

*International*

# *Epilepsy News*

Newsletter of the

International Bureau for Epilepsy Issue 2 - 2008



**IBE  
Wins!**



*Elections 2009*  
**Report from Ghana**

# The President's Message



Dear Friends

It seems such a short while since the last IE News was published, but yet so much has been happening at IBE since then.

As you will have seen Action Zone! has received some very prestigious awards - the Communiqué Best International Campaign and the Campaign of the Year. The awards were announced by a very eccentric celebrity, Dame Edna Everage, alias Barry Humphries from Australia. These awards are something IBE is very proud of and I would like to thank all those who contributed to the game, not least Marion Clignet, who first

suggested the idea. With the great skills of Ursula Davis, Global Patient Care Manager - Epilepsy at UCB Pharma and valuable input from the members of the Action Zone Advisory Group, the initial concept was brought to life. Now it is being played around the world by young, and not so young, people as a novel and enjoyable way of improving knowledge about epilepsy.

It is now late August and IBE is preparing for many busy activities in the coming months. The third round of the very much appreciated and successful Promising Strategy Program has just been launched. Preparations are well underway for the European Conference on Epilepsy & Society in Marseille and the attendance looks very promising. The European Regional Executive Committee has done a fantastic job together with the IDM office and our French friends to organise everything well and to present a very interesting programme. I am confident that the conference will be as great a success as it was last time in Copenhagen.

As I write, IBE Elections 2009-2013 are about to begin and I would encourage you to nominate candidates for both the International Executive Committee and the Regional Executive Committees. Please don't hesitate to contact us if you have any queries regarding the election procedures. An Election Task Force is in place - Mike Hills, New Zealand (Chair), Marshal Mo-Song Hsih, Taiwan and Philip Lee, UK (IBE Immediate Past President) and I am confident everything will run smoothly.

Until the next time - all the best!

Susanne Lund  
President

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## International Epilepsy News No. 2 - 2008

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# The Editor's Letter



Dear Friends

For an Editor, each issue is a challenge. We know that our readers are people of different ages, cultures, languages, but all with something in common: a person with epilepsy or a relative; a healthcare professional or somebody interested in the epilepsy field. Four years ago IE News began to be published in full colour. It has been a great advance offering an attractive appearance,

but the most relevant issue is the diversity and quality of the articles included in each issue of the magazine. But this does not happen automatically. It depends on the support of IBE Members and supporters, who take the time to send us news or interesting articles about different aspects of epilepsy; and I would encourage you to continue to do so. We are always happy to receive them and to include them in the next IE News.

In this issue we can read an important article about Ghana in a report prepared by Emilio Perucca. There is also the positive news of Australia's ratification of the UN Convention on the Rights of Persons with Disabilities. Still in Australia, there is an article on a new research study on the impact of epilepsy, which Carol Ireland has submitted. After two successful rounds of funding, IBE is pleased to launch the third round of Promising Strategies funding. With the next International Epilepsy Congress already in preparation, this issue carries preliminary information on the IBE Volunteer Award, which will be presented during the General Assembly in Budapest.

Apart from that, you can find news about the Regional Committees, including a report from Latin America. And don't forget the President's Message!

Finally, we have the elections for the International Executive Committee and the Regional Executive Committees, with the International Executive Committee Elections already underway. This issue describes the process involved and I would encourage all Full Members to be actively involved.

Best wishes

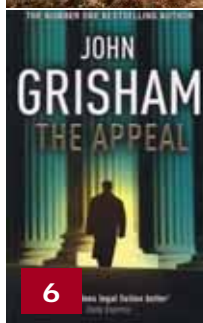
Carlos Acevedo  
Editor

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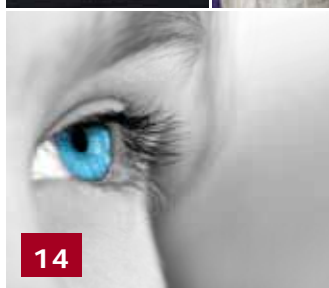
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## Action Zone! wins, not once but, twice!



*"Absolutely brilliant. So simple and yet so effective"*

When IBE heard that Action Zone! had been nominated for a Communiqué Award for public relations and medical education, there were smiles all round. Some weeks later we learned that the board game had been short-listed for the Best International Public Relations Campaign Award and we were even more excited. But nothing could have prepared us for the announcement at the Awards Ceremony in London on the 10th July, when Action Zone! was declared winner, not only of the Best International Public Relations Campaign award, but also the overall winner of the Communiqué Campaign of the Year 2008.

*"The level of creativity and excellence in execution was exceptional"*

The Communiqué judges described the Action Zone! campaign as "Absolutely brilliant. So simple and yet so effective" and "A truly outstanding entry. The level of creativity and excellence in execution was exceptional". One judge was so impressed that he awarded Action Zone! full marks!

Action Zone! was developed by IBE and UCB Pharma SA from an idea introduced by Marion Clignet, an Olympic silver medallist who has epilepsy.

*It is estimated that at least half a million people have played the game*

"What started as a small pilot project with an initial production run plan of 1,000 sets has grown into a major world-wide initiative that has benefited thousands of people with epilepsy and their families across the globe," said Ursula Davis, Global Patient Care Manager, at UCB. "More than





46 thousand games have now been distributed worldwide and Action Zone! has been translated into 17 different languages. These awards are welcome recognition of the work invested in this project by all those involved.” *und*

*“The response by our members around the world has been fantastic”*

Speaking at the Awards Ceremony in London, IBE President Susanne Lund said that with 50 million people living with epilepsy across the world, educational initiatives like Action Zone! were important in improving the knowledge of both people with epilepsy and the general public.

“IBE sees Action Zone! as being

effective in reducing the prejudice and misconceptions held about epilepsy. The response by our members around the world has been fantastic.

“Action Zone! is now being played in schools, clinics and hospitals, in family homes and at awareness-raising events by children with epilepsy, their families, friends and carers, in countries as far apart as Brazil and China, Sierra Leone and Australia, Canada and Mauritius.

The project also falls within IBE’s vision of a world where everywhere fear and ignorance about epilepsy are replaced by understanding and care,” explained Susanne Lund.

Master of Ceremonies for the Awards Ceremony, ensuring that everyone

enjoyed the evening, was Dame Edna Everage, the colourful and outrageous Australian ‘housewife’ character created by Barry Humphries.

*Images - previous page:*

**Top:** A representative of award sponsor Hanson Search; Helen Cross, Great Ormond St. Hospital; Ursula Davis, UCB Pharma; Peter Dommett, mxm Medical Communications; Susanne Lund, IBE President; and Marion Clignet, Olympic Silver Medallist and a person with epilepsy.

