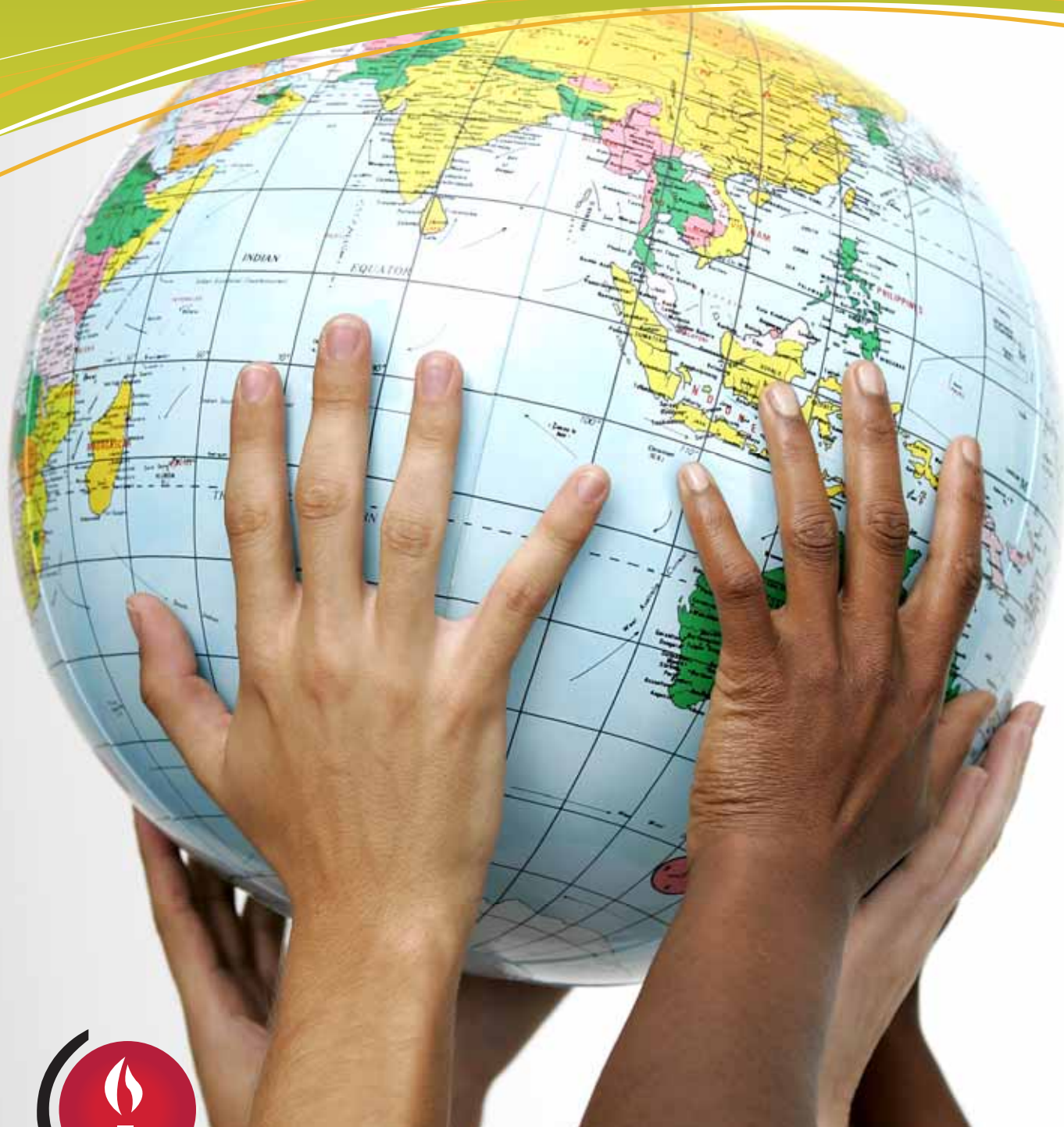


ANNUAL REPORT 2009



IBE

International Bureau for Epilepsy

International Executive Committee 2009-2013



- Top row, from left:** Mike Glynn (Ireland), President; Grace Tan (Singapore), Treasurer; Susanne Lund (Sweden), Immediate Past President
- Second row:** Anthony Zimba (Zambia), VP Africa; Abdulaziz Al-Semari (Saudi Arabia), VP Eastern Mediterranean; Janet Mifsud (Malta), VP Europe
- Third row:** Mary Secco (Canada), VP North America; Carlos Acevedo (Chile), VP Latin America; Vinod Saxena (India), VP South East Asia; Shunglon Lai (Taiwan) VP Western Pacific
- Bottom row:** Nico Moshé (USA) ILAE President; Sam Wiebe (Canada), ILAE Secretary General, Emilio Perucca (Italy), ILAE Treasurer.

