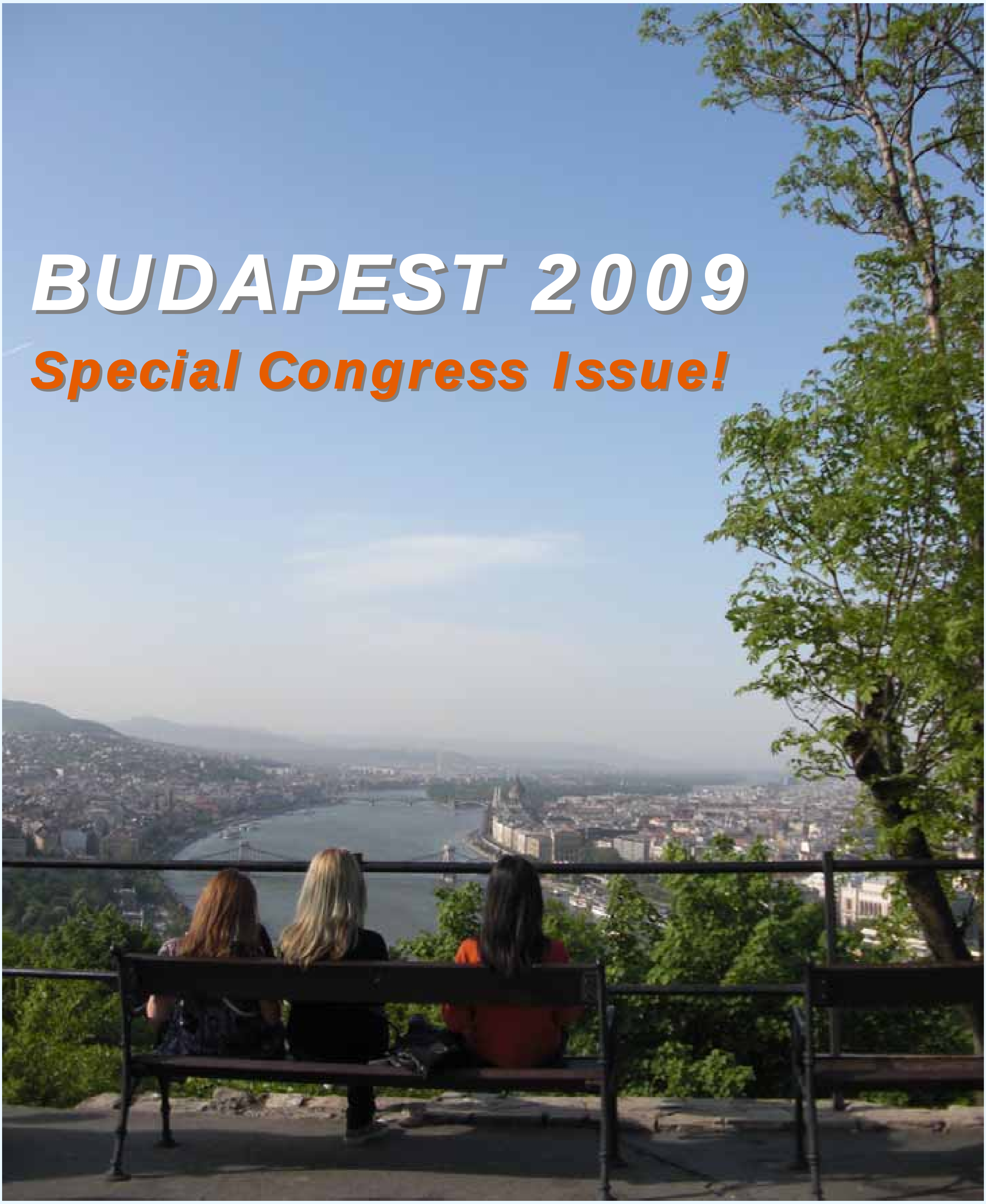
International Epilepsy News

Newsletter of the International Bureau for Epilepsy Issue 2 - 2009



BUDAPEST 2009

Special Congress Issue!

The President's Message

Dear Friends

I must admit it's a very strange and somehow sad feeling writing the last President's message on this page.

If you enjoy your work, time flies and this four year term has moved very quickly. I am both honoured and grateful to have been able to serve in this great organization, meeting so many talented and enthusiastic people involved in different areas in the field of epilepsy. It has been a very rewarding experience.

IBE has an important role to play to empower people with epilepsy to take control and to support each other for a better quality of life. During the last four years IBE has increased its membership to 126 Members in 93 countries! This could not have happened without the valuable efforts of dedicated people taking the first steps and encouraging others to follow, growing stronger and, from there, making necessary changes for the better in society. Political initiatives, public education and individual support are key elements in our activities and I would like to stress the importance of the IBE website which has proven to be an excellent tool for information and communication. And so has the IE News! This attractive magazine reflecting IBE's global activities is edited by Carlos Acevedo and coordinated by Ann Little. Thank you both for making a wonderful magazine! I will miss waving at the Editor on the opposite page!

I also would like to thank the IBE Members for their encouragement and for sharing their ideas and experiences. A special 'Thank You' to the Members of the International Executive Committee for their valuable support and to the Management Group for their support and confidence.

The always positive and helpful staff at the IDM office, organizing our congresses, with the leadership of Richard Holmes, has been much appreciated.

Finally I would like to thank the IBE Office with Ann Little, Executive Director and Vania Silva, Administration Assistant, for their great skills and positive support.

I look forward to seeing you all in Budapest celebrating with our friends in the International League Against Epilepsy who have always been supportive in our joint efforts!

Susanne Lund

President

IBE

The International Bureau for Epilepsy, with membership of 126 epilepsy associations based in 93 countries worldwide, works to improve the quality of life for all people affected by epilepsy.

International Epilepsy News No. 2 - 2009

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The Editor's Letter

Dear Friends

Welcome to the lovely city of Budapest.

You are going to find the usual interesting IE News content in this magazine included in your congress bag.

We have recent reports from conferences in India and Zambia as well as a report on the work of the Association Marocaine contre l'Epilepsie, IBE's Full Member in Morocco. So we continue with our commitment to inform you about the main activities of our Members. There is also a report related to the launch in Argentina of the first Epilepsy Law in favor of people with epilepsy in the Latin American region.

We have completed another relevant issue: IBE has finalised the election process of our new Regional Executive Committees. Therefore, I would like to welcome the newly elected members of these committees, both new and re-elected members, to our big family. We wish you the greatest success and best of luck for the next 4 years.

