

# Annual Report 2005



International Bureau for Epilepsy



## Our Vision

IBE has a vision of the world where everywhere fear and ignorance about epilepsy are replaced by understanding and care

## Our Mission

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

## Our Goals

**ORGANISATION:** To provide an international organisation for national epilepsy organisations and other epilepsy organisations whose primary purpose is to improve the quality of life of people with epilepsy and those who care for them.

**SUPPORT:** To provide a strong global network to support the development of new members, to support existing members to develop to their fullest potential and to encourage co-operation and contact between members.

**COMMUNICATION:** To promote the facts about epilepsy and to communicate the IBE's vision, mission and messages to the widest possible audience.

**EDUCATION:** To increase awareness, understanding and knowledge of epilepsy and to increase awareness, understanding and knowledge of how best to meet the needs of people with epilepsy and those who care for them.

**REPRESENTATION:** To provide an international and global platform for the representation of epilepsy in relation to national and international organisations and governments.



## Foreword



As the Special Rapporteur on Disability of the United Nations Commission for Social Development my primary role is to monitor the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly in 1993, and to advance the status of people with disabilities throughout the world. In that work I have met with IBE President Susanne Lund who introduced me to the important work of your organisation aimed at improving the quality of life of all those affected by epilepsy.

I have been told that for the 50 million people worldwide who have epilepsy, the associated stigma is often harder to live with than the condition itself. This stigma recognises no boundaries, being prevalent in both in developing and industrialised nations. While in the western world 70% of people with epilepsy will receive adequate medical intervention and have their seizures controlled, they will still be faced with stigma with regard to education, employment and social interaction.

In developing nations, where up to 90% of people with epilepsy receive neither diagnosis nor treatment, seizure control is seriously compromised. People in these less developed countries will often find themselves totally ostracised by their communities because of mistaken beliefs about the cause of epilepsy.

Increasing the availability of medical care to an acceptable level for all people with epilepsy, wherever they may live, will not happen overnight, but the situation is getting better. However more immediate

improvements can be made to the quality of life for people with epilepsy by raising awareness of the condition and thereby reducing stigma and discrimination.

I have learned that raising awareness is one of the principal tenets of the Global Campaign against Epilepsy “Out of the Shadow”, a joint initiative of the IBE, the International League Against Epilepsy (ILAE) and the World Health Organisation (WHO), which was first launched in Dublin in 1997. I applaud IBE and its partners on the ongoing success of this great initiative.

But, in being invited to provide the Foreword for the IBE Annual Report 2005, I would also like to congratulate all the member associations of IBE who though unique and particular efforts work tirelessly to improve the lives of all those affected by epilepsy.

I send you all my best wishes.

Hissa Khalifa A. Al-Thani  
UN Special Rapporteur on Disability



## President's Report



Dear Members

When looking in the rear-view mirror on the year 2005 it is an amazing view. IBE is growing and with its 113 members in 88 countries the Bureau plays a vital part in improving the quality of life for people with epilepsy and their carers.

Thanks to the dedicated hard work of the Constitution Task Force our new Constitution came into being on the 1<sup>st</sup> January 2005, heralding a new, more democratic era for IBE and its members. For the first time new election procedures were used to elect the IBE International Executive Committee 2005-2009, inviting all Full Members to nominate and elect all officers. In addition, the new Constitution gave recognition to the regional committees and elections also took place to fill positions on the Regional Executive Committees 2005-2009 in Africa, Europe, Latin America, North America, South East Asia and Western Pacific. Since then the regions have been busy formulating plans and objectives for the coming years and I look forward to seeing the strength and vitality of the regions grow and develop.

The newly elected International Executive Committee began its term of office at the close of the General Assembly held during the Paris Congress in late August. The General Assembly also marked the end of the terms of office of our Commissions. Members of IBE Commissions have worked tremendously hard over many years and for this reason it has been a very difficult decision not to renew their portfolios for another term. However I believe that by introducing time-limited Working Groups and Task Forces we will be able to direct attention on more focused areas of interest. We will also be able to introduce new Task Forces when an issue arises that requires review and study. I hope that I will be able to draw on the expertise and knowledge of many of our former commission members to assist these Task Forces in the future.

For the present time it has been agreed to introduce just two Commissions for a 4-year term: the Enlargement Commission and the Commission for the Regions. The aims of the Enlargement Commissions, chaired by Philip Lee, are to develop and in-

crease our membership, with special focus on less developed regions, and to support our existing members. The Commission for the Regions, chaired by Mike Hills, will monitor the implementation of the new Constitution and evaluate its impact and practical consequences in the regions. The Commission for the Regions will also assist the Regional Committees in creating regional commissions and task forces and will identify any need for special support.

The highlight of the year was undoubtedly the 26<sup>th</sup> International Epilepsy Congress in Paris. The Members Posters Display, the Special Members Session, the new IBE banners and the tremendous attendance at the General Assembly ensured IBE's high visibility at the conference. Once again I would like to welcome the 18 new members whose applications were ratified by the General Assembly.

The year 2006 will see the regional conferences in Latin America, Asia Oceania and Europe and I hope that we can be equally visible at these events.

The ILAE/IBE/WHO Global Campaign Against Epilepsy "Out of the Shadows" continues to impact in countries around the world. With the changeover in ILAE and IBE Executive Committees in Paris, Pete Engel and Hanneke de Boer stepped down as Co-Chairs of the Campaign after four years of tremendous progress. IBE is indebted to both Pete and Hanneke and is pleased to know that Hanneke will remain involved in the Global Campaign but in a new role. In the meantime we welcome the two new Chairs, Philip Lee and Giuliano Avanzini. The Global Campaign has now reached the end of its Second Phase and plans and priorities for the coming four years are currently being put in place.

Our other major initiative, EUCARE, has made strides forward in 2005. EUCARE has two principal elements – the Political Action Group and the FONDE Study. The Political Action Group has developed an epilepsy knowledge questionnaire and has circulated it to all Members of the European Parliament (MEP) to test their knowledge on epilepsy. There are plans to have meetings with MEPs in Brussels in the future. The FONDE Study, to be launched at the 7<sup>th</sup> European Congress on Epileptology in Helsinki, will be a major joint research project of IBE and ILAE that will follow the prognosis and lifestyle consequences of new diagnosed epilepsy in people living in different European Countries.

The IE News continues to introduce new changes and ideas and is now a very attractive communications vehicle for the Bureau. The magazine also has a new editor, Carlos Acevedo, who has plans for new regular columns and reports. Many associations have provided news items and photographs for the magazine during 2005 and I would encourage all members to submit reports from their region for inclusion in future issues. We are always delighted to be able to relay the activities of our members and welcome all reports, no matter how short.



Our website is now due for a major review and a Task Force has been introduced to assist with the job. The Website Task Force is chaired by Shung-lon Lai, Vice President Western Pacific and members will already have received correspondence from Shung-lon about the review.

On a more intimate scale, I have been delighted to be able to circulate regular short President's letters to all members to keep you informed on what has been happening, and what is planned to happen, within the Bureau. These messages will also be made available on our website.

