

INTERNATIONAL

Epilepsy News



459 MEPs support **European Declaration on Epilepsy**



PAHO: epilepsy a health priority



Holding the 29th International Epilepsy Congress in Rome to mark the 50th anniversary of IBE's founding, will undoubtedly be the highlight of 2011.

As part of the Jubilee celebrations, IBE made copies of the book "SUDEP continuing the global conversation" available free to all delegates at the congress.

A major highlight was the Presidential Symposium on the theme "Avoiding epilepsy deaths". Chaired by IBE and ILAE Presidents, Mike Glynn and Nico Moshé, it took place in a hall with a capacity of 1,200 - yet such was its popularity that a large number of people had to stand.

A great Congress and more good news!

Speakers included world experts in SUDEP - Prof Lina Nashef, Prof Dale Hesdorffer and Prof Jeffrey Noebels - but was opened with a stunning presentation by Mrs Susan Axelrod, the mother of a daughter with very difficult epilepsy. The final speaker, Dr John Paul Leach, told of advances in prevention of epilepsy deaths and offered much hope for the future.

The 50th anniversary celebrations continue after Rome and one of the ongoing projects is the "IBE News Jubilee Award". Broadcasting news about epilepsy has been a hallmark of IBE's work for the last 50 years and this award is intended to reward the best articles in 2011. You will find details elsewhere in this issue!

Of course, 2011 will be viewed as a landmark for epilepsy and IBE in many other ways also with exciting happenings in epilepsy around the world. In Europe the Declaration on Epilepsy is the starting

point for great developments in health-care, advocacy and research. The PAHO initiative offers equally rewarding prospects in Latin America and the Caribbean. In North America, the Institute of Medicine's report on epilepsy is due out next year. In Asia, many IBE member associations have been successful in changing the negative symbols for epilepsy, which have been used for hundreds of years, to more positive language symbols and I look forward to reading about this in the next issue.

The founding fathers of IBE could never have envisaged that such important projects would be taking place 50 years on but I am sure that they would be urging all of us not to rest on our laurels but to push on with the good work.

All the best

Mike Glynn
President



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News of two historical successes!

The second issue of IE News 2011 includes interesting issues for our readers. We are still excited by the recent celebration of the IBE Jubilee in Rome, and you will find some news on this in the magazine. We also have to suggest you to read an interesting research report on how stigma, that surrounds epilepsy, can have a negative impact simply by use of the word "epileptic" to describe a person with epilepsy and to join us in the campaign "Stop saying epileptic".

During the month of September the IBE achieved two historical successes in the field of epilepsy, the first concerning the

"European Written Declaration on Epilepsy", which was approved on the 15th September in the European Parliament carrying the signatures of 459 Members of Parliament (MEPs), and after much concentrated hard work by IBE and ILAE member associations throughout Europe.

In parallel and independently, on the 29th September the "Strategic Plan for Epilepsy" was approved and signed during the PAHO Annual Assembly of the Ministries of Health in Washington DC. Both of these initiatives represent milestones in Europe and in the Americas, which will be a challenge for IBE and the Global Campaign Against Epilepsy (GCAE) for the coming years.

You may be interested also to read about the Swiss Epilepsy Centre's 125th Anniversary celebrations in Zurich and of IBE

President, Mike Glynn's visits to India, Zambia and China. Of course, there are also many other interesting issues that I hope you will enjoy reading about in this latest issue.

Finally, can I remind you that we are always very happy to receive articles to include in future issues of IE News! With the IE News Jubilee Award, there is no better, or rewarding time, to submit a report to the magazine. Don't lose out on taking part of this great journalism award.

Kind regards,
Dr Carlos Acevedo
Editor

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The term “epileptic” tends to elicit more negative perceptions and a higher degree of stigma than does “person with epilepsy”

The purpose of the study was to evaluate the impact upon attitude and perceived stigma of using different terms for referring to persons with epilepsy among teenagers. High school students received one of two versions of a brief questionnaire and of the Stigma Scale of Epilepsy (SSE).

Epilepsy is a common neurologic condition, and the term epilepsy has negative connotations. This negative perception of epilepsy impairs the patient’s quality of life and reinforces the stigma (Scambler & Hopkins, 1990).

This has been observed in different societies (Herodes et al., 2001; Baker, 2002). This label has implications on work (Salgado & Souza, 2002), school (Baker, 2002; Fernandes et al., 2005), social interaction (Baker, 2002; Fernandes & Li, 2006), and stigma perception (Baker, 2002; Fernandes & Li, 2006; Fernandes et al., 2007b). Generally in the health area, the diagnosis of an illness involves a process of classifying and attaching a label.

Over the last two centuries, medical classification has increasingly been based on the underlying pathologic lesion or process (McPherson & Armstrong, 2006). Fundamentally, the more common classification is based only on symptoms of the disease (McPherson & Armstrong, 2006) and does not take into account characteristics of the person: biologic, psychological, religious, and social. The label is often associated

with a negative perception (Finlay & Lyons, 2005). When we use diagnostic labels to refer to a person, this tends to obscure the individual human being and focus only on the negative attribute (disease). This can result in a negative general perception and attitudes (Finlay & Lyons, 2005).

Language conveys information and allows construction of definitions or labels. In doing so, it may also shape or constrain how one thinks or perceives. This can be very dependent on the culture and language, as demonstrated by Winawer (Winawer et al., 2007). In their study on Russian Blues, they demonstrated that categories in language affect performance on color perception.

Currently the terms “person with epilepsy” and “epileptic” are used almost interchangeably by lay people, the media, and even healthcare professionals. Does the language used in this case shape the way we perceive the subject? Does the terminology matter?

Nevertheless, this difference has never been shown to bear different consequences in regard to stigmatization. In practical terms, is there an advantage to using “person with epilepsy” instead of “epileptic.”

The purpose of this study is to assess whether there is a difference in perception and stigma elicited by the expressions “epileptic” compared to “person with epilepsy” in a group of Brazilian teenagers.

Methods

The study was conducted during the summers of 2006 and 2007 at a summer camp program for gifted students. The students in this program were chosen based on a public examination involving a writing test and school grades.

Questionnaires were administered during a weekly workshop. The students were divided into four groups each year by the organizing committee of the program, using alphabetic order of the student’s first name. We then combined even-number groups into group-1 (person with epilepsy) and odd-number groups into group-2 (epileptic).

Instrument

Two versions of a four-question questionnaire were used. In one, the term “epileptics” was used, whereas in the other we used the expression “people with epilepsy.” The subjects answered “yes” or “no” to the following questions:

1. “Do you think that people with epilepsy/epileptics are rejected by the society?”
2. “Do you think that people with epilepsy/epileptics have more difficulties to get employed?”
3. “Do you think that people with epilepsy/epileptics have more difficulties at school?”
4. “Do you have prejudice toward people with epilepsy/epileptics?”

STOP!

saying "epileptic"

Study on stigma in epilepsy carried out by Paula T Fernandes, Nelson F de Barros, and Li M Li

In addition, we applied the Stigma Scale of Epilepsy (SSE), which was developed and validated by our group (Fernandes et al., 2007a,b). The SSE contains 24 items using a four-point scale (1 = not at all, 2 = a little, 3 = a lot, 4 = totally) about perception of epilepsy for the community, and the total score reflects the level of stigma perceived (0 = no stigma; 100 = highest level of stigma).

Two versions of the SSE were prepared. The term "epileptic" appeared in one version and the expression "person with epilepsy" in the other.

Assessment

The first group of teenagers referred to our activity was assigned to group-1 = "person with epilepsy" and the second group to group-2 = "epileptic." The other groups followed the same method of allocation. All participants were asked to complete the four questions and the SSE. One of the investigators (PTF) conducted the data collection.

First, study participants were asked to imagine a "person with epilepsy" in group-1 or an "epileptic" in group-2. The questions were then read aloud. The conditions of administration were similar for both groups, and all subjects answered all questions.

