refractory epilepsy is but one of many measures focused on the healthcare community that is needed to assure patients get state-of-the-art care. Beyond this there is much that people with epilepsy themselves can do to improve the care they receive, according to Eric Hargis. “Many people with epilepsy feel that what they experience from epilepsy and its treatment is ‘as-good-as-it-gets’. A perception they may get from healthcare providers. Programs are needed to inform patients that there are solutions to their feelings of depression and the treatment of side effects they experience. And, one of the keys is better communication with their doctors.”

A number of recent studies, including research supported by the Epilepsy Foundation, have found that mood disorders and drug toxicity affect quality of life of patients, more than the frequency or severity of their seizures. “Educational programs are needed that encourage healthcare providers to question patents and to offer appropriate remedial options for reducing co-morbidities and the impact of the disorder itself,” Eric Hargis says.

The heavy toll that undiagnosed, untreated and sub-optimally treated epilepsy imposes on the millions of people with epilepsy around the globe has led the WHO to raise the ILAE/IBE/WHO Global Campaign Against Epilepsy “Out of the Shadows” to the highest level within its organization. Closing the wide gap in treatment will require major efforts on the part of governments, healthcare communities, researchers, and affected individuals and families everywhere. But, with people's lives at stake, all those working in the field of epilepsy agree, there is no other course.

Source: American Epilepsy Society

EPICURE meets in Marseille

Janet Mifsud reports

EU Sixth Framework Programme
Project LSHM-CT-2006-037315

The Fourth annual EPICURE meeting was held in the French city of Marseille at the end of January 2010, bringing together over a hundred participants from the various partners involved in the project. EPICURE has received substantial research funding under the European Union Sixth Framework Programme. The meeting was held in the Alcazar Library in the centre of the city. This library was formerly a music hall and theatre where several operettas were performed in the 1920s and musical shows in the '50s and '60s.

Subprojects and work packages

The proceedings of the meeting showed how active the EPICURE consortium has been over the last year and the exciting results that are now emerging. The various speakers who presented during this workshop explained the range of subprojects and work packages being undertaken in EPICURE.

These bring together expertise and skills, which are both clinical and laboratory-based, with the common goal of advancing epilepsy research in Europe, and facilitate discoveries of novel therapies. This includes research being carried out on epilepsy and development, on genetics of human epilepsies, on the functional analysis of ion channel mutations in genetic epilepsies and pharmacoresistance, on acquired channelopathies and loss of control excitation, and shows how this research forms the basis of the development of new therapies for refractory epilepsy.

Peer reviewed papers

More than fifty peer reviewed papers were published in 2009 in journals, reviews and book chapters; there were sixteen conference abstracts and proceedings, participation in over fifty conferences and other events; two publications are in press, three in preparation, and two submitted. The collaboration between the various partners has been very effective, as testified by several co-signed publications and joint participation of partners' organizations to international conferences.

Telemetric system developed

A telemetric system has been developed within the EPICURE consortium in the frame of WP4.2. The possibility to further exploit this result is currently under discussion with a small German company to make the system commercially available.

In the frame of WP4.1 a "Cortical Malformation Filemaker database" has been developed. This result will be further exploited for further research. At present it is foreseen that access to this database will be only accessible free of charge to the partners involved in future research projects. It is not planned to exploit this result commercially. A number of posters supplemented the oral presentations.

The meeting was characterised by several interactive interventions between the participants. The development of a novel automated patch/voltage clamp technique which forms part of SP2 was also described.

Final meeting

The next and final meeting for the EPICURE project will be held in 2011 in San Servolo, Venice Italy, which was the venue for the first meeting in 2007.

In the meantime, IBE will continue in its role to disseminate and promote EPICURE through its media channels, including the IBE website, and at congresses.

The meeting in Marseille was supported by INSERM, Ville de Marseille, Provence-Alpes-Côte d'Azur, and Université de la Méditerranée Marseille.

Janet Mifsud is a Member of the EPICURE Dissemination Board and Advisory Group.

Removing the **‘E’** word from Epilepsy

Some years ago I wrote a article for International Epilepsy News entitled “Don’t mention the ‘E’ word” which it was hoped would help continue the movement to rid us of the scourge of the word ‘epileptic’ to describe people with epilepsy. The aim was to consign it to the bin along with similar derogatory terms such as cripple, spastic, retard etc. Such terms had been used in the past to describe people with other conditions but their use would now be considered the very height of bad manners.

