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.
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
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 1st 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 increase 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 26th 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 7th 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
**Financial Report**

**BALANCE SHEET**  
*Year ended 31st December 2005*  
*With comparative totals for 2004*

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>US$</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FIXED ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>5,889</td>
<td>4,490</td>
</tr>
<tr>
<td><strong>CURRENT ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors and prepayments</td>
<td>-</td>
<td>634</td>
</tr>
<tr>
<td>Cash at bank and in hand</td>
<td>1,503,936</td>
<td>1,569,619</td>
</tr>
<tr>
<td></td>
<td>1,503,936</td>
<td>1,570,253</td>
</tr>
<tr>
<td><strong>CREDITORS:</strong> (Amounts falling due within one year)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(152,242)</td>
<td>(103,965)</td>
</tr>
<tr>
<td><strong>NET CURRENT ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1,351,694</td>
<td>1,466,288</td>
</tr>
<tr>
<td><strong>CREDITORS:</strong> (Amounts falling due after more than one year)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deferred Income</td>
<td>(626,054)</td>
<td>(744,056)</td>
</tr>
<tr>
<td><strong>NET ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>731,529</td>
<td>726,722</td>
</tr>
<tr>
<td><strong>CAPITAL AND RESERVES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General reserve</td>
<td>491,724</td>
<td>561,855</td>
</tr>
<tr>
<td>Restricted fund</td>
<td>239,805</td>
<td>164,867</td>
</tr>
<tr>
<td></td>
<td>731,529</td>
<td>726,722</td>
</tr>
</tbody>
</table>
## STATEMENT OF INCOME AND EXPENDITURE
### Year ended 31st December 2003
### With comparative totals for 2001

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INCOME</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>International congresses and symposia</td>
<td>191,876</td>
<td>456,675</td>
</tr>
<tr>
<td>Commerce and industry</td>
<td>153,273</td>
<td>86,025</td>
</tr>
<tr>
<td>Membership dues</td>
<td>24,674</td>
<td>28,581</td>
</tr>
<tr>
<td>Society contributions</td>
<td>-</td>
<td>4,495</td>
</tr>
<tr>
<td>Investment income</td>
<td>27,022</td>
<td>16,140</td>
</tr>
<tr>
<td>Sale of materials</td>
<td>124</td>
<td>62</td>
</tr>
<tr>
<td>Other grants</td>
<td>392,401</td>
<td>280,775</td>
</tr>
<tr>
<td>Miscellaneous income</td>
<td>10,074</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td>389,416</td>
<td>872,755</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2004</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EXPENDITURE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Salary costs</td>
<td>85,692</td>
<td>95,668</td>
</tr>
<tr>
<td>Office expenses</td>
<td>8,577</td>
<td>8,155</td>
</tr>
<tr>
<td>Printing and postage</td>
<td>20,723</td>
<td>25,440</td>
</tr>
<tr>
<td>Printing and postage - International Epilepsy News</td>
<td>31,528</td>
<td>30,435</td>
</tr>
<tr>
<td>Travel</td>
<td>59,969</td>
<td>61,721</td>
</tr>
<tr>
<td>Global Campaign costs</td>
<td>25,000</td>
<td>31,411</td>
</tr>
<tr>
<td>Accountancy fees</td>
<td>10,873</td>
<td>10,873</td>
</tr>
<tr>
<td>Audit fees</td>
<td>4,127</td>
<td>4,127</td>
</tr>
<tr>
<td>Bank charges</td>
<td>954</td>
<td>1,314</td>
</tr>
<tr>
<td>Rent</td>
<td>4,903</td>
<td>(566)</td>
</tr>
<tr>
<td>Subscriptions</td>
<td>229</td>
<td>235</td>
</tr>
<tr>
<td>Depreciation</td>
<td>1,858</td>
<td>1,602</td>
</tr>
<tr>
<td>Website costs</td>
<td>2,887</td>
<td>2,593</td>
</tr>
<tr>
<td>EUCARE costs</td>
<td>311,052</td>
<td>210,246</td>
</tr>
<tr>
<td>Currency exchange fluctuations</td>
<td>226,265</td>
<td>(143,958)</td>
</tr>
<tr>
<td><strong>Total Expenditure</strong></td>
<td>794,637</td>
<td>339,296</td>
</tr>
<tr>
<td><strong>Operating Surplus/Deficit for year</strong></td>
<td>4,807</td>
<td>533,459</td>
</tr>
</tbody>
</table>
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 of Membership Certificates to new members at the close of the General Assembly
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 lead 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

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

“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.
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. Donations 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.