There are two miscellaneous items: the magnificent initiative of Purple Day, a growing and important new initiative created by a young Canadian girl; and the news about Prince, a famous showbiz figure, who reveals his childhood epilepsy.

Another important and topical item is the inclusion of tips and ideas on what to see and do during your stay in Budapest.

Finally, Susanne Lund has prepared an article to highlight the importance of the IBE-ILAE partnership in celebration of the 100th anniversary of the International League Against Epilepsy.

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.

Corrections

We would like to apologise to Dr Ozkara and Dr Delanty, whose names were incorrectly spelt on page 7 of issue 1-2009, in the list of new Ambassadors for Epilepsy. The names should have read Cigdem Ozkara and Norman Delanty.

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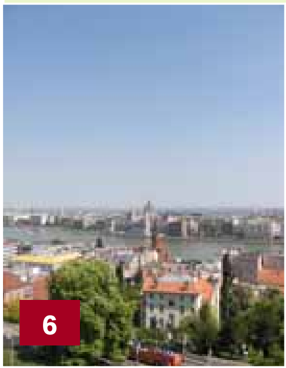

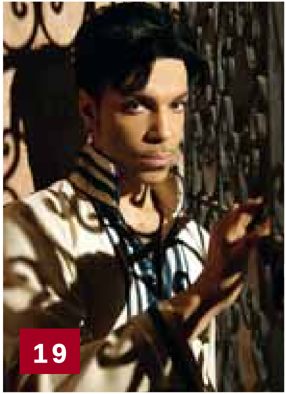

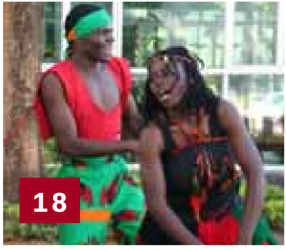


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Congratulations to ILAE!

Celebrating a Golden Jubilee and marking 46 years of close partnership with IBE

On this auspicious occasion, as the International League Against Epilepsy celebrates its first 100 years of dedicated service to people with epilepsy, IBE has great pleasure in sending warmest congratulations to the ILAE Executive Committee and to all of its chapters and individual members.

As this special event is celebrated at the time of the 28th International Epilepsy Congress in Budapest, IBE also would like to take the opportunity to recognise the terrific support that has been provided to IBE by the League since the Bureau was formed in 1961, and to highlight the close partnership of IBE and ILAE in the important initiatives in which both organisations work jointly.

Board Representation

To mark the solidarity between IBE and ILAE, the President, Secretary General and Treasurer of each organisation sit on the Executive Committee of the other as ex officio members. The ILAE members sitting on the IBE International Executive Committee also have full voting rights on the IBE committee. In addition, both committees come together at least once each year as the JEC (Joint Executive Committees of IBE and ILAE) to discuss issues of joint interest.

Joint Congresses

For decades IBE and ILAE have organised joint International Epilepsy Congresses. With programmes predominately scientific in their themes, there is also the inclusion of social topics, recognising the importance of addressing the social as well as the medical problems faced by people with epilepsy. By working together as a dynamic team, IBE and ILAE can help to ensure that people with epilepsy receive the best possible medical and social care. In more recent years, joint regional congresses have been introduced in the Asia Oceania, Latin America, and the East Mediterranean regions.

Global Campaign

In 1997, the biggest joint initiative of the League and the Bureau to date was launched in both Dublin and Geneva—the ILAE/IBE/WHO Global Campaign Against Epilepsy ‘Out of the Shadows’. Now in its 12th year, the campaign has had a significant impact on the lives of people with epilepsy, particularly in developing regions. The involvement of two major epilepsy organisations, as well as the partnership with the WHO, garners significant prestige for the campaign. The logo and the title ‘Out of the Shadows’ has been used widely by IBE and ILAE members in their own national campaigns, thus increasing the visibility of the campaign and the activities carried out in its name.

EUCARE

EUCARE - European Concerted Action for Research in Epilepsy, was launched in 1998 and has been a joint initiative of IBE and ILAE in Europe since 2001. The two-pronged focus of EUCARE—both scientific and political—fits neatly within the remit of both organisations and it is hoped that, in time, this initiative will broaden out to become international.

The Future

In the future it is hoped that further avenues for collaboration will open up, as new medical discoveries are made and patient power continues to gain momentum. But, for now, let us seize the moment and enjoy this great ILAE celebration!


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1. Susanne Lund and Peter Wolf, IBE and ILAE Presidents respectively, display the special IBE/ILAE flag made by Henry Stokes on the occasion of the 4th Latin American Epilepsy Congress in Guatemala, 2006.
2. Joint IBE/ILAE Executive Meeting 1985, from left to right: Richard Masland, Fritz Dreifuss, Robert Gourly, Bill McLin, Hanneke de Boer, Joop Loeber and Jeacqueline Beaussart. Front row: Francesco Castellano, Patsy Castellano, Raffaele Canger and Harry Meinardi.
3. Joint IBE and ILAE Executive Committee Meeting in Switzerland, 1986. Clockwise from bottom left: Bill McLin, Patsy Castellano, Rafaello Canger, Fritz Dreifuss, Dr l'Oiseau, Mogens Dam, Francisco Rubio Donnadieu, Robert Gourley and Dr Seino.
4. Joint IBE/ILAE meeting, Switzerland 1986. From bottom left: Francisco Castellano, Robert Gourley, Dr Seino, Hanneke de Boer, Joop Loeber, Richard Masland, Harry Meinardi and Arthur Ward.
5. Joint IBE/ILAE Management Group 1997-2001. From left: Michael Hills, IBE Secretary General; Philip Lee, IBE President; Giuliano Avanzini, ILAE Treasurer; Pete Engel, ILAE President; Peter Wolf, ILAE Secretary General; Johan Falk-Pedersen, IBE Treasurer.
6. Recipients of the IBE/ILAE Ambassador Awards attending a 'reunion meeting' during the 26th International Epilepsy Congress, Paris 2005.
7. Delegates attending a EUCARE meeting in Heemstede, The Netherlands, in May 2005. Back row from left: Karen Lee Donaldson, EUCARE Programme Manager; Peter Dahlqvist, IBE European Committee; Susanne Lund, EUCARE Management Group; Kristina Malgren, ILAE European Commission. Front row from left: Hanneke de Boer, EUCARE Management Group; Hilary Mounfield, IBE European Committee; Svein Johannessen, ILAE European Commission.
8. Launch of the 2nd phase of the ILAE/IBE/WHO Global Campaign Against Epilepsy in Geneva, January 2001. From left: Leonid Prilipko, WHO; Hanneke de Boer, Co Chair GCAE; Ted Reynolds, Co Chair GCAE; Dr Gro Harlem Brundtland, Director General, WHO; and Prof Jiangzhong Wu.
9. IBE Executive Committee 1989-1993, from left: Leena Hyvärinen, Robert Gourley, Liedewej Jepsen, Richard Masland, Bill McLin, Hanneke de Boer, Roger Porter, Paola Canevini, KS Mani, Harry Meinardi and Joop Loeber.
10. IBE International Executive Committee 2005-2009. Back row from left: Mike Glynn, Nico Moshé, Shunglon Lai, Martin Brodie, Mary Secco. Middle row: Abdulaziz Al Semari, Carlos Acevedo, Peter Wolf and Eric Hargis. Front row: Thanos Covanis, Zenebe Gedlie Damtie, Philip Lee and Susanne Lund.
11. Organising committee meeting for the 27th International Epilepsy Congress, Singapore. From left: Susanne Lund, Grace Tan, Dr Puvanendrun, Mike Glynn, Peter Wolf, Shih Hui Lim, and Andrew Pan.
12. Susanne Lund, IBE President and Peter Wolf, ILAE President, at the ILAE Executive Committee meeting in Washington DC, December 2005.

