



ANNUAL REPORT 2006

International Bureau for Epilepsy

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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



Our Vision

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

Our Mission

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

Our Goals

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

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

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



President's Report



A year seems a long time when you are at its beginning and then when you reach the end it seems that it all went very quickly. And as you all know, if you enjoy what you are doing it goes even faster. That has been the case with the year 2006 which proved to be an exciting and busy year for IBE with so many activities taking place.

A major initiative was the launch of the new and encouraging Promising Strategy Program (PSP), which provides some funding on a competitive basis for projects aimed at improving the life quality for people with epilepsy living in developing countries. I am proud to say it was a major success with a high number of applications received. In addition, IBE has been active promoting the Solidarity Fund which provides funding for the PSP as well as support to Members unable to meet their annual dues. It is a true spirit of solidarity in IBE that is reflected in this joint process. I would like to thank Members, corporations and others who contribute to the growth of the fund.

IBE Regional Committees have reported on a great number of activities, from educational activities and support groups to political influence and media events. The great variety of approaches is reflected in our IE News that is one of the most important and attractive publications of IBE. It gives a wonderful flavour of the great commitment and interest that is shown for people with epilepsy worldwide. It is a true source of inspiration and encouragement.

To highlight those people working untiringly, and often in silence, the International Executive Committee introduced the first IBE "Volunteer Award". A great number of nominations were received and the Award was planned to be presented at the International Epilepsy Congress in 2007. We all know that there are many hidden volunteers and IBE is more or less built by people who use their free time to work to support and encourage people in a less strong position. That is admirable and something that I am grateful for!

IBE has also been involved in Regional Congresses in Europe, Latin America, South East Asia and Western Pacific with important scientific and social programmes and intense debates. These regional meetings also gave us the opportunity to officially launch the IBE Regional Committees in South East Asia, Western Pacific and Eastern Mediterranean regions. This is a major development in IBE's new structure and I am confident that it will provide the platform for greater communication between the International Executive Committee and the regional groups.

The IBE office has gone through a hectic time during the year, including a move to new premises, and has been deeply involved in all IBE activities. IBE welcomed Liz Elkinson to the office who will act as Administrative Assistant to support the Executive Director Ann Little.

During this year a major review of the IBE website was initiated in order to meet the requirements of a modern website with interactive possibilities. This is a huge commitment for IBE and I expect it to be a terrific and useful tool for information as well as for communication. Together with our newsletter IE News, the website promotes IBE's profile to the world and highlights the importance of focussing on the social, as well as the medical, aspects of epilepsy.

During 2006 the Freedom in Mind artistic project also showed the human face of epilepsy, through the fantastic artwork submitted by people with epilepsy to the project. All of these initiatives improve the visibility of IBE and demonstrate to the world our commitment, and that of all our Members, to improve the quality of life for people with epilepsy.

The ILAE/IBE/WHO Global Campaign Against Epilepsy 'Out of the Shadows' continued to gain momentum during 2006. Many members undertook activities under the banner of the campaign and this has made the initiative truly global. The first steps were taken to create Global Campaign Regional Steering Committees, involving the regional committees of IBE and the regional commissions of ILAE. This greatly facilitates coordination and reporting of activities at regional level. I would like to thank Philip Lee and Giuliano Avanzini for their continued commitment to the campaign as its Co-Chairs. Thanks are also due to Hanneke de Boer who continues to devote her time generously to the campaign.

A major achievement for EUCARE was a meeting with interested Members of the European Parliament (MEPs) in Brussels as a prelude to the launch of the Parliamentary Advocates for Epilepsy. The response by MEPs was encouraging and work on this element of EUCARE will continue. The research element of EUCARE also moved along with preparations for the launch of the FONDE research study almost complete. This will be a very interesting scientific study on lifestyle consequences of newly diagnosed epilepsy in Europe.

EPICURE is another exciting new research project in which IBE has been invited to be a partner. Sponsored by the European Union's Sixth Framework Programme, thematic priority 'LIFESC/HEALTH' EPICURE is investigating developmental aspects of epileptogenesis, which, account for the high frequency of epilepsies in children and their often severe prognosis. EPICURE will last for 4 years and IBE is one of 29 European partners involved in the project. IBE's role will be to disseminate information and to promote the project in Europe and throughout the world.

I am happy to announce that IBE membership increased during 2006 with 6 new Full Members approved. Until now, membership applicants had to wait until the General Assembly met in person to have their applications approved. However with the new Constitution this can now take place using electronic balloting. So I would like to welcome our new Members in Cameroon, Egypt, Estonia, Morocco, Nigeria and Swaziland.

I would like to thank all the members of the International Executive Committee for all their time and support. I also want to thank IBE Full and Associate Members, our partners, Task Forces, the IDM office that organises the epilepsy congresses, members of the pharmaceutical industry and those dedicated individuals, for committed and encouraging contributions to the development of IBE.

Together we make a difference.

Finally I would acknowledge with much appreciation the fantastic work that is undertaken by Ann Little, Executive Director and Liz Elkinson, Administrative assistant at the IBE office.

Susanne Lund
President

International Executive Committee 2005—2009



Back row, from left: Abdulaziz Al-Semari, Vice President Eastern Mediterranean; Athanasios Covanis, Vice President Europe; Philip Lee, Immediate Past President; Carlos Acevedo, Vice President Latin America.

Centre row: Nico Moshé, ILAE Secretary General; Peter Wolf, ILAE President, Martin Brodie, ILAE Treasurer.

Front row: Shunglon Lai, Vice President Western Pacific; Mike Glynn, Treasurer; Susanne Lund, President; Zenebe Gedlie Damtie, Vice President Africa.

Inset Photos, from top: Anchor Hung, Vice President South East Asia and Eric Hargis, Secretary General.

