



**International Bureau for Epilepsy**  
**Annual Report 2008**



The IBE exists to improve the social condition and quality of life of all people with epilepsy and those who care for them.

## Report of Susanne Lund

### IBE President 2005 - 2009



It always surprises me, when I sit down to report on IBE's activities over the previous period, to see just how much has happened and how much has been achieved. The year 2008 has been no different!

During the year IBE was involved in three important regional congresses:

The 7<sup>th</sup> Asian Oceanian Epilepsy Congress took place in Xiamen, China in May. In addition to the scientific programme, the IBE Regional Committees South East Asia and Western Pacific also arranged a special programme for people with epilepsy and their families. I am grateful to all those involved for their great efforts in making this a wonderful congress.

The city of Marseille, France was the venue for the 11<sup>th</sup> European Conference on Epilepsy & Society. This is the only conference which is organized solely by IBE and its European Regional Committee. More than 300 delegates, some from distances as far away as Australia, traveled to France to participate in the meeting. Thanks are due to the European Committee for preparing a very interesting programme.

The third regional congress took place in the city of Montevideo, Uruguay in November. This was the 5<sup>th</sup> Latin American Regional Congress and introduced some new elements with a focus on education. The Latin American meetings attract a large number of delegates from Spanish and Portuguese speaking countries and the IBE Latin American Regional Committee plays an important role in the congress.

Following on the previous rounds of funding, the 3<sup>rd</sup> round of the Promising Strategies Program was launched in September 2008. IBE is now funding 29 projects aimed at improving the quality of life of people with epilepsy in developing nations. These projects are helping people to become self sufficient by way of education and employment and I would like to thank all those who have helped in this great endeavour.

IBE continues to grow and during 2008 I was very pleased to see three new Full Members and seven new Associate Members ratified by IBE's General Assembly. At the end of 2008, IBE had 126 Members in 92 countries worldwide. I would like to welcome our new Full Members in the Russian Federation, Dominican Republic and Nepal as well as our new Association Members in Togo, Lithuania, the United States, Bulgaria, Czech Republic and two new Associate Members in Australia.

The IE News and our website continue to provide excellent means of communicating our message and broadcasting news about our activities to our Members, supporters and to all those with an interest in the social aspects of epilepsy. As Editor of IE News, Carlos Acevedo has made great strides in making this an attractive and interesting magazine.

The ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows' continues to be the most important joint initiative of IBE and ILAE. During 2008, together with the ILAE President Peter Wolf, I was privileged to meet with Dr Ali Alwan,

Assistant Director General of the WHO in Geneva. Dr Alwan acknowledged the tremendous efforts of the campaign and looked forward to celebrating more success and achievement with IBE and ILAE in the future. He stated that challenges in the management of epilepsy concerning prevention, education and stigma should be addressed through the Global Campaign partnership and that the lessons learned from the demonstration projects now needed to be translated into wide practical action. I would like to extend my sincere thanks to Philip Lee and Giuliano Avanzini, co-chairs of the campaign, for their continued efforts during 2008.

EUCARE (European Concerted Action and Research in Epilepsy), another joint IBE/ILAE activity that is concentrated in Europe, continued to gain momentum during 2008. A special session on photosensitivity, organized by the Political Action Group of EUCARE, took place during the congress in Marseille. FONDE (Following Outcomes on Newly Diagnosed Epilepsy), the main scientific element of EUCARE has now reached the testing phase and is due to be launched in 2009.

The Bureau continues to act as the main disseminating partner in EPICURE. Funded by the European Union 6<sup>th</sup> Framework Programme Project LSH-037315, this project is in its 3<sup>rd</sup> year. Involving 29 European partners, EPICURE is investigating developmental aspects of epileptogenesis, which accounts for the high frequency of epilepsy in children.

Since IBE received Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC) in 2007, we have been keeping a very close watch on the activities of this important council and will continue to work to have our voice heard in the halls of the United Nations. To strengthen our contact, in 2008 IBE joined the Conference of NGOs in Consultative Relationship with the United Nations, CoNGO. CoNGO is an international membership association that facilitates the participation of NGOs in United National debates and decisions.

In July we had great reason to celebrate as Action Zone! was awarded two prestigious Communiqué awards in London. The board game, which has proven to be a fantastic success, was declared the Best International Public Relations Campaign Award and also received the top award— Communiqué Campaign of the Year 2008. Action Zone! was developed by IBE and UCB Pharma SA from an idea introduced by Marion Clignet, an

Olympic cycling silver medallist who has epilepsy. More than 46 thousand units of the game, translated into 17 different languages, have been distributed around the world.

The Travellers Handbook continues to be popular and is now available for automatic download from the IBE website. Hard copies can also be provided on request. The handbook is a valuable aid to people with epilepsy when travelling abroad and has been translated into 13 different languages.

A new initiative for 2008 was the Excellence in Epilepsy Journalism Award, a joint collaboration with UCB Pharma SA. The award aims to encourage journalists to raise awareness about epilepsy by recognizing and applauding journalists who produce stimulating, informed and compelling news, articles and feature stories on epilepsy. The first awards are due to be presented in September 2009. Encouraging accurate and appropriate reporting on epilepsy in print, on radio and TV and online, is vital and this award it to be encouraged.

As the term of office of the current committees now enters its final year, the election process to fill positions on the International Executive Committee and the seven Regional Executive Committees began in late 2008. This is a time consuming and complicated process and I would like to thank all those who made great efforts in being involved in this task.