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.
AFRICAN REGIONAL EXECUTIVE COMMITTEE

Chair: Zenebe Gedlie Damtie, Ethiopia
Vice Chair: Augustine Mugarura, Uganda
Secretary: Anthony Zimba, Zambia

MEMBERS OF THE AFRICAN REGIONAL COMMITTEE

CAMEROON
Association Camerounese Contre l'Epilepsie
Mission Catholique Nyamanga II
B.P. 47 Ombessa, Cameroon.
E: desimone.franca@yahoo.fr
Contact: Sr Franca de Simone

CONGO
Association Fallone,
188 Av de l’Indépendance Tié Tié,
BP 1533, Pointe Noire, Congo
T: +242 53 7134, F: +242 242 958
E: mounkounkou@yahoo.fr
Contact: Mrs Mireille Flore Kounkou

ETHIOPIA
Epilepsy Support Association of Ethiopia
PO Box 25516, Code 1000,
Addis Ababa, Ethiopia
T: +251 1553617, F: +251 1551981
E: zdamtie@yahoo.com, esae@CyberEthiopia.com
Contact: Dr Zenebe Damtie

GHANA
Ghana Epilepsy Association
c/o Box M230, Accra, Ghana.
T: +233 216 5421 ext 4420
E: avisu@hotmail.com
Contact: Mr Paul Ayisu

KENYA
Kenya Association for the Welfare of Epileptics
PO Box 60790,
0200 Nairobi, Kenya.
T: +254 020 570885
F: +254 020 57 4871
E: kawe@wananchi.com
Contact: Mr Gachegu Gitonga

MAURITIUS
EDYCS Epilepsy Group (Mauritius)
2nd Floor, Puretech Bldg,
8, Impasse Labourdonnais,
Port Louis, Mauritius.
T: +230 5080904, F: +230 2105655
E: edycs.org@imnet.mu
Contact: Mr Youssouf Noormamode

MOZAMBIQUE
Association Mozambiquaine Contre l’Epilepsie
Neurology Department,
University Hospital,
Marrakech, Morocco.
T: +212 60 213 1437
F: +212 22 443 2887
E: epilepsiasociation@yahoo.com
Contact: Prof Najib Kissani

NIGER
LNCEMNMC
Service de Psychiatrie,
Hôpital National de Niamey,
BP238 Niamey, Niger.
T: +227 723 393, F: +227 733 446
E: douma@caramail.com
Contact: Dr D Douma

NIGERIA
Epilepsy Association of Nigeria
No 2 Weeks Road by 84 Asa Road
Aba, Abia State, Nigeria.
T: +803 433 2275
E: drmohaniclinic@yahoo.com
Contact: Dr SE Nwakwue

SENEGAL
Ligue Senegalaise contre l’Epilepsie,
Clinique Neurologique,
Centre Hospitalo-Universitaire de Fann,
BP 5035, Dakar-Fann, Senegal.
T: +221 8253678, F: +221 8259227
E: epilepsie@sentoo.sn
Contact: Dr Gallo Diop

SIERRA LEONE
Epilepsy Association of Sierra Leone
10A Tokpa Estate, PO Box 381
Freetown, Sierra Leone.
E: epilepsy_easl@yahoo.com
Contact: Brother Max A Bangura

SOUTH AFRICA
Epilepsy South Africa
PO Box 73, Observatory 7935,
Capetown, South Africa.
T: +27 2144 73014, F: +27 2144 85053
E: noeline@epilepsy.org.za
Contact: Ms Noeline de Goede

SWAZILAND
Swaziland Epilepsy Association
PO Box 5138, Mbabane, Swaziland.
T: +260 9645 9688
E: eazepilepsy01@yahoo.co.uk
Contact: Mr Anthony Zimba

TANZANIA, UNITED REPUBLIC OF
Parents Organisation for Children with Epilepsy (POCET)
PO Box 65293, Dar Es Salaam
T: +744 822 517
E: skaaya@muchs.ac.tz
Contact: Mrs Aisia Mrema

UGANDA
Epilepsy Support Association
PO Box 16260, Wandegeya,
Kampala, Uganda.
T/F: +256 4852 0596
E: amugarura@yahoo.co.uk
Contact: Mr Augustine Mugarura

ZAMBIA
Epilepsy Association of Zambia
Motaxis Building, Kalundwe Road,
PO Box 32443, Lusaka, Zambia.
T: +260 9645 9688
E: eazepilepsy01@yahoo.co.uk
Contact: Mr Anthony Zimba

ZIMBABWE
Epilepsy Support Foundation
PO Box 104, Avondale
Old General Hospital,
Mazoe Street, Harare, Zimbabwe.
T: +263 472 4071
E: esi@healthnet.zw
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 Zimbabwe, 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.

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 Camerounese Contre 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.