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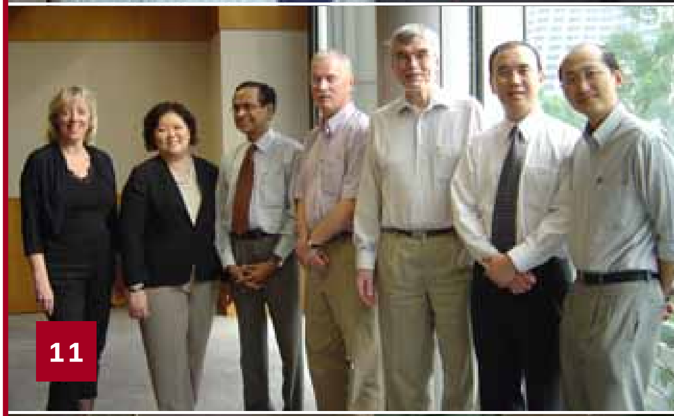

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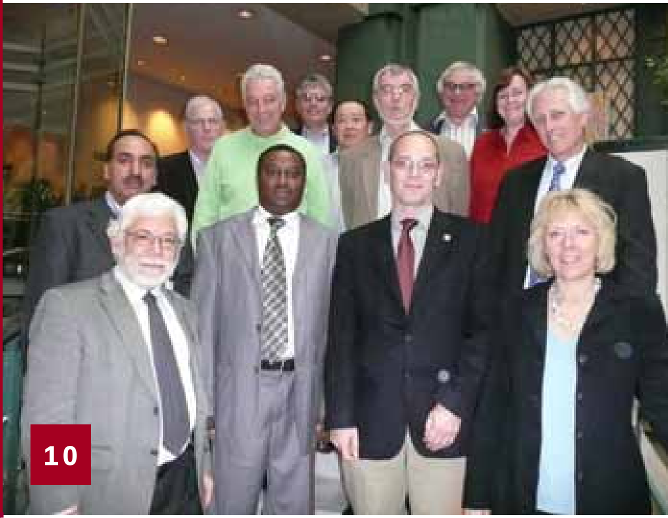

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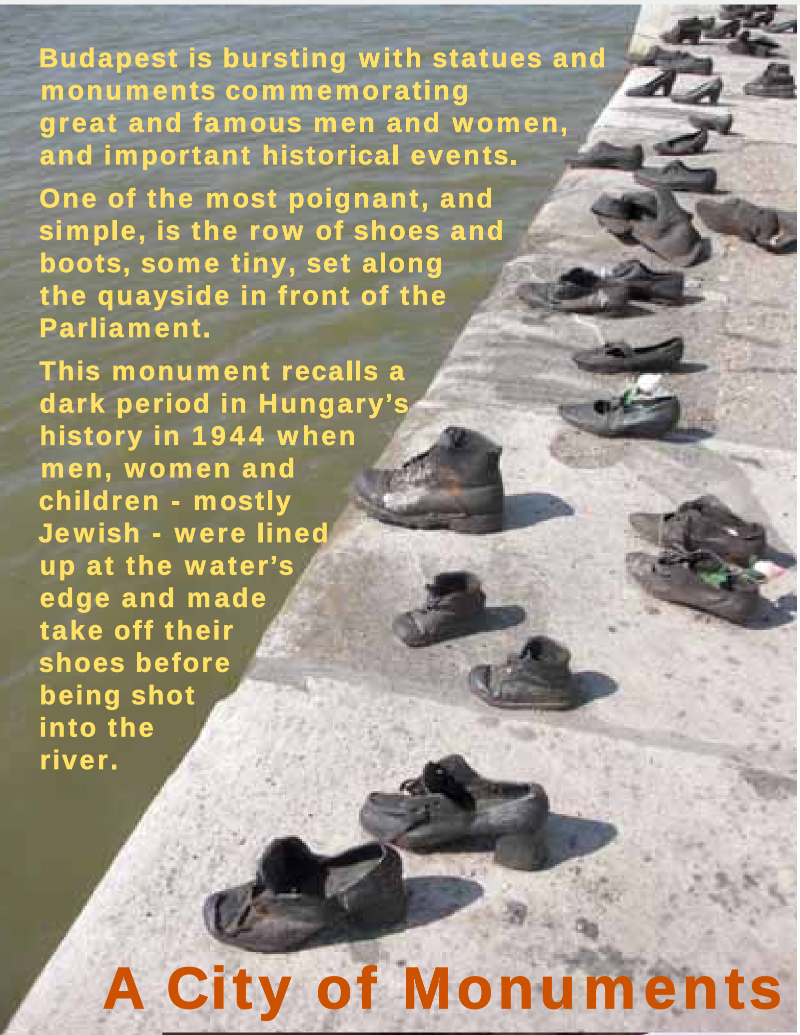
Time Out in Budapest

Outside of congress hours, there’s plenty to do, and see, in this beautiful city. Here are a few ideas!

Photos: Ann Little



A City of Monuments

Budapest is bursting with statues and monuments commemorating great and famous men and women, and important historical events.

One of the most poignant, and simple, is the row of shoes and boots, some tiny, set along the quayside in front of the Parliament.

