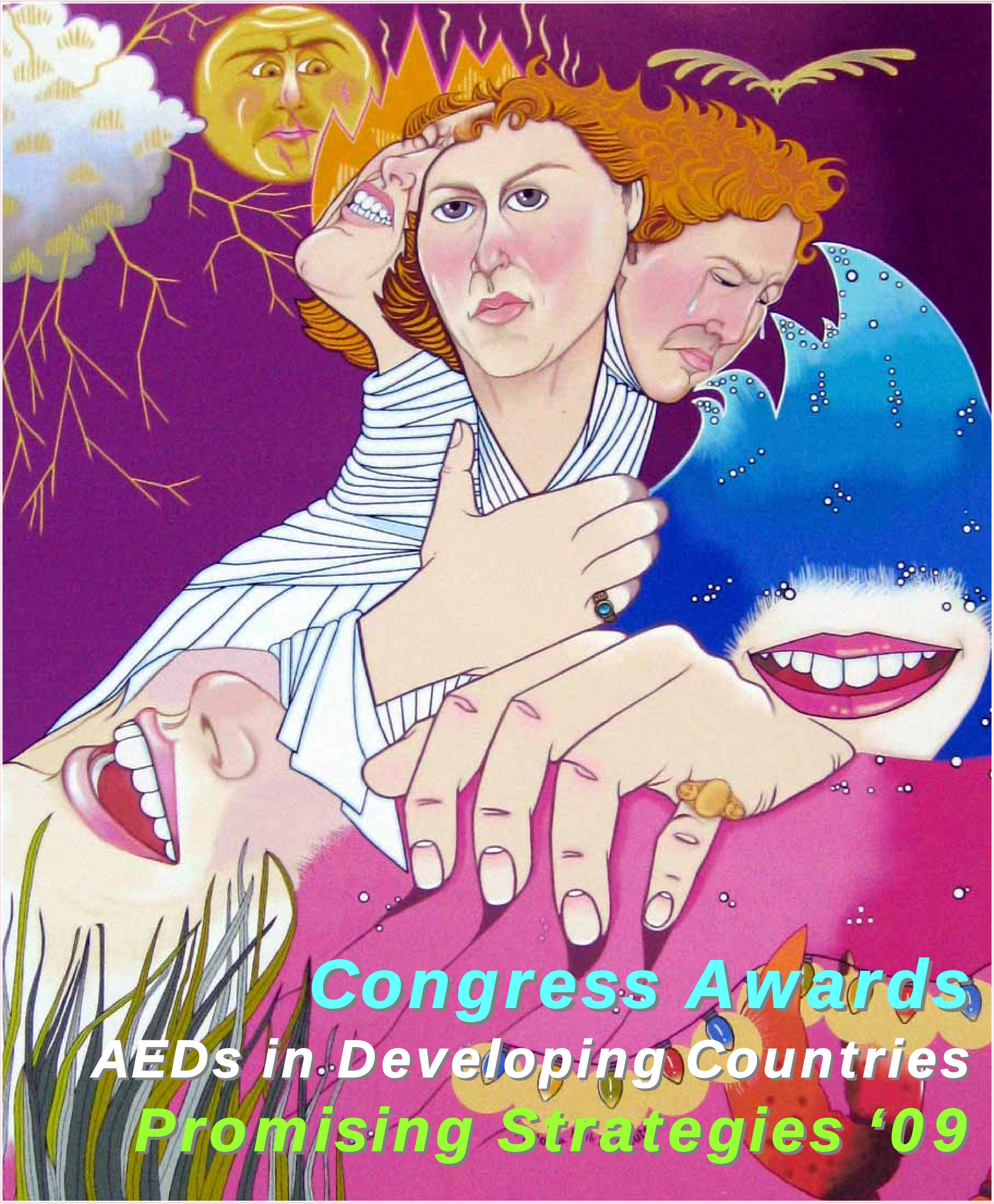
International
Epilepsy News
Newsletter of the International Bureau for Epilepsy Issue 1 - 2009



Congress Awards

AEDs in Developing Countries

Promising Strategies '09

The President's Message

Dear Friends

As always, the time has rushed by since the last IE News and I am sure all of you are busy introducing new activities for 2009.

For IBE this is also a busy time, as we draw close to the end of the current term of the International Executive Committee and prepare for the handover to the new committee, which will take place during the General Assembly in Budapest. So this is the second last time that I will write to you in the IE News in my role as President!

Apart from the 'changing of the guard' during the General Assembly, there is also a lot of other activities planned for Budapest. In this issue you will see the names of those dedicated people who have been selected to receive the Lifetime Achievement, Social Accomplishment and Ambassador for Epilepsy Awards. In addition, IBE will present the Volunteer Award during the General Assembly. The recipient has already been chosen but the name will remain a secret until 1st July. However, once you learn of the tremendous dedication that award winner has given to improve the lives of people with epilepsy, you will agree that the award is well merited.

The annual spring meetings of IBE, ILAE and the joint meeting of both committees (JEC), took place in Brussels in mid-March. At the meeting of the IBE International Executive Committee, the important decision was taken to approve the proposal to invite the General Assembly to amend the Constitution to allow for a new Regional Member status. Information on this proposal will be circulated by 1st May and I hope that all Full Members will ballot on the proposal.

Finally, I would like to encourage all Full Members to find time to vote in the regional elections. These elections are still ongoing, but the closing date for submitting votes is not too far away. By early June we will have completed all of the elections and will be able to announce the names of those to sit on the Regional Executive Committees for the term 2009-2013.

Until next - best wishes to all!

Susanne Lund
President

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The International Bureau for Epilepsy, with membership of 126 epilepsy associations based in 92 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

International Epilepsy News No. 1 - 2009

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The Editor's Letter

Dear Friends,

We have now moved to 2009 and in the first issue of the year we are including exciting information on the names of those selected to receive the IBE/ ILAE congress awards, at the end of June, during the Opening Ceremony of the 28th International Epilepsy Congress, in Budapest. It is always important and necessary to recognize the vital contributions of volunteers, all over the world, who devote their time and expertise in order to help people with epilepsy. Maybe it is a little unfair to give an award only to few of these worthy people, but they represent, somehow, all of you. One award that will remain secret until the IBE General Assembly is the winner of the Volunteer Award and I hope that many of you will be able to attend the assembly to hear this announcement.

Besides that, we have a report from Brazil on the issue of AEDs and generic substitution; a celebration of the artistic achievements of persons with epilepsy around the world; and an interesting article submitted by Dr Amza Ali from Jamaica on suggestions to coordinate the creation of an ILAE chapter and an IBE member at the same time, in order to develop a team work plan. I think there are interesting ideas in this article that could be picked up and developed by other IBE members.

Of course we must mention the report about the latest round of the Promising Strategies Program which presents the latest projects to be selected for funding.

Last, but not least, there is the important message from our President Susanne Lund.

Best regards

Dr Carlos Acevedo
Editor

International Epilepsy News on the Web

IE News is now available on the IBE website **www.ibe-epilepsy.org**
Previous issues can be found under the tab **IE News**, while the current issue is available to IBE Members on the **Members** section.

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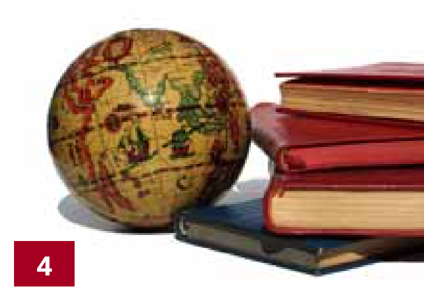

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Strategy Fulfils its Promise!

Harmiena Riphagen, from Epilepsy Namibia, sent us this happy photograph showing participants of the Onyose Project receiving their course certificates.

The Onyose Project, which received IBE funding through the second round of the Promising Strategies Program, was created following an enquiry from the mother of a child with epilepsy and was consequently planned with the support of the Care Centre the young boy attends.

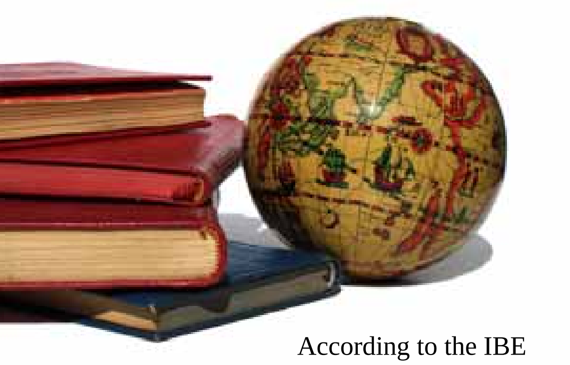
A four-day workshop was produced, with the objective of training the teachers, care givers and people with epilepsy at the Trust, to enable them to manage the condition effectively.