President's Report

Dear IBE Members and Supporters

It was with a great sense of pride and honour that I assumed the mantle of IBE President at the time of the General Assembly in Budapest in July 2009. Those of you who know Susanne Lund, my predecessor, will be aware of the very sizeable shoes I have to fill in order to continue the tremendous work undertaken by Susanne during her term of office. I would like to take this opportunity to congratulate her on her truly remarkable presidency and I know that I can count on her knowledge and experience to assist me in the coming four years.

During the first six months of 2009, Susanne oversaw several important activities, including the fourth round of the Promising Strategies Program, which provided funding to a further eight projects in Chile, Mongolia, Togo, Mauritius, Namibia, the Philippines, Zambia and Zimbabwe. A total of 27 projects have been supported by the program since it was first introduced at the beginning of Susanne's term as President in 2005.

The incoming International Executive Committee and the seven Regional Committees began their terms of office on 1st July and for the remainder of 2009 the focus was on developing plans of action and establishing new task forces and working groups. A special meeting of the International Executive Committee took place in Rome in November 2009, providing the ideal opportunity to develop a strategy for IBE's further development.

New Task Forces established are the Governance Task Force, a Research Task Force and an expanded Driving Task Force. The Governance Task, chaired by Johan Falk-Pedersen, has been tasked at reviewing the Constitution and Byelaws and will also review IBE's Election Procedures. The Research Task Force, chaired by Ley Sander, will consider how research already developed could be used to improve the

quality of life of people with epilepsy. With respect to the Driving Task

Force, this group has already been active for four years, initially focussing on driving regulations in Europe ahead of the new European Union Directive that was introduced in 2009. The group is now expanded and will look at national driving regulations, or the absence of such legislation, at global level.

One of the activities identified for particular attention during this term is the ILAE/IBE/WHO Global Campaign Against Epilepsy, which was launched in 1999 and which was co-chaired by Philip Lee (for IBE) and Giuliano Avanzini (for ILAE) from 2005—2009. I would like to thank them for their dedication to the campaign during this period. I would also like to thank Hanneke de Boer, who has been involved in the campaign since its launch and who continues to devote considerable time to its activities.

While the campaign has now been active for almost 14 years, in the intervening years the involvement and inclusion of IBE members and ILAE chapters in the campaign has slowly dissipated and Nico Moshé and I saw this as something that needed to be addressed. In order to be 'hands on' in this task, Nico and I will co-chair the campaign for the coming four years to the middle of 2013.

In the course of this period we would like to see visibility of the campaign increase and to have more involvement of members and chapters right around the world and not just in developing countries. By late 2009 we had identified a Global Campaign Task Force, which is co-chaired by Dr Shichuo Li and Dr Helen Cross and this group has already developed a new



Mike Glynn

**IBE President
2009-2013**

strategic plan for the campaign. In addition, the campaign website has been re-launched and is an important repository for campaign materials and reports. Another important activity of the campaign in 2009 was the publication of the final report on the Demonstration Project in China, which has been hugely successful.

The coming four years will be both busy and challenging with several landmark activities already on the horizon—including IBE's Golden Jubilee in 2011 and the launch of the European Epilepsy Day in February 2011. Other projects already established will continue to grow and develop, such as EUCARE, IBE's communications channels—IE News and our website, and the projects that we have developed in collaboration with our colleagues in the pharmaceutical company.

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. Together we can all continue to stride forward towards a better life for people with epilepsy.

With best wishes to all.

A handwritten signature in black ink, which appears to read "Mike Glynn". The signature is stylized and written in a cursive-like font.

Mike Glynn
President

Income and Expenditure Account

Year ended 31st December 2009
With comparative totals for 2008

	2009	2008
	US\$	US\$
INCOME	2,213,893	1,273,386
EXPENDITURE	(1,660,546)	(1,449,953)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>553,347</u>	<u>(176,567)</u>

Balance Sheet

Year ended 31st December 2009
With comparative totals for 2008

	2009	2008
	US\$	US\$
FIXED ASSETS		
Tangible assets	<u>3,599</u>	<u>8,422</u>
CURRENT ASSETS		
Debtors and prepayments	37,897	265,857
Cash at bank and in hand	<u>3,298,705</u>	<u>2,654,028</u>
	3,336,602	2,919,885
CREDITORS: (Amounts falling due within one year)	<u>(1,255,713)</u>	<u>(1,397,166)</u>
NET CURRENT ASSETS	<u>2,080,889</u>	<u>1,522,719</u>
NET ASSETS	<u>2,084,488</u>	<u>1,531,141</u>
CAPITAL AND RESERVES		
General reserve	1,552,345	1,252,901
Restricted and designated fund	<u>532,143</u>	<u>278,240</u>
	<u>2,084,488</u>	<u>1,531,141</u>