I would also like to thank my fellow members of the International Executive Committee for their great support and for their generosity in giving freely of their time to advance the work of the Bureau. I would also like to thank all IBE Full and Associate Members, Commissions, Task Forces and Working Groups, the IDM office for their professionalism in organizing our congresses, our partners and our supporters, members of the pharmaceutical industry and those dedicated individuals who continue to show commitment and dedication in working to make the world a better place for all people with epilepsy.

Finally I would like to note the terrific support that is provided by Ann Little, Executive Director and Vania Silva, Administrative Assistant, who have organised the necessary administrative support and back up at the IBE Office in Dublin.

Susanne Lund  
President

# Financial Report

## Income and Expenditure Account

Year ended 31st December 2008

With comparative totals for 2007

	2008	2007
	US\$	US\$
<b>INCOME</b>	811,063	548,988
<b>EXPENDITURE</b>	(987,630)	(516,650)
<b>OPERATING (DEFICIT)/SURPLUS FOR YEAR</b>	<u>(176,567)</u>	<u>32,338</u>

## Balance Sheet

Year ended 31st December 2008

With comparative totals for 2007

	2008	2007
	US\$	US\$
<b>FIXED ASSETS</b>		
Tangible assets	<u>8,422</u>	<u>14,423</u>
<b>CURRENT ASSETS</b>		
Debtors and prepayments	265,857	185,274
Cash at bank and in hand	2,654,028	3,055,551
	<u>2,919,885</u>	<u>3,240,825</u>
<b>CREDITORS: (Amounts falling due within one year)</b>	<u>(1,397,166)</u>	<u>(1,547,540)</u>
<b>NET CURRENT ASSETS</b>	<u>1,522,719</u>	<u>1,693,285</u>
<b>NET ASSETS</b>	<u>1,531,141</u>	<u>1,707,708</u>
<b>CAPITAL AND RESERVES</b>		
General reserve	1,252,901	1,324,491
Restricted and designated fund	278,240	383,217
	<u>1,531,141</u>	<u>1,707,708</u>

# Statement of Income and Expenditure

Year ended 31st December 2008

With comparative totals for 2007

	2008	2007
	US\$	US\$
<b>INCOME</b>		
Congress income received	159,158	43,580
Corporate donations	59,198	139,295
EUCARE management fees	60,392	
Membership dues and Solidarity Fund	15,903	18,009
Investment income	47,489	45,709
Promising Strategies	28,190	
Sale of materials	48	127
Other grants	435,299	300,221
Miscellaneous income	5,386	2,047
	<u>811,063</u>	<u>548,988</u>
<b>EXPENDITURE</b>		
Office expenses	5,241	33,108
Printing and postage	10,847	14,159
Printing and postage - International Epilepsy News	48,928	27,111
Travel	62,449	57,327
Global Campaign costs	3,856	30,000
Accountancy fees	33,298	27,666
Audit fees	15,000	12,000
Administration pay costs	170,968	162,465
Bank charges	2,887	2,061
Rent	36,904	29,941
Promising Strategies Program	24,037	30,313
Depreciation	6,001	7,044
Website costs	10,564	7,396
EUCARE costs	407,561	300,221
	<u>838,541</u>	<u>740,812</u>
Currency exchange fluctuations	149,089	(224,162)
	<u>987,630</u>	<u>516,650</u>

# Financial Report continued

## Congress Financial Information

International Bureau for Epilepsy engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 1 July 2005. This Agreement is effective for a five year term beginning on 1 January 2005. The Agreement will automatically extend for an additional five years at the end of the initial term.

The 2008 financial statements reflect the portion of assets, liabilities, net revenues and expenses held by the International Director of Meetings on behalf of the International Bureau for Epilepsy. An analysis of the proportion of congress assets, liabilities, income and expenses applicable to the Bureau is as follows:

	2008	2007
	US%	US\$
Cash at bank	303,766	607,837
Debtors and prepayments	256,992	172,965
Creditors	(328,994)	(293,714)
IDM congress income	602,377	1,793,322
IDM congress expenses	<u>(621,481)</u>	<u>(1,390,084)</u>

## Deferred Congress Income

	2008	2007
	US%	US\$
At 1 January 2008	403,238	-
Congress income	602,377	1,793,322
Congress expenses	(621,481)	(1,390,084)
At 31 December 2008	<u>384,134</u>	<u>403,238</u>



# Thank you for your support!

## Solidarity Fund

The following IBE Full and Associate Members donated generously to the Solidarity Fund during 2008. This fund was created as a means of supporting IBE members in low income countries to play an active role in the work of IBE, where financial hardship would otherwise have prevented this.

- Epilepsy Hospital Bethel, Japan
- Swedish Epilepsy Association
- Swiss Epilepsy Centre, Switzerland
- Greek National Association Against Epilepsy
- ANLICHE, Chile
- Indian Epilepsy Association
- Epilepsy Association of South Australia and the Northern Territory Inc.
- Epilepsy Vereniging Nederland, Netherlands
- Enlighten Hong Kong
- Cyprus Association for People with Epilepsy
- Jamaican Epilepsy Association
- AEAE, Spain
- Nepal Epilepsy Association
- EDYCS, Mauritius
- EOLE, France
- China Association Against Epilepsy
- LESIA, Lithuania
- Epilepsy and Environment, Georgia
- Caritas Malta Epilepsy Association

## Partnering Sponsors

To achieve its goals and realise its vision and mission, IBE works in partnership with other agencies around the world. Throughout 2008, IBE continued its collaboration with the pharmaceutical industry in identifying and establishing initiatives aimed at raising awareness about epilepsy both in the general public and in people with epilepsy and their carers. Financial assistance from pharmaceutical companies has also supported some of the new activities introduced by IBE to improve the quality of life of those affected by epilepsy.