Epilepsy Namibia created the education package, which includes information and care plans, in such a way that it has now become a reference work for the future. The pack will be made available to groups throughout Namibia that need similar training and lack access to information and communication.

Projects to receive support under the third round of Promising Strategies funding has just been announced and you can find out more on page 10 of this issue. In the meantime we send our congratulations to all those involved in the Onyose Project.

Regional Membership:

Proposed amendment to the IBE Constitution



According to the IBE Constitution, one of the criteria of Full membership is that an epilepsy organisation must have “national status”. However some countries in the world have a population number that is so small, or a level of development that is so low, that it is not possible to sustain any type of epilepsy organisation, let alone a national epilepsy association. Under the current Constitution, these countries and the people with epilepsy within them might never be able to access the benefits of membership of IBE.

A solution

Although an individual country might not be able to sustain its own epilepsy organisation, by acting collectively with other similar countries it might be possible to sustain one that covers more than one country – a “regional epilepsy organisation”. For example, a Caribbean Epilepsy Association that covers Caribbean countries that do not otherwise have a national epilepsy association.

Making this possible

To make this possible it is necessary to amend the Constitution so that epilepsy organisations that cover more than one country can be eligible for membership of IBE. In allowing for this, it seems sensible to pre-empt potential problems by adding a condition that regional organisations cannot include a country where there is an existing Full Member of IBE. Also, should a national organisation emerge in a country covered by a regional organisation then that national organisation can be considered for membership in its own right and if successful the regional organisation’s geographical remit as recognised by IBE is adjusted accordingly. Finally, to prevent a possible distortion of an IBE regional committee, a regional organisation covering more than one country would be counted as just one country for the purpose of calculating the 20% threshold required to form a regional committee.

Process

The International Executive Committee has considered and approved changes to the Constitution to allow for regional organisations to become Full members. These changes are being presented to the Full members of IBE for their consideration and decision. Article XIX requires any modification to the Constitution to be proposed either by the International Executive Committee or by at least 20% of the Full members of IBE. Approval of any changes requires a minimum two thirds majority of a minimum 50% plus one Full members voting in a ballot.

It is hoped that all Full members will take an active part in bringing about this Constitutional amendment. Balloting will take place during the General Assembly on 1st July and absent Full members will be encouraged to submit their votes by email.

AWARDS 2009

Lifetime Achievement Award

The Lifetime Achievement Award in Epilepsy is given jointly by the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE). The Award is given to an individual to recognise and honour his or her exceptional and outstanding personal contribution over a long period of time to activities that advance the cause of epilepsy.

The Award reflects international peer recognition. It consists of two commemorative and inscribed silver candlesticks, a financial prize of US$5,000, a scroll, and the name of each recipient is added to the Lifetime Achievement Award winners' Hall of Fame maintained by IBE and ILAE. In the event that the Award winner is not already an Ambassador for Epilepsy, this additional Award will also be given.

This Award is the highest honour in the gift of IBE and ILAE. As such candidates will be assessed accordingly and will need to demonstrate a quite exceptional record. As the title of the Award suggests, candidates must be able to demonstrate a long standing personal contribution (either voluntarily or professionally) in any scientific, clinical, educational or psycho-social field of epilepsy that contributes towards the significant development and permanent improvement of epilepsy care and/or the well-being of people with epilepsy in an international context. Following deliberation and discussion by the Joint Executive Committees of IBE and ILAE on the candidates suggested by member associations and nominated by a member (or members) of the IBE and ILAE executive committees, the following recipients were selected by blind ballot to receive the award in Budapest.

Further information on the award process is available on the IBE website or can be obtained from the IBE office on request.

Jean Aicardi, France

- Graduate, Paris Faculty of Medicine 1955 and Research Fellow, Harvard Medical School 1955-1956
- Assistant Physician Hôpital des Enfants Malades 1957-1964 and Hôpital Saint Vincent de Paul, Paris 1964-1979.
- Maître de Recherche, INSERM 1969-1986; Director of Research INSERM and Head Pediatric Neurology Unit, University Hospital Necker-Enfants Malades, Paris 1986-1991
- Visiting Scientist Miami Children's Hospital, USA, 1993 and Hon Prof of Child Neurology, Institute of Child Health, London 1992-1998
- Author 259 articles in international peer journals, 111 chapters, 5 books

Main Honours and Distinctions

- Cornelia de Lange Medallion
- Fellow Royal College of Physicians
- Honorary Fellow Royal College of Paediatrics and Child Health
- Hower Award, USA
- AES Milken Award
- Ambassador for Epilepsy
- Ramon y Cajal Award
- Peter Emil Becker Award, Germany
- Honorary Member, European Paediatric Society, Sweden 2005
- *Aicardi's syndrome* was described in 1969 (*Arch Fr Pediatr*) and *Aicardi-Goutières syndrome* in 1984 (*Annals of Neurology*).
- Editor-in-Chief, *Epileptic Disorders* 1999-2004.

Hanneke de Boer, Netherlands

Ms de Boer has worked in the field of epilepsy since 1966. She became editor of IE News in 1985, was IBE Secretary General 1989-1993 and President 1997-2001. She has been a member or chair of a number of IBE Commissions. In 1999 she joined the ILAE/IBE/WHO Global Campaign Against Epilepsy secretariat and was co-chair from 2001 to 2005. She is still involved in the campaign today.

Ms de Boer works at an epilepsy centre, Stichting Epilepsie Instellingen Nederland, where for the last 10 years she has been involved in developing international contacts for the centre, which was designated a WHO Collaborating Centre in 2004. She has presented and published numerous papers on the social aspects of epilepsy, in particular employment and employability of people with epilepsy, the influence of stigma on the lives of the people and the burden of epilepsy.

Ms De Boer has received a number of awards, including the Award of the Dutch Christian Society for the Care of People with Epilepsy, the IBE/ILAE Ambassador for Epilepsy Award, the Spike and Wave Award of the Dutch Branch of ILAE, the IBE/ILAE Award for Social Accomplishment, and the Dutch Royal decoration: Officer in the Order of Oranje Nassau.

Social Accomplishment Award

The Social Accomplishment Award in Epilepsy is given jointly by the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE) every two years. It is given to an individual to recognise his or her outstanding personal contribution to activities that have resulted in a significant advance in the social well being and or quality of life of people with epilepsy.
The Award reflects international peer recognition. It consists of an engraved glass trophy, a financial prize of US$5,000, a certificate and the name of each recipient is added to the Award winners' Hall of Fame maintained by IBE and ILAE.

Nominations submitted for the Social Accomplishment Award 2009 were discussed at the joint meeting of the IBE and ILAE executive Committees in March. Following discussion a secret ballot was held and Michael Hills received the highest number of votes and was duly selected to receive the award in Budapest

Michael Hills
New Zealand

Dr Michael Hills ONZM, BA, MA, PhD, DipTch, AFNZPsS, MRNZS is an Hon Fellow of the Dept of Psychology, University of Waikato, New Zealand. He graduated PhD in 1973 from Australian National University, Canberra, after a study of intergenerational values disparity in migrant families. His interest in the disability field originated in his own experience of epilepsy throughout adulthood. He has been an IBE Vice President, Past President of Epilepsy New Zealand, and on the Council of the New Zealand Neurological Foundation. He received an Ambassador for Epilepsy award in 1999 and ONZM for his work for people with epilepsy and in the community in 2002. He has over 100 publications and conference papers to his name. As IBE Vice-President he chaired a constitution review committee and the election task force. As Secretary-General he saw IBE membership expand to over 60 countries. He has been a speaker at 20 international epilepsy conferences. Recent research has focused on developing and evaluating systems for the provision of community care for people with epilepsy, especially minority indigenous groups. His research goal is to improve the quality of life for people with epilepsy and their families.

Ambassadors for Epilepsy

The Ambassador for Epilepsy Award is given jointly by the International Bureau for Epilepsy (IBE) and the International League against Epilepsy (ILAE) and not more than 12 Awards will be given at any one time.

The Award recognises outstanding personal contributions to activities that advance the cause of epilepsy.

The Award carries no monetary value but it does reflect international peer recognition and it is given for the lifetime of the recipient.

Close to 50 nominations were submitted by IBE Full Members and ILAE Chapters for consideration for the awards 2009. The following were selected to receive the award and will be presented with an Ambassador's pin during the Opening Ceremony of the 28th International Epilepsy Congress, Budapest 2009.

This brings to 277 the total number of Ambassadors for Epilepsy created since the award was first introduced at the suggestion of IBE in 1968.