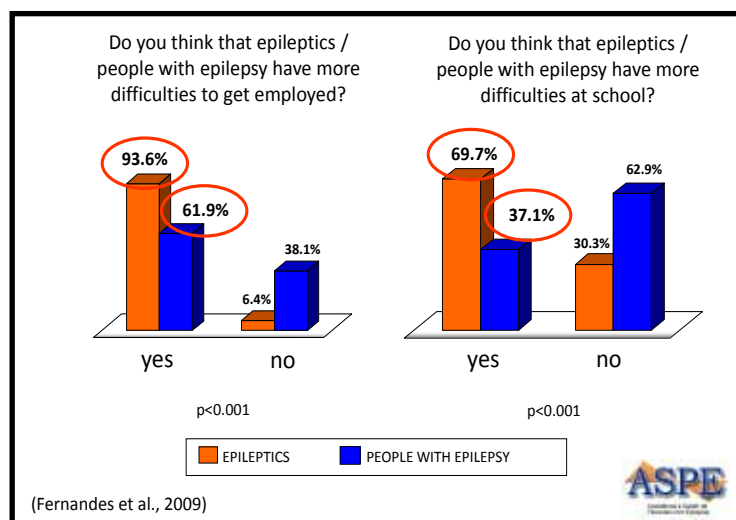
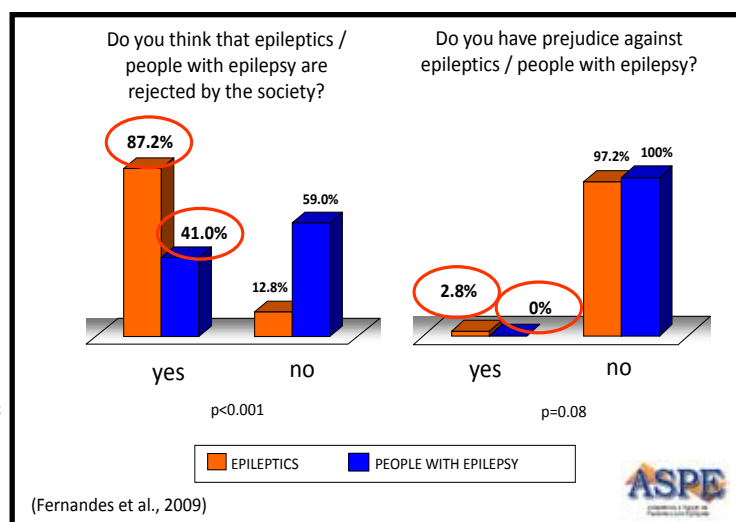
For statistical analysis we used a chi-square test for the four questions and independent t-test for the SSE scores to test group

differences. We also performed linear and binary regression analyses to determine whether sex, religion, or access to information about epilepsy explained the differences between the two groups. We did not use age, as it had a minimum variability. The level of significance was set at $p < 0.05$.

Results

Group-1 had 105 subjects (mean age = 16 years; CI = 15.9–16.3, SD = 1.0; 23.8% men; 83.8% of these students did not have information about epilepsy) and group-2 had 109 subjects (mean age = 16 years; CI = 15.8–16.1; SD = 0.8; 33.9% men; 82.6% of the subjects did not have information about epilepsy).

The differences between group-1 and group-2 for the four questions are shown in Tables 1 and 2.



Difference between "epileptics" and "people with epilepsy"

All indicated more negative perceptions in group-2 than in group-1.

The SSE score was higher indicating greater perceived stigma in group-2 (49, CI = 46.9–52.0) compared to group-1 (45, CI = 42.4–48.2) ($p = 0.03$). The linear and binary regression analyses using variable, sex, religion, access to information on epilepsy showed no significant differences between the two groups, and also they do not influence perceived stigma between groups 1 and 2.

Discussion

The results of this study demonstrate the importance of choice of language on perception and stigma. The term “epileptic” tends to elicit more negative perceptions and a higher degree of stigma than does “person with epilepsy.” According to the first four questions, we observed a large difference in responses depending on whether the expression used in the questionnaires was “epileptic” versus “person with epilepsy.” In addition, the SSE scores suggested higher stigma perception in teenagers using the term “epileptics” than in teenagers using the term “people with epilepsy.”

The two expressions we used are distinct; one is an adjective (epileptic) and the other a noun (person). Both of them carry some stigma “potential” (Schneider & Conrad, 1980); however, we found substantial differences when the emphasis was on the person compared to when it was on the disease. One study suggested that to “have” can imply possession and “to be” may imply identity. For this reason, it is less stigmatizing to use “to have” (Zola, 1988). Consequently, when the characteristic is negative, as is a disease, the recommendation was to use an expression that referred to a person with some characteristic. In some instances this is called person-first language (Zola, 1988).

Most models of stigma generally do not consider the subjective perception of stigma and emphasize the social context instead. A difference in perception is apparent between the two terms we used. This difference cannot be explained by social context alone. A model to explain social stigma must, therefore, consider more than a social context and include linguistic and other factors as well (Schneider & Conrad, 1980). The people learned, for example, how to proceed during an epileptic seizure, and this process can be maintained for one’s whole life. Maybe, for this reason, the learning process is very important to explain the differences between

the two terms of this study; on one hand you learn about a human being and on the other about a disease, with which you share no sympathy. This process of learning and consequent behavior is in part explained by our previous study on teenagers exposed to two situations of management of an enacted seizure: adequate versus inadequate approach. A group of teenagers exposed to an adequate management had a lower perception of epilepsy stigma than a group of teenagers exposed to inadequate management (Reno et al., 2007). So, also important is the emphasis on correct attitudes and correct information.

Another important aspect is the role of language in the thought process. In addition to differences seen on the effects of language on color discrimination (Winnawer et al., 2007), Boroditsky (2001) has shown that cultural background rooted on different language construction (English vs. Chinese Mandarin) can influence the thought about abstract domains such as time. Nevertheless, Chen (2007) was not able to replicate the findings of Boroditsky (2001). In a discussion with colleagues conducting a Demonstration Project in China, whereas epilepsy stigma is high, it appears that in Chinese Mandarin there are no such distinctions between epileptic (adjective) and person with epilepsy (noun) (W. Wenzhi, personal communication). Therefore, it reinforces the notion that the perception of stigma can also be influenced by language in the context of a given society.

Our study reflects the social attitude to epilepsy in a group of adolescents. At this age they are still forming values, attitudes, and behaviors, and consolidating their processes of concept building. The adolescents are part of a potential segment within the society in which intervention by means of adequate information could serve ultimately to reduce myths about epilepsy and minimize the effects of stigma.

In summary, the words we use can influence our perceptions and have consequences for social stigma. The use of “inadequate labels” hides the true identity of the person and can contribute to

increase the psychosocial difficulties. We recommend that we all refrain from using the term “epileptic,” and consider the effect of our choice of language and the consequences it may have in our efforts to bring epilepsy out of the shadows.

Acknowledgments

Limitations: This study was conducted with teenagers and cannot be generalized to other age groups. It should also be observed that the study was carried out in a Brazilian culture and the main determinant of the result was the local language (Brazilian Portuguese—Latin origin). It is necessary to conduct future studies in different societies, cultures, and to particularly assess this issue using other languages, such as those of Anglo-Saxon origin.