But the work of IBE would be to no avail if we did not have such fantastic membership. I am in awe

of the breadth and scope of work being undertaken by members right around the globe. Each association, large or small, works to improve the quality of life of those affected by epilepsy. Some work with impressive budgets and staffing, while others struggle to make ends meet. But each one achieves success when even the tiniest change is made to the lives of those living with epilepsy.

Over the coming four years I will be honoured to be working with you all and I am convinced that together we can achieve great things.

**Susanne Lund**  
President

## International Executive Committee 2005—2009

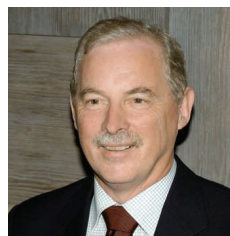
### Management Group



Susanne Lund  
President



Eric Hargis  
Secretary General



Mike Glynn  
Treasurer

### Immediate Past President and Regional Vice Presidents

*Balloting to elect Regional Vice Presidents in Africa, Eastern Mediterranean and North America is not yet completed*



Philip Lee  
Past President



Athanasios Covanis  
VP Europe



Carlos Acevedo  
VP Latin America



Anchor Hung  
VP South East Asia



Shung-lon Lai  
VP Western Pacific

### ILAE Representatives



Peter Wolf  
ILAE President



Solomon Moshé  
ILAE Secretary



Marin Brodie  
ILAE Treasurer

# Financial Report

## BALANCE SHEET

Year ended 31st December 2005

With comparative totals for 2004

	2005	2004
	US\$	US\$
<b>FIXED ASSETS</b>		
Tangible assets	5,889	4,490
	<hr/>	<hr/>
<b>CURRENT ASSETS</b>		
Debtors and prepayments	-	634
Cash at bank and in hand	1,503,936	1,569,619
	<hr/>	<hr/>
	1,503,936	1,570,253
	<hr/>	<hr/>
<b>CREDITORS: (Amounts falling due within one year)</b>	(152,242)	(103,965)
	<hr/>	<hr/>
<b>NET CURRENT ASSETS</b>	1,351,694	1,466,288
	<hr/>	<hr/>
<b>CREDITORS: (Amounts falling due after more than one year)</b>		
Deferred Income	(626,054)	(744,056)
	<hr/>	<hr/>
<b>NET ASSETS</b>	731,529	726,722
	<hr/>	<hr/>
	<hr/>	<hr/>
<b>CAPITAL AND RESERVES</b>		
General reserve	491,724	561,855
Restricted fund	239,805	164,867
	<hr/>	<hr/>
	731,529	726,722
	<hr/>	<hr/>
	<hr/>	<hr/>

## STATEMENT OF INCOME AND EXPENDITURE

Year ended 31st December 2003

With comparative totals for 2001

	2005	2004
	US\$	US\$
<b>INCOME</b>		
International congresses and symposia	191,876	456,675
Commerce and industry	153,273	86,025
Membership dues	24,674	28,581
Society contributions	-	4,495
Investment income	27,022	16,140
Sale of materials	124	62
Other grants	392,401	280,775
Miscellaneous income	10,074	-
	<u>389,416</u>	<u>872,755</u>
<b>EXPENDITURE</b>		
Salary costs	85,692	95,668
Office expenses	8,577	8,155
Printing and postage	20,723	25,440
Printing and postage - International Epilepsy News	31,528	30,435
Travel	59,969	61,721
Global Campaign costs	25,000	31,411
Accountancy fees	10,873	10,873
Audit fees	4,127	4,127
Bank charges	954	1,314
Rent	4,903	(566)
Subscriptions	229	235
Depreciation	1,858	1,602
Website costs	2,887	2,593
EUCARE costs	311,052	210,246
Currency exchange fluctuations	226,265	(143,958)
	<u>794,637</u>	<u>339,296</u>
Operating Surplus/Deficit for year	<u>4,807</u>	<u>533,459</u>



# International Highlights 2005



## 26th International Epilepsy Congress

The 26th International Epilepsy Congress, and planning for IBE activities during the congress, occupied much of the Bureau's time in 2005.

IBE congratulates Eric Hargis (Epilepsy Foundation of America) and Hilary Mounfield

(Epilepsy Scotland, now retired) who were presented with Ambassador for Epilepsy awards during the Opening Ceremony. The Bureau also congratulates Hanneke de Boer on receiving the Social Accomplishment Award.

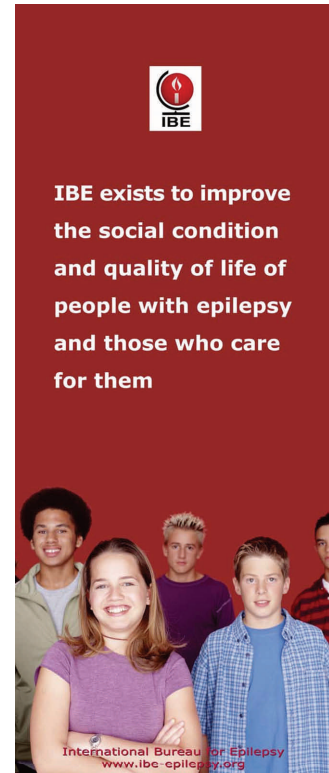
A major Members Survey was undertaken, with the results reported on during the Special Members Session in Paris.

The General Assembly was, without doubt, one of the highlights of the congress for IBE, with the transition to the new International Executive Committee and the ratification of 18 new members. It was also the time to acknowledge the work carried out by executive members who were retiring from the committee after several years of dedication to the Bureau.

Thanks to a tremendous response from members, the

Members Poster Display, with more than 40 different posters detailing the work and achievements of IBE members, provided visible evidence of the strength and diversity of IBE members working at national and local level. The posters, one metre wide and almost two metres high were hung in one of the main meeting room corridors and were much commented on by delegates. It is expected that the initiative will be repeated at the 27th International Epilepsy Congress, Singapore 2007.

IBE displayed new banners at the congress, one of which is pictured above. These 3-metre high banners highlight IBE's aims and objectives and will be used at other meetings in the future.



## New Full Members

- Epilepsy Association of Bangladesh
- China Association Against Epilepsy
- Association Fallone, Congo
- The Gambia Epilepsy Association
- Association of Care of People with Epilepsy in Lebanon
- EDYCS Epilepsy Group (Mauritius)
- Mongolian Epilepsy Association
- EVN, Netherlands
- FLAME, Pakistan

- Epilepsy Awareness & Advocacy Inc., Philippines
- Epilepsy Association of Sierra Leone
- AURA, Slovakia
- Association of People with Epilepsy, Turkey
- AUCLE, Uruguay

## New Associate Members

- Argentina: FUNDEPI
- France: EOLE
- France: Telley-Epilespoir
- Scotland: Quarriers

## Presentation to new Full and Associate Members



*Presentation of Membership Certificates to new members at the close of the General Assembly*

## EUCARE Political Action Group

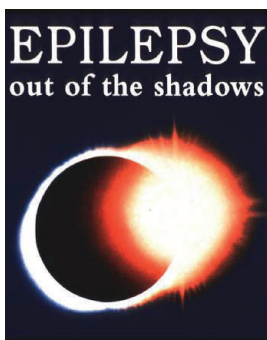


- The inaugural meetings of EUCARE's Political Action Group took place in the Netherlands in May.
- The aim of the group is to identify issues that can be addressed jointly by IBE and the International League Against Epilepsy (ILAE) within the political arena within Europe.
- The Political Action Group has formulated a plan of action to raise awareness through education. In a preliminary consultation phase all existing literature relating to discrimination and people with epilepsy will be reviewed.
- A questionnaire, structured to assess the level of knowledge of Members of the European Parliament (MEP) was prepared and circulated.
- A special symposium "Influencing Policy—Achievements and Aspirations" was held at the Paris congress.
- For further information visit [www.eucare.org](http://www.eucare.org).



