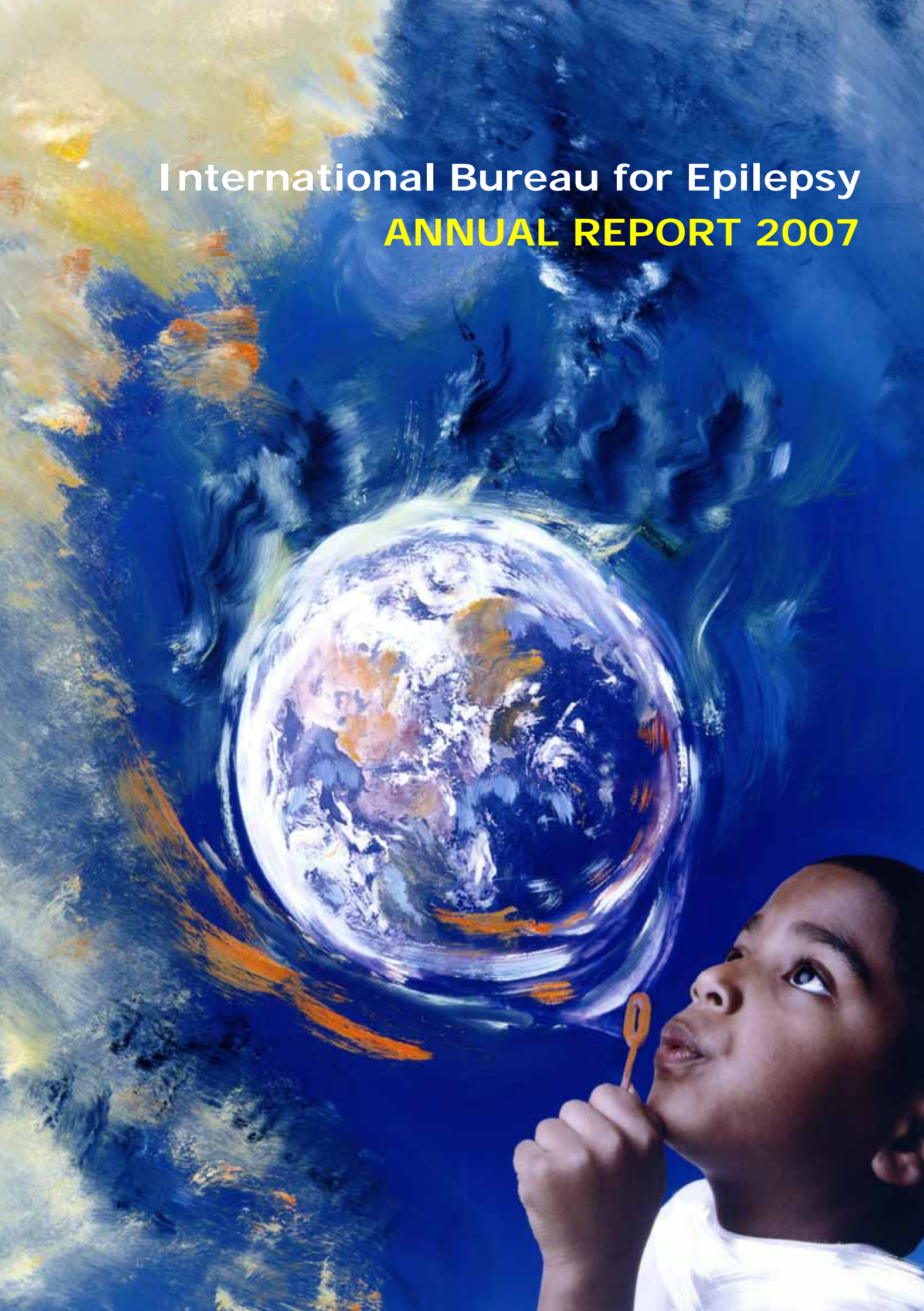


International Bureau for Epilepsy
ANNUAL REPORT 2007





Our Vision

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

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.

Our Mission

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

Communication: To promote the facts about epilepsy and to communicate 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.

International Executive Committee 2005 - 2009



Back row, from left: Abdulaziz Al-Semari, Vice President Eastern Mediterranean; Mike Glynn, Treasurer; Carlos Acevedo, Vice President Latin America; Nico Moshé, ILAE Secretary General; Shunglon Lai, Vice President Western Pacific; Peter Wolf, ILAE President; Martin Brodie, ILAE Treasurer; Mary Secco, Vice President, North America; Eric Hargis, Secretary General.

Front row: Anchor Hung, Vice President South East Asia (inset photo); Athanasios Covanis, Vice President Europe; Zenebe Gedlie Damtie, Vice President, Africa; Philip Lee, Immediate Past President; Susanne Lund, President.



- 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 relations with the World Health Organisation (WHO)

Report from the President

Another year has already passed and I am very pleased to announce that IBE is moving forward with many positive activities and with a strong determination to change conditions for people with epilepsy worldwide.

2007 was an exciting and historic year for the International Bureau for Epilepsy as IBE was formally recognised as having Special Consultative Status on the Economic and Social Council (ECOSOC) in the United Nations. As a non-governmental organisation with consultative status IBE will be able to contribute to the different programs of the UN and to serve as experts and advisors to governments and secretariats. With 50 million people with epilepsy worldwide I am happy that IBE has a voice in the world community, that our experiences can be used and highlighted in relevant issues. It is also encouraging for everyone working in the field of epilepsy that the word 'epilepsy' is being echoed in the halls of the United Nations. Epilepsy might be a sometimes invisible condition, but IBE will not be invisible in the fight against prejudice and discrimination of people with epilepsy, no matter where in the world they live.

This was also the year when IBE announced the winner of the first IBE Volunteer Award, which was presented at the General Assembly during the 27th International Epilepsy Congress in Singapore in July. The honourable and worthy winner was Mrs Margaret Fandiño-Merz from Colombia. She is one of the many hardworking volunteers who campaign tirelessly to improve the quality of life for people with epilepsy worldwide. IBE is very happy to have the opportunity, through the Volunteer Award, to highlight the efforts made by those often silent volunteers. The IBE/ILAE Ambassadors for Epilepsy and Social Accomplishment Awards were also presented during the congress in Singapore and IBE congratulates the twelve new Ambassadors and Dr John Kirker, who received the Social Accomplishment Award.

This was the year when a second round of IBE's successful Promising Strategies Program was launched, aimed at improving conditions in the field of epilepsy in developing countries. The Promising Strategy Program has provided funding for almost twenty exciting projects which focus on capacity building initiatives – both through training programs and advocacy projects.

Early in the year IBE celebrated the launch of the Regional Committee Eastern Mediterranean, at the time of the 1st East Mediterranean Epilepsy Congress in Luxor. IBE now has seven Regional Committees, matching the WHO regional boundaries.

IBE also enjoyed great growth in membership in 2007 with ten new epilepsy associations welcomed as IBE members during the year. This is very encouraging and we look forward to working with these new members over the coming years.

The face of IBE is of major importance and I am delighted to note that the IE News, edited by Dr Carlos Acevedo, has reported on a tremendous amount of global epilepsy activities and reports in a very attractive way. The magazine reflects the great scope of IBE's work and that of its

Members, including articles on medical issues, reports on best practice, news from congresses, and the latest activities in IBE initiatives and activities in which we work jointly with the International League Against Epilepsy.

During 2007 the major redesign of the website, which began in 2006, was completed. The site now offers a wider range of information, with particular reference to our regional bodies. The successful redevelopment of the website is another crucial element in our efforts to provide attractive and high quality information.

The ILAE/IBE/WHO Global Campaign Against Epilepsy is perhaps the longest running joint initiative in which we are involved. In 2007 it celebrated its 10th anniversary. This is a very visual and widespread activity and IBE is grateful to the co-Chairs Philip Lee (IBE) and Giuliano Avanzini (ILAE) who are heavily involved in its direction. However there was a sad moment in the campaign during the year with the death of Leonid Prilipko, who had worked on the campaign at the WHO. Dr Prilipko was devoted to his work and to the activities of the Global Campaign Against Epilepsy. His dedicated commitment facilitated the important link between IBE and WHO in maintaining the impetus of the campaign.

IBE continued its partnership on a number of interesting projects including the Action Zone! Game and the Freedom in Mind art competition. These collaborations with UCB Pharma have both been very successful and popular.

It is by working closely together on a common idea we can bring change for the many people with epilepsy around the world. By strengthening our network, by increasing contacts and building relationships, by sharing experiences and developing new strategies, valuable steps will be taken to improve the quality of life for people with epilepsy and those who care for them.

I would like to thank all those who have contributed to the great success of the IBE during the year. I thank the members of the International Executive Committee for all their time and efforts. IBE's superb office is also an important element of an efficient voluntary NGO and IBE is very fortunate to have Ann Little as its Executive Director.

Finally I would like to thank each and every Member of IBE who, both individually and collectively, devotes time and energy to the epilepsy movement worldwide and I am grateful for their great dedication and support.