Ettore Beghi
Italy

- President, LICE, Italy
- Former Member IBE Commission on Risk & Insurance
- Chairman First Seizure Trial Group in Italy
- Member ILAE Commissions on Antiepileptic Drugs and on Burden of Epilepsy

Anne Berg
USA

- Research Professor (Biology), NIU DeKalb IL
- Chair, ILAE Commission on Classification & Terminology
- Member IBE Risks & Insurance Commission 1997-2005
- Involved in NINDS-AES initiative on SUDEP

Warren Blume
Canada

- Prof Emeritus University of Western Ontario
- Co-founder Canadian League Against Epilepsy
- Served as Chair/Member on several ILAE Commissions
- Past President American Clinical Neurophysiology Soc

Carol D'Souza
India

- Invited speaker to several international congresses
- Manages IEA Bombay Chapter
- Member British Medical Journal patients advisory committee
- Spoke on behalf of persons with epilepsy at the WHO

Normal Delanty
Ireland

- Involved in Diaspora meetings of Irish Institute of Clinical Neurosciences
- Regular congress speaker
- Leads Irish section in major Genetics & Epilepsy research
- Helped combine Irish and UK pregnancy registrars

Jacqueline French
USA

- Co-Chair, ILAE Commission on Therapeutic Strategies
- Sub-commission Secretary VIREPA
- Co-organiser Anglophone Africa Initiative
- Member, ILAE Epilepsy Initiative in Ghana

Shunglon Lai
Taiwan

- Assisted the Quality of Life Program in Mongolia
- Facilitated development of self-help groups for lay people in China
- Created Taiwan Cycling for Epilepsy awareness program
- IBE Vice President Western Pacific

Shichuo Li
China

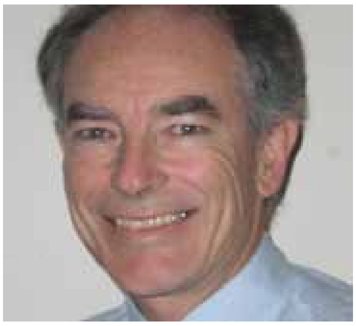
- Involved in WHO/NIH epidemiology study of epilepsy in China in 1980's
- Created first lay epilepsy organisation in China, 2005
- Developed IBE and ILAE associations in China
- Chaired 7th AOEC, Xiamen

Lilia Nunez Orozco
Mexico

- Member organising/scientific committees Latin American congresses
- Chair IBE Regional Executive Committee Latin America
- Founder IBE Full Member in Mexico
- Chair 3rd LACE, Mexico

Cidgem Ozkara
Turkey

- Encouraged development of lay organisation in Turkey
- Past President ILAE Turkey chapter
- Founding member EUREPA
- Initiated EPODES surgery education project
- Secretary ILAE Commission on European Affairs



Ernest Somerville
Australia

- Instigator/director East Timor Epilepsy Training Program
- Advocate for cooperation in epilepsy education in Asia Oceania
- Served on several international congress committees
- Past President Epilepsy Society of Australia

William Theodore
USA

- World leader in neuroimaging to investigate pathophsyiology
- Served on editorial board of Epilepsia and other journals
- ILAE representative to PAHO and involved in several PAHO projects
- Helped foster interaction between WHO and NINDS

Use of Different AED Formulations in Developing Countries

Survey of Associação Brasileira de Epilepsia, Brazil, by Laura Maria de Figueiredo Ferreira Guilhoto

Brazil, the largest country in Latin America, with a surface of 8.5 million km^2, has a GNI *per capita* of US$5,910 and a population of 190 million inhabitants, of which 22% are below national poverty line.[1] There is great disparity in income distribution in Brazil. In 2007 the richest 10% of the population accounted for 43.2% of the nation's income, compared to 44.6% in 2004.

Social achievements have been seen during the last decades, such as a decline in infant mortality from around 50 per 1,000 live births in 1990 to 21.1 per 1,000 in 2005. Although school enrolment in basic education rose from 85% in 1990 to 97% of the population in 2005, illiteracy was still great in 2007, with 10.0% of the country's population over the age of 15 being illiterate.[2]

The Brazilian health system is composed of public and private sectors; in 2005 58.6% of health facilities were public and 41.4% were private, with 30.6% of the latter having a partnership with the public sector. However only 18.5% of the Brazilian population had private health plans.[3]

During the last 20 years, Brazil developed one of the most encompassing and efficient strategies in the world to slow the rate of HIV/Aids infection and to care for those already affected. This program has shown a great discrepancy with other low- and middle-income countries, with estimate coverage of retroviral treatment of 80%, compared to 31% in these nations. [4]

Although the Brazilian government generics public policy (OGGPP) has been developed since the late 1990s and has been a very successful program, data from the Brazilian Statistical Office (IBGE, 2002-2003) shows that for 40% of the poorest people, the heaviest item in the health familial budget was medication costs—accounting for 68.5% of family health expenditure.[3] The estimated prevalence of epilepsy in Brazil is around 2%[5].

- Epilepsy treatment is available universally in the public sector, which dispenses the following antiepileptic drugs (AEDs) free of charge: phenobarbital, carbamazepine, phenytoin, valproate, lamotrigine, topiramate, clonazepam and vigabatrine.
- Oxcarbazepine, ethosuximide, clobazam, nitrazepam and divalproate are only available in private drugstores.
- Newer AEDs like levetiracetam, zonizamide, tiagabine, ganaxolone are not commercially available in Brazil, but can be obtained at high price by importation.

Despite of the fact that the OGGPP was published in Brazil in 1999, there are also available similar AED formulations that constitute copies of the brand drugs. Although most similar AEDs have passed through bioequivalence tests in recent years, they are not included in the OGGPP, but they can be obtained by the government if their price is lower.

The economic impact of generic drugs is well known and their use is recommended in most nations. It is widely accepted that generics have promoted a great impact in the treatment of several diseases world wide, especially in developing nations. Nevertheless in epilepsy treatment, controversy still persists on whether generic drugs are interchangeable with brand name and similar drugs regarding efficacy and adverse events.

Generic drugs are considered interchangeable with the reference, but several available generics are not interchangeable with each other. This is even more critical to AEDs that have a narrow therapeutic index like phenytoin, which has closer values of therapeutic and toxic levels, and also in the situation of some people with epilepsy (PWE) who only have their seizures controlled with high AEDs serum levels.

Bialer in 2007 declared that the bioequivalence tests of generic drugs

demanded by regulatory authorities are sufficient to compare drug prescribability, but do not guarantee drug switchability, nor that the change between them will be indifferent to the PWE, and this author suggested that individual bioequivalence study would be recommended in order to avoid adverse effects and breakthrough seizures.[6]

This issue is very relevant and still more important in developing countries with limited health expenditures. The "*Associação Brasileira de Epilepsia (ABE)*" (Brazilian Branch of International Bureau for Epilepsy) applied a questionnaire for PWE with 18 multiple-choice questions regarding formulations knowledge (reference, generic and similar drugs) and clinical change evidence during AED formulation switch.[7]

Seven hundred and thirty one (731) PWE from six Public System Hospitals from ABE chapters in Brazil participated, with 91% from middle/low income classes. From the PWE older than 18yrs 1/4 had less than 4 yrs of education; 1/4 between 5 and 8 yrs; 2/5 had at least 9 yrs of schooling. Two thirds obtained AEDs from public resources and 1/5 only in private pharmacies; 2/3 received more than one AED (1/2 carbamazepine, 1/4 valproate). From the 731 PWE, 2/3 did not know the existence of different AED formulations (more educated PWE, high income classes responded more correctly); only 1/3 (especially among more educated people) knew that the first produced drug is the reference and 10% considered generics "official governmental drugs".

After being instructed about formulations by the interviewers, 1/4 ignored generics are cheaper than reference drugs, 1/3 considered their quality worse and only 1/3 knew their packing details, in Brazil a letter G in a yellow band in the box (higher income classes were more informed). In the last year, 1/4 received different formulations (mainly carbamazepine and valproate) and 14.5% (especially lower educated PWE) referred breakthrough seizures after switching (mainly carbamazepine, valproate and lamotrigine) and 12.2%, increased side effects (carbamazepine, valproate and topiramate). The fact that level of education influenced more than the socioeconomic class in the presence of breakthrough seizures when the change was done, probably reflects a deeper neurological involvement in these PWE.[7] These findings are similar to the study by Crawford et al (1996) in the United Kingdom which observed that 29.5% of 251 interviewed PWE who changed the reference AED by generics reported a problem with the control of their epilepsy after a 'switch', that was validated by the doctor in 1/3 of the cases, and 11% and 12% referred drug toxicity and seizures, respectively.[8]

In conclusion, different formulations knowledge was small among the interviewed PWE in Brazil, especially those with less schooling level and of lower socioeconomic classes, and there was frequent AED formulation switching. Breakthrough seizures (14.5%) and increased adverse effects (12.2%) were referred when the AED formulation change was done, mainly by those PWE with less education, and probably the individuals more compromised by the epilepsy burden. This fact should alert health experts and regulatory authorities, especially in developing countries with limited health expenditures, in which generics promote a great impact in the treatment of several medical conditions, that AEDs should be considered a special group regarding generics and similar drugs public policies.