Financial Report

BALANCE SHEET

Year ended 31st December 2006
With comparative totals for 2005

	2006 US\$	2005 (as restated) US\$
FIXED ASSETS		
Tangible assets	11,842	5,889
CURRENT ASSETS		
Debtors and prepayments	160,038	199,243
Cash at bank and in hand	3,139,474	2,899,820
	<u>3,299,512</u>	<u>3,099,063</u>
CREDITORS: (Amounts falling due within one year)	(1,223,782)	(728,413)
NET CURRENT ASSETS	<u>2,075,730</u>	<u>2,370,650</u>
CREDITORS: (Amounts falling due after more than one year)		
Deferred Income	(412,202)	(626,054)
NET ASSETS	<u>1,675,370</u>	<u>1,750,485</u>
CAPITAL AND RESERVES		
General reserve	1,300,922	491,724
Restricted fund	374,448	1,258,761
	<u>1,675,370</u>	<u>1,750,485</u>

STATEMENT OF INCOME AND EXPENDITURE

Year ended 31st December 2006

With comparative totals for 2005

	2006	2005 (as restated)
	US\$	US\$
INCOME		
International congresses and symposia	813,684	2,448,417
Commerce and industry	125,094	153,273
Membership dues	14,133	24,674
Investment income	50,221	27,022
Sale of materials	247	124
Other grants	213,852	392,401
Miscellaneous income	2,483	10,074
	<u>1,219,714</u>	<u>3,055,985</u>
EXPENDITURE		
Congress expenditure	729,126	1,593,432
Distribution to Paris Congress	234,863	-
Administration pay costs	114,188	85,692
Office expenses	5,783	8,577
Printing and postage	8,133	20,723
Printing and postage - International Epilepsy News	30,974	31,528
Travel	87,966	59,969
Global Campaign costs	25,000	25,000
Accountancy fees	10,873	10,873
Audit fees	4,125	4,127
Bank charges	1,027	954
Rent	17,945	4,903
Subscriptions	-	229
Depreciation	6,539	1,858
Website costs	2,854	2,887
EUCARE costs	213,852	311,052
	<u>1,493,248</u>	<u>2,161,804</u>
Currency exchange fluctuations	(198,419)	197,449
	<u>1,294,829</u>	<u>2,359,253</u>

INCOME AND EXPENDITURE ACCOUNT

Year ended 31st December 2006

With comparative totals for 2005

	2006	2005 (as restated)
	US\$	US\$
INCOME	1,219,714	3,055,985
EXPENDITURE	(1,294,829)	(2,359,253)
OPERATING (DEFICIT)/SURPLUS FOR YEAR	<u>(75,115)</u>	<u>696,732</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 2006 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:

	2006	2005
	US\$	US\$
Cash in bank	796,145	1,395,283
Debtors and prepayments	148,113	199,243
Creditors	(792,588)	(576,171)
Revenue	813,684	2,448,417
IDM Congress expenses	<u>(729,126)</u>	<u>(1,593,432)</u>

International Highlights 2006

IBE Applies to the UN

At the beginning of 2006 IBE submitted an application to the United Nations to be considered for Consultative Status on the Economic and Social Council (ECOSOC) of the United Nations. A decision on the application was expected to be received in early 2007.

ECOSOC serves as a central forum for discussing international economic and social issues, and for formulating policy recommendations addressed to the Member States and the United Nations system. It is responsible for promoting higher standards of living, full employment, and economic and social progress; identifying solutions to international economic, social and health problems; facilitating international cultural and educational cooperation; and encouraging universal respect for human rights and fundamental freedoms.

As a non-governmental organisation (NGO) in Consultative Status on ECOSOC, IBE would be able to contribute to the programs and goals of the United Nations, serving as experts, advisors and consultants to governments and to the Secretariat.



Volunteer Award Announced

The IBE Volunteer Award was introduced as a means of recognising the efforts of lay volunteers working with IBE member associations to improve the quality of life of people with epilepsy at national and local level. It will highlight the tremendous efforts undertaken by those working without recompense, and often without recognition, to help people with epilepsy and their families.

The award will be presented every two years during the IBE General Assembly and is in addition to the Ambassador for Epilepsy and Social Accomplishment awards.

The prize consists of an engraved plaque, as well as travel and accommodation to attend the General Assembly. In addition, the nominating association receives an award of US\$5,000 to finance a special epilepsy programme.

The first presentation of the award would take place in 2007 during the 27th International Epilepsy Congress in Singapore.

Promising Strategies Program is launched!

Improving life quality in emerging nations!

In its continuing commitment to identify innovative solutions to the problems impacting people with epilepsy and their families, IBE introduced its Promising Strategies Program in mid-2006. The program will provide financial support to member organisations, on a competitive basis, for initiatives aimed at improving quality of life for people with epilepsy in developing nations. The first call for proposals resulted in over forty applications and the first projects to receive funding were due to be announced in early 2007. It is hoped to continue with further rounds of funding in the future. IBE is grateful to Epilepsy Foundation of America for its generous donation to the program.



Solidarity Fund Makes a Difference!



Supporting Members in Developing Regions

The creation of the Solidarity Fund in 2005 was consistent with IBE's strategic goals of supporting its members and their involvement in IBE activities. One of the purposes of the fund is to provide financial support to those IBE members who can demonstrate financial hardship.

In 2006 some funds from the Solidarity Fund were used to underwrite the annual dues of IBE Full Members in countries whose economies are deemed, using World Bank classification, to be 'low income'. In 2006 these members were based in Congo, Senegal, Pakistan, Mongolia, Kenya, Zambia, Bangladesh, Ghana, Tanzania, Gambia, Uganda, Niger, Sierra Leone, Ethiopia and Zimbabwe. Without this support it is unlikely that the members in these countries would have been able to meet their dues obligations.

During 2006, Members were encouraged to donate to the Solidarity Fund at the time they settled their annual dues. However it is important to remember that donations, however small, are welcome at any time. IBE is pleased to accept donations from Member associations, individuals, companies and other organisations. As the funds grow, IBE will be able to provide a greater range of support to those Members of limited financial means, so that they

can play an active part in the work programs of IBE.

If you, or your organisation, would like to donate to the Solidarity Fund, please contact Mrs Ann Little, Executive Director, International Bureau for Epilepsy at ibedublin@eircom.net for details. Donations can be made by credit card, bank draft, or bank transfer.

IBE would like to thank the following organisations which supported the Solidarity Fund financially in 2006:

- Epilepsie Dachverband Österreich (EDO), Austria
- Epilepsy Canada
- Liga Chilena contra la Epilepsia, Chile
- Brainwave The Irish Epilepsy Association
- Epilepsy Connections, Scotland
- Slovenian League Against Epilepsy
- AEAE, Spain
- Swedish Epilepsy Association
- Epi-Suisse, Switzerland
- Swiss Epilepsy Centre, Switzerland
- Taiwan Epilepsy Association

Functioning Genomics & Neurobiology of Epilepsy: A Basis for New Therapeutic Strategies

IBE accepted the invitation of Professor Giuliano Avanzini, Coordinator of this project, to be one of 29 collaborating partners in EPICURE. This important research project, involving research centres in 13 European countries will work to identify disease-causing genes and their functional role in the pathophysiology of neuronal excitability and network synchronization, using complementary advanced methods.