IBE welcomes the interest of donors and recognises and acknowledges the total value of their support through Platinum, Gold and Silver partnerships:

### Platinum Partner

- UCB Pharma

### Gold Partners

- Dainippon Sumitomo Pharma Co., Ltd
- Eisai Europe Ltd

### Partnering Opportunities

To find out how your company can become a Partnering Sponsor, contact [ibedublin@eircom.net](mailto:ibedublin@eircom.net)



# Global support through innovative projects

## Worldwide presence

2008 was another exciting and challenging year for IBE as our membership continued to grow and develop. At year end we had:

- A total of 125 members - 92 Full and 33 Associate members.
- Representation in 93 countries.
- A member in 45% of the 206 countries of the world.

- 5.6 billion people out of an estimated global population of 6.4 billion live in countries with an IBE member. That represents 88% of the world's population.

Although impressive statistics, IBE will continue to encourage the development of new epilepsy associations as well as supporting

associations already in existence around the world.

During the year, we welcomed new Full Members in the Russian Federation, Dominican Republic and Nepal and new Associate Members in Togo, Lithuania, the United States, Bulgaria, Czech Republic and two new Associate Members in Australia.

## International partnerships

### World Health Organisation (WHO):

IBE has been in official relations with the WHO for many years. Since 1997 this relationship has been strengthened and enhanced through the ILAE/IBE/WHO Global Campaign Against Epilepsy "Out of the Shadows".

### Economic and Social Council of the United Nations (ECOSOC):

IBE was recognised as having Special Consultative Status on ECOSOC in 2007, allowing the Bureau to contribute to various programs of the United Nations (UN) and to ensure that the word 'epilepsy' is heard within the UN.

### Conference of NGOs (CoNGO):

Founded in 1948, the Conference of NGOs in Consultative Relationship with the UN is an international membership association that facilitates the participation of NGOs in United Nations debates and decisions.

## Communications

### International Epilepsy News:

- First published in 1963 and now in circulation for 45 years
- Published quarterly and circulated to 118 countries

Edited by Carlos Acevedo, the newsletter reports on activities of IBE and its members, addresses important topics of interest to people with epilepsy and their carers.

### IBE website

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

- First launched in 2001
- New site launched in 2007
- A crucial element in providing high quality information.

The website is a window to the world on the work of the Bureau at both regional and international levels and continues to enjoy ongoing growth in visitor numbers.

### Other communications:

The President's Letter, a regular electronic communication to members and supporters, has become an important element in IBE's communications strategy.

Circulated by email and uploaded to the website, it allows for prompt alerts to breaking news affecting IBE, its members or the epilepsy community in general.





## ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows'

Launched in 1997, the Global Campaign Against Epilepsy (GCAE) is a multi-faceted initiative involving a three-way partnership between IBE, ILAE and the WHO that aims to reduce the treatment gap and the burden of epilepsy.

### Measuring Impact

IBE member associations were inspired to use the logo and title of the campaign in their own national initiatives. To measure this usage, Philip Lee, co-Chair of the GCAE carried out a survey in 2008, with interesting findings:

- 59 IBE and ILAE associations in 48 countries used the campaign in their national events.

- 71% of campaigns used the slogan 'Out of the Shadows'.
- The events were in 30 countries classified as high or upper middle income by the World Bank. Eight of the countries were classified as low income.
- 53 organisations in 41 countries would use the campaign again. 39 reported that their campaign activity had been successful.

### Other recent projects:

**Demonstration Project in Georgia:** with a long term objective of integrating epilepsy management into the existing health delivery system in rural areas.

**Project on Legislation & Epilepsy:** the first comprehensive study to determine the presence or absence of effective or ineffective legislation promoting and protecting civil and human rights of persons with epilepsy.

**Epilepsy Atlas Project:** to map resources available within countries to tackle the huge medical, social and economic burden of epilepsy.

**Project on the burden of epilepsy:** study to establish comprehensive estimates of the burden of epilepsy, its disabling sequelae and its role as a risk factor for other diseases and injuries.

## Education and Research

**EUCARE:** a joint initiative of IBE and ILAE, with an educational grant from UCB Pharma that aims to raise the profile of epilepsy in Europe through educational and political actions. The main focuses are the Political Action Group and the FONDE scientific research project.

**EPICURE:** IBE is one of 29 partners in a project funded by the European Union Sixth Framework Programme Project LSH 037315, which aims to take advantage of the potentially powerful insights into pathophysiological pathways provided by genetics.

### Promising Strategies

- Supporting members in low income countries to improve the quality of life for people with epilepsy by providing modest levels of funding.
- 29 projects funded to date, mostly in sub-Saharan Africa.
- US\$95,100 provided as grants in past three years.
- Projects range from textile production to horticulture, from poultry and pig rearing to peanut butter production, as well as the development appropriate epilepsy legislation.