*Pictured at the inaugural meeting of the Political Action Group, back row from left: Karen Donaldson, EUCARE Programme Manager; Peter Dahlqvist, IBE European Regional Committee; Susanne Lund, EUCARE Management Group; Kristina Malgren, ILAE European Commission. Front row: Hanneke de Boer, EUCARE Manager; Hilary Mounfield, IBE European Regional Committee; Svein Johannessen, ILAE European Commission.*

## Global Campaign Against Epilepsy 'Out of the Shadows'



Since its launch in 1997, the ILAE/IBE/WHO Global Campaign Against Epilepsy has gathered momentum and activities carried out under the Global Campaign banner are now spread worldwide. The twin-track strategy of the campaign is to raise general awareness and understanding of epilepsy, and to support national Departments of Health in identifying needs and promoting education, treatment services, research and prevention, has led to a wide range of actions.

The Global Campaign is currently nearing the end of its 2nd Phase, during which the most significant activities relating to Demonstration Projects. Each Demonstration Project has four aspects:

- Educational and social intervention;
- Epidemiological assessment and case-finding;
- Service delivery and intervention;
- Outcome measurement.

Projects have been completed in Senegal, Zimbabwe,

Argentina, Pakistan and China. There is an ongoing project in Brazil and further projects are planned for Kenya, Georgia and China.

In addition to the Demonstration Projects, other activities have been initiated as a result of Campaign activities. These are based on protocols developed in collaboration with the Campaign, but with no active involvement of the Campaign in their execution. Such activities are ongoing in Congo, India, Indonesia, DPR Korea, Maldives, Myanmar and East Timor.

A highlight of 2005 was the publication of the WHO Atlas of Epilepsy Care in the World, as a result of a GCAE project that started in 2002. The publication contains data collected from 160 countries.

The terms of office of Hanneke de Boer and Pete Engel as Co-Chairs of the Global Campaign came to an end at the end of August 2005. The Co-Chairs for the term 2005—2009 are Philip Lee (IBE) and Giuliano Avanzini (ILAE). Hanneke de Boer has been working on the Global Campaign since its launch and will remain involved in a newly developed role.

The 3rd Phase of the campaign will introduce initiatives aimed at directly impacting on the burden of epilepsy across the world. Actions planned include completion of Demonstration Projects, development of regional atlases of epilepsy resources, and a review of epilepsy legislation.



# International Highlights 2005

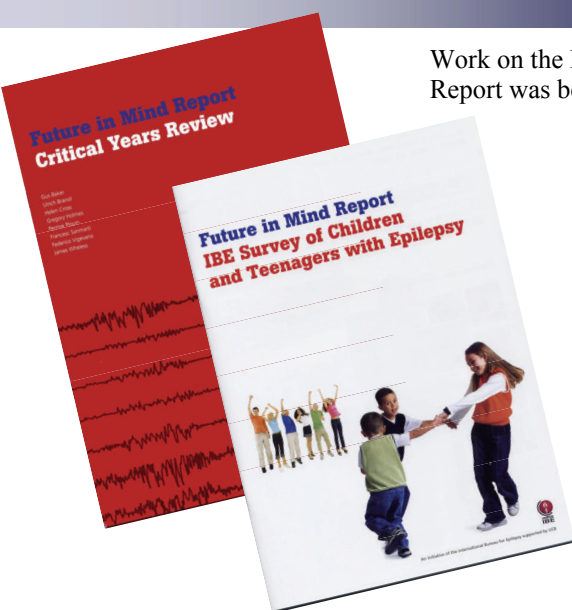


## EYiE8 Epilepsy: Gaining the Initiative

The 8th EYiE project of the IBE Employment Commission took place in early August 2005, just before the close of the Commission's term. The 5-day event was held in Sligo, in the North West of Ireland, and used the structure of workshops aimed at informing participants about the European Union Youth Programme and building skills and knowledge on applying for EU grants.

Participants travelled from Romania, Sweden, Germany, Malta, Iceland, Portugal and France. The event was hosted by Brainwave the Irish Epilepsy Association and was grant aided by the European Union.

## Future in Mind Report



Work on the Future in Mind Report was begun in 2005. The first part of the report, the Critical Years Review, was published towards the end of 2005 and was developed in collaboration with IBE.

The Critical Years Review looked at published evidence on childhood epilepsy and explores factors influencing de-

velopment and outcomes. Contributors to the report included Gus Baker (former Chair of the IBE Research Commission), Perrine Plouin, Helen Cross and Federico Vigeveno.

"I have missed quite a lot of school due to my epilepsy, but I don't want it to stop me doing anything."

The second part of the report, the IBE Survey of Children and Teenagers with Epilepsy, presents the findings of a survey of over 1,000 children and teenagers with epilepsy, their parents, care-givers and medical professionals in 16 different countries. The aim of the survey, which began in May 2005, was to assess the perceptions of people directly involved with childhood epilepsy. Among those who participated in the survey were IBE members in Austria, Belgium, Denmark, France, Germany, Italy, Norway, South Korea, Switzerland, Taiwan, UK and the USA. The aim of the survey was to gain insight to the real-life effects that epilepsy can have on areas of quality of life, development and opportunities for the future. IBE Members of the medical and scientific panel included Eric Hargis, Hilary Mounfield, and Marshal Mo-Song Hsih.

The report, supported by UCB, was circulated to IBE members and copies are available on request from [ibedublin@eircom.net](mailto:ibedublin@eircom.net).



# Solidarity Fund

supporting IBE Members in developing regions



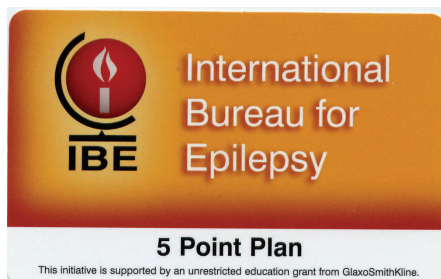
The Solidarity Fund was launched in early 2005 and to date the response of members has been very encouraging. The purpose of the fund is to provide financial support to IBE members who can demonstrate financial hardship and can be used to subsidize their involvement in IBE activities. It does not provide funding to support members indigenous activities.

Several members who now pay significantly lower annual dues due to the change in the fee structure introduced in 2005, have made generous donations to the Solidarity Fund. However all donations to the fund, no matter how small, are very welcome. Dona-

tions can be made at any time by bank transfer, credit card payment, or bankers cheque. Donations are invited from member associations, companies and individuals.