The main effort of EPICURE is devoted to investigating developmental aspects of epileptogenesis that account for the high frequency of epilepsies in children and their often severe prognosis. EPICURE intends to bring together expertise from different research areas, both clinical and laboratory-based, with the common goal of advancing European epilepsy research to bring about new therapeutic benefits for people with epilepsy. EPICURE is receiving substantial funding under the Sixth Framework Programme LSH-CT-2006-037315 (EPICURE) thematic priority LIFESC/HEALTH of the European Union.



Sixth Framework
Programme Project
LSH-037315



Action Zone

A novel way to learn about epilepsy

Action Zone is a new children's board game aimed at anyone from five years and upwards, which has been developed in collaboration with IBE by UCB Pharma. Using a series of multi-choice questions about epilepsy, the aim of the game is to improve the players knowledge on the true facts about epilepsy. Action Zone has been made available to IBE member associations free of charge and with free delivery and more than 45,000 games were requested.

In addition to the English version, Action Zone will also be available in a number of other languages including Arabic, Chinese (Mandarin and Cantonese), Danish, Dutch, French, German, Greek, Italian, Korean, Norwegian, Portuguese, Spanish and Swedish.



European Parliament lines up to support EUCARE

A long-anticipated lunch meeting between EUCARE and Members of the European Parliament (MEP) took place in April, as a first step in the creation of a Parliamentary Advocates for Epilepsy Group. As a warm-up exercise, a short questionnaire was circulated to all 700 members of the European Parliament, which received an excellent response. The meeting in Brussels was attended by 19 MEPs or their representatives and, given the high number of meetings that MEPs have to attend each week, this was a very positive turnout.

Pictured left to right:

Gay Mitchell MEP; Mike Glynn, IBE Treasurer; Kathy Sinnott, MEP; Rick O'Shea, Irish radio presenter; Mairead McGuinness MEP; and Simon Coveney, MEP.



Freedom in Mind

The invitation extended to people with epilepsy to express what epilepsy meant to them through participation in the Freedom in Mind artistic project, met with an excellent response during the year. Whether using traditional media, such as painting and sculpture, or choosing more modern techniques including computer-generated imagery or video diaries, the medium of art has long been favoured as a means of self-expression.

A selection of artwork submitted to the Freedom in Mind Experience will form major exhibitions at a number of congresses from mid-2006 to the end of 2008. Freedom in Mind was promoted during the 10th Epilepsy & Society Conference in Copenhagen in August 2006 and the first major exhibition took place in Glasgow at the time of the EFNS congress in September.

This joint initiative of IBE and UCB Pharma will continue until the end of 2008 with further exhibitions including Singapore 2007 and Marseille 2008. Whilst there are no prizes, every entrant is a winner, receiving a specially commissioned Freedom in Mind t-shirt. Submitted artwork is on ongoing display on the Freedom in Mind website www.freedominmind.com.



A New Look for our Website www.ibe-epilepsy.org

IBE launched its first website in May 2001, at the time of the 24th International Epilepsy Congress in Buenos Aires. In 2006, five years later, the decision was taken to overhaul the site and a Website Task Force, chaired by Shung-lon Lai was charged with overseeing the redevelopment of the IBE site. In doing so, the Task Force sought the views of the regional committees as well as those of individual member associations. All feedback received was incorporated into the new design layout.

The new site will include a password protected Members section, where files such as election documents and dues forms will be available for download. There will also be a large photo gallery, pages for each of the seven regional committees and a Networks section. The home page will feature an easy to use members location map, with member details shown by region. To encourage dialogue and feedback, many of the website news articles and reports will invite visitors to the site to leave their views and comments.

This is a major initiative, involving a great deal of hard work by a dedicated Task Force and an ambitious launch date has been set for the end of 2007.

New Chair of Editors Network

Robert Cole, Australia, pictured right with IBE President Susanne Lund at the congress in Kuala Lumpur, accepted the invitation to Chair the Editors Network, an IBE User's Group that facilitates discourse and sharing of information between the editors of national epilepsy newsletters.

A meeting of regional editors took place during the 6th Asian & Oceanian Regional Congress in November 2006.



4th Latin American Epilepsy Congress

The 4th Latin American Epilepsy Congress took place in Guatemala City in early September 2006 and attracted over 350 delegates. The busy programme included morning plenary sessions that were followed by afternoon discussion groups on subjects such as Stigma, Disability Support Groups and Education.

Highlights involved the celebration of Latin American Epilepsy Day on the 9th September with the participation of the IBE and ILAE Presidents; the invocation of the Latin American Declaration on Epilepsy; and the presentation of a new book for lay people called "Epilepsy: all

you need to know without being a doctor". The Latin American Regional Steering Committee of the Global Campaign Against Epilepsy was announced following a Brain Storming Session that focused on issues of importance in the region. Pictured (left) is Dr Henry Stokes, Guatemala, being interviewed by a TV crew. At the congress Opening Ceremony Dr Stokes was conferred with the "Messenger of Peace" award by a representative of the President of Guatemala in recognition of his dedication in helping people with epilepsy in Guatemala.



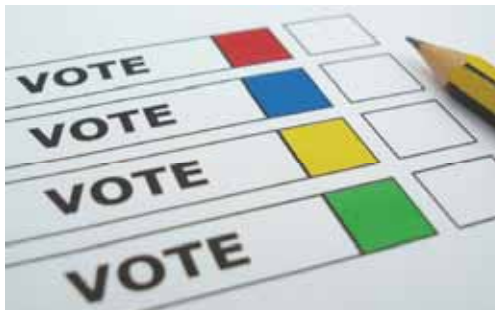
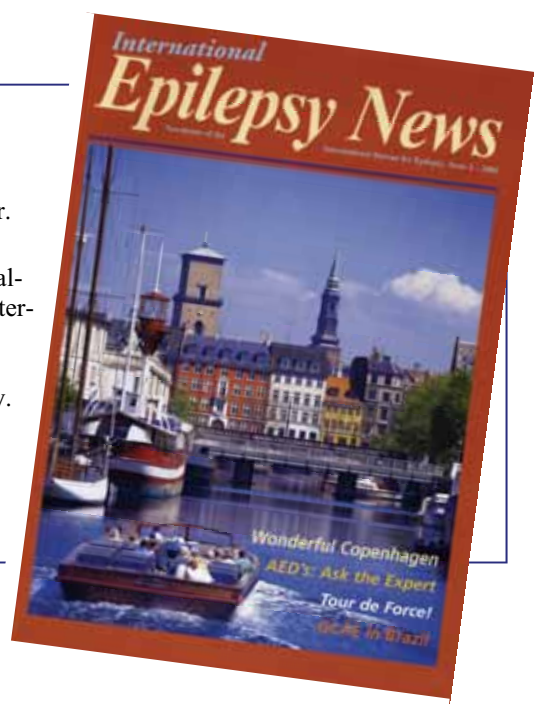
International Epilepsy News

Throughout 2006 IE News, edited by Carlos Acevedo, provided the platform for the dissemination of interesting news and reports concerning IBE and its Members.