### Congresses

#### 7th Asian & Oceanian Epilepsy Congress

- Xiamen, China (May)
- A total of 1,604 delegates
- Representing 56 countries

#### 11th European Conference on Epilepsy & Society

- Marseille, France (October)
- Attended by 645 delegates
- Delegates from 34 countries

#### 5th Latin American Epilepsy Congress

- Montevideo, Uruguay (Nov.)
- Attracted 316 delegates
- From 51 countries worldwide

## Sponsored initiatives

### Travellers Handbook

- Contains first aid information, useful phrases and general advice on travel for people with epilepsy
- Published in 13 languages
- Available as a hardcopy or for download on the IBE website
- Assisted by an educational grant provided by UCB.

### Action Zone!

- Board game for children and adults to teach the true facts about epilepsy
- Produced in 17 languages
- 46,000 units circulated globally
- Received the Communiqué awards for Best International Public Relations Campaign and Campaign of the Year 2008.

### Excellence in Journalism

- Aims to encourage accurate reporting on epilepsy issues
- Recognising journalists who produce stimulating, informed and compelling news and feature stories on epilepsy
- Three award categories
- First winners to be announced in late 2009.

## African Regional Committee

- Members of the African Regional Executive Committee travelled to Rwanda to help in the setting up of a national epilepsy association.
- Members attending the 11th European Conference on Epilepsy & Society in Marseille took the opportunity to meet informally.

## Promising Strategies in Africa

Five new projects were selected for funding under the Promising Strategies Program, bringing to 13 the number of projects supported in the region since it began in 2007. The new projects are:

- Tailoring training in **The Gambia**
- Training in epilepsy management in **Kenya**
- Vegetable growing in **Tanzania**
- Workshops in **Namibia** to train teachers, caregivers and people with epilepsy to enable them to manage the condition effectively
- Awareness raising project in **Ethiopia** aimed at schoolchildren and their teachers.

## Mauritius

- Edcys Mauritius celebrated the foundation stone laying by Hon Dr R Beebeejaun, Deputy Prime Minister for its Multipurpose Epilepsy Center.
- A Research Guide in Epilepsy for Professionals was published with funding from the European Union Decentralised Cooperation Program.

## Togo

- A new polyclinic in Sangera provides epilepsy care and treatment and helps dissuade people from using traditional medicines.

## Namibia

- The Epilepsy Training Workshop, organised by Epilepsy Namibia and funded by the Promising Strategy Program included Theatre Therapy. Groups were challenged to use elements of drama to illustrate situations that might arise and to explain the handling of seizures to the public.
- The certificate ceremony at the end of the workshop was a proud moment for some participants, including Brenda, who had overcome great obstacles to achieve it.

## Zimbabwe

- 2008 was a stressful time for the Epilepsy Foundation of Zimbabwe (ESF). The political, economical and social situation made 2008 a very difficult year for the Foundation and its members.
- The collapsing banking system trapped funds in transfer making them valueless. Inflation eroded the value of donations within hours, if not minutes.
- Members were unable to afford medication and treatment. Although ESF received donations of medication, some members could not afford bus fares to collect it. As a result more people with epilepsy died in 2008 than in any other year in the 20 year history of the Foundation.
- The tragic death of Jens Mielke, one of few neurologists in Zimbabwe and who also travelled to Botswana regularly (where there is no neurologist), was a further terrible blow.

## South Africa

- A Blogspot created by Epilepsy South Africa serves as medium of reporting activities and opens the floor for dialogue.
- A page was created on the Facebook social networking site for Epilepsy South Africa. The association has responded to comments posted and referred enquiries and queries.
- The drummer of the Jo Ellis Band is a person with epilepsy and a role model for young people with epilepsy. There are hopes for further joint between Epilepsy South Africa and the Band to increase awareness.

## Uganda

- A 2-day national workshop in Kampala in May discussed the serious increase in neurocysticercosis in sub-Saharan Africa, the most common cause of epilepsy in the region, and responsible for more than 30% of epilepsy cases.

A very proud moment for Brenda at the end of the training workshop in Namibia





In sub-Saharan Africa  
there are fewer than  
one neurologist for  
every one million  
of population.  
In some countries  
there are none.

AFRICA



Children with epilepsy at a Fun Day organised by Iran Epilepsy Association

### Eastern Mediterranean Regional Committee

- Elections were completed in early 2008, with the regional Chair, Vice Chair and Secretary announced. The committee will remain in place until July 2009.
- At its first meeting in May held in Cairo, Egypt, key issues for discussion were means of supporting less developed members and promotion of best practice through the sharing of experiences on successful programmes.
- There is ongoing discussion to establish a means of collaboration between the committee and its ILAE counterpart, the Commission for Eastern Mediterranean Affairs (CEMA).
- Throughout the year both the IBE and ILAE regional groups were involved in discussing plans for the 2nd East Mediterranean Regional Congress, which will now take place in early 2010 in Dubai.

### Iran

- Iran Epilepsy Association's Educational Unit organised the 5th Annual Professional Epilepsy Seminar with professional certification & Epilepsy Workshop for specialists & physicians, as well as three education sessions for people with epilepsy and their families.
- The Research Unit held two congresses with public lectures for people with epilepsy.