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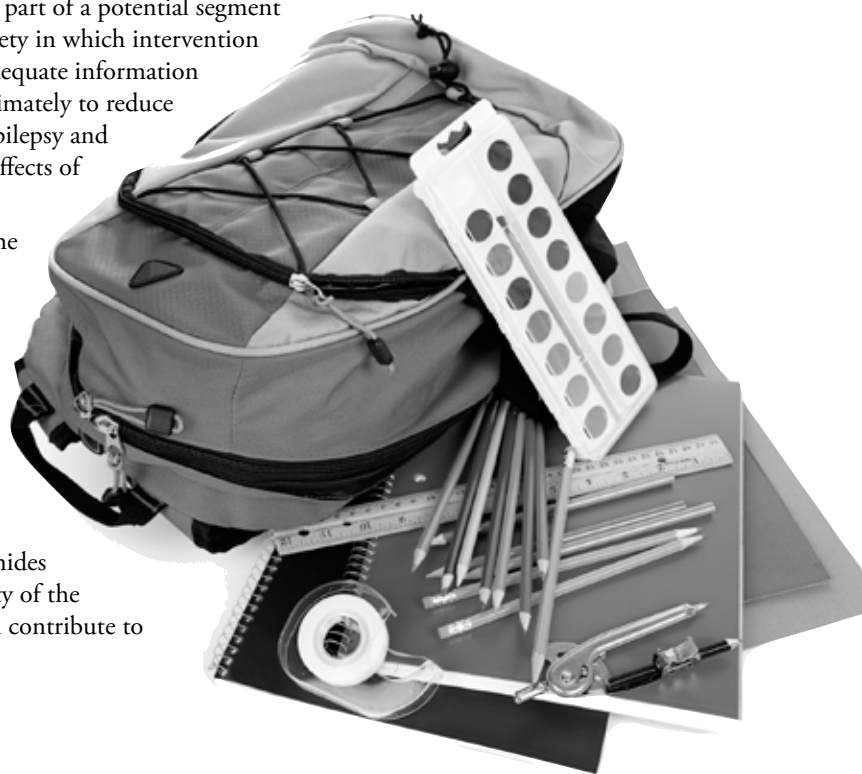
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Undergoes Rebranding

Enlighten-Action for Epilepsy, Hong Kong, has changed its charity colour and logo as part of a rebrand.

Claudia Schlesinger, CEO of Enlighten Hong Kong said, "Our new logo gives us a symbolic identity. The caring hand holding a burning candle aptly illustrates Enlighten's mission: To provide support and care to those affected by epilepsy. To remove prejudice through community education. The caring hand signifies our support for those with epilepsy, and the burning candle signifies our efforts towards lighting up the cause of epilepsy awareness and also for enlightening the lives of those affected by epilepsy."

The new logo also incorporates the name change in Chinese for epilepsy. The Chinese name for epilepsy was "Dean Gan" which translated into 'crazy' and was only recently changed to "No Gan" which translates into 'brain.'

"We hope this rebranding will help us reach more people affected by epilepsy. Our new website (www.enlightenhk.org) has incorporated the colour change and has been enhanced to be an online



knowledge resource, a knowledge portal for all ages to benefit from. It has a wealth of information about the challenges faced by people living with epilepsy and is targeted to different audiences.

"There are more than 64,000 people with epilepsy in Hong Kong, almost one percent of our population, but still the epilepsy knowledge and awareness is absolutely minimal.

"Enlighten runs various complimentary bi-lingual programmes including community support programmes to support those affected by epilepsy; education and training programmes to improve epilepsy knowledge and eliminate the unjustified stigma; community epilepsy awareness programmes to raise epilepsy awareness in the general Hong Kong community."



Vice President Latin America

Following the election of Carlos Acevedo to the position of IBE Secretary General, Lilia Núñez-Orozco, from Mexico, has been selected to be the new Vice President Latin America for the remainder of the current term. Dr Núñez was elected Chair of the Latin American Regional Executive Committee in 2009 and will continue to host this position also. The new Vice President was introduced to the General Assembly in Rome.

Changes on the Regional Committees:

- Mauricio Claves, Colombia, has accepted the invitation of the International Executive Committee to become a full voting member of the Latin American Regional Executive Committee.
- Following a change of career, Aisling Farrell has stepped down from the European Regional Executive Committee (EREC). Her duties as Secretary of the EREC will be looked after by Michael Alexa, who is also Vice Chair of the EREC.
- Svetlana Simich from Slovenia has agreed to join the EREC as a full voting member.
- Noeline de Goede has resigned from Epilepsy South Africa and stepped down from the African Regional Executive Committee. The arising vacancy is expected to be filled in the near future.



Photo: Floris Meinardi

Harry Meinardi

continues his personal memoir of IBE's interesting history

The information presented in the IBE Newsletter during the third constitutional quadrennial of IBE (1970-1974) reflects its growth. The profile of its working mode starts to develop contours that have withstood wear and tear.

Regularly, information is provided about new members, which can belong to one of three categories:

- 1) National and State Associations
- 2) Institutions
- 3) Individual Members

In this period four new National/State organisations joined, 5 Institutions, and 102

individual members, from 33 different countries. Reports are presented of the origins of member organisations and about their activities.

Denmark tells (Newsletter January 1970) how in 1958 almost simultaneously two organisations, one for professionals and one for lay persons devoid of medical partaking, were founded but that the latter, after four years, decided their organization was not viable without help from the doctors' group.

The origins of the New Zealand Epilepsy Association in 1956 are narrated in the April 1970. In 1970, the Czechoslovak Bureau for Epilepsy is established. The Turkish association, founded in 1968, becoming member of IBE in 1971, introduces itself as does the Korean National Epilepsy Association. The Indian Epilepsy Association reports that it has been formally registered in 1971.

There are, of course, also organisations with a more general scope as regards those with a disability that they try to support. Sometimes these organisations turn to IBE for advice or assistance for persons in their care who also suffer from epilepsy. Such an appeal came from the Association of Physically Disabled of Kenya (Newsletter July 1971). Sometimes they actually become members of IBE as was the case with Foyer Savoy Quebec, Canada, (Newsletter April

1970); The Foyer Léopold Bellan, Ile de France (Newsletter April 1970); the Royal Talbot General Rehabilitation Hospital in Victoria, Australia (Newsletter January 1971); the Nairobi Neurological Centre, Kenya (Newsletter January 1973).

Reciprocally, IBE hooked its earlier meetings on to meetings of more general organisations; it considers its first specific meetings to be the two "IBE European Institutes" held respectively in Paris, France (1967) and Dunblane, Scotland (1968).

Then from 1970 until 1975 the name IBE European Symposium was used, but counting was carried on.

The 3rd IBE European Symposium was held in Elsinore, Denmark and the answer to Hamlet's question was obviously "To Be!" Officers of the ILAE and IBE who were present at Elsinore held a joint meeting to discuss co-operation, in particular in countries and regions where epilepsy care was still underdeveloped - such as Africa, India and Latin America - but where focal points were available. In the Newsletter, the Secretary-General of ILAE is cited:

"It is evident that this is a vast programme which goes beyond the present scope and also the present means of the ILAE and the IBE, both financially and as regards personnel. Still this should not discourage us. Much can be achieved by making use of existing channels and programmes. In fact it would be completely useless to start activities without being informed, as well as possible, about programmes already in operation. On the other hand it may be feasible to obtain much larger funds than are at present available provided that: a) the problem is presented clearly, and that b) practical programmes of action are put forward."

As a first step, a meeting to discuss Treatment of the Epilepsies was planned to precede the Third Pan-American Neurological Congress in San Paolo, Brazil, February 1971. Not everyone in the ILAE executive agreed with the policy suggested by their Secretary-General, which led him to resign from his post. We shall see, when discussing the next quadrennial period, that the same forces in ILAE also opposed the activities of IBE in the developing world, which led to the resignation of IBE

1970-1973
Third constitutional quadrennial

Look Back with Pride



Secretary-General, George Burden, in 1977. In the previous quadrennial the Secretary-General had started to look into the best way to keep workers in the developing world abreast of modern approaches to the problems associated with epilepsy. In the July 1971 the Newsletter had to report that attempt to organise a workshop in Kampala, Uganda had failed. Twelve doctors and health workers would have attended from Uganda and only five, maybe less, from outside Uganda. This ignited the plan for a Travelling Workshop a concept which proved to work. A full report is presented in the September 1973 Newsletter.

Ghana, Sierra Leone, Nigeria, Uganda, Kenya, Tanzania, and Malawi were visited in a period of six weeks by Dr Maurice Parsonage, Dr Peter Jeavons, George and Sylvia Burden, and 1,100 persons were met and spoken with!