The front covers highlighted events of particular importance such as the 10th European Conference on Epilepsy & Society in Copenhagen, the 4th Latin American Epilepsy Congress in Guatemala, and the 6th Asian & Oceanian

Epilepsy Congress in Kuala Lumpur.

A newly introduced feature was the Ask the Expert column where specialists addressed issues of particular interest to people with epilepsy such as Support Groups, Complementary Treatments, and Epilepsy & Surgery. The newsletter is distributed in over 100 countries each quarter, to IBE Members, supporters, collaborating NGOs and to subscribing readers.



Election Task Force

The Election Task Force continued its task to monitor IBE's first fully democratic elections with all candidates nominated and elected by Full Members. Many elections were completed in 2006 and thanks are due to the members of the task force for their dedication and commitment in fulfilling this onerous duty.



Successful Congress in Kuala Lumpur

The Asian & Oceanian Epilepsy Congress, which took place in Kuala Lumpur in November, was one of the largest meetings organised jointly by IBE and ILAE in the region. The modern convention centre with cutting edge facilities, and with a backdrop of the famous Twin Towers through giant picture windows, provided a dramatic setting for the congress.

IBE had a busy time in Kuala Lumpur with a special reception to officially launch the IBE Regional Committees South East Asia and Western Pacific. These new Regional Committees will provide a focus for all IBE members in the region to come together on issues of mutual interest and to develop activities to improve the quality of life of those with epilepsy in this large and important part of the world.

Preparations for the next Asian & Oceanian Congress, which will take place in China in 2008, are already underway. Visit the congress website to find out more. www.epilepsyxiamen2008.org

Working Commissions

Following the adoption of the new IBE Constitution in January 2005, IBE's 7 Regional Committees are now constitutionally recognised. A Commission for the Regions has been created, whose main task is to support the Regional Committees and to monitor the adoption of IBE's new Constitution in particular with regard to the new regional structures.

The Enlargement Commission plays an important role in identifying areas where IBE is not currently represented and in supporting new membership applications. The Commission also provides a supporting role to all IBE Full and Associate Members.



AFRICA

AFRICAN REGIONAL EXECUTIVE COMMITTEE

Chair: Zenebe Gedlie Damtie, Ethiopia

Vice Chair: Augustine Mugarura, Uganda

Secretary: Anthony Zimba, Zambia

MEMBERS OF THE AFRICAN REGIONAL COMMITTEE

CAMEROON

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Contact: Mrs Sigudu.



Zenebe Gedlie Damtie elected VP Africa

Dr Damtie was elected Vice President Africa in mid-2006 and is the principal liaison point between IBE members in Africa and the International Executive Committee, of which he is a member. Dr Zenebe is President of the Epilepsy Support Group of Ethiopia and is also the elected Chair of the Regional Executive Committee Africa. He is Consultant Neurosurgeon and Assistant Professor Neurosurgery at Black Lion Teaching

Hospital, Addis Ababa. In his election statement, Dr Damtie stated his interest in strengthening the working partnership and network communication between members in Africa. He would also like to encourage exchange of experiences in an holistic treatment approach for people with epilepsy, including the sharing of facilities to facilitate at least one centre of excellence in epilepsy surgery in Africa.

New Members in the Region

The Full Members of IBE ratified three new Members in the African region in 2006. This was the first time the General Assembly had approved applications by email following the implementation of the new Constitution. The new Full Members are:

- Association Camerounese Contre l'Epilepsie
- Epilepsy Association of Nigeria
- Swaziland Epilepsy Association

IBE and the African Regional Committee welcomes these new Members and looks forward to a close working relationship in the coming years.

In North and South Africa there are 350,000 people to one neurologist and 500,000 people living with a neurological problem to one neurosurgeon. In Central Africa there is an average of 2.1 million people to one neurologist and one neurosurgeon to about 1.15 million people.

Capacity-building in Zimbabwe

A capacity-building workshop, organised in April by the Epilepsy Support Foundation in Zimbabwe, had as its main objective the training of its members so that they could coordinate epilepsy activities in their own areas and to increase resource mobilisation capacities of the association's coordinators. However the association still experiences problems with non-compliance to medication by members due to lack of income. Penetrating rural districts to promote treatment for people with epilepsy in remote areas remains a major difficulty.

KAWE has successful year

The Kenya Association for the Welfare of People with Epilepsy (KAWE) treated more than 10,000 people, trained 158 medical personnel, 100 Community Health Volunteers and educated more than 53,000 people during 2006. KAWE involved people with epilepsy and their families through the formation of 18 community based organizations (CBO). The government supports KAWE's training of medical personnel (mostly nurses and clinical officers) but more lobbying and advocacy is needed to ensure AEDs are supplied to rural clinics.

Support to EAZ, Zambia

During the year, the Epilepsy Association of Zambia received support from the Ministry of Health, which provided financial aid for activities carried out under the banner of the Global Campaign. The Ministry also took an active part in celebrating the National Epilepsy Week. The association also enjoyed good media exposure and TV and radio programmes were dedicated exclusively to epilepsy issues. Pictured below are members of the Epilepsy Association of Zambia appearing on national TV.



Epilepsy South Africa

In 2006 Epilepsy South Africa's focus was on internal strengthening and growth to sustain and increase its high quality service delivery. This was achieved through a National Governance Training programme. Services were expanded to previously under-serviced and remote rural areas within South Africa. Epilepsy South Africa remains committed to the empowerment of people with epilepsy throughout the country.

Mauritius Epilepsy Centre

2006 was a very important year for Edycs Epilepsy Group in Mauritius as the lease contract for a state plot of land allocated by the Government of Mauritius for the building of a new Epilepsy Center was signed.

This marks the first step in a long-held dream of the association and the culmination of a lengthy process of campaigning and lobbying. There is still a lot of work and fundraising ahead in order to bring to fruition this major new development.

