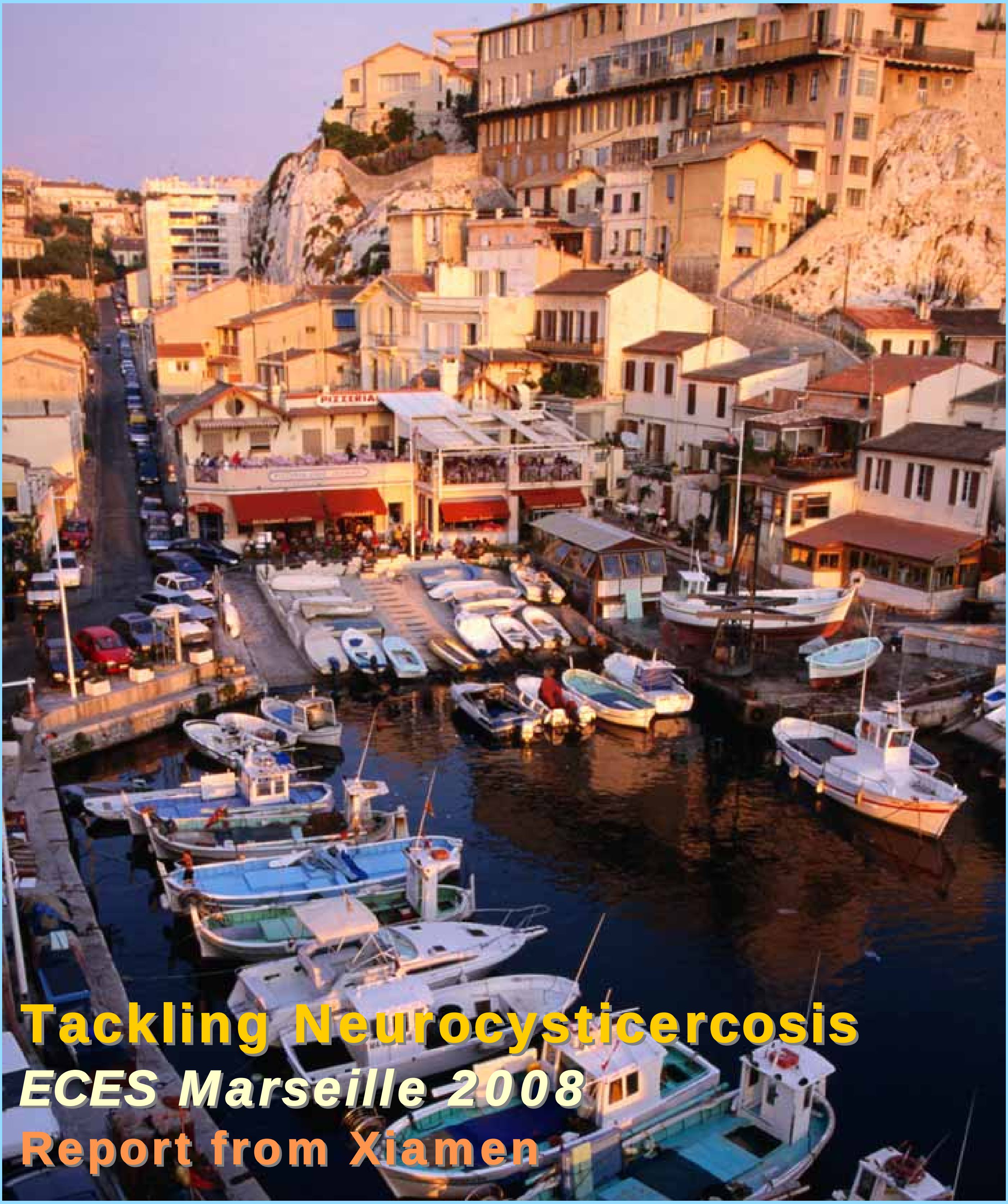
International
Epilepsy News
Newsletter of the International Bureau for Epilepsy Issue 1 - 2008



Tackling Neurocysticercosis

ECES Marseille 2008

Report from Xiamen

The President's Message

Dear Friends

I have just enjoyed midsummer in Sweden, which means long days and bright nights and, of course, sunshine mixed with plenty of rain - just a normal Swedish summer!

When looking back it seems only a few short weeks since we enjoyed the wonderful hospitality of the Chinese people and the congress in Xiamen. Due to the tremendous efforts of Dr Shichuo Li and his colleagues in the Chinese epilepsy association, the congress was a great success, despite the sad situation with the earthquake that caused such devastation and destruction to the people of Sichuan province.

I am very sad to have to announce that Mrs Jónína Björg Guðmundsdóttir passed away on the 13th June after a long and courageous battle with cancer. She was a very much appreciated member of the European Regional Executive Committee and I am grateful for all her important contributions to the IBE during her years of dedicated involvement.

Time is now moving on very quickly and I look forward to meeting many of you at the next regional congress, which will take place in Marseille in October. I know preparations are well underway with an exciting programme planned by the European Regional Committee and our friends in France.

Later in the year, in early November, the Latin American Regional Congress will take place in Montevideo with many IBE Members and supporters expected to participate and to attend the meeting of the IBE Latin American Regional Committee. I hope that this will provide the opportunity to promote the work of IBE and to encourage further membership in the region.

Finally, I would like to thank all of you who have provided funds towards the Solidarity Fund in the past few months. Every little helps and I would like to encourage further contributions so that we can make an even bigger difference to the lives of people with epilepsy, particularly in developing countries where the financial situation is most difficult.

Until next time - best wishes to all!

Susanne Lund
President

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The International Bureau for Epilepsy, with membership of 118 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 - 2008

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The Editor’s Letter

Dear Friends

In this latest issue of International Epilepsy News we have, once again, a lot of interesting articles for you to enjoy. Just as a tree needs roots, sun, rain and nutrients in order to grow and have branches, leaves and fruits, IBE also needs the input of all its Members about their daily work and the initiatives that they have introduced. This is the only way to succeed in our commitment to improving the quality of life of people with epilepsy all over the world.

This issue of the magazine has reports on and news about the activities of IBE Members in Taiwan, Hong Kong, Lithuania, New Zealand, Ireland, and Uganda. Of course I would like to encourage the rest of our Members to submit news and reports of their ongoing or new activities. The door is open, so please don’t hesitate!

An important issue, the serious high incidence of epilepsy caused by neurocysticerosis in much of Africa, is highlighted in an important report from a meeting held in Kampala earlier in the year. Neurocysticerosis is a major cause for concern not only on the African continent, but also in Latin and Central America. Neurocysticercosis is a prevalent , serious and preventable disease that is a consequence of deficiencies in hygiene and sanitation in developing countries and is a cause of symptomatic focal epilepsy that can lead to death.

Every other year we hold the Regional Congresses all over the world and 2008 is one such year. So you can read in this issue a report from the 7th Asian & Oceanian Epilepsy Congress that took place in Xiamen, China in May. You can also enjoy the photo gallery from the meeting.

Besides that there is a report of the first meeting of the Regional Executive Committee Eastern Mediterranean and of course we bring you up to date with preparations for the 11th Epilepsy & Society Conference in Marseille that will take place in France in October.

As usual we are going to enjoy reading the President’s message prepared by Susanne Lund. So, as you can see, there are a lot of interesting and different issues to read in the magazine.

Kind regards

Carlos Acevedo
Editor

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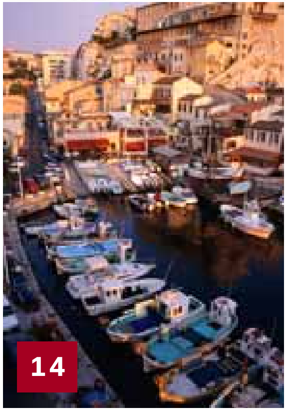


I am the Same as You

Danute Murauskaite reports from Vilnius on a new initiative in Lithuania

Trakai Island Castle, Lithuania

From left: LESIA Board Member Laimutis Packauskas; President of LESIA, Danute Murauskaite; LESIA Board Member and lawyer, Vilma Kazlauskaite

LESIA a new IBE Associate Member in Lithuania, has undertaken sociological research to establish the needs and problems of people with epilepsy at national level, and how these can be addressed.