Statement of Income and Expenditure

Year ended 31st December 2009

With comparative totals for 2008

	2009	2008
	US\$	US\$
INCOME		
Congress income received	1,958,233	621,481
Corporate donations	154,518	59,198
EUCARE management fees	50,690	60,392
Membership dues and Solidarity Fund	16,027	15,903
Investment income	50,163	47,489
Promising Strategies		28,190
Sale of materials	29	48
Other grants	(16,192)	435,299
Miscellaneous income	425	5,386
	<u>2,213,893</u>	<u>1,273,386</u>
EXPENDITURE		
Congress expenditure (inc foreign exchange gain/loss)	1,248,607	568,307
Office expenses	12,295	5,241
Printing and postage	17,945	10,847
Printing and postage - International Epilepsy News	39,791	48,928
Travel	55,713	62,449
Global Campaign costs	(18,342)	3,856
Accountancy fees	36,399	33,298
Audit fees	15,000	15,000
Administration pay costs	175,036	170,968
Bank charges	1,887	2,887
Rent	33,790	36,904
Promising Strategies Program	24,854	24,037
Depreciation	4,823	6,001
Website costs	1,037	10,564
EUCARE costs	96,391	407,561
	<u>1,745,226</u>	<u>1,406,848</u>
Currency exchange fluctuations	(84,680)	43,105
	<u>1,660,546</u>	<u>1,449,953</u>

Financial Report continued

Congress Financial Information

International Bureau for Epilepsy engages the services of a contracted International Director of Meetings (IDM) under the terms of an Agreement dated 1 July 2005. This Agreement is effective for a five year term beginning on 1 January 2005. The Agreement will automatically extend for an additional five years following the original agreement expiration on 31st December 2009.

The 2009 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:

	2009	2008
	US\$	US\$
Cash at bank	482,426	303,766
Debtors and prepayments	31,584	256,992
Creditors	(181,521)	(328,994)
	(462,142)	(384,134)
IDM congress income	1,958,233	621,481
IDM congress expenses	<u>(1,248,607)</u>	<u>(568,307)</u>



International Highlights 2009



PROMISING STRATEGIES Newly funded projects 2009

Supporting members in low income countries to improve the quality of life of persons with epilepsy. Over \$100,000 of support has been provided to date. Latest projects:

CHILE: Animated education video

MONGOLIA: Quality of Life Program

MAURITIUS: Epilepsy Advocacy Network

NAMIBIA: Awareness DVD

PHILIPPINES: Multimedia educational pack

ZAMBIA: Market gardening skills training

ZIMBABWE: Peanut butter processing project

TOGO: Education project directed at women



GLOBAL CAMPAIGN Structure changes

For the term 2009-2013, the ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows' is co-chaired by **Mike Glynn**, IBE President, and **Nico Moshé**, ILAE President.

The Global Campaign Task Force is co-chaired by **Helen Cross** and **Shichuo Li**, with members and liaison points chosen from within each region.

IMPORTANT PARTNERSHIPS

- IBE is in official relations with the World Health Organization (**WHO**) and works closely with the WHO on the ILAE/IBE/WHO Global Campaign Against Epilepsy
- IBE has Special Consultative Status on the Economic and Social Council of the United Nations (**ECOSOC**)
- IBE maintains a close working relationship with the International League Against Epilepsy (**ILAE**).

TASK FORCES

- **Governance Task Force:** to review the Constitution and Election Procedures
- **Research Task Force:** to consider how research already undertaken could help identifying new means of increasing life quality for people with epilepsy
- **Jubilee Task Force:** to develop and oversee a program of activities to celebrate IBE's Golden Jubilee in 2011
- **Epilepsy and Driving:** to study existing driving legislation, or the lack of such, around the world.

GENERAL ASSEMBLY

- The biennial General Assembly was held on 1st July during the 28th International Epilepsy Congress in Budapest. An important issue, the introduction of a new

membership class, Regional Membership, was voted in by Full Members during the assembly. The meeting also marked the handover to the incoming International Executive Committee.

EXCELLENCE IN JOURNALISM AWARDS

- Promoting an accurate understanding of epilepsy and its consequences remains a priority for IBE. **Excellence in Journalism Awards**, a collaboration of IBE and UCB Pharma, were awarded for the first time in 2009 to journalists working in print and broadcast media.

COMMUNICATIONS

- **IE News** is published each quarter with global circulation. It is also available for download on the IBE website
- The IBE website, **www.ibe-epilepsy.org**, contains a wealth of information and reports on activities and initiatives
- The **President's Letter**, circulated every two months, updates members and supporters on emerging news.

SOLIDARITY FUND

- IBE thanks Members who donated to the Solidarity Fund in 2009. The fund helps Members in low income countries to maintain their membership and partly funds the Promising Strategies Program.