Eastern Mediterranean

EASTERN MEDITERRANEAN REGIONAL EXECUTIVE COMMITTEE

Elections to fill the positions of Chair, Vice-Chair and Secretary on the Eastern Mediterranean Regional Executive Committee are currently underway.

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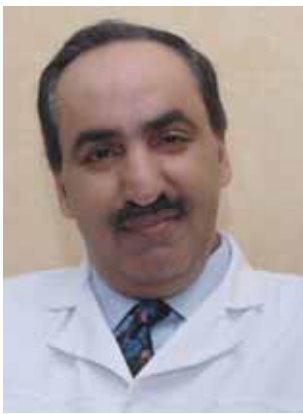
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Abdulaziz Al-Semari Elected Vice President Eastern Mediterranean

The election of Dr Al-Semari as the first Vice President Eastern Mediterranean was completed just prior to the end of 2006. Dr Al-Semari was instrumental in founding the Epilepsy Support & Information Centre in Saudi Arabia and is its current President. Among his many achievements are the creation of the first Arabic web portal for information on epilepsy; collaboration with the Ministry of Health and Ministry of

Education to promote epilepsy awareness; establishment of a program for healthcare professionals and the creation of a Teachers Awareness Program (TAP). Dr Al-Semari was also instrumental in the creation of the Saudi Arabia Epilepsy Register in 1998. During his term of office he will work to encourage and facilitate other members in the Eastern Mediterranean region to undertake successful advocacy programs.

Launch of the Eastern Mediterranean Regional Committee

A special reception was arranged to mark the launch of the Eastern Mediterranean Regional Committee. This was due to take place in Sharm El Sheik in 2006 during the 1st Eastern Mediterranean Epilepsy Congress. However, due to terrorist bombs close by, the congress was postponed to February 2007 and moved to a new venue in Luxor.

All delegates to the congress were invited to attend the launch and were welcomed by Susanne Lund, IBE President. Thanos Covanis, Vice President Europe, who chaired the Eastern Mediterranean Task

force, which had worked towards the creation of the Regional Committee, spoke about the history of IBE in the region; Philip Lee, Co-chair of the Global Campaign Against Epilepsy outlined the role of the campaign in the region; while Mike Glynn, IBE Treasurer spoke about IBE's plans to encourage regional activities.

Most important of all was the address of Dr Al-Semari who described his hopes for the future of the Eastern Mediterranean Regional Committee.



SAUDI ARABIA

Epilepsy Support and Information Centre (ESIC)

In a major drive to raise public awareness about epilepsy, ESIC arranged the inclusion of a 4-page Epilepsy Fact Sheet that was inserted into one of the main national newspapers in Saudi Arabia, which has a circulation of 140,000 copies.

The 6th Annual **"Family Festival for Epilepsy Awareness"** was attended by over 800 people and was a huge success. (photo left). The association also sponsored a national art contest, inviting children with epilepsy to illustrate their experiences in art form.

ESIC also organised a series of Teacher Awareness Conferences to educate school administrators and teachers about epilepsy, seizure first aid and classroom management during or after a seizure in the classroom.



There was much disappointment when a difficult last minute decision had to be taken to postpone the 1st Eastern Mediterranean Epilepsy Congress just weeks before it was due to take place in Sharm El Sheik.

Despite this problem, the organising committee maintained its commitment to the event and a new date and venue was found. The successful congress eventually took place in Luxor in late February 2007.

Future Elections

As 2006 came to a close arrangements were being put in place for the first elections for the positions of Chair, Vice Chair and Secretary of the Eastern Mediterranean Regional Executive Committee.

All members of IBE Full Members in the Region are eligible to stand for election and each Full Member has the right to cast votes. This marked an important new era for IBE heralding increased involvement of all its members in future activities in the region.

Europe

EUROPEAN REGIONAL EXECUTIVE COMMITTEE

Chair: Peter Dahlqvist, Sweden

Vice Chair: Athanasios Covanis, Greece

Secretary: Andreas Habberstad, Norway

Members: Jónína Gudmundsdóttir, Iceland and Seppo Sarkkula, Finland

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Another Busy Year in Europe

Under the guidance of Chair, Peter Dahlqvist, the European Regional Executive Committee, (EREC) enjoyed several achievements during the year. Not least was the European conference in Copenhagen at the beginning of August. The meeting of the Regional Committee, which was held during the conference, had an attendance of almost 30 people during which plans and objectives for the future were discussed.

The EREC also continued its drive to facilitate the establishment of the Advocates for Epilepsy Group in Brussels, as part of the political agenda of EUCARE. An informal meeting with MEPs took place in late 2006 and future actions are planned. Having a group of MEPs with an interest in epilepsy advocate in the European Parliament on behalf of people with epilepsy in Europe would be a major achievement.



10th Epilepsy & Society Conference

For the European Regional Committee, the highlight of 2006 was the Epilepsy & Society Conference in Copenhagen with an attendance of almost 300 delegates. In addition to delegates from Europe, some people had travelled from as far away as Australia, the Philippines, Korea, Argentina and Uganda to enjoy three days of some excellent presentations and debate.

Organised by the European Regional Executive Committee and hosted by the Danish Epilepsy Association, the theme chosen for the conference was 'A Better Quality of Life'.

The conference got underway with a special pre-congress Epilepsy and Empowerment Session for Professionals Allied to Medicine (PAMs) based on the MOSES programme, which was well attended.

The main programme began with an unusual presentation by guest speaker Peter Lund Madsen, an expert on the brain, who spoke to the topic "Sex on the Brain". This entertaining session marked the start of a very lively and interactive conference.



Danish association fights issue of generic substitution

For two years the Danish Epilepsy Association has worked intensely, with the support of Prof Peter Wolf, to have Danish politicians understand the problems generic substitution of antiepileptic medication can cause for some people with epilepsy.

As a result of campaigning, the association succeeded in having some changes made in legislation with effect from 1st January 2007. But the association says there is much still to be done.



The most important activity of the Swedish Epilepsy Association during 2006 was an Epilepsy Tour campaign, which visited 10 cities and provided public education about epilepsy with the support of external partners. The campaign involved 17 epilepsy specialists who participated as speakers, including neurologists, neurosurgeons, epilepsy nurses and social workers.

Men in Tights!

During Spring 2006 a daring, and amusing, campaign was launched by the Nationaal Epilepsie Fonds, an IBE Associate Member in the Netherlands. The aim of the campaign was to bring the word epilepsy to the public's lips.