In the Newsletter, information from member organisations about issues in their

country could have stimulated awareness and action elsewhere, such as “driving licences for persons with epilepsy” (Newsletter July 1970), “special medical and rehabilitation centres” (Newsletter January 1971), and “changing public attitudes”, for example the unwillingness (at that time) of hotels and boarding houses in England to accept guests with epilepsy for fear of upsetting their clientele (Newsletter July 1971).

Apart from the Newsletter itself, IBE fulfils its objective, to increase awareness, understanding and knowledge of epilepsy and how best to meet the needs of people affected by epilepsy, by initiating in 1969 a Film Festival where films dealing with various aspects of epilepsy are shown and compete for an award. Subsequently a film catalogue was produced and distributed.

Furthermore an International Glossary of Anticonvulsants was produced. In the first (1969) edition 19 generic drugs and 105 listed by proprietary names were described.

The second (1971) edition, comprised 72 generic drugs and 379 listed by proprietary names. Five thousand copies of the 2nd edition were distributed free of charge.

This period ends with the IBE General Assembly in Barcelona, November 1973. A revised constitution was adopted with a number of amendments which all served to bring the organization of the ILAE and IBE closer together. From then on the Executive Committees will include the President and Secretary-General of its counterpart as ex-officio members. Another new member of the IBE executive was the appointment of an honorary editor of the Newsletter, a task until then taken care of by the Secretary-General.



A reel of memories from the international epilepsy congress

Snapshots of Rome



Spiralling upwards from bottom left:

- 🌀 A special birthday cake to celebrate IBE's 50th Anniversary. A surprise for participants attending IBE's General Assembly.
- 🌀 Hanneke de Boer and Caroline Morton on duty at the Global Campaign Against Epilepsy section of the IBE Exhibition Booth, with posters celebrating IBE in the background.
- 🌀 Participants attending the Editors Network meeting, chaired by Robert Cole. Pictured back row, from left: Shichuo Li, China; Hidemoto Kubota, Japan; Yuan-fu Tseng, Taiwan; Michael Alexa, Austria, Paul Sharkey, Ireland; Helinä Kujansuu, Katja Seppinen, and Sari Tervonen, Finland; René Børg-Larsen, Denmark; Peter Murphy, Ireland; Vinod Saxena, India. Front row, from left: Ann Little, IBE; Ding Ding, China; Susanne Lund, Sweden; Robert Cole, Australia; Victoria Dimech, Malta; Rajib Kissani, Morocco.
- 🌀 Rosey Panelli, Australia, receives her Ambassador for Epilepsy Award from Nico Moshé, ILAE President (left) and Mike Glynn, IBE President (right).
- 🌀 Shunglon Lai, IBE Vice President Western Pacific, and an Ambassador for Epilepsy, at the special Ambassadors evening.
- 🌀 Pravina Shah, India, is presented with the Social Accomplishment Award by Mike Glynn (left) and Nico Moshé (right).
- 🌀 IBE Milestones: a special poster exhibition highlighting important events in IBE's 50 years of service to people with epilepsy.
- 🌀 From left: Donatella Amicucci, Massimo Martinelli, Tenente-Colonnello of the Banda dei Carabinieri and Annalisa Amicucci. Thanks are due to Donatella for her great help with the special concert at the Auditorium Conciliazione, IBE's birthplace in 1961!
- 🌀 Mahlalela Mbusomuni, Swaziland, attending the meeting of the African Regional Committee.
- 🌀 A group photograph of Ambassadors for Epilepsy, who have been presented with their Ambassador pins since the award was first suggested by IBE in 1967. Several former recipients of the award had travelled to Rome specifically to attend the special Ambassador's evening, organised by IBE as part of its Golden Jubilee celebrations.
- 🌀 Enjoying the Ambassadors evening, from left Danielle Wiebe, Canada; Tita Perucca, Italy; Natalie Wiebe, Joanna Wiebe, and Ana Wiebe, Canada; and Masako Watanabe, Japan
- 🌀 Athanasios Covanis, Chair of the IBE European Regional Committee (Greece) with Simon Shorvon (UK), two of the more than one hundred Ambassadors who attended the Ambassadors evening.
- 🌀 Mike Glynn, IBE President, with the scroll presented to IBE by ILAE to mark its Golden Jubilee.
- 🌀 Eleven of the 12 new Ambassadors for Epilepsy, who were presented with their Ambassador pins in Rome, from left: Steven Schachter, USA; Eli Mizrahi, USA; Jaime Fandiño-Franky, Colombia; Walter van Emde Boas, Netherlands; Rosey Panelli, Australia; Susan Axelrod, USA; Asla Pitkänen, Finland; Hasan Aziz, Pakistan; Wolfgang Löscher, Germany; Weiping Liao, China; Lionel Carmant, Canada. Missing from the photograph is Andres Kanner, USA.

459 MEPs Stand Up for Epilepsy!

IBE is delighted to announce that on 15th September 2011, the European Written Declaration on Epilepsy was passed by the European Union (EU) Parliament. This was a very significant moment for all people who have been fighting over the years for just recognition of the importance of epilepsy in the political agenda of Europe.

In order to have a written declaration approved, a majority of the 768 elected MEPs (i.e. 369 MEPs) must sign it within a tight time limit. When the declaration closed for signatures it had received 90 more signatures than was required for approval. With the signatures of 459 MEPs supporting the declaration, it has the third highest number of signatures of all disease related declarations since 2004 – which are the earliest available records.

This great achievement is thanks to the IBE members and ILAE chapter associations in Europe who diligently and repeatedly contacted their local MEPs to encourage them to sign.

Particular thanks are due to those who were able to travel to Strasbourg and Brussels to meet with MEPs during the monthly plenary sessions, to talk to them about epilepsy issues and the declaration itself: Christian Elger (Germany); Mike Glynn (Ireland); Astrid Nehlig (France); Guido Rubboli (Italy); Wim van Paesschen (Belgium), Hanneke de Boer (Netherlands) and Pete Scott (UK). We appreciate very much that they took time out of their busy schedules to assist us.

The declaration was initiated by the European Advocates for Epilepsy Working Group, working with the IBE/ILAE Joint Task Force: Epilepsy Advocacy Europe, and was submitted by its President, Gay Mitchell MEP. Four other members of the European Advocates for Epilepsy Working Group were also signatories: Marian Harkin MEP (Ireland), Nirj Deva MEP (UK), Angelika Werthmann MEP (Austria); and Peter Skinner MEP (UK). Special thanks are due to these five MEPs, without whom the declaration would not have been introduced; to all members of the European Advocates for Epilepsy group, who encouraged their national and party group colleagues to sign; and, of course to all the MEPs who supported the Declaration with their signature. Within the next few weeks the Written Declaration on Epilepsy will be officially communicated from the



European Parliament Building, Strasbourg

Front cover: images of the 459 MEPs who signed the declaration

Parliament to the Commission and to the Parliaments of the EU Member States.

So, what will a Written Declaration on Epilepsy mean for people with epilepsy and their families? At national level, the Declaration demonstrates that the EU Parliament recognises the need for improved services for people with epilepsy. This is an important mechanism for those who have epilepsy, their families, friends and carers, as well as for ILAE and IBE associations, to approach national governments and advocate for improved allocation of resources to epilepsy care. There have already examples of this occurring successfully not only in some EU member states, but also in countries outside the EU.

Epilepsy research is grossly underfunded in the EU. The Written Declaration signals to the European Commission the need to support research on the mechanisms of epilepsy and the development of more effective treatments.

Equally, there is a need for a European-wide awareness program to address the stigma which affects all aspects of the life of people with epilepsy, including legislation, schooling, employment, and personal

relationships. Meetings have already been initiated with DG Sanco (the EU Health Commission) and the EU Research Commission to seek their support.