Susanne Lund
President



Financial Report

Balance Sheet

Year ended 31st December 2007

With comparative totals for 2006

	2007	2006
	US\$	US\$
FIXED ASSETS		
Tangible assets	14,423	11,842
	<hr/>	<hr/>
CURRENT ASSETS		
Debtors and prepayments	185,274	160,038
Cash at bank and in hand	3,055,551	3,139,474
	<hr/>	<hr/>
	3,240,825	3,299,512
CREDITORS: (Amounts falling due within one year)	<hr/> (1,144,302)	<hr/> (1,223,782)
NET CURRENT ASSETS	<hr/> 2,096,523	<hr/> 2,075,730
CREDITORS: (Amounts falling due after more than one year)		
Deferred Income	-	(412,202)
	<hr/>	<hr/>
NET ASSETS	<hr/> 2,110,946	<hr/> 1,675,370
	<hr/> <hr/>	<hr/> <hr/>
CAPITAL AND RESERVES		
General reserve	1,324,491	1,300,922
Restricted fund	786,455	374,448
	<hr/>	<hr/>
	2,110,946	1,675,370
	<hr/> <hr/>	<hr/> <hr/>

Statement of Income and Expenditure

Year ended 31st December 2007

With comparative totals for 2006

	2007	2006
	US\$	US\$
INCOME		
International congresses and symposia	1,793,322	813,684
Commerce and industry	139,295	125,094
Membership dues	18,009	14,133
Investment income	45,709	50,221
Sale of materials	127	247
Other grants	343,801	213,852
Miscellaneous income	2,047	2,483
	<u>2,342,310</u>	<u>1,219,714</u>
EXPENDITURE		
Congress expenditure	1,390,084	729,126
Distribution to Paris Congress	-	234,863
Administration pay costs	162,465	114,188
Office expenses	33,108	5,783
Printing and postage	14,159	8,133
Printing and postage - International Epilepsy News	27,111	30,974
Travel	57,327	87,966
Global Campaign costs	30,000	25,000
Accountancy fees	27,666	10,873
Audit fees	12,000	4,125
Bank charges	2,061	1,027
Rent	29,941	17,945
Promising Strategies Program	30,313	-
Depreciation	7,044	6,539
Website costs	7,396	2,854
EUCARE costs	300,221	213,852
	<u>2,130,896</u>	<u>1,493,248</u>
Currency exchange fluctuations	(224,162)	(198,419)
	<u>1,906,734</u>	<u>1,294,829</u>

Income and Expenditure Account
Year ended 31st December 2007
With comparative totals for 2006

	2007	2006
	US\$	US\$
INCOME	2,342,310	1,219,714
EXPENDITURE	(1,906,734)	(1,294,829)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>435,576</u>	<u>(75,115)</u>

Auditor's Note:

All gains and losses have been recognised in the income and expenditure account. The deficit arises solely from continuing activities.

Congress Financial Information

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

The 2007 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:

	2007	2006
	US\$	US\$
Cash in bank	607,837	796,145
Debtors and prepayments	172,965	148,113
Creditors	(293,714)	(792,588)
Revenue	1,793,322	813,684
IDM Congress expenses	<u>(1,390,084)</u>	<u>(729,126)</u>

International Activities 2007



IBE Joined the UN!

May 18th marked a special occasion as IBE was formally recognised within the United Nations as an NGO in Special Consultative Status on the UN Economic and Social Council (ECOSOC).

This important relationship enables IBE to contribute to the programs and goals of the United Nations by serving as experts, advisers and consultants to governments and to the Secretariat. In addition, some of the approved NGOs can also propose new agenda items for consideration by ECOSOC and may be invited to attend at international conferences and special sessions called by the UN.

ECOSOC serves as the central forum for discussing international economic and social issues, and for formulating policy recommendations addressed to Member States and the United Nations system.

It is responsible for promoting higher standards of living, full employment, and economic and social progress, for identifying solutions to international economic, social and health problems; for facilitating international cultural and educational cooperation; and for encouraging universal respect for human rights and fundamental freedoms.

ECOSOC was established under the United Nations Charter as the principal organ to coordinate economic, social and related work of the 14 United Nations specialized agencies, 10 functional commissions and five regional commissions.

To be eligible for consultative status, an NGO must have an established headquarters, a democratically adopted constitution, and democratic and transparent decision-making processes.

New Members Welcomed

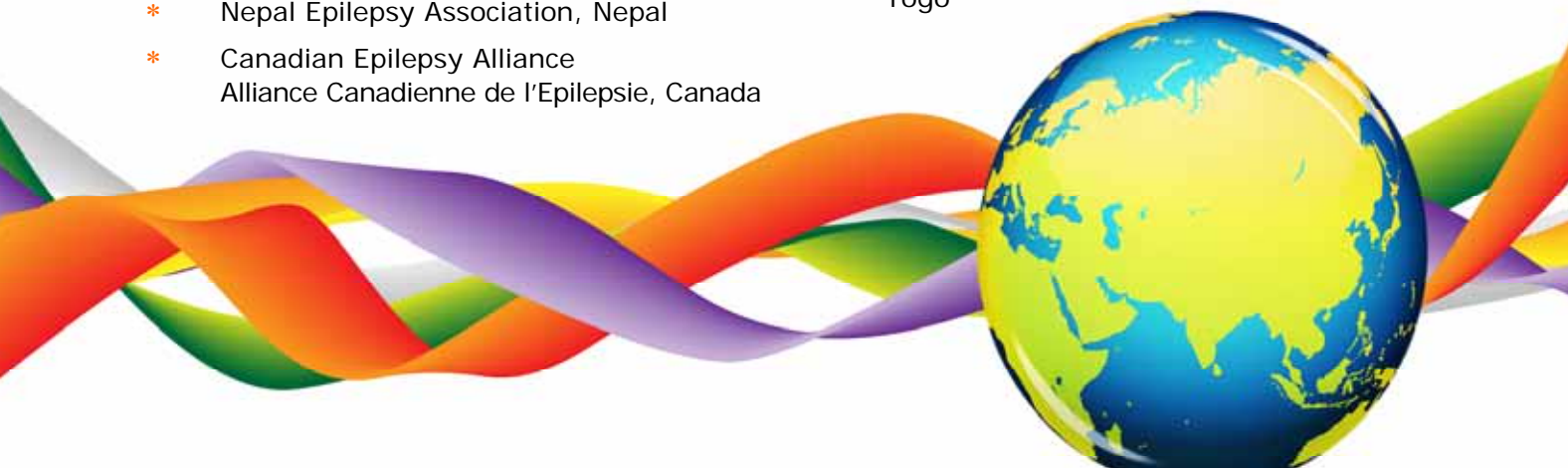
The applications of six new Full Members and four new Associate Members were ratified by the General Assembly during 2007. This brought membership figures to 118 Full and Associate Members working for people with epilepsy in 92 countries worldwide.

Full Members:

- * FIRE, Colombia
- * Epilepsy Namibia, Namibia
- * Epi-Apfape (EPI), Portugal
- * Association for the Future of People with Epilepsy in Hungary, Hungary
- * Nepal Epilepsy Association, Nepal
- * Canadian Epilepsy Alliance
Alliance Canadienne de l'Epilepsie, Canada

Associate Members:

- * Epilepsy Action, Australia
- * Epi-Rodina, Czech Republic
- * Lithuanian Association for Integration of People with Epilepsy (LESIA), Lithuania
- * Association Clinique des Epileptiques, Togo





EUCARE

experienced a busy year focussing on the development of the sophisticated software required for the scientific element of

EUCARE. FONDE (Following Outcomes in Newly Diagnosed Epilepsy) will be a major prospective observational study of pharmacological and social outcomes in people newly diagnosed with epilepsy in Europe.

The study will generate a major resource in terms of prospective clinical and sociological data, that will ultimately stimulate improvements in epilepsy care.

The second element of EUCARE, that of advocacy, is already underway through the Political Action Group. Following a very successful meeting with Members of the European Parliament in mid-2006, the EUCARE Political Action Group is now creating the Parliamentary Advocates for Epilepsy Group. The group will comprise MEPs with an interest in epilepsy.

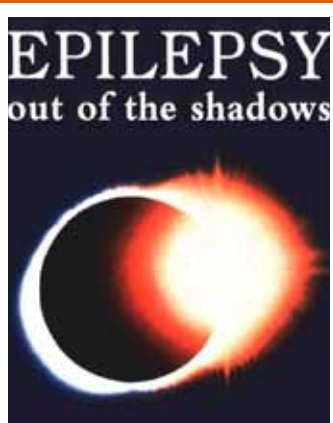
At a meeting of the group in November 2007, a series of



From left: Mike Glynn, Ann Little, Andreas Habberstad, Hanneke de Boer and Thanos Covanis

future activities were planned, including the collection of information on epilepsy centres in Europe, preparations for the EUCARE session at the 11th Conference on Epilepsy & Society in Marseille 2008, and the production a best practice handbook showcasing advocacy initiatives introduced by associations that have been successful in bringing about legislative change.

In December 2007, following the resignation of Karen Lee-Donaldson, Programme Manager, administration of EUCARE was taken over by the IBE office.



ILAE/IBE/WHO Global Campaign Against Epilepsy

2007 was an active year for the Global Campaign.

Demonstration Projects

Several projects are ongoing including:

Georgia: A project protocol was unanimously agreed by all stakeholders with funds made available through the Dutch government and *Nationaal Epilepsie Fonds*.

China: A major project in China has been finalised and the activities concerning the treatment of epilepsy have been taken over by the Chinese Ministry of Health. It is planned to cover the entire rural area of China and to include epilepsy in the national health programme. This project has now been incorporated into the national health programme of China.

Project Evaluation: It is intended to evaluate all completed demonstration projects to assess their impact on the treatment gap.

Consultant to the Campaign

A contract between IBE/ILAE and the WHO was signed at the end of the year, formalising the agreement to finance Dr Tarun Dua, a Medical Officer working on the Programme for Neurological Diseases and Neuroscience at the WHO in Geneva, to work on the Global Campaign within the WHO. It is anticipated that this connection will enhance the working relationship of the Global Campaign partners.

10th Anniversary of GCAE

A proposal was put forward for a commemorative brochure

to mark 10 years of the campaign. Dr Ted Reynolds, who first introduced the idea of the campaign, which was launched in Dublin and Geneva in 1997, has been invited to prepare a history of the Campaign.

Short annual reports about Campaign activities in 2005 and 2006 are also being drafted.

Project on Legislation

This newly introduced project is collecting information on existing epilepsy legislation and regulations in the areas of civil rights, education, employment, residential and community services, and provision of appropriate health care world wide, in order to review the comprehensiveness and adequacy of these measures in promoting and protecting civil and human rights of people with epilepsy.

Collation of GCAE activities

Aware that the Global Campaign name and logo are often used by ILAE chapters and IBE members for a wide range of projects at local, national and regional level without prior reference to the Campaign, it is planned to establish what activity has already taken place, what activity is currently underway, and what is planned for the future.

