ANNUAL REPORT 2011

Shining a light on epilepsy for 50 years
IBE exists to improve the social condition and quality of life of all people with epilepsy and those who care for them.

Contents

Financial Report 4
A Year of Achievements 8
Contact Directory 14

The International Bureau for Epilepsy is a non-governmental organisation (NGO) in Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

The International Bureau for Epilepsy is in official working relations with the World Health Organization (WHO).
The past year has been a very busy year for the IBE, a year of great celebration and, despite the global recession, one in which tremendous achievements in the cause of epilepsy were made.

A long term ambition of the IBE has been to hold a European Epilepsy Day (EED) and on Tuesday 15th February this goal was realised when the first EED was launched in the European Parliament in Strasbourg. It was with great pleasure that I welcomed representatives from IBE member associations in 20 European countries to this auspicious occasion. IBE members were afforded the opportunity to meet with their national MEPs in a series of private meetings to raise issues of national concern. Nico Moshé, ILAE President and I held meetings with two key Commissioners, John Dalli, Commissioner for Health and Public Policy and Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science. A lunch discussion, hosted by Gay Mitchell, MEP, heard from a series of speakers about their experiences of epilepsy. An evening reception to open the excellent poster exhibition “The Many Faces of Epilepsy” was opened by EU Vice President, Edward McMillan-Scott.

Following the success of EED 2011, a European Advocates for Epilepsy working group of MEPs interested in epilepsy was created. In April, Mr Gay Mitchell MEP, President of the group submitted an EU Written Declaration to the parliament. The declaration called on the EU Commission to improve research and awareness of epilepsy in Europe. During the following months IBE member associations and ILAE chapters in EU countries worked tirelessly to get MEP signatures. On the 15th September, the European Declaration on Epilepsy was passed. The total number of signatures obtained was 459, which was 90 more than required, making it the third highest number of signatures of all disease related declarations since 2004.

In 2011, the IBE Promising Strategies Program welcomed projects in India, Tibet-China, Zimbabwe, Lithuania, Haiti, Swaziland, China, Nepal, Ecuador, Colombia and the Western Pacific Islands. This program has been one of the most successful of all IBE’s initiatives with 50 projects in 33 countries supported in order to improve the quality of life of people with epilepsy at national and regional levels.

On my own behalf, and on behalf of my predecessors, it was an honour to welcome IBE members to our Golden Jubilee celebrations, during the 29th International Epilepsy Congress in Rome, the city in which the IBE was founded in 1961. To mark this event an IBE history booklet “50 Years Focused on Epilepsy” was launched and remains available from www.ibe-epilepsy.org for download. The Ambassador for Epilepsy Award was given pride of place at a special event to honour all those who have received the award since it was first introduced in 1968. The top 60 images from the Epilepsy Without Words IBE Jubilee Photography completion were prominently displayed with the winning four images available to delegates as postcards. A major highlight of the celebrations was the Presidential Symposium on the theme “Avoiding epilepsy deaths” a subject which has been one of the enduring passions of my work with IBE. The session was chaired by Nico Moshé, ILAE President and I in a hall packed to capacity. The symposium was opened with a presentation by Mrs Susan Axelrod, a parent of child with difficult epilepsy and other speakers were world experts in SUDEP. I would like to thank them all for their excellent contributions.

At the 51st Assembly of the Pan American Health Organisation (PAHO) on the 29th September the Strategic Plan for Epilepsy in the Americas was approved. As a result of this approval epilepsy will now become a priority in the National Health Plan of every single nation in the PAHO region for the next 10 years. This has been on the goals of the Global Campaign Against Epilepsy (GCAE) Task Force and I would like to thank them for their tenaciousness in achieving their goal.

On the 29th November, a Roundtable event was jointly organised by the European Advocates for Epilepsy group and the IBE/ILAE Joint Task Force - Epilepsy Advocacy Europe - in the European Parliament in Brussels. Three athletes spoke passionately about their participation in sport at an international level and their epilepsy. The event was hosted by Mrs Angelika Werthmann, MEP, on behalf of the European Advocates for Epilepsy group.

It would not be possible to achieve any of these projects without the help and support of my fellow members on the International Executive Committee, members of the Regional Committees, IBE member associations, and our friends in the International League Against Epilepsy. Collectively we can raise awareness, reduce stigma and champion the cause of epilepsy in order to improve the lives of people with epilepsy on a global scale.

With best wishes to all
Mike Glynn
President
### Income and Expenditure Account

**Year ended 31st December 2011**

<table>
<thead>
<tr>
<th></th>
<th>2011 US$</th>
<th>2010 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INCOME</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2,574,239</td>
<td>1,359,254</td>
</tr>
<tr>
<td><strong>EXPENDITURE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(1,597,933)</td>
<td>(1,305,711)</td>
</tr>
<tr>
<td><strong>OPERATING (DEFICIT)/SURPLUS FOR YEAR</strong></td>
<td>976,306</td>
<td>53,543</td>
</tr>
</tbody>
</table>