This monument recalls a dark period in Hungary’s history in 1944 when men, women and children - mostly Jewish - were lined up at the water’s edge and made take off their shoes before being shot into the river.

Hop-on Hop-Off

If your time is limited, the Hop-On Hop-Off open top tourist buses will take you round most of the cities most famous and scenic sites. You can get off at your favourite places to spend some time exploring and then pick up a later bus to continue the tour anytime between 10:00 and 17:30. The buses also provide a commentary in 16 languages using headphones.

The most relaxing way to see Budapest!

Fisherman’s Bastion

No stay in Budapest is complete without a visit to the castle district in Buda. Apart from the wonderful historic buildings, including the Fisherman’s Bastion, there is also a great view over the Danube towards the Parliament Buildings.

THE SPA

Medicinal baths were introduced by the Turks, who were in occupation during the 16th and 17th centuries. One of the most popular baths for tourists are at the Gellért Hotel, a monumental building situated on the Buda side of Liberty Bridge, next to Gellért Hill. There are indoor and outdoor baths both beautifully decorated in the Art Nouveau style, with stained glass windows, impressive mosaics and, of course, a considerable number of statues.

The Citadel

For the best views of the city, climb up to the Citadel atop Gellért Hill. If you are feeling energetic you can do so on foot, winding your way up steep leafy pathways and steps towards the summit. Be warned, it's very hard work, but the view from the top is worth it—see cover photo!

The fortress is also served by the tourist buses.

Margrit Island

MARGRIT ISLAND

Budapest summers can be stiflingly hot, but there is somewhere to escape to, right in the heart of the city.

Margrit Island, situated in the middle of the river Danube and accessible by foot from the Margrit Bridge—where there is also a tram stop—is a great place to relax. This enormous park boasts riverside walks, a proper jogging track, ornamental gardens (including a Japanese garden), children's zoo and parkland. There are also sports facilities and two hotels.

Hire a fun bike to tour the island, then relax with a cool drink at one of the island's bars or restaurants.

Need a Restaurant?

Budapest has a terrific café society. Everywhere you go you will find cafes and restaurants, most of which have outdoor seating to take advantage of the warm summer weather.

Goulash, dumplings, chocolate cake and strudel are the dishes that spring to mind when we consider Hungarian cuisine. And it is true that you will see traditional restaurants in Budapest serving these popular dishes. But you will also find a more modern take on these Hungarian staples, as well as thousands of international and ethnic restaurants in every price range and to suit every palate.

If you would like to escape from the hot sun, but still eat outdoors, then head for Liszt Ferenc Square, a leafy place lined on both sides with cafes and restaurants. At one end of the square is the Liszt Ferenc Music Academy and sheltering among the trees is a lively statue of the composer.

Liszt Ferenc Square

ECON 2009

Tirupati - India

ECON 2009, the 10th annual conference of the Indian Epilepsy Association (IEA) and the Indian Epilepsy Society (IES), took place in Tirupati on the 7th and 8th February. Several distinguished speakers addressed the delegates during the impressive opening ceremony.

Dr B Vengamma, Professor and Head, Department of Neurology, Sri Venkateswara Intitute of Medical Sciences (SVIMS) and Organizing Secretary of ECON 2009 delivered the welcome address, while Dr VS Saxena, IEA President spoke about the past history of IEA and about the first scientific conference held in Chennai.

Dr Rakesh Shukla, IES President reported that epilepsy is a growing problem with more than 75% of the global burden of epilepsy being found in developing countries, such as India.

Dr HV Srinivas, Secretary General of the IEA, remarked that epilepsy, which does not spare the rich or the poor, the developed or the developing world, still remains affected by stigma, superstition and myth. He remarked that while people do not hesitate to talk openly about cancer and AIDS, they hesitate to do so about epilepsy.

Dr Satish Jain, IES Secretary General, reported that IES was the first professional body in India to have produced guidelines for the management of epilepsy, the “Guidelines for epilepsy management in India (GEMIND)”.

Dr Arjundas, senior neurophysician and the Chairman of the first IEA annual meeting in December 1993, was the Chief Guest of the inaugural function. He lamented that very little has happened in the field of epilepsy research and remarked that there was a need for young doctors to undertake serious research in epilepsy in order to benefit humankind.

Dr G Subramanyan, Director and Vice-Chancellor of SVIMS, Tirupati told delegates that the presence of luminaries in the field of epilepsy at SVIMS would serve as a stimulus for young minds to carry out such quality research in the field of epilepsy and was hopeful that SVIMS would emerge as a centre of excellence for epilepsy research.

Dr Kanaka, who was the first female neurosurgeon in Asia, and who has been serving the Tirumala Tirupati Devasthanams (TTD) for the last 30 years launched the “Souvenir and Abstract Book” published to mark the occasion. After the opening ceremony, a colourful cultural program by talented children representing Srivari Kalashetra was enjoyed by all those present.

ECON 2009 attracted delegates from all parts of India. In addition, there were several distinguished guest delegates and speakers from other parts of the world, including Nico Moshé, ILAE President-elect, and Pete Engel, a former ILAE President.

The scientific programme covered both medical and social sciences streams. There were free paper and poster sessions showcasing original research, discussions of interesting cases, symposia on epilepsy and sleep. Mortality in epilepsy and alternative methods treatment of epilepsy such as the ketogenic diet and yoga, and the psychosocial dimensions of epilepsy were unique features that marked ECON 2009.

Dr KS Mani’s Patients Forum saw inspiring presentations by students of the College of Nursing, SVIMS, Tirupati, the IEA Mumbai branch. Several persons with epilepsy from Tirupati and Mumbai bravely shared their views and experiences on living with epilepsy.

Migraine and Epilepsy

Dr Ambar Chakravarty, Kolkata

The association between migraine and epilepsy was first pointed out by William Gowers in 1907 and migraine was considered to lie in the borderland of epilepsy. Gowers thought that cortical centres in the brain were involved in migraine and postulated of a peculiar activity which seemed “to spread like the ripples in a pond”. This sounds very similar to the concept of spreading depression in the pathogenesis of migraine aura which was demonstrated by Leao, many years later. Gowers also noted the

Indian Epilepsy Association and Indian Epilepsy Society celebrate 10th Joint Annual Conference

Reported by Dr Vengamma, Organising Secretary

distinguished features of migraine and epilepsy specially in relation to duration of the aura. We, however, now know that migraine auras are monochromatic, whereas epileptic visual auras are generally coloured. The principal similarity between migraine and epilepsy is that both are paroxysmal disorders of the brain.