- The issue of insurance for people with epilepsy was addressed and financial support was made available. Loans were also provided to 42 people to assist with medical treatment costs.
- The Communications Unit arranged three Fun Tours for children with epilepsy, including a visit to a Fun Fair. Social days were also organised for adults, visiting historic venues.
- The Computer Unit completed the design of its comprehensive databank, which includes data for over 3,000 members with epilepsy, 405 neurologists, 174 specialists, 117 GPs and 256 volunteers.

### How to help children with epilepsy

- Several members in the region agreed to assist the WHO Eastern Mediterranean Regional Office in field-testing a manual produced in Arabic that provides basic information and knowledge for caretakers, mainly mothers, families and teachers dealing with children with epilepsy, as well as for the children themselves.



Around fifty million people have epilepsy.  
Many of them suffer silently.  
Many of them suffer alone.

*Dr Gro Harlem Brundtland  
Former Director General, WHO*



EASTERN MEDITERRANEAN

## European Regional Committee

- The year began on a very sad note for the committee, with the death of Mrs Jónína Björg Guðmundsdóttir, a hardworking member of the committee. Jónína was greatly admired and much respected by all those who came in contact with her and her infectious personality was sadly missed by her fellow committee members during 2008.
- The main focus of the committee in 2008 was the 11th European Conference on Epilepsy & Society in Marseille. Attracting more than 300 delegates from 51 countries—some travelling from as far away as Australia—this was a very successful meeting.
- Apart from the official programme for the conference, the annual business meeting for members in Europe was also arranged.
- As the year closed, the committee was considering a short list of venues for the next European Conference on Epilepsy & Society and it was expected that the location would be announced in mid 2009.
- Committee members remain involved in the Political Action Group of EUCARE and a session on epilepsy and photosensitivity was organised in Marseille.
- Efforts to encourage new membership applications continued during the year. As a result of successful contacts, the region welcomed some new members during the year:
  - The All Russian Charity Foundation (Russian Federation) was ratified as a Full Member;



Enjoying a Demonstration Project meeting in Georgia

- EpiStop (Czech Republic) and the Foundation of Parents with Children with Epilepsy (Bulgaria) became Associate Members.
- Communication continues with a number of associations in Europe, in particular Eastern Europe, and it is hoped that further new Members will be announced shortly. Europe continues to be the largest region as regards membership, with 35 Full Members and 17 Associate Members at the end of 2008.
- The proposal for a European Directive to fight discrimination against people with a disability was warmly welcomed by the committee. The proposed legislation will tackle discrimination outside employment on the ground of disability, age, religion and belief, or sexual orientation. Once implemented, the directive will be a useful tool to fight for the right to services, education and employment for people with epilepsy.
- The committee was also pleased to learn from the Alliance for MRI that the European Parliament Environment and Public Health Committee had committed support for a derogation for MRI from the Electromagnetic Fields (EMF) Directive. The Alliance stressed that the medical application of magnetic resonance imaging which solely uses magnetic fields, needed to be clearly distinguished from electromagnetic fields related to power lines and mobile phones.

## France

- As host country for the 11th European Conference on Epilepsy & Society, AISPACE played a part in promoting the conference and also provided some support.
- Research studies on Benign Rolandic Epilepsy, Rights of Persons with Epilepsy and Epilepsy, and Mental Disability were undertaken.

## Georgia

- Focus of the Epilepsy & Environment Association of Georgia was on the launch of the Global Campaign Demonstration Project “Epilepsy Management at Primary Health Care Level in Georgia”. The project is supported by the Ministry of Labour, Health and Social Affairs and the Georgian Parliament. Its execution has been delegated to the Centre for Epilepsy Management, Research and Education and the Centre of Epilepsy Control and Prevention.



Children's self-esteem  
and levels of  
achievement are  
enhanced by a  
knowledge of their own  
condition

EUROPE



A group of delegates from Belgium enjoy the European Conference in Marseille

## Ireland

- To celebrate Brain Awareness Week, Brainwave The Irish Epilepsy Association held a seminar for politicians, media and health professionals. The event highlighted issues facing people with epilepsy in Ireland and marked 10 years of the Global Campaign Against Epilepsy, which was launched in Dublin in 1997. Government Ministers and Senators from all major Irish political parties attended the event and offered their support to Brainwave's work in advocating for better epilepsy services.

## Italy

- Results of a 10-year initiative in Milan: A survey on employment training for people with epilepsy and a disability, following the completion of the final course element supported by Fondazione Adecco per le Pari Opportunita and the Regional Epilepsy Centre, S Paolo, showed that 70% of participants found a job within one year, although the majority were temporary positions. Participation in an educational programme offered better technical and social training and was particularly useful for people who are over-represented in unskilled or semiskilled positions.

## Lithuania

- Lithuanian Association for Integration of People with Epilepsy (LESIA) represents and protects the rights of 240,00 people with epilepsy.
- The most important direction of LESIA is social rehabilitation services, which include the MOSES

program to improve the quality of life for people with epilepsy and their carers. MOSES has been used since 2006 with support from Bethel Epilepsy Centre (Germany). In 2008, 392 people received social rehabilitation services, including 31 children.

Poster of the Norwegian Epilepsy Association





- The main activity in 2008 was a public media campaign “Me the same as you”. Two thousand adults and 1,000 schoolchildren were surveyed with the purpose of establishing public knowledge about epilepsy.
- The association also organised a conference for people with epilepsy: “Non-medical Epilepsy Treatment Options”. An art exhibition, created by people with epilepsy, was displayed during the conference.