**Middle:** Dame Edna Everage entertains the audience.

**Bottom:** Marion Clignet, Susanne Lund and Ursula Davis, proudly display the two award plaques.

## A Letter from Togo

*Your donation to the Solidarity Fund helps to make a difference*

Dear Friends

Thank you so much that IBE will be paying our annual fees for 2008. We are very pleased and most thankful about this!

Since we opened the polyclinic in Sangera, many people with epilepsy have come for treatment. Most of them are young, aged between 5 to 30. They travel from the country side which means that they have a long journey from their homes to the polyclinic in Sangera. We have to give the patients detailed information about epilepsy (what kind of illness, how it will be treated, etc.).

Most of the patients suffer already for many years from epilepsy. It is common in Togo that epilepsy is treated in a traditional way. This means that the patients drink, for example, a special tea and take traditional “medicine”. They do this for many years and hope it will help. But it does not! With the therapy they get in the polyclinic in Sangera they are very happy. They soon feel better and realise that they are able to attend school and can go to work.

Thank you very much again for the support!

Dr Kokou Sodjéhou



*People with epilepsy and their families at the polyclinic in Sangera, with Dr Sodjéhou (in green T-shirt)*

### Please make a donation

Donations to IBE’s Solidarity Fund are welcome at any time. Funds received are used to support the membership dues of associations based in Low Income countries. The Solidarity Fund also supports the participation of such members in IBE activities, where lack of funds would

otherwise would have prevented this. A donation can be made at anytime and any amount, no matter how small, is gratefully received and acknowledged in IE News and on the IBE website. Find out more at [www.ibe-epilepsy.org/funding/solidarity-fund](http://www.ibe-epilepsy.org/funding/solidarity-fund) or from [ibedublin@eircom.net](mailto:ibedublin@eircom.net)

# Fiction writer gets his Facts wrong

## Epilepsy Foundation takes author John Grisham to task

American writer, John Grisham is one of the world's best known, and most read, authors of modern legal drama. With 16 novels published to date, 11 of which have been made into films, and with another book due to hit the bookshelves in January 2009, John Grisham has, to date, sold over 235 million copies of his books worldwide.

As an ex-politician and retired attorney, his writing is well respected for its accuracy in detail, which comes from painstaking research. So it is of concern to see that his latest novel *'The Appeal'* contains inaccurate, not to mention dangerous, information on how to help someone having a seizure.

In response to the misinformation contained in *'The Appeal'*, Eric Hargis, President and CEO of Epilepsy Foundation of America wrote to John Grisham to voice concern:

"As you know, on pages 343-344 of the hardcover edition of *The Appeal*, Ron Fisk's son Josh has a seizure when he's in the hospital. Ron rushes to his side and grabs his shoulders to settle him; then the nurse comes in and shoves a tongue depressor into Josh's mouth. Both of these are potentially harmful things to do to a person who is experiencing a seizure," wrote Eric Hargis.

"As a bestselling novelist, someone who reaches millions of people—and, furthermore, has their respect and attention—you could really help the more than three million people in the United States (and more than 50 million people worldwide) who have epilepsy by promoting proper seizure first aid and dispelling rumors and urban legends about it," the letter continued.

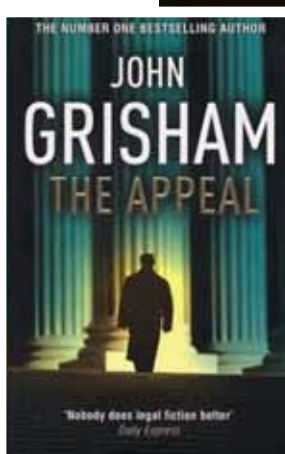


Photo by Lynne Brubaker/TIME

"It would be immensely helpful to all people with epilepsy if, when *The Appeal* is reprinted or printed in paperback, you would add an author's note indicating proper first aid for a seizure so the millions of people who read your book have a clear and correct idea of what should—and should **not**—be done when a person has a seizure," Epilepsy Foundation requested.

As a writer who once stated that *"Everything I'm thinking about writing now is about politics or social issues wrapped around a novel,"* let's hope that the request of Epilepsy Foundation is met. If you would like to support the complaint of Epilepsy Foundation, John Grisham can be contacted at the following address:

Mr John Grisham, c/o The Gernert Company, 136 East 57th Street, New York, NY 10022, USA.

## IBE Membership Expands

### General Assembly ratifies 3 New Membership Applications

Following an electronic ballot of Full Members, IBE is pleased to welcome the following new Associate Members:

- **USA: The Anita Kaufmann Foundation**
- **Australia: Epilepsy Australia Ltd**
- **Bulgaria: Foundation of Parents with Children with Epilepsy**

IBE now has 122 Full and Associate Members in 92 countries worldwide.







Ballot Paper  
International Executive  
Committee 2009-2013

## IBE Elections 2009

Full Members nominate candidates to stand for election to the International Executive Committee 2009—2013

### Election Task Force

The IBE Election Task Force was established in 2005 to act as the guardian of IBE in the election process and to ensure that procedures are adhered to and are applied fairly in all of the IBE elections. Chair of the Election Task Force is Mike Hills, New Zealand. Mike was a member of the Executive Committee from 1993 to 2005, serving as both Vice President and Secretary General. He is supported by Marshal Mo-Song Hsih, Taiwan and by Philip Lee, UK.

### Process to date

In early September the Election Task Force wrote to Full Members giving notice of the elections and inviting the Members to nominate candidates to stand for election to the positions of President, Secretary General and Treasurer on the International Executive Committee for the term 2009-2013. Members were also invited to nominate candidates for the position of Vice President for their region. In total, seven Vice Presidents will be elected.

The nomination period ended in early October and the Election Task Force is currently reviewing all of the nominations submitted to ensure that they meet the criteria as laid down in Bye Law III of the IBE Constitution.

### Next step

Once nominations have been processed, those nominated will be invited to prepare and submit an Election Statement, which will be circulated to Full Members in early November, along with the ballot papers. All of

the ballot papers, election statements and associated documents will also be available to view and download on the Members Section of the website: [www.ibe-epilepsy.org/Members](http://www.ibe-epilepsy.org/Members).

### Balloting

Full Members will be able to vote for the candidates of their choice until early January 2009 and it is expected that the results will be announced by mid-January.

The election of the President, Secretary General and Treasurer will be decided by a ballot of all Full Members. The election of each regional Vice President will be decided by a ballot of all Full Members within the region in which the candidate is standing. In each election the delegate receiving the most votes will be deemed to be elected.

### Immediate Past President

In addition to the election of Officers and Vice Presidents, Full Members will also be invited to ratify the appointment of the current President, Susanne Lund, as the Immediate Past President for the term 2009-2013. This is to meet the requirement in the Constitution that the appointment of the Immediate Past President must have been approved by a simple majority vote of Full Members.