The incidence of migraine in epilepsy patients and vice-versa is extremely variable. For example, in the VIMS study, the incidence of epilepsy in migraine subjects had been low whereas the incidence of migraine in JME subjects had been relatively high. Certain brain diseases may present with both migraine and epilepsy and include cerebral AVM, MELAS and Cerebral lupus.

Occipital epilepsy whether idiopathic (Benign Occipital Epilepsy in Children of Gastaut) or symptomatic (vascular, neoplastic, inflammatory like NCC) may present with visual aura like migraine. Hemicrania Epileptica is a rare entity and had been described in a handful of patients where focal epileptiform discharges were noted during migraine aura and where removal of the affected area ameliorated both the migraine and the seizures.

On the other hand, migraine aura can occasionally result in seizure. This may occur in Basilar Migraine where interictal EEG changes may occur in 20% of subjects. These are probably variants of occipital epilepsy. The International Headache Society however gives a rather strict definition of migralepsy which should occur only with migraine with aura. But exceptions have been reported. Seizures may induce migraine as in postictal migraine which would fulfil the diagnostic criteria of migraine and would respond to triptans. Postictal migraine commonly occurs following occipital lobe and temporal lobe seizures.

The pathogenic link between migraine and epilepsy has been postulated on the basis of ionic shift in neurons during spreading depression phase of migraine aura. Recent studies indicate dorsal pontine activation in migraine. This sounds very similar to the concept of centrencephalon in epilepsy proposed by Hughlings Jackson over 100 years ago.

The Ketogenic Diet—an Indian Experience

Dr K Nathan, Mumbai

The ketogenic diet (KD) has seen a surge in use for uncontrolled epilepsy all over the world. However, the original protocol used by the John Hopkins Hospital and in many other centres has several drawbacks. These include:

- Fasting and hospitalization period
- American and western recipes
- High keto ratios, high fate content and poor palatability
- High lipid levels.

Indianisation of the ketogenic diet, which was started in Mumbai 1996, has tried to address the above and to find easier solutions for Asian and developing countries to counter these problems. In addition, maintaining normal uric acid levels is achieved by less animal protein and more soy products.

- Introduction of 4++ concept – If the urine ketone strip changes to the darkest (4+- 120 mg/dl) in less than 10 seconds we designate as 4++. We have found that this correlates well with high ketosis and is a harbinger of poor appetite, apathy and even vomiting. Caregivers are taught to use this as a warning marker.
- We have trained around 16 teams from various centers in India and several teams in Malaysia and Indonesia.
- We have used a modified Atkins diet (mAD) and found that the results are almost as good as the ketogenic diet.

Use of mAD in rural areas could be more convenient and could facilitate training and spreading the use of th ketogenic diet in India and to other parts of Asia.

Regional Executive Committees 2009 - 2013

The elections to fill positions on IBE's seven regional committees has concluded. The Election Task Force would like to thank all those who allowed their names to go forward for nomination, as well as all those Full Members who took an active part in the election process.

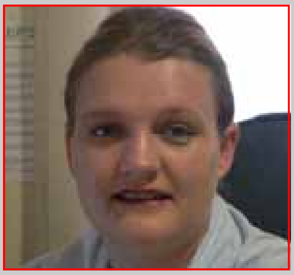
The following list shows all those elected to serve for the coming term of office, as well as the regional Vice Presidents who are voting ex-officio members of their relevant Regional Executive Committee. The inclusion of the Vice Presidents on the regional committees serves as the liaison point between them and the International Executive Committee.

The newly elected Regional Executive Committees will begin their term of office at the time of the General Assembly in Budapest on Wednesday 1st July 2009.

AFRICA

Chair
Anthony Zimba
Zambia

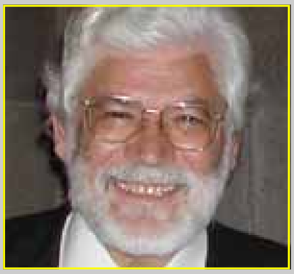
Vice Chair
Jacob Mugumbate
Zimbabwe



Secretary
Noëline De Goede
South Africa

Vice President Africa
Anthony Zimba
Zambia

EUROPE



Chair
Athanasios Covanis
Greece

Vice Chair
Michael Alexa
Austria

Secretary
Aisling Farrell
Ireland

Member
Victoria Dimech
Malta

Member
Seppo Sarkkula
Finland

Vice President Europe
Janet Mifsud
Malta

NORTH AMERICA

A representative from each of IBE's three Full Members in the region make up the membership of the Regional Executive Committee North America: Canadian Epilepsy Alliance, Epilepsy Foundation of America and the Jamaica Epilepsy Association.

Mary Secco (Canada), pictured left, is the elected Vice President North America on the International Executive Committee.

EASTERN MEDITERRANEAN


Chair
Najib Kissani
Morocco

Vice Chair
Asma Enright
Saudi Arabia


Secretary
Chahnez Triki
Tunisia


Vice President Eastern Mediterranean
Abdulaziz Al Semari
Saudi Arabia

LATIN AMERICA


Chair
Lilia Nuňez Orozco
Mexico


Vice Chair
Elza Marcia Yacubian
Brazil


Secretary
Tomás Mesa
Chile


Vice President Latin America
Carlos Acevedo
Chile

SOUTH EAST ASIA


Chair
HV Srinivas
India

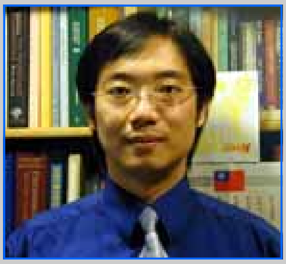

Vice Chair
MM Mehndiratta
India


Secretary
M Mannan
Bangladesh


Vice President South East Asia
Vinod Saxena
India

WESTERN PACIFIC


Chair
Robert Cole
Australia


Vice Chair
Yuang Fu Tseng
Taiwan


Vice Chair
Denise Chapman
Australia


Vice President Western Pacific
Shunglon Lai
Taiwan

Moroccan Society Against Epilepsy extends its reach

Report by: Harkani Abdellatif, Junior Neurologist and Member of MSAE and Kissani Najib, Head of Neurology Department, University Hospital of Marrakech and President of MSAE.

Epilepsy still constitutes a serious health problem in Morocco with a prevalence estimated at 1.1%[1]. The great majority of our patients with epilepsy have a very poor knowledge about the condition. Most patients resort to marabountic methods, especially in rural areas. On the other hand, our patients also suffer from professional and social discrimination.