Historically, when Lithuania was still part of the Soviet Union, epilepsy was considered to be a mental illness and was treated entirely by psychiatrists. However, although since independence epilepsy has been accepted as a neurological illness, many people still consider it to be a mental illness.

LESIA's research (involving 1,020 people) showed that there is a very high level of stigma in society. People know very little about the condition and are therefore unable to give first-aid to a person having a seizure.

To address this problem, in 2008 LESIA announced a new public awareness initiative "I am the same as You" where, by the means of mass media, people will be informed about epilepsy, its symptoms, treatment and the role of the public in improving the quality of life for people with epilepsy.

The first step in this initiative took place on 26th April when LESIA organized a conference "Epilepsy: opportunities for non pharmaceutical treatment". About 100 people from all over Lithuania took part. Some statistical evidence proving that there are clear manifestations of discrimination against people with epilepsy were presented during the conference e.g. low level of education, a high number unemployed and, what is more, those people still are not provided with rehabilitation services, without which integration of people with epilepsy is quite complicated.

According to LESIA sources, up to 67% of people with epilepsy in Lithuania have psychological problems. During the conference participants were introduced to LESIA's mobile community rehabilitation service, which is effective, inexpensive and available to a great number of people with epilepsy since it can be moved to wherever it is needed and is therefore easily accessible.

The rehabilitation services include training to live with a diagnosis of epilepsy, advice of a psychologist, and the use of craft therapy. LESIA introduced this methodology in six regions of the country and 224 individuals, including 34 children, have availed of the service. The rehabilitation service is presented by specialists with university education and with training from LESIA. The participants of the LESIA conference decided to apply to the Ministers of Health, Social Security, and Labour to register the service to allow it to be used by self help groups established in local lay epilepsy associations.

During the conference, the leaders of lay epilepsy associations from six regions, who are also members of LESIA, spoke about their work in this field. The conference concluded with a small concert and an exhibition of craftwork.

Danute Murauskaite, President of LESIA, believes that the association managed to create a positive atmosphere and to show that people with epilepsy are just the same as everyone else, and that by teamwork LESIA can help people with epilepsy to gain self-confidence, because LESIA is ready to fight for their rights. They are not alone anymore!

Forgotten your Dues?

If payment of Annual Dues for 2008 has slipped your association's mind, we would like to remind you that all dues should have been paid by the end of April.

We would appreciate if all outstanding dues payments could be settled as soon as possible.

EPILEPSY ALLIANCE

A great way forward in New Zealand

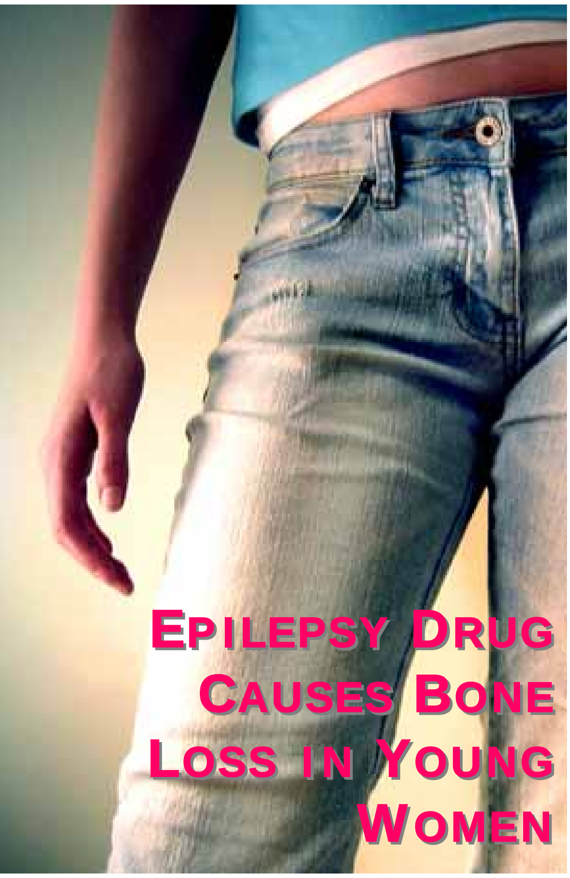
Lake Wakatipu at Kinloch, near Queenstown, New Zealand

In a country with a highly competitive nature, especially in the field of sport, a solution was needed to bring five not-for-profit organisations together, instead of each one competing against each another in the public arena, weakening their voice and their ability to attract funds.

While each organisation had a point of difference, the average person was not able to establish this too easily. The solution was to bring the organisations together to work as one. The Epilepsy Alliance of New Zealand, an idea driven by Frank Gouveia, General Manager for the Association established a working agreement with the NZILAE, The Foundation and Trust (both investment organisations) plus the NZ Epilepsy Assist Dog Trust.

A meeting of all parties has established involvement of each member and co-operation has already begun on a non-competitive front. The result is greater funding opportunities, better provision of services for people with epilepsy in New Zealand, as well as community education in general through public awareness campaigns. If you would like to learn more, you can contact Frank Gouveia at national@epilepsy.org.nz.

Epilepsy Drug Causes Bone Loss in Young Women



Young women who took the commonly used epilepsy drug phenytoin for one year showed significant bone loss compared to women taking other epilepsy drugs, according to a study published in the April 29, 2008, issue of *Neurology*, the medical journal of the American Academy of Neurology.

Researchers tested the bone health of 93 women with epilepsy who were between the ages of 18 and 40 and were taking the epilepsy drugs phenytoin, carbamazepine, lamotrigine or valproate. Bone mineral density was measured at the spine and two areas of the hip, (the femoral neck and total hip) at the beginning of the study and one year later.

Researchers also evaluated each woman's nutrition and physical activity, along with other factors that affect bone health.

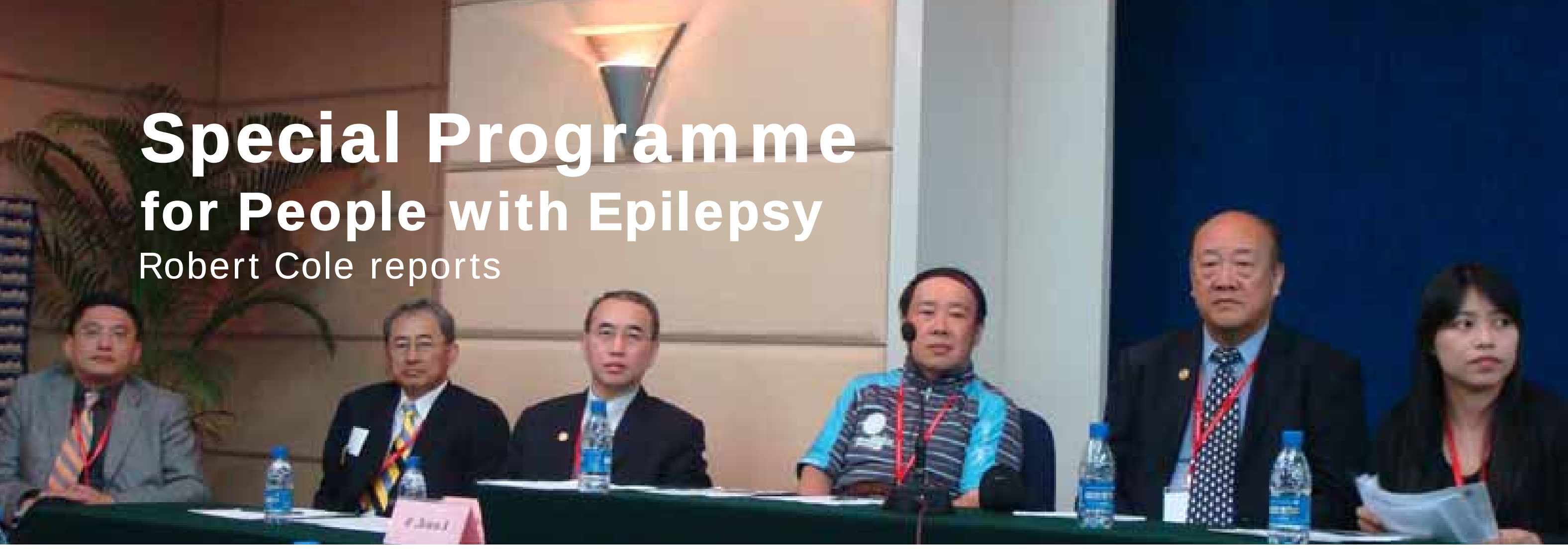
The study found women taking phenytoin for one year lost 2.6 percent of the bone density in the femoral neck of the hip. Women taking the other epilepsy drugs did not lose any bone density in the femoral neck. There was no bone loss at the spine or the total hip in any group.