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Promising Strategies 2009

Helping to make a difference!

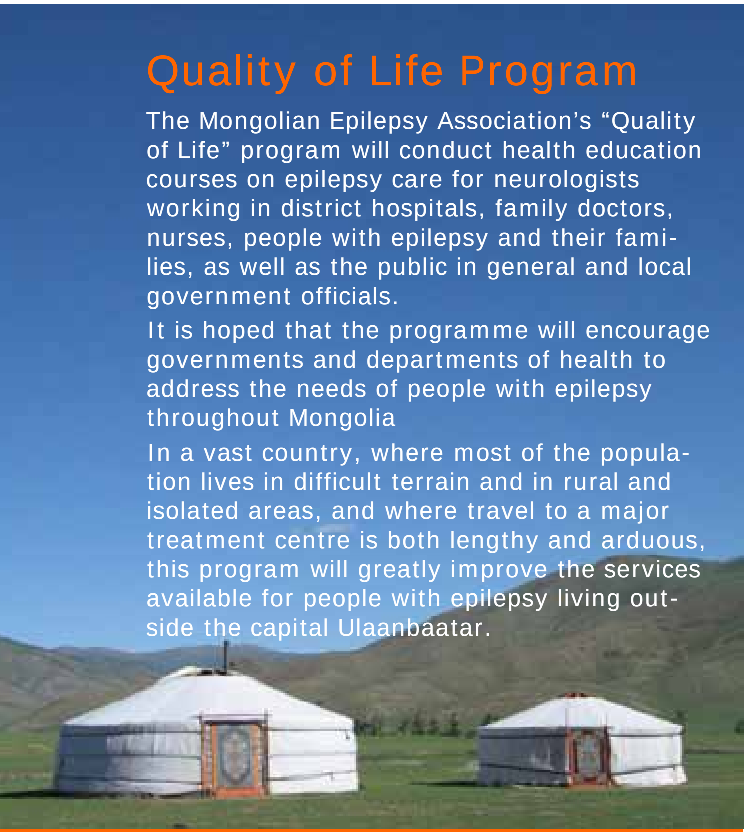
www.ibe-epilepsy.org/promising-strategy

CHILE

Educational Puppet Show

All young children love puppets and puppetry has been shown to be a successful means of educating young people and of dealing with issues that can be otherwise more difficult to confront. ANLICHE, IBE's Full Member in Chile, will use a puppet family in a video aimed at 7 to 12 years olds. The puppet story will start with the diagnosis of epilepsy in a family member and look at how the family learns to confront and to then accept the diagnosis.

The video, which will be shown to more than 5,000 students in 20 primary schools in the Metropolitan Area of Chile, aims to eliminate stigma thereby improving the self-esteem and self-confidence of children with epilepsy. Following screening of the video, a social worker will be in attendance for discussion on the subject. In addition, the Chilean Ministry of Education has agreed to make more than 200 copies of the video available to schools throughout Chile.



Quality of Life Program

The Mongolian Epilepsy Association's "Quality of Life" program will conduct health education courses on epilepsy care for neurologists working in district hospitals, family doctors, nurses, people with epilepsy and their families, as well as the public in general and local government officials.

It is hoped that the programme will encourage governments and departments of health to address the needs of people with epilepsy throughout Mongolia

In a vast country, where most of the population lives in difficult terrain and in rural and isolated areas, and where travel to a major treatment centre is both lengthy and arduous, this program will greatly improve the services available for people with epilepsy living outside the capital Ulaanbaatar.

MONGOLIA

MAURITIUS

Teacher Training

Edycs Epilepsy Group in Mauritius is creating an Epilepsy Advocacy Network, one action of which will be to train teachers working with special needs children. Other elements will include:

- Lobbying the health and education ministries to support the initiative;
- Development of an Advocacy Tool Kit for school boards;
- Training workshops for teachers on the management of epilepsy;
- Recruitment of a part time Visiting Liaison Officer to support and facilitate the programme;
- Development of an assessment tool to evaluate the programme.

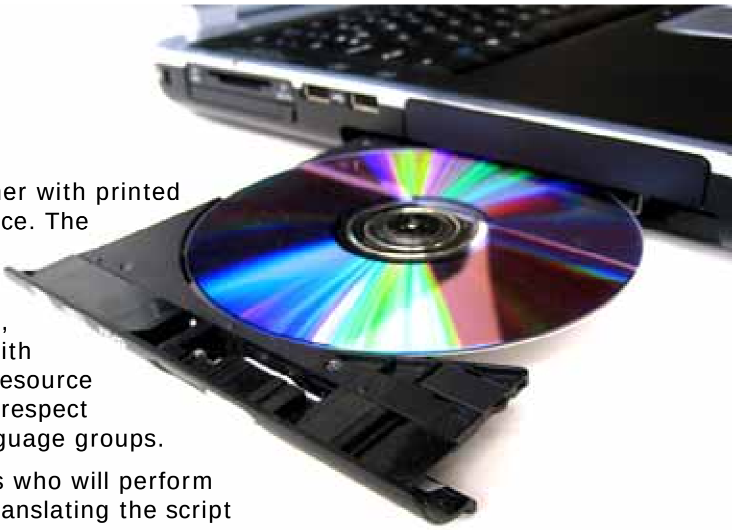
From peanut butter to video production, from puppetry to vegetable farming, the six projects selected for funding under the third round of the IBE Promising Strategies Program will provide training and a means of self-sufficiency for people with epilepsy living in Chile, Togo, Mauritius, Zambia, Namibia, Philippines, Zimbabwe and Mongolia.

Promising Strategies has now funded 27 projects around the world, thanks to the generous donations of IBE members and supporters.

www.ibe-epilepsy.org/promising-strategy

NAMIBIA

DVD Awareness Pack



Epilepsy Namibia is producing a DVD presentation, together with printed information on lifestyle management and seizure assistance. The presentation will be translated into six languages, with distribution of 600 units of the completed package.

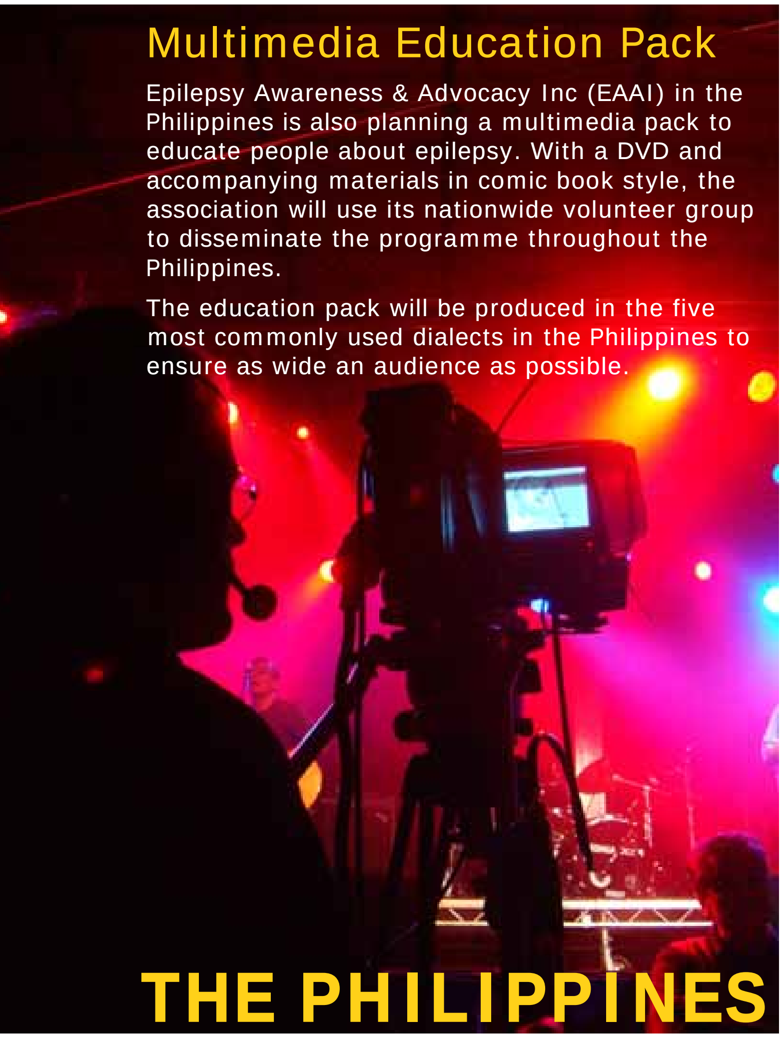
The multimedia pack will explain the condition of epilepsy, lifestyle management and seizure assistance for people with epilepsy and their caregivers who do not have access to resource centres in the rural areas of Namibia. The production will respect indigenous cultures and will be available in the major language groups.