The Moroccan Society Against Epilepsy (MSAE) a non-profit association, was created to:

- promote and improve management of epilepsy;
- sensitise patients, their families and all persons concerned by epilepsy (teachers, social workers, pharmacists, students, etc);
- eradicate the distorted beliefs about epilepsy, to collaborate with regional and other national societies involved in epilepsy and, of course;
- support persons with epilepsy and their families to overcome all kinds of material, social and professional difficulties.

Since its creation in November 2001, our society has been regional (Regional League Against Epilepsy in Marrakech and its countryside) but, in 2005, it became a national society covering the whole country, because of the non-existence of any other society focussed on the social aspects of epilepsy. MSAE ensures many important activities, but there are two main priorities:

- To inform, educate and sensitive people with epilepsy and the general public.
- To encourage better management of epilepsy in Morocco.

In Morocco, as in many similar countries, distorted beliefs about epilepsy drive people with epilepsy to marabountic practices, which are sometimes dangerous and which often retard or limit access to medical structures. They also worsen the prognosis. Two studies carried out in Morocco indicated that up to 75% of patients who have epilepsy consult healers at least once before moving to modern medicine[3].

This is the reason why MSAE has been organizing biannual social meetings for people with epilepsy, their families and all persons interested in epilepsy.

In addition, our society organizes regular TV and radio programs to sensitise all Moroccan citizens about epilepsy. Within this framework the local radio operator is committed to broadcasting regular radio programs about epilepsy, and our specialists answer all kinds of questions during these interviews.

Particular emphasis is given to school teachers, students and workers in factories, because of the lack of basic knowledge about epilepsy which can cause exclusion from schooling or employment. Education is achieved through information days in schools and factories. Our society will soon begin a partnership with imam mosques, in order to inform Muslims during Fridays' prayers about epilepsy, the risks of traditional practices and the need to consult with specialists to achieve appropriate care.

Improved management of epilepsy in Morocco will not be possible as long as we continue to have many cities without a neurologist and in which general practitioners are not involved in epilepsy management.

To help solve these two major problems, MSAE will use two strategies:

- Providing medical services in remote cities by way of regular specialised consultations.
- Working side by side with general practitioners; because of the high number of people with epilepsy in Morocco (more than 340,000); the high proportion of distorted beliefs; the use of marabountic practices; the small number of specialists (nearly 80 neurologists for a country with a population of 34 millions inhabitants)[2]; and the poor involvement of general practitioners in epilepsy.

Morocco, as with other North African countries, suffers from a lack of trained neurologists; a situation that makes it difficult to access specialized consultants, in particular for people living in small cities and rural areas. This is especially the case in southern Morocco (where less than 10% of neurologists are based, but where 30% of the population live).

Many people with epilepsy, especially

in the south of Morocco, cover long distances in order to visit a consultant in Marrakech, Agadir, Laayoun or Tiznit (the only cities with neurologists in southern Morocco), spending a great deal of time, energy and money to get there.

Since April 2006 we have provided quarterly specialized consultations in cities without neurologists, such as Ouarzazate, and since February 2008 this services is also provided in Kelaa Sraghna, sponsored by Sanofi-Aventis and the French League Against Epilepsy. Our experience shows that the service has been very successful and, since October 2006, we had transferred many in– and out-patients from Marrakech to Ouarzazate, where we have started an EEG unit with a trained technician. The technician prepares the EEGs for our neurologists, to be interpreted twice a week, and for urgent cases we use scan and email or arrange for the EEGs to be sent to us.

All these activities initiated in Ouarzazate have solved many problems in this isolated city, separated from the rest of Morocco by the Atlas Mountains. On occasions during the winter season, the road is blocked between Marrakech and Ouarzazate, and for this reason it is far better for people to be able to access a trained general practitioner locally rather than trying to reach Marrakech. In the end this initiative will avoid expensive travel to Marrakech. This approach will, on the other hand, attenuate medical demand in the neurology department of Marrakech and could assure better management of neurological diseases in general, and epilepsy in particular, in cities without neurologists.

We realize that the easiest and best way to improve the management of epilepsy is to focus on general practitioners. To this end we have now established collaboration with local health authorities and pharmaceutical laboratories to meet the cost of training sessions for regionally based general practitioners. This began in 2001 in Marrakech, than in Kelaa Sraghna (80 km north of Marrakech), then in Essaouira (170 km west), in Casablanca (240 km north-west), and in Ouarzazate (200 km south). In 2008 a regular program was instituted for these meetings.

In the short term, MSAE will consolidate its main priorities: on one hand, to educate and inform the general public and to sensitize people with epilepsy and their families and, on the other hand, to improve the management of epilepsy throughout Morocco.

Since December 2006, information leaflets and brochures have been distributed and, during 2008, posters in Arabic highlighting the dangers of traditional practices, dispelling misconceptions about epilepsy and informing on the true facts of the condition have been widely distributed through pharmacists throughout the country. We will begin video projection in public transport and TV spots about epilepsy, to assure more sensitization concerning epilepsy.

In mean and long term, we expect that MSAE will cover more than 70% of Moroccan territory and will create delegations in other big cities; a bimonthly bulletin will be set-up to keep adherents and practitioners updated. We expect to encourage an improvement in driving legislation for people with epilepsy because it has not been updated since it was first launched in 1973, and is now unsuitable. MSAE will collaborate more closely with the Moroccan League Against Epilepsy, to decentralize epilepsy surgery in Morocco because since 2004, when it was first started in Rabat city, it remains concentrated only in this city. In the end, we hope to establish good relationships with other neighbouring countries, North African, francophone, and sub-Saharan countries, to share and also to diffuse our experiences.

The Moroccan Society Against Epilepsy, in spite of its young age, is trying to improve the management of epilepsy in Morocco by focusing on 2 main points:

1. Involving general practitioners as an inevitable partner.
2. And, insisting on the education and sensitization of people with epilepsy, their families and the general public.

Maybe one of the reasons for the dynamism and efficacy of our young society is the mixture of experienced persons involved in epilepsy and in social activities, giving very efficient ideas and working hard to improve conditions for people with epilepsy.

References:

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3. *Louhab N, Jafoui M, Stoti N, Kissani N. Prospective evaluation of traditional practices for epileptic patients of Marrakech. Epilepsia 2005; 46, Supp 6: 356.*

The following is a translation of a recent report in Jujuy al día – (Agencia CyTA-Instituto Leloir)

Ten years since its first presentation to the Senate, the national epilepsy legislation has now been approved in Argentina. The new law establishes the right to free medication for people with epilepsy, it penalizes discrimination and promotes the diffusion of information about epilepsy.

