

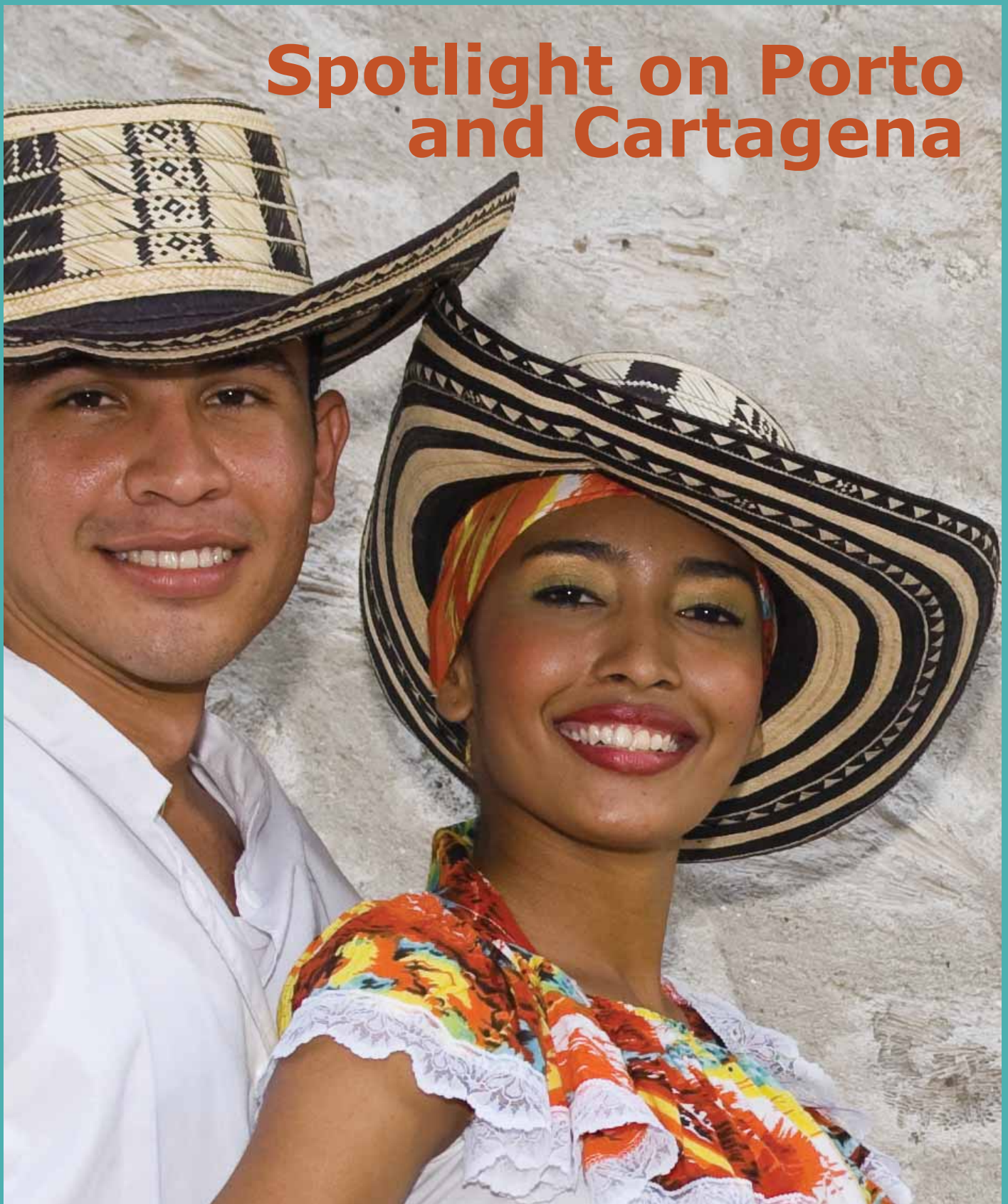
*International*

# *Epilepsy News*

Newsletter of the

International Bureau for Epilepsy Issue 2-2010

## **Spotlight on Porto and Cartagena**



# The President's Message



Dear IBE Members and Supporters

There have been some important and positive achievements at IBE in the last few months.

Firstly, I would like to share with you the good news that an annual European Epilepsy Day will be celebrated for the first time next year.

The date set is the second Monday of February which is the closest weekday to St Valentine's Day. And, in 2011, happily it falls on the 14th February. This important event is a joint initiative of the Political Action Group of EUCARE and the IBE European Regional Committee with the support of ILAE. Already there is a

Latin American Epilepsy Day each 9th September and, in due course, I would hope to see epilepsy days celebrated annually in each IBE region.

The Global Campaign has also been busy and the campaign taskforce has now completed the strategic plan, which will help steer the campaign forward in the coming years. An important event will be the launch of the Euro Report on Epilepsy, published by the WHO, which will be celebrated during the Epilepsy & Society conference in Porto in August.

The rest of the year will be busy for IBE with three more regional congresses: the 6th Latin American Epilepsy Congress in Cartagena in early August; the 12th European Conference on Epilepsy & Society in Porto in late August; and the 8th Asian & Oceanian Epilepsy Congress in Melbourne in October.

The organising committees for each of these meetings have put in place very interesting and stimulating programmes, and in Cartagena and Melbourne there are special programmes aimed specifically at persons with epilepsy and their families. The European conference, being the only IBE specific meeting, is always special and Porto promises to be just as successful as previous meetings. I hope to meet many of you in Cartagena, Porto or Melbourne.

Finally, behind the scenes, the Golden Jubilee Taskforce chaired by Susanne Lund is busy at work planning for our special celebrations in 2011. The first activity to be launched is the Photography Competition, which you can read about in this issue. I would encourage you to promote this competition, which has a major prize fund, to members, colleagues and friends, as well as to camera clubs and art colleges in your area.

All the best,

Mike Glynn  
President

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The International Bureau for Epilepsy, with membership of 122 epilepsy associations based in 92 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

## International Epilepsy News No. 2 - 2010

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### Subscription

Three years: US\$30

Five years: US\$48

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# The Editor's Letter



Dear Friends:

In the Southern Hemisphere we are starting the rainy season and in Chile, two months after the terrible earthquake and its aftershocks, things are gradually beginning to improve for the many thousands of people who lost their homes.

In this issue of IE News we have a lot of different and interesting articles. First of all there are the updates for the 12th European

Conference on Epilepsy & Society in Porto and the 6th Latin American Epilepsy Congress in Cartagena de Indias. Since we are including the newsletter in the delegate bags of each of these meetings, it is possible that you are reading this message as you attend one of these important congresses.

There is also the announcement of the projects selected to receive financial support under the latest round of the Promising Strategies Program. And, while we are on the subject of finances, could I send a gentle reminder to those who have yet to pay their membership dues for this year, that a donation to the Solidarity Fund, to allow us to support even more projects, would also be gratefully received when you pay your dues!

Another relevant issue relates to the Outstanding Persons with Epilepsy awards that will take place during the 8th Asian & Oceanian Epilepsy Congress in Melbourne later in the year. If your association is based in the South East Asian or Western Pacific regions I would encourage you to take part in this great initiative that celebrates the extraordinary achievements of people living with epilepsy.