With epilepsy now recognised as a health priority by the World Health Organization (WHO), the Pan American Health Organization (PAHO) and the US Institute of Medicine (IOM), endorsement of the Written Declaration on Epilepsy by the European Parliament will add further impetus to this international effort.

IBE and ILAE, supported by the European Advocates for Epilepsy Group in the EU Parliament, are working towards the creation of the first European epilepsy programme. The Written Declaration is the first essential step in this direction.

A special workshop on Epilepsy and Sport will take place at the end of November in the Brussels parliament, hosted by MEP Angelika Werthmann and organised jointly by the European Advocates for Epilepsy Working Group and Epilepsy Advocacy Europe. At the time, the Epilepsy Advocacy Europe task force will also finalise first plans for European Epilepsy Day February 2012.

EUROPEAN WRITTEN DECLARATION ON EPILEPSY

No 22/2011

Submitted by **MEPs Gay Mitchell, Nirj Deva, Marian Harkin, Peter Skinner, and Angelika Werthmann**

The European Parliament,

- having regard to Rule 123 of its Rules of Procedure,
- A.** whereas epilepsy is the most common serious disorder of the brain,
- B.** whereas 6 000 000 people in Europe have epilepsy, with 300 000 new cases diagnosed each year,
- C.** whereas up to 70% of people with epilepsy could be seizure-free with appropriate treatment, while 40% of people with epilepsy in Europe do not receive such treatment,
- D.** whereas 40% of children with epilepsy have difficulties at school,
- E.** whereas people with epilepsy in Europe experience high levels of unemployment,
- F.** whereas people with epilepsy are exposed to stigma and prejudice,
- G.** whereas epilepsy damages health but also disrupts every aspect of life, and can impose physical, psychological and social burdens on individuals and families,
- 1.** Calls on the Commission and Council to:
 - encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy;
 - prioritise epilepsy as a major disease that imposes a significant burden across Europe;
 - take initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice;
 - encourage effective health impact assessments on all major EU and national policies;
- 2.** Calls on the Member States to introduce appropriate legislation to protect the rights of all people with epilepsy;
- 3.** Instructs its President to forward this declaration, together with the names of the signatories, to the Commission and the Parliaments of the Member States.



Rewarding contributions to IE News

This special award will reward the best contribution submitted to International Epilepsy News and has been introduced as part of IBE's Golden Jubilee celebrations and to mark 48 years of IE News, the quarterly magazine of IBE.

Whether you report on epilepsy at international or local level, on medical or social aspects of the condition, you could win this great award!

Award Rules

- Reports and articles, to be considered for the award, must be submitted by email to ibedublin@eircom.net before the closing date of 31st December 2011.
- Articles must be written in English and be the original work of the applicant.
- The article must be between 750 and 2000 words in length.
- Photographs may accompany the submission but it is not compulsory to do so.
- IBE reserves the right to publish any article submitted.

Prize

There will be one prize winner, who will receive financial support to attend an IBE or IBE/ILAE congress of the winner's choice, up to a maximum of US\$2,000. The prize funds may not be used for any other purpose and must be used before the end of 2013.

Award Criteria

An independent judging panel will judge entries, looking for responsible, informed and original stories. Entries will also be assessed on the following specific criteria. The work:

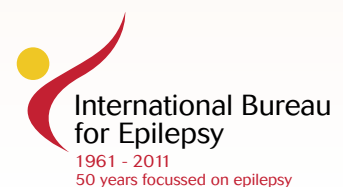
- Helps increase awareness and understanding of epilepsy
- Gives a voice to people with epilepsy
- Is well researched, compelling, and uses language responsibly when writing about epilepsy.

Remember!

Closing Date: 31st December

Entries to: ibedublin@eircom.net

Good Luck!



The Americas resolve to support Strategic Plan on Epilepsy

Participants attending the special PAHO workshop in Honduras to launch the Strategic Plan on Epilepsy



El jueves 29 de septiembre, en la 51ª Asamblea de la Organización Panamericana de la Salud (OPS), realizada en la ciudad de Washington, fue aprobado el Plan Estratégico para las Epilepsias, que implica que la epilepsia constituirá, por los próximos 10 años, una prioridad en los planes nacionales de salud de cada uno de los países de las Américas. Las firmas de los Ministros cierran un proceso de un año en el cual, dentro del marco de la Campaña Mundial “Sacando a las Epilepsias de las sombras”, la OPS, ILAE e IBE, representados por el Dr. Jorge Rodríguez, Dr. Marco Tulio Medina y Dr. Carlos Acevedo, elaboraron el Plan Estratégico, recibiendo información de la OMS, Europa, Norteamérica y Latinoamérica, lo que permitió la edición de un documento técnico con una sólida base, especialmente por la revisión realizada en OPS.

El Plan Estratégico, fue lanzado oficialmente en un Taller Regional Latinoamericano entre el 19 y 21 de octubre en Honduras. Asistieron las autoridades máximas de la ILAE e IBE, además de la Dra. Tarun Dua en representación de la OMS y Hanneke de Boer en representación de la Campaña Global contra la Epilepsia (GCAE).

En el curso del Taller se presentaron las visiones de la OPS, ILAE e IBE y se analizó las realidades en salud de algunos países en Latinoamérica, particularmente de Centroamérica y el Caribe. En el último día se realizó un Taller especial dedicado

a establecer las líneas generales más importantes que debiera cubrir este Plan Estratégico. Además, en una reunión entre el encargado de Salud Mental de la OPS y los Presidentes de ILAE e IBE, los Doctores Tarun Dua, Hanneke de Boer, Marco Tulio Medina, Carlos Acevedo y Lilia Núñez Orozco se acordó firmar, a futuro, una Carta Acuerdo para delimitar la forma en que se va a desarrollar el Plan Estratégico y que expresamente excluye compromiso monetario de los participantes.

Además se acordó la formación de una Task Force que va a dirigir el Plan Estratégico que está conformada el Dr. Jorge Rodríguez, representando a la OPS, los Doctores Marco Tulio Medina, Alejandro Scaramelli y Manuel Campos representando a la ILAE y los Doctores Carlos Acevedo, Lilia Núñez Orozco y Li Li Min, representando al IBE, con el fin de preparar un plan de trabajo para el año 2012, que defina las actividades concretas con las cuales se va a dar comienzo a esta iniciativa regional.

La implementación efectiva de la estrategia regional en los distintos países de las Américas implicará la participación de los mejores expertos en cada uno de las áreas prioritarias definidas en el Plan Estratégico, lo cual será una de las primeras medidas que tomará el grupo de trabajo.

Los Presidentes de la ILAE e IBE, Solomon Moshe y Mike Glynn, enviaron una carta a todos los Ministros de Salud de las Américas para agradecer su apoyo a

la iniciativa. Todas las ideas y sugerencias que puedan ustedes hacer llegar a la Task Force serán bienvenidas, las cuales deben ser canalizadas a sus miembros integrantes.

No podemos sino felicitarnos por constituir América la primera región del mundo en iniciar un Plan de esta naturaleza, el cual servirá de espejo y modelo a otras regiones en el futuro. Desde el inicio, ha existido un gran interés y una participación destacada de Norteamérica en la elaboración del proyecto. Es así como, durante el próximo Congreso de la American Epilepsy Society (AES) en Baltimore, se sostendrá una reunión de trabajo entre los miembros latinoamericanos y norteamericanos de los Comités Regionales.

Es nuestro compromiso mantenerlos informados regularmente, porque es necesario comenzar a trabajar en las actividades que se desarrollarán localmente en cada uno de los países.

Finalmente, creo indispensable recordarles que la implementación del Plan Estratégico es responsabilidad de los gobiernos y nosotros, como organizaciones científicas y sociales, tendremos que ayudar a los Ministerios de Salud, en cada uno de los países, a buscar cuáles son las acciones más importantes a desarrollar y no olvidar que disponemos de un plazo de 10 años para ello.