Unfortunately, this is not the case with the “E” word and we are now printing again an updated version of the article. This is one of the first steps in a new anti-epilepsy stigma campaign which IBE is commencing. I would appeal to all of you involved in IBE member associations to do your utmost in your own countries to change the mindset of, in particular, media and medical personnel. We need to demand that they show proper respect to people with epilepsy by refusing to refer to them by this outdated and inappropriate term. The IBE office can provide any help and advice you may need to do this and I look forward to the day when, as a result of the efforts of all of us working together, the use of this word to describe people who have epilepsy will be a thing of the past.

Don’t mention the “E” word

Mostly, it is true to say that words do not hurt us in the same way as ‘sticks and stones’. But there are some words that do have the capacity to cut very deeply when they are used in the wrong way. The use of inappropriate terms to describe seizures - such as fits, attacks, turns etc. - do not have this power. The mention of grand mal, petit mal and similar descriptions do nothing worse than cause mild irritation. However, there is one word which, for all people living with epilepsy and all who work in the field of epilepsy, has this impact. It is the adjective ‘epileptic’ when abused into a noun to describe a person with epilepsy. This is the dreaded “E” word.

The print media that continue to use the “E” word are the greatest offenders in the perpetuation of this misuse. However, it is possible to change this situation because we have seen evidence of achievements in the past with other similar words. For example, imagine that you pick up your newspaper tomorrow and you see headlines such as these:

- *“Cripple who killed nun found not guilty”* Cherry (2010)
- *“Gloomy Ezekil was a retard”* Bates (2001)
- *“Spastics waiting 18–24 months to see neurologist ”* Donnellan (2009)
- *“Fatty diet helps lunatics”* Anon (2003b).

In most countries there would be outrage at the use of the words in these headlines; yet, if you substitute “*epileptic*” for “*cripple*”, “*retard*”, “*spastic*” and “*lunatic*” you get four recently published headlines. Journalists and, especially, sub-editors will always try to get away with using one word where three are required. But newspaper proprietors respond to public opinion and it is for this reason (and the threat of reduced sales) that words like cripple, retard and spastic could not be used any more.

In the case of the “E” word, we have found that, when approached by an epilepsy organisation, journalists will often respond that complaints are based on political correctness. However, it should be noted that all disability groups object to this type of lazy shorthand. For example, people with diabetes or asthma object strongly to the use of terms like “diabetic” or “asthmatic” being used to describe them. These, and similar groups, object principally because these labels seek to identify them by their disability alone. In relation to people with epilepsy, there is also a stigma attached to the condition that is due to historical demonology. In Europe, since medieval times, the term “epileptic” conjures up dreadful vistas of people driven out, exorcised, stigmatised, locked up and even worse. Unfortunately, this type of treatment of people with epilepsy still continues today, even in the western world, because the term “epileptic” continues to carry this historic significance.

In a major study on the presentation of epilepsy in the English language, Kraus, et al (2000) suggested that: “the media and their sources have

Mike Glynn, IBE President, reminds us of an article he wrote for IE News some years ago, in which he deplored the misuse of the term ‘epileptic’, and encourages us to remain vigilant

motivations to keep these fears alive. Historic misconceptions about epilepsy dovetail neatly with the goals of reporters, on the one hand, and those promoting new treatments or research, on the other. Both seek to heighten the drama: hoping their stories will be played prominently in the paper, and researchers and pharmaceutical firms trying to promote new advances. What better way to achieve this sensationalism than by invoking malevolent supernatural causes, grim prognosis, and heavenly magical cures?”

Without the use of a handy one word label to describe the people involved, it would be much more difficult for reporters to create their lurid stories. The headline “*Person with epilepsy punched and abused at bus stop*” Anon. (2003b) would not conjure up the images the journalist was aiming for in the original version. Ultimately, by using the phrase “*people with epilepsy*” the user must first think of the person, not the condition.

Unfortunately, the widespread use of the internet has also added to this problem. Many articles are appearing on the web without journalistic checks of any sort on the content. So, epilepsy associations, who have made such positive use of the internet, must also actively address this medium if they are to change the use of language for the benefit of their members.

Obviously, this is a cultural issue, as well as a language one, and the term “*epileptic*” may translate quite differently into other languages thereby losing its pejorative impact. In fact, some IBE member organisations have used the word (as a noun) in the English version of their names; this is something IBE actively discourages.