'This is a significant amount of bone loss and raises serious concerns about the long-term effects of taking phenytoin in young women with epilepsy,' said study author Alison M. Pack, MD, with Columbia University in New York, NY, and member of the American Academy of Neurology. 'This is one of the first prospective studies to examine the long-term effects of common epilepsy drugs on rates of bone loss in young women.'

'This amount of bone loss, especially if it continues over the long term, could put these women at increased risk of fractures after menopause,' Pack said. Femoral neck fractures are tied to a higher risk of death in elderly people.

The study was supported by grants from the National Institutes of Health and GlaxoSmithKline.

Special Programme
for People with Epilepsy
Robert Cole reports



Now a well-established activity of the programme of the biennial Asian & Oceanian Epilepsy Congress, the Special Programme for People with Epilepsy was again conducted over 2 days during the 7th Asian & Oceanian Epilepsy Congress in Xiamen, China in mid-May.

It is good to report that the event was very successful with more than 60 participants. An initiative of IBE's Regional Committees South East Asia and Western Pacific, Dr PK Sethi, (Chair, South East Asia) and Dr Hidemoto Kubota (Chair, Western Pacific) had made available funds from their budgets to support the attendance of up to two participants from each country in the region.

Ms Anchor Hung (Vice President South East Asia) and Dr Shung-Lon Lai (Vice President Western Pacific), who are also ex-officio members of their respective Regional Executive Committees provided terrific support to the Chairs in undertaking much of the organisation of the event, and the programme they created was very well received.

A highlight was the presentation of Outstanding Persons Awards to Fang-Chih Chi (Taiwan), Rose Marie M Espina (Philippines), Ming Ying Goi (Singapore), Pang Hoi Keung (Hong Kong), Ting-ting Lu (China), Moses Ong (Singapore), Xiao-fei Shang (China) and Carol De Souza (India). Each recipients was recognized for their achievements in facing issues related to their epilepsy and each one detailed their special and wonderful stories to the group.

A popular fixture of the programme, the Sharing of Asian & Oceanian Experiences, introduced animated discussion as always. The session was very informative and detailed programs that have been established within associations, as well as advice on forming support groups and tips on expanding the work of national associations. The speakers provided valuable information and insights.

Speaking to the topic "IBE Initiatives in South East Asia & Western Pacific" IBE President, Susanne Lund detailed the IBE programs and promotion within the region, while Dr Wang Wenzhi (China), Dr Tovuudorj (Mongolia) and Dr Mehndiratta (India) explained some of the initiatives being undertaken in their respective countries.

"Is the Name of Epilepsy in some Languages causing Misconceptions & Stigma" raised a very important issue that was strongly debated. Dr Wang Wenzhi and Anchor Hung provided information and insights into stigma research. This was a thought provoking session and canvassed the possibility of changing the Chinese name for epilepsy which causes a negative view of the condition and of persons with epilepsy. To address this issue a special Task Force has been established. There is no doubt that stigma is a key issue on a global level and this topic is sure to feature in many future discussions.

Dr Yuan-Fu Tseng (Taiwan) introduced the HOPE program, a new model to support people with epilepsy and to help build confidence and self-belief. HOPE Ambassador Marion Clignet (France) an Olympic cycling silver medal winner, provided her inspiring, emotional and provoking story on her battle for recognition of epilepsy within the Olympic cycling fraternity. Hope Ambassadors, Guo-Jr Yu and Shih-Minh Li from Taiwan shared their inspirational life stories with the group, demonstrating tremendous courage and determination; a fitting climax to a wonderful day of reflection and debate. We look forward to the 8th Asian & Oceanian Congress, which will take place in Australia in 2010!

Photo top of page: Session Speakers, from left Ms Anchor Hung, Dr Shichuo Li, Dr Shung-lon Lai, Dr Shih Hui Lim, Dr Marshal Mo-Song Hsih, and Dr Wang Wenzhi.
Photo below: Some of the participants to the meeting.

Xiamen on Camera!

CAPTIONS: clockwise, from below:

Cultural Evening: Peter Wolf, ILAE President; Susanne Lund, IBE President; Shichuo Li, China Association Against Epilepsy; and Shih Hui Lim, Singapore Epilepsy Foundation.

IBE Stand: Delegates play the Action Zone game.

Editors Network Meeting: Ann Little, IBE Executive Director; Jacinta Cummins and Denise Chapman, Australia; Anthony Zimba, Zambia; MM Mehndiratta, India; Robert Cole, Chair Editors Network; Susanne Lund, IBE President; Carol Ireland, Australia; Vinod Saxena, India; Allison Clarke and Christine Walker, Australia.

Outstanding Persons Award: Recipients receive their certificates.

China Earthquake Disaster Fund: Nico Moshé, ILAE Secretary General and Susanne Lund, IBE President, make donations on behalf of IBE and ILAE at a special collection arranged during the congress.

Jónína Björg Guðmundsdóttir

It is with great sadness, and a deep sense of loss, that we bring you the news that one of IBE's enthusiastic supporters has passed away.

Jónína Björg Guðmundsdóttir was a member of LAUF, the IBE Full Member in Iceland, for many years. In that capacity she represented her association on the IBE European grouping, which evolved to become the European Regional Committee when the new IBE Constitution came into force at the end of 2004.

In 2005 she was elected a Member of the European Regional Executive Committee and served an active role on the committee in advancing its activities and objectives as it set up its plan of action for 2005-2009. Jónína also represented the Icelandic association on the Nordic Group, an informal gathering of lay epilepsy associations in the Nordic region, which meets for a full day each year to exchange experiences and to identify opportunities to work as a unit together.

Unfortunately, Jónína became ill before the International Epilepsy Congress in Paris in 2005 and was unable to attend. However she had made a good recovery and attended the 10th Epilepsy & Society Meeting in Copenhagen in 2006 - a meeting that is organised by the European Regional Committee.

Jónína was again with us last year in Singapore and our photo of Jónína, pictured with her husband (to her right) together with Paul Sharkey from Brainwave the Irish Epilepsy Association, shows her familiar happy smile. But her recovery was to be short-lived and by the end of the year Jónína's cancer had returned.

Sadly, on Friday 13th June, her brave battle ended.

Jónína was greatly admired and much respected by everyone she came in contact with in IBE; you always felt better having spoken with her. Her smile was infectious as was her deep commitment to improving the quality of life of people with epilepsy, not just close to home, in Iceland, but throughout Europe and further a-field.

IBE would like to extend its sincere sympathy to Jónína's husband, her children and her grandchild on this very sad occasion.

Jens Mielke dies in Plane Crash

Tragic loss of one of Zimbabwe's few Neurologists

On 20 March we learned the sad news that Dr Jens Mielke had died tragically the day before when his light aircraft crashed on take-off from Harare Airport in Zimbabwe.

Gretchen Birbeck, a close colleague of Dr Mielke wrote: "Dr Mielke served on the Faculty at the University of Zimbabwe for many, many years and was perhaps the last bastion of academic neurology in the country. He also travelled monthly to Botswana to provide services to yet another African country that literally has no neurologists. Many collaborated with Jens on projects related to addressing the needs of people with neurological conditions in resource poor settings. He made himself and his expertise available in any way he thought would be helpful".