### Balance Sheet

**Year ended 31st December 2011**

<table>
<thead>
<tr>
<th></th>
<th>2011 US$</th>
<th>2010 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FIXED ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tangible assets</td>
<td>-</td>
<td>1,772</td>
</tr>
<tr>
<td><strong>CURRENT ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Debtors and prepayments</td>
<td>173,159</td>
<td>172,009</td>
</tr>
<tr>
<td>Cash in hand and at bank</td>
<td>3,540,934</td>
<td>2,585,403</td>
</tr>
<tr>
<td>Amount held on behalf of the IBE/ILAE Joint Task Force</td>
<td>310,699</td>
<td>454,137</td>
</tr>
<tr>
<td></td>
<td>4,024,792</td>
<td>3,211,549</td>
</tr>
<tr>
<td><strong>CREDITORS (Amounts falling due in one year)</strong></td>
<td>(910,455)</td>
<td>(1,075,290)</td>
</tr>
<tr>
<td><strong>NET CURRENT ASSETS</strong></td>
<td>3,114,337</td>
<td>2,136,259</td>
</tr>
<tr>
<td><strong>NET ASSETS</strong></td>
<td>3,114,337</td>
<td>2,138,031</td>
</tr>
</tbody>
</table>

### Capital and Reserves

<table>
<thead>
<tr>
<th></th>
<th>2011 US$</th>
<th>2010 US$</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Reserve</td>
<td>3,044,534</td>
<td>2,085,505</td>
</tr>
<tr>
<td>Restricted and designated fund</td>
<td>69,803</td>
<td>52,526</td>
</tr>
<tr>
<td></td>
<td>3,114,337</td>
<td>2,138,031</td>
</tr>
</tbody>
</table>
Statement of Income and Expenditure
Year ended 31st December 2011
With comparative totals for 2010

<table>
<thead>
<tr>
<th>INCOME</th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congress income received</td>
<td>1,488,131</td>
<td>1,116,985</td>
</tr>
<tr>
<td>Congress income receivable</td>
<td>670,766</td>
<td>-</td>
</tr>
<tr>
<td>Corporate donations</td>
<td>204,284</td>
<td>141,192</td>
</tr>
<tr>
<td>IBE/ILAE JTF management fee</td>
<td>39,076</td>
<td>-</td>
</tr>
<tr>
<td>IBE/ILAE JTF reimbursement of expenses (IBE 50%)</td>
<td>75,695</td>
<td>15,983</td>
</tr>
<tr>
<td>Membership dues and solidarity fund</td>
<td>21,136</td>
<td>17,451</td>
</tr>
<tr>
<td>Investment income</td>
<td>52,887</td>
<td>44,616</td>
</tr>
<tr>
<td>Other grants</td>
<td>20,386</td>
<td>22,616</td>
</tr>
<tr>
<td>miscellaneous income</td>
<td>1,878</td>
<td>411</td>
</tr>
<tr>
<td><strong>Total Income</strong></td>
<td>2,574,239</td>
<td>1,359,254</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EXPENDITURE</th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congress expenditure</td>
<td>1,008,964</td>
<td>641,552</td>
</tr>
<tr>
<td>Office expenses</td>
<td>19,248</td>
<td>16,141</td>
</tr>
<tr>
<td>Printing and postage</td>
<td>13,790</td>
<td>18,398</td>
</tr>
<tr>
<td>Printing and postage - International Epilepsy News</td>
<td>29,755</td>
<td>29,170</td>
</tr>
<tr>
<td>Travel</td>
<td>27,530</td>
<td>49,151</td>
</tr>
<tr>
<td>Global Campaign costs</td>
<td>43,580</td>
<td>28,040</td>
</tr>
<tr>
<td>Accountancy fees</td>
<td>10,626</td>
<td>16,698</td>
</tr>
<tr>
<td>Audit fees</td>
<td>7,000</td>
<td>7,000</td>
</tr>
<tr>
<td>Administrator costs</td>
<td>166,734</td>
<td>144,520</td>
</tr>
<tr>
<td>Bank charges</td>
<td>595</td>
<td>760</td>
</tr>
<tr>
<td>Rent</td>
<td>30,514</td>
<td>27,970</td>
</tr>
<tr>
<td>Promising Strategies</td>
<td>45,811</td>
<td>52,525</td>
</tr>
<tr>
<td>Website costs</td>
<td>3,943</td>
<td>-</td>
</tr>
<tr>
<td>IBE JTF expenditure</td>
<td>75,695</td>
<td>15,983</td>
</tr>
<tr>
<td>EPICURE costs</td>
<td>20,386</td>
<td>22,616</td>
</tr>
<tr>
<td>Depreciation</td>
<td>1,772</td>
<td>4,017</td>
</tr>
<tr>
<td>Marketing</td>
<td>62,595</td>
<td>13,036</td>
</tr>
<tr>
<td><strong>Total Expenditure</strong></td>
<td>1,568,538</td>
<td>1,087,577</td>
</tr>
</tbody>
</table>

| Loss of foreign exchange                    | 29,395  | 218,134 |
| **Total**                                   | 1,597,933 | 1,305,711 |
IBE/ILAE Joint Task Force

The IBE/ILAE Joint Task Force programme, formerly known as the EUCARE programme, is a joint 50:50 initiative of the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE). Its aim is to raise the profile of epilepsy across Europe by undertaking new research and educational activities. The initiative received corporate sponsorship and the fund is jointly owned by IBE and ILAE. IBE administer the programme and the fund, and received a management fee of US$39,076 for 2010 and 2011.

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opening balance</td>
<td>454,137</td>
<td>486,103</td>
</tr>
<tr>
<td>Bank interest received</td>
<td>7,952</td>
<td>7,358</td>
</tr>
<tr>
<td>Expenditure incurred</td>
<td>(151,390)</td>
<td>(39,324)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closing balance</td>
<td>310,699</td>
<td>454,137</td>
</tr>
</tbody>
</table>

Congress Financial Information

The International Bureau for Epilepsy and the International League Against Epilepsy (ILAE) engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 2 February 2010. The IDM is charged with the organisation of various European and International Congresses.