A technical committee of experts, organisers, people with epilepsy and their families was created with the support of the Pan-American Health Organisation (PAHO) in order to ensure that the law was applied. As a result, the condition of epilepsy is now included in the Obligatory Medical Program.

Argentina has promoted the creation of epilepsy legislation in order to bring attention to the condition, to make available free medication for people with epilepsy, and to penalise those to discriminate against persons with the condition.

According to the Argentine office of the WHO, the regulation of Law No. 25404 was signed on the 27th January 2009, ten years after the project was first presented to congress by Dr Silvia Kochen and Dr Jorge Lovento, Chief of the Epilepsy Section of the Neurology Division of the Hospital Ramos Mejía, in Buenos Aires and board members of FUNDEPI, a lay association for persons with epilepsy in Buenos Aires.

> “Now people with epilepsy will have access to diagnosis and treatment without any difficulties or prejudice.

The rule was sanctioned in March 2001, but for 8 years had not been signed into law by the Executive.

“Now people with epilepsy will be able to have access to diagnosis and treatment without any difficulties or prejudice. In work, the law will protect them from discrimination they might face due to their condition” celebrated Kochen. Lovento suggested that the new legislation “will bring great benefits to all persons with epilepsy, who will be happier and will enjoy a better life quality”. For the Director of FUNDEPI, the organisation that has been putting self-help groups together for 20 years, “to wait all these years made gaining access to medication more difficult since there has been obstacles to all social work.” Now, this medical condition is included in the Obligatory Medical Program.

The law addresses three essential aspects for those who suffer from this condition:

1. the right to receive free antiepileptic drugs, when required;
2. the ending of discrimination in work, school and in the social environment;
3. the implementation of permanent strategies for education about epilepsy and campaigns for the dissemination of information to the general public, people with epilepsy and their families, and medical professionals.

Epilepsy is one of the most frequent and common neurological disorders. It is a situation of crisis. A person with epilepsy can experience seizures,

New legislation in Argentina

Silvia Kochen and Jorge Levanto of FUNDEPI in Buenos Aires spent 10 years campaigning for laws to safeguard the rights of persons with epilepsy.

Their patience and determination has now paid off with the introduction, by the Argentinean Chamber of Deputies, of new legislation to defend the rights of persons with epilepsy and to prevent stigma and discrimination.

together with tongue-biting and incontinence. In less serious cases, it can be manifested by a lack of stimulus, staring and absent-mindedness.

"Between 80 and 90% of cases can be treated with an appropriate medication and the person with epilepsy can live a normal life" explains Hugo Cohen, consultant in the Mental Health Department of the WHO.

He described the situation thus: "there aren't specific programs. The number of trained neurologists is inadequate, and most neurologists are concentrated mainly in the big cities. There are a lot of people who do not get treatment due to fear, shame and lack of resources. Some are ill-treated. Nevertheless, there are still stories in some regions where the arrival of medical treatment is slow". According to Cohen, the newly introduced law "is an initiative that will help to change this, favouring accessibility to adequate treatment".

In addition, this expert pointed out that it is important to provide access to a healthcare system that will provide medical prescriptions to those who suffer from this condition and ensure that medication will be provided as required. The specialist can provide support systematically and in every necessary case.

For more information on this law, you can contact FUNDEPI via email at jorge_lovento@yahoo.com.ar.

Good news from Mauritius!

Youssouf Noormamode, President of Edycs Epilepsy Group, IBE's Full Member in Mauritius (pictured in blue shirt), was recently decorated to the rank of Commander of the Order of the Star and Key of the Indian Ocean (CSK) by the President of the Republic of Mauritius on the occasion of Mauritius National Day.

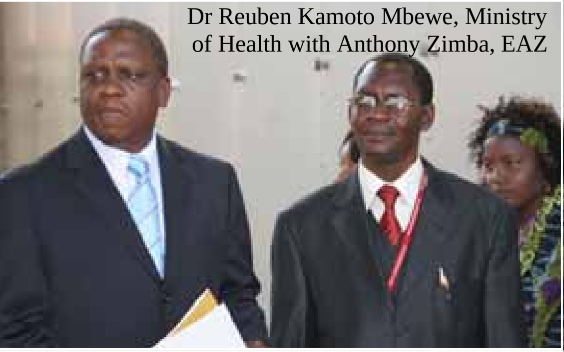
In addition, last December Edycs Epilepsy Group won the National Ngo Award for 2008 in the Health Category on International Volunteer Day, organised by the Ministry of Social Security, Ngo Trust Fund & the Mauritius Council of Social Services.

IBE sends congratulations to Edycs Epilepsy Group and to Mr Noormamode on these well deserved awards!

Addressing Stigma in Africa

Betty B. Nsachilwa, Administrative Secretary, Epilepsy Association of Zambia (EAZ) sent IE News a report on a recent conference in Lusaka

Dr Susan deRiemer with conference ushers



Dr Reuben Kamoto Mbewe, Ministry of Health with Anthony Zimba, EAZ

Conference speaker

The Epilepsy and Stigma Conference, held in Lusaka in April, was an initiative of the Epilepsy Association of Zambia, University of Zambia School of Medicine, Meharry Medical College and Vanderbilt University in Nashville, USA.

Initial attendance was projected at 500 but the number was reduced to 200 due to lack of funds. The meeting welcomed speakers and delegates from Malawi, Mozambique, Gambia, South Africa, Zimbabwe, Cameroon, USA, Belgium, Sweden, Israel, UK, The Netherlands and Australia. Including Zambia, 14 countries were represented.

The organizing committee arranged a walk to raise public awareness and to promote the conference. First Lady Mrs Thandiwe Banda; Mrs Irene Kunda, wife of the Vice President; as well as the wives of other government ministers were involved in the organizing team. The committee held fundraising collections at a large shopping centre for two weeks prior to the conference and a number of pharmaceuticals companies provided financial and material support.

The conference had 187 registered delegates of which 112 were from within Lusaka, 40 from other districts and 35 foreign delegates. Student nurses, clinical officers and people with epilepsy were allowed to attend free of charge, which brought the total attendance to 250. People with epilepsy attended the conference and had an opportunity to interact.

A number of institutions sponsored delegates, e.g. Michigan State University sponsored members of the Epilepsy Associated Stigma Team; Norma Project sponsored students and staff from the Medical School in Lusaka; and the Epilepsy Association of Zambia sponsored some of its members.