**Important note:** Although a candidate may be nominated to stand for election for one or more Officer positions on the International Executive Committee, votes received are not transferable in the case where a candidate fails to be elected to an-

other position for which he or she has stood.

### Your vote is important

It is very important that every Full Member exercises its franchise by voting, so that the incoming International Executive Committee will have the clear mandate of the electorate. However, bear in mind, that only those Full Members in good standing, without outstanding dues payments, are able to cast votes.

Regional Committee elections will begin in February 2009.

## Election Schedule

### International Executive Committee

**1st September 2008:** Notice of election and call for nominations.

**Early October:** Close of nomination period.

**1st November:** Ballot papers will be circulated.

**2nd January 2009:** End of ballot period and results announced shortly after.

### Regional Executive Committees

**Early February:** Call for nominations.

**Early March:** Close of nomination period.

**Early April:** Ballot papers will be circulated.

**Early June:** End of balloting period and results shortly thereafter.

# Reunión del Comité Ejecutivo Regional Latinoamericano del IBE

Entre los días 17-18 de Mayo 2008 en Santiago de Chile, se reunió el Comité Ejecutivo (REC) del Comité Latinoamericano del IBE, con la asistencia de:

- ◆ Dra Lilia Núñez Orozco, Presidente
- ◆ Dr Tomás Mesa, Secretario
- ◆ Dr Carlos Acevedo, Past President

Por razones de fuerza mayor de último minuto, no pudo asistir la Dra Elza Marzia Yacubian, Vice Presidenta.

## La Agenda

Revisión de las actividades propuestas al inicio de la gestión del REC en Septiembre del año 2005 y seguimiento de las acciones realizadas.

Continuidad de las actividades del Comité anterior:

- ◆ Edición del libro *'Epilepsia, lo que usted debe saber sin ser médico'*, presentado durante el Congreso Latinoamericano en Guatemala, 2006. Segunda edición en Septiembre del año 2007.
- ◆ Mantenimiento del sitio Web IBE en Español para establecer diálogo y dar acceso a los pacientes. Además ampliar la sección LA mediante la incorporación de una sección en idioma Portugués. Las páginas de México ([www.epilepsiahoy.com](http://www.epilepsiahoy.com)) y de Chile ([www.ligaepilepsia.cl](http://www.ligaepilepsia.cl)) pueden albergar información de otros países donde su sitio web aún no se organiza. Se actualizará también esta información en la página del IBE.
- ◆ Mantenimiento de la sección en Español de IE News con colaboraciones de diferentes países de la región. Se proyecta su traducción al Portugués.
- ◆ Reanudar el proyecto de intercambio de Adolescentes Europa-Latinoamérica que fue muy enriquecedor con los dos eventos realizados (Alemania y Santiago)



Foto: Carlos Acevedo, Lilia Núñez Orozco, y Tomás Mesa

pero por el momento no hay presupuesto.

## Congresos:

- ◆ Contribución en la organización de los congresos Regionales LA en conjunto con nuestros pares de ILAE. El Comité Latinoamericano ha participado activamente en la organización de los congresos regionales, desde el de 2000 en Chile, 2002 en Iguazú, 2004 en México, 2006 en Guatemala y el próximo este año en Montevideo donde participamos en la elaboración del programa, la selección de trabajos y el otorgamiento de becas.
- ◆ Se han incluido temas relativos a problemas psicosociales en las sesiones plenarias y en los grupos de discusión a partir del congreso de México y no en actividades separadas de las de la ILAE como se hacía anteriormente, con lo que la temática psicosocial es de conocimiento más amplio entre los asistentes.
- ◆ Participamos en el Congreso Internacional de Singapur y estamos formando parte del Comité Organizador del Congreso Internacional en Budapest para el próximo

año, también con temas del IBE.

## Otras Actividades

- ◆ Incrementar el número de capítulos IBE en LA. Actualmente en proceso final de su trámite República Dominicana y Honduras. Se continúa buscando contactos en otros países de la región.
- ◆ Mantener una comunicación fluida con el IEC a través del Vicepresidente Latinoamericano y de la presidenta del REC.
- ◆ Promoción y coordinación para la realización de protocolos multicéntricos en investigaciones sociales relacionadas con epilepsia: estigma, educación, empleo, tránsito, costos, etc.
- ◆ Preparación del congreso regional de Montevideo 2008: colaboración en la organización, selección de tópicos y conferencistas, reglamento de becas y selección de los trabajos presentados.
- ◆ Promoción de la asistencia de líderes de países posibles de incorporarse al IBE.
- ◆ Análisis de los resultados de la iniciativa *Promising Strategies* de IBE para informar y postular



con mayores posibilidades en el futuro.

- ◆ Trabajo conjunto con ILAE para la recientemente creada Academia LA de Epilepsia (ALADE), e informe sobre LASSE II (curso anual Sao Paulo).
- ◆ Preparación de la agenda para la reunión de los comités ejecutivos IBE-ILAE en Montevideo.
- ◆ Preparación de la agenda del comité regional LA IBE para la reunión de Montevideo.
- ◆ Análisis de postulaciones de países aspirantes a organizar el Congreso Regional 2010.
- ◆ Selección de tópicos para el congreso de Budapest y sesión conjunta IBE-ILAE.

## Focus on Montevideo

### 5th Latin American Epilepsy Congress 5th - 9th November 2008

[www.epilepsymontevideo2008.org](http://www.epilepsymontevideo2008.org)



**I**t seems no more than a few months since we celebrated the New Year and the start of 2008. At that time, November seemed a long way off in the distance and yet, already, it is just around the corner.

With November comes the 5th Latin American Epilepsy Congress, in Montevideo, Uruguay; which is the final regional epilepsy congress planned for 2008.

The congress programme has been in place for some time and full details of the Scientific Programme, Social Programme and details of the congress speakers can be found on the congress website.

A special feature of the congress will be the Special IBE Day. This one-day

event will take place on Wednesday 5th November. The IBE Day will be of interest to people with epilepsy and their carers, as well as the general public.

The programme for the day, drawn up by the Latin American Regional Executive Committee, is aimed specifically at teachers and educators working in primary and secondary levels, given that these are the key providers of information in society.

Chaired by Dr Alicia Bogacz (Uruguay), speakers and topics for the session are:

- *Definition of Epilepsy and Types of Seizures*  
Isabel Rega (Uruguay)
- *Diagnostic methods*  
Tomás Mesa (Chile)

- *Treatment - What to do and what not to do when somebody has a seizure.*

Carlos Acevedo (Chile)

- *What are the Yes's and No's throughout life for people with epilepsy?*

Roberto Caraballo (Argentina)

- *Learning disorders in children and adolescents with epilepsy*

Eduardo Barragán (Mexico)

A meeting of the Latin American Regional Executive Committee will take place during the congress and members will receive details and agendas in advance of the congress. Members are also invited to use the IBE Stand in the Exhibition Area to display publications produced by their associations.