### Norway

- During the general assembly in 2008, the Norwegian Epilepsy Association received an extra donation of 500.000 NOK. The donation was used to fund an information campaign with focus on first aid for people with tonic clonic seizures and complex partials seizures. The material which was developed during this campaign will also be used in the future, and the organisation was able to reach a new target group.

### Scotland

- Epilepsy Scotland just got bigger! Edinburgh based charity Enlighten – Tackling Epilepsy merged with IBE’s Full Member and together they can now offer even more direct services including groups for children, young people and parents. Scotland’s Cabinet Secretary for Health and Wellbeing officially launched the new Edinburgh office
- One in 5 Members of the Scottish Parliament sits on the Epilepsy Cross-Party Group.
- Epilepsy Scotland campaigned for More Specialist



Nicola Sturgeon, Scotland's Cabinet Secretary for Health and Wellbeing launched Epilepsy Scotland's Edinburgh Office

Nurses, Better Epilepsy Care. There are just 24 specialist nurses to deliver care to the 40,000 people in Scotland who have epilepsy. Hundreds of people signed an electronic petition for more nurses on the Scottish Parliament’s website. Epilepsy Scotland also gave evidence to the Petitions Committee. The result to date is the employment of four more nurses since the campaign was launched in May 2008.



Communiqué Awards Ceremony

## Latin American Regional Committee

- One of the main activities of the committee in 2008 was preparation for the 5th Latin American Epilepsy Congress, which took place in Montevideo in November and which attracted over 600 delegates.
- A meeting of WHO/PAHO experts in the field of epilepsy took place in Honduras in August, with the aim of expanding sub-regional plans and initiatives for Spanish-speaking Central American and Caribbean countries.
- The committee is involved in a Global Campaign Against Epilepsy initiative to create a legislative framework to assist in the creation of new legislation in favour of people with epilepsy on a global level.
- A significant development in the region was the decision of the IBE Latin American Regional Committee and the ILAE Latin American Commission to consider opportunities for joint collaboration. The first joint meeting of the regional groups took place during the congress in Montevideo towards the end of the year.

## Argentina

- In 2008, FUNDEPI continued to work to set standards of good practice in the care of people with epilepsy, in particular in primary care. The association works on special issues,

including health and social care of people with epilepsy, improving access to antiepileptic drugs and/or to surgery. The targets of its campaigns are principally people with epilepsy, medical professionals and health service administrators.

- The most important national activity in 2008 was efforts to have the new Law of Epilepsy N° 25.404 adopted by the government.

## Brazil

- Associação Brasileira de Epilepsia received support through the Promising Strategies Program to educate teachers and children, in elementary schools, the basic facts about epilepsy. It is intended that the program can be used in other Portuguese speaking countries.

## Colombia

- FIRE, IBE's Full Member, advocated for the introduction of legislation to protect the 800,000 people living with epilepsy in Colombia from discrimination. The aims are:
  - To enhance public education, thus decreasing fear and misconceptions;
  - To improve diagnosis and treatment by providing diagnostic facilities and modern antiepileptic medication;
  - To eliminate discrimination and improve access to education and employment for people with epilepsy.

Delegates attending the joint meeting of the IBE Latin American Regional Committee and the ILAE Latin American Commission in Montevideo, Uruguay





Because people are living longer, old age is now the most common time in life to develop epilepsy

# LATIN AMERICA

## North American Regional Committee

- As the region with the fewest number of members, the North American Regional Committee does not have an elected regional executive committee but meets informally and communicates through email.
- Despite having only three Full Members and two Associate Members, the committee has committed to several significant priorities, including continued outreach to recruit new Members in the region; support to the Promising Strategies Program through the provision of part of its annual budget to the program; support for national initiative in the region.

## Canada

- Nine-year-old Cassidy Megan of Nova Scotia, a young person with epilepsy, was instrumental in creating a major new international awareness campaign called Purple Day for Epilepsy. On March 26th, people around the world are encouraged to wear purple and spread the word about epilepsy. "I wanted kids with epilepsy to know that they are not alone" Cassidy explained. The successful launch saw two well known American TV stars and members of the Canadian Parliament don purple for the day. A site was also launched on Facebook and plans were laid for a second Purple Day in 2009. The initiative is supported by the Anita Kaufman Foundation (USA) and the Canadian Epilepsy Alliance.
- A team of neurologists, teachers and university students have written, and are pilot testing,

a teaching unit for senior science biology students, the brainchild of the Canadian Epilepsy Alliance. The interactive unit can be taught in three hours and includes seizure videos, cell biology animation, and career links. The goal is to introduce epilepsy as a career choice for future health scientists.

## USA

- Epilepsy Foundation of America, together with other US organisations working on behalf of people with disabilities, celebrated a momentous occasion on 25th September, when President Bush signed the Americans with Disabilities Act (ADA) of 2008 into law. In a private signing ceremony, the US President secured protection against discrimination in the workplace for every American with a disability. Epilepsy Foundation joined hundreds of employer, disability, civil rights and other organisations in a strong collaboration that resulted in the introduction of the new law.