MEMBERSHIP GROWS

With ratification of new members in 2009, IBE now has **122 members** based in **92 countries** world wide, covering **more than 90%** of the world's population.



SPONSORING PARTNERS

IBE acknowledges sponsorship received from the following companies during 2009:

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

AFRICA Region



The Solidarity Fund and Promising Strategies Program have had a significant impact in the African region

- Ghana:** The Ministry of Health sent an official request to develop a model to ascertain the prevalence of epilepsy and the magnitude of the treatment gap in Ghana. The program is being considered for a Demonstration Project and could capitalize on interventions already being developed by Ghana Health Services in conjunction with BasicNeeds Ghana and other non-governmental organisations. Much work has already been done in collaboration with BasicNeeds Ghana, including the organisation of educational courses for professionals.



Sister Franca de Simone

a nursing religious sister from Italy, who began working in Cameroon in 1980, in Nyamanga, a poor and isolated area north of the capital Yaoundé, was awarded the IBE Volunteer Award during the General Assembly in Budapest. Sr Franca was responsible for developing IBE's Full Member in Cameroon and helped young people with epilepsy to develop agricultural skills supported by the Promising Strategies Program.

ZIMBABWE: ADDRESSING STIGMA

- An Epilepsy & Stigma Conference,** held in Lusaka with 200 delegates, was the initiative of Epilepsy Association of Zambia, University of Zambia School of Medicine, Meharry Medical College and Vanderbilt University of Nashville. The meeting programme included workshops for people with epilepsy and healthcare providers, which prompted some people with epilepsy to arrange consultations to review their treatment and care.

REGIONAL COMMITTEE MEETING

- The African Regional Executive Committee organised a meeting in Budapest, which provided the opportunity for members to discuss issues of concern in the region. Based on discussions, the committee will draft a strategic plan, to be finalised at a meeting in Cape Town in January 2010.

GLOBAL CAMPAIGN IN AFRICA

- Cameroon Demonstration Project:** A technical meeting to prepare for an Demonstration Project on epilepsy was convened in Cameroon, involving all stakeholders in the field in epilepsy and the Ministers of Health and of Women's Empowerment and Family. The aim of the meeting was to assess the will and motivation of all involved and its feasibility. A Project Protocol was drafted and was approved unanimously by the stakeholders participating in the meeting.



MAURITIUS:

Creating an Epilepsy Advocacy Network that will train teachers of children with special needs and that will develop a new Advocacy Tool Kit.



NAMIBIA:

Production, in six of the main languages of Namibia, of a DVD presentation and printed material on lifestyle management and seizure assistance.



ZAMBIA:

Developing a skill can increase confidence and self worth. The market gardening training module will also generate self-sufficiency.



ZIMBABWE:

The Peanut Butter processing project will benefit 100 people, all of whom have epilepsy, by providing a means of generating an income.



TOGO:

A knowledge building project to bridge the gender gap, which hinders women from obtaining appropriate epilepsy treatment and care.

EASTERN MEDITERRANEAN Region



ILAE/IBE/WHO
GLOBAL
CAMPAIGN
Epilepsy in the
WHO Eastern
Mediterranean
Region
Bridging the Gap



MOROCCOAN SOCIETY AGAINST EPILEPSY EXTENDS ITS REACH

- In Morocco, distorted and misled beliefs about epilepsy drive people with epilepsy to maraboutic practices, which are often dangerous and which can limit access to appropriate medical structures. They also worsen the prognosis.
- Two studies carried out in Morocco indicated that up to 75% of patients who have epilepsy consult healers at least once before moving to modern medicine.
- A further problem is the lack of neurologists in many cities in Morocco. For a total population of 34 million, there are 80 neurologists and most of these are in the major cities. Just 10% of neurologists are based in the south of the country, while 30% of the population live in that region.
- General practitioners (GP) have not been involved in epilepsy management. This has

meant that many people with epilepsy, in particular in the south of the country, had to travel long and arduous routes in order to see a consultant in Marrakech, Agadir or one of the main cities. Now that a group of consultants travels out to remote regions each quarter, these arduous journeys are a thing of the past.

- The society has also been working side by side with GPs in order to increase their knowledge of epilepsy, so that they can provide care and treatment at local level. Collaboration has been established with local health authorities and pharmaceutical laboratories to meet the cost of training sessions for regional based GPs.
- In the long term, it is expected that the Moroccan Society Against Epilepsy will be able to reach 70% of the population.



2ND EAST MEDITERRANEAN EPILEPSY CONGRESS, DUBAI

- During 2009, a major focus of the Eastern Mediterranean Region was preparation for the 2nd East Mediterranean Epilepsy Congress 2010, with Dubai being selected in mid-year to be the host venue for the meeting. The previous congress took place in Luxor, Egypt, in 2006.