El Plan Estratégico para las Epilepsias se encuentra disponible en la página web de la GCAE: <http://www.globalcampaignagainstepilepsy.org>

Carlos Acevedo, IBE Secretary General and one of the key people involved in ensuring its adoption, brings us up to date on this very significant plan that sets epilepsy as a health priority for the next decade throughout the Americas region

On Thursday 29th September, at the 51st Assembly of the Pan American Health Organization (PAHO), in Washington DC, the Strategic Plan for Epilepsy was approved. This means that epilepsy will constitute, for the next 10 years, a priority in the national health plans of each country in the Americas. The signatures of the Ministers closed a year long process in which, under the banner of the Global Campaign Against Epilepsy 'Out of the Shadows', PAHO, ILAE and IBE, represented by Dr Jorge Rodríguez, Dr Marco Tulio Medina and Dr Carlos Acevedo, developed the Strategic Plan, with information from the WHO, Europe, North America and Latin America, which enabled the creation of a technical document with a solid base, for review by PAHO.

The Strategic Plan was officially launched in a Latin American Regional Workshop from 19th to 21st October, in Honduras. Participants included the highest officers of IBE and ILAE, as well as Dr Tarun Dua representing the WHO and Hanneke de Boer representing the Global Campaign Against Epilepsy (GCAE). During the course of the workshop, the visions of the WHO, ILAE and IBE were presented and the health situation in some countries in Latin American, in particular those in Central America and the Caribbean regions, were discussed.

On the last day a workshop took place dedicated solely to establishing the most important issues that the Strategic Plan should cover. In addition, during a meeting between Mental Health leaders of PAHO and the Presidents of IBE and ILAE, Dr Tan Dua, Mrs Hanneke de Boer, Dr Marco Tulio Medina, Dr Carlos Acevedo and Dr Lilia Núñez Orozco agreed to sign a Letter of Agreement to limit the form in which the Strategic Plan can be rolled out and which expressly excludes monetary commitment to the participants. In addition, it was agreed to form a Task Force that will direct the Strategic Plan, whose members will be Dr Jorge Rodríguez, representing PAHO; Doctors Marco Tulio Medina, Alejandro Scaramelli and Manuel Campos, representing ILAE and Doctors Carlos Acevedo, Lilia Núñez Orozco and Li Li Min, representing IBE; with the aim of preparing a work plan for

2012, which will define the concrete activities that will begin this regional initiative.

Effective implementation of the regional strategy in the various countries in the Americas, will involve participation of the best experts in each of the defined areas of priority in the Strategic Plan, which will be one of the first issues to be addressed by the working group. ILAE President, Nico Moshé and IBE President, Mike Glynn, will send a letter to each of the Ministries of Health in the Americas region to seek their support for the initiative. All ideas and suggestions of IBE and ILAE members and other interested parties will be gladly received by the Task Force.

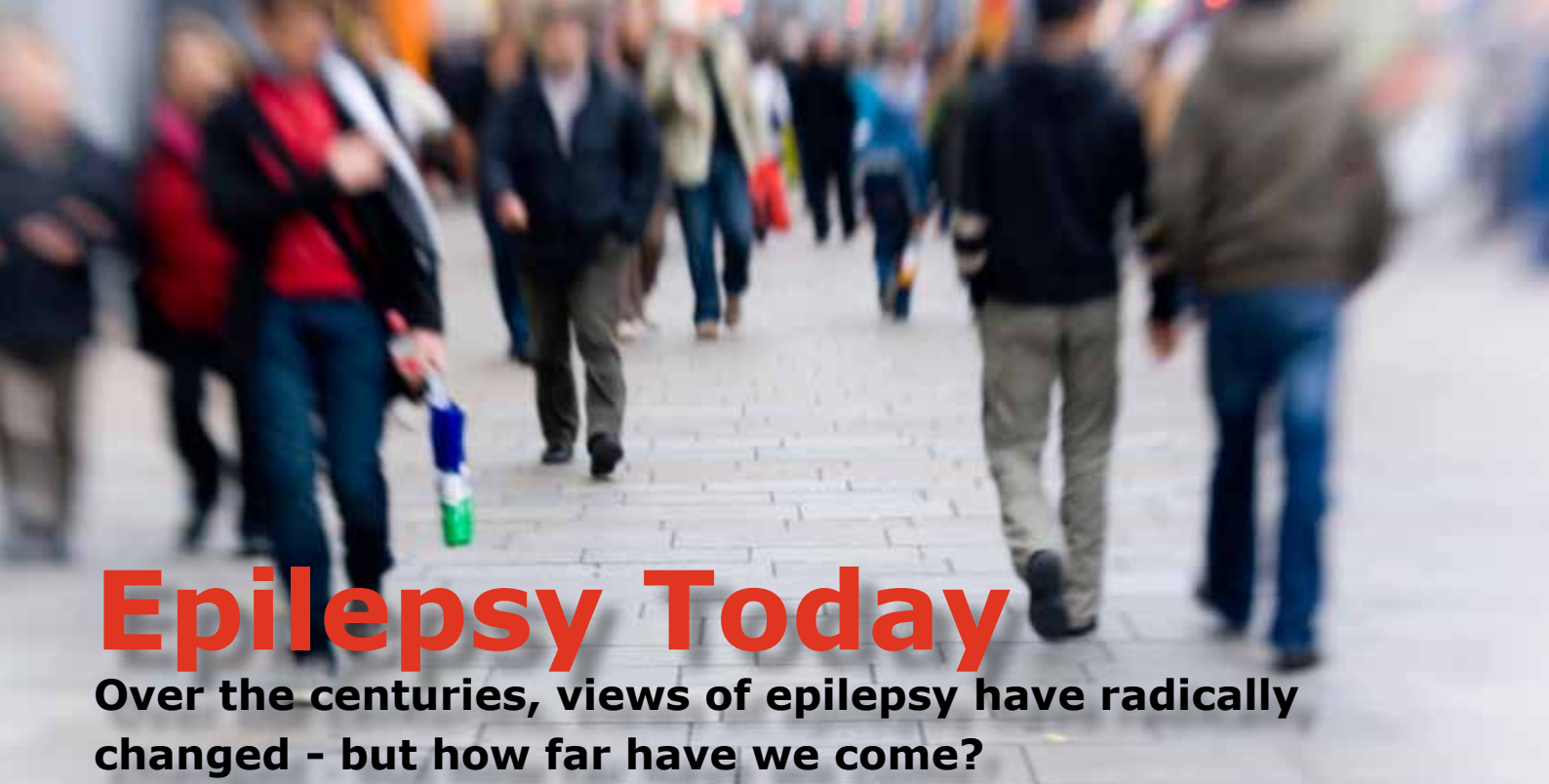
We celebrate the fact that America is the first region in the world to initiate a Plan of this nature, which will serve as a mirror and a model to other regions in the future. From the start, there has been great interest and participation by North America in the development of this project. For example, during the next congress of the American Epilepsy Society (AES) in Baltimore, a working meeting will take place involving members of the Latin American and North American regional committees.

We promise to keep you informed regularly of developments, because it is necessary to begin work on activities that will be rolled out locally in every country.

Finally, I believe that it is vital to remind you that the implementation of the Strategic Plan is the responsibility of governments and that we, as social and scientific organisations, much assist the Ministries of Health, in each of country, to establish which are the most important actions to undertake and to remind ourselves that we have a timespan of 10 years to achieve this.

The Strategic Plan for Epilepsy can be found on the webpage of the Global Campaign Against Epilepsy <http://www.globalcampaignagainstepilepsy.org>.





Epilepsy Today

Over the centuries, views of epilepsy have radically changed - but how far have we come?

With 2.4 million new cases globally each year and a tremendous advancement in treatments in the last century, the future for people with epilepsy is, in theory, better than ever. But due to persistent misconceptions and a shortage of treatment availability, particularly in under-resourced nations, there is still great room for improvement.

So just how much have the lives of people with epilepsy changed, and what progress is needed?