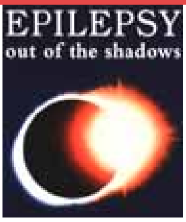
The first time I met Dr Mielke was at the Regional Conference *'Epilepsy: a Health care priority in Africa'* held in Senegal in May 2000. He participated enthusiastically in writing the African Declaration on Epilepsy 2000. But we were to meet many times after that and worked closely together on a Demonstration Project in Zimbabwe, a pilot project in Africa under the ILAE/IBE/WHO Global Campaign Against Epilepsy.

His ability to pursue neurology in Zimbabwe during the most difficult circumstances was admirable; an inspiration to many others. He was a remarkable man, conducting academic work under difficult conditions, never giving up hope that neurological services and teaching might be improved in the region.

Jens Mielke will be missed by friends and colleagues all over the world. But especially by the people with epilepsy in Africa who he served so well.

Hanneke de Boer
Former Co-Chair
ILAE/IBE/WHO Global Campaign Against Epilepsy

Brainwave, the Irish Epilepsy Association, marks Brain Awareness Week in Ireland and celebrates 10 years of the Global Campaign Against Epilepsy



To celebrate Brain Awareness Week in Ireland last March, Brainwave held a seminar for politicians, media and health professionals at the Mansion House, the official residence of the Lord Mayor of Dublin. The event highlighted issues facing people with epilepsy in Ireland today and marked 10 years of the Global Campaign Against Epilepsy, which was launched in Dublin in June 1997.

Hanneke de Boer, former co-Chair of the Global Campaign and still involved in its secretariat, spoke about the history, activities and successes of the campaign to date. She also highlighted the current poor services for people with epilepsy in Ireland.

"Ireland is a high-income country with a population of over 4.2 million people, yet the country has just 20 adult and five paediatric neurologists. Of these, only five adult neurologists and two neuropaediatricians are trained epileptologists," she stated.

Dr Tarun Dua, from the World Health Organization (WHO), spoke about the WHO's Programme on Neurological Diseases and Neurosciences, which aims to strengthen the capacities of countries to improve neurological care. Statistics in Dr Dua's presentation indicated that, when it comes to the number of neurologists per head of population, Ireland is in the same league as countries such as Mexico, China, Colombia, Ecuador and much of North Africa. This is significantly behind North America and even much of Eastern Europe.

WHO has identified epilepsy as one of eight priority disorders in the WHO's wide-ranging category of "neurological, mental and substance use disorders".

Dr Norman Delanty, Consultant Neurologist at Beaumont Hospital in Dublin called for the establishment of a National Centre for Epilepsy to correct the deficits in providing multi-disciplinary care.

The event received widespread media attention on TV, radio and in the printed press. Government Ministers and Senators from all major Irish political parties attended the event, many of whom spoke on the day, offering their support to Brainwave's work in advocating for better epilepsy services.

Solidarity Fund Acknowledgements

The IBE Solidarity Fund was introduced as a means of supporting IBE Members in developing countries, to enable them play an active role in IBE's activities, where lack of funds would otherwise have prevented this. The fund is now also used to support the annual dues payments of members in countries deemed to be Low Income according to World Bank figures. In 2007, the fund was also used to support the Promising Strategy Projects. For information or to arrange a donation, please contact Ann Little, IBE Office, ibedublin@eircom.net.

All donations to the fund are gratefully accepted, no matter how small, and IBE would like to thank the following, who donated to the fund between 1st January and 30th June 2008:

Donations of US$1,000 and over

- Epilepsy Hospital BETHEL, Japan
- Swedish Epilepsy Association, Sweden

Donations between US$150 and US$300

- Swiss Epilepsy Centre, Switzerland
- Greek National Association Against Epilepsy, Greece

Donations up to US$100

- Epilepsy Association of South Australia and the Northern Territory Inc., Australia
- Epi-Suisse, Switzerland
- Epilepsie Vereniging Nederland, The Netherlands
- Epilepsy Connections, Scotland
- Enlighten Hong Kong, Hong Kong
- Cyprus Association for People with Epilepsy, Cyprus
- Jamaican Epilepsy Association , Jamaica
- AEAE, Spain
- Nepal Epilepsy Association, Nepal
- EDYCS, Mauritius
- EOLE, France

IBE would also like to acknowledge a generous donation of US$4,000 provided by Epilepsy Foundation, USA towards the Promising Strategies Program.

TAENIA SOLIUM TAPEWORMS AND EPILEPSY IN UGANDA

A recent meta-analysis of epilepsy attributable to neurocysticercosis indicated that more than 30% of epilepsy cases in sub-Saharan Africa may be due to the parasitic disease.

Arve Lee Willingham III, DVM, PhD, WHO/FAO Collaborating Center for Parasitic Zoonoses, Faculty of Life Sciences, University of Copenhagen, Denmark and Augustine Mugarura, MA, Vice Chair of the IBE Regional Executive Committee Africa and National Director of the Epilepsy Support Association, Uganda (ESAU) write about the growing concern regarding the spread of neurocysticercosis and a workshop held in Uganda address the problem

Cysticercosis is emerging as a serious public health and agricultural problem in Eastern and Southern Africa (ESA). Caused by the pork tapeworm, *Taenia solium*, this zoonotic disease forms larval cysts in humans and pigs that can lead to epilepsy and death in humans, makes pork unsafe to eat and reduces the value of pigs. It occurs where sanitation is poor, meat inspection is inadequate and pigs range freely, and so is strongly associated with poverty.

People become infected with the adult tapeworm form of the parasite (taeniosis) by eating infested raw or undercooked pork. Large numbers of the eggs of the tapeworm are shed in the infected person's stool and can be ingested by free-roaming pigs if people defecate outdoors. Pigs develop the immature larval form of the parasite (cysticercosis) with hundreds to thousands of small cysts, commonly called 'pork measles', forming in their muscles, heart and brain, rendering the pork unfit for consumption. Pigs thus affected usually show no signs of disease.

You can become infested with cysticercosis without eating pork

People can also become infected with the cystic larval form of the parasite by ingesting *T. solium* eggs either from direct contact with a human tapeworm carrier or from contaminated food and water - thus one does not need to raise pigs or consume pork to become infected with cysticercosis! In humans the cysts often develop in the brain, causing a condition called neurocysticercosis, which can cause severe headaches, epileptic seizures and sometimes death.

Neurocysticercosis is considered to be the most common preventable cause of epilepsy in the developing world, rendering people incapacitated and unproductive, and sometimes leading to fatal accidents as a result of seizures. Although, theoretically, easy to control and declared eradicable, cysticercosis remains neglected in ESA, due to lack of information and awareness about the problem's extent, lack of suitable diagnostic and management capacity, and a lack of appropriate control strategies.

The connection between tapeworms and epilepsy

The relationship between tapeworms and epilepsy came under the spotlight at a two day national workshop held 29-30 May in Kampala, Uganda. The workshop brought together animal and human health professionals from sixteen districts of Uganda which are considered likely to be endemic for *Taenia solium* cysticercosis.

The workshop, hosted by the Faculty of Veterinary Medicine, Makerere University, Kampala was called to launch a one year project "*Impact assessment and capacity building for prevention and control of Taenia solium cysticercosis in Uganda*" which is being funded by the Technical Cooperation Programme of the

United Nations Food and Agriculture Organization (FAO). The projects main objectives are:

- To assess the extent of *T. solium* cysticercosis in pigs and humans.
- To contribute to the design and implementation of a strategy for effective surveillance, prevention and control of *T. solium* infections.

The Ugandan Minister of Animal Industry opened the workshop noting that pork consumption has greatly increased in the country during the past few years and that the Government of Uganda is encouraging pig rearing as a way to boost rural incomes, especially among rural women.