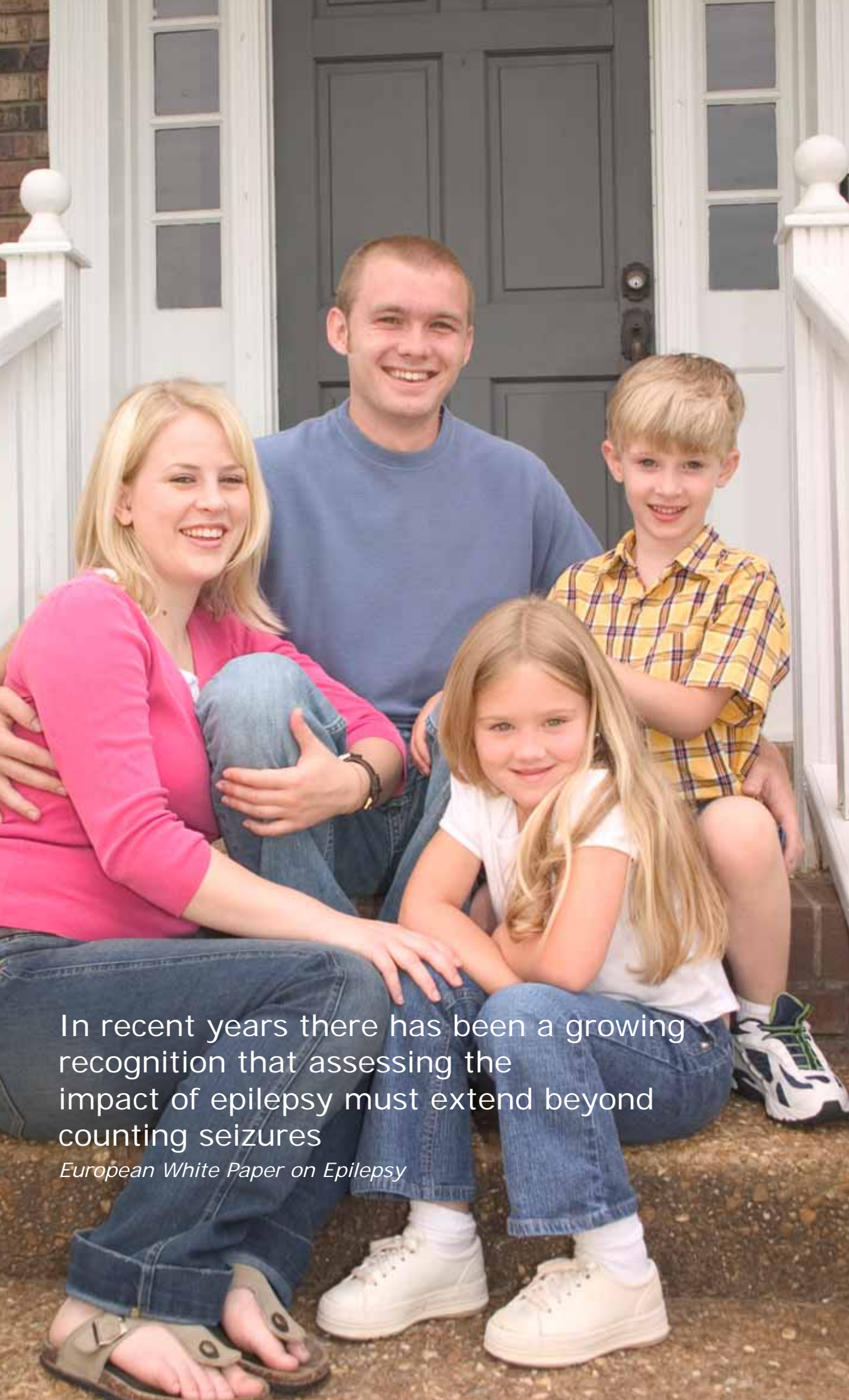
## Jamaica

- Until recently, no structured programme for epilepsy healthcare existed in Jamaica. Epilepsy care was delivered solely on a one-to-one basis by individual medical practitioners with varying seizure control outcomes. The Jamaican Epilepsy Association, working with the ILAE chapter in Jamaica has introduced The Jamaican Model for the advancement of epilepsy healthcare in poorly served populations. This 14-point model is designed to be adoptable by associations in other countries.



Left: Nine-year-old Cassidy Megan, who created Purple Day for Epilepsy. Below: Tony Coelho, immediate past chair of Epilepsy Foundation and who has epilepsy, speaking at the signing ceremony of the ADA Act 2008 in Washington





In recent years there has been a growing recognition that assessing the impact of epilepsy must extend beyond counting seizures

*European White Paper on Epilepsy*

# NORTH AMERICA

## South East Asian Regional Committee

- The 2-day Special Programme for People with Epilepsy, which ran during the 7th Asian & Oceanian Epilepsy Congress in Xiamen, China, was one of the highlights of the committee during 2008. This congress welcomed participants from throughout Asia, Oceania and from other countries around the world.
- To recognise people with epilepsy who portray a positive attitude towards epilepsy and living with epilepsy, the Outstanding Persons with Epilepsy Awards were presented during the congress to award winners living in India and Hong Kong.
- The South East Asian and Western Pacific regions continue to work closely and, to this end, a joint meeting of the committees was held in Xiamen in May.
- In Chinese the term for epilepsy translates as 'goat sickness'. This creates a high level of stigma people with epilepsy, in particular in Hong Kong and China. In order to reduce this problem, it is proposed that the Chinese term be changed. This will remain an ongoing issue to be addressed in the future.