This information will assist in appreciating how and where the Global Campaign is being used; determining its value as an international brand for epilepsy; establishing the quantity and quality of projects being carried out in its name; and applying control measures to identify inappropriate use of the Campaign.

Eventually it planned to establish an official process to license the use of the Global Campaign name and brand. On a sad note, the Global Campaign lost one of its strongest supporters with the death of Dr Leonid Prilipko in



International Executive Committee Meets in Scotland

To mark the mid-point in the term of office of the International Executive Committee, a two day meeting was held in Glasgow in November.

The meeting focused in particular on a review of the IBE Long Term Strategy, with the revised document circulated to all stakeholders shortly after the meeting.

The committee also identified future activities, the main decision being the introduction of a third tier for Annual Dues, to assist those members who face financial hardship; the creation of a Fundraising Task Force to draft a strategy for future fundraising; consideration of a new Membership category to facilitate applications from associations in small, low-population countries or regions; and the launch of a special Membership Drive for 2008.

IBE acknowledges the support of Eisai and the Glasgow Convention Bureau.

Solidarity Fund

Supporting Members in Developing Regions

In 2007 the Solidarity Fund provided the means of supporting the annual dues of Full Members in 19 countries categorised as Low Income by the World Bank. Without this support it is likely that several of these members, who operate with very little financial backing, would not have been able to meet their dues obligations.

The generosity of many Members was shown through their donations to the Fund in 2007, and IBE would like to thank the following:

- Epilepsy Hospital Bethel, Japan
- Epilepsy Connections, Scotland
- Swiss Epilepsy Centre, Switzerland
- Gravesend Epilepsy Network, UK
- Joint Epilepsy Council of Australia, Australia
- ANLICHE, Chile
- AURA, Slovakia
- Swedish Epilepsy Association, Sweden
- Epi-Suisse, Switzerland

The **PROMISING STRATEGIES PROGRAM**, first launched in 2006, gathered momentum in 2007 as the first initiatives received funding.

In 2007, a total of 13 initiatives, which aimed at improving quality of life for people with epilepsy in developing nations, were supported. The funded projects were in Argentina, Cameroon, Ecuador, Gambia, Guatemala, Mauritius, Mongolia, Sierra Leone, South Africa, Romania, Uganda, Zambia and Zimbabwe.

In September 2007, a second round of funding was launched, with more than 20 applications received and with successful applicants due to be announced in early 2008.

IBE is grateful to Epilepsy Foundation of America which has provided annual support to the initiative. IBE would also like to thank the staff of UCB Pharma who donated the proceeds of a Fun Run to the program. The staff members have pledged to provide further sponsorship in 2008.

www.ibe-epilepsy.org/promising-strategy

Promising Strategies



Sixth Framework Programme Project LSH-037315



EPICURE kicked off with a meeting in Venice in January 2007, attended by representatives of the 30 partners connected to the project, including IBE. Involving 13 European countries, EPICURE is one of the most exciting European epilepsy research projects, with a budget exceeding €13 million.

During 2007, several integrated lines of research aimed at advancing the problem of preventing epileptogenic process and at understanding the role of genes in different types of epilepsy began and some preliminary results were obtained. Of

interest was the identification of 20 potentially important genes. Some molecular mechanisms responsible for the epileptogenic process in experimental models of post traumatic epilepsy were analysed. In this, and in other epilepsy models, the role of inflammatory molecules was highlighted, opening new perspectives in the prevention of the epileptogenic process.

It was agreed that the second annual meeting would take place in Malta. EPICURE is due to run for 4 years.

Vice President North America

Mary Secco joined the International Executive Committee at the end of 2007 as Vice President North America to fill the vacancy created by the resignation of Mrs Denise Crépin in early 2007.

Mrs Secco has been Executive Director of Epilepsy Support Centre, a community-based centre in London, Canada, for the past seven years.

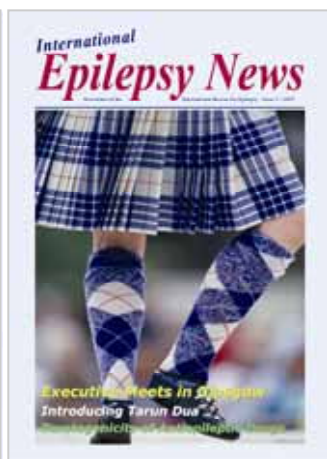
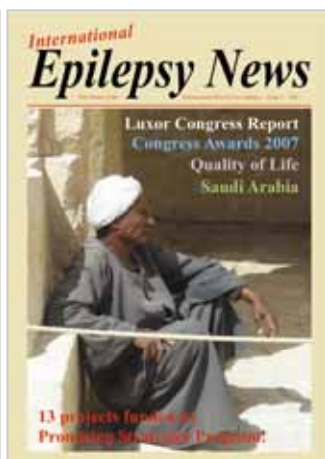
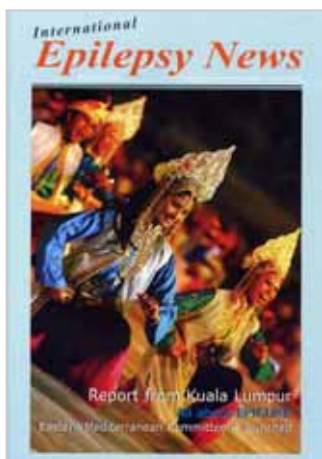


COMMUNIQUE AWARDS 2008

At the end of 2007, IBE learned that Action Zone, the board game developed to educate children about epilepsy, would be submitted for the Communiqué Awards 2008.

Action Zone is one of IBE's most successful and popular educational initiatives, with almost 46,000 units of the game distributed world wide in 2007.

The annual Communiqué Awards recognise best practice in pharmaceutical Public Relations and medical education.



International Epilepsy News

Edited by Dr Carlos Acevedo, IE News continues to be one of the most important voices of IBE and is used with great success to promote the activities both of IBE and of its Members.

Published four times each year, the newsletter is distributed in more than 120 countries world wide to IBE Members, Commissions and Task Forces, ILAE Chapters, Members of the European Parliament, UN representatives, WHO Regional Health Advisors, other NGOs, members of the pharmaceutical industry, and to libraries and subscribers.

During 2007 the magazine was made available on the IBE website for automatic download in full for the first time. The latest issue is uploaded to the password protected Members Section as soon as it is finalised, and at the

same time the previous issue is made available to all visitors to the site.

The success of the newsletter is made possible through the help and support of IBE Members who provide news, articles and photographs, so that IE News can truly reflect the trials and achievements of its members globally. The Editor is also assisted by the Regional Sub-editors and by members of the Regional Executive Committees, who play an important role in helping to identify reports and news items that will be of interest to readers.

During 2007, a new Experts column was introduced and has proven to be a very popular section of the newsletter. The magazine also continues to include regular reports in Spanish to highlight the work of IBE Members in Spanish-speaking countries and particularly in Latin America.

Website Refreshed!

After almost a year of hard work, the new IBE website was launched at the end of November 2007. Thanks are due, in no small measure, to the members of the Website Task Force: Shunglon Lai (Chair), Paul Sharkey and Ken Lowenberg, who oversaw much of the elements involved. This was the first major overhaul of the site since it was first launched in May 2001.

Attention has been paid to ensuring that the pages are easy to navigate, with many sections now accessible directly from the home page.

Special pages are provided for each of the seven Regional Committees, with a range of articles and reports that are regularly updated.

A dynamic new feature is the photo gallery that shuffles the photos displayed each time a page is refreshed. Another addition is the Google mapping feature that allows visitors to find the location of each member with pinpoint accuracy.

For Members, there is now a dedicated password protected section that hold reports, downloads, logos, forms, ballot papers and procedural documents and guidelines, for easy access by Full and Associate Members.

So why not pay us a visit at www.ibe-epilepsy.org.



www.ibe-epilepsy.org

Regional & International Congresses 2007



In early July, the 27th International Epilepsy Congress took place in Singapore. It had been 20 years since the congress had last been hosted in Asia, when India played host in the late 1980's.

Singapore proved to be a successful and popular destination, attracting three thousand delegates from all regions of the world. The dedicated Organising and Scientific Committees, with great assistance from the local IBE and ILAE member associations, ensured that the Scientific Programme was of high quality. All of the sessions and workshops were very well attended and provided a good mix of social and medical debate.

Apart from the Scientific Programme, there were also special sessions and events organised by IBE.

The special Symposium for People with Epilepsy and their Carers, organised jointly by the IBE Regional Committees in South East Asia and Western Pacific was fully booked, signifying the ever increasing popularity of this congress event. In addition to lay people and their families, the symposium was also attended by a large number of neurologists and doctors. The symposium ran in tandem with the scientific programme and included both formal and social activities.

As usual, the IBE General Assembly was held on the second last day of the congress, with an attendance of over 120 members. The assembly marked the mid-point of the term of the current committee and to mark this the Open



Forum element of the assembly discussed IBE's Long Term Strategy. There was also the opportunity to provide a platform to some members who had specifically requested time to present news from their associations. These included Sari Tervonen from Finland who showed a short clip from the film *The Year of the Wolf*; Shichuo Li from China who talked about the annual Epilepsy Day in China that has been launched; and Anthony Zimba from Zambia who had delegates clapping in rhythm to a terrific music CD which the association has produced to raise funds and to educate people about epilepsy.

Other activities included the display of posters promoting the work of more than 42 member associations, a display of Promising Strategy initiatives, and a very professional exhibition of Freedom in Mind artwork mounted by UCB, which showed a selection of entries to the project, which is a joint initiative of IBE and UCB.

IBE Volunteer Award

The IBE Volunteer Award, introduced in 2006 as a means of recognising the efforts of lay volunteers to improve the quality of life of people with epilepsy at national and local level and to highlight the tremendous efforts undertaken without recompense, was announced for the first time during the General Assembly in Singapore.