The 2011 financial statements reflect the portion of assets, liabilities, net revenues and expenses held by the International Director of Meetings on behalf of the International Bureau for Epilepsy. An analysis of the proportion of congress assets, liabilities, income and expenses applicable to the Bureau is as follows:

<table>
<thead>
<tr>
<th></th>
<th>2011</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash at bank</td>
<td>343,946</td>
<td>344,832</td>
</tr>
<tr>
<td>Debtors and prepayments</td>
<td>155,928</td>
<td>161,206</td>
</tr>
<tr>
<td>Creditors</td>
<td>(110,222)</td>
<td>(102,771)</td>
</tr>
<tr>
<td>Deferred income</td>
<td>(1,011,214)</td>
<td>(378,702)</td>
</tr>
<tr>
<td>IDM-Congress income received</td>
<td>1,488,131</td>
<td>1,116,985</td>
</tr>
<tr>
<td>IDM-Congress income receivable</td>
<td>670,766</td>
<td>-</td>
</tr>
<tr>
<td>IDM-Congress expenses</td>
<td>(1,008,964)</td>
<td>(641,552)</td>
</tr>
</tbody>
</table>
IBE acknowledges the very generous support of the members listed below, whose donations to the Solidarity Fund in 2011 helped to meet the membership dues of members in emerging nations, who might, otherwise, have been unable to meet their dues payments.

**US$3,000**
Epilepsy Foundation of America, USA

**US$2,000**
Epilepsy Hospital Bethel, Japan

**US$1,500**
Swedish Epilepsy Association, Sweden

**US$500**
Epilepsy New Zealand (ENZ)

**US$200**
Indian Epilepsy Association, India

**US$150**
Canadian Epilepsy Association, Canada

**US$100**
Epilepsy Action, Australia
Epilepsy Queensland, Australia
Epilepsy Australia, Australia
JECA, Australia
CAAE, China
Caritas Malta Epilepsy Association, Malta
Epilepsy Vereniging Nederland, The Netherlands
Stichting Kempenhaeghe, The Netherlands
Epilepsy Connections, Scotland
AEAE, Spain

**Under US$100**
Slovenian League Against Epilepsy, Slovenia
ParEpi, Switzerland
Cyprus Association for People with Epilepsy
Japan Epilepsy Association, Japan
Korean Epilepsy Association, Korea
Taiwan Epilepsy Association, Taiwan
Epilepsy & Environment, Georgia

**Members supported by the Solidarity Fund**

1. **ALBANIA:**
   Albanian Association of Epilepsy

2. **BANGLADESH:**
   Bangladesh Epilepsy Association

3. **CAMEROON:**
   Association Camerounaise Contre l'Epilepsie

4. **CAMEROON:**
   Community Development and Epilepsy Foundation

5. **CONGO:**
   MHCD Centre for prevention and treatment of Epilepsy

6. **ETHIOPIA:**
   Epilepsy Support Association

7. **GAMBIA:**
   Gambia Epilepsy Association

8. **GHANA:**
   Ghana Epilepsy Association

9. **KENYA:**
   Kenya Association for the Welfare of People with Epilepsy

10. **MONGOLIA:**
   Mongolian Epilepsy Association

11. **NEPAL:**
    Nepal Epilepsy Association

12. **NIGER:**
    LNCEMNMC, Service de Psychiatrie

13. **NIGERIA:**
    Epilepsy Association of Nigeria

14. **PAKISTAN:**
    FLAME

15. **SENEGAL:**
    Ligue Senegalaise contre l’Epilepsie

16. **SIERRA LEONE:**
    Epilepsy Association of Sierra Leone

17. **SWAZILAND:**
    Swaziland Epilepsy association

18. **TANZANIA:**
    Parents Organisation for Children with Epilepsy

19. **TOGO:**
    Association Clinique de l’Epilepsie

20. **UGANDA:**
    Epilepsy Support Association

21. **ZAMBIA:**
    Epilepsy Association of Zambia

22. **ZIMBABWE:**
    Epilepsy Support Foundation

**CORPORATE SPONSORING PARTNERS**

IBE acknowledges the support of its sponsoring partners, whose funding to the Bureau in 2011 enabled the organisation to maintain its services and to introduce a number of new innovative initiatives to improve the quality of life of persons with epilepsy, their families and their carers.

**Gold Partner**
- Dainippon Sumitomo Pharma Co., Ltd

**Silver Partners**
- Eisai Europe Ltd
- GlaxoSmithKline
- UCB Pharma

**Other Partners**
- Cyberonics
A year of tremendous achievements

Launch of European Epilepsy Day

With the theme *The Many Faces of Epilepsy*, the first European Epilepsy Day (EED) was launched in the European Parliament in Strasbourg, on Tuesday 15th February, and was the first highlight of what was to be a very busy and exciting year for IBE. Representatives from IBE member associations in 20 European countries travelled to Strasbourg to be part of this momentous occasion.

Hosted by Gay Mitchell MEP, a Lunch Discussion and a Reception to open the Many Faces of Epilepsy poster exhibition were attended by a total of 56 MEPs.