Likewise, some descriptions can be acceptable in some countries but not in others. For example, the phrase “*mentally retarded*” is still in widespread use in the USA but would be completely unacceptable in most other English speaking countries. In addition, the term “*handicapped*” continues to be used extensively throughout the non-English speaking world to describe people with disabilities. The phrase “*handicapped*” originated centuries ago from the perception that people with disabilities should ‘go cap in hand’ for charity in order to survive. Because of this origin, the term is becoming increasingly unpopular in disability groups.

In the epilepsy world, some people with epilepsy themselves continue to perpetuate usage by describing themselves as “epileptics”. Often they see this as a way of confronting the reality of their lives. For some it is a type of rebellion and they take the view that they are entitled to call themselves anything they want to.

Most IBE Full and Associate Members have been actively considering ways of using the press and other media in order to publicise the cause of epilepsy in their countries. In the past, very successful sessions discussing the eradication of the E-word have been held at IBE conferences. It is worth noting that considerable progress has been made in this area and in the developed world, at least, the term “*epileptic*” seemed largely to disappear. However, recently there has been an alarming proliferation amongst journalists of the use of this appalling term. A new anti-stigma campaign is currently being planned by the International Bureau for Epilepsy (IBE) that will seek to eradicate the use of the “E” word.

Ultimately, with the international community working together to push home this message at every possible opportunity, we will ensure that in time nobody will ever be called an “epileptic” again.

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Chinese Demonstration Project Report Launched

Hanneke de Boer, GCAE Co-ordinator reports

The final report on the Demonstration Project: *"Epilepsy Management at Primary Health Level in rural China"* was launched during a 2-day workshop "Epilepsy Control Project in Rural China" following the 3rd International Forum on Epilepsy in Beijing, China on 15 November 2009. The workshop was organised by the China WHO Office in collaboration with the Chinese Association Against Epilepsy (CAAE). Participants at the workshop included Chinese collaborators in the Demonstration project, the WHO Country Representative, Ministry of Health Officials, IBE President Mike Glynn, ILAE President Nico Moshé, Tarun Dua from WHO Headquarters and Hanneke de Boer. The report was published in English and Chinese.

Work on the report was supervised and co-ordinated by Hanneke M de Boer (SEIN), Tarun Dua (WHO) and Josemir W Sander (UCL and SEIN); the latter also participated in the workshop.

The report documents the success of the Chinese Demonstration Project in reducing the epilepsy treatment gap in China by managing convulsive forms of epilepsy at primary healthcare level.

The epilepsy project in China shows a number of successful partnerships: the partnership between IBE, ILAE and WHO as well as the partnership with China's Ministry of Health, the IBE and ILAE members associations in China, scientific societies, WHO regional and country offices, NGOs and WHO Collaborating Centres.

Writing in the preface to the report, Mike Glynn, Nico Moshé and Benedetto Saraceno (Director, Department of Mental Health, WHO) stated that the success of any intervention involves longterm sustainability. This report also presents the lessons derived from the development of an effective and sustainable framework for epilepsy care and scale-up in resource-poor settings.

The success of the project has led to publications in international, as well as Chinese, medical journals. It has also inspired the Chinese government to expand the initiative. By the end of 2008 it included 79 counties in 15 provinces in China, and over 35,000 people with epilepsy were treated by trained clinical physicians, following the Demonstration Project's protocol. Furthermore, 1,838 physicians from county hospitals were (re)trained by the end of June 2009. During 2010, six to eight more counties in will be included.

The Demonstration Project in China, and the intervention model described in the report, achieved the ultimate goal: to make epilepsy a national health priority in China, thus bringing epilepsy "out of the shadows".

Photo: Ann Little

Pictured from left: Tarun Dua, Khalid Saaed Mike Glynn, Hanneke de Boer and Nico Moshé. *Photo: Carla Glynn*

Global Campaign Against Epilepsy

celebrates launch of Eastern Mediterranean regional report

The eagerly awaited launch of the regional report “Epilepsy in the WHO Eastern Mediterranean Region – Bridging the Gap” took place during the 2nd East Mediterranean Epilepsy Congress in Dubai at the beginning of March. Both Global Campaign Co chairs – Nico Moshé and Mike Glynn - were in attendance while the WHO was represented by Tarun Dua from Head Office in Geneva and Khalid Saaed, Regional Advisor for Mental Health and Substance Abuse. Others who participated included members of the IBE Eastern Mediterranean Regional Committee and ILAE Commission on Eastern Mediterranean Affairs, as well as Hanneke de Boer, Global Campaign Coordinator.