Epilepsy Namibia has begun the process of training actors who will perform on the video and has also begun the lengthy process of translating the script into the six languages in which the production is to be produced.

Multimedia Education Pack

Epilepsy Awareness & Advocacy Inc (EAAI) in the Philippines is also planning a multimedia pack to educate people about epilepsy. With a DVD and accompanying materials in comic book style, the association will use its nationwide volunteer group to disseminate the programme throughout the Philippines.

The education pack will be produced in the five most commonly used dialects in the Philippines to ensure as wide an audience as possible.



THE PHILIPPINES

Market Gardening Skills

Learning a skill increases self-confidence and self-worth and when that skill leads to self-sufficiency the value is multiplied. The Market Gardening Skills project of the Epilepsy Association of Zambia will train people with epilepsy in basic gardening and vegetable production skills. In this way, those attending the course will acquire, perhaps for the first time in their lives, the means of generating funds to support themselves and their families.

This project follows on the earlier very successful Promising Strategies Project in poultry rearing, which the association established in 2007.

ZAMBIA

Promising Strategies is supporting programmes in:

- Argentina
- Brazil
- Cameroon
- Chile
- Ecuador
- Ethiopia
- The Gambia
- Guatemala
- Kenya
- Mauritius
- Mongolia
- Namibia
- Philippines
- Romania
- Sierra Leone
- South Africa
- Tanzania
- Togo
- Uganda
- Zambia
- Zimbabwe

www.ibe-epilepsy.org/promising-strategy

ZIMBABWE

Peanut Butter Project

Epilepsy Support Foundation of Zimbabwe has been provided with financial support to establish a peanut butter processing project that will benefit 70 rural dwelling people and 30 city dwellers, all of whom have epilepsy.

The main objective of the project is to improve income generating skills of the 100 people selected for training, who are all currently unemployed. Training will take place over a period of two months.

The association is renovating an existing building at the Epilepsy Centre that will serve both as a training area and an employment workshop, where the peanut butter will be produced.

The provision of training, in a skill that can lead to employment, will remove the dependence of these people with epilepsy and give them the opportunity to support their families, including funding for their own medication. The Epilepsy Centre provides the ideal location for the workshop, providing a clinic, social support and is located in Harare, Zimbabwe's largest commercial zone.

TOGO

Bridging the Gender Gap

In Togo, as in other areas of the developing world, poverty, illiteracy, language barriers and gender discrimination are great obstacles to obtaining proper epilepsy treatment. The population to be targeted in the project in Togo, concerned with health care education, are women and children with epilepsy as well as their family members. The project will include:

- Knowledge building on seizure recognition and prevention, and first aid and drug treatment
- A seizure calendar using symbols and pictures
- The importance of taking medication as prescribed
- Knowing which elements of traditional medicine are helpful and which herbal medicines are harmful
- Information on schooling, employment, sleep, and pregnancy.

Find out more

Detailed information on each of the 27 projects funded through the Promising Strategy Program since 2007 can be found on the IBE website at **www.ibe-epilepsy.org/promising-strategy**

Information on what constitutes an IBE Promising Strategy, and how projects are selected, is also included on this webpage.

Donate to the Program

The number of projects funded through the Promising Strategies Program is limited to the level of funding available to IBE. If you would like to help us support even more projects, please consider making a donation to the program.
Contact Ann Little, IBE Executive Director to find out more **ibedublin@eircom.net**.

Robert Bentley Todd remembered

Brainwave The Irish Epilepsy Association marks the 200th anniversary of epilepsy pioneer.

2009 marks the 200th anniversary of the birth of one of the true epilepsy pioneers - Irishman Robert Bentley Todd (1809-1860). Todd was the first man to identify the role of electricity in epilepsy. To celebrate this milestone, Brainwave The Irish Epilepsy Association recently hosted the Robert Bentley Todd Memorial Lectures at Trinity College Dublin, the university where Todd himself was educated. The event took place as part of Brain Awareness Week 2009.

Dr Edward Reynolds, former ILAE President (1993 - 1997), founder of the ILAE/IBE/WHO Global Campaign Against Epilepsy and co-Chair of the campaign from 1997 to 2001, is an expert on the career and work of Robert Bentley Todd. At the special event in Trinity College Dublin he outlined Todd's pioneering contribution to our modern understanding of epilepsy.

Electrical theory of epilepsy

Todd spent all his working life in England, helping to establish King's College Hospital London in 1840, where he subsequently built a reputation as an outstanding physician and teacher. It was Todd's collaboration with Michael Faraday, the greatest electrical scientist of all time, that led to the development of a radical new theory of epilepsy based on electrical "disruptive discharges" in the brain. He also anticipated, by over 50 years, the neuron doctrine that won the 1906 Nobel Prize for Golgi and Cajal.

Todd presented his epilepsy theories in a series of Lumelian lectures to the Royal College of Physicians in 1849, over 40 years before John Hughlings Jackson, commonly referred to as the father of epilepsy, presented his own electrical theories. Todd's earlier theory was not referenced by Hughlings Jackson and, as a result, it has often been overlooked. Today, Todd is best remembered for lending his name to Todd's paralysis, the temporary stiffening of the limbs that may follow some seizures. Dr Reynolds, a successor of Todd's at Kings College, described Todd as the "first outstanding neurologist and neuroscientist before these disciplines existed" and "one of the greatest ever alumni of Trinity College Dublin".

"1809 was a vintage year for distinguished births," he said. Charles Darwin, William Gladstone, Abraham Lincoln and Felix Mendelssohn were all born in that year and, according to Dr Reynolds, such was Todd's contribution that he deserves to be included in this company.

Guidelines needed for photosensitive epilepsy

The second keynote address was delivered by Prof Graham Harding, one of the world's foremost experts in photosensitivity and the developer of the Harding Flash and Pattern Analyser used to analyse broadcast material for harmful images. Prof Harding called for the introduction of broadcast guidelines in Ireland to protect people with photosensitive epilepsy. Currently in Ireland, verbal warnings may be given about upcoming sequences, but no production guidelines are in place.

Prof Harding has assisted with the development of broadcast guidelines in the UK and Japan. He said that the most common trigger for photosensitive epilepsy in Europe is the domestic television set, which causes about 60% of seizures.

"The onset of photosensitive epilepsy in an individual occurs typically around the time of puberty and is slightly more common in girls. It affects approximately one in 4,000 people, or about 3-5% of all people with epilepsy. Three quarters of patients remain photosensitive for life" said Prof Harding. In relation to broadcast material, Prof Harding said that almost 50% of people with epilepsy are sensitive to the 50Hz flicker of television, and up to 75% are sensitive to the 25Hz flicker. Plasma screen televisions are better that their regular counterparts, he advised, but there is still a long way to go before people are completely safe.

Photo, pictured from left: Professor Graham Harding, Dr John Kirker (President, Brainwave The Irish Epilepsy Association) and Dr Ted Reynolds.

This report is based on an article that appeared in Epilepsy News, the newsletter of Brainwave The Irish Epilepsy Association, and IE News acknowledges the assistance of Mike Glynn and Peter Murphy.

CreativeSparks

For centuries there has been an important connection between art and epilepsy, both in the representation of the condition through art and literature, and as depicted in the artistic endeavours of persons with epilepsy.

On the 7th May Jim Chambliss will see a dream come through when a new website devoted to works created by persons with epilepsy globally is launched.

Also, on page 18 you can meet John Bramblitt, an American who had to overcome more than just his epilepsy in order to become an accomplished artist.

Cover image: *Fear of Fear Itself* by Vicki Deutsch

Image left: *Blindsided* by Jim Chambliss

Although Jim Chambliss began his professional career as an attorney, his epilepsy drove him in an entirely different direction - to art. Now his goal is to give voice to a global community of artists with epilepsy, many of whom use their artistic talents as a way of describing their epilepsy, the sensation of having a seizure, or how their lives are affected by epilepsy. Chambliss explains:

"One of the things that describes what I am doing as a goal is to show how a picture is worth a thousand words. And we are going to find over a thousand pictures as we begin to help people understand the individual with epilepsy rather than just the condition.

"Some of the artistic expression will provide a visual dialogue of what occurs during seizures and interictal behavioral changes. The nature of our research focuses on how epilepsy can, in some circumstances, be enabling - not just disabling - through the stimulation and enhancement of artistic expression."

Chambliss is now just one step away from his goal, as the final touches are put in place prior to the official launch of the website in Melbourne on 7th May 2009.

Artists whose work will be displayed on the website are also invited to write about the most significant influences in their art.

Again Chambliss explains: "We are interested in artistic influences of people with chronic medical conditions such as epilepsy and migraines. What is it that sparks creativity?"

He adds, "Almost all artists want to have their artwork seen and interpreted. However, what we want to convey in an exhibit is not cause and effect; that is, you are not a good artist because you have epilepsy, but rather epilepsy is simply one of the many factors that make a person uniquely human."