Although the fund is in the early stages of development, already it has been used to support IBE members in very low income countries, who have difficulty in meeting dues payments.

IBE thanks all those members who have supported the Solidarity Fund to date. For further information on this initiative, please contact the IBE office [ibedublin@eircom.net](mailto:ibedublin@eircom.net).



## Continuity of Supply of AEDs

With many epilepsy drugs now coming to the end of their licences and with the availability of new generic AEDs, there is now a real risk that people with epilepsy may have their medication switched either by their physician or by the dispensing pharmacy. In some countries Departments of Health are looking to reduce the cost of medical care by encouraging, and sometimes legislating for the use of substitutes. There is concern about the risk of break-through

seizures when medication is changed either from licenced drug to generic or vice versa. This can be devastating for someone who has been seizure-free for years. During 2005 IBE launched the 5-Point Pledge Card, supported by GlaxoSmithKline to highlight the importance of continuing of supply for people with epilepsy.



## Brain Storm

One of the last IBE activities of 2005 was the first live performance of Brain Storm, a theatre productions focussing on epilepsy, that was staged at the World Congress of Neurology in Sydney, Australia. The play dramatises the effect that uncontrolled seizures can have on the lives of people with epilepsy. The play was commissioned by UCB in collaboration with IBE and was written by UK journalist and broadcaster Polly Toynbee.

There are plans to use the play at future IBE conferences, including the 10th Epilepsy & Society Conference in Copenhagen in August 2006.



# Africa

## AFRICAN REGIONAL EXECUTIVE COMMITTEE

**Chair:** Zenebe Gedlie Damtie, Ethiopia

**Vice Chair:** Augustine Mugarura, Uganda

**Secretary:** Anthony Zimba, Zambia

## MEMBERS OF THE AFRICAN REGIONAL COMMITTEE

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Contact: Mrs Sigudu





The African Regional Committee is the fastest growing IBE region. In 2000 IBE had seven members in Africa; just five years later there are now 18 Full Members in the region. This makes Africa the second largest of IBE's Regional Committees. Much of this success is due to activities of the ILAE/IBE/WHO Global Campaign Against Epilepsy in the region and to the dedicated work of the African Commission 2001-2005.

Following its election, the African Regional Executive Committee, set about drafting a programme of activities which the African Regional Committee will pursue over the coming years. The programme reflects much of the excellent strategy documented by the African Commission and the stated goals for the region remain unchanged:

- The establishment of a regional communications network for the exchange of information related to epilepsy service provision
- To ensure that education and awareness take priority within the African region
- Support to existing initiatives that can be applied in other countries through skills transfer
- Promotion of sustainable and accessible services for people with epilepsy
- Promotion of the human rights and dignity of people with epilepsy through advocacy actions
- Promotion of greater participation by people in Africa in global epilepsy affairs
- Support to research into epilepsy in Africa.

An African Regional Epilepsy conference took place in Ethiopia in October 2005 with participants from Zim-



*The Organising Committee of the African conference, with Augustine Mugarura in traditional dress.*

babwe, Zambia, Senegal, Kenya, Ethiopia, Rwanda, South Africa, Denmark hosts Uganda. Organised by the Epilepsy Support Association, Uganda in conjunction with the Ministry of Health and sponsored by the Danish Epilepsy Association (IBE's Full Member in Denmark), the theme of the meeting was "Epilepsy: a healthcare priority".

The Chief Guest at the conference was the Hon Jim K Muhwezi, Ugandan Minister of Health, who advised that the Ugandan government recognised epilepsy as a development issue and pledged that the Ministry of Health would train more health workers in epilepsy related services. The keynote address was presented by Dr Kamadore Toure, a neurologist from the University of Dakar, Senegal, who gave the following statistics on the provision of health care

in Africa:

- In North and South Africa there are 350,000 people to one neurologist and 500,000 people living with neurological problems to one neurosurgeon.
- Central Africa has an average of 2.1 million people to one neurologist and one neurosurgeon to approximately 1.15 million people.
- There are approximately 325 EEG machines in Africa for about 730 million people.

The Epilepsy Association of Sierra Leone, one of IBE's newest members in Africa, celebrated its 6th birthday in December. Addressing the celebrations, Max Bangura stated that, while there are approximately 50,000 people living with epilepsy in Sierra Leone, poor public transport made it difficult to access people living outside major towns.



*Birthday celebrations in Sierra Leone*

The Epilepsy Support Foundation in Zimbabwe reported that, despite the socio-economic challenges facing Zimbabwe, the corporate, welfare and government sectors continued to support the fight against epilepsy. The major highlight of the year was the development of an Epilepsy Centre. Medication supply is a challenge for many people and this affected compliance. A vision for the Foundation is to improve quality of service by setting up an epilepsy clinic at the Epilepsy Centre.

The Epilepsy Association of Zambia had three main activities last year. In August National Epilepsy Day was celebrated with the theme 'Epilepsy is not a Hindrance to Progress'. A workshop on Epilepsy and Women's Issues was held in July, targeting health workers and, in particular, midwives. A new Seizure Diary was designed and launched at a special event in December, with the Deputy Minister of Health in attendance.

The Cameroon association changed its name to the Association Camerounaise Centre l'Epilepsie in order to facilitate its growth throughout the country. Lobbying by the association has led to the establishment by the Cameroon government of the first National Epilepsy Day, which will take place in May 2006.

In a unique event, bringing together ancient cultural beliefs and modern medical science, the Senegalese League Against Epilepsy welcomed a group of traditional healers to the University Hospital of Dakar. The traditional healers spent a day with neurologists and psychiatrists discussing the burden of epilepsy and learning about the anatomy and the physiology of the brain. The neurologists also advised the traditional healers of the importance of anti-epileptic drugs and the dangers of withdrawing medication.





# Eastern Mediterranean

## EASTERN MEDITERRANEAN TASK FORCE

During his IBE Presidency, Philip Lee established a Mediterranean Task Force, the objectives of which were as follows:

- The creation of new chapters of IBE in the Eastern Mediterranean Region
- Support to existing Chapters of IBE in the region
- Encouragement of collaborative studies in the region
- Distribution and exchange of information from different countries in the Eastern Mediterranean Region
- Encouraging participation of local IBE chapters at future Mediterranean Meetings on Epilepsy.

Membership of the Task Force, which was chaired by IBE Vice President Athanasios Covanis, was open to all interested parties in the region. The Task Force met for the first time at the 25th International Epilepsy Congress in Lisbon and further meetings were held in Marrakech and Paris. By mid-2005, through the encouragement of the Task Force, IBE membership in the region had developed to the point where the criteria for the establishment of a Regional Committee in the area had been met.

With its main objective reached, the Task Force is now relieved of its duty and the first steps in creating an Eastern Mediterranean Regional Committee are being taken.