Before signing off, I must mention a few more important issues: the announcement of the European Epilepsy Day; the launch of the second round of the journalism award and the announcement of the Photography Competition as part of IBE's Golden Jubilee celebrations for Rome. Finally, we have a new regular section about the history of IBE and epilepsy.

I hope you find plenty to enjoy in this issue of IE News.

Best regards,  
Dr Carlos Acevedo

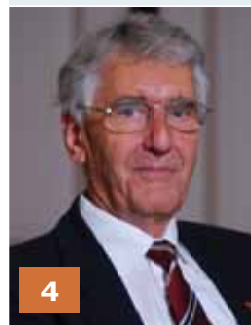
## International Epilepsy News on the Web

IE News is also available on the IBE website  
[www.ibe-epilepsy.org](http://www.ibe-epilepsy.org)

Previous issues can be found under the tab **IE News**, while the current issue is available to IBE Members on the **Members** section.

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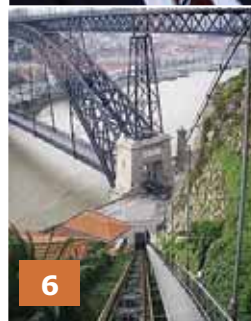
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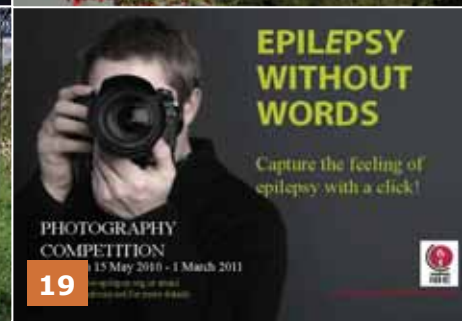
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# Look Back with Pride

By Harry Meinardi

Part 1 of a series of articles to mark IBE's Golden Jubilee in 2011



Harry Meinardi  
Photo: Floris Meinardi

## Editor's Note

In 2009 the International League Against Epilepsy celebrated its centenary; in 2011 the International Bureau for Epilepsy will celebrate the fact that it was conceived half a century ago.

Half a century is a time-span after which certain governments allow secret archives to be opened for public scrutiny. IBE never had secret archives but reviewing its history and its background for an increasing number of people who were too young to have been aware of it seems like a good idea.

Over the next number of issues of IE News Ted Reynolds and Harry Meinardi will write, on an alternating basis, about the past - each from a different perspective. Ted Reynolds will focus on various aspects of epilepsy and on the ILAE; Harry Meinardi will review the development of IBE as witnessed by past issues of IE News.

Ted and Harry first met in 1968 at the "European Institute" - a joint meeting of the International Bureau for Epilepsy, the British section of the International League against Epilepsy and the Scottish Epilepsy Association, held in Dunblane, Scotland. Ted, a university-based neurologist in the U.K., continued to put his organisational capabilities at the service of the British Section of ILAE and later of ILAE itself. Harry, who in 1968 was director of research at a special centre for Epilepsy in the Netherlands, was involved both in IBE and ILAE matters, reflecting the situation in his country.

I am sure you will enjoy their contributions!

International Epilepsy News issue number 142 March 2001 celebrated the 40<sup>th</sup> anniversary of IBE, presenting an overview of the executive committees from 1966 to 2001 and a brief account ("In the beginning" p.19-21) of how IBE emerged in 1961 as "the social arm of ILAE". With the 50<sup>th</sup> anniversary forthcoming, IBE's history will be sketched in a series of articles. Since historians should not bore their readers with matters that they are well aware of,

because they witnessed it, this series of papers will cover the first 25 years. Original texts copied from IE News will be printed in italics.

In January 1963 the first stencilled Newsletter of IBE left 21 Nassau Street, London W1, signed: Yours Sincerely George Burden. George Burden was co-founder and Secretary-General of IBE until 1977.

This newsletter informed its readers about who had agreed to become

members of the Board of Directors and from which organisations they stemmed:

- *Mrs Ellen Grass, Vice President, American Epilepsy Association*
- *Dr Francis McNaughton, President of the ILAE*
- *Prof Henri Gastaut, Secretary of the ILAE*
- *Dr AM Lorentz de Haas, Medical Director of the Meer en Bosch Clinic, Netherlands*





Quarterly Newsletter of the International Bureau for Epilepsy

24th International Epilepsy Congress,  
Buenos Aires, 13-18 May 2001

- *Mr H Brulleman, also representing the Netherlands*
- *Mrs Irene Gairdner, Honorary Secretary of the British Epilepsy Association*
- *Dr D Pond, Chairman of the Medical Committee of the British Epilepsy Association*
- *Dr J Romanes Davidson, Bridge of Weir, Scotland*
- *Dr K-A Melin, Medical Director of the Stora Skondal, Farsta, Sweden.*

*Mr Lew Simons has agreed to share the duties of Secretary with me and to represent the interests of the Bureau in the United States.*

The following envisaged activities were mentioned:

1. *To participate in the congress of the International Society for the Rehabilitation of the Disabled in Copenhagen June 1963. We have approached Dr Kiørboe to ask whether we might organise a short seminar on Epilepsy and Employment at Dianalund immediately preceding this congress.*
2. *I am meeting professor Gastaut in Marseilles at the end of January to discuss with him the possibility of organising a seminar on Epilepsy and Education sometime in 1964.*
3. *Dr Romanes Davidson has proposed that a 3<sup>rd</sup> meeting on Juvenile Epilepsy should be held following the very successful meeting at the Maudsley Hospital, London in 1956 and at Stora Skondal (Sweden), in August 1959. The venue of this meeting is not yet agreed, but the Bureau has been asked to undertake the necessary arrangements once this has been settled.*
4. *We are engaged in compiling a list of centres for the care of people with epilepsy throughout Europe; when this is complete it can be made available to all members.*
5. *I have asked Mr Simons if he will make a collection and assessment of films about epilepsy in the United States; it would seem more convenient if our film library were kept in two parts. All the films made in Europe and the East might be kept in London and the American films kept in Boston. Where there is an exceptionally good film it would clearly be an advantage to have duplicate copies, one in each office.*
6. *We propose that the Bureau should be the channel of distribution of literature. We shall ask all members to send us 50 copies of their more important publications and the Bureau will then be responsible for sending them on to members who wish to receive literature in this way. As a beginning, we propose sending out the Journal of the British Epilepsy Association to all members.*

*In this letter also receipt of grants and donations from the Swedish, British and Scottish Epilepsy Associations and from the ILAE and the Dutch Branch of the ILAE, while there was hope to receive donations from the American Epilepsy Society and Canadian Neurological Society.*

Looking back at this newsletter 47 years later there are a few points which catch the eye:

In fact three of the members of the new Board of Directors are members of the Executive Committee of the ILAE, but this is only mentioned for McNaughton and Gastaut. Lorentz de Haas, at that time Vice-President of ILAE, is apparently considered to represent the special centre for Epilepsy in the Netherlands.