"There are things more scary than epilepsy" was the name of the campaign which used posters and TV commercials. As you can imagine from the photo, it raised a lot of attention!

In November the organisation held a successful congress for epilepsy researchers to discuss the future of epilepsy research in the Netherlands. The Nationaal Epilepsie Fonds plans to give a major impulse to clinical epilepsy research.



Congratulations!

The year 2006 marked milestones for some IBE Members in Europe.

Those celebrating 25th anniversaries were

- Gravesend Epilepsy Network, an Associate Member in the UK
- AISPACE, Full Member in France.

Deutsche Epilepsievereinigung eV in Germany celebrated 25 years production of its magazine *einfälle*.

Caritas Malta Epilepsy Association enjoyed its 10th anniversary, while in Portugal there were celebrations of a slightly different kind, with the birth of the new association for people with epilepsy EPI-APFAPE. Until now both lay and medical people were represented by the Portuguese League.

Swiss Epilepsy Centre Zürich Promotes FAMOSES

The Modular Service Package Epilepsy (MOSES) is an educational program for people with epilepsy and their relatives to enable them to increase their knowledge about epilepsy. Courses are run regularly by the Swiss Epilepsy Centre in Zurich and well as by other centres in Europe.

During 2006, in addition to the MOSES program, members of staff in the Zurich centre became trainers of the FAMOSES programme, aimed at supplying information for children and their parents, that is, the FAMILY.



The analysis of a national survey, involving more than 3,000 members of the Swedish Epilepsy Association, was completed with conclusions and necessary action points to further improve epilepsy health care and treatment in Sweden. The survey had begun in 2005 with the circulation of survey papers,



Spolecnost „E” Czech Republic

Throughout 2006 the association provided services in the first short-stay hospital for people with epilepsy in the Czech Republic and successfully continued its other activities. These included psychological services, social counselling and social clubs, as well as training courses

(computer training, English classes, chess, art and swimming).

The special annual integrated summer camp, both for children who have epilepsy and those who don't, again provided respite breaks for parents and an enjoyable summer holiday for the children.



Interessenvereinigung für Anfallskranke in Köln e.V. Germany

The most enjoyable activities in 2006 were the weekly meetings of the Epilepsy Sports Team in Cologne (pictured above). Participation in leisure activities including walking, playing games and boating trips are organised to assist people with epilepsy to improve their self confidence and self-esteem.



Mrs Lorne Nørager Kristensen, President of the Danish Epilepsy Association, speaking during the congress Opening Ceremony with Mr Ib Haurum, Copenhagen Assistant Director of Health and Social Welfare in the background.



EPILEPSY CONNECTIONS Scotland

What a great year 2006 was for us! We extended our fieldwork services into the Forth Valley area and also launched 2 new projects and increased our staff to 13:

- **Mainstreaming Project** offers adults with epilepsy the chance to access education, training, and voluntary and paid employment. This project is unique in Scotland.
- **Living Well With Epilepsy Project** provides epilepsy awareness workshops to people with epilepsy throughout the Forth Valley area.



ANBER Romania

ANBER launched the first Romanian colouring book on epilepsy, which is used to show children, with and without epilepsy, what epilepsy is and how it should be dealt with. And all this in a fun and pleasant way. The associa-

tion plans to continue distributing the book throughout Romania. The most exciting activity for the association was preparations to open the first epilepsy clinic in Romania; the clinic is due to open in 2007.

Caritas Malta Epilepsy Association

held its fourth one day seminar in February, marking its 10th anniversary. The seminar was attended by more than 200 delegates including healthcare professionals, teachers, facilitators, social workers, pharmacists and parents.

The association has also managed to obtain EU funding under the Grundtvig programme, which will be used to organise a training programme for professionals working with persons with epilepsy. The other partners in the project are from the European Epilepsy Academy, Germany and Hungary.

The photo top right shows members of Caritas Malta Epilepsy Association enjoying the Opening Ceremony of the Epilepsy & Society Conference in Copenhagen.



Epilepsie Euro Services

Based in France, the organisation continues its work in the EQUAL Programme of the European Union, collaborating with other epilepsy organizations in Europe. EQUAL focuses on discrimination in employment for people with epilepsy. Other participants include Ireland, Malta and Hungary.

Members of EPI-APFAPE, Portugal, enjoying Epilepsy Week in March



Gravesend Epilepsy Network, UK

2006 marked the association's 25th anniversary, a highlight of which was a free holiday for members and their carers. Thanks to ongoing fundraising, GEN continues to be able to make donations to nationally recognised research projects, and has donated over £60,000 to date.

Epi-Suisse, Switzerland

Epi-Suisse cares for more than 3,000 people with epilepsy and their relatives in Switzerland, supporting different self-help groups, and launching several information campaigns yearly. Cooperation with other foundations and associations in all regions of Switzerland ensures a wide spread of public activities throughout the country.

Cooperation with neurological clinics brings professional support and strengthens the quality of social support services.

Photographed right are leaders of Epi-Suisse - Doris Gerber (in front), Regina Henggeler (President) and Ernest Zweifel - at one of the outdoor events organised by the association during 2006.



Latin America

LATIN AMERICAN REGIONAL EXECUTIVE COMMITTEE

Chair: Lilia Nuñez Orozco, Mexico

Vice Chair: Elza Marcia Yacubian, Brazil

Secretary: Tomás Mesa, Chile

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Lilia Nuñez Orozco steers the Latin American Regional Committee through a busy year

The focus of the Regional Executive Committee during the year was on preparations for the 4th Latin American Epilepsy Congress, held in Guatemala in September. Apart from the Scientific Programme, a special one-day seminar was arranged for people with epilepsy and their carers.

A meeting of the Regional Committee (below) was also arranged and for the first time all IBE Members in the region were represented. Also attending were guests Philip Lee, Co-Chair of the Global Campaign Against Epilepsy (back row third from left) and Susanne Lund, IBE President (middle front row).



FUNDEPI, Argentina

Activities were undertaken to increase awareness, to inform opinion and to help create a public policy to benefit people with epilepsy and increase quality of life. FUNDEPI set standards of good practice in the care of people with epilepsy, in particular in primary care. The target of campaigns are people with epilepsy, medical professionals and health service administrators.



Learning through play

ANLICHE, Chile, introduced a special summer initiative for children who have epilepsy, aged from 7 to 12 years. Based on the theory of learning through play, the project brought together a group of children to enjoy games and other group activities such as crafts and drama.