MEMBERS IN THE EASTERN MEDITERRANEAN REGION

EGYPT
Dr Hassan Hosny
Egyptian Epilepsy Association
40 Safeya Zaghlol Street
Alexandria
21111
Egypt.
T: +203 303 3338
F: +203 304 7117
E: hhosny@internetegypt.com
Contact: Dr Hassan Hosny

IRAN
Iranian Epilepsy Association
PO Box 16315/1419
Tehran
Iran.
T: +98 21753 3847
F: +98 21869 153
E: iranepi@hotmail.com
Contact: Dr D Nassabi

LEBANON
Association of Care of Epileptic Patients
Saida – Lebanon
Khan al Efranj
Lebanon.
T: +961 3388 713
F: +961 7731 383
E: epilepsy@hotmail.com
Contact: Mrs Manar Sawwan

PAKISTAN
FLAME
83 Shah Jamal Colony
Lahore
Pakistan.
T: +92 4275 81724
F: +92 4275 72488
E: ppnc@wol.net.pk
E: saadh@brain.net.pk
Contact: Dr Rashid Chaudhry

SAUDI ARABIA
Epilepsy Support and Information Centre
PO Box 3354
MBC 76
Riyadh, 11211,
Saudi Arabia.
T: +966 1464 7272 ext 32833
F: +966 1442 4755
E: admin@epilepsyinarabic.com
Contact: Dr Abdulaziz Al-semari

TUNISIA
Tunisian Epilepsy Association
Department of Neurology
Hôpital Habib Bourguiba
3029 Sfax.
Tunisia.
T:+216 98 413 776
F: +216 74 651 975
E: chahnez@gnet.tn
Contact: Dr Chahnaz Triki
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.

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.

Free Psychiatric / Epilepsy Clinic, Alhabab 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.

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.
## 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

### MEMBERS OF THE EUROPEAN REGIONAL COMMITTEE

<table>
<thead>
<tr>
<th>Country</th>
<th>Organization</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AUSTRIA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Full Member: Epilepsie Dachveband Osterreich (EDO)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wichtelgasse 55, 17-19, 1170 Wien, Austria.</td>
<td>T: +43 1489 5278, E: <a href="mailto:epilepsie@aon.at">epilepsie@aon.at</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BELGIUM</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Les Amis de las Ligue Nationale Belge contre l’Epilepsie asbl</td>
<td>T: +32 2344 3263, F: +32 234 36837</td>
</tr>
<tr>
<td></td>
<td>Avenue Albert 135, Brussels 1190, Belgium.</td>
<td>E: <a href="mailto:epilepsy.belgium@skynet.be">epilepsy.belgium@skynet.be</a></td>
</tr>
<tr>
<td><strong>BULGARIA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Association for Assistance of Patients with Epilepsy</td>
<td>T: +359 2740 946</td>
</tr>
<tr>
<td></td>
<td>Mladost 1, Bl. 65, Ent. A, App 10, 1784 Sofia, Bulgaria.</td>
<td>E: <a href="mailto:aape_bulgaria@yahoo.com">aape_bulgaria@yahoo.com</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CROATIA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Croatian Association for Epilepsy General Hospital “Sveti Duh”, Sveti Duh 64, 10000 Zagreb, Croatia.</td>
<td>T: +385 13712114, F:+385 13712372</td>
</tr>
<tr>
<td></td>
<td></td>
<td>E: <a href="mailto:info@epilepsija.hr">info@epilepsija.hr</a></td>
</tr>
<tr>
<td><strong>CYPRUS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Cyprus Association of Support for People with Epilepsy, Makarios III Hospital 1474 Nicosia, Cyprus.</td>
<td>T: +357 9967 1844, F: +357 2251 8408</td>
</tr>
<tr>
<td></td>
<td></td>
<td>E: <a href="mailto:goula_stylianidou@yahoo.co.uk">goula_stylianidou@yahoo.co.uk</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CZECH REPUBLIC</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spolecnost “E”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Liskova 3, 14200 Prague 4 Czech Republic.</td>
<td>T: +4202 4172 2136 E: <a href="mailto:cea@volny.cz">cea@volny.cz</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DENMARK</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dansk Epilepsiforening</td>
<td>T: +45 6611 9091, F: +45 6611 7117</td>
</tr>
<tr>
<td></td>
<td>Kongensgade 68, 2. Tv.</td>
<td>E: <a href="mailto:epilepsi@epilepsiforeningen.dk">epilepsi@epilepsiforeningen.dk</a></td>
</tr>
<tr>
<td></td>
<td>DK-5000 Odense C, Denmark.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Contact: Mrs Jutta Houmoller.</td>
<td></td>
</tr>
<tr>
<td><strong>FINLAND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Epilepsialiitto</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Malmink kauppatie 26 FIN-00700 Helsinki, Finland.</td>
<td>T: +358 9350 82320</td>
</tr>
<tr>
<td></td>
<td></td>
<td>F: +358 9350 82322 E: <a href="mailto:epilepsialiitto@epilepsia.fi">epilepsialiitto@epilepsia.fi</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FRANCE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>AISPACEN</td>
<td></td>
</tr>
<tr>
<td></td>
<td>38 Rue du Plat, F-59000 Lille, France.</td>
<td>T: +33 3205 71941, F: +33 3200 94124</td>
</tr>
<tr>
<td></td>
<td></td>
<td>E: <a href="mailto:lille.aspace@wanadoo.fr">lille.aspace@wanadoo.fr</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>GEORGIA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Epilepsy &amp; Environment Association of Georgia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dept of Neurology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tbilisi State Medical University</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Jacob Nicoladze str. 6, appt 22, 380079 Tbilisi, Georgia.</td>
<td>T: +995 32233 551, F: +995 32221 965</td>
</tr>
<tr>
<td></td>
<td></td>
<td>E: <a href="mailto:okjava@geo.net.ge">okjava@geo.net.ge</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ICELAND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>LAUF The Icelandic Epilepsy Association</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hatuni 10b, 101 Reykjavik, Iceland</td>
<td>T: +354 551 4570, F: 354 551 4580</td>
</tr>
<tr>
<td></td>
<td></td>
<td>E: <a href="mailto:lauf@vortex.is">lauf@vortex.is</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IRELAND</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Brainwave The Irish Epilepsy Association</td>
<td></td>
</tr>
<tr>
<td></td>
<td>249 Crumlin Road, Dublin 12, Ireland</td>
<td>T: +353 1455 7500, F: +353 1455 7013</td>
</tr>
<tr>
<td></td>
<td></td>
<td>E: mikeglyn@<a href="mailto:brainwave@epilepsy.ie">brainwave@epilepsy.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ISRAEL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Israel Epilepsy Association</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 Avodat Israel, PO Box 1598,</td>
<td></td>
</tr>
</tbody>
</table>
Contact: Mr Ton Tempels.
Ul Fabryczna 57, 15-482 Bialystok, Poland.
T/F: +48 8567 54420.
Contact: Mr Tadeusz Zarebski.