At a time when 19 national leagues against epilepsy were registered as members of ILAE, only Sweden, Great Britain, the Netherlands and Scotland have paid money to the bank account of IBE which, by the way, is acknowledged as a grant or donation, and it is expected that the American and Canadian Epilepsy Societies will also make payments. However, there may have been a deal that the donation of US\$600 by the ILAE should be considered a summed membership contribution of all its 19 associated members, while Sweden, Britain, Scotland and the Netherlands donated and the USA and Canada promised extra gifts. In fact all these six countries are also represented on the Board of Directors!

Organising meetings and the provision of educational material about epilepsy appear to be the activities which IBE, at its onset, was focusing on. Members would receive the Journal of the British Epilepsy Association, however, in this first newsletter it is not revealed who are considered to be members of IBE or how membership can be obtained.

# An ABC of Porto

## What to see and do before and after the conference



is for **Port**, the ruby red fortified wine that takes its name from the city of Porto.

Wine produced in the Douro region began to be fortified with brandy in the 18th century to stop fermentation and to allow the wine to travel better. The result was Port and even

today its production is restricted to the Douro valley area, at the mouth of which sits Porto.

The conference Social Evening will be held in the very special venue **Três Séculos** within Taylor's Port lodge, one of the world-famous port wine cellars of Porto. Sitting on a hill overlooking the river, Três Séculos promises to be a great location for a very enjoyable evening.

Tickets cost €35 and the price includes a port wine reception, tour of Taylor's warehouse and a seated dinner. Tickets can be bought when registering or by email at [registration@epilepsycongress.org](mailto:registration@epilepsycongress.org).



is for the Old Town, known as **Cais da Ribeira**. Atmospheric and full of colour and life, this is the very soul of Porto.

The wonderful district of Ribeira is made up of medieval streets and narrow shaded alleyways. It is a crumbling but fascinating place, ending at a riverfront square - the Praça da Ribeira. With photogenic

traditional boats moored at the quayside, over-

looked by colourful ancient houses, this is the most picturesque spot in the entire city and the place everyone loves - UNESCO did too, and declared the area a **World Heritage Site**.

Enjoy a cool refreshing drink, take in the unique atmosphere, and don't forget to bring along your camera. Then return at night when the place is especially lively. There are dozens of cafés, bars, and restaurants sheltered under medieval arches, making it the most popular district in the city for eating and drinking.



is for river, the **River Douro**. With the quaysides of the Ribeira district on one side and Cais de Gaia with its multitude of port wine lodges on the other, you can cross from one side of the river to the other using the pedestrian level of the breathtaking double-decker

Ponte Dom Luiz (Dom Luiz bridge).

From the Cais de Gaia side you can get fantastic views of the city's skyline, with Cais da Ribeira on the other side, the Dom Luiz bridge soaring high above and the picturesque port wine boats, used to transport port barrels down river, moving gently in their moorings along the quayside.

Of course, **R** is also for river cruise, of which there are several to choose from!



is for tram or train — although in this case we are referring to the **Funicular dos Guindais**, Porto's cable car.

The funicular runs down a steep cliff from Batalha to the quayside at Ribeira. Originally constructed to facilitate the movement of cargo, particularly port wine, the funicular is now promoted as a tourist attraction.

While the journey is short, at just three minutes, after emerging from the tunnel at the top you are given a panoramic view of the city.

The cable car runs from 8am to 8pm on weekdays, later at weekends, and you can use the Andante ticket, allowing a trip on the funicular to be combined with a journey on the Porto Metro and on selected bus routes.



is for **Ocean**, the Atlantic Ocean. Foz is one of the most sophisticated districts of Porto, with seafront bars, cafés and restaurants. It has a village-like feel, but eventually when the waterfront avenue becomes Avenida do Brasil, the wide open spaces, big attractive houses, beaches and cafés give it the look of a resort.

Most of the beaches here are dotted with outcrops of rocks, so they are not recommended for swimming. But they're a great escape in the city, allowing you to lie on the sand and get your feet wet in the warmer summer months. To reach Foz take bus number 1 from the centre of the city or numbers 21 or 24 from the Boavista roundabout.







25th-27th August 2010



# PORTO

12th European Conference on Epilepsy & Society

*From a very full and exciting programme, here is a small taste of the sessions and other activities that will take place in Porto. It promises to be a great meeting!*

## European Regional Committee Meeting

IBE Full and Associate Members in Europe are encouraged to send representatives to attend the Regional Committee Meeting on Wednesday 25th August. Agendas and other information will be circulated to all European members well in advance of the meeting date.

## Launch of Euro Report

**Thursday 26th August  
08:00–09:00**

One of the most significant events at the conference will be the launch of the European Report on Epilepsy of the Global Campaign Against Epilepsy. This long-awaited important report, which is being published by the WHO, will be officially launched by Dr Matt Muijen, WHO Regional Advisor for Mental Health.

The report will bring together, for the first time, all available evidence from the region on the epidemiology, etiology and management of epilepsy and will be a valuable tool for those working for change at national level.



## Opening Ceremony

*Wednesday 25th August At 19:00*

All conference delegates are invited to the Opening Ceremony Reception at Santa Casa da Misericórdia do Porto. This building, which belongs to the Misericórdia charitable foundation, holds an important collection of paintings donated by benefactors. These are on display in its picture gallery, located in a former open air interior patio which was roofed over in the 19th century and recently restored.



## Session Highlights

Epilepsy Brain and Mind  
Photosensitivity and Epilepsies  
Influencing Policy  
Ethics in Epilepsy

## Workshop Highlights

Training for Success  
Personal Development Opportunities  
Driving and Epilepsy

## Youth Session

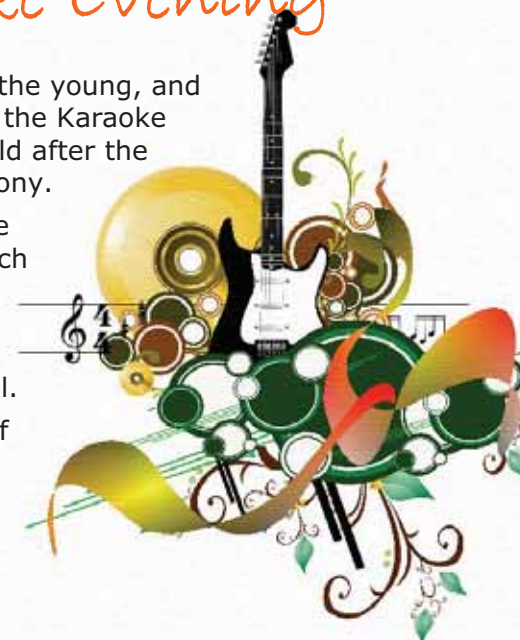
Sex, Drugs and Lifestyle Choices

## Karaoke Evening

A fun event for the young, and young at heart, the Karaoke event will be held after the Opening Ceremony.

The venue is the Triplex Bar, which is just a five minute walk from the conference hotel.

The fun kicks off at 20:30.