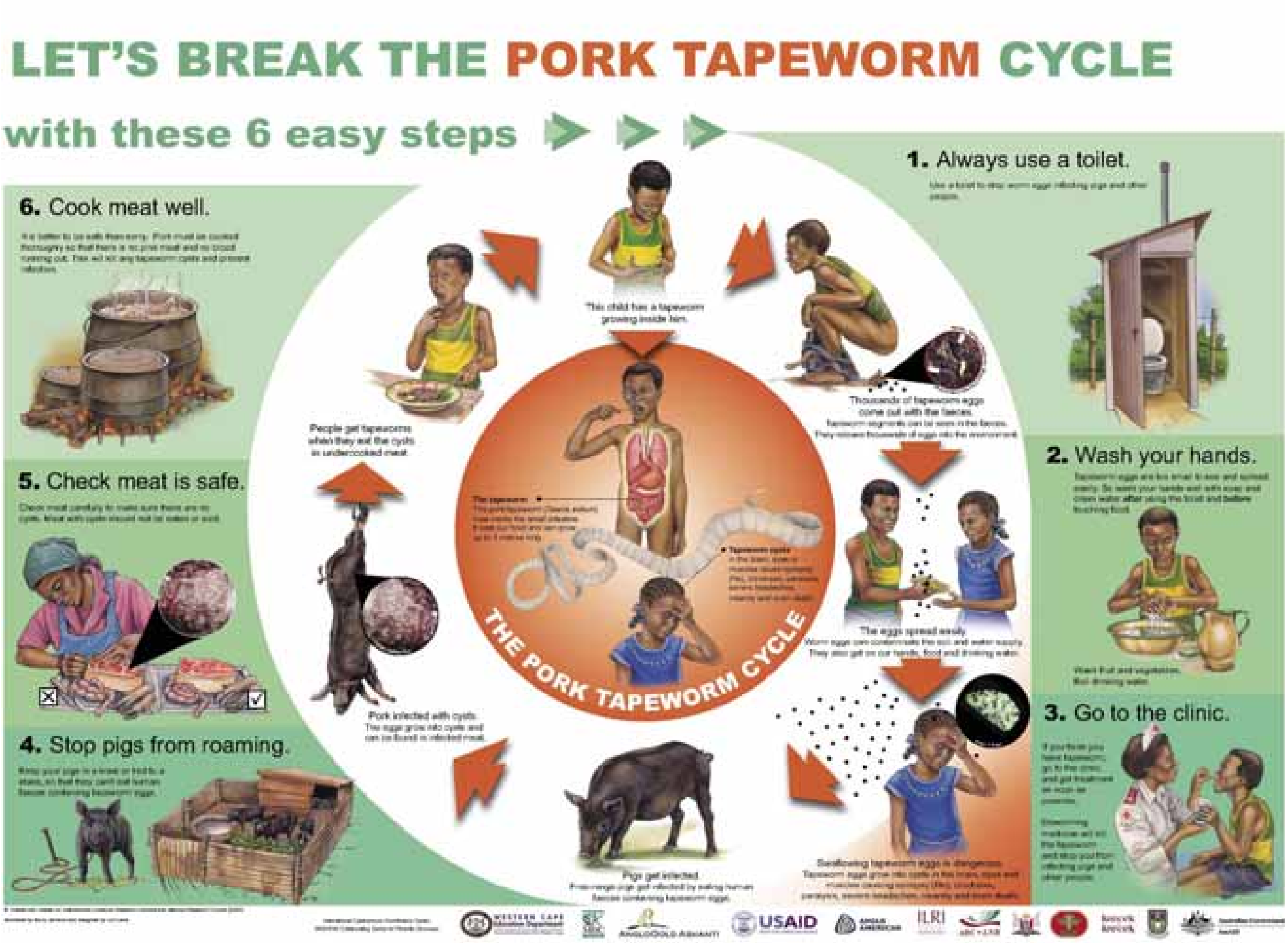
He welcomed the project, as it will enhance the government's vision to combat rural poverty and benefit farmers, consumers and professionals. He appealed both to participants at the workshop and to those involved in the project to find ways and means through which pork consumers, those involved in pig rearing, and the animals being reared could be protected from infection with *T. solium*. The Minister encouraged the professionals to promote safe and hygienic pork production and consumption.

Migration aids the spread of neurocysticercosis

Evidence presented by researchers in both veterinary and medical fields painted an alarming picture of the level of *T. solium* infection in humans and pigs in the eastern and southern Africa region, underlining the fact that this disease is a serious public health risk not only to rural people in pig rearing communities but also in urban areas due to the migration of human tapeworm carriers and the transport of infected pigs and pork for consumption.

It was mentioned that in endemic communities pigs kept by many rural farmers are allowed to roam about to search of food and have access to human waste, which may contain *T. solium* eggs, as latrines/toilets may not be present or used and people may defecate in the bushes (being coprophagic, pigs like to eat human/animal solid waste). It was noted that, in Uganda, the government is vigorously promoting pig rearing but in many areas, both rural and urban, there are few or no established formal facilities for slaughtering pigs or inspecting pork; thus pork infected with *T. solium* may be available for consumption. People may be aware of cysts in the pork but may not be aware that it is dangerous to eat. A recent meta-analysis of epilepsy attributable to neurocysticercosis indicated that more than 30% of

People become infected with the parasite by eating infested raw or undercooked pork



An educational poster designed to highlight the causes and effects of *Taenia solium*

People may be aware of cysts in the pork but may not be aware that it is dangerous to eat.

epilepsy cases in sub-Saharan Africa may be due to the parasitic disease. A recent study in northern Tanzania indicated about 15% of people with epilepsy involved in a small-scale survey were found to have neurocysticercosis, using CT scanning.

A Ugandan psychiatrist from the Medical Faculty of Gulu University, with a keen interest in epilepsy and public health issues, informed the meeting that he had documented cases of epilepsy in Uganda attributable to *T. solium* infection and he confirmed the direct relationship between epilepsy and *T. solium* neurocysticercosis.

The workshop participants were briefed about the ILAE/IBE/WHO Global Campaign against Epilepsy “Out of the Shadows” that aims to create awareness about epilepsy, and the epilepsy support programme in Uganda. Linkage to these epilepsy initiatives was considered essential, since it is anticipated that neurocysticercosis may be a major preventable cause of epilepsy in the country.

Staff from the Vector Control Division of the Ugandan Ministry of Health showed evidence from the onchocerciasis control programme that dermal lesions, initially attributed to onchocerciasis, another parasitic disease thought to cause epilepsy, were actually found to be subcutaneous cysts of *T. solium*.

The Ministry of Health is involved in conducting large-scale control programs for some other neglected tropical diseases including lymphatic filariasis, schistosomiasis, and soil-transmitted helminths (intestinal worms) and is actively participating in an integrated approach to surveillance and control of these diseases. It was discussed that a national initiative to map the endemic areas for these neglected tropical diseases should be extended to include *T. solium* infections, as it would be good to know areas of co-endemicity to understand the effects of treatment for these other diseases on human *T. solium* infections.

Some of the drugs being used can cure tapeworm infections; however they can also affect *T. solium* cysts though perhaps not killing them but affecting them enough that they may elicit seizures in previously nonsymptomatic neurocysticercosis cases.

Thus it will be important to know where cysticercosis is co-endemic with the other diseases, so that appropriate treatment and monitoring protocols can be introduced. Participants were led through a stakeholder analysis process and identified the relevant stakeholders, their roles and how to ensure their continued interest and participation in the cysticercosis surveillance and control initiative.

It was noted that for efforts to be effective and sustainable it is important to maintain open dialogue and communication and to deliver on all commitments made.

For more information please contact
Dr Lee Willingham at the WHO/FAO Collaborating Center for Parasitic Zoonoses in Denmark
Email: awi@life.ku.dk

Peter Wolf, ILAE President, comments:

Neurocysticercosis (NCC) is one of the most common causes of epilepsy in large parts of the developing world, particularly in Central and Latin America, Africa and parts of South East Asia. It is prevalent wherever pigs are raised in unsatisfactory hygienic conditions. In Southern and Eastern Africa where pig raising is becoming increasingly popular and the risks are largely unknown in the villages, there is a dramatic increase of tapeworm infection and NCC. There is also increasing awareness that human NCC does not require any contact with pigs or pork but is due to the ingestion of tapeworm eggs. Tapeworm carriers are largely unidentified and excrete daily great numbers of tapeworm eggs. With lacking hygiene these are easily passed around with even minor contact. Changes in life habits in cities, such as trends to consume food prepared in the street without even the most basic hygiene, increase the risk, and urban NCC involves also Islamic and Hebraic populations who do not eat pork.