PORTUGAL
Portuguese League against Epilepsy
Av da Boavista, 1015-60—Sala 601, 4100-428 Oporto, Portugal.
T/F: +351 22 605 49 59
E: epicentroporto@oninet.pt
Contact: Mr Paulo Nuno Oliveira.

ROMANIA
National Association of People with Epilepsy in Romania
Str. Aurel Vlaicu nr. 11
b. Vl, sc. 2, ap.1, Cluj-Napoca
cod 400581, Romania.
T/F: +40 264 599 500
E: anber@epilepsie.ro
Contact: Mr Gelu Stanculescu.

RUSSIAN FEDERATION
Associate Member:
“Mutual Assistance” Epilepsy Association
Kirovogradskaya ul 7 kv 517, 113587 Moscow, Russian Federation.
T/F: +7 09531 61808
E: chepurnova@yahoo.com
Contact: Mr Viktor Poldolski.

SCOTLAND
Epilepsy Scotland
48 Govan Road, Glasgow G51 1JL, Scotland.
T: +44 141 424 7491, F: +44 141 419 7109
E: sdouglas-scott@epilepsyScotland.org.uk
Contact: Ms S Douglas-Scott.

Associate Members:
Epilepsy Connections
100 Wellington Street, Glasgow G2 6DH Scotland.
T: +44 141 248 4125, F: +44 141 248 5887
E: smaxwell@epilepsyconnections.org.uk
Contact: Ms Shirley Maxwell.
Quarriers
Quarriers' Village, Bridge of Weir PA11 3XJ, Scotland.
E: phil.robinson@quarriers.org.uk

SERBIA MONTENEGRO
Serbian Epilepsy Society
Slobodana Penezic-Krcuna 23
Beograd, Serbia Montenegro.
T: +381 1168 6155, F: +381 1168 6656
E: yusepi@ztp.co.yu
Contact: Dr Maria Popovic.

SLOVAKIA
AURA
Prvá Neurologická Klinika Fakultnej Nemocnice, Dúbravská cesta 1
PO Box 116, 84005 Bratislava 45, Slovakia.
E: epilepsia@pobox.sk
Contact: Dr. Jozef Vrátil.