# Promising Strategies 2010

## UGANDA

### Goat Rearing Enterprise

In rural Uganda goat rearing ranks high in animal husbandry and the average household will own 4 or 5 goats. In addition to generating income through goat's milk and goat meat, goats are considered as a symbol of wealth and are used as dowry payments in arranged marriages.

This project will assist 48 people with epilepsy. Each participant will be provided with a pregnant goat and receive instruction on its care. In return each person will be asked to give back two goats to the project within a period of 2 years. As most goats produce twin kids, this should be easily achievable. The young goats will then be used to extend the program further. Profits will provide a means of independent living and improve self esteem for many members of the Epilepsy Support Association of Uganda.



## RE-

### A new concept in retailing

The concept of the second hand shop is not new: it's a tried and tested way of generating funds for charities around the world. However, the plans Epilepsy Namibia has for RE- will broaden the scope of this enterprise to great effect.

RE- will follow the structure of any commercial retail outlet with a shop manager, sales assistants and stock controllers. People with epilepsy will be given preference in the selection of staff and the shop will also act as an awareness and information centre. Sales training will be provided for all RE- employees.

In addition, it is envisaged that others not directly involved in RE- will have the opportunity to create new employment opportunities through the creation of spin-off businesses, such as laundry and alteration services.



## NAMIBIA

## ARGENTINA



### A Legal Brief

Monitoring the newly introduced Argentinean legislation on epilepsy, National Law of Epilepsy N° 25.404, the FUNDEPI association will study how successfully the law is being implemented. The association will monitor, in particular:

- whether the new legislation has had an impact on the gap between diagnosis and treatment,
- the implementation of the legislation with respect to employment issues,
- the situation for indigenous communities where the use of traditional medicines still exists,
- implementation of educational programmes for health care professionals at primary level,
- whether the law has had an impact on stigma related to epilepsy. This element will be addressed by way of a planned survey.



The IBE Promising Strategies Program was set up in 2006 in order to support IBE Members by providing financial help for projects aimed at improving the quality of life of people with epilepsy. We are delighted to introduce the 11 new projects recently selected to receive funds under the 4th round of the program. The program is now supporting 38 projects around the world.

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

## Learning by the Book

Epilepsy South Africa is developing a self-advocacy, human rights and rights-to-health training manual to be used by its National Social Development Manager in self-advocacy training workshops for members of the community and staff members from the association's branches. A secondary objective is to train 30 trainers, from seven Epilepsy South Africa branches during 2010-2011. These trainers will then have the potential to facilitate further training of 600 persons with epilepsy and other disabilities each year.

The organisation also plans to conduct a pilot study with the two-fold aim of:

- Training members of staff in implementing and facilitating the training programme in their respective Epilepsy South Africa branches.
- Monitoring to establish how successful the training program is and the level of learning achieved by participants during and after training.

**SOUTH AFRICA**



## Jamming it in **ZAMBIA**

Epilepsy Association of Zambia plans to add value to the tomato-growing enterprise already in place in the association's garden by embarking on a jam-making enterprise. Not limiting production to tomato jam, there are also plans to extend the range by buying fruits such as mangos, pawpaws, oranges, strawberries and bananas at the local market which will also be used to produce jam.

The finished product will be sold in a new association shop that will be located in the garden. The shop will also stock garden and poultry products produced by people with epilepsy working in the garden and more produce will be sold at wholesale prices to local shops.

The enterprise will train people with epilepsy in jam-making techniques and the profits will be used to pay the workers and to fund the Epilepsy Association of Zambia.

The ANLICHE hairdressing workshop will train 15 people with epilepsy in hairdressing techniques for ladies, gents and children. The workshop participants will also undertake a course on running a small business, so that they can set up their own micro enterprises once they are trained.

The workshop is aimed primarily at housewives whose epilepsy is now well controlled. These women would have had little chance to study or work when they were still having seizures and will have neither social benefits nor healthcare assistance within the normal parameters of a national health system.

It is expected that up to 80% of participants will find work within a period of 8 months.



**CHILE**

## The Cutting Edge

## The Promising Strategies Program has supported projects in:

- Argentina
- Bangladesh
- Brazil
- Cameroon
- Chile
- China
- Czech Republic
- Ecuador
- Ethiopia
- The Gambia
- Guatemala
- Kenya
- Lebanon
- Mauritius
- Mongolia
- Namibia
- Philippines
- Romania
- Sierra Leone
- South Africa
- Tanzania
- Togo
- Uganda
- Zambia
- Zimbabwe

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

## Artistic Direction in **CHINA**

In late 2007, the Sea Horse self-help club of the China Association Against Epilepsy conducted an art and crafts competition in Shanghai for persons with epilepsy. The artworks created were both elegant and valuable, representing the fighting spirit to overcome difficulties faced by those living with epilepsy. The artworks were of very high quality and were showcased on the IBE website.

In follow up to the art competition, a 4-week course in handcrafts, which took place in August 2009, also proved both popular and successful. Feedback from Sea Horse club members indicated that these activities were much appreciated and there was a desire for people with epilepsy to have a central place where they could relax and create artworks.

In response to this, the China Association Against Epilepsy has taken the decision to create an Art Studio for people with epilepsy in Shanghai. Based on the train the trainers model, the studio will provide an artistic environment for people with epilepsy and their care-givers. Here they will be able not only to learn and share art techniques, but to exchange their experiences related to epilepsy.

Through future planned exhibitions of artwork created in the studio, the China Association Against Epilepsy also hopes to be able to raise awareness and understanding of epilepsy in the general public as well as improving the quality of life and self esteem of all those involved in the project.

## REPUBLIC

## CZECH

### Children's Survey

Using existing methodology and verified questionnaires, Epistop plans to undertake a survey involving school children, their teachers and parents to establish whether the situation has changed for children with epilepsy in the Czech Republic since similar surveys were carried out in 1995 and 2007. Based on the data obtained, the association will inform all those interested how it is possible to improve the quality of life of children with epilepsy. These questionnaires could be a reliable tool for the next investigation in the Czech Republic.

The next plan will be to use the results of the survey to prepare an information brochure or leaflet and to upload the information on websites with a pro link to the website of the Ministry of Education.





Details on the projects supported under this round, as well as in previous rounds of the Promising Strategies Program, can be found on the website. The next round of the program will begin in late 2010, when IBE member associations will be invited to submit letters of intent. Full details on the application process are also available on the IBE website.

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

**Raising Awareness** is the main goal of the Romanian project planned by EpiRomania. Despite the obvious beauty of the architecture and countryside of Transylvania, stigma, prejudice and ignorance about epilepsy are still widespread in this region—both in people with epilepsy and the general public.



ROMANIA



LEBANON

## Lights, Camera, Action!

With a high level of illiteracy in Bangladesh, the written word is not always the best way of educating the public. With that in mind, the Epilepsy Association of Bangladesh has decided to use the medium of film to inform people about epilepsy.

The documentary film has already generated interest from a media partner. It is planned to use famous local actors in the production, in order to increase public interest and to attract media interest in the project.