# Visit to Ghana

*Report by Emilio Perucca, First Vice-President, ILAE and Coordinator for ILAE activities in Africa*

From April 27<sup>th</sup> to May 3<sup>rd</sup> 2008, Giuliano Avanzini, Co-Chair of the ILAE/IBE/WHO Global Campaign against Epilepsy '*Out of the Shadows*', and I travelled to Ghana to survey conditions for the establishment of a programme to improve the care of people with epilepsy in collaboration with BasicNeeds Ghana, a British non-governmental organization, and with the Ghana health services.

More specifically, our visit had the following objectives:

1. to become acquainted with key professionals responsible for the care of people with epilepsy in Ghana;
2. to understand the structure of the local health care system, with special reference to how the needs of people with epilepsy were addressed;
3. to survey the logistics and to understand the functioning of Basic-

Needs Ghana and their respective programmes;

4. to identify areas where the ILAE could assist in improving the quality of care for people with epilepsy in Ghana, and the best modalities by which this could be provided;
5. to determine whether an ILAE Chapter in Ghana could be created in the near future.

Over a period of 7 days we had the privilege of meeting with Dr A Dwuma Odoom, Deputy Minister of Health; Dr E Sorey, General Director of Ghana Health Services; and Dr A Osei, Chief Psychiatrist for Ghana Health Services, in addition to many other health officials in different parts of the country.

We also interacted with key medical professionals involved in the care of people with epilepsy, and we spent considerable time with Dr S Ohene

and Dr A Akpalu, in particular, who have been actively working towards establishing an ILAE Chapter in Ghana.

We visited BasicNeeds facilities in Accra and Tamale, the Korle Bu Teaching Hospital in Accra, the Accra Mental Hospital, the Ghana Institute of Management and Public Administration in Accra, and the offices of the Regional Health Services for the Northern Region in Tamale and for the Upper West Region in Wa.

We also had the opportunity to visit community clinics, poor city neighbourhoods and rural villages, and to interact personally with people with epilepsy and their families.

Everyone we spoke to was hospitable and eager to establish collaborative links. Every health official showed a remarkable knowledge of the medical and social problems associated with epilepsy, and a keen interest in sup-





porting initiatives to reduce stigma and to improve the quality of epilepsy care in the country.

There are no data on the prevalence of epilepsy in Ghana, although all the physicians we spoke to commented that epilepsy is a major health problem not only in terms of the medical and social burden but also in terms of epidemiological dimension.

Epilepsy in Ghana is treated almost exclusively by psychiatrists, partly because the boundaries between psychiatry and epilepsy are blurred in the traditional culture, but mainly, because the local health system favours the channelling of people with epilepsy (and people with other neurological disorders) to psychiatric services.

Medical practitioners and health workers are fully aware of the distinction between epilepsy and mental disease, but they have not encouraged a differential approach to the care of these conditions, for at least two reasons:

Firstly, people with mental disorders and people with epilepsy share similar challenges with respect to stigma and discrimination, and it therefore makes sense to have comprehensive advocacy and educational programmes for both conditions.

Secondly, an integrated approach for both conditions allows people with epilepsy to benefit from important resources which have been allocated to psychiatric care, including the establishment of dedicated health centres and personnel, and a provision whereby all patients registered at psychiatric centres receive free medical care and free medication. Therefore, for people with epilepsy, being treated within this framework provides special benefits - which are not available to the general population.

In terms of medical personnel, Ghana faces significant shortages and a continuous brain drain, since many medical specialists tend to emigrate to wealthier regions. This implies that the care of people with epilepsy rests primarily on general practitioners, assistant medical officers (non-medical but well trained health personnel supporting the activities of

physicians in rural areas) and, most importantly, psychiatric nurses. The latter consists of health personnel who have undergone at least 3 years training in nursing plus at least 6 months specialized training in psychiatry.

Healthcare in rural areas is a special challenge, and for many people with epilepsy the nearest facility for accessing physicians and obtaining a supply of medication might be as far as 30 kilometers distance from where they live. Although antiepileptic drugs are provided cost-free to all patients attending psychiatric health centres, there are frequent shortages in medication. Availability of laboratory services, such as EEG, is also very restricted.

The size of the treatment gap has not been investigated, but it is estimated that most people with epilepsy have not been reached by the health services and have no access to medical treatment. The gap is largely filled by traditional healers. Misperceptions about epilepsy are highly prevalent. We met women with severe burns who had fallen into fires because of seizures (a common event, as fire is used for cooking) without being rescued by bystanders. In fact, many believe that epilepsy is contagious and can be transmitted simply by touching an affected person.

The primary objective of BasicNeeds' programmes in Ghana is to give voice to people with epilepsy and people with mental disease, and to support initiatives to address the medical and social needs of these people. BasicNeeds' main strategy is to liaise closely with national, regional and community-level health authorities, to provide complementary services by addressing shortcomings in the healthcare system, and to feed back to authorities their experience in order to improve the quality of healthcare.

A key aspect in these activities is to

reach out to neglected communities to inform them about the nature of epilepsy and mental disease (thus fighting stigma and discrimination through education), and about the services which exist to address the medical and social needs of affected people. This is done initially by approaching local community leaders, by setting up community meetings and by recruiting networks of volunteers who help in locating needy people and channelling them to health clinics. This is followed up by the



establishment of support groups and regular monitoring of all those who are enrolled in the programme.

BasicNeeds also supports the healthcare system by motivating all parties involved and through addressing directly any dysfunctions. Examples of such activities include:

1. direct and indirect support of medical and nursing personnel;
2. taking responsibility for the transportation of physicians to health clinics throughout the regions covered by the programme, including rural areas;
3. making regular bulk purchases of medication to meet recurrent shortages in the distribution system;
4. providing modest funding for infrastructure, such as the construction or the upgrade of community clinics;



- liaising with local authorities and other non-governmental agencies to address specific needs, including professional rehabilitation training for people with epilepsy to allow them play an active and productive role in society. This might include the provision of micro-loans to start small businesses.

Based on this background, there was general agreement among all parties that the ILAE, by linking with BasicNeeds' personnel and infrastructure, could provide an important contribution to improve the lives of people with epilepsy in the country.

One way in which the ILAE could contribute usefully is in assisting in the training of healthcare workers in the country. This is of great importance, because the primary deliverers of healthcare to people with epilepsy (general practitioners and community psychiatric nurses) have limited expertise in epileptology.