The award was presented to Mrs Margaret Fandiño Merz, Colombia, who had been nominated by the Foundation for the Rehabilitation of People with Epilepsy (FIRE) and the Colombian League Against Epilepsy.





The ancient city of Luxor in Egypt with its historic temples and tombs, provided a wonderful venue for the 1st East Mediterranean Epilepsy Congress in February 2007.

This joint congress of IBE and ILAE, with more than 400 delegates attending from within the region and further a-field, was an important inaugural meeting.

During the congress IBE celebrated the launch of the Eastern Mediterranean Regional Committee and introduced Dr Abdulaziz Al Semari, Vice President for the region.

Elections have now been held to fill positions on the Regional Executive Committee Eastern Mediterranean, with the following results:

- Chair: Mrs Manar Sawan (Lebanon)
- Vice Chair: Dr Muhamed Aldossari (Saudi Arabia)
- Secretary: Dr Najib Kissani (Morocco).

Ambassador for Epilepsy Awards 2007

Ambassador for Epilepsy Awards were bestowed on the twelve worthy recipients pictured below. IBE President Susanne Lund and ILAE President Peter Wolf made the presentations during the Opening Ceremony of the 27th International Epilepsy Congress, Singapore 2007.



Eva Andermann



Alexis Arzimanoglu



Helen Cross



Yukio Fukuyama



Pierre Genton



Gregory L Holmes



Reetta Kälviäinen



Shih Hui Lim



FH Lopes de Silva



MM Mehndiratta



Tomás Mesa



Paolo Tinuper

Social Accomplishment Award 2007

The Social Accomplishment Award was presented to Dr John Kirker from Ireland to recognise his outstanding activities aimed at the social benefit of people with epilepsy.

Dr Kirker's medical career dates back to 1944. He has been involved at international level for much of that time and chaired the

IBE Driving Commission for many years. He is currently a member of the Second European Working Group on Epilepsy and Driving - which is an advisory group to the European Union.

Dr Kirker had already been presented with an Ambassador for Epilepsy Award in 1974.





AFRICA

AFRICAN REGIONAL EXECUTIVE COMMITTEE

Chair: Zenebe Gedlie Damtie, Ethiopia

Vice Chair: Augustine Mugarura, Uganda

Secretary: Anthony Zimba, Zambia

Zenebe Gedlie Damtie

MEMBERS OF THE AFRICAN REGIONAL COMMITTEE

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Strategies with Promise in Africa



Tomato growing
Cameroon



Vegetable farming
The Gambia



Massage therapy
Mauritius



Tailoring workshop
Sierra Leone



Entrepreneur Program
South Africa



Anti-Epileptic Drugs Bank
Uganda



Poultry rearing
Zambia



Awareness Raising Program
Zimbabwe

Introduced in 2006, the Promising Strategies Program provided financial support to a total of eight new and innovative initiatives in Africa under the first round of funding in 2007. The projects are aimed at improving the quality of life for people with epilepsy using diverse and often novel methods.

In **Cameroon**, where 5.8% of the population has epilepsy, a tomato growing and pig rearing initiative was created under the leadership of Sr Franca de Simone at the Cameroon Association Against Epilepsy. The project will help people with epilepsy to become self-sufficient.

Agriculture was also the focus in **The Gambia**, where 30 people with epilepsy were trained in vegetable growing at the Gambia Epilepsy Association. The Gambian project also included instruction in tailoring and in food and nutrition.

To improve the quality of life of people with refractory epilepsy, Edycs Epilepsy Group **Mauritius** introduced Massage Therapy Training in collaboration with the Massage Therapy Clinic of Port Louis. One of the objectives of the programme is to promote massage as a complementary treatment for people with uncontrolled seizures.

Tailoring was also the focus in **Sierra Leone** where the Epilepsy Association of Sierra Leone sought funding

to training 50 people with epilepsy in textile tailoring.

In **South Africa** Promising Strategies funding helped Epilepsy South Africa to roll out the International Labor Organisation's Start and Improve Your Business (SIYB) Program. This entrepreneur program is currently used in 90 countries world wide.

Following on the model introduced by ANLICHE in Chile, the Epilepsy Support Association, **Uganda** introduced a Community Drugs Bank, offering affordable AEDs to people with epilepsy. With 90% of the population living in remote rural areas, nurses and healthcare workers will take the AEDs to people living in remote regions.

Poultry husbandry and egg production was the concept of the Epilepsy Association of **Zambia**. The association provided tuition in raising chickens, providing two sources of income—the chickens and the eggs they laid. A portion of the profits is also pumped back in to the association to meet the cost of further training programmes.

Epilepsy Support Foundation, **Zimbabwe** initiated a special programme targeting rural districts in order to dispel the myths surrounding epilepsy that discourage people from seeking diagnosis and treatment. An important element of the program is the creation of educational workshops for traditional healers and herbalists.

Meeting in Cape Town, South Africa



A Consultative Meeting for IBE Members in the southern region of Africa took place during the year. The event, attended by member associations from South Africa, Zambia, Swaziland and Zimbabwe, provided the opportunity to share common interests and to map out areas where members could collaborate productively. Common goals identified included a common

agenda in human resource development, improvement of communications in the region, the idea of an African Epilepsy Day and a proposal to hold future collaborative meetings.

Inclusion South Africa

Inclusion South Africa (ISA) was established by Epilepsy South Africa, the South African Federation for Mental Health, Down Syndrome South Africa and Autism South Africa to focus attention on the so-called “second tier of discrimination within the disability sector”. Since it was set up in 2007, ISA has successfully obtained membership of Inclusion International.

Edycs Epilepsy Group

For Edycs Epilepsy Group, Mauritius, a highlight of 2007 was the opening of a Epilepsy Health Service Centre, in Port Louis.

The Opening Ceremony was attended by the Right Hon. Sir A Jugnauth, President, Republic of Mauritius.

The European Union Decentralised Cooperation Programme supported Edycs in the purchase of medical equipment for the new centre.

Edycs also received a new vehicle from the Prime Minister’s Office through the Ministry of Social Security to help with the activities of both Edycs Epilepsy Group and the new epilepsy centre.



Mauritius

Epilepsy South Africa Capacity Building

Epilepsy South Africa supports and develops various income generation projects within communities, such as textile weaving, where people with epilepsy and other disabilities work or perform craftwork for financial gain.

Through these programmes people with epilepsy and other disabilities are empowered to increase their skills and knowledge, which will in turn increase their ability to earn money and become self sufficient.

Pictured right are some of the colourful floor rugs spun by South African women at one of Epilepsy South Africa’s income generation projects in 2007.



Swaziland Epilepsy Association

Swaziland Epilepsy Association held a dinner to formally introduce the Board of Trustees to His Royal Highness Prince Bandzile, Patron of the organization. Each board member introduced themselves and gave a brief background of their work.

His Royal Highness Prince Bandzile warmly welcomed the board of Trustees and thanked them for voluntarily

availing themselves for a worthy cause.

An important issue that was raised was that there was clearly a need to raise awareness in the public and to reach out to as many people as possible.



Epilepsy Support Association Uganda

The main activity of the Epilepsy Support Association Uganda (ESAU) is to mobilize people with epilepsy, their parents and guardians into support groups. So far the association boasts 139 support groups in 20 districts. During 2007:

- ◆ Over 5,000 Brochures in 6 local languages and English were produced.
- ◆ Over 1,000 Posters were produced in conjunction with Ministry of Health.
- ◆ Calendars with epilepsy messages were printed at the start of the year and distributed.
- ◆ Spots messages were aired on 3 regional radio stations on epilepsy and a few hosted a talk show as well.
- ◆ In 2007 forty new volunteers were trained in community mobilization, volunteering, basic counselling and referral, bringing the number to 465 volunteers in total.
- ◆ ESAU formed partnerships with Local District governments and has signed memoranda of understanding with a number of these.



Association Clinique des Epileptiques TOGO

The activities of the association in Togo in 2007 concerned both ongoing patient care, established by Dr Sodjehoun after his return to Lomé in 2001, as well as the construction project in Sanguera, where a new outpatient clinic was being built on the outskirts of the capital, Lomé. The construction of a single-building outpatient centre in Sanguera was made possible by donations from German, French and Swiss support groups. With the opening ceremony due to take place in Spring 2008, it is the only facility of its kind in Togo and hopes to serve patients' needs from the entire region including the neighbouring countries Benin and Ghana.

Epilepsy Support Foundation of Zimbabwe

2007 will be remembered in Zimbabwe as the year a specialized epilepsy clinic started at the Epilepsy Rehabilitation Centre in Harare.

We are also grateful to the Ministry of Health for providing a grant each month to pay the nurse and assistant. The clinic supplies medication which has been donated to it by corporate partners. But this medication is never adequate. Most of the time patients return home without medication and their families struggle to purchase it. Unfortunately, the prices are

so prohibitive that compliance is greatly affected. The major challenges facing the Foundation are resources in general, compounded by high levels of inflation in Zimbabwe. The clinic has been hardest hit by a shortage of medication.

The EpiAction group of youngsters with epilepsy, supported by those affected in one way or the other, has done extremely well in empowering youth to live positive lives. They have recorded drama and poems and they have plans for an audio album in 2008.





Eastern Mediterranean

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Vice Chair: Muhammed Aldossari, Saudi Arabia

Secretary: Najib Kissani, Morocco

Vice President: Abdulaziz Al Semari, Saudi Arabia (*ex officio*)

Manar Sawan

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Association of Care of People with Epilepsy Lebanon

The Association of Care of People with Epilepsy in Lebanon has helped 500 people with epilepsy by providing medical checkups, laboratory tests and reports and social and healthcare support.