Chambliss's piece "Blindsided" is one example of this: "This is a representation of when I had a seizure in December 1998. I stiffened and fell flat on my face on a hardwood floor, but I have no memory of the event. Later my face and persona were not recognizable to me. I had a broken nose, chipped teeth, and one eye swollen closed."

Chambliss says, "I am often reluctant to speak of the cognitive damage from my brain injury and the altered behaviors from epilepsy, because of the stigma that can stem from brain impairment. It is so easy for even the best intentioned of people to proliferate the stigma of epilepsy through focusing only on the negative impact that confronts a person with partial brain impairment without balancing the positive attributes of the individual as a whole."

"I have fortunately been able to recover, adjust, and move on to a point where the brain injury in 1998 and epilepsy do not hold me back in 2009. My personal experiences have made me more empathetic and understanding of the plight and frustrations of people with epilepsy, while more impassioned to help."

Of the website Chambliss explains: "Everyone deserves the opportunity to be understood. We need to express ourselves. But sometimes in order to do so, we need an open door. We are opening the door for articles and art work for those people who have a gift and who also have epilepsy.

"There is still a stigma. I am not an artist because I have epilepsy. I am an artist with epilepsy and it opens the door to novel thoughts, to thinking outside of the box."

As a preview, here is a small selection from the huge collection that will be on view when the site goes live. After 7th May, you can visit the site to enjoy more of the images and sculptures. You can also contact Jim at jimchambliss@msn.com

www.creativesparks-ep.com

Up Against the Glass

Phil Thomson

Australia

I want to make reference in my art to the fact that I have epilepsy because it has such a profound effect on my imagination, visual senses, emotions, and on my perception and observation of everything around me. What I would most like people to know about epilepsy is that it is a condition that effects and alters every aspect of human consciousness. It exposes someone who has epilepsy to states of perception that are experienced by relatively few of the overall population surrounding them.

Spring

Emma Brockett

Australia

Our personalities are governed by our brains. Obviously those with epilepsy, in theory, will perceive art and make art in a different way from those who don’t have epilepsy. Also artists with epilepsy may display similarities only found in people with epilepsy, or, the same type of epilepsy. I hope the exhibition makes people start to think about epilepsy and its consequences and opens up a dialogue, which leads to a better understanding of the condition. I think art is a great way to do this as, I believe that, everyone will have an opinion of what they see.

I would like to encourage people with epilepsy, including myself, to feel that they can be upfront about their epilepsy and not fear the consequences of such a disclosure. I have been told many times, living in fear, is not a productive way of living at all.

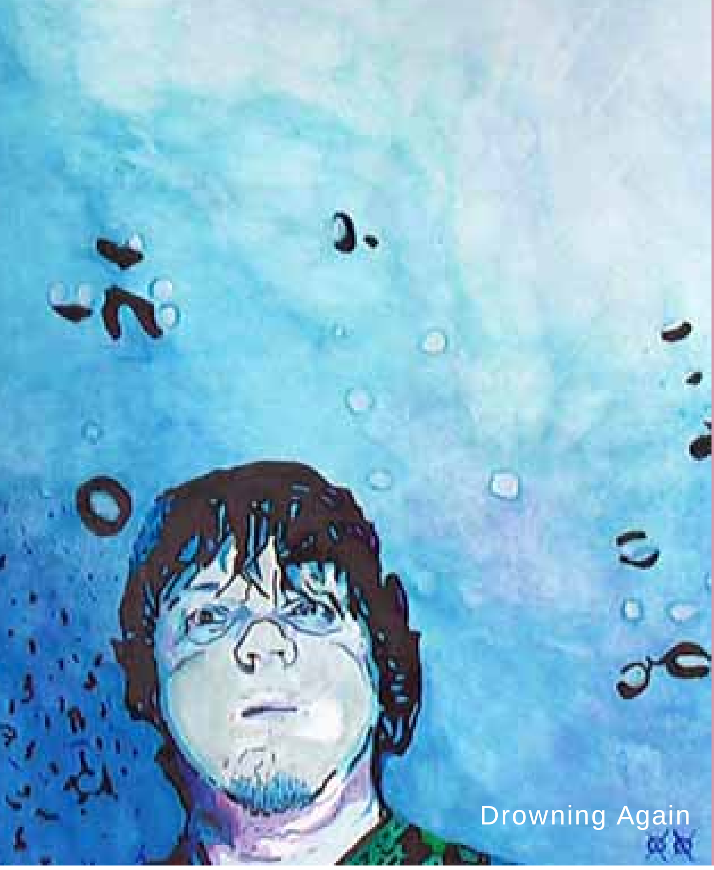
The Guardian

Myron Dyan

USA

I have been showing my work for a few years now, and my main theme is that all people regardless what their condition or circumstance can contribute not only to themselves, but to others as well. I have attempted to show in all my work all the inner pain and beauty that can be manifested with a condition as severe as epilepsy, but also a way out of that pain!

Life is not always kind but we must be strong and fight for our dreams and never, never give them up for any one, any condition, or circumstance. Once we have found our way down the pathway to our dreams then giving to others become part of that healing process. So I hope that in some small way my art will help others find their own way to wholeness so that we can all see all the way home!!



Drowning Again

Portrait of the Artist as a Blind Man

John Bramblitt has epilepsy and is blind; he is also a talented artist

With thanks to Lisa Boylan, Epilepsy Foundation, who sent us this story.

Blue Buddha

www.bramblitt.net

John Bramblitt's sight began to deteriorate when he was 11 years old, but no one realized what was happening. He started having seizures when he was two years old and his doctors think his loss of vision is due to nerve damage, possibly caused by his seizures.

A student at North Texas University, he was majoring in English and creative writing when he lost his eyesight completely. Suddenly, all of his main artistic diversions were derailed. He could no longer draw, read or write—passions he believed would carry him through the worst of times.

"For about a year I couldn't do anything," he says. He became deeply depressed and worried about being a burden on his parents, even though he had been living independently since he was 18 years old.

He knew people, even friends, perceived him differently because of his visual impairment and he wanted to prove to them that he was not the sum of his disabilities.

"I wanted to tell people that even though I have a disability, I'm still me," he explains. He wanted to connect with people visually—for people to look at his paintings and realize, "Hey, he does relate. He does see the world."

"Your eyes don't actually make the image. It's just information coming in, and your brain forms the images that you see," he says.

As a budding writer and artist who suddenly had to contend with blindness and intensifying seizures, John seemed to have every reason—every excuse—to descend into self pity and artistic paralysis. But, instead, he found a way to overcome the obstacles in his life. The desire to communicate in images in his head to the rest of the world spurred him on. He just needed to find a way to make it happen.

So he taught himself to draw all over again.

His first objective was to find a means of marking the outlines of his drawings with raised lines—something similar to the way Braille is written as raised dots. This is what he calls the "bones" of the painting. Eventually he came across a fast drying substance called Puffy Paint, that served his purpose. John draws mainly in loops and circles and, he says, each circle represents in his mind some colour or shadow or place of light.

Then he searched for the best type of paint. Living in Denton, Texas, a college town, because artists' supply shop was nonplussed when he asked to look at all the paints, touch them and determine which one was going to work best. It seems that different colour oil paints feel unlike one another because they are made of different substances.

When he first started paining, he was angry. He signed his paintings with two circles that are X'd out to signify his lost sight. He painted almost constantly for six months and, before he knew it, his anger had subsided and he felt calmer than he ever had. He credits his concentration on projects as a calming force that ultimately allowed him to sometimes anticipate his seizures. He would have an aura or the sensation of smelling popcorn burning. The advance notice gave him the chance to relax, which would diminish the intensity of his seizures. He says, "Sometimes I wouldn't have a seizure at all."

John's friends encouraged him to exhibit his paintings in local coffee shops. He did, but he was reluctant for people to know he was visually impaired when they were viewing the paintings. Not because he was ashamed or embarrassed, but, he says, "What does it matter if the person has epilepsy or they're blind or they're deaf?"

In the midst of his collection, a laughing blue Buddha takes centre stage. He says he was drawn to the figure of Buddha because of his seizures. The statue of Buddha looked so calm and happy—like "a calm little centre of the universe that everything can rotate around." He wrote in Braille on the canvas, "I am," to remind him to remain in the moment.

John is married to Jacqi, and they have a 10-month-old son, Jackson.

Berlin Brain Works:

EPICURE hosts its 3rd annual meeting in Berlin

Janet Mifsud reports

Funded by the EU
6th Framework Programme
Project LSH-037315

Over 100 participants attended the 3rd Annual Meeting of the EPICURE project, which was held at the Charite in February.

The meeting was opened by Prof Giuliano Avanzini, coordinator of EPICURE, who reported on the current status of the project, now practically half way through its 48 months term. Carla Finocchiaro from CF Consulting, the professional company administering the project, then presented a review of the management aspects of the project.