Of special importance were private meetings with Mrs Maire Geoghegan-Quinn, Commissioner for Research, Innovation and Science, and Mr John Dalli, Commissioner for Health and Consumer Policy.

Across Europe, at national level, epilepsy associations organised awareness raising events to celebrate the day, using the newly created EED logo.

Almost immediately following EED 2011, Gay Mitchell MEP created the *European Advocates for Epilepsy* - a working group of MEPs with a special interest in epilepsy.

At its first meeting, the group took the decision to submit a *Written Declaration on Epilepsy* to the parliament. The declaration called on the EU Commission to improve research and awareness in epilepsy in Europe.

To be successful, a declaration must attract the signatures of a majority of MEPs and there is also a time limit of three months, after which time a declaration lapses.

IBE and ILAE associations in Europe played a very important role in a concerted effort to have the declaration approved.

On the 15th September 2011, *European Declaration 22-2011 on Epilepsy*, was carried with the signatures of 459 MEPs, which was 90 more than the 369 required to achieve a majority!
**IBE-ILAE JOINT TASK FORCE IN EUROPE**

In March 2011 the newly created IBE-ILAE Joint Task Force met, for the first time, to lay down plans and objectives and to set its agenda for future activities. This was a significant development and facilitates joint IBE/ILAE activities in Europe for the first time in many years.

The Joint Task Force will serve as the political and advocacy arm of the IBE Regional Committee and the ILAE Commission on European Affairs, and its membership comprises four representatives each from IBE and ILAE.

The group is co-chaired by Mike Glynn, for IBE, and Emilio Perucca, for ILAE, and is working closely with the European Advocates for Epilepsy special MEP group. During 2011 the Task Force was responsible for directing efforts to the successful passing of the European Written Declaration on Epilepsy and early arrangements for EED 2012.

The task force also arranged, with the Advocates for Epilepsy Group, a special Workshop on Epilepsy & Sport in the EU Parliament in Brussels.

---

**EPILEPSY AND SPORT**

In November, a Roundtable event was organised jointly by the IBE-ILAE Joint Task Force and the European Advocates for Epilepsy group. The main speakers, who spoke with passion and eloquence, were people with epilepsy who have sporting talents. Emma Beamish, Ireland (pictured second from right) is an Irish International cricketer, who represented Ireland at the 2005 Cricket World Cup in South Africa.

Jérome Becher, Germany (third from right) holds the Guinness world record for the longest uninterrupted swim (80km) as well as the European record in 24-hour swimming.

Georg Thoma, Germany (back row) is a marathon runner, who has even run a marathon along the Great Wall of China. He undertakes distance races for charity, including a 630km charity run across Germany.

The event was hosted in the European Parliament in Brussels by Mrs Angelika Werthmann, MEP, on behalf of the European Advocates for Epilepsy group.

Also included in the picture above are (far left) Asla Ptitkänen and (far right) Mike Glynn, both members of the Joint Task Force, and Gay Mitchell MEP (pink tie).
Throughout 2011, the Institute of Medicine (IOM) in the US was working on a new study on epilepsy in the United States. The IOM had been asked to examine the public health dimensions of the epilepsies, focusing on public health surveillance and data collection; population and public health research; health policy, healthcare and human services; and education for people with epilepsy and their families, health care providers, and the public. Epilepsy groups working closely with the IOM included Epilepsy Foundation of America, IBE’s Full Member in the US, and the International League Against Epilepsy.

Following original discussions at the Latin American Epilepsy Congress in Cartagena, Colombia in August 2010, there was a major drive during 2011 to create a Strategic Plan for Epilepsy for the Americas.

The significance of such a plan could not be underestimated since, if approved by the Pan American Health Organization (PAHO), it would result in epilepsy being a priority in the National Health Plan of every single nation in the PAHO region for the following 10 years. This would be the first time that this would be achieved in the 100 years of PAHO’s existence and would be significant for the future care and treatment of people with epilepsy and for their quality of life.

Thanks to sustained hard work and with the tremendous support of Dr Jorge Rodríguez, PAHO Regional Mental Health Advisor, the dream became a reality with the approval of the Strategic Plan for Epilepsy by PAHO at the 51st Assembly of the Pan American Health Organization in Washington DC on 29th September 2011.
2011 saw the fifth round of the annual Promising Strategies Program, which is one of IBE’s most successful initiatives to date. A Promising Strategy is one that has the potential to foster effective and innovative public health practice with regard to epilepsy.

Set up in 2006, as a means of supporting members through the provision of financial support for projects aimed at improving the quality of life of people with epilepsy, by the end of 2011 IBE had provided support to 50 projects in 33 countries, with a total of US$250,000 of funding allocated.

Eleven new initiatives were selected to receive funds in 2011:

**Swaziland:** Poultry rearing enterprise to provide training and employment for people with epilepsy

**Zimbabwe:** An innovative lobbying and advocacy programme where people with epilepsy speak and write about the challenges and successes in their lives

**China:** Caring for the carers project, to improve quality of life of those who care for people with epilepsy

**Nepal:** Production of ‘A new life for Juneli’ a docudrama film to educate people on the importance of seeking appropriate treatment for epilepsy

**Ecuador:** Neuropsychomotricity training - a modern inter-disciplinary science that provides guidelines for harmonious development of the individual

**Colombia:** Home Clinic - a project that helps people with epilepsy and their families through the provision of life skills for a more independent life

**Western Pacific Islands:** Survey on the prevalence of epilepsy, services available and the treatment gap, with the ultimate aim of creating a self sufficient epilepsy association in each island nation

**India:** Training in baking skills to assist people with epilepsy to find employment

**Tibet:** Awareness programme targeting Tibetans living in remote regions of the country

**Lithuania:** Survey of national legislation in the area of disability, in light of the UN Convention, in order to evaluate existing legislation and to make recommendations for change

**Haiti:** Summer Soccer Camp for children with epilepsy, who are often excluded from sports.
With a prize fund of US$7,000, more than 300 entries were received from all over the world for the IBE Jubilee Photography competition. The top 60 images were exhibited at the International Epilepsy Congress in Rome, with the winning four images available to delegates as souvenir postcards.