On the other hand, NCC is preventable and is, in fact, an almost ideal target for concerted action involving education and public awareness, hygienic measures, veterinary and human medical approaches of prevention, diagnosis, medical and neurosurgical treatment. Many of these aspects were addressed in the workshop in Kampala, Uganda which is reported here.

A joint project against NCC of the North and Latin American ILAE Commissions on the island of Hispaniola is about to start, and the ILAE has recently established an NCC task force. We don't stand alone but several organizations and initiatives are interested in a partnership with us. I believe the time has come for IBE and ILAE to focus on *Taenia solium* and NCC.

european disability forum

Sends an ‘Open Letter’ to José Manuel Barroso, President of the European Commission

José Manuel Barroso

> It’s positive news that the EU Parliament has voted in favour of support for legislation tackling discrimination outside employment on the ground of disability, age, religion, and belief and sexual orientation. The work of EDF - European Disability Forum has been fruitful. When the directives have been decided and implemented they will be good tools for our organisations and for persons with epilepsy to fight discrimination and for the right to services, education, employment, etc.
>
> The UN Convention on The Rights of Persons with Disabilities provides a recognised international standard for disabled people’s human rights in one document. This will also help the international community to put pressure on countries whose work on disability rights could be improved.
>
> *Peter Dahlqvist*
> *Chair*
> *IBE European Executive Committee*

Brussels, 22 April 2008

Dear President,

It is with great satisfaction that I am writing to you, following public announcements made by your services, that a proposal for a European directive fighting discrimination against disabled people will be proposed to the College of Commissioners at the end of June as part of a comprehensive ‘Social Package’.

This is the best response that you, together with Commissioner Vladimir Spidla, could give to the ‘1million4disability’ campaign that EDF has led over last year, and that has gathered the support of over 1,364,984 citizens including prominent national and European politicians, representatives of a wide variety of civil society organizations, trade unions, and heads of State. It is also very significant as it is the first citizen’s initiative that is followed up by the European Commission, even before the entry into force of the Lisbon Treaty. All citizens will rejoice of your decision, as it sets a positive example of democratic dialogue between the European Commission and the people of Europe.

EDF had been campaigning for a disability specific directive since 2000. In 2003, at the closing of the European Year of People with Disabilities, the European Commission, while stating that the time was not ripe, announced that there would be a disability specific directive.

This directive is also a first significant step in the process of implementation of the United Nations Convention on the Rights of Persons with Disabilities that the European Commission is about to ratify, as non discrimination is a prominent element in this new binding Human Rights instrument, which covers civil, political, social, economic and cultural rights.

EDF would like to express its gratitude and support for such an important initiative, which will contribute to strengthening non discrimination *acquis*, and to establishing a strong link between disability, non discrimination and Human Rights, across the European Union.

Until today, too many citizens with disabilities have remained among the most invisible and neglected, segregated in institutions or even in their homes; they have been denied access to education, employment, transport, social or health services, they have been unable to access information, watch television, to go to cinemas and restaurants as any other citizen.

A European legislation will allow persons with disabilities to have access to the same rights across the EU, and to benefit for the first time from free movement rights, from which they have been so long deprived.

50 million disabled persons across Europe and their families are looking forward to an ambitious and effective legislation tackling rights of disabled people in all areas of life, able to create change and making the EU the most advanced region for disability rights. EDF has drafted a proposal for legislation with the support of legal experts, published on our website. We are at the disposal of your services for further contributions.

It is also critical that such legislation adequately addresses situations of multiple discrimination, in which all disabled people may find themselves, regardless of their age, sex, religion or belief, ethnic origin, or sexual orientation. EDF also calls on all EU institutions to move forward the debate on legislative measures that will strengthen provisions fighting discrimination on all grounds of Article 13.

EDF is also calling on the Council of the EU, the Member States who will be called to decide on such a proposal, and the European Parliament that has supported a disability specific directive in so many statements, resolutions and reports over the last seven years, to carry forward such disability legislation, which will undoubtedly bring citizens closer to the European Union.

Yannis Vardakastanis, President, European Disability Forum

Marseille

IBE

11th EUROPEAN CONFERENCE ON EPILEPSY & SOCIETY

15th-17th October 2008

The Conference

The 11th European Conference on Epilepsy & Society is shaping up to being a wonderful meeting. With the closing date for Early Registration just passed, the number of delegates expected to attend is already very promising. It is expected that the number of delegates in Marseille will exceed the attendance figure at the last conference, which took place in Copenhagen in 2006.

The theme of the 2008 Conference is **Active Life and Epilepsy** and the Organising Committee has put together a very interesting programme under this title. As at previous Epilepsy & Society Conferences, the programme will review various quality of life issues, with a special focus on achieving life goals, both for individuals and for organisations.

The programme will also concentrate on interpreting information and how to successfully communicate one's messages through public media. During the sessions and the workshops there will, of course, be time for questions and discussions about the important topic of **Active Life and Epilepsy**.

But there will also be time to relax and socialise with friends old and new. A special new addition to the social programme is a Karaoke Night for young people and for those who don't sing like angels, there will still be the Opening Night to enjoy, and the opportunity for fine dining at Le Yacht.

The facing page will give you a taste of what is planned. Enough, we hope, to encourage you to come and join us in October in the heart of Provence!

www.epilepsyandsociety.org

The City

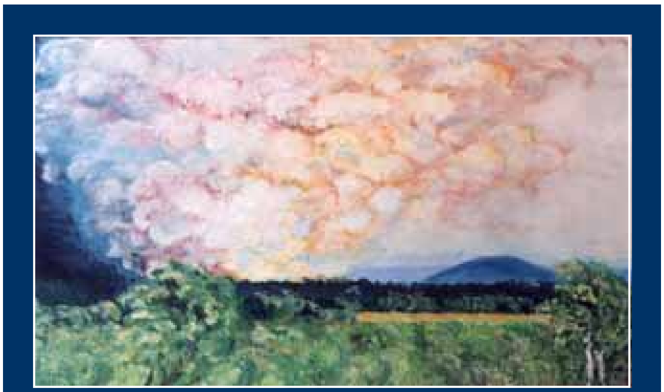
Basking in warm Mediterranean sunshine for much of the year, Marseille is known for its beaches, almost 60 kilometers of wonderful coastline, not to mention its superb *bouillabaisse*. The city, the 2nd largest in France, is a showpiece of brilliant white stone rising above a picture perfect seaport framed by enormous neo-Byzantine churches. Marseille is a dynamic city, buzzing with '*joie de vivre*', as cosmopolitan now as when ancient Phocaeans first founded it as an international shipping port 2,600 years ago.

It's a great place to spend a few days either before or after the conference, when you can take more time to enjoy the old port and the narrow streets of the old town, or laze on one of the beaches close by.

If you have more time to spend in Provence, there is a wonderful array of beautiful and historic towns and villages close by. Visit Aix en Provence to enjoy the city's numerous fountains, made possible by the Verdon canal. Or journey to the old city of Avignon with its ruined bridge made famous by the song "Sur le Pont d'Avignon" and the historic Papal Palace close by.

In Arles you can pay homage to Van Gough and visit its ancient bullring; while Orange has a must-see Roman theatre. Both Arles and Orange are UNESCO Heritage sites. And then there's the jet-set coastline where the rich and famous drop anchor - St Tropez, Cannes, Nice, Monaco, or Antibes - to name but a few!

So, come and join us in October - you won't be disappointed!



Freedom in Mind Exhibition

Take the final opportunity to enjoy some of the artwork and poetry submitted to the Freedom in Mind project. The last live exhibition is being mounted at the Marseille conference, although the artwork and poetry will still be available to view on www.freedominmind.com

Annual Meeting of the European Regional Committee

All IBE Members based in the European Region are invited to attend the annual meeting of the European Regional Committee, which will take place in Marseille on Wednesday 14th October from 13.00 to 15.00.

Further details, including the meeting agenda, will be circulated by Peter Dahlqvist, Chair, European Regional Executive Committee closer to the meeting date.