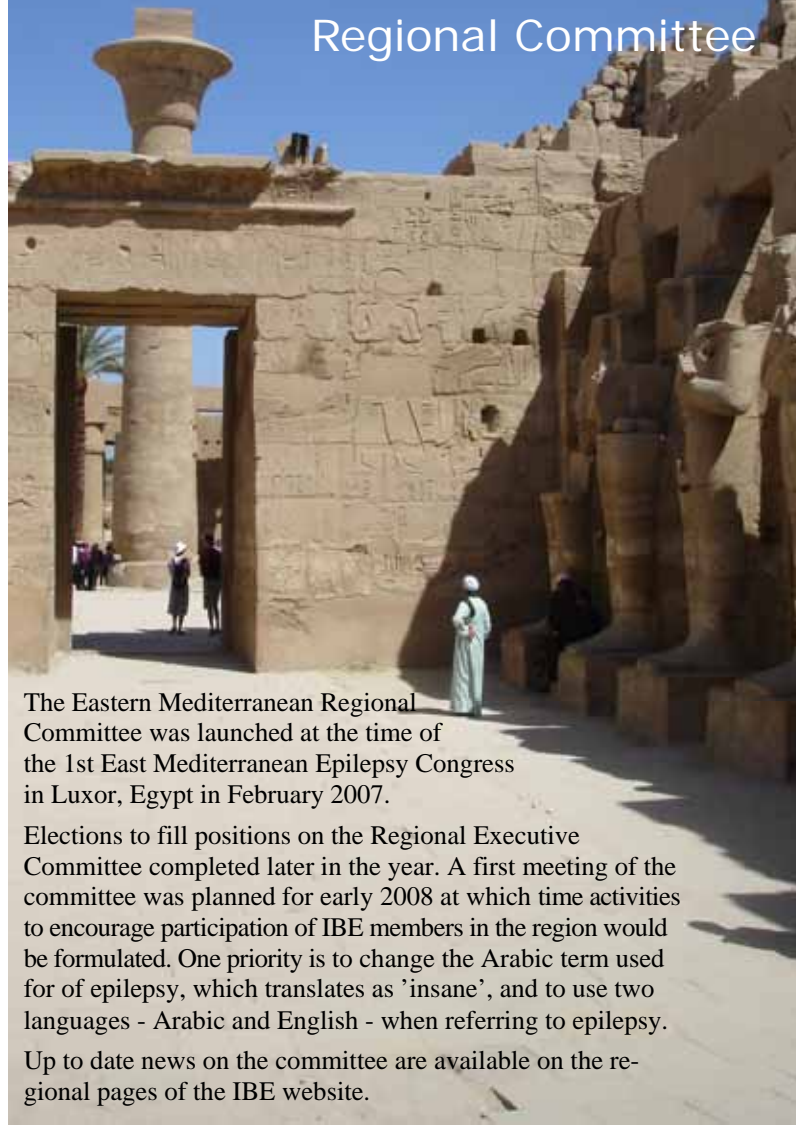
The association is carrying out epilepsy research, holding information meetings to acquaint people with what epilepsy means, and participating in talk shows through which people will learn to recognise the symptoms of epilepsy and how to help someone having a seizure.

A VNS transplant took place in Lebanon for the first time in 2007; the cost of the apparatus and treatment, totalling US\$30,000, was met by donations.

The association participated in local awareness raising events that were held in private schools, in addition to the ongoing exhibition held in Khan Al Efranj in Saida for the purpose of promoting the jewellery and other craft goods produced by members of the association.



Launch of Eastern Mediterranean Regional Committee



The Eastern Mediterranean Regional Committee was launched at the time of the 1st East Mediterranean Epilepsy Congress in Luxor, Egypt in February 2007.

Elections to fill positions on the Regional Executive Committee completed later in the year. A first meeting of the committee was planned for early 2008 at which time activities to encourage participation of IBE members in the region would be formulated. One priority is to change the Arabic term used for of epilepsy, which translates as 'insane', and to use two languages - Arabic and English - when referring to epilepsy.

Up to date news on the committee are available on the regional pages of the IBE website.

Epilepsy Support and Information Centre Saudi Arabia

2007 has been a very busy year for the Epilepsy Support and Information Centre (ESIC) of Riyadh, Saudi Arabia.

Teacher Awareness Program (TAP)

ESIC significantly accelerated implementation of the Teacher Awareness Program (TAP) by negotiating the support and collaboration of the Riyadh Branch of the Ministry of Education (Women's Section). Ministry support enabled ESIC to develop a regular two monthly Seminar Schedule of elementary and secondary schools in Riyadh.

The Teacher Awareness Program (TAP) is designed to educate teachers and other school staff members to recognize seizures and respond appropriately to seizure types, and to encourage educators to be more accepting and understanding of the child or adult with epilepsy.

In support of this program, ESIC has developed standardized lecture-presentations that may be utilized by various speakers in each individual workshop.

Symposiums for Healthcare Professionals

To promote enhanced medical care and strengthen

medical emergency response to epilepsy, ESIC organizes regular accredited full day Epilepsy Symposiums for Primary Health Care Professionals.

The 4th in a series of Symposiums, *Women and Newborns with Epilepsy*, was held in three cities in Saudi Arabia. In support of this symposium, ESIC developed and published two separate booklets on Women and Epilepsy; one booklet for Healthcare Professionals and a second booklet designed specifically for women with epilepsy.

Family Festival for Epilepsy Awareness

Each year, ESIC organizes an all-day Epilepsy Family Festival to promote increased recognition and awareness of epilepsy in the community and to provide support, recognition and respect for children with epilepsy and their families.

This successful public event mixes games and entertainment, with educational activities including an epilepsy facts quiz draw, seizure first aid demonstrations and brief lectures about epilepsy.

Attendance at the Festival usually exceeds 800 people.



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Vice Chair: Athanasios Covanis, Greece

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Photo: Peter Dahlqvist

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Activities of the European Regional Executive Committee 2007



Photo Finola Quinn

Marseille conference planning meeting: from left: Peter Dahlqvist, Seppo Sarkkulla, Jacqueline Beaussart (AISPACE), Andreas Habberstad and Thanos Covanis

11th European Conference on Epilepsy & Society—Marseille 2008

Preparations for the European Conference on Epilepsy & Society were ongoing during 2007. The committee worked on the conference programme and other details in collaboration with AISPACE, the French IBE member and with the IDM office.



The theme of the conference in 2008 is Active Life and Epilepsy. Planned highlights included sessions on Epilepsy and Humour and Epilepsy in Contemporary literature. The UN Convention on the Rights of Persons with Disabilities was expected to stimulate lively discussion.

A EUCARE Best Practise session with excellent speakers was also on the programme as well as parallel workshops in both English and French. The European Regional Committee had also provided a significant amount of funding from its budget to make a number of bursaries available to help some delegates to attend the meeting.

27th International Epilepsy Congress Singapore 2007



The Regional Executive Committee initiated and participated in one of the parallel sessions held during the international congress in Singapore, titled *European and Asian Action to Improve Quality of Life*, in collaboration with the IBE Regional Committee South East Asia.

The session focused on actions taken on both European and Asian regional levels as well as at national level in order to improve Quality of Life for people

with epilepsy and their families or caretakers. It is vital to take action to reduce stigma and other negative consequences of epilepsy and to focus on promoting positive attitudes to allow people with epilepsy to live rich and fulfilled lives in spite of their condition. National epilepsy organizations and their international bodies contribute to introducing change, both by offering services, training and education aimed at individuals, and by political actions and campaigns to make their voices heard and to put epilepsy on the political agenda. Improved legislation regarding for example driving license regulations is important and actions aimed at raising awareness among political bodies and authorities is vital.

EUCARE

The European Committee participates in EUCARE – European Concerted Action on Research in Epilepsy – a joint project of ILAE and IBE in both the Management Group as well as the EUCARE Political Action Group; the latter has as its focus activities within the European Parliament and other European political bodies.

New Members Action Plan

The committee has introduced steps to support the development of new member organisations from 2007 until the end of the term of office in mid-2009. It invited representatives from Armenia, FYR Macedonia and Albania to attend its meeting in Athens on 11th November. The purpose was to inform and to encourage the implementation of initiatives to create new epilepsy organisations which, in



Aerial view of Athens
Photo: Ann Little

time, could become new IBE member associations. The committee believes that some progress has been made.



Caritas Malta Epilepsy Association

final year. The partners for this program are from Malta, Germany and Hungary. As a result of the work carried out, a 'Guidebook' for Mentors who want to use it as a tool to train the trainers was formulated.

In November 2007 Caritas Malta Epilepsy Association organised a seminar in collaboration with the Malta Union of Nurses and Midwives.

During 2007, our President, Mr. Mario Dimech was also invited to give a 'patient perspective' during a two day seminar for medical professionals. Participants travelled from all over Europe.

For the third year running, an in-service course for teaching professionals was organised in 2007 by Caritas Malta Epilepsy Association in collaboration with the Ministry of Education. The Grundtvig program – 'Education for Professionals Allied to Medicine' came to its third and

In September, the National Association of People with Epilepsy in Romania - EpiRomania - opened the first epilepsy clinic in Romania - EpiCenter. This would not have been possible without the support of Nationaal Epilepsie Fonds (Netherlands).

Seven years of working directly with people with epilepsy throughout Romania identified the need for good quality medical services as one of the most important issues to be met. The clinic has a team of young and dedicated professionals, as well as high quality medical equipment. Unfortunately, people with epilepsy have to pay for the services provided by the clinic but, even so, 771 people have been seen in the clinic in the first 10 months since its opening in September. Approximately 50% of those attending the clinic have come from other regions, some as far as 700 kilometres away.

Knowing the importance of accurate diagnosis and appropriate treatment of epilepsy, the clinic is committed to offering continued high quality services for all people with epilepsy; thus contributing to the improvement of the quality of life of people with epilepsy in Romania.

EpiRomania



Spolecnost "E., realize the wide range of problems concerning epilepsy and the need to align these problems according to their urgency. Epilepsy affects not only as an illness but also through its social consequences. It can complicate integration into schools and colleges, partnerships and relationships, employment, etc. We have concentrated on a topical problem – the shortage of information about epilepsy among teachers, the public, other specialists, police and fire departments.

Since 1991 we have been publishing the magazine Aura. It is one of the important sources of current information about the treatment of epilepsy, medication and readers' opinions. It also functions as an informative bulletin.