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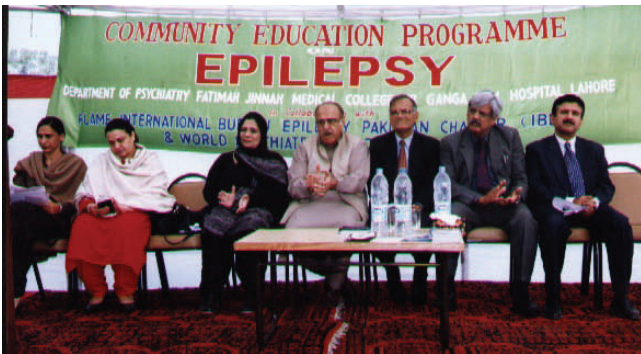
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The Eastern Mediterranean Task Force met for the last time during the 26th International Epilepsy Congress in Paris. As at previous meetings, participants included representatives from IBE member associations as well as from countries where IBE is not yet represented. IBE is hopeful that IBE's representation in the Eastern Mediterranean Region will continue to grow and develop as new associations are formed.

There have been major developments in the region since the Eastern Mediterranean Task Force was set up in 2003 and, with the ratification of new members at the General Assembly Meeting in Paris, IBE's membership in the Eastern Mediterranean Region has now reached the point where an Eastern Mediterranean Regional Committee could be formed.

Membership of the Eastern Mediterranean Regional Committee is open to all Full and Associate Members within the IBE region. Each IBE Regional Committee has an elected Regional Executive Committee which coordinates the activities of the Regional Committee. In addition, each region elects a Vice President who sits on the IBE International Executive Committee and acts as a liaison point between the International Executive Committee and the Regional Committee.



Speakers at one of the Community Education Programmes organised by FLAME, Pakistan

During 2006 balloting will take place in the Eastern Mediterranean Region to elect a Vice President Eastern Mediterranean and members of the Eastern Mediterranean Regional Executive Committee.

During the 8th EPIMED Congress, held in Marrakech at the end of 2004, it was agreed that future Mediterranean congresses would be joint ILAE/IBE meetings. Throughout 2005 plans have been forming for the 1st Eastern Mediterranean Epilepsy Congress to be held in Egypt. It is expected that the conference will take place early in 2006.



Mrs Manar Sawwan (pictured centre in white) a founder member of the Association of Care of Epilepsy Patients, Lebanon, at a special meeting for women members of the association

Free Psychiatric / Epilepsy Clinic, Ahbab Hospital; Ravi Road Lahore, Pakistan is the largest outpatient facility in the country for patients with Epilepsy working since 1985 being run by FLAME. This clinic completed its 20 years in November 2005. During 2005, around 44800 patients were given treatment.

Three community education programmes in addition to annual programme were conducted for patients with epilepsy, their families, teachers and media highlighting etiology, management, precautions addressing career, marriage and pregnancy. Patients working in community and their caregivers were awarded gifts and special prizes.

The Epilepsy and Support Information Centre (ESIC) organised the 'Year 2005 Epilepsy Update for Primary Healthcare Professionals' in Riyadh, Saudi Arabia in March 2005. The primary aim of the meeting was to enhance diagnosis, treatment and management of epilepsy, in particular at primary healthcare level. The association also held its annual 'Family Festival for Epilepsy Awareness'. The event, which attracts almost 1,000 people uses a mix of family entertainment and educational activities about epilepsy to raise public knowledge and awareness about epilepsy.

The Association of Care of Epilepsy Patients in the Lebanon continues to struggle to make AEDs available to those with financial hardship.



Participants attending the 'Year 2005 Epilepsy Update for Primary Healthcare Professionals in Saudi Arabia



A colourful poster promoting the Saudi Arabian 'Family Festival for Epilepsy Awareness'.





# Europe

## EUROPEAN REGIONAL EXECUTIVE COMMITTEE

**Chair:** Peter Dahlqvist, Sweden

**Vice Chair:** Athanasios Covanis, Greece

**Secretary:** Andreas Habberstad, Norway

**Members:** Jónína Gudmundsdottir, Iceland and Seppo Sarkkula, Finland

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# Europe

The European Regional Committee met for the last time under the chairmanship of Hilary Mounfield during the Paris Congress in August. The Committee had been chaired by Ms Mounfield since 2001 and the meeting closed with the handover to the newly elected Regional Executive Committee.



*Peter Dahlqvist, Chair of the European Regional Executive Committee*

The new IBE Constitution was the focus for some discussion at the Paris meeting, with a recommendation to the International Executive Committee that a review of the constitution be carried out at some point in the future to consider whether any adjustments were required. There was general consensus that members were pleased with the new democratic procedures introduced, particularly in relation to executive committee elections,

but some concern was voiced about the complicated nature of the election process.

The European Regional Committee works closely with the Commission on European Affairs of the International League Against Epilepsy, in particular on the EUCARE Political Action Group. This close partnership is valued by the European Regional Committee and it is hoped to work in partnership on other projects in the future. The inaugural meeting of the Political Action Group took place in the Netherlands in May 2005, with Hilary Mounfield and Peter Dahlqvist attending on behalf of the Regional Committee.

For much of 2005 the emphasis of the European Regional Committee was on preparations for the 10th European Conference on Epilepsy & Society. The venue had been announced in 2004, at the time of the 9th Epilepsy & Society Conference in Malta, and initial work on drafting a programme and identifying speakers was undertaken by the committee under the chairmanship of Hilary Mounfield. Following the Regional Committee elections in mid-2005,

10th EUROPEAN CONFERENCE ON  
**EPILEPSY & SOCIETY**  
2nd-5th of AUGUST 2006 - COPENHAGEN - DENMARK



the new Regional Executive Committee 2005—2009, chaired by Peter Dahlqvist, took over responsibility for the conference in 2006.

The Regional Committee approved the provision of 20 bursaries for the Copenhagen conference. The bursary funds will provide for travel, accommodation and registration fees at the conference and will be awarded on the basis of merit as decided by the Regional Executive Committee.

One of the difficulties most often mentioned by people with epilepsy relates to driving licences. While regulations in some European countries have been improved in recent years, there is wide disparity in legislation in Europe. The Regional Committee initiated a survey of European Members during 2005 to form a full picture of the European perspective on driving. The results of the survey will form the basis of a presentation during the 10th European Epilepsy & Society Conference in 2006.

Finally, IBE membership in Europe increased significantly in 2005 and several new members were approved during the General Assembly Meeting on 31st August:

#### **New Full Members:**

- AURA, Slovak Republic
- Estonian Epilepsy Association, Estonia
- EVN, The Netherlands
- Association of People with Epilepsy, Turkey

#### **New Associate Members:**

- EOLE, France
- Telley-Epilespoir, France
- Quarriers, Scotland

*Colourful harbour-side buildings in Copenhagen, venue for the 10th Epilepsy & Society Meeting in August 2006.*





At national level, many of IBE's 51 member associations in Europe introduced new and exciting projects during 2005, all aimed at improving the quality of life of their members.

In Turkey stigma is still a huge problem for people with epilepsy. It is not unusual for a school to refuse to enroll a child solely on the basis that he or she has epilepsy, or for friends to stay away when they hear that a member of the family has epilepsy. This prejudice by Turkish society makes it very difficult for people with epilepsy to be open about their condition. With the support of the Association of People with Epilepsy in Turkey, the Governor of Istanbul has agreed to promote seminars for teachers and the police throughout the Istanbul area, which will inform about the association and its services. The association is also involved in a new UNICEF project that focuses on children at risk. The project involves 18 non-governmental organizations in Turkey. Because of the difficulties faced through stigma and financial hardship, children with epilepsy in Turkey are considered to be at risk.