Initiatives which were discussed, and which are now being planned, include the organization of intensive courses targeted at highly motivated physicians and nurses from all regions of Ghana, using a train-the-trainer model, whereby attendees will be subsequently expected to cascade down the training to other health personnel in their geographical area.

These courses must take into account

the peculiarities of epilepsy care in Ghana, i.e. differential diagnosis of seizures and epilepsies without laboratory resources, recognition of treatable causes, psychiatric issues in epilepsy, as well as basic management principles.

Information on epidemiological methods will also be included in preparation for a demonstration project to be carried out in a second phase, to determine the prevalence of epilepsy in representative districts, as well as the size of the treatment gap, and to establish intervention programmes to improve access to care and social support services. An epidemiological study would also be important in providing health authorities with sound data concerning the size of the epilepsy problem and related unmet needs, and to stimulate the required interventions.

Further discussions are ongoing with BasicNeeds and Ghana health officials to determine how these initiatives could be organized into a comprehensive, long-term, self-sustainable programme. These developments will be facilitated by the establishment of a Ghana ILAE Chapter, which is virtually completed, and by involvement of local advocacy groups.

Although we did not succeed yet in establishing contact with the Ghanaian IBE office, we count on IBE's

collaboration in this programme as part of a future Global Campaign initiative. The dedication of so many local people to the cause of fighting epilepsy and its consequences was something that touched us, and makes us more optimistic that our programme will become a successful reality.

I cannot close this report without mentioning the hospitality of the BasicNeeds personnel and volunteers, and the Ghanaian people in general. "Akwaaba", which means "Welcome" in the Akan language, and its English equivalent, were the words that met us everywhere we went, and we always felt at home in environments which were strikingly different from our real home. Ghana is a beautiful country with a remarkable variety of landscapes, from the lush green South to the bushlands of the North.

Giuliano and I brought home a bag of tiny wild mangoes which were given to us by a group of young children in a rural village, and they tasted sweeter than any other fruit we have ever eaten.



# Australia Ratifies UN Disabilities Convention

On 18th July Australia became one of the first Western countries to ratify the UN Convention on the Rights of Persons with Disabilities. In doing so, Australia joined 29 other countries around the world in a move that aims to promote a global community in which all people with disability are equal and active citizens.

"Ratifying the Convention clearly demonstrates the Rudd Government's international commitment to ensuring people with disability are treated equally and not as second class citizens," Australia's Attorney-General Robert McClelland said.

"This significant achievement is the result of substantial collaboration by Government and Non-Government stakeholders," Mr McClelland

"I applaud the co-operation of these bodies who have successfully worked together to promote this historic international instrument," commented Australia's Minister for Foreign Affairs Stephen Smith.

"Australia has a long-standing commitment to upholding and safeguarding the rights of people with disability. Ratifying the Convention sends this unequivocal message to the world," stated Bill Shorten MP, Parliamentary Secretary for Disabilities.

Having ratified the Convention, Australia will not be invited to participate in the inaugural election of the Committee on the Rights of Persons with Disabilities; which will oversee the implementation of the Convention.

*Photo: Parliament House, Canberra*



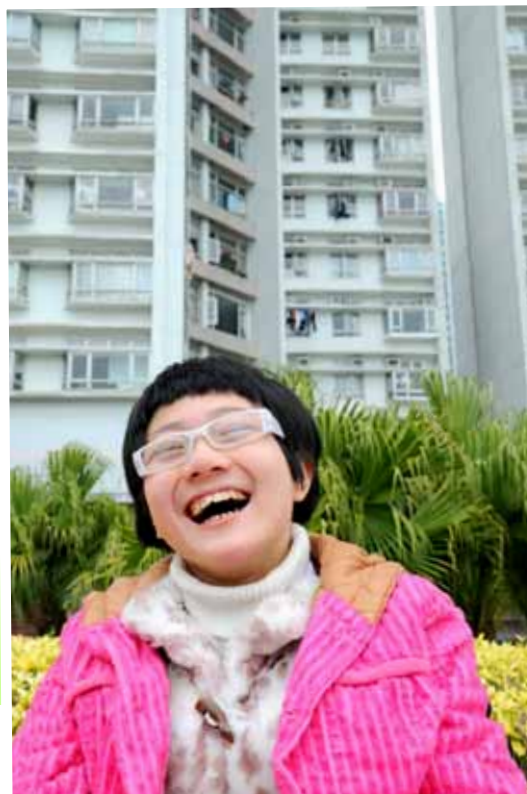
## Happy Faces

In June Enlighten Hong Kong held a "Happy Faces" Photographic Exhibition in a major shopping centre in Hong Kong.

"I decided that we needed to and would hold a photo exhibition to show and share with our community how people with epilepsy are positive, happy and no 'different' to anyone else.

"We worked with eight Enlighten families who had the most wonderful photographs taken by our volunteer, Ms Benna Lo.

"The stigma and fear that surrounds Epilepsy in Hong Kong still exists. We know from feedback we received from those who visited this wonderful exhibition that they benefited from this positive message," Orla Gilroy, Chief Executive of Enlighten Hong Kong explained.



# IBE VOLUNTEER AWARD

## Award 2009 launched

The Volunteer Award, introduced in 2006, recognises the efforts of volunteers working with IBE member associations, without financial award, to improve the quality of life of people with epilepsy at local level. The first award was presented to Margaret Fandiño, Colombia, in Singapore in 2007.

IBE now invites its members to submit nominations for the prestigious Volunteer Award 2009.

The recipient will be selected by the International Executive Committee and the award will be presented at the General Assembly, in Budapest in August 2009. The award comprises an engraved plaque, as well as travel and accommodation costs to attend the General Assembly. The nominating association will receive an award of US\$5,000 to finance a special programme.

Further information on the award is available on the IBE website and Nomination Forms are available for download on the Members section of the site.

Nomination forms may also be requested by email to [ibedublin@eircom.net](mailto:ibedublin@eircom.net).