Many people with an illness or condition feel the need to communicate with those who are in a similar position to share experiences and to learn how others deal with the social consequences of the illness. That is why respite stays organized by our association for children and adults both within the country and abroad are so popular. A neurologist is always present at such events. It has been proven that these stays have a beneficial effect not only on psyche of the person with the condition but also on family members.

Spolecnost "E," Czech Republic

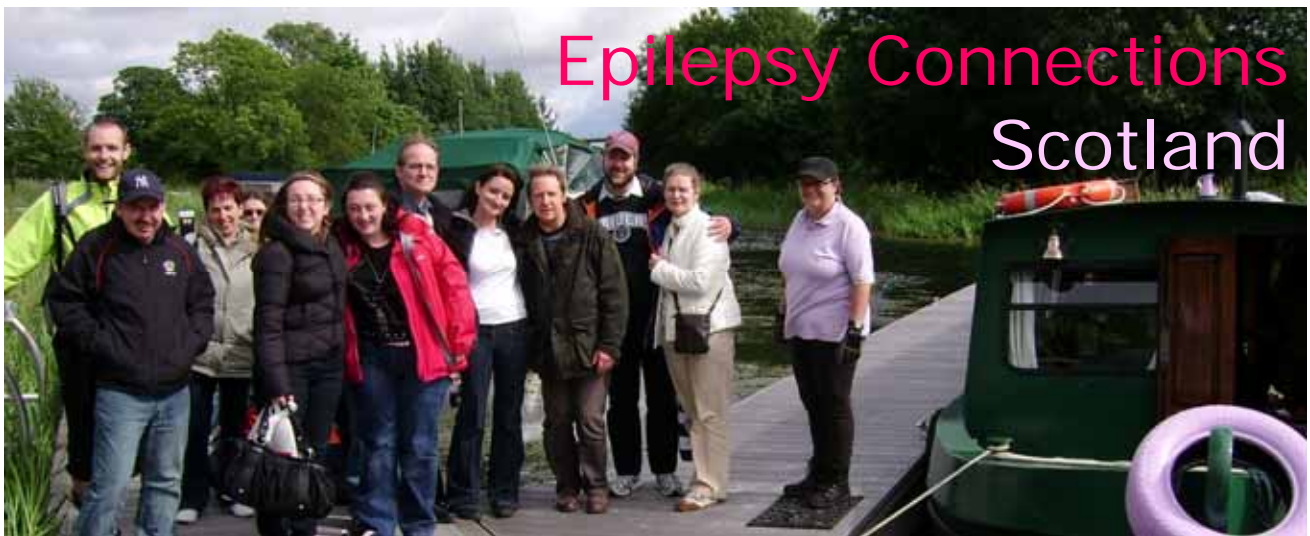
Deutsche Epilepsievereinigung Germany

Besides the information we offer on epilepsy, the focus of our work lies in improving awareness on epilepsy in the public and reducing negative attitudes and the social consequences that may arise when epilepsy is diagnosed. That aim is connected with supporting self-help groups financially as well as in structural issues.

We are very happy that, despite difficult circumstances, we had a very successful year. The most important activities during the year included:

- ◆ Maintaining special information and advice services for parents.
- ◆ National event on 5th October with the theme “Epilepsy – don’t fall over.”
- ◆ Arranging a cooperative initiative for professionals (doctors, pharmaceutical industry, health insurances, etc.)

We also arranged a series of workshops covering a wide range of themes and directed at various audi-



During the year we produced three new leaflets: *Non-Epileptic Attack Disorder*, *Epilepsy and Memory* and also *Dental Health Care* as well as guidelines to help in completing Disability Living Allowance Forms for adults with epilepsy and a Home Safety Pack.

We ran glass painting events for Black Minority Ethnic (BME) carers of people with epilepsy, adult art sessions, drama classes, a Pantomime session for children, and a series of complementary therapy sessions in Glasgow and

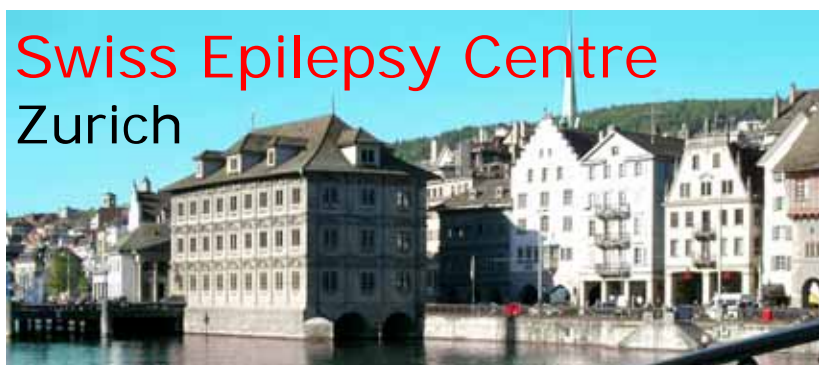
Stirling, as well as having a band of volunteers growing fruit and vegetables on our allotment – all of which have proved to be extremely popular. Our Multicultural Project also held a Dissemination Event to share the findings from the report ‘Epilepsy, Culture and Religion: Working with BME Groups in Glasgow’ produced by Farhat Khan. All of the above have been run in addition to our Fieldwork, Befriending, Schools, Multicultural, Mainstreaming and Living Well with Epilepsy Projects.

At the Swiss Epilepsy Centre activities in 2007 were aimed at information about epilepsy. Themes ranged from epilepsy in daily life, through teenagers with epilepsy and career training, to nursing and care of geriatric patients with epilepsy. The aim was to reach a variety of target groups including education departments and schools, churches, residential homes, rehabilitation clinics, general and specialised nursing schools.

Special courses were organised by our nursing and pedagogic department for staff of other institutions involved in the care of people with epilepsy.

The social department also organised evening information sessions on various aspects for parents of children with epilepsy.

The Swiss Epilepsy Foundation encourages and promotes integration of people with epilepsy, one example being



the new “Epi prize”. This award, with a prize fund of Swiss Francs 10,000 is awarded bi-annually to persons or companies that play an active role in the integration and / or employment of people with epilepsy.

Danish Epilepsy Association Denmark

Odense, Denmark

During 2007, the Danish Epilepsy Association (DEA) completed a survey on living conditions for adult members, the results of which help identify areas of political interest. We are now undertaking a similar survey of children, adolescents and their relatives. Documenting the needs of this group is very valuable. Once the survey of children and adolescents is completed, we will look at how siblings of children with epilepsy cope.

DEA has been working to change Danish law on generic substitution of AEDs. Improvements have been made but the problems have not yet been solved.

We continue to cooperate with the Epilepsy Support Association of Uganda on a project funded by Danida. Like most of the voluntary corps in Denmark, DEA is finding problems in recruiting members and volunteers to the association. It is also difficult to recruit people to fill important political posts for association boards, committees and forums to which we might dispatch a representative.

Epilepsy Scotland Scotland

- ◆ This was election year for the Scottish Parliament. Our campaign manifesto for new candidates included the call for more first seizure clinics, shorter waiting times to see a specialist, additional epilepsy specialist nurses and epilepsy in later life training.
- ◆ The Scottish Parliament Cross-Party Group on Epilepsy was re-established. It has the second largest membership among politicians.
- ◆ A 'Kerr in the Community' conference for over 100 health professionals looked at how Government policy will assist epilepsy services in local communities.
- ◆ We successfully campaigned for a less complicated scheme to help people with epilepsy access a Scotland-wide free bus pass. We worked closely with the Scottish Government department Transport Scotland. Our work was aided by epilepsy specialist nurses, the Scottish Parliament's Cross-Party Group on Epilepsy and the Joint Epilepsy Council of the UK and Ireland.
- ◆ We found new ways to provide information. The Royal College of Physicians and Surgeons of Edin-



burgh asked us to prepare direct online information for GPs. Doctors could download our epilepsy information from their own health database.

- ◆ A User Involvement Officer was appointed to develop our services. Hundreds of people attended a series of monthly information events held across the country.

Photo: Cross-Party Group on Epilepsy with guest speaker from NHS Lothian epileptologist Susan Duncan; Co-Convenor Mary Mulligan MSP; Epilepsy Scotland's Chief Executive Susan Douglas-Scott and second Co-Convenor, Alasdair Allan MSP (who has epilepsy).

Epilepsie Euro Services France

Activities in 2007:

- ◆ A European Comparative Study 'Fear, Prejudice and Representation' relating to employment, or safeguarding employment, of persons with a chronic illness such as epilepsy.

- ◆ The European Programme EQUAL 'Epilepsies, businesses and public collectives—discrimination in employment' in which the partners include Bethel in Budapest, Brainwave The Irish Epilepsy Association and Caritas Malta Epilepsy Association.
- ◆ Development of the training department, with sessions for employers and practical analysis sessions.
- ◆ Production of a Best Practice Guide for Employers.



Latin America

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Chair: Lilia Nuñez Orozco, Mexico

Vice Chair: Elza Marcia Yacubian, Brazil

Secretary: Tomás Mesa, Chile

Vice President: Carlos Acevedo, Chile (*ex officio*)

Lilia Nuñez Orozco

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Informe 2007

Comité Latinoamericano del IBE



27° Congreso Internacional de Epilepsia, Singapur

- ◆ La Dra Alicia Bogacz, IBE de Uruguay y la Dra Lilia Núñez, junto con dos miembros de la Comisión Latinoamericana de ILAE integraron el panel de Medicina Alternativa en Epilepsia, presentado en sesión de grupos de discusión.
- ◆ La Sra Margaret Fandiño-Merz, de Colombia, postulada por Liga Colombiana contra la Epilepsia y la Fundación para rehabilitación del personas con Epilepsia, obtiene el premio de voluntariado del IBE 2007 (IBE Volunteer Award).
- ◆ El Dr. Tomás Mesa, de Chile, recibe la nominación de Embajador de la Epilepsia.