**Joint 3rd Prize**

Title: Look
Photographer: Kai Löffelbein, Germany

**ILAE Jubilee Fund to support Promising Strategies**

IBE acknowledges with thanks the gift of US$20,000, spread over four years, which was presented to the Bureau by the ILAE, to support the further development each year of one already successful Promising Strategies project. This gift recognises the significant impact that the Promising Strategies Program has had, in supporting IBE members associations in the creation of innovative initiatives to benefit people with epilepsy and their families, since its creation in 2006.

**A TOAST TO IBE!**

Every birthday deserves a special cake and for IBE’s 50th birthday, there was no exception. The General Assembly in Rome on 1st September closed with delegates enjoying a slice of an enormous birthday cake, decorated with the Jubilee logo, washed down with a glass of Italian prosecco.

It was fitting that the celebration took place in the city where IBE was founded 50 years earlier in 1961!
Celebrating 50 years of achievement

Honouring Ambassadors for Epilepsy

Introduced by then IBE President, Mrs Ellen Grass, in 1967, the Ambassador for Epilepsy award has, to date, been bestowed on almost 300 individuals. To highlight the tremendous contribution which they have made to the field of epilepsy, both medical and social, IBE organised a Gala Dinner in Rome, at which a special souvenir badge was presented to each Ambassador who attended.

A nice surprise at the Opening Ceremony of the 29th International Epilepsy Congress was the presentation of a commemorative scroll, by ILAE President Nico Moshé to IBE President Mike Glynn, to mark IBE’s Golden Jubilee. The framed hand-calligraphed scroll now hangs pride of place in the IBE office - photo right.

A special IE News Jubilee Award, with a prize of up to $2,000 to cover attendance at a future IBE congress, ran throughout 2011. The winning article, the D-side of Epilepsy, submitted by Paula T Fernandes from Brazil (who co-wrote the piece with Li Min Li), was published in Issue 4-2011 of International Epilepsy News.

You don’t have to be a Newshound!
You just need good writing skills to win ...
IE NEWS JUBILEE AWARD

Annual Report 2011 13
Offices, Committees, Task Forces and Networks

IBE HEAD OFFICE
Ann Little,
IBE Executive Director,
11 Priory Hall,
Stillorgan Road, Blackrock,
Co Dublin,
Ireland.
T: +353 1 210 8850
ibeexecdir@eircom.net
www.ibe-epilepsy.org

CONGRESS OFFICE
IBE/ILAE Congress Secretariat
7 Priory Hall,
Stillorgan Road, Blackrock,
Co Dublin,
Ireland.
T: +353 1 205 6720
info@epilepsycongress.org
www.epilepsycongress.org

INTERNATIONAL EXECUTIVE COMMITTEE
President
Mike Glynn
mikeglynn@epilepsy.ie
Secretary General
Carlos Acevedo
carlosedoacevedo@yahoo.com
Treasurer
Grace Tan
gracetan@epilepsy.com.sg
Immediate Past President
Susanne Lund
Susanne.Lund@epilepsy.com.sg

VICE PRESIDENTS
Africa
Anthony Zimba
anthonymzmb@gmail.com
Eastern Mediterranean
Abdulaziz Asemari
alsemari@ksfhr.edu.sa
Europe
Janet Mifsud
janet.mifsud@um.edu.mt
Latin America
Lilia Núñez Orozco
lilianuor@yahoo.com
North America
Mary Secco
ed@epilepsyupport.ca
South East Asia
Vinod Saxena
drvssaxena@gmail.com
Western Pacific
Shung-lon Lai
shunglon@mail.nsysu.edu.tw

ILAE REPRESENTATIVES
Nico Moshé, President
Sam Wiebe, Secretary General
Emilio Perucca, Treasurer

NETWORKS
Editors Network
Chair: Robert Cole
rcole@epilepsycentre.org.au
CEO Network
Contact: Ann Little
ibeexecdir@eircom.net

REGIONAL COMMITTEES
Africa
Chair: Anthony Zimba
anthonymzmb@gmail.com
Eastern Mediterranean
Chair: Najib Kissan
najibkiss@gmail.com
Europe
Chair: Athanasios Covannis
acovannis@otenet.gr
Latin America
Chair: Lilia Núñez Orozco
lilianuor@yahoo.com
North America
Contact: Mary Secco
ed@epilepsyupport.ca
South East Asia
Chair: HV Srinivas
hvsrinivas@gmail.com
Western Pacific
Chair: Robert Cole
rcole@epilepsycentre.org.au

TASK FORCES
Elections
Chair: Susanne Lund
Susanne.Lund@epilepsyi.se
Members: Mike Hills, Pete Engel
Epilepsy & Driving
Contact: Mike Glynn
mikeglynn@epilepsy.ie
Members: Eric Schmedding,
Marshall Mo-Song Hsih, Silvia
Kochen, Andrew Pan