Janet Mifsud, from the Dissemination Board, reported that during 2008 EPICURE participants had produced several scientific publications and presented results at several conferences, and that a Google search for EPICURE has increased to 10,000 hits. Janet Mifsud also emphasized the importance of reaching out and informing other scientists, patient organizations and the lay media about the project.

The meeting continued with an overview of the various EPICURE work packages. During these sessions, both young and professional investigators presented some of the data from the numerous scientific publications that have emerged from the project over the last year.

The first day focussed on Acquired Channelopathy and Neuronal Network Reorganisation, and Pharmacogenetics of Refractory Epilepsy, Mechanism of Drug Resistance and New Therapeutic Strategies. Data from the EPICURE Brain Databank was presented showing the importance of a European critical mass in the collection of such samples.

Professor Heinemann underlined the importance of having valid models in epilepsy research that can help by leading to an *epi'cure'* for patients with his now famous quote: '*the best model of a cat is a cat*'.

During the second day the emphasis was on progress made in the work packages related to Genetics of Human Epilepsy and Functional Consequences of Mutations in Ion Channel Genes and updates from the work package on Epilepsy and Development.

In his concluding remarks, Prof Avanzini commented on the positive effect of EPICURE in stimulating new co-operation between scientific researchers and partners in the project.

The official meeting then continued with the organization of a week-long hands-on training session at the Institute of Neurophysiology at the Charite, which was attended by over 50 participants including young researchers, tutors and lecturers.

The EPICURE annual meeting coincided with the Berlin Film Festival. EPICURE may not have been so glamorous, nor attracted as much media attention as the more famous festival, but the very active interaction, networking and fruitful discussions among the participants certainly made up for this.

Editor's note:

As IBE is the EPICURE partner charged with dissemination of the project, it was good to note that in a Google search on 'epicure' the IBE website is in the first 3 results and tops the list of results related to the project. IBE has a page dedicated to EPICURE on its site, which is regularly updated as new information is received from the other partners in the project.

BUDAPEST 2009

With the 28th International Epilepsy Congress looming on the horizon, we would like to remind you of some of the activities planned by IBE for its Members.

General Assembly

The General Assembly begins at 12:00 on Wednesday 1st July. Agenda and reports will be circulated shortly.

Regional Committee Meetings

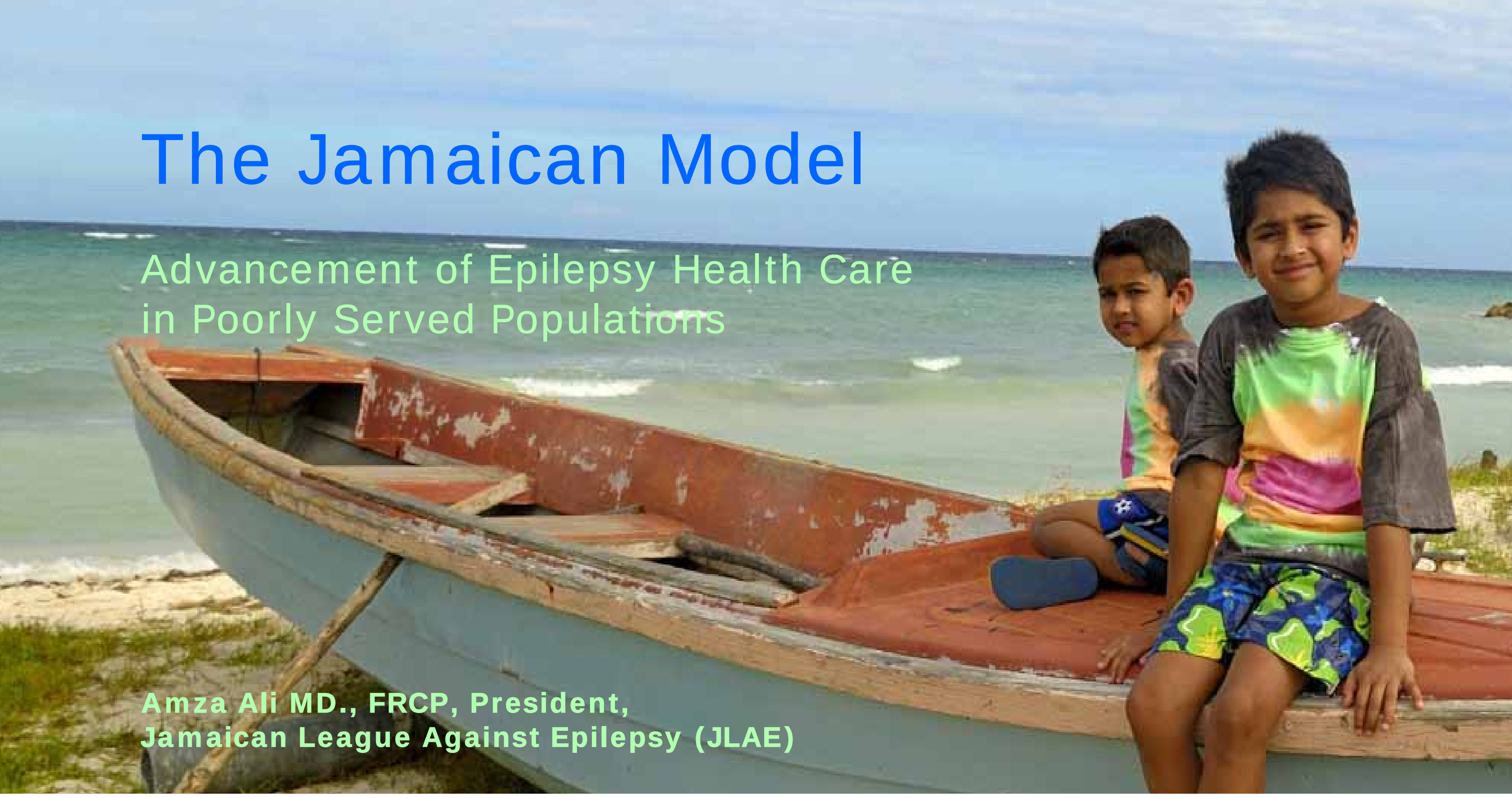
Each Regional Committee - Africa, Eastern Mediterranean, Europe, Latin America, South East Asia and Western Pacific - has a meeting planned during the congress.

Poster Display

Visit the special Members Poster Display to find inspiration for future activities.

IBE Exhibition Stand

Drop by the IBE stand to meet up with friends old and new. Both the Global Campaign Against Epilepsy and EUCARE will have stands next to the IBE stand.



The Jamaican Model

Advancement of Epilepsy Health Care in Poorly Served Populations

Amza Ali MD., FRCP, President,
Jamaican League Against Epilepsy (JLAE)

Approximately 90% of people with epilepsy (PWE) in the world do not currently receive adequate care[1]. Indeed, most obtain either no care or inappropriate and ineffective treatment. Disparities in epilepsy care may be increasing, not only between countries and regions but also within individual countries, due to widening gaps in economic circumstances. This situation is not restricted to developing countries but, of course, is much more pervasive in such areas.

Jamaica is a small independent island in the Caribbean, geographically located approximately 450 miles southeast of Florida, USA. It is roughly 150 miles long and about 60 miles at its widest. The population is approximately 2.65 million people. The island is classified as middle income by the World Health Organisation (WHO).

Until recently, no structured programme for epilepsy health care existed in Jamaica. Epilepsy care was delivered solely on a one-to-one basis by individual medical practitioners to their patients with varying seizure control outcomes, depending on individual proficiencies.

No facilities existed for regular education of PWE, the population as whole, or medical practitioners after graduation from medical school. Electroencephalography (EEG) services were extremely limited with most patients treated without ever having an EEG performed. Widely held misperceptions about epilepsy were observed in the evaluation done for the North American Report on Epilepsy. Most PWE were unemployed and driving was prohibited, although medical practitioners tended to follow the older UK rules precluding driving until after 2 years of seizure freedom.

> “Until recently, no structured programme for epilepsy health care existed in Jamaica

In recognition of the severe deficiencies in delivery of appropriate health care to PWE in the island, the JLAE was launched in 2001 as part of the Global Campaign Against Epilepsy. As an English-speaking island it has been included, for administrative purposes, in the North American Region of the International League Against Epilepsy[2].

In addition, since epilepsy is as much a social disorder as a medical one, a local chapter of the International Bureau for Epilepsy, the Jamaican Epilepsy Association (JEA) was launched in 2002. Over the years the JLAE and JEA have identified several areas that should be the focus of any initiative to improve epilepsy care in any currently underserved country or region. These fourteen recommendations are outlined below.