Speaking at the launch, Dr Dua stated that no developmental projects on the condition were being carried out in the region at the present time.

“Treatment guidelines have been formulated but complex beliefs surrounding the condition prevent people from seeking treatment,” she added.

Experts from the WHO Regional Office agreed that epilepsy treatment should be integrated in primary healthcare systems in all countries around the world.

Epilepsy affects an estimated 4.7 million people in the region. Despite the fact that treatment can cost as little as 30 US cents, up to 98% of people with epilepsy are unable to benefit in some countries in the region.

“Epilepsy, a common neurological disorder, is a target of enduring myths which have shaped social and cultural attitudes and practices. Such myths continue to survive, and contribute in no small measure to the stigma and discrimination faced by people affected by epilepsy and their families. This, in turn, feeds into a vicious circle, where those affected individuals and their families do not access treatment, even where it is available,” said Dr Saeed.

The report brings together, for the first time, all the available evidence from the region on the epidemiology, etiology and management of epilepsy. Trauma was assessed as the reason behind the most frequently reported cause of epilepsy in the region. This was followed by infections and tumours.

“Lack of resources and qualified staff also hampers treatment,” added Dr Saeed.

GCAE Regional Representatives

In a move to further strengthen communication channels of the ILAE/IBE/WHO Global Campaign Against Epilepsy, the Co chairs have recently invited a number of people to become Global Campaign Regional Representatives. Their task will be to act as liaison points between the Global Campaign Secretariat and Task Force and the IBE and ILAE member associations. While this will be a two-way channel of communication, particular focus will be placed on reporting back the activities of the campaign to local level.

Epilepsy in Vietnam

Medical and Psychosocial Issues

Report by Shung-Lon Lai, Vice President, Western Pacific Region, IBE

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% - and higher among males (5.1) than females (3.7).

In some areas, due to those who have developed epilepsy because of cysticercosis, 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 last year (2009). However, unfortunately, there has not been any lay association addressing the social needs of people with epilepsy in Vietnam. Therefore, they do not have 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 organizations, 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, a meetings were arranged in Hanoi and Ho Chi Minh City that took place from 27 to 29 November, 2009.

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

Sponsors for the meeting were:

- Asian Epilepsy Academy
- ILAE Commission on 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 organizations
- To discuss the solution of coping with psychosocial care for persons with epilepsy in Vietnam

Organization of the Workshop:

Academic Program

- Professor Jing-Jane Tsai

Associate Dean for 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 addressed were experiences 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:

1. Promote education and increase awareness about epilepsy.
2. Organize retraining courses for doctors to reinforce the basic knowledge of epilepsy in order to improve quality of treatment.
3. Develop the etiology diagnosis of epilepsy, especially of genetic disorders.
4. 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.
5. Organize an IBE member association to promote comprehensive care for people with epilepsy.

US medical dramas show incorrect seizure response treatment

Some of the most popular TV drama series around at the moment are the American medical dramas that we all love to watch. Think *Grey's Anatomy*, *House* or *ER*. We love them for their multitalented characters who can look good in any medical crisis, and for their dramatic scenes of stretchers (gurneys) being rushed out of ambulances and down busy corridors. But if you are depending on these dramas to broadcast accurate medical procedures, then you can forget it. As least as far as the treatment of epileptic seizures goes.

A number of Canadians recently spent some time 'glued' to their TV screens watching House, Grey's Anatomy, ER and Private Practice, all in the name of research. They wanted to find out whether or not the dramas were educating people about first aid and seizures.

The study showed that of the 59 seizures shown (they watched 327 episodes!), almost 50% were inappropriately treated. In some cases the 'patient' was held down or otherwise restrained and in others there were attempts to put something in the person's mouth. The correct first aid was delivered in less than 30% of seizure cases, while the quality of care was "indeterminate" in the remainder.

One of those involved in the study, researcher Andrew Moeller from Dalhousie University in Halifax, Nova Scotia, said in a statement:

"People with epilepsy should lobby the television industry to adhere to guidelines for first aid management of seizures."

The cast of Grey's Anatomy

The results of the study were presented recently at the annual meeting of the American Academy of Neurology, where concern was raised that people watching these shows could receive incorrect information, which could result in broken teeth, or worse.