The eagerly awaited publication of the regional report on epilepsy in the Eastern Mediterranean region moved close to realization during 2009, as the final changes were made to earlier drafts.

The report brings together, for the first time, all the available evidence from the region on the epidemiology, etiology and management of epilepsy. **Trauma** has been assessed as the reason behind most frequently reported cases of epilepsy in the region. This is closely followed by **infections** and **tumours**. Full and detailed statistics on the causes of epilepsy, available treatments, stigma, and the treatment gap are comprehensively reviewed in the report.

The official launch of the report is planned for the 2nd East Mediterranean Epilepsy Congress, to take place in Dubai in early March 2010.

Dr Khalid Saaed, WHO Regional Advisor for Mental Health and Substance Abuse is expected to formally launch the report.



EUROPE Region

EU DIRECTIVE ON DRIVING Harmonizing regulations

The Driving and Epilepsy Task Force welcomed the [European Directive 2009/112EC](#) that came into law on 29th August 2009. The Directive put into force recommendations on Epilepsy and Driving of the expert working force led by Dr Eric Schmedding, which reported back its findings to the European Commission in 2005.

The Directive provides for a [one year seizure-free period for Group 1 vehicles](#) (cars, vans, motorcycles). The Directive also regulates that drivers who are seizure free for 10 years may obtain a Group 2 licence (heavy goods vehicles including buses).

Although the Directive increases the time ban in France and the Netherlands, it greatly improves the situation in countries that have recently joined the EU, where there has been either no legislation in place or a complete ban on driving for people with epilepsy.

EU Member States have 12 months to implement the new Directive.

EUROPEAN EPILEPSY DAY

- After many years of consideration and discussion, a major development in 2009 was the decision to launch the first European Epilepsy Day in February 2011. The initiative has now received the approval both of the IBE International Executive Committee and the ILAE Executive Committee .

The IBE European Regional Committee will play a significant role in preparing for and promoting this event, which will take place in the EU Parliament in Strasbourg. More importantly, epilepsy associations in Europe are being encouraged to organise local events to highlight the day.

GLOBAL CAMPAIGN IN GEORGIA

- ‘Epilepsy Management at Primary Health Care Level’, a demonstration project of the Global Campaign Against Epilepsy, which began in 2008, made considerable strides in promoting public awareness about epilepsy by means of an educational programme aimed at reducing stigma. The program is due to be completed in 2011.

EPICURE

- As the partner responsible for dissemination of information on the EPICURE project, involving 30 centres in Europe, IBE attended the 4th annual meeting for EPICURE partners in Marseille. The meeting was attended by more than 100 participants. The EPICURE project, funded by the EU 6th Framework Programme (Project EC LSH-037315) hopes to identify disease causing genes for both inherited and acquired epilepsies and will end in 2011.

IBE EUROPEAN REGIONAL COMMITTEE

- The committee met in Porto in late 2009 to finalise the program for the 12th European Conference on Epilepsy & Society 2010. Plans were also put in place to create a regional newsletter to keep members in Europe updated on activities within the region.

2009 was a significant year for people with epilepsy in Europe, with the development of important initiatives within the European Parliament as well as at local level

DEROGATION FOR MRI IN EUROPE

- The European Regional Committee is working with the Alliance for MRI to seek its derogation from an EMF Directive. The aim of the Directive is to safeguard people from the harmful effects of magnetic fields. However, in drafting the Directive, the EU failed to recognise the important use of MRI in medical diagnosis and treatment.

Local Initiatives

- **Brainwave** the Irish Epilepsy Association, marked the 200th anniversary of Irishman Robert Bentley Todd—a true epilepsy pioneer who identified the role of electricity in epilepsy
- **LESIA**, Lithuania, completed the ‘I am the same as you’ initiative aimed at decreasing stigma in society
- Having epilepsy is not good for your teeth, with dental injuries caused by seizures and falls. In recognition of this, the **Danish Epilepsy Association** is working to have dental treatment costs covered by the government for people with epilepsy
- **Caritas Malta Epilepsy Association** is using the Action Zone! board game in its in service teacher training courses. The game is one of the most successful initiatives introduced by IBE, in collaboration with UCB Pharma.



A visit to Paraguay; animated puppets; a workshop in Chile on organic disability; new disability legislation in Argentina—just some of the activities in the region during 2009

LATIN AMERICA Region



TESTING KNOWLEDGE OF GENERIC MEDICATION IN BRAZIL

- The Associação Brasileira de Epilepsia carried out a survey on patient knowledge on AED substitution and discovered levels of knowledge, particularly in social disadvantages areas, to be very low, with frequent formulation switching. The results, which showed evidence of breakthrough seizures and increased adverse effects, pointed up the importance of alerting health experts and regulatory authorities, especially in developing countries with limited health expenditures in which generics promote a great impact in the treatment of several medical conditions, that AEDs should be considered a special group regarding generics and similar public policies on drugs.