Recognition and funding

Epilepsy imposes a heavy burden on societies worldwide. Its economic implications relate to health care needs, premature death and lost work productivity. One Indian study calculated the total cost per epilepsy case was US\$344 per annum or 88% of the average income per capita¹.

Yet even the most developed nations are not allocating enough funds to address the sweeping needs of the condition.

In the US, epilepsy receives far less funding than other neurological disorders such as stroke, dementia or Parkinson's disease, which affects a quarter of the number of people². Epilepsy research funding in the US in 2009 worked out at about US\$35 a patient compared to US\$129 for Alzheimer's disease and US\$280 for multiple sclerosis³. Yet epilepsy is about 10 times more common than multiple sclerosis³.

Australia also experiences under-funding for research, whether through stigma, lack of interest or knowledge, says neurologist Dr Andrew Bleasel, director of the Epilepsy Unit at Sydney's Westmead Hospital and President of the Epilepsy Society of Australia.

Much of the problem globally stems from inadequate and dated information about how epilepsy affects every aspect of life, from mental health and employment to activities like driving. In the US, according to Edwin Trevathan, MD, Dean of the St Louis University School of Public Health and a member of the *Neurology* journal's editorial board, "our health leaders and some of our best researchers are analysing data that are 30 to 50 years old."

Treatment advances

Approximately 70% of people have seizures that could be stopped or well controlled by antiepileptic medications without major side effects. Of the remaining 30%, about a third could be helped with surgery that, due to medical advances, has become much safer.

Vagal Nerve Stimulation is being more widely used, and deep brain stimulation offers much hope. "Surgery is under-utilised because it's considered a last resort or too risky so it's mainly a question of perception," says neurologist Prof Ernie Somerville, Director of the Comprehensive Epilepsy Service of Sydney's Prince of Wales Hospital and regional chair of The Global Campaign Against Epilepsy.

For paediatrics, the biggest improvement is thoroughly tested new drugs that have become available in the last 10 years – since the US Food and Drug Administration and European Drug Commission began to approve drugs only after they had been trialled both on children and adults.

There's also been renewed interest in eating plans like the ketogenic diet, which was popular in the 1920s and 1930s and

involves a high fat, rather than high carbohydrate, diet causing the body to produce ketones that have an antiepileptic effect for some people.

Stigma

Historically, ignorance has led to cruel and inappropriate treatment of people with epilepsy. Some were placed in psychiatric wards, others not allowed to attend school or forbidden by law to marry (legislation not repealed until 1970 in the UK¹, and 1999 in India) or have children.

Despite 1% of the world's population having active epilepsy at any one time, many harmful misconceptions linger. These include that epilepsy is a mental illness or contagious.

The Global Campaign Against Epilepsy – an initiative of the International Bureau for Epilepsy, the International League Against Epilepsy and the World Health Organization – has helped raise awareness within governments and communities worldwide.

Groups like Australia's Parliamentary Friends of Epilepsy, established in 2008, have made inroads raising awareness within government.

In Europe, a special interest group of MEPs (Members of the European Parliament) – European Advocates for Epilepsy – has been created. In the Americas, PAHO and WHO have recently established epilepsy as a health care priority in the region.

The media can also play a role in reducing stigma. Television shows such as America's *House* and Australia's *Packed to the Rafters* have recently featured epilepsy storylines.

Developing countries

According to the World Health Organization, nearly 90% of people with epilepsy live in developing regions where treatment is often limited, under-resourced or not prioritised¹. In Africa, 9 out of 10 people with epilepsy remain untreated.

In developing countries, including much of Africa and South East Asia, many cases are related to preventable parasitic diseases such as malaria, neurocysticercosis (tapeworm in the brain) and schistosomiasis (disease caused by worms). "A very small expenditure, mostly on educating health professionals, could change the world for people in developing countries," says Dr Bleasel. "Very cheap drugs can have an enormous impact too."

In such nations, often there are not people trained to diagnose and treat epilepsy, and medication may be unavailable or unaffordable. "It's relatively common among nursing staff to have supernatural beliefs about epilepsy and be unaware it's treatable," says Prof Somerville, who established the East Timor National Epilepsy Training Program, which carries out community education and trains health workers. "They often don't think it's a medical problem but that it's caused by evil spirits; a curse; the sins of your ancestors; or food."

The solution is coming in the form of education and funding that also contributes towards more advanced drugs than the inexpensive Phenobarbital – used routinely in the developing world but rarely in the developed world due to adverse side effects. "One of the other issues is competition from other health problems like malaria, tuberculosis and HIV and trying to get health departments, who have to deal with epidemics, to realise epilepsy is worth worrying about," says Prof Somerville.

Social impacts

In developed nations social problems and unemployment are higher among people with epilepsy. In the UK about 50% of people with epilepsy are unemployed or underemployed. That spikes to 100% in some developing countries⁴.

Some studies estimate as many as 55% of people with epilepsy will experience depression in their lifetime, and 10% to 25% will have anxiety disorders. Generally the higher the burden or impact of epilepsy (usually because of poor seizure control) the greater the likelihood of developing depression and anxiety⁵.

Depending where you live, not being able to drive because you have epilepsy can be a huge concern. Prof Somerville, who is chair of the Epilepsy Society of Australia's

driving committee, says "for a lot of Australians driving is the most important disability that epilepsy produces, whereas in developing countries it's not an issue." In children, the entire family is affected with parents "missing work and the family being incredibly socially restricted, not going on holidays or even going out in public, so they can be in much more social isolation," says Dr John Lawson, child neurologist and epileptologist at Sydney Children's Hospital.

Research measuring impacts includes:

- The 2004 US study 'Special Education Needs of Children Newly Diagnosed with Epilepsy' concluded that children with epilepsy face a range of social problems including social isolation, poor education results and behavioural difficulties because of the implications of being diagnosed with a chronic illness, drug side-effects, seizure effects and the behavioural and cognitive consequences of the condition.
- Canada's 2007 'Long-term Social Outcomes for Children with Epilepsy' found that children and teens with epilepsy would be more likely as adults to have social problems such as unemployment, fewer social relationships including marriage, and would be less likely to live independently than the rest of the population, including people with other chronic childhood diseases.
- The 2008 Japanese study 'Factors Associated with Impaired Quality of Life in Younger and Older Adults with Epilepsy' discovered that depression suffered with epilepsy will have the greatest impact on quality of life, even more than seizure frequency. As depression increases likelihood of suicide, psychological assessment and treatment of people with epilepsy is important.

With this insight and increased awareness, health professionals are more likely to be able to identify those who are at increased risk of developing mental health problems and detect issues when they arise. Early recognition and management of psychiatric disorders in people with epilepsy is extremely important because it improves quality of life, decreases risk of suicide, and helps improve seizure control⁶.

Research projects

Epilepsy research is enormously broad and comprehensive with numerous programs underway at any given time, each making a valuable contribution to epilepsy

knowledge. These span many scientific disciplines and areas of exploration⁷.

Research into epilepsy has progressed rapidly over the last 30 years⁴.

There are two chief fields of enquiry: Laboratory research and Clinical Research. These two fields are complementary and using them in tandem is enabling speedier application of scientific findings in neurological patients. The potential now for rapid breakthroughs leading to better clinical care is unprecedented.

Overall progress

In developed countries, more advanced drugs and growing awareness of beneficial effects and side-effects have made a considerable difference, as has improvement in surgery and diagnostic equipment like MRI. But, says Prof Somerville, "we need better drugs because there are still a significant number of people who aren't well controlled and aren't amenable to surgery. And we need ways to predict which drug is the best in any given person."

Greater knowledge of epilepsy within the health field and more services for all aspects of life affected by the condition has made a big impact. "Another important step would be having more people involved in epilepsy care and improving the overall care," says Dr Lawson.

The future is bright if we continue to raise awareness and funds, reduce stigma and improve treatments. Overcoming the barriers is particularly important in developing countries where the biggest gains can be made.

"Because the room for improvement is so massive you can improve people's lives enormously," says Prof Somerville.