Dr Jeremy Moeller, who co-authored the study, reported that epileptologists had noticed people doing very inappropriate things on television and had seen some of the same sorts of things happening to their patients in real life. "It's impossible to definitively prove the connection, but one of the potential sources of misinformation is TV," said Dr Moeller, a postdoctoral clinical fellow at the Comprehensive Epilepsy Center at Columbia University Medical Center Deptartment of Neurology in New York.

Previous research has shown that patients, misinformed by TV dramas, overrate the effectiveness of cardiopulmonary resuscitation. Proper seizure first aid that emphasizes a relatively hands-off approach might not be as interesting to watch, Dr Moeller said.

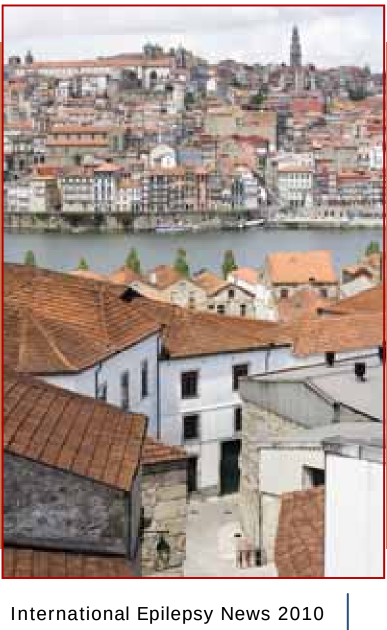
"We noticed that the doctors and nurses responding to these seizures were not remaining calm," he said. "That serves dramatic purposes, but it's not the way we'd educate the family members of our patients, which is that at the time of the seizure, put something under their heads, put them on their sides and don't panic."

Porto Website Goes Live!

With less than 5 months to go to the start of the 12th European Congress on Epilepsy & Society and with full information now available on the congress website, **isn't it time you considered registering for the meeting?** Following the very successful conference in Marseille in 2008, Porto promises to be just as great.

The conference website includes comprehensive information on the programme and also details the social events that are being planned around the meeting. So, what's keeping you?

www.epilepsyandsociety.org



PORTO 2010

Decade of Action for Road Safety

“This will help us increase action to address what will otherwise become the fifth leading cause of death by 2030” said WHO Assistant Director-General Dr Ala Alwan

On the 2nd March national governments around the world took the major decision to increase action to deal with the crisis in road safety over the coming 10 years.

The World Health Organization (WHO) has welcomed the proclamation by the UN General Assembly of the first “Decade of Action for Road Safety 2011-2020” which it is hoped will stop the ever increasing trend in road traffic deaths and injuries worldwide.

While road traffic death rates have stabilized or even reduced a little in high income countries in the recent past, research is now suggested that in most regions of the world the numbers are on the increase and could reach a figure of 2.4 million deaths a year by 2030.

Throughout the Decade of Action for Road Safety, Member States, with the support of the international community, will look to introduce actions in areas such as developing and enforcing legislation on key risk factors. With head trauma a major cause of epilepsy, any reduction in the incidence of road accidents can only help to reduce the number of people who develop epilepsy as a result of a road accident.

Epilepsy organisations and all those involved in the epilepsy field will also be hoping that focus on road safety will highlight the need to introduce appropriate driving regulations for people with epilepsy where no regulations currently exist or where regulations that are in place are problematic.

EU Directive on Driving and Epilepsy

The decade on road safety also coincides with the recent European Union Directive on Driving 209/112EC, which came into law in August 2009. The directive puts into force recommendations on epilepsy and driving made by the expert working group that was led by Dr Eric Schmedding. Dr Schmedding is a member of the IBE Driving and Epilepsy Task Force.

EPILEPSY?

Improving Our Knowledge

National Conference in Malta

Caritas Malta Epilepsy Association welcomed 200 participants to their National Conference in February, which was opened by Health Minister Dr Joe Cassar and Monsignor Victor Grech Director of Caritas Malta.

Speakers included Prof Brian Neville, a paediatric neurologist with a special interest in epilepsy. He has been a visiting specialist in paediatric neurology in Malta for 15 years and advises several parent support groups.

Another speaker was Mr Rick O’Shea a radio presenter on the Irish national broadcasting company RTE, who recounted his experience with epilepsy over 20 years. In 2007 he became patron of Brainwave The Irish Epilepsy Association and since then has spent time speaking publicly in Ireland and other countries about being a public figure living with epilepsy.