SLOVENIA
Slovenian League against Epilepsy
Institute of Clinical Neurophysiology
Hospital of Neurology, Medical Centre, SL-1525 Ljubljana, Slovenia.
T: +386 1522 9200, F: +386 1522 9357
E: ljubica.vrba@kclj.si
Contact: Mrs L. Vrba.

SPAIN
AEE
c/Berlin 5, 4o Piso, 28028 Madrid, Spain.
T: +34 91726 2727, F: +34 91356 0926
E: amgs@hotmai.com
Contact: Mrs Ana Cristobalina Morena.

SWEDEN
The Swedish Epilepsy Association
PO Box 1386, 172 27 Sundbyberg, Sweden.
T: +46 866 94306, F: +46 866 91588
E: Susanne.lund@epilepsi.se
Contact: Mrs Susanne Lund.

SWITZERLAND
Epi-Suisse
Seefeldstrasse 84, Postfach 313
CH-8034 Zurich, Switzerland.
T: +41 4348 86880, F: +41 4348 86881
E: ez@epi-suisse.ch
Contact: Mrs R Henggeler.

Associate Members:
Par Epi
Seefeldstrasse 84, CH-8008 Zurich, Switzerland.
T: +41 4348 88560, F: +41 4348 86881
E: parepi@bluewin.ch
Contact: Mrs R Henggeler.

Swiss Epilepsy Center
Bleulerstrasse 60, CH-8008 Zurich, Switzerland.
T: +41 1387 6202, F: +41 1387 6249
E: pachlatko@swissee.ch
Contact: Dr Chr Pachlatko.

TURKEY
Association of People with Epilepsy
Bati Mahalleli Ankara Caddesi Somits Sitesi Sokak
T: +90 216 354216, F: +90216 4832383
E: alpvaner@yahoo.com
Contact: Mr Alparslan Varer.

UK
Epilepsy Action
New Anstey House, Gate Way Drive
Yeadon, Leeds LS19 7XY, UK.
T: +44 113 210 8800, F: +44 113 210 8856
E: epilepsy@epilepsy.org.uk
Contact: Mr John Murdoch.

Associate Members:
David Lewis Centre
Mill Lane, Warford, Alderley Edge
Cheshire SK9 7UD, UK.
T: +44 1565 640000, F: +44 1565 640200
E: johnm@davidlewis.org.uk
Contact: Mr John Murdoch.

Gravesend Epilepsy Network
13 St George's Crescent
Gravesend DA12 4AR, UK.
T: +44 1603 676222, F: +44 1603 676228
E: pachlatko@swissee.ch
Contact: Mrs R Henggeler.

Swiss Epilepsy Center
Bleulerstrasse 60, CH-8008 Zurich, Switzerland.
T: +41 1387 6202, F: +41 1387 6249
E: pachlatko@swissee.ch
Contact: Dr Chr Pachlatko.

TURKEY
Association of People with Epilepsy
Bati Mahalleli Ankara Caddesi Somits Sitesi Sokak
T: +90 216 354216, F: +90216 4832383
E: alpvaner@yahoo.com
Contact: Mr Alparslan Varer.

UK
Epilepsy Action
New Anstey House, Gate Way Drive
Yeadon, Leeds LS19 7XY, UK.
T: +44 113 210 8800, F: +44 113 210 8856
E: epilepsy@epilepsy.org.uk
Contact: Mr Philip Lee.

Associate Members:
David Lewis Centre
Mill Lane, Warford, Alderley Edge
Cheshire SK9 7UD, UK.
T: +44 1565 640000, F: +44 1565 640200
E: johnm@davidlewis.org.uk
Contact: Mr John Murdoch.

Gravesend Epilepsy Network
13 St George's Crescent
Gravesend DA12 4AR, UK.
T: +44 1603 676222, F: +44 1603 676228
E: pachlatko@swissee.ch
Contact: Mrs R Henggeler.

Swiss Epilepsy Center
Bleulerstrasse 60, CH-8008 Zurich, Switzerland.
T: +41 1387 6202, F: +41 1387 6249
E: pachlatko@swissee.ch
Contact: Dr Chr Pachlatko.

TURKEY
Association of People with Epilepsy
Bati Mahalleli Ankara Caddesi Somits Sitesi Sokak
T: +90 216 354216, F: +90216 4832383
E: alpvaner@yahoo.com
Contact: Mr Alparslan Varer.

UK
Epilepsy Action
New Anstey House, Gate Way Drive
Yeadon, Leeds LS19 7XY, UK.
T: +44 113 210 8800, F: +44 113 210 8856
E: epilepsy@epilepsy.org.uk
Contact: Mr Philip Lee.

Associate Members:
David Lewis Centre
Mill Lane, Warford, Alderley Edge
Cheshire SK9 7UD, UK.
T: +44 1565 640000, F: +44 1565 640200
E: johnm@davidlewis.org.uk
Contact: Mr John Murdoch.