The conference was officially opened by the Vice President of the Republic of Zambia, Mr George Kunda who was accompanied by the Minister of Health Mr Kapembwa Simbao, the Permanent Secretary Ministry of Health Dr Velepi Mtonga, wife of the Vice President Mrs. Irene Kunda, and three Ministers wives who represented the First Lady as Patron of the conference. The First Lady was not present as she was attending the African First Ladies Seminar in Malaysia.

The conference had 41 sessions, including a workshop for people with epilepsy and health care providers. Topics included:

1. Epilepsy Anti-Stigma Toolkit
2. Epilepsy: portrait of a Zambian woman
3. Managing an Epilepsy Centre
4. Determinants of Stigma in Epilepsy: the situation in Cameroon
5. Management of Adult Epilepsy in Malawi: a patient’s perceptive
6. Management of Human Cysticercosis in Mozambique
7. Causes and Sequelae of Neonatal Seizures

The workshop for people with epilepsy, their families and health providers provided a chance for people to ask questions and give their views on stigma and discrimination in the community. The audience was also able to hear experiences from different countries, specifically Malawi, Mozambique, Zimbabwe, UK, USA, Pakistan, South Africa and Zambia. There were even reports from some districts within Zambia. The discussions included observations on how health providers treat patients whenever they visit health centres or hospitals. Health care providers were encouraged to treat all patients equally and to give the needed care to people with epilepsy.

This workshop led some people to arrange further meetings with consultants during the conference to enquire about their condition and what improvements could be made to help them manage their seizures.

The conference concluded with a summary on the way forward to meet the challenge of epilepsy stigma in Africa.

Prince's Childhood no Fairytale

World famous pop star reveals he had epilepsy as a child

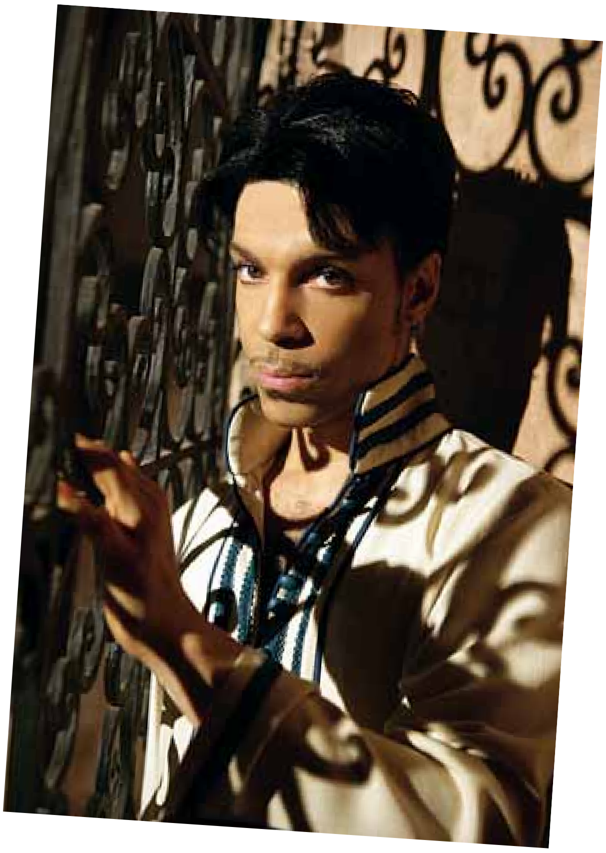
In a recent interview on the American chat show Tavis Smiley, pop star Prince spoke about having epilepsy as a child and how his parents had problems in dealing with his seizures.

"My mother and father didn't know what to do or how to handle it but they did the best they could with what little they had," he said.

During the interview he also talked about compensating for his epilepsy by being as noisy and flashy as possible. This was possibly the first beginnings of a colourful and exuberant lifestyle.

While most people were very surprised to hear Prince make the revelation about his epilepsy, it seems that this is not the first time the artist has made reference to having epilepsy as a child. As far back as the 1990s Prince made first reference to having the condition with the words "Epileptic 'til the age of seven", which appear in a track titled "The Sacrifice of Victor".

The interview on the Tavis Smiley show has garnered a significant amount of publicity. It is reported on the website of Epilepsy Foundation USA and on the websites of several IBE members associations. More importantly, there was wide coverage on international media websites, such as the BBC. This may help increase awareness and acceptability of epilepsy and encourage more celebrities to come 'out of the shadows'!



Solidarity Fund

Supporting Members in Developing Countries

IBE gratefully appreciates donations to the Solidarity Fund, submitted between 1st July 2008 and 31st May 2009. All donations are acknowledged in the IE News, the Annual Report and on the IBE Website.

These funds are used to support IBE Members based in developing countries. In particular, the fund is used to support the Promising Strategies Program, which is now in its third year of funding, and to meet the dues payments of Members in countries deemed to be Low Income according to World Bank figures.

All donations, no matter how small, are welcome at any time from both Members and supporters. Contact ibedublin@eircom.net to find out how you can help.

Donations received since 1st July 2008

US$500 and over

2008

- Epilepsy Hospital Bethel, Japan

2009

- Swedish Epilepsy Association, Sweden

US$150 to US$300

2008

- Swiss Epilepsy Centre, Switzerland
- ANLICHE, Chile
- Indian Epilepsy Association, India

2009

- Swiss Epilepsy Centre, Switzerland
- Canadian Epilepsy Alliance, Canada

Up to US$100

2008

- Epilepsy and Environment, Georgia
- Caritas, Malta
- Par-Epi, Switzerland

2009

- Epi-Suisse, Switzerland
- Epilepsy Connections, Scotland
- JECA, Australia
- Par-Epi, Switzerland
- Epilepsy Queensland, Australia
- Stichting Kempenhaeghe, Netherlands
- Slovenian League Against Epilepsy, Slovenia
- Epilepsie Vereniging Nederland, Netherlands
- Taiwan Epilepsy Association, Taiwan
- Epilepsy and Environment, Georgia
- LESIA, Lithuania

Getting ready for 2010

IBE will be involved in the organisation of the following regional congress, which will take place next year.

2nd East Mediterranean Epilepsy Congress

Marrakech, Morocco

Dates to be confirmed

12th European Conference on Epilepsy & Society

Dates and venue to be announced shortly

6th Latin American Epilepsy Congress

Cartagena, Colombia
August 2010

8th Asian & Oceanian Epilepsy Congress

Melbourne, Australia
21st - 24th October 2010