MEETINGS IN PARAGUAY AND PANAMA

- Members of the Latin American Regional Executive Committee visited Paraguay to support local people in establishing an IBE Full Member. The Chair of the Regional Executive Committee visited Panama on a similar exercise and both visits had very promising results. In Panama a significant problem is local registration of the organization, because of slow local procedures. It is hoped that both countries will soon be ready to submit membership application documents.

NEW LEGISLATION IN ARGENTINA

- Silvia Kochen and Jorge Levanto, two doctors involved in FUNDEPI in Buenos Aires, spent 10 years campaigning for laws to safeguard the rights of persons with epilepsy in Argentina. Their patience and determination paid off in 2009 with the introduction, by the Argentinean Chamber of Deputies, of new laws to defend the rights of persons with epilepsy. The new legislation establishes the right to free medication, penalizes discrimination and promotes diffusion of information about epilepsy to help reduce stigma.

WORKSHOP IN CHILE

- A workshop on epilepsy, intellectual disability, and dementia, held in Santiago de Chile in August 2009, was attended by:
 - Dr Benedetto Saraceno, WHO Geneva
 - Dr Jorge Rodríguez, Dr José Luis di Fabio, and Mr Javier Vásquez, WHO/PAHO Washington
 - Dr Hugo Cohen, WHO/PAHO South America
 - Dr Armando J Vásquez Barrios, WHO/PAHO Chile
 - Dr Victor Aparicio, WHO/PAHO Mexico and Central Latin-America
- The Chilean Ministry of Health was also represented and significant progress was made.

PROMISING STRATEGIES JUANITO—the animated puppet

Think Pixar and it's easy to see how young children love puppet animation. Puppetry has also been shown to be a great way to deal with issues that can be otherwise difficult to confront.

Juanito, a Chilean animated video uses puppets in a light-hearted way that has proven to be very popular with young children. The video is part of an initiative that also surveyed the children's knowledge on epilepsy both before and after viewing the four-part video that shows Juanito at the doctor's surgery, at home, in school and playing with friends.



CARTAGENA DE INDIAS

Cartagena, a World Heritage city in Colombia, was chosen to host the 6th Latin America Epilepsy Congress 2010. The Latin American Regional Committee worked throughout 2009 to finalise a program that would be attractive to all delegates.

The organizing Committee used teleconferences to define congress topics, identify session chairs and speakers, and deadline dates for submission of abstracts and bursaries requests. Lilia Núñez Orozco and Carlos Acevedo also prepared for the special one-day IBE program.

NORTH AMERICA Region



SCIENCE TEACHING UNIT IN CANADA Encouraging career choices



Canadian Epilepsy Alliance, working with neurologists, teachers and university students has been writing and pilot testing a new teaching unit for senior science students majoring in biology. The interactive course includes seizure videos, cell biology animation, laboratory and case studies and career links.

The aim of the project, which was three years in developing, is to encourage students to consider epilepsy as a career choice for future health scientists.

ADVANCEMENT OF EPILEPSY HEALTH CARE SERVICES IN JAMAICA

- Until recent years, no structured programme of epilepsy health care existed in Jamaica. Care was delivered solely on a one-to-one basis by individual medical practitioners to their patients, with varying seizure control outcomes. EEG services were extremely limited, with most patients treated without ever having an EEG performed.
- To address the problem the Jamaican Epilepsy Association, working with the Jamaican League Against Epilepsy (ILAE chapter), has identified fourteen issues that should be the focus of any new initiative. These include:
 - the importance of identifying motivated people within each branch who can collaborate on programs;
 - developing contacts with associations in other countries to learn from their experiences;
 - determining existing knowledge and knowledge gaps;
 - educating health care workers, parents and families of persons with epilepsy, and the general population;
 - developing advocacy plans;
 - encouraging focussed research in those areas where epilepsy care urgently needs to be improved.