Gravesend Epilepsy Network
13 St George's Crescent
Gravesend DA12 4AR, UK.
T: +44 1603 676222, F: +44 1603 676228
E: pachlatko@swissee.ch
Contact: Mrs R Henggeler.

Swiss Epilepsy Center
Bleulerstrasse 60, CH-8008 Zurich, Switzerland.
T: +41 1387 6202, F: +41 1387 6249
E: pachlatko@swissee.ch
Contact: Dr Chr Pachlatko.

TURKEY
Association of People with Epilepsy
Bati Mahalleli Ankara Caddesi Somits Sitesi Sokak
T: +90 216 354216, F: +90216 4832383
E: alpvaner@yahoo.com
Contact: Mr Alparslan Varer.
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.

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, 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!

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 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.
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.

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 1st 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.

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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 10th European Conference on Epilepsy & Society that takes place in Copenhagen 2nd – 4th 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

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.

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-
Latin America

LATIN AMERICAN REGIONAL EXECUTIVE COMMITTEE

Chair: Lilia Nuñez Orozco, Mexico
Vice Chair: Elza Marcia Yacubian, Brazil
Secretary: Tomás Mesa, Chile

MEMBERS OF THE LATIN AMERICAN REGIONAL COMMITTEE

ARGENTINA
Asociación de Lucha contra la Epilepsia
Tucuman 3261
1189 Buenos Aires
Argentina.
T/F: +54 11 4620 440
E: gonzalezgartland@aol.com
Contact: Mr G Gartland

Associate Member:
FUNDEPI
Rocamora 4122
Ciudad de Buenos Aires (148)
Argentina.
E: skochen@mail.retina.ar
Contact: Dr Silvia Kochen.

BRAZIL
Associação Brasileira de Epilepsia
Rua Napoleão de Barros 715
Vila Clementino
São Paulo, 04024-002
Brazil.
T: +55 11 5549-3819
F: +55 11 5081-5005
E: abe@epilepsiabrasil.org.br
Contact: Laura M F F Guilhoto

CHILE
Liga Chilena contra la Epilepsia
Patriotas Uruguayos 2236
Codec Postal: 6501205
Santiago
Chile.
T: +56 2699 2288
F: +56 2699 4084
E: anliche@ligaepilepsia.cl
Contact: Dr Tomás Mesa.

COLOMBIA
Junta National Liga Colombiana contra la Epilepsia
Cap de Bolivar, Barrio Ternera
Calle 1a., El Eden
Y 5007 Cartagena
Colombia.
T: +57 56618 127
F: +57 56618 111
E: fandino2@enred.com
Contact: Dr J Fandino-Franky.

CUBA
Capitulo Cubano de la IBE,
Hospital Psiquiatrico de la Habana
Ave Independencia No 26520
Reparto Mazorra, Boyeras
Ciudad Habana, CP 19220
Cuba.
T: +53 7811 057, F: +53 7451
Contact: Dr S Gonzalez Pal.

ECUADOR
Centro National de Epilepsia,
APNE
Berrutietta sn y Acevedo
(Sector la Gasca)
Quito
Peru.
T: +59 3290 5405
E: spesantez@uio.telconet.net
Contact: Dr S Pesantez.

Associate Member:
Liga Tungurahuense de Control de la Epilepsia
Mera 5 - 14 y Sucre
2 do Piso
Ambato
Peru.
T: +59 3034 23097
Contact: Dr Luis Cordovilla

GUATEMALA
IBE Guatemalan Chapter
6a Calle 2-48
Zona 1
Guatemala City
Guatemala.
T: + 50 2232 7258
F: +50 2251 4008
E: hstokes@infovia.com.gt
Contact: Dr Henry Stokes

MEXICO
Group “Acceptation” of Epileptics
Amsterdam 1928 No 19
Colonia Olimpica-Pedregal
Mexico 04710 DF.
F: +525 575 3250
E: nuol@prodigy.net.mx
Contact: Dr Lilia Nuñez Orozco.

PERU
Peruvian Association of Epilepsy
Jr Castilla 678 E-101
Lima 32
T: +51 1460 7502
Contact:

URUGUAY:
Asociación Uruguaya contra la Epilepsia
Ciudadela 1217
Montevideo CP 11 200
Uruguay.
E: abogacz@hotmail.com
Contact: Dr Alicia Bogacz.

VENEZUELA
Venezuelan National Bureau
Avenida Francisco de Miranda
Torre Country Club, Piso 6
Chacao
Venezuela.
E: livece@lycos.com
Contact: Mrs Adriana Loscher
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 prepare those patients for the work-place, who, through economic problems have not been able to take part in tradition 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.