## The Traveller's Companion

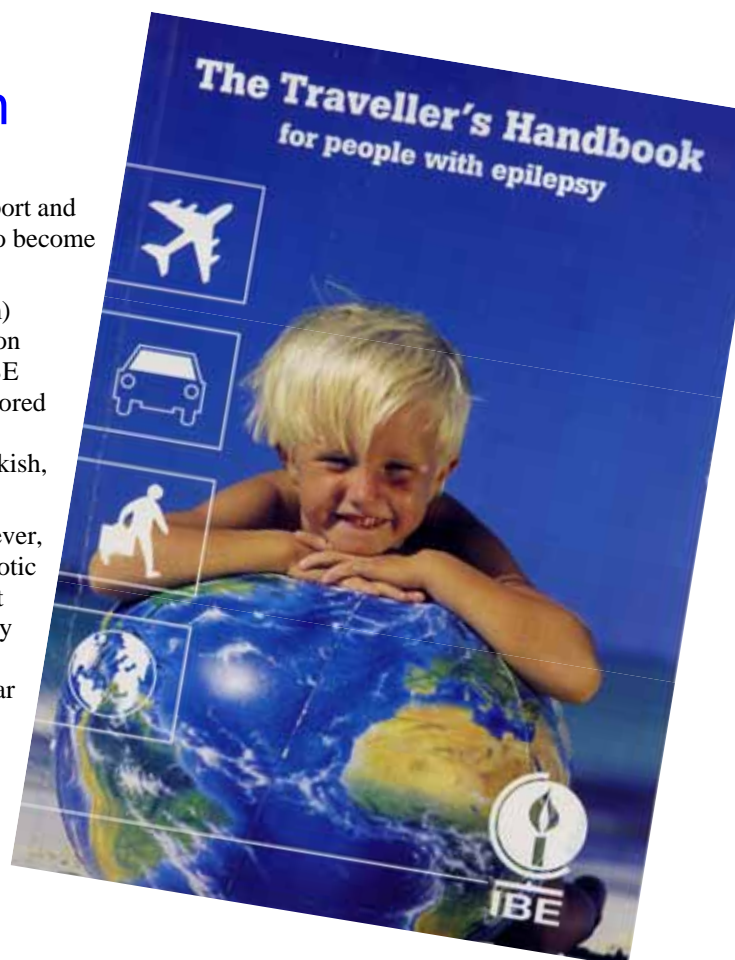
Two of IBE's most popular publications ever, the Epilepsy Passport and the Travel Handbook have recently been revised and combined to become The Traveller's Handbook for people with epilepsy.

The easy to carry book (measuring approximately 10cm by 15cm) contains first aid information, useful phrases and general advice on travel in 13 languages, thanks to the help and support of many IBE Members and supporters. Publication of the handbook was sponsored by UCB Pharma. The contents are in English, French, Spanish, Italian, German, Greek, Portuguese, Dutch, Arabic, Russian, Turkish, Cantonese (Chinese) and Mandarin (Chinese).

With international travel now more popular and affordable than ever, more and more people are travelling - more often and to more exotic destinations. The era of the independent traveller has arrived. But with independent travel comes the onus on the traveller to be fully responsible for all arrangements, including dealing with medical issues. So, we hope that the new booklet will prove just as popular and helpful as the earlier edition.

A copy of the handbook has been sent to every IBE Member and further copies will be made available at future epilepsy congresses.

The handbook is also available for automatic download on the Publications section of the IBE website.





# Announcing Promising Strategies

# 2009

Improving the quality of life for people with epilepsy in emerging nations!

In 2006 IBE launched the Promising Strategies Program, aimed at helping Members in emerging nations implement innovative initiatives to improve the quality of life for people with epilepsy and to find solutions to the problems impacting on epilepsy with epilepsy and their families worldwide.

Since then IBE has been able to provide support to 19 projects implemented by 18 Member associations in Africa, Latin America, Eastern Europe and Western Pacific regions. This has been made possible through the generous donations received from the staff of UCB Pharma and from Epilepsy Foundation in the USA. Contributions to the Solidarity Fund, made by many IBE Members, have also helped in funding the Promising Strategies Program.

## Third Round of Funding

IBE has recently launched a third round of funding - Promising Strategies 2009. An call for Letters of Intent has been circulated, inviting qualifying IBE members to indicate their interest in submitting a proposal for consideration. Members will have until Friday 24th October to submit a short resume of their proposed projects, on foot of which a shortlist of applicants will be asked to submit full proposals to be reviewed by the International Executive Committee. Proposals selected for funding will be announced in April 2009, once the committee has completed its review.

The extent to which IBE can provide support to Members in developing regions is limited only by the amount of funds provided. Given the limited amount of funding available, IBE invests Promising Strategies in those regions of greatest need. As such, only IBE members in a country whose gross national income (GNI) is less than US\$10,000, according to World Bank figures, will be eligible to apply.

The level of funding awarded to successful initiatives will vary based on budget and merit. Awards will generally range from US\$1,000 to US\$5,000.

## Get involved!

IBE would like to encourage Members in developed countries to consider being involved in Promising Strategies in a supportive role. This could be through the voluntary provision of technical support, staff training, or the provision of materials or equipment. If this is something that interests your association, please let us know. You may direct any queries to [ibedublin@eircom.net](mailto:ibedublin@eircom.net).

## Find out more

If you can find full details on all projects funded to date on IBE's website

[www.ibe-epilepsy.org/promising-strategy](http://www.ibe-epilepsy.org/promising-strategy)



## Important Dates

- **Letter of Intent Close Date**  
*24th October 2008*
- **Announcement of approved Letters of Intent and Call for Full Proposals**  
*21st November 2008*
- **Deadline for the submission of Full Proposals**  
*16th January 2009*
- **Successful applicants announced**  
*April 2009*



# Epilepsy: measuring the impact

Australia's first population-based study of epilepsy incidence could open up new possibilities for managing the condition.

Epilepsy affects up to 200,000 people in Australia, yet little is known about its impact on Australians with regard to health services, or the effect on major life roles such as employment, relationships, education and caring. In turn it is not understood which factors could potentially be modified to improve a person's quality of life.

Epilepsy Action Australia held a series of national forums in 2007, asking people about epilepsy impacts. To further explore and quantify these needs, Epilepsy Action Australia has now partnered with the international health-research organisation, The George Institute, to undertake a major epidemiological research project. The Sydney Epilepsy Incidence Study to Measure Illness Consequences (SEISMIC) will explore the incidence, psychosocial impact and the household economic burden of epilepsy in a large population. It is the first time this kind of study has been conducted in Australia. The new information it uncovers could bring many benefits to people living with the condition.

"The study will provide a unique opportunity to collect long-term outcome data about a broad group of people living with epilepsy," says Epilepsy Action Australia Chief Executive Officer, Carol Ireland. At a broader level, it will enable the Australian government and health-care practitioners to make more informed decisions about policy, funding, treatment and management.

According to Prof Craig Anderson, Director of Neurological and Mental

Health at The George Institute, "This will be one of the largest, most comprehensive studies of epilepsy in the world." The data "will not only be useful for Australians, it will have international significance."

## The need for new research

Epilepsy affects an estimated 120,000 to 200,000 Australians. This wide range arises from a lack of population-based data and hampers planning of services, both health and social, to identify and to meet the significant needs of people who are affected.

The unpredictable nature of epilepsy, the need for long-term medication, and the associated stigma, often results in high psychosocial disability. The wide-ranging impacts include being unable to drive legally, unemployment, higher rates of depression and anxiety, school-age children performing less well academically, and fewer people with the condition marrying or having children than in the general population.