Epilepsy Scotland successfully challenged Scotland's National Health Services' Information and Statistics Division about low numbers of epilepsy patients recorded by General Medical Practitioners – as a result the official figures have doubled!



*A poster image used by Epilepsy Scotland to highlight the increasing number of older people diagnosed with epilepsy*

Epilepsy affects increasing numbers of older people but often goes unrecognised. A major conference with the theme 'Epilepsy in Later Life' was organised by Epilepsy Scotland and attracted over 100 health care service representatives from all regions of Scotland - and national media interest. Speakers and delegates considered the needs of people aged over 65 with epilepsy.

Epi-Suisse, IBE's Full Member in Switzerland, in cooperation with the Swiss Federal Department of Social Welfare, the Eclipse Foundation in the French-speaking region and the SeSi-Association in the Italian speaking part of Switzerland, has introduced many new public awareness activities in Switzerland. The association has also teamed up with the Swiss Epilepsy Centre to work together to strengthen the quality of services for support groups. The value of joining forces with other groups with similar aspirations to undertake advocacy actions, is now being recognised in many



*Stigma and misconceptions about epilepsy by Turkish society means that children with epilepsy are considered as being at risk.*

countries as the way forward in instigating legislative change.

After several years of dedicated effort, Spolecnost "E" celebrated the opening of the first short-term hospital for people with epilepsy in the Czech Republic. The facility was officially opened in May 2005. This is just one of a range of facilities provided by the Czech association for people with epilepsy and their families. The association continues to hold annual summer camps for children and summer holiday breaks for families who otherwise would be unable to enjoy holidays as a family.

AISPACE, IBE's Full Member in France, together with the French League Against Epilepsy, played hosts to the 26th International Epilepsy Congress, attended by over 5,000 delegates in August 2005. As part of the celebration, AISPACE, together with other epilepsy associations in France, organised the 1st Francophone Epilepsy Day, with speakers and delegates from many French-speaking countries from round the world taking part.



*AISPACE members launch celebratory balloons, each carrying a postcard with the association's details, to mark the occasion of the international congress in Paris.*





*The Croatian Association for Epilepsy focused its public meetings on issues relating to epilepsy in children and adolescents.*

In Croatia a special effort was made to induce changes to the rigid legislation concerning driving license – although the Croatian Association for Epilepsy is disappointed in the progress it has managed to achieve to date. Nevertheless the association will continue to advocate for change and is hopeful of future success. On a happier note, the association website was launched. [www.epilepsija.hr](http://www.epilepsija.hr). In public meetings special focus was placed on the problems of epilepsy in children and adolescents.

Finnish Epilepsy Association (FEA) dedicated 2005 to *self-management of epilepsy*. FEA promoted active involvement by persons with epilepsy and their families to enhance well-being (by taking medication regularly, applying different self-control strategies, alleviating stress by openness etc.). A nation-wide awareness campaign was carried out together with 36 public lectures on self-management and good care of epilepsy and 20 rehabilitation courses were organized for nearly 500 people helping them to adjust with the illness.



*Delegates to the Nordic Epilepsy Committee Meeting held in Helsinki in June 2005.*

Each year epilepsy national epilepsy associations in the Nordic Region (Norway, Sweden, Denmark, Finland and Iceland) come together for the annual meeting of the Nordic Epilepsy Committee. The purpose of the meeting is to exchange experiences and information and to identify new ideas for improving services. The honour of hosting the meeting rotates each year and in 2005 it was the turn the Finnish Epilepsy Association to welcome delegates. Participants were also welcomed from Estonia, Russia and the Faeroe Islands and the theme of the meeting was epilepsy

care and treatment and quality of life issues.

IBE was delighted to welcome Epilepsie Vereniging Nederland (EVN) as a Full Member once more. Throughout 2005 the Dutch association worked towards the provision of special epilepsy healthcare insurance for people with epilepsy; the insurance cover is available since the 1<sup>st</sup> January 2006. Among the benefits of the policy, apart from a 10% reduction in costs, is the guarantee that the insured person with epilepsy will not have their AED medication substituted, except for medical reasons.

EVN is one of six epilepsy organisations in the Netherlands that have come together to set up an internet healthcare shop for members. Members can purchase products or services, such as alarm or track-and-trace equipment, and will also have access to a pharmacist service that will deliver AED prescriptions.

In Norway someone was making a lot of noise about epilepsy during the year, and that someone was Nicholas Roberts who undertook a series of exhausting endurance rides on a quad-bike to get the public's attention. One the journey's travelled was a 5,800 kilometre 7-day trip from Oslo to the North Pole and back. Mr Roberts also travelled to the epilepsy congress in Paris from Oslo on his quad-bike and then back home again. The latest plan is to go from Gothenburg in Norway to London by sea. This time the mode of transport is to be a jet ski.



*Nicholas Roberts on board his quad bike*

The Swedish Epilepsy Association launched a Youth Project with regional weekend meetings for young persons with epilepsy and a large National Survey among 3,000 members was carried out to investigate the contents and quality of



epilepsy health care in Sweden. Through active and open communication with pharmaceutical and other medical corporations the Swedish association received support to perform an Epilepsy Tour with public evening lectures with a neurologist and an epilepsy nurse in six cities, as well as a help line operated by an epilepsy nurse one evening per week.

In the course of twelve months Epilepsy Action, IBE's Full Member in the UK, raised the equivalent of US\$6.3 million and spent the equivalent of US\$5.3 million, operated 94 local branches throughout the United Kingdom and appointed 12 new epilepsy specialist nurses (Sapphire nurses) within the National Health Service (NHS). The 54 full time staff responded to 20,066 contacts on the telephone advice and information service and a staggering 1,028,219 people visited the association's website.

The Danish Epilepsy Association was involved with several international issues during 2005. In cooperation with the European Regional Committee the association spent a lot of time preparing for the 10<sup>th</sup> European Conference on Epilepsy & Society that takes place in Copenhagen 2<sup>nd</sup> – 4<sup>th</sup> August 2006. In 2006 the Nordic Epilepsy Committee will meet in Denmark and work commenced in 2005 in putting everything in place for the committee. The Danish association also continued its involvement with and support to the



*Schoolchildren in Uganda, photographed by Jutta Houmøller, Chief Executive of the Danish Epilepsy Association*

Epilepsy Support Association of Uganda project "Bringing Epilepsy in Uganda out of the Shadows" and supported an international workshop held in Kampala in October 2005.

Deutsche Epilepsievereinigung e.V., Germany, launched a its new corporate style and designed silver fundraising pins styled on the new logo. A further achievement for 2005 was the agreement by public health insurance to cover the costs of the ketogenic diet for people with epilepsy under certain conditions.