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.

MEMBERS OF THE NORTH AMERICAN REGIONAL COMMITTEE

CANADA
Epilepsy Canada
1470 Peel Street
Suite 745
Montreal
Quebec H3A 1T1
Canada.
T: +1 514 845 7855
F: +1 514 845 7866
E: crepin@epilepsy.ca
Contact: Mrs Denise Crépin

JAMAICA
Jamaican Epilepsy Association
PO Box 675
Kingston 8
Jamaica.
T: +876 969 6717
F: +876 906 5339
E: eperez@anngel.com
Contact: Mrs Nora Perez

USA
Epilepsy Foundation
8301 Professional Place
Landover
MD 20785-2238
USA.
T: +1 301 459 3700
F: +1 301 459 0340
E: ehargis@efa.org
Contact: Mr Eric Hargis.

Associate Member:
Epilepsy Foundation of New Jersey
429 River View Plaza
Trenton
New Jersey 08611
USA.
T: +1 6090 392 4900
F: +1 609 392 5621
E: epil215@aol.com
Contact:
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.

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

MEMBERS OF THE SOUTH EAST ASIA REGIONAL COMMITTEE

BANGLADESH
Bangladesh Epilepsy Association
3/1 Lake Circus Kalabagan
Dhaka 1205
Bangladesh.
E: epilepsy_bd@yahoo.com
Contact: Dr MA Mannan.

HONG KONG
Hong Kong Epilepsy Association
G/F, Blk 6, Kornhill Garden
1120 King’s Road
Quarry Bay
Hong Kong.
T: +852 2794 7006
F: +852 2794 7178
E: anchor@rehabsoociety.org.hk
E: hkea@hkepilepsy.org
Contact: Ms Anchor Hung.

Associate Member:
Enlighten Hong Kong Ltd
Flat B, 12/F
Shun Pont Commercial Building
No. 5-11 Thomson Road
Wanchai
Hong Kong.
T: +852 2820 0112
F: +852 2820 0113
E: admin@enlightenhk.org
Contact: Ms Orla Gilroy.

INDONESIA
PERPEI
Bagian Neurologi FKUI
Jl. Salemba 6
Jakarta Pusat 10430
Indonesia.
T: +62 2133 5044
F: +62 21314 9424
E: perpei2004@yahoo.com
Contact: Dr Silvia Lumempouw

Associate Member:
Yayasan Epilepsi Indonesia
Jl. Hang Jebat II/2
Kebayoran Baru
Jakarta Selatan 12120
Indonesia.
T: +62 217251710
F: +62 217247366
Contact: Ms Ning Mahar Mardjono

SRI LANKA
Epilepsy Association of Sri Lanka
10, Austin Place
Colombo 8
Sri Lanka.
Contact: Mrs. Mangala Samarawickrama

THAILAND
Epilepsy Association of Thailand
Dept of Paediatrics
Faculty of Medicine
Ramathibodi Hospital
Mahidol University
Rama VI Road
Bangkok 10400
Thailand.
T: +662 201 1488
F: +662 201 1850
E: rapvs@mahidol.ac.th
Contact: Prof. Pongsadki Visudhiphan

INDIA
Indian Epilepsy Association
613, 15th Cross
1st Phase
JP Nagar K-10/10
Bangalore 560 078
India.
T: +91 080 - 25588274
E: ieaibr@vsnl.net
Contact: Dr HV Srinivas.
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

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

WESTERN PACIFIC REGIONAL EXECUTIVE COMMITTEE

Chair: Hidemoto Kubota, Japan
Vice Chair: Andrew Pan, Singapore
Secretary: Yuang Fu Tseng, Taiwan

MEMBERS OF THE WESTERN PACIFIC REGIONAL COMMITTEE

AUSTRALIA
Joint Epilepsy Council of Australia Ltd
818 Burke Road
Camberwell, Victoria 3124
Australia.
T: +613 9805 9111
F: +613 9882 7159
E: rpollard@epilepsy.asn.au
Contact: Mr Russell Pollard.

Associate Members:
Epilepsy Association of South Australia Inc
Epilepsy Centre SA & NT
25 Kilkenny Road
Woodville Park SA 501
Australia.
T: +61 088445 6131
F: +61 088445 6387
E: rcole@epilepsycentre.org.au
Contact: Mr Robert Cole.

Epilepsy Association of Western Australia (Inc)
Centre for Neurological Support
The Niche, Suite B
11 Aberdare Road
Nedlands WA 6009, Australia.
T: +61 89346 7699
F: +61 89436 7696
E: epilepsy@cnswa.com
Contact: Mr David Sharp.