Win Yourself a Prize

EUCARE
European Concerted Action and Research in Epilepsy

By attending the EUCARE Session on Friday 17th October you could go home from Marseille with a brand new digital camera! All you will need to do is to answer some simple questions based around the topics being presented and you will be in with a chance of bagging yourself a prize. First prize is a digital camera and there will be two runner-up prizes.

Speakers at the session will include Tarun Dua from the WHO; Jean George, Alzheimer Europe, who will speak on Public Relations; Graham Harding, who will talk about epilepsy and photosensitivity; and Martin Brodie who will bring us up to date on the EUCARE FONDE study.

Dine on board Le Yacht

A social evening with a difference is promised as a highlight of the conference. Delegates will have the chance to enjoy a very special evening on Thursday, 16th October on board **'Le Yacht'**, an elegant modern boat moored close to Fort St Jean, where dinner will be served.

Enjoy a great evening with friends old and new, while taking in the spectacular illuminated views of the city and harbour set against the night sky.

Tickets for the Social Evening cost €35 each and can be booked when registering for the conference. Numbers are limited, so it is advisable to book as soon as possible to avoid disappointment.

Publications on Display

A special display of publications produced by IBE Members will form part of the Exhibition Area at the conference in Marseille.

Member associations are being invited to send single copies of recent books, brochures, magazines and flyers for display at the conference. The display is designed to promote the work of the associations and to provide best practice inspiration for other associations.

Members will be provided with full details of how, when, and where to send their printed materials in the coming weeks.

Marion Clignet Peddles East

Shung-Lon Lai, IBE Vice President Western Pacific region, outlines the lead up to a great cycling event in Kaohsiung

In March 2007, I travelled to Seoul to visit Dr Kyoon Huh, then current president of the Korean Epilepsy Association. Seoul is a very modern and beautiful city. I was stunned by the modern high rise buildings and convenient subway system in Seoul, but I was also shocked to hear about the profound stigma that people with epilepsy suffer there. Dr Kyoon Huh told me that most people with epilepsy are very afraid to talk about their condition publicly. In Korea, most people respect athletics. He told me if Marion Clignet, the Olympic silver medal winner could visit and talk about epilepsy in Seoul, it would have a great impact on the issue of stigma in Korea.

Marion had been invited to speak at the 27th International Epilepsy Congress in Singapore in July 2007. I made first contact with her after her impressive presentation and invited her to visit the region and to become involved in tackling the issue of stigma. At the same time I learned about the UCB Ambassador program; of which Marion was the first one in Europe. Soon after, I participated in the first Ambassador program in Asia, which took place in Taiwan in July, 2007. We started looking at the possibility of inviting Marion to travel to Taiwan and Korea in 2008. With the idea of planning an event to highlight issues related to stigma, the IBE Regional Executive Committee Western Pacific presented a budget plan to the International Executive Committee in January 2008, which would cover the cost of Marion's participation in such an event.

Marion was due to attend the 7th Asian & Oceanian Epilepsy Congress in Xiamen in May 2008, so we planned that the first activity would be held in Taiwan just before the congress. The objective of the project was to make the public become aware that people with epilepsy are not so different from everyone else. They can still overcome difficulties they face to achieve the best possible quality in their lives. We needed to attract television, radio, newspapers and internet groups to spread this positive message, so we planned a very large bike ride with Marion as leader, which we thought would be picked up by the media.

We chose Kaohsiung (southern part of Taiwan) as the target city. The national chapter in Taipei and the local chapter in Kaohsiung worked together to make the event a success. The cycle ride also provided a fund-raising opportunity; the funds raised will help with future activities. I also believe that this is a model that can successfully be adopted by other IBE Member associations.

While preparing for the cycle ride, I travelled again to Korea and learned that Korea will also have a similar activity later in this year. I also wish them a very successful event in highlighting publicly the need to address the issue of stigma.

Cycling for Epilepsy

An extraordinary spirit helps promote public awareness and social education in epilepsy through a Cycle Ride in Taiwan. Dr Marshal Mo-Song Hsih, Honorary and Founding President, Taiwan Epilepsy Association reports on the day when 2000 people peddled against stigma

The big Cycle Ride, arranged in just 3 months, went exactly to plan on May 11, 2008. Success was due to a combination of passion from local people, members of Lion Clubs and local epilepsy associations, together with the great support of IBE, ILAE and the UCB Ambassador Program.

A total of almost 2,000 people took part in the event, including children, teenagers, adults and older people. Some brought along their pets, which made the event even more fun. The cycle course was a distance of about 8 kilometres. Water stops, medical facilities and traffic management were all arranged.

By 6.30 in the morning of May 11, people were already arriving at the start. Before the whistle sounded that would set wheels rolling, people shared their personal experiences of cycling and discussion on the topic of epilepsy was also encouraged by the flyers detailing general information about epilepsy that were distributed.

At 7.30, Miss Marion Clignet, Dr Shunglon Lai, Dr Yuan Fu Tseng, Mr Gin Tsai Lin (President of Kaohsiung Lions Club) and I pressed the starting horn and led out the large group of cyclists. Our route took us alongside Love River from Nong 16th to Glory Pier. Love River is considered to be the spine of Kaohsiung, playing a similar role to the River Thames in London. The river is of great cultural significance to the people of Kaohsiung and plays an important role in its economy and tourism. Along the way the riders were supplied with water by many volunteers and enjoyed the large numbers of flags promoting the event. It took 2 hours for all 2,000 people to complete the course.

At about 9.30, Marion delivered a speech, talking about her experience with epilepsy and how she found her way out and, finally, a very successful life. She demonstrated a special fighting spirit against any obstacle. Her speech was simultaneously translated into Chinese by Miss Liu, who also has epilepsy. I am sure that those listening to Marion's speech will have been deeply be touched and, hopefully, will adopt Marion's spirit of never giving up or surrendering. To finish, Marion was surrounded on the podium by many local Epilepsy Ambassadors for a memorial photo.

Finally, I would like to express my grateful thanks to those who helped us achieve the impossible mission of this Cycle Ride, to promote public awareness and social education in epilepsy.

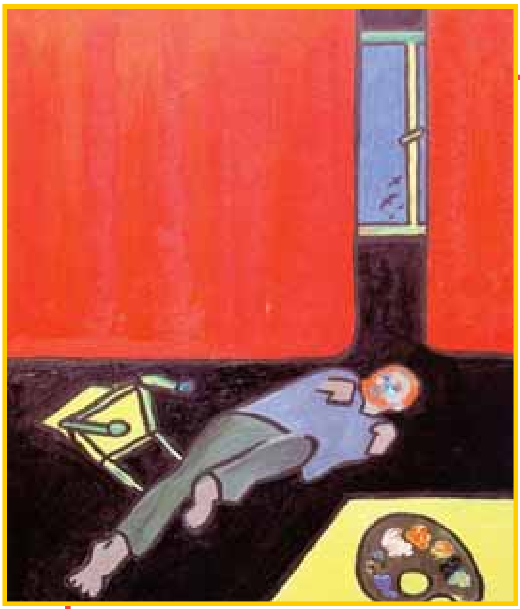
Photo captions:

- Facing page: riders line up for the start.
- Top from left: Marshal Mo-Song Hsih and Marion Clignet lead participants in limbering up exercises; cyclists, including Shun-lon Lai (first left) pose for a photo; one of the many unusual bikes that took part in the Cycle Ride.
- Photos bottom of page: the event attracted all age groups and a strange range of bikes. Pets were also welcome!

Hard to Miss Message!

On billboards twice the height of a double-decker bus, Enlighten Hong Kong's latest Epilepsy Awareness project is hard to miss.

The initiative is made possible through the Hong Kong Lands Department 'Street Banner' project. The location and dates when a banner can be displayed free of charge depends on availability of space. The banner in the photo, right, is in the very busy Wanchai, Queens Road to Happy Valley, District of the city.



MICHAEL PRIZE 2009

The MICHAEL PRIZE is a highly regarded international awards for the best contribution to scientific and clinical research promoting further developments in epileptology. It is awarded biennially and is specially designed to attract younger scientists (45 years and under). The prize fund is €15,000.

Publications which have appeared in 2007/2008, or papers of the same period and not yet published will be considered by the jury, which consists of Uwe Heinemann, Germany; Brian Meldrum, UK; and Solomon Moshé, USA.