With a huge population, most of whom have little or no formal education, the incidence of epilepsy in Bangladesh is still unknown.

## Good news for chocoholics!

The initiative of the Association for the Care of People with Epilepsy will come as good news to all those with a sweet tooth! The ECAL project is a chocolate making workshop which will also teach chocolate moulding and wrapping. The project is open to people with epilepsy and to anyone else interested in learning the craft of the chocolate maker.

Once the techniques of chocolate making have been mastered, the chocolates produced at the workshop will be sold to generate income for the chocolate makers. Some of the profits will also be used to support people with epilepsy who come from poor backgrounds.



BANGLADESH

# Bienvenido a Cartagena

Cartagena de Indias is one of the oldest cities in the Americas, founded by the Spanish conquistador Pedro de Heredia in 1533. Its famed colonial Old City with San Felipe fortress is a UNESCO World Heritage Site. There is much to do and see in Cartagena; here's a small preview of the city's unique charms.



## Centro Amurallado Walled City

Everyone is drawn to the old quarter of the city, the centro amurallado. This is the heart of Cartagena, the old walled city protected by the fortress intended to help defend the city from pirates and storms. Within the walls there are colonial buildings, plazas, churches and convents. Also within the walled area, the section of Getsemani is worth exploring during the day.

To enjoy this attraction you need to throw away the map and wander aimlessly along the narrow streets. Inside the walled city you feel more secure, but you should also remain vigilant for pickpockets. In this part of the city every block is different from the other. It is so true that the streets gain different names after every crossroads!

Tourists are a common species there, and that of course means the ever present taxis and salespeople hoping to do business. As the streets begin to get more and more narrow, this has the potential to be a nuisance. But you do get used to it quite quickly.

In Cartagena's historic side, you will find beauty in every building, with old damaged bricks, flaking paint and a down at heel scruffiness that has the ability to beguile. This is not a sanitized tourist spot, scrubbed clean and shiny, it is a lived-in, vibrant neighbourhood where life goes on despite the daily influx of tourists and their guides. It has to be one of the favourite parts of the city for all who visit it.



**Dipping a toe in the ocean. After the congress, what better way to wind down and relax!**

Bocagrande beach

## Plaza San Pedro Claver

At the end of the Plaza de la Aduana, is the Plaza San Pedro Claver, a small square dominated by a sanctuary, a museum and the Church of Saint Peter Claver.

Within the Church are the remains of St Peter Claver, the first canonised saint in the Western Hemisphere, who worked in Cartagena for 40 years, defending and nursing African slaves arriving in the port following weeks living in inhuman conditions on board slave ships.



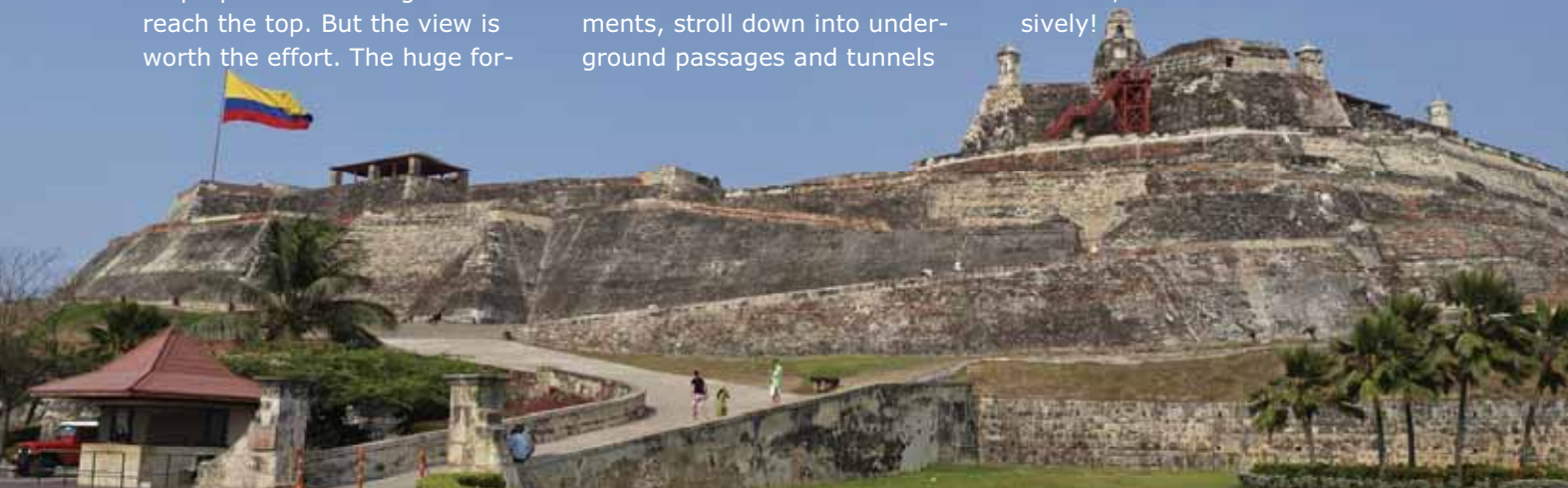
Plaza San Pedro Claver

## San Felipe de Barajas Castle

This is a must see attraction. In Cartagena's hot humid climate, be prepared for a tough climb to reach the top. But the view is worth the effort. The huge for-

ress that dominates the old town took 150 years to build. Visitors can now walk the battlements, stroll down into underground passages and tunnels

and wonder at the work that went into building a fort that, in the end, was never used defensively!





# IBE en Cartagena de Indias

Las futuras actividades del IBE en el VI Congreso Latinoamericano de Epilepsia

Tomás Mesa Latorre,  
Secretario Comité Latinoamericano del IBE



**D**urante el VI Congreso L.A. de Epilepsia a realizarse en Cartagena de Indias, que tendrá lugar entre los días 1 y 4 de Agosto 2010, habrá varias actividades que el IBE desarrollará, destacando entre ellas, las siguientes:

## Grupos de discusión

Uno de los grupos de discusión, presentará la siguiente temática: *Desafíos en calidad de vida en personas con epilepsia* donde habrá exposiciones de las experiencias en Brasil, Chile, El Salvador y Uruguay. Habrá además una proposición de cómo evaluar estos aspectos.

## Jornada del Buró

La Jornada del Buró, la cual estará abierta a la participación del público en general y particularmente a personas con epilepsia y sus familiares. Las jornadas estarán especialmente dedicadas a docentes y educadores de las áreas primarias y secundarias, como importantes agentes difusores a la sociedad. Habrá información de algunos aspectos de especial relevancia relacionados con la Ley de Epilepsia en Colombia y cambios realizados en el sistema de salud, de vital importancia para el conocimiento de personas con epilepsia y sus familiares.

## Epilepsia y Legislación

En el programa científico se tratará *Epilepsia y Legislación*, destacando lo realizado en Colombia y Argentina, con la visión mundial de la Campaña Global.

## Estrategias Promisorias

Está prevista la reunión desayuno sobre los proyectos de Estrategias Promisorias, donde se mostraran algunas de las actividades ya realizados en nuestra región, incluyendo Argentina, Chile y Guatemala, con el objetivo de estimular a otros países a concursar a nuevos proyectos y desafíos.