REGIONAL INITIATIVES
Global Campaign
Mike Glynn, Co-chair
Global Campaign Against Epilepsy,
Mikeglynn@epilepsy.ie
www.GlobalCampaignAgainst-
Epilepsy.org

IBE-ILAE Joint Task Force in Europe
Administration: Ann Little
ibeexecdir@eircom.net
Co-chairs: Mike Glynn, Emilio Perucca
Members: Asla Pitkänen, Hanneke
de Boer, Reetta Kälviäinen, Janet
Mifsud, Michel Baulac, Christian
Elger

IE NEWS EDITOR
Editor: Carlos Acevedo
carlosedoacevedo@yahoo.com
Co-ordinator: Ann Little
ibeexecdir@eircom.net

Full and Associate Members - Listed by Region

AFRICA

CAMEROON
Association Camerounaise contre
l’Epilepsie
S/C Coordination Diocésaine de
la Santé
BP 70 Baña,
Cameroun.
T: +237 743 33375
santba@ yahoo.fr
Contact: Sr. Marie Christine Long.

CONGO, DR - Associate Member
MHCD Centre for the Preven-
tion and Treatment of Epilepsy
Luvungi Naturopathic Hospital,
Luvungi/Uvira, DR Congo.
T: +243 994 931 840
E: moulymasu@yahoo.fr or
moulymasu@gmail.com
Contact: Dr Luc Mulimbali-
Masuru.
http://www.mhcdafri ca.org/

ETHIOPIA
Epilepsy Support Association of
Ethiopia
PO Box 25516,
Code 1000,
Addis Ababa,
Ethiopia.
T: +251 1553617,
E: dr.zenebe.gedlie@ethionet.et
Contact: Dr Zenebe Damtie.

RESEARCH TASK FORCE
Contact: Rosey Panelli
roseypunep@gmail.com
Members: Ley Sander, Janet Mifsud,
Tomás Mesa, Li Li Min, Malachy
Bishop, Ding Ding, Patrick Kwan

GOVERNANCE
Chair: Johan FALK-PEDERSEN
johan.falk-pedersen@sverdruplaw.no
Members: Susanne Lund, Grace
Tan, Sandy Finnucane, Christopher
Morris-Coole

JOINT IBE/ILAE INITIATIVES
Global Campaign
Mike Glynn, Co-chair
Global Campaign Against Epilepsy,
Mikeglynn@epilepsy.ie
www.GlobalCampaignAgainst-
Epilepsy.org
IBE-ILAE Joint Task Force in
Europe
Administration: Ann Little
ibeexecdir@eircom.net
Co-chairs: Mike Glynn, Emilio
Perucca
Members: Asla Pitkänen, Hanneke
de Boer, Reetta Kälviäinen, Janet
Mifsud, Michel Baulac, Christian
Elger

IE NEWS EDITOR
Editor: Carlos Acevedo
carlosedoacevedo@yahoo.com
Co-ordinator: Ann Little
ibeexecdir@eircom.net

AFRICA

Association Camerounaise contre
l’Epilepsie
S/C Coordination Diocésaine de
la Santé
BP 70 Baña,
Cameroun.
T: +237 743 33375
santba@ yahoo.fr
Contact: Sr. Marie Christine Long.
GAMBIA
Gambia Epilepsy Association
PO Box 132, Banjul, The Gambia.
T: +220 9955 414
E: gambiepilepsy@yahoo.co.uk
Contact: Mrs Rita Harding.

GHANA
Ghana Epilepsy Association
c/o Box M230, Accra, Ghana.
T: +233 2116 5421 ext 4420
ayisu@hotmail.com
Contact: Mr Paul Ayisu.
Alternate: Mr Leonard Agbley
PO Box SD 233, Stadium, Accra, Ghana.
E: agbleleco@yahoo.com.

KENYA
Kenya Association for the Welfare of People with Epilepsy (KAWE)
PO Box 60790 00200, Mbaazi Avenue - Lavington,
Nairobi, Kenya.
T: +254 620 387 0885
Mobile: +254 0721 742 558
E: info@kawe-kenya.org or Rosemary@kawe-kenya.org
Contact: Mrs Rosemary Gathara.

MAURITIUS
EDYCS Epilepsy Group, Mauritius
442 State Land, Boulevard Rivalz,
Port Louis, Mauritius.
T: +230 213 1733,
E: edycs.org@intnet.mu
Contact: Mr Y Noornamide.
http://edycesepilepsy.intnet.mu

NAMIBIA
Epilepsy Namibia
PO Box 11822, Klein Windhoek, Namibia.
T: +264 813 226834
E: namep@epilepsynamibia.org
Contact: Ms H Riphagen.

NIGER
LNECMNMC
Service de Psychiatrie, Hôpital National de Naimey,
BP 2388 Niamey, Niger.
T: +227 72 24 42
E: djibo.doumamaigai@gmail.com
Contact: Dr D Douma.

NIGERIA
Epilepsy Association of Nigeria
No 2 Weeks Road by 84 Aisa Road,
Abia, Abia State, Nigeria.
T: +234 708 1832837
E: drmohanclinic@yahoo.com
Contact: Dr SE Nwokwue.