There were three local speakers at the conference: Sr Geswina Mangion, a nurse in a residential home for disabled people; Caroline Attard, a mother of a young man who has epilepsy; and Victoria Dimech (Secretary of Caritas Malta Epilepsy Association and Member of the IBE Regional Executive Committee Europe), whose husband has epilepsy.

Delegates pay close attention to a conference speaker

Meet Emilie

Emilie Clément is a beautiful young French girl, who recently played a star role in a TV advertisement promoting Epilepsie France, one of IBE's Associate Members in France. The TV 'spot', which aimed at raising awareness about epilepsy, and the fact that there is more than one kind of epilepsy, was made possible through the assistance of Emilie's uncle, Romain Clément. Epilepsie France was also very grateful to Emilie's parents who gave permission for their young daughter to take part in the advertisement.

Produced by 2Balles Productions, the advertisement ran over two months and was shown on a number of French TV channels, including Canal+, Jimmy, Planète, and Infosport. Epilepsie France noted its thanks to NBC-Universal, Pascale Jiquello and Carine from Canal+, TFI, SNPTV, ARPP as well as many others who made the production possible.

NOTE: This article must not be used elsewhere without the prior permission of Mrs Laila Adhhar at Epilepsie France.

Epilepsy Foundation stages its 4th National Walk in Washington, DC

Supported by a large number of American sports stars, not to mention star of the TV show *Heroes*, Greg Grunberg, several thousand people with epilepsy and their families took to the street in Washington DC on the 27 March in the Epilepsy Foundation National Walk for Epilepsy. This was the 4th time the family oriented, non-competitive walk in country's capital city has taken place. The aim of the event is to raise funds for research, education, advocacy, and services for people with epilepsy and their carers.

To date, excluding this year's walk, a total of more than 20,000 people have taken part, raising more than a staggering three million dollars.

Greg Grunberg, pictured right with his arms raised, is taking part in the walk on behalf of his son who has epilepsy. "With all of us raising our voices together on March 27th, everyone will hear why it is so important to learn about epilepsy, how to get your seizures under control, and about seizure first aid and how to make a difference," he said.

Welcoming New Members

IBE is delighted to welcome two new Associate Members to the Bureau, whose applications were recently ratified by the General Assembly:

- Epilepsy Association ACT Inc., Australia
- National Society for Epilepsy, UK

Generic Drugs

European Union announces decision to monitor pharma patent deals

The European Commission recently announced it has asked to see contract agreements on patents made by a number of pharmaceutical companies, as part of a wide investigation into generic medicines. The Commission, which is the regulatory body of the European Union, has requested “a selected number of originator and generic companies” to disclose all patent agreements relevant for the EU/EEA markets covering the period July 2008 to the end of December 2009.

It is expected that emphasis will be put on patent settlements where “an originator company pays off a generic competitor in return for delayed market entry of a generic drug”.

The investigation follows results of an enquiry carried out in early 2009, that highlighted the possibility of European consumers being deprived of a wider choice of medicines at lower prices due to settlement deals between pharmaceutical companies and generic drugs makers to delay the release of cheaper medicine.

Competition Commissioner for the European Union, Neelie Kroes said: “We need to monitor this type of agreement in order to better understand why, by whom and under which conditions they are concluded. Since completing the sector inquiry, the Commission has launched a number of new antitrust investigations and we will continue to do so should this be necessary.”

The Commission has not named the companies approached or the patented medicines involved. It should be noted that this investigation is targeted at a wide spectrum of medication for a range of illnesses and conditions.

With regard to anti epileptic drugs, IBE and its member associations both in Europe and in the rest of the world remain concerned at the implications of inappropriate switching of medication (from branded to generic or vice versa; from generic to generic; or from branded to branded).