## Asamblea General del Comité Latinoamericano del IBE

Como es habitual, se llevará a efecto la Asamblea General del Comité Latinoamericano, recordando lo sesionado en el Congreso Mundial de Epilepsia en Budapest y los planes futuros de cada Capítulo Latinoamericano.

## Reunión IBE/ILAE

Por tercera vez, se llevará a efecto la reunión de las directivas del Comité Latinoamericano del IBE y de la Comisión Latinoamericana de la ILAE, con el objetivo de seguir trabajando en proyectos Latinoamericanos en conjunto.

## Campaña Global

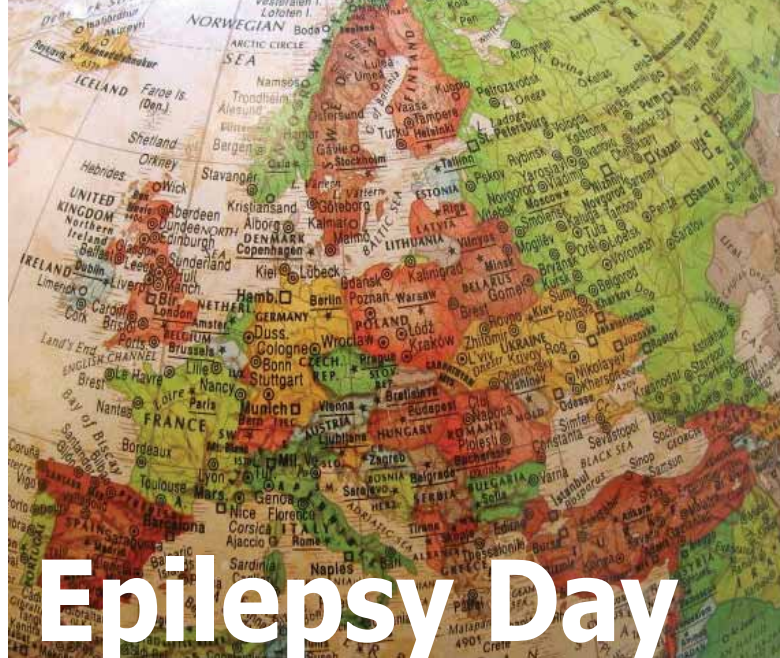
Una de las actividades más importantes será la centrada en el lanzamiento de la tercera etapa de la *Campaña Global contra la Epilepsia*, con una sesión y además la formación de un comité para planificación y desarrollo en este nuevo periodo.

## Afiches

Habrá nuevamente, la tradicional exposición de Afiches (Posters), relativos a la conformación y actividades que desarrolla cada Capítulo del IBE. En esta oportunidad es enfocado a los Capítulos Latinoamericanos del IBE. Esta idea es promocionada por el Comité Ejecutivo Internacional del IBE y estos mismos afiches, serán expuestos en el Congreso Mundial de Epilepsia en Roma, el 2012.

## Otras Actividades

Serán tratados durante el congreso, varios *trabajos relativos a los social o educacional*, ya sea en Afiches o Conferencias que fueron enviados por autores de diferentes países de nuestra región. Como es habitual, habrá una *Estación (o Stand) del IBE*, para poder conversar, presentar y mostrar material, afiches, revistas, material educativo, etc, que cada país realiza en sus actividades diarias.



# European Epilepsy Day

Dear IBE members and supporters

### Background

I am delighted to report that one of the more important decisions taken at the recent meeting of the IBE and ILAE Executive Committees was to move forward with the creation of a European Epilepsy Day.

This follows from background research undertaken by the Political Action Group of EUCARE, including a survey of IBE and ILAE member associations in Europe to gauge interest in such an initiative. The results of the survey showed that both IBE and ILAE associations were very enthusiastic about the plan and were also in favour of holding the event in February each year.

Given the magnitude of the planned European Epilepsy Day and the impact it could achieve, the Political Action Group approached the IBE European Regional Committee which has since indicated its agreement and enthusiasm in being involved. The ILAE Commission on European Affairs has also been invited to take part in the event. This will not be a fundraising event, since several IBE and ILAE members already use annual or biennial national events as a means of generating funding (as well as awareness) for their associations.

### Launching European Epilepsy Day

European Epilepsy Day will be launched on 14th February 2011 (the Feast Day of St Valentine, who is reputed to have had epilepsy) and the Political Action Group, in liaison with the IBE and ILAE European structures, will develop a launch activity with the potential to generate a good level of response from both Members of the European Parliament and journalists.

The aim of European Epilepsy Day will be to promote epilepsy awareness at regional level through educational and promotional activities.

Over the coming months EUCARE, together with the IBE Regional Committee and the International League Against Epilepsy, will be setting plans in place for next year's launch. As details are confirmed we will be able to provide you with more information on how the

day will be celebrated and how our members in Europe can become involved in the event.

### Planned objective

The European Epilepsy Day is an important development and will serve to send out the right signals to the European Union, where more and more emphasis is being placed on the need for medical and lay associations to work together on initiatives requesting the support of the European Parliament.

European Epilepsy Day will add to the other regional epilepsy days already organised by IBE members and regional committees. For several years the IBE Latin American Regional Committee has celebrated an annual Latin American Epilepsy Day on the 9th September, while an epilepsy day introduced in China, after discussion with IBE, is supported by several other members in the Asian region. In time it is planned to have annual epilepsy days in each of IBE's seven regions.

### International Epilepsy Day

Such events would respond to the often voiced request of IBE members that an International Epilepsy Day be created. Although such a day has been discussed by the IBE and ILAE Executive Committees, further consideration was postponed until the WHO would provide it's support.

The support of the World Health Organisation is seen as vital for the International Epilepsy Day and the success of the European Epilepsy Day and other regional epilepsy days may be crucial in achieving this.

All the best,

Mike

Mike Glynn  
President





## Outstanding Persons with Epilepsy Award



### Time is running out!

If your association is located in the South East Asia or Western Pacific regions, this is an urgent reminder to submit your nomination for the 2010 Outstanding Persons with Epilepsy Awards, which will be presented in Melbourne during the 8th Asian & Oceanian Epilepsy Congress (AOEC) in October.

These special awards were first introduced at the 4th AOEC in Nagano, Japan 2002. The idea behind the award is to encourage people living with epilepsy to talk openly about their condition, thereby overcoming the heavily culturally defined stigma and discrimination that exists within the region. Since 2002, the award has

been presented to worthy recipients at congresses in Bangkok 2004, Kuala Lumpur 2006, and Xiamen 2008.

The Regional Executive Committees in the South East Asia and Western Pacific regions would like to encourage IBE Members in these regions, who have not already done so, to select a candidate from within their association to receive the award in Melbourne. Each member in these regions is entitled to nominate one recipient.

Suitable candidates may have made a significant contribution to community service; have given longstanding support for people with epilepsy; had a significant individual achievement;

be a staunch advocate for epilepsy; or have given distinguished service to a local epilepsy association.