Also focussing on young people with epilepsy, ANLICHE organised a special symposium on Childhood Epilepsy and Learning in March 2006

IBE in Ecuador

Ecuador celebrated the inauguration of the new Centro Nacional de Epilepsia, made possible thanks to the assistance of CITOTUSA. The

association also continued its service of provision of free medication for people with limited means who cannot afford to buy their own AEDs.



GCAE in Brazil

A Global Campaign Demonstration Project, which was launched in 2002 in Brazil, and which was carried out over six phases, was officially closed during the 4th project workshop, held in May in Campinas.

An important element of the workshop was discussion on the establishment of a National Epilepsy Policy.

Flag of Distinction

IBE President Susanne Lund and ILAE President Peter Wolf display the special 'joint' flag, which was created by Dr Henry Stokes to celebrate the 4th Latin American Epilepsy Congress in Guatemala. Dr Stokes is involved in both the IBE and ILAE member associations in Guatemala.

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.

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Jamaican Epilepsy Association

The association produced a children's brochure early in the year entitled "Does Your Child Have Epilepsy?" The brochure was produced in conjunction with the Jamaican League Against Epilepsy (JLAE) and was distributed to Paediatric Neurologists and other doctors.

In November the JEA and JLAE launched the first ever Jamaica Epilepsy Awareness Week. Our 2007 calendar entitled "How Does My Garden Grow" and a children's book "Way To Go Flash!" was also launched that evening. Government dignitaries, members of the Press, the models for the calendar and

sponsors, were among the invited guests and the event was covered locally in many newspapers.

Epilepsy Awareness Week also saw many appearances on television and radio interviews for the JEA Executive. A Public Service Announcement giving details of First Aid Procedures was aired on television, featuring the island's well-known actress and Executive Director of JEA, Beth Hyde.

Both the JEA and the JLAE plans to continue working closely together in Jamaica in order to raise public awareness for persons with epilepsy.



Epilepsy Foundation of America

continues its work to put a human face on epilepsy, making it more meaningful to people who don't have, or know anyone who has, epilepsy, through programs such as **Kids Speak Up!**

The program rallies young people with epilepsy from around the country to personally petition congressional leaders at Capital Hill for aid in assuring better access to care, improved public education and greater support of research towards a cure for epilepsy.

Way to go, Flash!

This children's book, published by the Jamaica Epilepsy Association (JEA) and written by Barbara Ann Rigbye, uses the story of a horse with epilepsy to tell young people about the condition. The photography shows Heather-Dawn Brown, JEA Executive Director, presenting a gift to the author, Barbara Ann Rigbye, at the book's launch.



Senator Hillary Rodham Clinton Presented with Distinguished Leadership Award

Epilepsy Foundation of America's new Distinguished Leadership Award, which honours dedicated leadership and support, was presented for the first time in 2006. The recipient was Senator Hillary Rodham Clinton. Senator Clinton introduced a Lifespan Respite Care

Act to US Congress. The Senator was also the original sponsor of Epilepsy Foundation's epilepsy appropriations sign-on letter. In addition, Senator Clinton produced a special video for the foundation's Gala event, which took place in New York City in late 2006.



South East Asia

SOUTH EAST ASIA REGIONAL EXECUTIVE COMMITTEE

Chair: PK Sethi, India

Vice Chair: HV Srinivas, India

Secretary: VS Saxena, India

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Launch of the Regional Committee

A highlight of the Regional Committee South East Asia was its official launch at the time of the 6th Asian & Oceanian Epilepsy Congress in Kuala Lumpur. A reception was held to celebrate the launch of both the South East Asian and Western Pacific Regional Committees and was well attended by delegates from these regions.

The impetus generated in Kuala Lumpur will set a lively pace for future activities in the region. A meeting of the Regional Committee in Kuala Lumpur as well as a meeting of the members of the Regional Executive Committee in Bangalore has provided the platform for consideration of future plans and objectives.



A Distance Education Programme course “Diploma in Epilepsy Care” was launched by the Indian Epilepsy Association in collaboration with Bangalore University. The next admission period will be June 2007. The course is available in the English language and is open to national and international students. Full information on the programme and how to apply for the next session is available on www.epilepsyindia.org.

Indian Epilepsy Associations holds 7th Annual Conference

The National Institute of Mental Health and Neurosciences, Bangalore was the venue for the Annual Conference of the Indian Epilepsy Association and Indian Epilepsy Society. To promote epilepsy awareness, special **Fit For Life** t-shirts were created. Held over 2-days, the first day focussed on medical issues, while social issues formed the programme on the second day.

Anchor Hung, Vice President South East Asia was a speaker at the conference and

this provided the Regional Executive Committee South East Asia with the ideal opportunity to hold its first planning meeting. Also invited to the meeting was Dr MM Mehndiratta, who attended for discussions on the preparations for the special programme for people with epilepsy, that would take place in Kuala Lumpur in late 2006.

The photo shows Anchor Hung, second from left, with conference delegates, two of whom are sporting the special t-shirts.



Committee Meets

A first meeting of the Regional Committee South East Asia was held in Kuala Lumpur, and took place jointly with a meeting of the Regional Committee Western Pacific. This was a lively event, with much debate and discussion. Delegates from South East Asia included Dr VS Saxena, India (extreme left of photo), and Dr MM Mannan, Bangladesh and Dr MM Mehndiratta, India (seated in second row).

Music Quiz raises funds in HK

The Hong Kong Gaelic Athletic Association (HKGAA) raised HK\$25,000 for Enlighten Hong Kong through a Music Quiz held in Delaneys Irish pub in the city. HKGAA plays Gaelic football and hurling and is made up mostly of Irish people working and living in Hong Kong who enjoy getting together to play Irish sports.



Western Pacific

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Chair: Hidemoto Kubota, Japan

Vice Chair: Andrew Pan, Singapore

Secretary: Yuan-fu Tseng, Taiwan

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Dr Hidemoto Kubota elected as Regional Chair

Following a ballot of IBE Full Members in the region, Dr Hidemoto Kubota from Japan was elected to chair the Regional Executive Committee Western Pacific. Dr Kubota has a special interest in issues relating to rehabilitation, including employment and driving and was a member of the IBE Employment Committee 1999 - 2003. Dr Kubota has been working in Shizuoka

at the National Epilepsy Centre since 1998. He has been a board member of the Japanese Epilepsy Association since 1996 and became its Vice President in June. Under his chairmanship, the first meeting of the Regional Committee took place in November at the time of the 6th Asian & Oceanian Epilepsy Congress in Kuala Lumpur, Malaysia.