Much of the disorder's poor health-related quality of life outcome relates to its social burden, more commonly identified as a problem by people with epilepsy than by health care professionals.

Traditional treatment aims to prevent seizures, however, only around 60-70% of people experience seizure freedom through medication and epilepsy is still associated with greater morbidity.

Further, treatment is complicated by delays in diagnosis or seeking help, and lack of adherence relating to fac-

tors including a person's attitudes, drug availability and treatment costs. Lack of effective treatment reduces many patients' quality of life, leading to adverse outcomes and increasing healthcare costs.

## Why conduct a population-based study in Australia?

Few rigorously designed studies have investigated the impact of epilepsy. Currently most Australian data is from cross-sectional, retrospective or single centre studies. It doesn't explore the rate of emergence of long-term sequelae (or effects) or new diagnoses of the condition in a given population. In addition, most available population-based data is 10-15 years old and was undertaken in North America or Western Europe, so doesn't reflect Australia's unique situation - in particular its multicultural population and socio-economic circumstances.

By contrast with previous data, the new information will:

- Measure or quantify impacts and highlight the impact of the illness of epilepsy.
- Enable better understanding of local contextual factors relevant to health outcomes and assist with the development of interventions.
- Provide more reliable data for making general conclusions about the whole population.

## What will be done?

A population-based epilepsy register will be created of people living in the central-west area of Sydney over 36 to 48 months.





“The ultimate goal is to map the onset and course of epilepsy for all residents in this area,” says Prof Anderson. “We will invite participants to be interviewed then monitor their health over the next few years, covering the type of epilepsy, seizures, various risk factors, size and composition of a family, among other things.”

The study is prospective; in other words it will be undertaken over time. All new cases of epilepsy – defined as having two or more recurrent unprovoked seizures – will be ascertained from facilities including hospitals and nursing homes over a six month period. These will be followed up by telephone interviews at three, six and 12 months intervals after the index (or first) seizure due to epilepsy.

“Worse situations tend to make a greater impact on memory,” explains Professor Anderson. “So when you ask a person something at a single point in time, their response may only be related to their feelings at that low point.”

By talking with people over time, “the errors of measurement are less, and we can determine cause and effect to better understand the impact of certain events or interventions.”

Data will be collected on areas including daily living, experiences of anxiety and depression, psychosocial disability, economic hardship and education/employment status – including days absent from school/work. Methods will follow the International League Against Epilepsy protocol for epidemiologic studies,

which include criteria for epilepsy diagnosis, classification and case ascertainment. The study location was chosen because it is large, with around 500,000 residents, and because it covers a range of people with different characteristics and situations. The population’s socioeconomic, ethnic (39% speak a language other than English at home), and indigenous (1% are Aboriginal) characteristics are representative of Australia as a whole.

### **Aims and hypotheses**

The study will determine the incidence of epilepsy in Australia and examine how psychological factors, socioeconomic circumstances and healthcare delivery influence the experience of epilepsy for individuals and families. Long-term follow-up of this population-based cohort (or group) and randomised controlled trials of intervention strategies to improve outcome are the longer term aims of this study.

More specific aims of the project include determining:

- The overall age and sex-specific incidence rates of epilepsy in the population.
- The magnitude of geographic (rural versus urban) variations in epilepsy incidence.
- The natural history, time course and progression of epilepsy in people under 16 years, of working age, and over 65 years.
- Factors associated with greater psychosocial disability.

### **Conduct of the study**

The study will be co-ordinated by a multidisciplinary team of researchers experienced in observational epidemiological studies. Centrally managed at The George Institute, academic oversight of the study will be undertaken by a Steering Committee with representatives of Epilepsy Action Australia, The George Institute, the University of Sydney, and the Area Health services. A Scientific Advisory Committee comprising key neurologists and experts on epilepsy from across Australia will advise on conduct and analysis. A Project Management group will oversee the study’s daily operations, including data collection and analysis.

### **Looking to the future**

Ultimately, this type of study will “impact all levels of the healthcare sector,” says Prof Anderson. “You will get the big picture of epilepsy. This is a voice that can then be used to action government.” Most importantly, “it should help to provide better ways to empower people with epilepsy to take control and cope with aspects of the unpredictable nature of epilepsy.”

For Epilepsy Action Australia, “this is a huge step towards turning our vision of confident living into a reality,” says Carol Ireland. “We hope it will herald the start of a new era for Australians with epilepsy.”

*Original report first published in **Epilepsy360** and is reproduced by kind permission of Epilepsy Action Australia, an IBE Associate Member.*

# IBE/ILAE Congress Awards BUDAPEST 2009

IBE and ILAE member associations have been invited to submit nominations for the Awards of Ambassador for Epilepsy and Social Accomplishment, to be presented at the time of the 28th International Epilepsy Congress, Budapest 2009.

Full details are available on the IBE website, with award guidelines and nomination forms available for automatic download on the password protected Members Section.

Further details are also available from [ibedublin@eircom.net](mailto:ibedublin@eircom.net)



## Centenary Award for Film

Over the past 100 years, epilepsy has stimulated many artists, writers and film makers. Images of epilepsy are embedded in several important themes in western culture and many famous film directors have used these images and themes in their films.

Now, as part of major centennial celebrations, the International League Against Epilepsy (ILAE) has announced a Centenary Film Competition, with a prize fund of US\$10,000.

The award will be for the best films made since January 2000 which are inspired by, or relate to, epilepsy. Entries from all film genres are eligible, with the exception of edu-

cational films and clinical teaching materials. The competition organisers are interested in film entries that have creative or artistic value or which show novelty in using epilepsy as a theme for the production.

The connection with epilepsy can be direct, indirect, central or merely tangential. The criteria for judging will be artistic and creative merit.

Films should not exceed 2 hours in length and short films are particularly welcome. Entries are encouraged from all professional, student and amateur sectors of the film making community worldwide and the closing date for entries is 28th



February 2009. Entries will be judged by an international, multi-disciplinary panel.

The winners will be presented with their prizes at the 28th International Epilepsy Congress, Budapest 2009. Travel, registration, and accommodation costs to attend the congress will be provided.

Contact Professor Simon Shorvon email: [s.shorvon@ion.ucl.ac.uk](mailto:s.shorvon@ion.ucl.ac.uk) for further details.





# NEW AWARD IN JOURNALISM

## IBE and UCB launch the Excellence in Epilepsy Journalism Award

Despite its extensive impact around the world, the need for education on the correct facts about epilepsy is still great. Many people still hold misconceptions about the true facts about the condition and, as a result, those living with epilepsy will often experience strong feelings of stigma, isolation and helplessness.