## Hong Kong

- To further its advocacy and public education work for people with epilepsy in Hong Kong, Hong Kong Epilepsy Association organised visits to schools, to care centres for the elderly and also cooperated with other rehabilitation groups to arrange exhibitions and medical

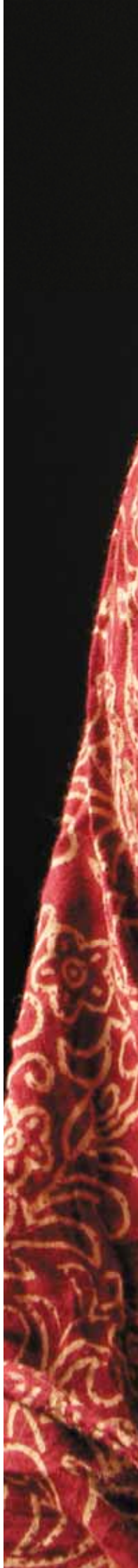
seminars for people with epilepsy and their families.

- On billboards twice the height of a double-decker bus, Enlighten Hong Kong's Epilepsy Awareness project was hard to miss. Huge posters were displayed on buildings in busy streets through the support of the Hong Kong Lands Department 'Street Banner' project.
- In June, Enlighten Hong Kong mounted a 'Happy Faces' Photographic Exhibition in a major shopping centre in the city to show the Hong Kong community that people with epilepsy are positive, happy and no 'different' to anyone else.

## India

- Supported by the 18th International Epilepsy Congress Trust, the Indian Epilepsy Society produced a Guidelines for the Management of Epilepsy in India manual. With a population of more than one billion, it is estimated that India accounts for 10-20% of the global burden of epilepsy, according to the foreword written by Prof Gourie-Devi and Dr VS Saxena. The manual has been uploaded to the website of the Indian Epilepsy Association.
- A Diploma in Epilepsy Care was introduced by Bangalore University, in collaboration with CBR Network and the Indian Epilepsy Association. The diploma, which is open to both national and international students, is a value-added course for teachers and nurses.

*Young delegates enjoy the Special Programme during the 7th Asian & Oceanian Epilepsy Congress in Xiamen.*





# SOUTH EAST ASIA

With a population of more than one billion, it is estimated that India accounts for 10-20% of the global burden of epilepsy

## Western Pacific Regional Committee

- Working with the South East Asian Regional Committee, the congress in Xiamen was a highlight for the committee in 2008. Members from the Philippines, Singapore and China were presented with Outstanding Persons with Epilepsy Awards.
- A joint meeting of the Western Pacific and South East Asian committees discussed first preparations for the next congress, which will take place in Melbourne in October 2010.

## Australia

- E-JOB: a programme introduced by Epilepsy Association of South Australia and the Northern Territory Inc to develop social and life skills to enable people with epilepsy to lead fully integrated lives in the community. Course topics include motivation, money handling, stress management, team building, decision making, self esteem and the job application process - ultimately achieving skills to locate and obtain open paid employment.
- Epilepsy Action Australia held its inaugural 'Epilepsy: Top of Mind' consumer symposium in Sydney. The need for information about living with epilepsy had been expressed by consumers and the event was highly successful with participants and exhibitors travelling from across Australia to attend.

## China

- Hosting the 7th Asian & Oceanian Epilepsy Congress in Xiamen was a proud moment for China Association Against Epilepsy (CAAE).
- The Patient's Self Help Cluster organized awareness education and question and answer sessions in 10 cities in China, with audiences of 2,000 at each session. Three or four

nationally known experts spoke on the need for scientific knowledge of epilepsy care and self-help from different angles. Participants were then invited to submit individual written questions for the experts to answer.

## Japan

- The Hans-Berger Association (HBA) and the CARE-Sendai, Epilepsy Hospital BETHEL celebrated 10 years collaboration. Covering more than 3,000 registered patients, Epilepsy Hospital BETHEL continues to provide epilepsy care. The HBA, as a NGO for epilepsy, has been offering rehabilitation programs mainly for young adults.

## Singapore

- Raising awareness continued to be a major objective for Singapore Epilepsy Foundation in 2008, with focus on public education for stakeholders, namely people with epilepsy and their carers, healthcare professionals, teachers, instructors and the general public. 250 participants attended a public forum on epilepsy, with discussion on stress management, medical trends in epilepsy, the role of support groups, and recommended reading.
- The association's medical panel shared their expertise with teachers, law enforcement officers, swimming instructors and lifeguards.
- Epilepsy Care Group (ECG) Singapore enjoyed 15 minutes of fame when a journalist and a photographer from The Straits Times came onboard its dragonboat during a training sessions. A special feature was published in the paper giving a good insight to the team and to ECG's goals in helping people with epilepsy through this team-building sport.

*At the Gala Event in Xiamen, from left: Prof Peter Wolf, Mrs Susanne Lund, Dr Shichuo Li and Dr Shih Hui Lim*





It is estimated that two million new cases of epilepsy occur each year

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# Getting ready for 2010

IBE will be involved in the organisation of the following regional congress, which will take place in 2010.



## **2nd East Mediterranean Epilepsy Congress**

Dubai, UAE

3rd - 6th March 2010



## **12th European Conference on Epilepsy & Society**

Porto, Portugal

Dates to be confirmed



## **6th Latin American Epilepsy Congress**

Cartagena, Colombia

Dates in August 2010



## **8th Asian & Oceanian Epilepsy Congress**

Melbourne, Australia

21st - 24th October 2010

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