SENEGAL
Ligue Senégalaïse contre l’Epilepsie
Clinique Neurologique, Centre Hospitalo-Universitaire de
Fann, BP 5035, Dakar-Fann, Senegal.
T: +221338 253678
E: agallodiop@gmail.com
Contact: Prof Amadou Gallo Diop.

SIERRA LEONE
Epilepsy Association of Sierra Leone
8 Mansaray Street,
PO Box 381, Freetown,
Sierra Leone.
E: durodamil@yahoo.co.uk
Contact: Dr Radcliffe D Lisk.

SOUTH AFRICA
Epilepsy South Africa
PO Box 12100 N1 City, 7463, Cape Town,
South Africa.
T: +27215954900
E: nationaldirector@epilepsy.org.za
Contact: Ms Marina Clarke.
www.epilepsy.org.za

SWAZILAND
Swaziland Epilepsy Association
PO Box 7220 Mbabane H100, Swaziland.
T: +268 4047028
E: admin@epilepsy.org.sz
Contact: Mr Mbuso Mahlalela.

TANZANIA, UNITED REPUBLIC OF
Parents Organisation for Children with Epilepsy (POCET)
PO Box 65293, Dar Es Salaam,
Tanzania.
T: +255 754 822 517
E: basamwenc1@yahoo.com
Contact: Mrs Asia Matowo Mrema.

AUSTRIA
Epilepsie Dachverband Österreich (EDO)
Wichtelgasse 55/17-20, 1170 Wien, Austria.
T: +43 1 4895278
Mobile: +43 664 1254788
E: office@epilepsie.at
Contact: Mrs L. Grüssing Soldan
www.epilepsie.at

BELGIUM
Les Amis de la Ligue Nationale Belge contre l’Epilepsie
Dr Vrienden van de Belgische Liga tegen Epilepsie,
Bernard Spaelaan 141, 9000 Gent,
Belgium.
T: +32 9 222 0404,
E: oostvlaanderen@epilepsieliga.com
Contact: Ms Claudine Van Daele.

TOGO
Association Clinique de l’Epilepsie
155, Carrefour de Rio, 11 BP 75,
Lomé, Togo.
T: +228 22403018
E: kokouso@aol.com
Contact: Dr Kokou Sodjiéhoun.

UGANDA
Epilepsy Support Association Uganda (EUSAU)
Plot 605 Gombe B Off Kayunga-
Kiconi-Wakiso Rd, Wakiso Town Council,
PO Box 16260
Wandegeya, Kampala, Uganda.
T: +256 772 450 383
Private: +256 774 077 589
E: mugarura2012@gmail.com
Contact: Mr A Mugarura.
www.epilepsy.org.ug

ZAMBIA
Epilepsy Association of Zambia
Amanda Ethu Building,
Kalundwe Road,
PO Box 32443, Lusaka, Zambia.
T: +260 977 789042
E: ezepeilepsy@hotmail.com
Contact: Ms Betty B Nsachilwa.

ZIMBABWE
Epilepsy Support Foundation
43 St David Road, Hatfield,
Harare, Zimbabwe.
T: +263 571 225
E: jmuguo@yahoo.co.uk
Contact: Mrs Sigudu.
www.epilepsyzimbabwe.co.zw.

EGYPT
Egyptian Epilepsy Association
40 Safeya Zaghlol Street,
Alexandria 21111, Egypt.
T: +203 303 3338
E: hassanhsosn@link.net
Contact: Dr Hassan Hosny.

IRAN
Iranian Epilepsy Association
No 1352, Resalat Exp, Tehran,
Iran.
T: +982 188 463271
E: iraneji@gmail.com
Contact: Dr Gharagozli.

LEBANON
Association of Care of People with Epilepsy
Hobaika Bldg, 1st Floor,
Qayaaal Wosta, Saiday, Lebanon.
T: +961 3 388713 or 961 7 731383
E: epilepsyl@hotmail.com
Contact: Mrs Manar Sawwan.

PAKISTAN
FLAME
83 Shah Jamal Colony, Lahore,
Pakistan.
T: +92 4275 81724
E: ppicc@wol.net.pk
Contact: Dr. Afzal Javed.

SAUDI ARABIA
Epilepsy Support and Information Centre
PO Box 3354, MBC 76,
Riyadh, 11211,
Saudi Arabia.
T: +966 1552 4755
E: alsemaris@kfshc.edu.sa
Contact: Dr A Alsemaris.

TUNISIA
Tunisian Epilepsy Association
Child Neurology Department,
EPS Hedi Chaker 3029 Sfax,
Tunisia.
T: +21 674 242 564
E: chahnez@gnet.tn
Contact: Dr Chahnez Triki.

ALBANIA
Albanian Association of Epilepsy
Dibra St #372,
Tirana,
Albania.
T: +355 4 234 5219
E: jkuja@gmail.com or epiabania@live.com
Contact: Dr Jera Kruja.

NORTH MEDITERRANEAN

AUSTRIA
Epilepsie Dachverband Österreich (EDO)
Wichtelgasse 55/17-20, 1170 Wien, Austria.
T: +43 1 4895278
Mobile: +43 664 1254788
E: office@epilepsie.at
Contact: Mrs L. Grüssing Soldan
www.epilepsie.at

BELGIUM
Les Amis de la Ligue Nationale Belge contre l’Epilepsie
Dr Vrienden van de Belgische Liga tegen Epilepsie,
Bernard Spaelaan 141, 9000 Gent,
Belgium.
T: +32 9 222 0404,
E: oostvlaanderen@epilepsieliga.com
Contact: Ms Claudine Van Daele.