To encourage journalists to raise awareness of epilepsy and to help break down these barriers, IBE and UCB Pharma are pleased to launch the Excellence in Epilepsy Journalism Award. The award will recognise journalists who produce stimulating, informed and compelling news and feature stories on epilepsy.

Despite major scientific and medical advances in the understanding and management of epilepsy, the condition is still often misunderstood in many communities. This situation could be improved through sensitive and informed media reporting and this new journalism award aims to encourage such reporting, which would assist in creating a better understanding about the true facts on epilepsy.

### Who can enter

The international award is open to consumer, health and medical journalists from around the world writing for print, broadcast or online media and will celebrate journalism that challenges stereotypes. Freelance journalists are also eligible to enter.

Reports and articles submitted for consideration must have been pub-

lished or broadcast between 1st July 2008 and 30th June 2009.

Journalists may either submit their work personally or be nominated by a peer or colleague. Journalists nominated must consent to their work being entered.

### Award Criteria

An independent panel will judge entries on the basis of responsible, informed and original reporting. Entries will be assessed using the following specific criteria (although entries will not be required to fulfil each of the criteria to be considered for an award):

#### The report or article:

- Helps to increase awareness and understanding of epilepsy
- Gives a voice to persons with epilepsy
- Is conceptually or visually innovative and creative
- Is well structured, well researched and makes for compelling reading or listening
- Uses language responsibly when reporting or writing on epilepsy.

### General Rules

Submissions are welcome in English or in another language. Where the original report is not in English, a summary in English must also be provided.

All entries must be the original work of the applicant and must not violate another party's copyright. Joint appli-

cations will be accepted, provided that all collaborators grant consent.

Journalists may enter more than one article or report for consideration, although each report or article must be submitted as separate entries.

### The Prizes

Prizes will be presented in three separate categories:

- Medical print/online
- Consumer print/online
- Broadcast

One prize of €4,000 in travel vouchers will be awarded for each category. Certain local restrictions may apply regarding the award; therefore the award will be available only where not prohibited or restricted by local laws or regulations.

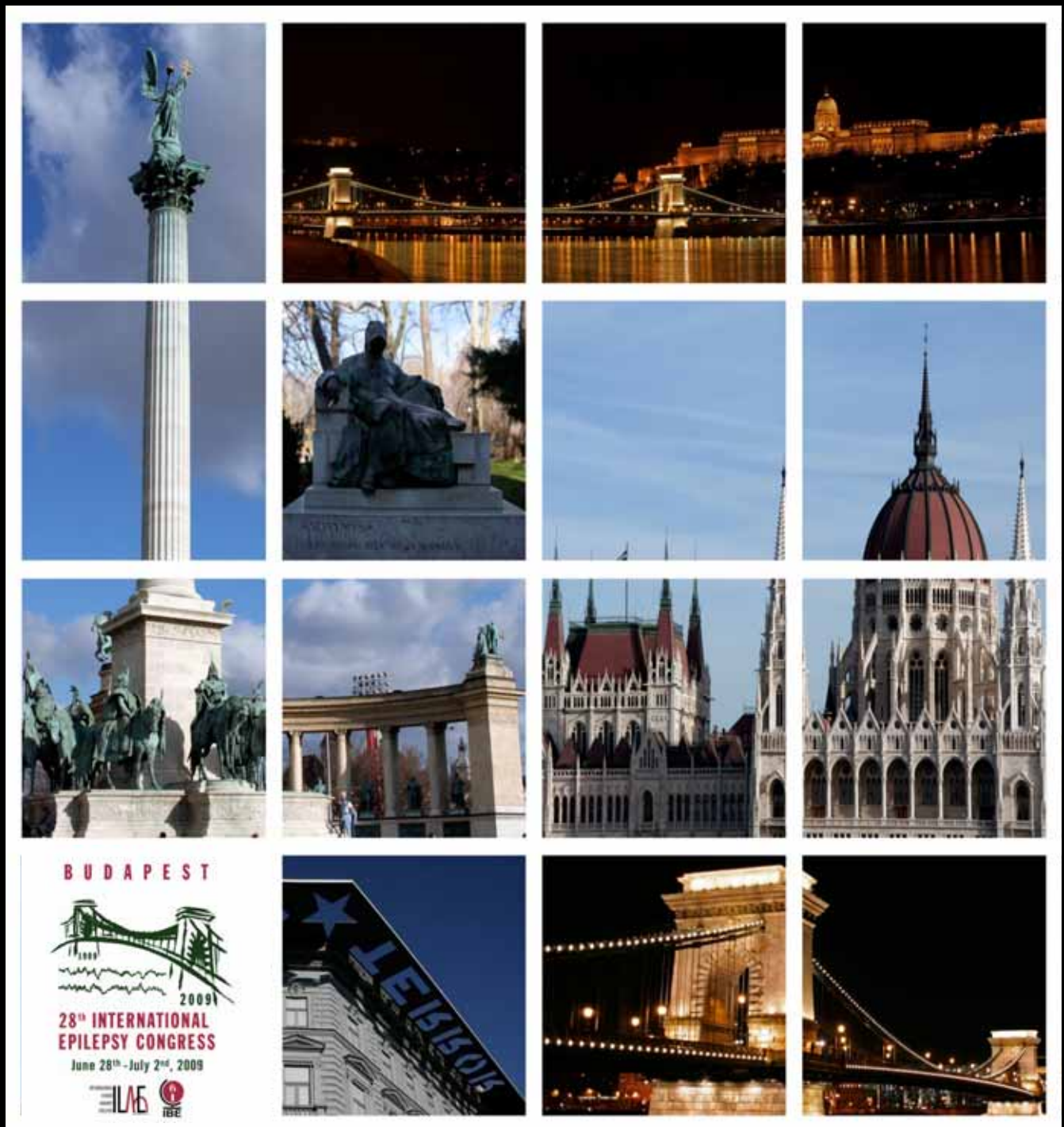
Prize-winners will be announced at the time of the 28th International Epilepsy Congress in Budapest, 2009.

### How to Enter

Full details of the award, including Entry Forms and Award Rules, can be found on the IBE website [www.ibe-epilepsy.org/activities](http://www.ibe-epilepsy.org/activities). Entry Forms will also be available at the Epilepsy & Society Conference in Marseille or may be requested by writing to [ibedublin@eircom.net](mailto:ibedublin@eircom.net).



# 28th International Epilepsy Congress Budapest, Hungary June 28th—July 2nd 2009



Congress Secretariat: 7 Priory Hall, Stillorgan, Dublin 18, Ireland  
Telephone ++353-1-20-567-20      Email [info@epilepsybudapest2009.org](mailto:info@epilepsybudapest2009.org)  
[www.epilepsybudapest2009.org](http://www.epilepsybudapest2009.org)