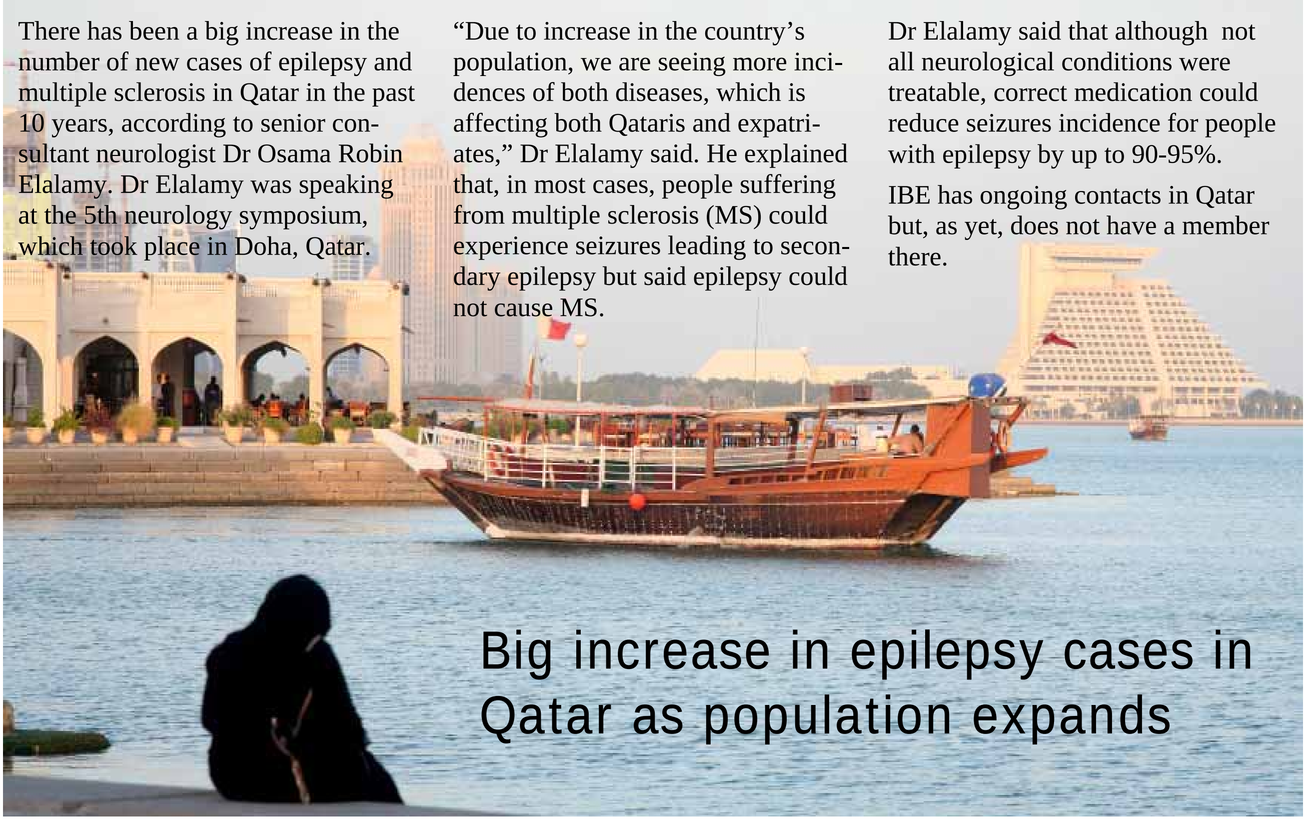
Big increase in epilepsy cases in Qatar as population expands

There has been a big increase in the number of new cases of epilepsy and multiple sclerosis in Qatar in the past 10 years, according to senior consultant neurologist Dr Osama Robin Elalamy. Dr Elalamy was speaking at the 5th neurology symposium, which took place in Doha, Qatar.

“Due to increase in the country’s population, we are seeing more incidences of both diseases, which is affecting both Qataris and expatriates,” Dr Elalamy said. He explained that, in most cases, people suffering from multiple sclerosis (MS) could experience seizures leading to secondary epilepsy but said epilepsy could not cause MS.

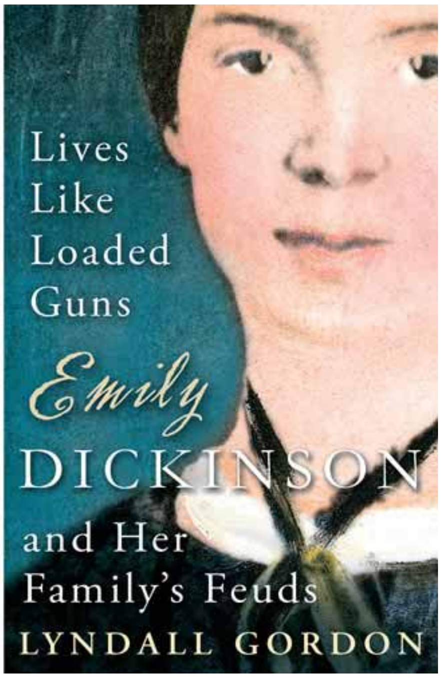
Dr Elalamy said that although not all neurological conditions were treatable, correct medication could reduce seizures incidence for people with epilepsy by up to 90-95%.