Gung Hay Fat Choy!

Singapore Epilepsy Foundation celebrated the Chinese Lunar New Year with a special gathering for its support group. Special guests were Susanne Lund, IBE President and Mike Glynn, IBE Treasurer, who were entertained by the SEF dance troupe and heard moving presentations by Ms Selina Yeo and Ms Lisa Elaine Redick.

The President and Treasurer were in Singapore to attend for a meeting of the organising committee for the 27th International Epilepsy Congress 2007.



Epilepsy & Driving

Speakers at a Symposium on Driving and Epilepsy, which took place at the time of the Annual Academic Meeting and General Assembly of Taiwan Neurological Society 2006, were (from left to right) Dr Tsai, Prosecutor Deng, Dr Kubota, Mrs Chen, Dr Hsi, Officer Chen, President Shih, and Dr Lai.

During the year the Epilepsy Association of South Australia and the Northern Territory Inc. took epilepsy awareness to rural areas with its Epilepsy Aware Schools Program



Beijing Epilepsy Forum

The 2nd Beijing International Epilepsy Forum took place in October with speakers from Japan, India, Australia, Korea, Sweden, the US and UK. Allied to the forum was the inaugural special meeting for people with epilepsy.

Mrs Susanne Lund, pictured left with Dr Shichuo Li, President of China Association Against Epilepsy, spoke at the Opening Ceremony of this new event. A large number of the participants registered as the first members of the newly formed CAAE Patients Care Cluster.



Retail Therapy - with a difference!

The people of Singapore love to shop and with the large number of enormous shopping centres and arcades both above and below ground in the city, such as the famous Bugis Street (*left*) there is no shortage of places to enjoy this pastime.

Taking advantage of Singaporeans passion for shopping and to encourage people with epilepsy to become independent, thereby creating a living for themselves, Singapore Epilepsy Foundation (SEF) rented booth space at a large popular shopping centre in the city, and invited members to use the space as a base for selling products.

Vice President Western Pacific visits Mongolia

Dr Shung-lon Lai, Vice President Western Pacific, was happy to accept the invitation of the Mongolia Epilepsy Association to be involved in the 2nd phase of its "Quality of Life" program, which took place in Zuun Mod, a city in the central province of Mongolia. The objectives of the program are to improve health education on epilepsy in the general public; to conduct research and to provide health education

on epilepsy care for neurologists in district hospitals, family doctors, nurses and people with epilepsy and their families; to identify the needs of people with epilepsy at both city and national level; and to encourage government departments to address the needs of people with epilepsy, including diagnosis, treatment services and prevention.



Getting together in Kuala Lumpur

IBE member associations in the Western Pacific Region were well represented at the 6th Asian & Oceanian Epilepsy Congress in Kuala Lumpur with almost 150 attending the special 2-day programme, which was organised for people with epilepsy.

Singapore Epilepsy Foundation had 20 of its members at the congress, while Epilepsy Care Group (Singapore) sent a team of 22 of its members to the meeting.

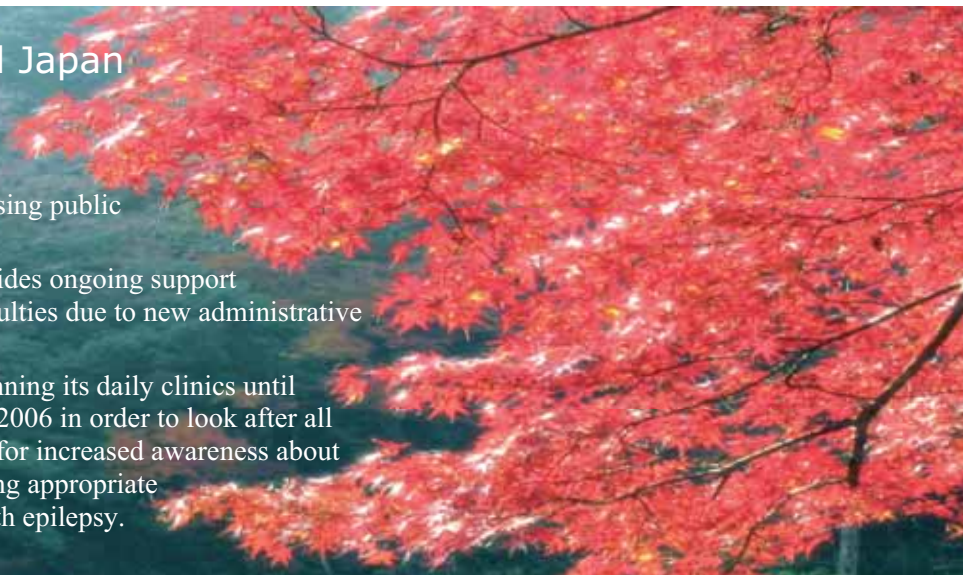
Attending the congress were (from left to right) Dr VS Saxena, India (South East Asia Region); Robert Cole, Australia; Sherman Goh, Choong Chew Thye and Grace Tan, Singapore; Denise Chapman, Australia; and Diana Koh Hwee Hoon, Singapore.

Epilepsy Hospital Bethel Japan

Sendai CARE group at the Epilepsy Hospital Bethel published the third and fourth booklets in a series called Epilepsy Care Sendai aimed at increasing public knowledge.

Hans Berger Association, which provides ongoing support for its clients, met with funding difficulties due to new administrative legislation.

Epilepsy Hospital Bethel has been running its daily clinics until mid-night each day, right throughout 2006 in order to look after all of its patients. The hospital is calling for increased awareness about epilepsy and for assistance in providing appropriate medico-social services. for people with epilepsy.



Future Congresses



7th Asian & Oceanian Epilepsy Congress

Xiamen, China
15th - 19th May 2008



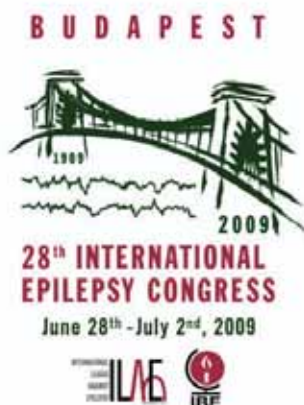
11th European Conference on Epilepsy & Society

Marseille, France
15th - 17th October 2008



5th Latin American Epilepsy Congress

Montevideo, Uruguay
5th - 9th November 2008



28th International Epilepsy Congress

Budapest, Hungary
28th June - 2nd July 2009

For full details visit the congress website or contact the IBE/ILAE Congress Secretariat
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