Meanwhile in Ireland, Brainwave The Irish Epilepsy Association was tackling epilepsy in a different way and turned to the world of the celebrity to find support in raising awareness about epilepsy. Irish rugby star Gordon D'Arcy joined forces with Scottish star Tom Smith (who has epi-



*Gordon D'Arcy (left) and Tom Smith, with assistance from junior supporters, launch Brainwave's 'Wanted' campaign*

lepsy) to launch Brainwave's 'Wanted' campaign. The aim of the campaign is to encourage celebrities who have been touched by epilepsy in some way to become spokespersons for Brainwave. The originality of the campaign ensured great media coverage and by the end of the year a well-known national radio presenter had 'come out of the shadows'. The campaign continues.

The most outstanding factor of 2005 for the Portuguese League Against Epilepsy (LPCE) was the creation of a new Epilepsy Association, which will focus on social issues relating to epilepsy and will become the IBE Full Member in Portugal. Until now the Portuguese League Against Epilepsy was a 'dual-purpose' association, with scientific and social functions.

Through meetings with members LPCE was able to form a committee of people with epilepsy, parents and friends, willing to invest in the project. The association also used congresses, seminars and lectures as a platform to promote EPI-APFAPE – Portuguese Association of Family Members, Friends and People with Epilepsy.



*Twinkling nightlights form a dramatic display of the EPI-APFAPE logo in Oporto.*



# Latin America

## LATIN AMERICAN REGIONAL EXECUTIVE COMMITTEE

**Chair:** Lilia Nuñez Orozco, Mexico

**Vice Chair:** Elza Marcia Yacubian, Brazil

**Secretary:** Tomás Mesa, Chile



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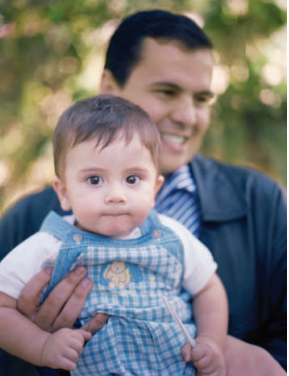
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The first meeting of the Latin American Regional Committee under the leadership of the newly elected Regional Executive Committee took place in Paris in August where the main focus was the drafting of a short-term plan of activities for 2006, which will form the basis from which a long term strategy will be produced.



The 4th Latin American Epilepsy Congress takes place in Guatemala City in September 2006 and will begin with a special one-day IBE pre-congress event that will be of particular interest to people with epilepsy and their families.

It has been agreed that the 5th Latin American Epilepsy Congress will be held in Uruguay in 2008. Exact dates are not yet identified.

The 5th Latin American Epilepsy Day was celebrated on 9th September in many countries in the region and is gaining momentum since it was launched in 2000. In 2006 the day will once again fall during the Latin American congress and special celebrations are planned for Guatemala.

Although a long time in preparation, and after some delay in completion, a book dedicated to people with epilepsy and written in Spanish, is almost ready to print. The book is due to be launched during the congress in Guatemala.

The Chilean League against Epilepsy, as well as helping people with epilepsy to receive adequate treatment through the provision of its Medication Bank, medical, clinical laboratory and EEG services, also offers self-empowering and psychosocial initiatives.



One of these is a series of Capacity-building Courses, free of charge and running for one semester each. The subjects covered by the courses include hairdressing, confectionary, photography and computer-training. The object of these courses is to pre-

pare those patients for the work-place, who, through economic problems have not been able to take part in traditional educational courses, and have therefore limited work competence.

Through weekly sessions directed by monitors who, as well as being experts in their subject areas, have direct experience of epilepsy because they, or a family member, have epilepsy, the participants are helped to discover personal potential that they did not believe they possessed. In this way a cohesive group is formed, which, by the end of the process, can demonstrate increased self-esteem, leaving behind emotional problems caused by the stigma of epilepsy.

In March 2005, the Associação Brasileira de Epilepsia held an educational event in Sao Paulo in celebration of International Women's Day. A multidisciplinary group made up of gynaecologists, neurologists and specialists in foetal and sleep medicine talked about the influence of hormones, in particular during pregnancy.

A special book 'Epilepsia & Mulher', edited by Dr Elza Marcia Yacubian and published by the Associação Brasileira de Epilepsia, contains the proceedings of the event. The Brazilian Association also has a new President, Dr Laura Giulhoto.



*Members of the Associação Brasileira de Epilepsia*

In Venezuela, LIVECE celebrated the acquisition of a new headquarters and also expanded the association with the creation of several new chapters. LIVECE continues to provide medication to members facing financial hardship.

A National Forum on Epilepsy took place in November in the Chamber of Mexican Deputies. The purpose of the Forum was to raise awareness on the problems related to epilepsy research being carried out in relation to AED nano-material implants with slow release in animal experimentation, but which it is planned to use eventually in humans.





# North America

## NORTH AMERICAN REGIONAL EXECUTIVE COMMITTEE

For the present time, it is agreed that it is not necessary to form a Regional Executive Committee for North America through an election process. Instead representatives from the IBE member associations will meet informally and communicate largely through email.



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The Epilepsy Foundation of America initiated several major new projects during 2005. The most visible of these involved a famous America pop idol who joined forces with Epilepsy Foundation in the US in 2005 to Chair the foundation's exciting new 'Out of the Shadows' campaign.

Amy Lee, lead singer of the rock band Evanescence had long been a financial supporter of epilepsy research, through the Amy Lee Fund, but in 2005 her commitment went one step forward when she agreed to chair the new campaign. Ms Lee has a personal connection to epilepsy; her brother developed epilepsy as a young boy.

The Epilepsy Foundation 'Out of the Shadows' campaign is tailored specifically to appeal to teenagers and young adults, a target group the foundation had never solely focused its attention on before. To attract this age group to the campaign, an interactive website was created that contains a mix of epilepsy facts and information about the artist herself. The site also features a running Juke Box that plays some of the singers most famous songs, together with video clips. To see what it's all about visit [www.outoftheshadows.com](http://www.outoftheshadows.com).

As part of an ongoing effort to address issues affecting women and epilepsy, a Women's Health Roundtable took place in New York City in June 2005. The event attracted the country's major women's health organizations and focused on the effects of anticonvulsants on women of child-bearing age, as well as issues and concerns related to pregnancy, mood disorders and cognition.

The Epilepsy Foundation partnered with the national Centers for Disease Control and Prevention and the Health Resources and Services Administration on several important minority outreach efforts. In one such effort, the Foundation expanded its Hispanic outreach program and created a Hispanic Council, which will provide leadership in Hispanic public health education, consult with Hispanic epilepsy specialists and target Hispanic media.

The Epilepsy Foundation's Public Policy Institute and Kids Speak Up! Program continued in 2005 and drew more than 250 participants, including 82 children. Representatives from 33 Epilepsy Foundation affiliates from across the United States were on hand, as were several doctors from the Foundation's professional advisory board, American Epilepsy Society and the American Academy of Neurology.

The Canadian Epilepsy Association continued its successful 'Lavender, Think Epilepsy' campaign which it began in 2004. Lavender is associated with seclusion and isolation

and was adopted by the Canadian association to symbolise the rejection and loneliness experienced by many people with epilepsy. To add new impetus to the project a special lavender shaped pin was created. Sales of the pin will also generate funds for the association to help with its work.