Those wishing to be considered should submit, in triplicate, papers and publications, together with a curriculum vitae and a photo, to Stiftung Michael before the deadline of December 31, 2008.

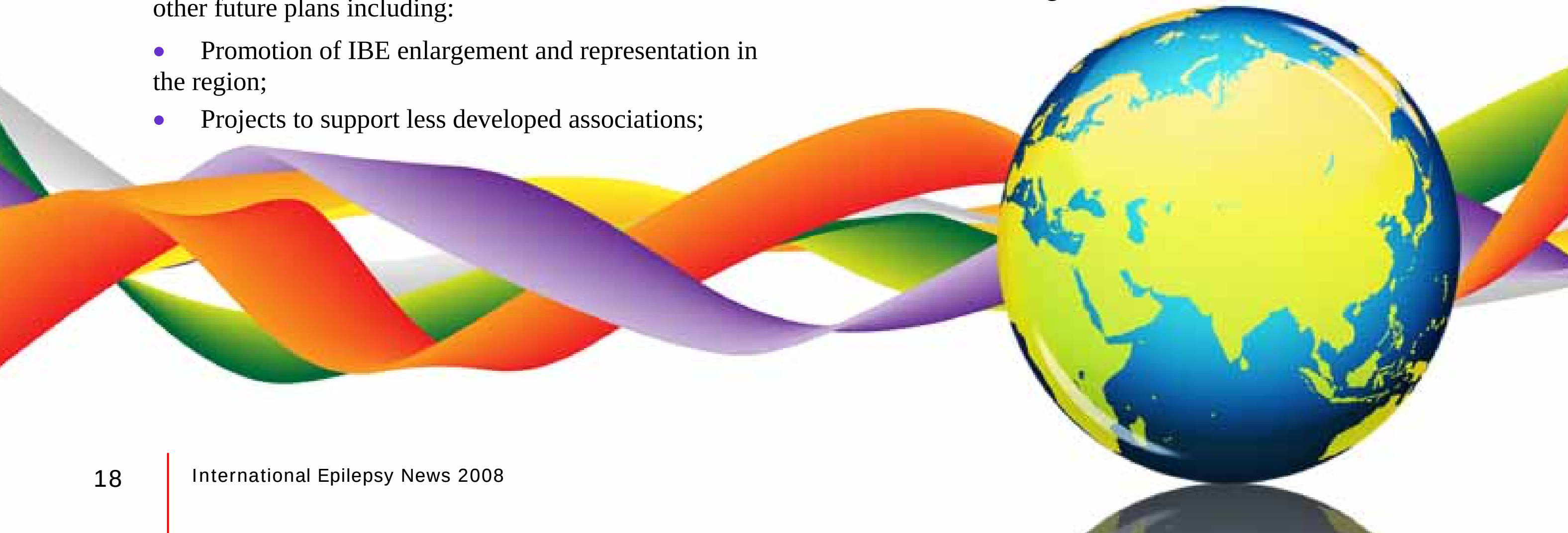
For applications or more information contact:

Stiftung Michael, Muenzkamp 5, D 22339 Hamburg, Germany
e-mail: stiftungmichael@t-online.de

Eastern Mediterranean Regional Executive Committee Meets

The newly elected members of the Eastern Mediterranean Regional Committee met together for the first time in Cairo in May. One of the key issues for discussion was proposals for the next IBE/ILAE East Mediterranean Regional Epilepsy Congress. The group also discussed other future plans including:

- Promotion of IBE enlargement and representation in the region;
- Projects to support less developed associations;
- Promotion of best practice through the sharing of experiences on successful programs;
- Collaboration and contact between the IBE Eastern Mediterranean Regional Committee and the ILAE Commission for the region.



Take the initiative!

Danish research on living conditions for persons with epilepsy

Report by Lone Nørager Kristensen, President of the Danish Epilepsy Association (pictured far left) and Claus Langkjær, Project Manager, Danish Epilepsy Association (pictured left)

In Autumn 2006 the Danish Epilepsy Association (DEA) conducted a questionnaire survey focusing on living conditions of adults with epilepsy (PWE) in Denmark. In May 2007 the report was presented at our biennial epilepsy conference. The report can be downloaded free of charge from our website and there is a Danish, as well as an English, summary in the report. The questionnaire was sent to 1,000 adult members of the DEA and the response rate was 65 percent, which was very satisfactory.

The purpose of the survey was to obtain solid and scientific knowledge of the living conditions for PWE. Most of the epilepsy related research in Denmark, as in many countries around the world, is very specific, i.e. it is medical research on a specific topic or is very vague in its epilepsy focus, i.e. it is a general disability research project. Before we launched this research project, there was no comprehensive, scientific knowledge of how epilepsy influences people's lives in terms of cognitive problems, psychological disorders, side effects of medicine, barriers to education, labour and leisure, health, quality of life etc.

Take matters into your own hands

Therefore, we initiated the research ourselves. It was very important for us to ensure the quality of the research in order to obtain valid and reliable knowledge and in order to get the results recognized professionally and politically. This is why we chose to enter into a partnership with a recognized Danish senior researcher who has carried out disability research for a long period of time.

At the present time, we are carrying out questionnaire surveys among children with epilepsy (0 to 17 years) and their parents, young people with epilepsy (18 to 30 years) and their parents, and spouses of people with epilepsy. In additions, we are planning to do research (qualitative or quantitative) on siblings of children with epilepsy.

Comparability is vital

In all surveys we use questionnaires and questions which have been used in recognized, scientific surveys on the issue at hand. Using recognized methods for the survey increases the probability of the results being used practically and politically. For the survey on children, for instance, we have used many questions from the *Health Behaviour in School-aged Children (HBSC)* - a WHO international study involving 40 countries. Using standardized questionnaires such as the HBSC allows us to compare data for children of the same age in the Danish 'normal population'. This is a powerful tool, politically, because we can point out specific focal points where children with epilepsy differ negatively from those without epilepsy. Furthermore, it is possible for us to compare results over time (continuing surveys) and place (40 participating countries).

Use the results

It is immensely important for epilepsy associations world wide to be active in the production of knowledge of PWE. With this knowledge we can qualify and focus our work on improving the living conditions for PWE and we will be able to help epilepsy professionals to have better understanding of the living conditions of PWE and, ultimately, we will acquire a powerful political tool to influence legislation and public administration in the field of epilepsy. All reports will be available for download at the Danish Epilepsy Association website: www.epilepsiforeningen.dk.

Share Your News

Does you association have a news story or an article that you would like to share with others?

Do you have a photo of a successful event that could inspire others?

Then why not send your story to the IBE office? IBE is always delighted to receive news and articles that can reproduced in IE News. And readers are always pleased to read them!

Future Congresses

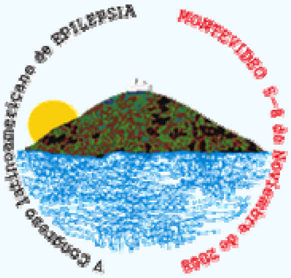
Regional Congresses

11th European Conference on Epilepsy & Society

Marseille, France

15th - 17th October 2008

www.epilepsyandsociety.org



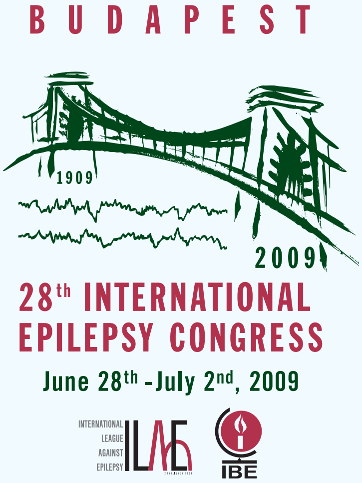
5th Latin American Epilepsy Congress

Montevideo, Uruguay

5th - 9th November 2008

www.epilepsymontevideo2008.org

International Congress



28th International Epilepsy Congress

Budapest, Hungary

28th June - 2nd July 2009

www.epilepsybudapest2009.org

For full details on all future epilepsy congresses, visit the congress website

www.epilepsycongress.org