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IBE acknowledges with grateful thanks, permission of Epilepsy Action Australia to reproduce from an article published in its September 2011 edition of Epilepsy360°.

Celebrating 125 Years of Service



Significant year for Swiss Epilepsy Centre

This year the Swiss Epilepsy Centre in Zürich, an Associate Member of IBE, is celebrating its 125th anniversary. The EPI, as it is usually called, was founded by a Christian Association in 1886, dedicated to help people with epilepsy, “the poorest of the poor”. Since its foundation in the 19th century, the Swiss Epilepsy Centre, whose impressive grounds are pictured above, has developed into a specialised centre for comprehensive epilepsy care. It offers ambulatory as well as inpatient care in the short-stay department. It also provides surgical treatment for people with epilepsy in co-operation with the nearby University Hospital. The EPI also includes a long-stay department for 177 residents with disabilities and epilepsy. The Swiss Epilepsy Centre is run by the Swiss Epilepsy Foundation, which supports the Centre with private funds for buildings, research, social tasks, public relations, projects, and other activities.

On the occasion of its 125th anniversary the Swiss Epilepsy Foundation invited the European Association of Epilepsy Centres (EAEC) to hold its 20th meeting at the EPI in Zürich. Twenty-two colleagues (pictured below) from various Epilepsy Centres in Europe attended the meeting in January this year.

The EAEC was founded in 1988 by the initiative of the Swiss Epilepsy Centre. The Medical and Managing Directors of the Epilepsy Centres meet once a year to discuss strategic management issues of Epilepsy Centres. All the member centres of the EAEC were founded at least a hundred years ago or more, mostly by Christian associations, offering special care for people with epilepsy. The following Epilepsy Centres are members of the EAEC:

- Epilepsihospitalet Filadelfia, Dianalund, Denmark
- Etablissement Medical de la Teppe, Tain l'Hermitage, France

- V. Bodelschwingsche Stiftung Bethel, Germany
- Epilepsie-Zentrum Bethel, Germany
- Epilepsie-Zentrum Berlin-Brandenburg, Germany
- Diakonie Kork Epilepsiezentrum, Germany
- Sächsisches Epilepsiezentrum Radeberg, Germany
- Epilepsiecentrum Kempenhaeghe, Heeze, Netherlands
- Stichting Epilepsie Instellingen, Heemstede, Netherlands
- The National Centre for Epilepsy, Sandvica/Oslo, Norway
- Schweizerisches Epilepsie-Zentrum, Zürich, Switzerland
- The National Society for Epilepsy, Bucks, UK

At this year's meeting the EAEC discussed, in particular, the important issue of co-operation between Epilepsy Centres and University Hospitals. The discussion also

covered hot topics like reimbursing systems, comprehensive epilepsy care, trends in ambulatory care, patient safety, etc. To manage an Epilepsy Centre always requires a combination of medical, organizational and financial perspectives. Sharing experience through annual meetings has proven to be a very valuable activity for the association.

*Report by
Christoph Pachlatko
Managing Director
Swiss Epilepsy Foundation*





Dispelling Darkness

The traditional "Lighting the Lamp" ceremony at the start of a satellite meeting of the IBE South East Asian Regional Committee held during the annual ECON conference of the Indian Epilepsy Association and the Indian Epilepsy Society, in Kochi in early August. Pictured from left: Dr HV Srinivas, Dr Vinod Saxena, Mr Mike Glynn, Dr Man Mohan Mehndiratta and Dr B Rajendran.

In June, IBE President Mike Glynn paid a visit to Zambia, at the invitation of Epilepsy Association of Zambia. Of his experience, he reported:

"An impressive schedule of events was prepared by Anthony Zimba, IBE Vice-President Africa and his excellent team, which included inspection of Promising Strategies projects in Lusaka; visits to hospitals, schools, Ministry of Health, WHO, and medical societies; a huge round of press, radio and media engagements, together with a wonderful walk for epilepsy in which hundreds took part.

All of the activities were both productive and informative, and provide a solid base on which to work in preparation for the proposed 1st Regional Epilepsy Congress in Africa in 2012."



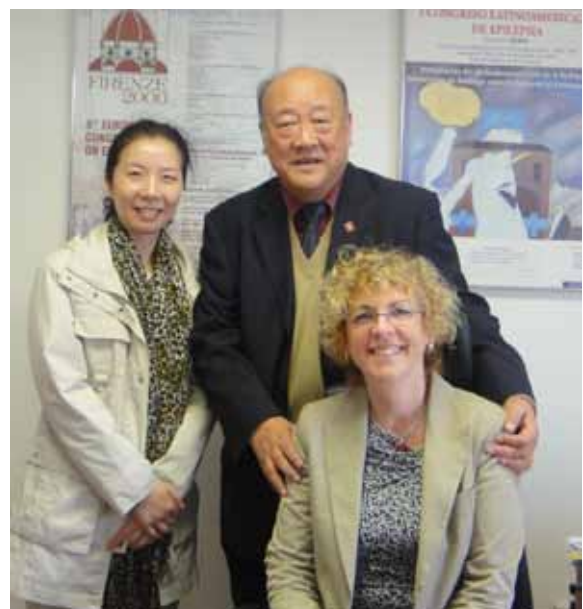
A Visit to AFRICA

To China and Back!

The 4th China International Epilepsy Forum, organised by China Association Against Epilepsy (CAAE) took place in Nanjing City in Jiangsu Province from 21st to 24th September. Pictured, below left, are speakers from the event (from left): Dr Ding Ding (Huashan Hospital, Fudan University Shanghai); Dr Ping Liu (UCB China); Dr Dong Zhou (Huaxi Hospital, Sichuan Province); Anchor Hung (Hong Kong Society for Rehabilitation); Dr Zhen Hong (Huashan Hospital, Fudan University Shanghai);

Hanneke de Boer, SEIN Netherlands; Mike Glynn, IBE President; Dr Shichuo Li (CAAE); Dr Yi Wang (Children's Hospital, Fudan University Shanghai).

In turn, IBE was delighted to welcome a delegation from the China Association Against Epilepsy, who visited the office in Dublin on 4th November. Pictured below, from left, are: Dr Ding Ding, Dr Shichuo Li and Ann Little.



Future Congresses 2012



**9th Asian Oceanian
Epilepsy Congress**
Manila, Philippines
22nd - 25th March 2012
www.epilepsymanila.org



**1st African
Epilepsy Congress**
Nairobi, Kenya
21st - 23rd June 2012
www.epilepsycongress.org



**7th Latin American
Epilepsy Congress**
Quito, Ecuador
14th - 17th November 2012
www.epilepsyquito2012.org



Congress Secretariat: 7 Priory Hall, Stillorgan, Dublin 18, Ireland
Telephone: ++353-1-20-567-20 Email: info@epilepsycongress.org
www.epilepsycongress.org

The PCDH19 gene mutation causes severe epilepsy in female babies.

Research that began in 2008 has recently shown that mutations in PCDH19, the gene on the X chromosome that encodes the “Protocadherine 19” protein, cause the onset of a form of drug-resistant epilepsy in female subjects aged between 3 months and a few years.

The seizures, focal or generalized, may be accompanied by a fever and often occur in clusters that can last for several days. Neuro-imaging techniques such as MRI do not show any cerebral alterations.

This form of epilepsy is often associated with the presentation of mild to severe mental retardation, sometimes with autistic traits.

The mechanism with which the PCDH19 mutations determine this clinical condition is still unknown. Molecular diagnosis is important to initiate the best treatment possible in the acute phase, as well as for prognosis and genetic counseling.

In April 2011, in Italy, the families of some affected girls founded the non-profit orga-

PCDH19 Gene Mutation in Baby Girls



nization “Insieme per la ricerca PCDH19” (Together for research on PCDH19).

The primary objectives of the organization are to promote and fund the scientific research on PCDH19, and to create a

network to connect families to support the exchange of experiences and updates.

For more information and to support scientific research in this field, please visit: <http://www.pcdh19research.org>