Otras Actividades

- ◆ Publicación de la II Edición del Libro: **Epilepsia: lo que Ud. debe saber.**



Tomás Mesa recibiendo la nominación de Embajador de la Epilepsia en Singapur

Reunión del Comité Latinoamericano in Singapur:

Laura Guilhoto, Brazil; Tomás Mesa, Chile; Ann Little (IBE Office); Lilia Núñez Orozco, Mexico; Susanne Lund (IBE President); Jaime Fandiño Franky, Colombia; Alicia Bogacz, Uruguay; Manuel Campos, Chile; Marco Tulio Medina, Honduras; Carlos Acevedo, Chile; and Patricia Braga, Uruguay.

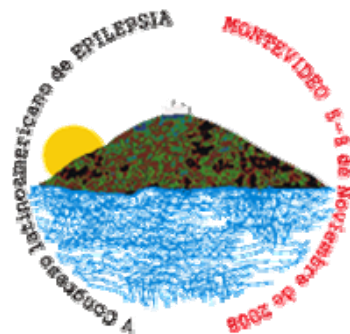
- ◆ El IBE de Colombia, encabezado por el Dr Jorge Fandiño, logró la aprobación de una legislación a favor de las personas con epilepsia.
- ◆ Se publicó un artículo sobre Trabajo y Epilepsia en International Epilepsy News.
- ◆ Se han hecho gestiones con personas que encabezan asociaciones de pacientes con epilepsia en diversos países latinoamericanos para que se integren al IBE: Honduras, Republica Dominicana, Bolivia, Paraguay.
- ◆ Se planifica reunión del Comité Ejecutivo del IBE Latinoamericano para Mayo 2008 en Chile, para analizar y programar las acciones de dicho comité en la región, aprovechando el Simposio Internacional de la Liga Chilena contra la Epilepsia, con motivo de la celebración de sus 55 años de vida.

5° Congreso Latinoamericano de Epilepsia - Montevideo 2008

Participación en la primera reunión organizativa del 5° LACE Montevideo 2008.

Se decidió que uno de los co-chairs fuera la presidenta del Comité LA de IBE, Dra Lilia Núñez, quien asistió a dicha reunión en Montevideo en Marzo.

Se hizo la visita de inspección y el programa preliminar donde se incluyen temas de interés para el IBE en sesiones plenarias.



Group 'Acceptation' of Epilepsy Mexico

- ◆ The association arranges an annual program of information sessions, which are held on the first Saturday each month, with average attendance of 200 persons.
- ◆ There is also an annual program of psychological support with group therapy, provided 3 times each month, to build self confidence and to improve understanding of the consequences of epilepsy for persons with epilepsy, their relatives and friends.
- ◆ We provide information on epilepsy to the general public through posters located in Metro Stations of Mexico City.
- ◆ A new edition of the book *Clinical Handbook on Epilepsy for Lay People*, written by Dr Lilia Núñez-Orozco was published.
- ◆ Dr Núñez-Orozco participated in the session *Alternative Medicine in Epilepsy* during the 27th International Epilepsy Congress in Singapore, June 2007.
- ◆ Organization of the 2nd Congress of the Mexican Chapter of IBE in Guadalajara with a 3-day program and attendance of 350 persons from different cities of the country representing support groups for people with epilepsy.



FUNDEPI Argentina



Each year we organise a programme of activities for a special epilepsy week to promote awareness and to improve the quality of life of people with epilepsy. This year we tried to involve other hospitals in Argentina to make it a national event.

- ◆ We encourage health departments to address the needs of people with epilepsy, including awareness, education, diagnosis, treatment, care and prevention.
- ◆ We advocate for new epilepsy legislation in respect of treatment and anti-discriminatory regulation.
- ◆ We analyze the social and economic situation of 3,217 people with epilepsy who attend our centre. The ability to hold down a suitable job is a pivotal step in the rehabilitation of the persons with epilepsy.

The rate of unemployment is around three times higher than in the general population. So, however impressive scientific and therapeutic progress may be, its full effect cannot be achieved without tackling the complex problems of the social and economic aspects of epilepsy, which are far from being solved.

Venezuelan League Against Epilepsy—LIVECE Venezuela

During 2007 educational campaigns on various topics, with specific emphasis on Neurocysticercosis in those areas where research has shown a high prevalence of epilepsy caused by parasites, took place using radio and the Press.

Screening consultations, diagnostics, control, treatment, and follow up visits of people with epilepsy (children and adults) take place in LIVECE's office on a daily basis.

Workshops on epilepsy, its definition, causes, prevention, diagnosis and treatment are planned in the *Jardín Botánico de la Universidad Central de Venezuela's* auditorium for consultants and GPs, nurses, and other professionals.

The Social Security Program, involving the supply of AEDs at cost price, was set up by specialized pharmacological laboratories.

This year, plans were drafted for the establishment of the Venezuelan Academy against Epilepsy, in conjunction with the Venezuelan Society of Neurology and selected expert Professors in the field.

Caracas, Venezuela



IBE Ecuador Chapter



y también en la prevención de dichas dificultades.

Durante el mes de Abril, el Centro Nacional de Epilepsia, conjuntamente con la Asociación de Padres de Niños con Epilepsia, organizaron un evento internacional en el que se trataron sobre dificultades afectivas y la plasticidad cerebral en el paciente con epilepsia. Dentro del aspecto educativo también se han confeccionado folletos informativos que se han difundido a través de centros educativos y de salud.

Con el propósito de mejorar la calidad de vida al paciente con epilepsia, el Centro Nacional de Epilepsia ha establecido conjuntamente con la Delegación Ecuatoriana de la Organización Internacional de Psicomotricidad de París, un convenio que posibilite la formación de profesionales en el ámbito de la Neurología del Desarrollo y la Psicomotricidad (NEUROPSICOMOTRICIDAD) con el propósito de difundir conocimientos dentro de este arte-ciencia, alternativa terapéutica que permitiría actuar sobre las deficiencias neuro-psico-relacionales de los pacientes

El banco de medicamentos con el que cuenta el Centro Nacional de Epilepsia se ha mantenido constante durante todo este tiempo y esto ha sido posible gracias a la ayuda de algunos laboratorios farmacéuticos y de forma especial al International Bureau for Epilepsy dentro de su proyecto Promising Strategies, lo cual nos ha permitido entregar medicación gratuita a personas de escasos recursos económicos. Conviene también señalar que el Consejo Nacional de Discapacidades, organización gubernamental, ha señalado su intención de mantener esta ayuda de carácter social.

Asociación Uruguay contra la Epilepsia Uruguay



The activities of the Asociación Uruguaya contra la Epilepsia, AUCLE, during 2007 were concentrated on a campaign to obtain a “House for People with Epilepsy” to give an opportunity to people with epilepsy to improve their level of education and assist them in obtaining employment skills.

- ◆ There were interviews in magazines and on TV shows.
- ◆ The principal fundraising event was a gala dinner in the Uruguayan Golf Club, which was very successful.

Our picture shows the AUCLE fundraising team attending the gala dinner.



North America

NORTH AMERICAN REGIONAL EXECUTIVE COMMITTEE

Due to the number of members in the region, there is no elected Regional Executive Committee for North America. Instead representatives from the IBE member associations meet informally and communicate largely through email.

Mary Secco, Vice President North America

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Activities in the North American Region 2007

Jamaican Epilepsy Association Jamaica

During 2007 many of the goals of the Jamaican Epilepsy Association (JEA) were achieved, despite reduced corporate support due to the downturn in the economy. We achieved our main goal in October 2007 with the opening of our Secretariat at Andrews Hospital. We now have a permanent office with an administrative secretary and a 'home' for our members to visit. This was made possible by support from the local CHASE FUND and by the fund-raising efforts of the JEA.

We raised great media and public interest with the production of our 2007 calendar 'How Does My Garden Grow' featuring twelve of the islands well-known women in a garden setting. The calendar was sponsored by local corporations and had uplifting messages from each model. The calendar along with

our children's book 'Way to Go Flash', about a Jamaican horse with epilepsy, has helped to spread the word about epilepsy.

The Association teamed up with human resource company, Hamilton Knight Associates, which offers free CV preparation to our members and will assist with job placement in the workforce. Through the kindness of a psychiatrist and psychologist we now offer discounted counseling to our members.

With the guidance of our seven member executive committee and our members, the JEA will continue to work closely with the Jamaican League Against Epilepsy to improve epilepsy care in Jamaica.



Epilepsy Foundation USA

The Epilepsy Foundation has been in existence for nearly 40 years and works as a partner for the over 3 million Americans with epilepsy to ensure that people with seizures are able to participate in all life experiences, and to prevent, control and cure epilepsy through services, education, advocacy and research.

The Epilepsy Foundation is working hard to close the treatment gap between what is being done for people with epilepsy and what can be done and has launched a new program called **No More Seizures** (www.NoMoreSeizures.org) to reach people with epilepsy and to let them know that, even if they are receiving treatment, they may be able to improve seizure control and reduce side effects with newer treatment options.

An upbeat, highly energized crowd of 8,000 people gathered in Washington, DC, on March 29 to participate in the second annual National Walk for Epilepsy, the largest single gathering of people with

epilepsy in US history. People travelled from throughout the US, drawn by a desire to increase awareness about epilepsy and to raise funds for research.

Seizures and You: Take Charge of the Facts is an education program conducted in classrooms, as part of the school health curriculum, by local Epilepsy Foundations across the US. The program, which includes a cutting-edge DVD about epilepsy, reached over 25,000 students last year with reliable information about epilepsy in a way that catches the attention of teens - a hard-to-impress segment of the population.

In the past year, the Epilepsy Foundation provided funding for 45 fellowships and grants for pre-doctoral, post-doctoral and clinical investigators. The Foundation also launched a new targeted research program addressing epilepsy in the elderly. The New Therapy Grant program under the Epilepsy Research Foundation is accelerating the development of innovative new therapies with important, near-term benefits for people with epilepsy.