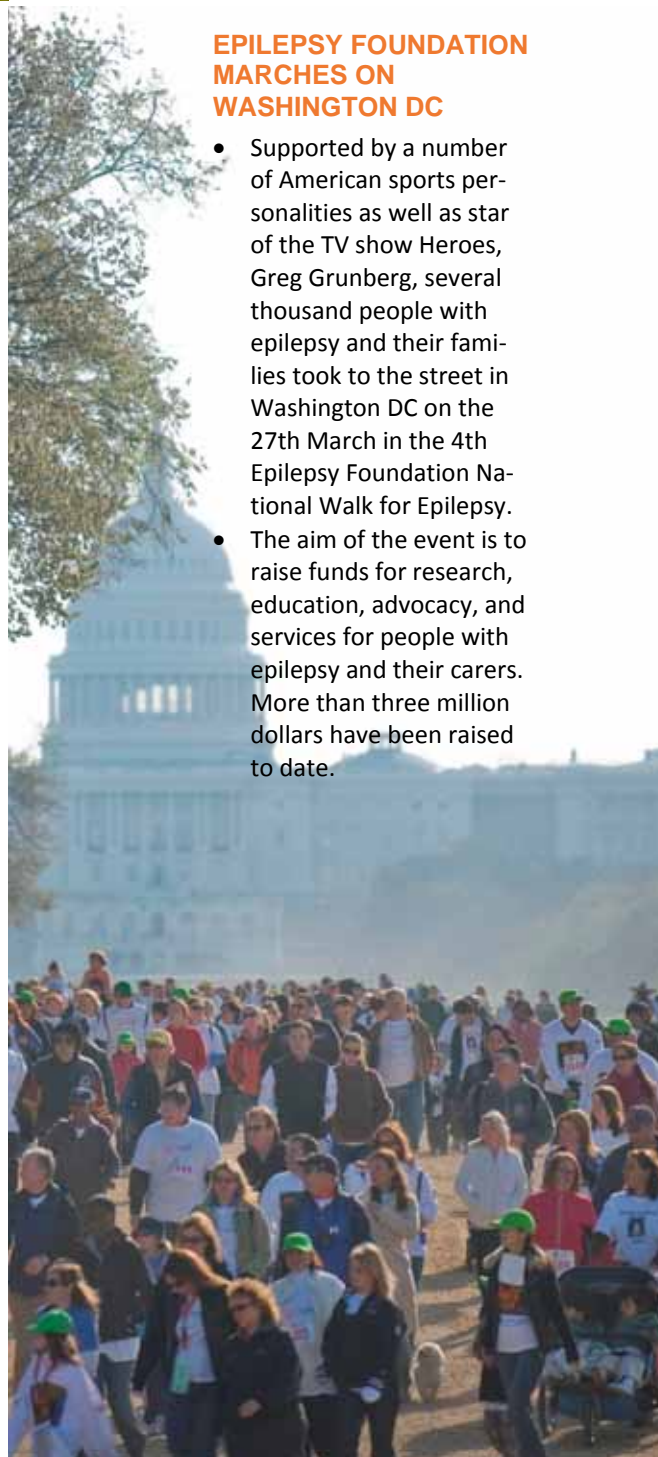
JOURNALISM AWARD WINNER

- Aliyah Baruchin was announced winner of the print/online category of the 1st Excellence in Journalism Awards, an initiative of IBE and UCB Pharma. The winning article "*Epilepsy in the African-American Community: Access Education and Advocacy*" was first published in EpilepsyUSA, the news magazine of Epilepsy Foundation.
- In accepting her award, Ms Baruchin indicated that she would use the prize fund to help in compiling a report on epilepsy in Sierra Leone.

Encouraging senior students in Canada to studies in epilepsy; improving epilepsy care services in poorly served populations in Jamaica; walking to raise awareness in the USA

EPILEPSY FOUNDATION MARCHES ON WASHINGTON DC

- Supported by a number of American sports personalities as well as star of the TV show Heroes, Greg Grunberg, several thousand people with epilepsy and their families took to the street in Washington DC on the 27th March in the 4th Epilepsy Foundation National Walk for Epilepsy.
- The aim of the event is to raise funds for research, education, advocacy, and services for people with epilepsy and their carers. More than three million dollars have been raised to date.





SOUTH EAST ASIA Region

Providing financial support for education in Nepal, using street theatre to raise awareness in India, film-making in Bangladesh; three novel ways to support people with epilepsy in the region

INDIAN
EPILEPSY
ASSOCIATION
ENTERS THE
WEDDING
BUSINESS
Marriage Bureau
for People with
Epilepsy



It is still quite common in India for marriages to be arranged by parents. This has led to great difficulties for people with epilepsy looking for a marriage partner.

In addition, when a woman hide the fact that she has epilepsy before marriage, it is not unusual for the husband to seek a divorce once he finds out after the wedding has taken place.

But help is at hand, at least for people with epilepsy living in the Pune region.

In Pune, **Sanvedana**, an epilepsy support group, assisted by the able advice and guidance of **Yashoda Wakankar**, has set up a marriage bureau for people with epilepsy, in order to facilitate marriages.

Already the initiative has met with great success with several marriages already arranged.