Once a candidate is selected, a nomination form should be completed and sent by email to the IBE office [ibedublin@eircom.net](mailto:ibedublin@eircom.net).

The South East Asian and Western Pacific Regional Committees have allocated some financial support within their budgets to assist those nominated for the award to attend the congress in Melbourne for the award ceremony. A closing date for nominations is 15th July.

The nomination form is available on request from [ibedublin@eircom.net](mailto:ibedublin@eircom.net). But hurry! There is no time to waste!

## Epilepsy Report tabled in Australian Parliament



*Jill Hall MP, Mark Coulton MP, Wally Lewis, Graeme Shears, Chair Joint Epilepsy Council of Australia, Damian Hale MP, and Bill Shorten MP and Parliamentary Secretary for Disabilities and Children's Services.*

In early March, Parliamentary Friends of Epilepsy, Jill Hall MP and Senator Gary Humphries, tabled the Friend's Report on the Informal Inquiry into Epilepsy in the Australian House of Representatives and the Senate.

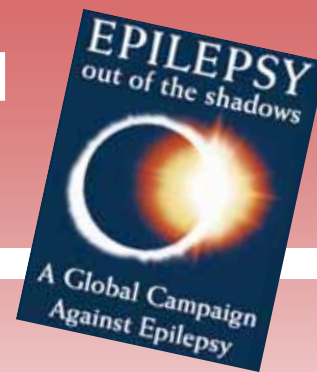
"These recommendations range from the need for comprehensive education and awareness to educating government departments, the need for positive employment initiatives and looking at issues surrounding travel. One that I support quite strongly is a national health survey to provide accurate information on the data concerning the incidence and treatment of epilepsy," stated Jill Hall.

Senator Gary Humphries highlighted those recommendations that proposed more research; better education of practitioners, doctors and nurses; and, of course, measures to reduce the stigmatisation that people with epilepsy tend to suffer by virtue of the nature of seizures that they might experience.

Graeme Shears, Chair of the Joint Epilepsy Council of Australia (JECA), IBE's Member in Australia, said members concurred with the recommendations contained in the report, particularly regarding employment access, and funding for projects such as research and awareness-raising.

# Addressing the Task at Hand

## Work gets underway for the Global Campaign Against Epilepsy Taskforce



At the Taskforce meeting in December 2009

*Back (from left):* Anthony Zimba (Zambia), Charles Begley (USA), Emilio Perucca (ILAE Treasurer), Raida Al Baradie (Saudi Arabia), Nico Moshé (ILAE President), Sam Wiebe (ILAE Treasurer), Carlos Acevedo (Chile)

*Front (from left):* Mike Glynn (IBE President), Tarun Dua (WHO), Helen Cross, (Co Chair, UK), Hanneke de Boer (Campaign Coordinator), Shichuo Li (Co Chair, China)

One of the first tasks of the Global Campaign Taskforce was to develop a strategic plan to be submitted to the Executive Committees of ILAE and IBE for discussion during the Joint Executive Committee Meeting in March 2010. It was agreed that the plan should include:

- a vision to raise visibility of the campaign, its activities and products;
- development of one external harmonised message;
- strategies to work with governments to enhance epilepsy-related policies and programmes;
- recruitment of junior people from the regions to assist with the work of the Taskforce/Campaign;
- strategies to further address the treatment gap and knowledge gap worldwide;
- an outline of priorities for research. Research considered should ultimately lead to better quality of life for people with epilepsy and their carers. Population based research is an important component of GCAE work;
- issues to be addressed in both developed and developing countries.

### Goals and recommendations

During the meeting of the Taskforce, held in Boston in December 2009, the following needs were discussed:

1. Need for internal collaboration and cooperation. It is essential that the Task Force involve the ILAE/IBE Regional Committees from the time of its conception;
2. Information sharing, dissemination and promotion mechanisms: both internally and externally. Increasing awareness of existing Demonstration Projects.;
3. Developing new Demonstration Projects. Consider as a goal the initiation of new projects in each region over the next 4 years;
4. Improving the visibility of epilepsy and the Global Campaign in all countries (both developed and developing);
5. Identification and capitalisation of Campaign entry points with other international organisations and initiatives;
6. Collaboration with regional and topic-specific ILAE and IBE Commissions and Committees;
7. Encouragement of participation of individual chapters/members;
8. Partnerships with other international organisations and identification of such organisations;
9. To act as liaison for information gathering and feedback on the burden of epilepsy project;
10. Assessment of the role and methodology for country need resource assessment and resource mobilisation.

The discussion led to the identification of five possible goals and recommendations as a start to the formulation of a strategic plan:

### Goal 1.

Improve the visibility of epilepsy and the activities of the Global Campaign in all countries.

### Goal 2

Promote activities of epilepsy projects at country and regional level.

### Goal 3

Assess and strengthen health care systems analysis for epilepsy by acquiring a better understanding of the conceptual model, magnitude and scope of the coverage gap including the treatment and knowledge gap (definition), measuring the burden of epilepsy and methods for conducting country resource assessments.

### Goal 4

Increase partnerships and collaboration with other organisations.

### Goal 5

Develop the necessary infrastructure and resources to achieve the expanded goals of the Campaign.

Some members of the Taskforce will meet in Rhodes during the ILAE European Congress on Epileptology to discuss the action plan that has been drafted and which will ensure that this strategic plan becomes a reality.





Paul Harding

# Tinkers

Novel involving epilepsy wins the Pulitzer Prize for fiction

Author Paul Harding has won the Pulitzer Prize for fiction with his debut novel *'Tinkers'* which has been described by critics as "a powerful celebration of life".

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

Central to his reminiscing are memories of his father Howard, who had epilepsy. Harding's description of the father's seizures, and the chemical electricity that

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

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

Harding, formerly the drummer for rock band Cold Water Flat, now teaches at Harvard.

Publisher: Bellevue Literary Press

ISBN-10: 193413712X

ISBN-13: 978-1934137123

## Light-sensitive genes to tackle EPILEPSY

Inserting light-sensitive molecular pumps into brain cells could help scientists better understand and eventually even control epilepsy, delegates at a recent conference at the Royal College of Surgeons in Ireland (RCSI) were told.

Professor Merab Kokaia from Lund University Hospital in Sweden told Ireland's first national research conference on epilepsy about his work, which puts light-sensitive chloride pump genes from bacteria into mammalian brain cells growing in the lab to look at their effects on epilepsy-related activity. When triggered by light, the bacterial system dampens down seizure-associated electrical signals between brain cells.

This "optogenetic" approach, that uses light-activated genes, provides a

powerful tool to research brain function, according to Kokaia.

"Our data show that specific cell populations can be addressed by optogenetics in epilepsy models, and that such selective approach may be effective in suppressing seizure activity," he said. However, he noted the approach would not be applied to patients in the short term: "There is a long way between showing the principle in laboratory conditions and human application."

Prof Kokaia's work is a first step towards possible light-based neural prosthetics that could help control seizures by stimulating appropriate electric patterns in the brain, said Dr David Henshall who, together with Dr Gianpiero Cavalleri from the RCSI, organised the conference.