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Vice Chair: HV Srinivas, India

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Activities of the South East Asia Regional Committee 2007



Special Symposium in Singapore

The Regional Committee played an active part in the very successful Special Symposium for People with Epilepsy and their Carers, during the 27th International Epilepsy Congress in Singapore. A large portion of budget funds were used to support several members from the region to travel to Singapore.

The purpose of the symposium was to identify critical issues and challenges faced by people with epilepsy; to investigate in depth upcoming information regarding epilepsy; and to encourage those attending to form new friendships and to foster closer ties between local and international peers.

Pictured clockwise from top left: Michael Alexa, Austria and Carol D'Souza, India; delegates listening intently to a presentation at the symposium; Shun-glon Lai, Taiwan (IBE Vice President Western Pacific Region) and Vinod Saxena, India (Secretary, Regional Executive Committee South East Asia).

Indian Epilepsy Association India

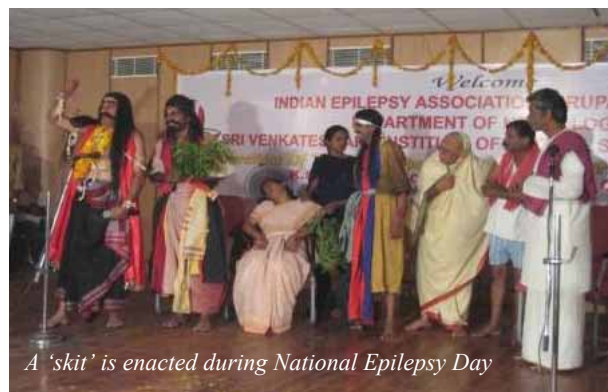
National Epilepsy Day celebrations were held in November with lectures, painting and essay competitions for children, stage plays and 'skits', epilepsy quizzes for lay persons, and CME programs for doctors. The two-day Annual Conference of India Epilepsy Association was held in October in Mumbai. People with epilepsy participated actively by presenting personal experiences and taking part in interactive sessions.

Indian Epilepsy Association Tirupati Branch conducted its 100th monthly camp for persons with epilepsy in May; the camps began in February 1999. One month's supply of AEDs is given free to all people with epilepsy who attend and an average of 500 persons take part in the camp each month. Information about epilepsy is also provided.

It is heartening to note that the Health Ministry, Government of India, has finally sent its recommendation to the Ministry of Surface Transport, so that certain categories of people with epilepsy may be issued a driving licence. This has come after several years of petitions to the

authorities. At present people with epilepsy are denied driving licences even when they are seizure free for a number of years.

Efforts are made to identify people with epilepsy who are disabled because of frequent seizures requiring polytherapy and large doses of AEDs. The group will be known as "Persons with Disabling Epilepsy" and will derive benefits under the "The Person with Disability Act of India". A one-year Distance Education Programme leading to a "Diploma in Epilepsy Care" has been started by Indian Epilepsy Association in collaboration with Bangalore University and the first batch of students has completed the course successfully.





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Activities of the Regional Committee Western Pacific 2007

Symposium for People with Epilepsy

Singapore Epilepsy Foundation and the Epilepsy Care Group jointly organised a Symposium for People with Epilepsy and Their Carers, which was held in conjunction with the International Epilepsy Congress in Singapore in July. The aim was to raise greater awareness of issues which impact on the quality of life for people with epilepsy.

The symposium also provided a platform for people with epilepsy, their carers, volunteers, healthcare professionals, employers and regulators to network and to learn from each other. The panel of speakers shared their expertise and experiences on issues identified to impact on the quality of life for people with epilepsy:

Topics and Speakers

- ◆ *Introduction to Epilepsy* Dr Andrew Pan
- ◆ *Children and Epilepsy* Dr Choong Chew Thy
- ◆ *Education and Epilepsy* Dr Mike Hills
- ◆ *Employment - Taiwan's experience*
Dr Marshal Hsieh Mo Song
- ◆ *Employment Opportunities in Singapore*
Ms Lieng Sheau Yea
- ◆ *Driving (Overseas Experience)*
Mr Mike Glynn
- ◆ *Driving (Singapore Perspective)*
Mr Edmond Pereira
- ◆ *Women and Epilepsy* Dr Andrew Pan
- ◆ *Family and Marital Relationships*
Ms Anchor Hung

There were lively discussions and exchanges during the Symposium. Participants were actively engaged during the Questions and Answers sessions and also took the opportunity to share their experiences and encounters.

The Indian Epilepsy Association arranged a video presentation on its activities and on efforts in raising epilepsy awareness in India. The Taiwan Epilepsy Association also showcased its video production that addresses epilepsy in the workplace and with personal testimonies of persons with epilepsy in Taiwan.

In total, there were about 200 participants from 11 countries: Austria, Argentina, Hong Kong, India, Indonesia, Japan, Malaysia, Mongolia, Philippines, Singapore and Taiwan. Some delegates came with their family members and young children

Breakdown of delegates:

- ◆ 60% Persons with epilepsy
- ◆ 25% Caregivers
- ◆ 15% Volunteers and Healthcare professionals.

Everyone enjoyed the experience, with the opportunity to network and make new friends.



Top: delegates from Taiwan including Dr Andrew Pan (second from left)

Bottom: three delegates from Singapore who attended the symposium

After a long day at the Symposium, the finale was the Welcome Dinner held at the Raffles City Convention Centre for all participants. As part of the entertainment, participants present took to the stage to sing songs associated with their home countries, leading to much fun and laughter.

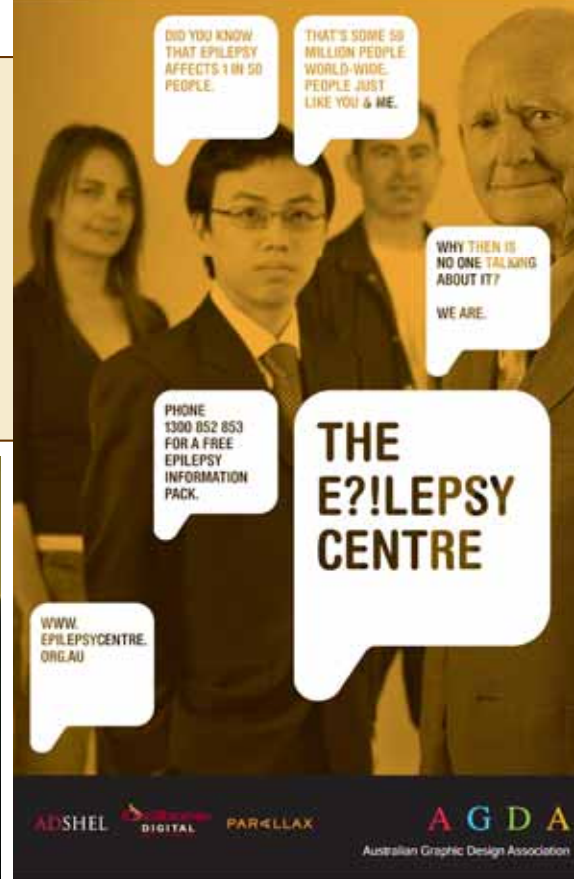
The Symposium Organising Committee comprised representatives from Singapore Epilepsy Foundation and Epilepsy Care Group of Singapore, and was chaired by Dr Andrew Pan. The committee would like to record its sincere appreciation and thanks to sponsors namely, GSK, Janssen Cilag and UCB for their generous donations; IBE for its grant; ILAE and the IDM office for their assistance; and the many volunteers who gave freely of their time and efforts to ensure a successful event.

The symposium was promoted jointly by the Regional Committee South East Asia and the Regional Committee Western Pacific. Both Regional Committees provided a number of bursaries to delegates wishing to attend the symposium.

Epilepsy Association of South Australia and the Northern Territory Australia

This poster was produced for the association, as a pro bono initiative, and was awarded an Australian Graphic Design Award. It will now be placed in Bus Shelters across Adelaide for twelve months, and free of charge, to create Epilepsy Awareness in South Australia.

The value to the association is in excess of Australian Dollars 33,000.



Epilepsy Action Australia Australia

Collaboration in Western Australia

As a first step in collaborative services in the non-medical services sector, Epilepsy Action, Australia and the state-based Epilepsy Association of Western Australia (EAWA) have joined forces to work collaboratively to offer a comprehensive range of education and support services including seizure-management planning, first-aid training for seizures, education programs, counselling and peer support, to the people of Western Australia.

Research collaboration

Epilepsy Action, Australia has teamed up with The George Institute for International Health to take a comprehensive look at the lives of people newly diagnosed with epilepsy and explore the incidence, psychosocial impact

and household economic burden of epilepsy in a large population in Australia. The recruitment phase will run for two years with a 12-month follow up period. The study will help government, healthcare practitioners and service providers such as Epilepsy Action, Australia to make more informed decisions about service design, policy, funding, treatment and medical management.

East Timor

Epilepsy Action, Australia has been involved in the East Timor National Training Program since 2005 with Prof Ernie Somerville from Sydney's Prince of Wales Hospital. Epilepsy Action continues to refine and deliver the community leader education component of this program despite numerous challenges presented as a result of the recent civil unrest and change of government. The aim is to raise awareness that epilepsy is a medical condition and to encourage the utilisation of the free, newly developed epilepsy services set up in local clinics across the country.

Singapore Epilepsy Foundation Singapore

The highlight of the year was undoubtedly hosting the 27th International Epilepsy Congress in July and much of the focus of Singapore Epilepsy Foundation (SEF) was on preparations for the event. We were delighted to welcome so many members from other countries and were pleased at the great success of the meeting. As the year progressed we also looked to develop plans for 2008, some of which include:

- ◆ The HOPE Programme - collaboration with UCB with a planned launch in July 2008.
- ◆ Disability Information and Referral Centre (DIRC) - A public forum organised jointly between SEF and DIRC.
- ◆ Working with Ministry of Education to promote awareness of epilepsy amongst primary and secondary schools and junior colleges.
- ◆ Plan of activities for the Persons with Epilepsy & Carers Support Group.



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