Recommendations

1. Form local chapters of the ILAE and IBE. These must, from inception, agree to work together as closely as possible, with mutual respect for their differing areas of expertise.
2. Choose highly motivated people to form the core of each group, preferably people who already know each other and can work well together.
3. Affiliate your chapters with well established chapters in other countries. They serve as models and as motivation. Distance is much less an obstacle than before and much can be achieved utilising the internet and video-conferencing.
4. Determine the existing knowledge, attitudes and practices (KAPs) to epilepsy in the country/region. This will help to identify where to focus energies and resources.
5. Education: Inevitably, education will be essential. Improving education must focus on 3 major groups:
    - Health Care workers: to improve diagnosis and treatment.
    - Patients and their families:

  to deal with emergencies and to understand the importance of adherence to treatment.

- The population as a whole: to address problems related to misperceptions and social stigma. Develop a relationship with the media to keep Epilepsy in the News!

6. Advocacy: Focus on areas determined as most needed from the baseline KAP study. Usually the following two areas will require particular attention.
    - Employment
    - Driving
7. Service: Determine areas of deficiency from the KAP and focus on them. Fundamental to appropriate treatment is to make digital EEG available. It is critical to ensure that EEGs are read by suitably trained electroencephalographers. If necessary, an individual should be identified and sent for appropriate training. This individual can, in time, identify and train others as required.
8. KAPs should be continually reassessed, to determine on an ongoing basis the impact of interventions and to determine areas to focus on.
9. Research: Apart from KAPs, other research must be conducted. It must be evident that not all research in highly advanced regions can be applicable, or even be relevant, to less fortunate regions. Therefore it is crucial that research be done in every area where epilepsy care is being advanced, to better understand and address local problems. It will serve as a guide to the further refinement of efforts and can also be rewarding to the investigators from an academic perspective. Conceivably, the publication of good data might help to attract funding from international organisations as well.
10. Develop sub-committees to work in the principal areas of clinical service, research and advocacy. Match individual skills to areas best suited to each member.
11. Financial limitations should prompt creativity rather than pessimism as, unless the situation is dire, there often can be found funds to make significant local interventions.
12. There is no need to re-invent the wheel. Look at what has been done elsewhere and apply to local circumstances.
13. Be persistent! Obstacles will arise but, working as a group, these can be overcome.
14. Last but not least: Recognise everyone’s contributions including funding sources and volunteerism.

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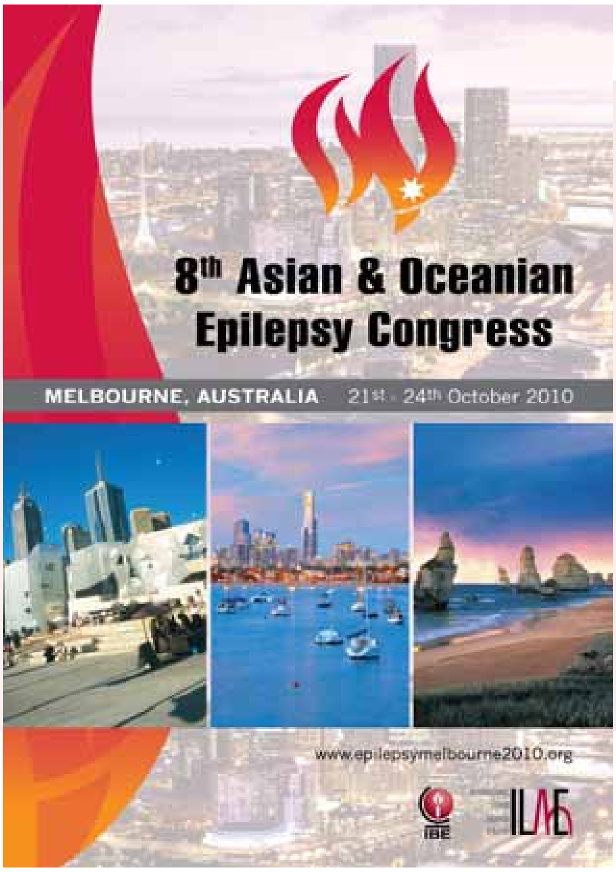
2. ILAE Report: Epilepsy in North America:Theodore W.T, Spencer S, Wiebe S, Langfitt J.T, Ali A, Shafer P.O, Berg A.T, Vickrey B.G. *Epilepsia* 2006 47 (10) 1700-1722.



8th Asian & Oceanian Epilepsy Congress

MELBOURNE, AUSTRALIA 21st - 24th October 2010

www.epilepsymelbourne2010.org

IBE

ILAE

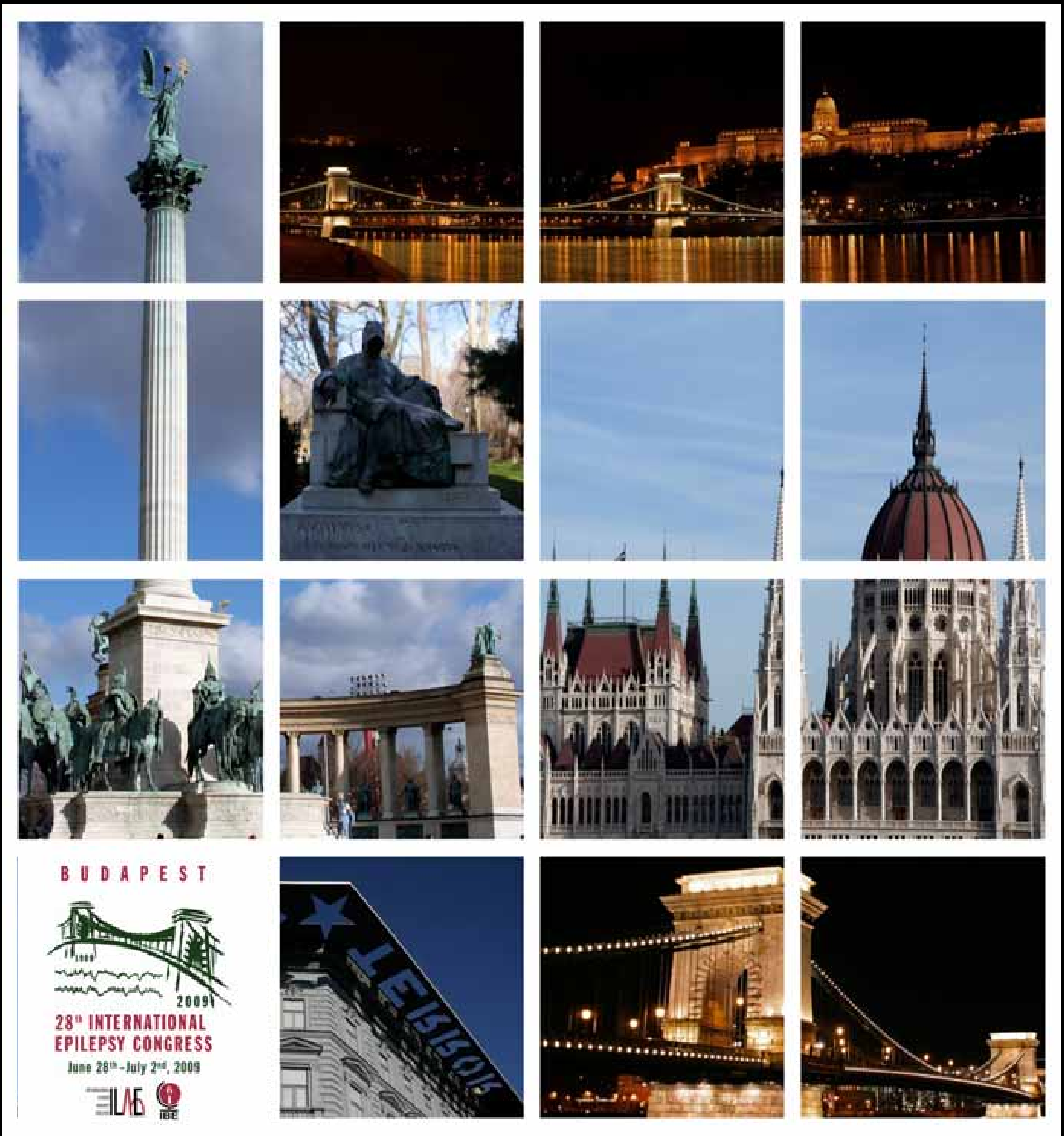
8th AOEC 2010

Melbourne was recently announced as the venue for the 8th Asian Oceanian Epilepsy Congress, which will take place next year. This will be the first IBE/ILAE congress to been held in Australia since Sydney hosted the 21st International Epilepsy Congress in 1995.

The first announcement is now in circulation and the congress website will soon be live. In the coming months we will also be bringing news of the special programme for people with epilepsy and their carers to be held during the congress.

For further information or to receive a copy of the first announcement contact **Melbourne@epilepsycongress.org**

28th International Epilepsy Congress
Budapest, Hungary
June 28th—July 2nd 2009



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