CHINA:
China Association Against Epilepsy
Room 703, Unit 2, Bldg 3
#31 Cheng-shou-si Lu
Fengtai District
Beijing, Post Code 100078
China.
Email: shichuoli@yahoo.com
Contact: Dr Shichou Li.

JAPAN
The Japan Epilepsy Association
5F Zenkokujaian Building 2-2-8
Nishiawaseda Shinjuku-ku
Tokyo 162-0051
Japan.
T: +81 3320 25661
F: +81 3320 27235
E: nami@scan-net.ne.jp
Contact: Mr T Udagawa.

Associate Member:
Epilepsy Hospital Bethel
27-4 Hata-Mukaiyama-Minami Kita- hase
Iwanuma City 989-2455, Japan.
T: +81 2232 41211
F: +81 2232 42265
E: betheljlp@topaz.ocn.ne.jp
Contact: Mr T Soga.

KOREA
Korean Epilepsy Association
#110-021, Room No 301 Buwon Bld
175-1 Baum-dong
Chongno-ku
Seoul, Korea.
T: +82 2294 2375
F: +82 2294 34716
E: khuh@ajou.ac.kr
Contact: Dr Kyoon Huh.

MALAYSIA
Malaysia Society of Epilepsy
Suite 1-02, 1st Floor, No 119, Jalan SS 21/10
Damansara Utama
47400 Petaling Jaya
Selangor Darul Ehsan
Kuala Lumpur, Malaysia.
T: +603 77222962
F: +603 77259406
E: azmi_rash@yahoo.com
Contact: Dr Azmi Abdul Rashid.

MONGOLIA
Mongolian Epilepsy Society
MNUM, Sukhbaatar distr.
Jamyanjarav str.
Ulaanbatar, Mongolia.
T: +976 9917 7153
F: +976 991 132 6699
E: tovudorj@yahoo.com
Contact: Dr A Tovuudorj.

NEW ZEALAND
Epilepsy New Zealand (ENZ)
PO Box 1074
Hamilton
New Zealand.
T: +64 7834 3556
F: +64 7834 3553
E: gm@epilepsy.org.nz
Contact: Mr Frank Gouveia.

PHILIPPINES
Epilepsy Awareness & Advocacy Inc.
17th Floor, Pacific Star Building
Sen. Gil Puyat corner Makati Ave.
Makati City
Philippines.
T: +63 811 5804
F: +63 811 5715
E: guerero.mm@uob.com.ph
Contact: Mrs Marianne Malate-Guerrero.

SINGAPORE
Singapore Epilepsy Foundation
149 Rocher Road
#04-07 Fu Lu Shou Complex
188425 Singapore.
T: +65 3344 302
F: +65 3344 669
E: gracetan@saica.org.sg
Contact: Ms Grace Tan.

Associate Member:
Epilepsy Care Group (Singapore)
No 26 Dunearn Road (Level 2)
Singapore 309423.
T: +65 6358 0566
F: +65 6358 0567
E: eecs93@singnet.com.sg
Contact: Mr Sherman Goh.

TAIWAN
Taiwan Epilepsy Association
1st Floor, No 5, Alley 2
Lane 199, Tun-Hwa N. Road,
Taipei 105
Taiwan.
T: +886 2251 49682
F: +886 2251 49687
E: twn-tea@ms1.seeder.net
Contact: Dr Marshal Mo-Song Hsih.
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.

On 11th 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.
CENTRAL OFFICES and CONTACTS

**International Headquarters**
Ann Little  
Executive Director  
International Bureau for Epilepsy  
Unit 4 Hillview House  
Bracken Road  
Sandyford  
Dublin 18  
Ireland  
T: +353 1 2934961  
F: +353 1 2934963  
E: ibedublin@eircom.net  
www.ibe-epilepsy.org

**ILAE/IBE/WHO**  
**Global Campaign Against Epilepsy**  
Philip Lee  
Co-Chair Global Campaign Against Epilepsy  
New Anstey House  
Gate Way Drive  
Yeadon  
Leeds LS19 7XY  
UK  
T: +44 113 210 880  
Email: plee@epilepsy.org.uk

**EUCARE**  
Karen Lee-Donaldson  
EUCARE Programme Manager  
PO Box 187  
Leeds LS16 9WA  
UK  
T: +44 113 203 7508  
Email: karen.leedonaldson@eucare.org

**IBE/ILAE Congress Secretariat**  
Richard Holmes  
7 Priory Hall  
Stillorgan  
Dublin 18  
Ireland  
T: +353 1 20 567 20  
F: +353 1 20 561 56  
Email: info@epilepsycongress.org  
www.epilepsycongress.org