IBE has ongoing contacts in Qatar but, as yet, does not have a member there.



From the Book Shelf

Two recently published books - one a biography, the other an autobiography - both involving epilepsy



Lives Like Loaded Guns: Emily Dickinson and Her Family's Feuds By Lyndall Gordon
Published by Virago
ISBN: 978-1844084531

Emily Dickinson (1830—1886) is considered as one of America's greatest poets. Although only ten of her poems were published during her lifetime, she left a legacy of over 1,700 poems when she died. Consider:

"Because I could not stop for death, He kindly stopped for me; The carriage held but just ourselves and immortality."

"That it will never come again is what makes life sweet."

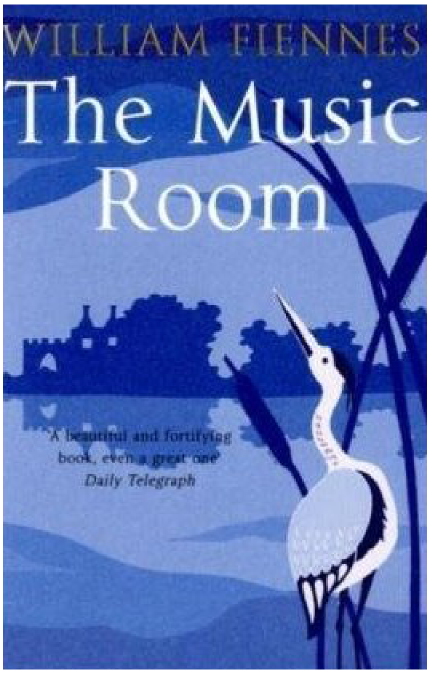
"How strange that nature does not knock, and yet does not intrude! "

Suffering ill health almost her entire life, it had been widely written that poor health and disappointment in love were the reasons why Emily chose to shut herself away from the world for much of her adult life. However, this book by Lyndall Gordon paints another picture.

Based on extensive research into Emily's medical records, Gordon identifies this ailment as, most likely, epilepsy. It is known that epilepsy ran in the family and Emily also suffered blackouts. Epilepsy was, at that time, considered a shameful ailment which needed to be concealed from all but immediate family.

And love did not pass her by either. The poet was in love at least twice. At the age of 47 she tell in love with a supreme court judge and there was talk of marriage although this did not come to pass, possibly because of her health.

Apart from Emily's own story, what makes this book a real page turner are the scandalous affair of her brother Austin and Mabel Loomis Todd and the battle raged for ownership of her work after the poet's death.



The Music Room By William Fiennes
Published by Picador
ISBN: 978-0330444415

Following its success in hardback, the Music Room has just been published in paperback and is bound to attract a large readership.

This is a wonderfully recounted narrative by William Fiennes (a second cousin of the famous movie star Ralph Fiennes) of growing up in Broughton Castle in Oxfordshire - a 700-year-old stately home which is used regularly as a film location. The author has written his own personal account of growing up in this amazing setting with a moat to swim in, gardeners and housekeeping to keep things in order, and an unending number of rooms to explore. Yet the name of Broughton Castle is not mentioned at any stage in the book.

Central to the narrative, and to William's childhood, is his older brother Richard who suffered from severe epilepsy and was often very difficult and even violent. One of the great achievements of the book is the way that Richard is shown as a brave and loving person with a passion for herons and football (Leeds United in particular).

The book covers a roughly 25-year time span, up to the time of Richard's death at the age of 41.

Interspersed throughout the book are snippets of the history of epilepsy and its treatment. The books recounts how neurologist John Hughlings Jackson began cataloguing patients seizures in a London Hospital in 1862 in order to have a better understanding of the condition. This was a turning point in medical terms, but in social terms we still have a long way to go, as William's tender recounting of his brother's life demonstrates.

Future Congresses 2010

6th Latin American Epilepsy Congress

Cartagena, Colombia

1st - 4th August 2010

12th European Conference on Epilepsy & Society

Porto, Portugal

25th - 27th August 2010

8th Asian & Oceanian Epilepsy Congress

Melbourne, Australia

21st - 24th October 2010

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