## This little Piggie stays at home!

Researchers in Kenya have been trying a seemingly unlikely, but simple, tactic to prevent epilepsy: encouraging farmers to keep their pigs tethered rather than running free.

The aim is to stop the pigs from spreading *Taenia solium*, the tapeworm that causes neurocysticercosis in humans, a major cause of epilepsy in poor countries, particularly in Africa, Asia and Latin America, where millions are infected. Humans pick up the tapeworm from infected animals by eating undercooked pork meat.

Farmers in western Kenya are being taught how the disease spreads and shown how to identify infected meat, cook it to destroy worms, recognize tapeworms and tether or confine pigs to keep them away from human waste.



## Excellence in Journalism Award 2010

### Second round of competition announced

Following the very successful first Excellence in Journalism Award, we are pleased to announce that a second round of the initiative is now underway. The aim of the award, which is a collaboration of IBE and UCB Pharma, is to encourage journalists to raise awareness about epilepsy and to help break down the barriers faced by people with epilepsy through education on the true facts about epilepsy.

The international award recognises journalists who produce stimulating, informed and compelling news and feature stories on epilepsy, and 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 published or broadcast between 30th June 2009 and 29th October 2010 and articles must fulfil some or all of the following criteria:

- Help to increase awareness and understanding of epilepsy;
- Give a voice to persons with epilepsy;
- Is conceptually or visually innovative and creative;
- Uses language responsibly when reporting or writing on epilepsy;

- Is well structured, well researched and makes for compelling reading or listening.

Prizes will be presented in three categories:

- Print
- Broadcast
- Online

Entries accompanied by a completed entry form will be accepted until 29th October 2010.

Further information on the award can be found on the IBE website [www.ibe-epilepsy.org/activities/excellence-in-journalism-award](http://www.ibe-epilepsy.org/activities/excellence-in-journalism-award).

## Michael Prize 2011

The Michael Prize was awarded in Germany for the first time in 1963, for the best contribution to scientific and clinical research which promoted further development in epileptology. The prize is now highly regarded as an international award for research that promotes further development in epileptology.

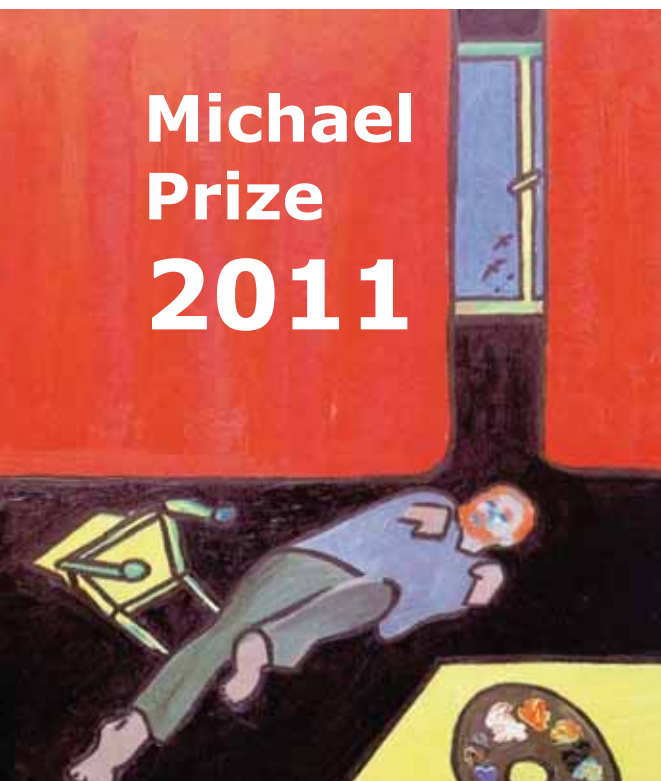
The Michael Prize is awarded biennially and is specially designed to attract younger scientists (normally less than 45 years of age).

The prize fund is €20,000.

For the Michael Prize 2011, up to a maximum of three papers in the English language may be considered, at least one of which – published or not yet published – must be from the period 2009/2010. The papers, together with a curriculum vitae, should be submitted by electronic mail before 31st December 2010.

For information and/or submission of applications contact:

Stiftung Michael, Muenzkamp 5, D -22339 Hamburg, Germany  
e-mail: [StiftungMichael@t-online.de](mailto:StiftungMichael@t-online.de)





# EPILEPSY WITHOUT WORDS

Capture the feeling of  
epilepsy with a click!

## PHOTOGRAPHY COMPETITION

runs from 15 May 2010 - 1 March 2011

Visit [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org) or email  
[ibedublin@eircom.net](mailto:ibedublin@eircom.net) for more details



International Bureau for Epilepsy

## Golden Jubilee Photography Competition

A photography competition, open to everyone, is the first of many initiatives being planned by the Bureau to celebrate IBE's Golden Jubilee in 2011. The competition, which is titled *Epilepsy Without Words* is now open for entries and the closing date is not until 1st March 2011.

A special photo gallery, which will display all of the entries that are received, will be open on the IBE website from 1st June 2011 and the competition winners will be announced during the 29th International Epilepsy Congress in Rome in late August 2011.

Full information on the photo competition, including a list of rules, is available for download from the IBE website: [www.ibe-epilepsy.org](http://www.ibe-epilepsy.org).

### Categories

In addition to a category for regular digital camera photos, there is also a special category for photos taken using a mobile or cell phone. As most people now carry a phone with an inbuilt camera, there is no excuse for not taking part in this competition. And, who knows, you could be the winner of one of the major prizes!

### Who can enter?

The competition is open to everyone – professional and amateur photographers alike. We are also looking for your help in attracting entries.

If you are part of a camera club or know someone who is, we would ask you to encourage promotion of the competition to club members. Entries from students at art

and design colleges are also welcome and the competition could be used by first and second level schools to raise awareness about epilepsy in schoolchildren. IBE would also welcome contact details for interested clubs and schools in your area, so that we can contact them directly.

Finally, if you are under 16 years old, you will need the permission of a parent/guardian to take part.

### PRIZES

#### Digital Camera Category:

- 1st Prize: US\$3,000
- 2nd Prize: US\$2,000
- 3rd Prize: US\$1,000

#### Mobile Phone Category:

- 1st Prize: US\$500
- 2nd Prize: US\$300
- 3rd Prize: US\$200

# Future Congresses 2010



## 6th Latin American Epilepsy Congress

Cartagena, Colombia

1st - 4th August 2010



## 12th European Conference on Epilepsy & Society

Porto, Portugal

25th - 27th August 2010



## 8th Asian & Oceanian Epilepsy Congress

Melbourne, Australia

21st - 24th October 2010

IBE/ILAE Congress Secretariat  
7 Priory Hall, Stillorgan, Blackrock, Co Dublin, Ireland

Email: [info@epilepsycongress.org](mailto:info@epilepsycongress.org)

Phone: ++353 1 20 567 20

Website Portal: [www.epilepsycongress.org](http://www.epilepsycongress.org)