BULGARIA
Association of Parents of Children with Epilepsy
Triadica district,
Strelbishte Bl 10, entr. G,
floor 7, ap 67,
Sofia 1408, Bulgaria.
T: +359 248 883 594
E: frde@abv.bg
Contact: Mrs Veska Sabeva.
LATIN AMERICA

ARGENTINA

ALCE
Tucumán 3261, 1189, Buenos Aires, Argentina.
T/F: +54 114 8620 440
E: asoalice@aol.com
Contact: Mr Gonzalez Garralda.

Associate Member:
Epilepsy Association Doctors for Support - Argentina
Professor Ernesto Adorana
Contact:
E: eradorana@claro.net.ar
T: +54 11 5126 264

BRAZIL

Asociación Brasilera de Epilepsia
Rua Botucatu 740, CEP 04023-900, São Paulo, Brazil.
T: +55 11 5549 3819
E: vba@epilepsiasul.org.br
Contact: Luís Falcão.

Asociación Nacional de Ligas Chilenas contra la Epilepsia, ANLICHE
Patriotas Uruguayos 2236, Código Postal: 8340594, Santiago de Chile, Chile.
T: +56 2 699 2288
ANLICHE@lignapelnie.sch.ch
Contact: Mr. Guillermo Silva.
Website: www.lignapelnie.sch.ch

COLOMBIA

COLOMBIA
Fundación Instituto de Rehabilitación para Personas con Epilepsia - FIRE
Barranquilla, Calle 1a., Calle del Edén, Cartagena, Colombia.
T: +57 56618 127
E: fandinojai@gmail.com
Contact: Dr. J.F. Fandino-Franky.

ECUADOR

Centro Nacional de Epilepsia, APNE
Berruneta Oeste 180 y Pasaje Abrego, Quito, Ecuador.
T: +59 3290 5405
E: cnepilepsia@andinanet.net
Contact: Dr. J. Del Reinaldo Fabelo.

GUATEMALA

IBE Guatemalan Chapter
6a Calle 2-48, Zona 1, Guatemala City, Guatemala.
T: +50 222 382 107
E: henryostokes@neurologiaparatodos.com
Contact: Dr. Henry Stokes.

HONDURAS

Fundación Honduras de Epilepsia
Col. Universidad Norte, Francisco Morazán, Tegucigalpa, Honduras.
T: +504 2232 2074
E: fundhap@epay.com
Contact: Dr. Eduardo Rodas.

MEXICO

Group “Acceptation” of Persons with Epilepsy - GADEP
San Francisco 1384, 7to Piso B, Col. Del Valle, Mexico DF 03100.
T: +52 555 034 3745
E: liliu@lignapelnie.sch.ch
Contact: Dr. Lilia Nunez Orozco.
KOREA
Korean Epilepsy Association
Department of Neurology,
Ajou University Hospital,
San-5 Woncun-dong,
Suwon 443-721, South Korea.
T: +82 1090 967 911
E: khuh@ajou.ac.kr
Contact: Dr Kyoon Huh.

MALAYSIA
Malaysia Society of Epilepsy
Jabatan Neurologi,
Kuala Lumpur Hospital,
505086 Jalan Pahang,
Kuala Lumpur, Malaysia.
T: +603 2615 5405,
E: drhussain@hkl.gov.my
Contact: Magrette Selvy Anthony

MONGOLIA
Mongolian Epilepsy Association
HSUM
PO Box 48/28, Ulaanbataar,
Mongolia.
T: +976 9917 7153,
E: tovuudorj@yahoo.com,
Contact: Dr A Tovuudorj.

NEW ZEALAND
Epilepsy New Zealand (ENZ)
PO Box 1074,
Waikato Mail Centre,
Hamilton 3240,
New Zealand.
T: +64 78 343 446
E: ceo.nsc@epilepsy.org.nz
Contact: Mr Frank Gouveia.
www.epilepsy.org.nz

PHILIPPINES
Epilepsy Awareness & Advocacy Inc.
151-B Scout Rallos Extension,
Sacred Heart, Kamuning,
Quezon City, 1103,
Philippines.
T: +632 414 4638
E: ph.eaai@yahoo.com
Contact: Ms J Desiree Khonghun.

SINGAPORE
Singapore Epilepsy Foundation
149 Rocher Road,
#04-06 Fu Lu Shou Complex,
188425, Singapore.
T: +65 3344 302
E: admin@epilepsy.com.sg
Contact: Dr Yuan-Fu Tseng.

ASSOCIATE MEMBER:
Epilepsy Care Group (Singapore)
No 26 Dunearn Road (Level 2),
Singapore 309423.
T: +65 6358 0566
E: ects93@singnet.com.sg
Contact: Mr Sherman Goh.
www.epilepsycare.org

TAIWAN
Taiwan Epilepsy Association
B1F, #41, Alley 66, Lane 155,
Tun-Hwa N. Road,
Taipei 105,
Taiwan.
T: +886 2251 49682
E: didikun@gmail.com
Contact: Dr Yuan-Fu Tseng.

Congresses 2013

2013 MONTREAL
30th INTERNATIONAL EPILEPSY CONGRESS
23rd - 27th JUNE, 2013
28th - 30th August 2013

13th EUROPEAN CONFERENCE ON
Epilepsy & Society
LJUBLJANA, SLOVENIA

Annual Report 2011 19