NEPAL

- Nepal Epilepsy Association (NEA), Nepal has been operating epilepsy clinics in Kathmandu and at Dolakha in the Himalayan foothills for several years. However, the mountainous terrain of the country made it difficult for people to access medical care.
- At present 700 people with epilepsy receive regular follow up at the Epilepsy Center, Kathmandu. The epilepsy clinic is open twice a week, on each Saturday and Sunday.
- NEA organises a monthly programme for doctors, not only in Kathmandu but also outside the capital. The programme provides updates on epilepsy care and management.
- NEA is also providing scholarships to disadvantaged students in orphanages as well as through hospitals and health centres to help them remain in education.

INDIA

- The Indian Epilepsy Association has 27 chapters spread all over the country, each of which works actively to dispel the myths, fears and stigma attached to epilepsy.
- Tirupati chapter has been conducting monthly epilepsy camps for more than 10 years. During camp event, an average of 350 to 400 patients are seen. Free medication is also provided each month.
- Bangalore chapter has been practicing an innovative method of public education through street plays (Road Shows) in semi urban and rural areas. The initiative, which was introduced 10 years ago, operates on one Sunday each month and so far 500 road shows have been conducted. Each month the event takes place in two or three different villages and includes the short play as well as educational talks and the provision of information materials.
- The Diploma in Epilepsy Care was introduced by Bangalore University in collaboration with IEA and CBR network, three years ago. This is a distance education programme with 17 participants enrolled for 2009. The aim of the programme is to provide add-on benefit and education on epilepsy for teachers, primary health care workers, nurses etc.
- An unusual method of providing epilepsy care is arranged through an outreach project, the Lifeline Express Train, which travels to rural India. The train has been working for 20 years, visiting a new village each month and staying in the village for about three weeks to provide medical care.

PROMISING STRATEGIES PROGRAM

BANGLADESH

An application for support under the Promising Strategies Program, to help fund an information video, has been approved by IBE for funding. In a country where the level of literacy is very low, printed materials are usually not suitable in educating the public. Work on the video, which will be shown on TV, is expected to begin in the early part of 2010.



PROMISING STRATEGIES

Two new projects receive funding



MONGOLIA

The Mongolian Epilepsy Association's **Quality of Life Program** conducted courses on epilepsy care for neurologists in district hospitals, family doctors, nurses, people with epilepsy and their families, as well as local government officials.

As most of the population live in difficult terrain and isolated areas, travel to a major treatment centre is lengthy and arduous. The programme will improve services for those not in the capital Ulaanbaatar.



THE PHILIPPINES

Epilepsy Awareness & Advocacy Inc is producing a multimedia pack in English and in five of the most commonly used dialects in the country to educate people about epilepsy. The pack comprises a DVD and accompanying materials in comic book style and will be disseminated throughout the Philippines vast archipelago of more than 7,000 islands by local volunteer groups.

WESTERN PACIFIC Region



CHINA: GLOBAL CAMPAIGN REPORT

- The final report on the Global Campaign Demonstration Project '*Epilepsy Management at Primary Health Level in rural China*' was launched in Beijing in late 2009 by Dr Michael O'Leary, WHO Representative in China. Ministry of Health Officials and project collaborators also attended. IBE was represented by Mike Glynn, President.
- The report, which was published in both English and Chinese, documents the success of the Chinese Demonstration Project in reducing the epilepsy treatment gap in China through the management of convulsive forms of epilepsy at primary healthcare level.
- The project has inspired the Chinese government to further expand the initiative in rural China. By the end of 2008 the programme included 79 counties in 15 provinces of China and over 35,000 people with epilepsy were treated by trained clinical physicians, as a direct impact of the Demonstration Project's protocol. In addition, 1,838 physicians from county hospitals in China were either trained or re-trained by the end of 2009.
- At the end of 2009, the indications were that the project would be extended to a further six or eight counties in 2010.
- The Demonstration Project in China, and the intervention model described in the report, achieved the ultimate goal: to make epilepsy a national health priority in China, thereby bringing epilepsy 'out of the shadows'
- The report is available on the campaign site www.globalcampaignagainstepilepsy.org.

AUSTRALIA: PARLIAMENTARY FRIENDS OF EPILEPSY GROUP

- Following on the successful establishment of the Australian Parliamentary Friends of Epilepsy Group, a first meeting was held in late 2008. During that meeting, co-convenor of the group, Jill Hall, proposed that an inquiry into epilepsy be conducted by the Friends during 2009.
- Early in 2009 it was confirmed that the inquiry would be conducted and terms of reference were submitted to the Parliamentary Friends of Epilepsy Group.
- The main hearings were held in the capital, Canberra, and a number of smaller hearings were held in other locations throughout the country during the year.
- This was the first time that Australians living with epilepsy will have had the opportunity to personally inform federal politicians of the impact epilepsy has on their lives.



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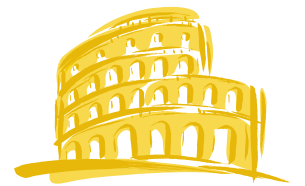



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