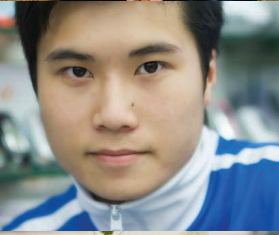
In Jamaica, Mrs Nora Perez, President of the Jamaican Epilepsy Association, has long been campaigning for a relaxation in Jamaican legislation that forbids anyone with epilepsy, irrespective of how long they might be seizure-free, to apply for a driving licence.

As part of her campaign for change, she invited the Jamaican press to the Video-EEG Unit at the Andrews Memorial Hospital in order to encourage the publication of the true facts about epilepsy in Jamaica and to encourage a review of legislation.

That small step had a major impact with excellent media coverage in the Jamaican Press. The story was also picked up by several epilepsy organisations around the world, who reported on the initiative in their magazines.







# South East Asia

## SOUTH EAST ASIA REGIONAL EXECUTIVE COMMITTEE

**Chair:** PK Sethi, India

**Vice Chair:** HV Srinivas, India

**Secretary:** VS Saxena, India

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The South East Asia Regional Committee is one of the newest of IBE's Regional Committees and comes about as the result of the division of the previous Asia Oceania Regional Committee into South East Asia and Western Pacific. There are just 11 countries or territories within the South East Asia region:

- Bangladesh
- Bhutan
- Democratic People's Republic of Korea
- India
- Indonesia
- Maldives
- Myanmar
- Nepal
- Sri Lanka
- Thailand
- Hong Kong.

IBE has a Full Member in 6 of these countries as well as Associate Members in Indonesia and Hong Kong. The application of our newest member, the Bangladesh Epilepsy Association was ratified by the General Assembly at the time of the 26th International Epilepsy Congress in Paris in August 2005.

While in terms of countries, the number might be low, in terms of population this is a very large region with more than a billion people living in India.

The South East Asia Regional Committee elections were completed towards the end of 2005 and, as a result, plans and objectives for the region are still being considered. The Regional Executive Committee is aware of the importance of involving all members in the region to participate in drafting a plan of action and to this end it is planned to hold the first meeting of the Regional Committee at the time of the 6th Asia Oceania Epilepsy Congress in Kuala Lumpur 2006. All IBE members in the region will be invited to attend and actively participate.

A special programme for IBE members during the Kuala Lumpur congress will run in parallel with the scientific programme. A welcome party, keynote addresses, exciting drama, group discussions, a painting exhibition and a full day tour of Kuala Lumpur are some of the activities on offer.

There will be special presentations by national winners of the Outstanding Person with Epilepsy awards and their participation is being assisted through grants provided by the regional committee.

Throughout 2005 national actions continued to be introduced by IBE members in the region, with efforts to educate, to raise awareness and to reduce stigma.

The Indian Epilepsy Association has 22 branches based throughout India. New projects for 2005 included the introduction of a distance learning course "Diploma in Epilepsy Care" developed by IEA through Bangalore University. The course is available in English and is open to both national and international students. The course is one year duration and is aimed at imparting knowledge about social aspects of epilepsy. For more information log on to [www.indianepilepsyassociation.org](http://www.indianepilepsyassociation.org)

One of the methods adopted by the Indian Epilepsy Association to create public awareness in illiterate people is through street plays and road shows which have been successfully presented for the past three years. The awareness programme was developed through audio cassettes and also in the form of dance drama in a video CD by some of the association's branches.

Enlighten Hong Kong, an Associate Member of IBE, holds regular outings and events for its members. One of the more popular in 2005, for its younger members at least, was a visit to the cinema to see 'Madagascar'.





# Western Pacific

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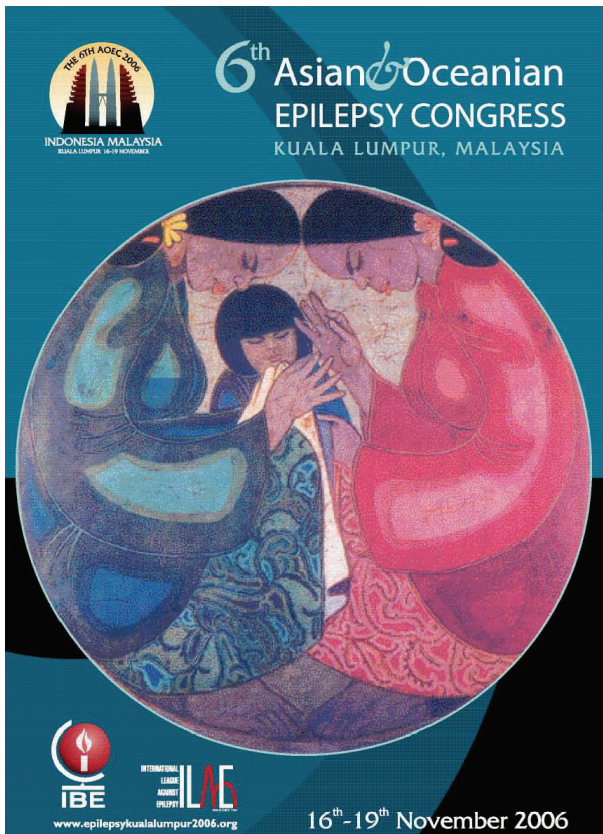
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In conjunction with the South East Asia Regional Committee, IBE members in the Western Pacific Regional Committee will be involved in organising the special programme during the 6th Asia Oceanian Epilepsy Congress in Kuala Lumpur in November 2006. Members in the region have been encouraged to participate in the Outstanding Persons with Epilepsy award programme, introduced for the first time in 2004.

The Regional Committee grew in strength in 2005, with the approval of three new Full Members by the

General Assembly in Paris. The new members are:

- China Association Against Epilepsy
- Epilepsy Awareness & Advocacy Inc., Philippines
- Mongolian Epilepsy Society

IBE is grateful to the dedication of Dr Marshal Mo-Song Hsih for his work in encouraging new members during his term as Chair of the Asia Oceania Regional Committee.

In Taiwan an excellent new DVD has been launched by the Taiwan Epilepsy Association. Produced by Chen Rye-Jen 'The Moment I Lost Myself' looks at a wide range of epilepsy issues, such as employment, through the eyes of persons with epilepsy, their work colleagues, friends and family. The 30-minute DVD is in Chinese with English sub-titles and copies are available on request to the association.



*Pam Reynolds and Sharon Wills*

On 11<sup>th</sup> May 2005 in conjunction with Epilepsy Awareness Week the Epilepsy Australia of South Australia and the Northern Territory Inc (EASANT) held its inaugural Epilepsy Seminar. EASANT members Sharon Wills and Pam Reynolds spoke on their own very moving experiences as mothers of children with severe epilepsy.

The Mongolian Epilepsy Association has established a government approved epilepsy centre which has begun providing modest consultancy services. The association is now actively seeking financial support to widen the range of support and services it can provide to people with epilepsy.

*Members of the Taiwan Epilepsy Association and their families get together for a day's outing.*



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