

INTERNATIONAL

Epilepsy News

Reporting epilepsy news for 50 years

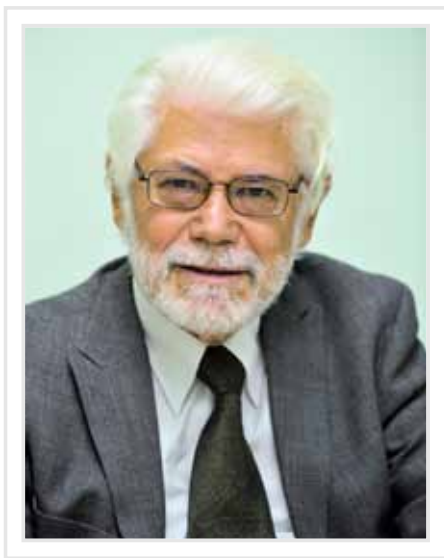
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HAPPY NEW YEAR

The International Bureau for Epilepsy wishes its Members, Partners, Friends and Supporters every success in their projects and initiatives to improve the quality of life for people with epilepsy in 2014

PRESIDENT'S LETTER



Dear Friends

As we come to the end of the year, it is nice to review what has been achieved since the new committee began its term at the end of June. The months have passed very quickly but not without significant achievement.

In October, Emilio Perucca and I, as co-chairs of the Global Campaign Against Epilepsy, attended an important meeting at the WHO headquarters in Geneva. This was the mhGAP Forum at which the WHO Director-General launched the Mental Health Action Plan 2013-2020. At the same time, we had the opportunity to meet again with Tarun Dua and to discuss our future three-way collaboration. We are confident that the collaboration of the three Global Campaign partners will continue to develop in a most positive way.

At regional level, IBE was represented at three annual meetings of WHO Regional Committees and interesting reports are included in this issue. I would like to thank Michael Alexa (Europe), Man Mohan Mehndiratta (South East Asia) and Robert Cole (Western Pacific) for taking time from their busy schedules to attend their relevant regional meeting. For the 13th year, our friends in the Latin American region celebrated Latin American Epilepsy Day. Congratulations to all those who have marked the day every year since the year 2000.

Travel has also been to the fore over the last six months. I was delighted to speak at the training programme organised by SEIN, an IBE Associate Member in the Netherlands. This programme, supported by the WHO and by the pharmaceutical industry, brings students from less developed countries to

Happy New Year!

spend three weeks in Heemstede broadening their epilepsy knowledge. In November I travelled to Kazakhstan together with the ILAE President, on an invitation to participate in their epilepsy conference with several international speakers. I was delighted to meet the people involved and to visit the office of one of IBE's newest Full Members. Ann Little represented IBE at a meeting in the Lithuanian Parliament in Vilnius, on the invitation of LESIA, our Associate Member in Lithuania.

The Joint Task Force – Epilepsy Advocacy Europe – has also been busy. Its plans include European Epilepsy Day 2014; finalisation of its Strategic Plan, matched by a Business Plan prepared as a pro bono by the accountancy firm, BDO Consulting; and a session at the 11th European Congress on Epileptology in Stockholm in June.

We recently welcomed our latest new Full Member - Turkish Association for People with Epilepsy and their Carers. We continue to communicate with a number of other associations and look forward to welcoming more new members in 2014.

Next year will be busy with three regional congresses taking place. I hope to meet some of you at the meetings in Cape Town, Singapore or Buenos Aires. You will find the dates of these meetings on the back cover of the newsletter and you will also be receiving regular updates from the congress office.

European Epilepsy Day will take place on 10th February throughout Europe and in the European Parliament on 5th February. Latin American Epilepsy Day will again be celebrated in September and our colleagues in China will celebrate China International Epilepsy Day in June.

For now, I will take this opportunity to wish you all a Happy New Year!

With best wishes to all,

Athanasios Covanis
President



International Epilepsy News
Issue 3 - 2013

EDITORIAL TEAM

Editor and Coordinator: Ann Little
Email: ibedublin@eircom.net

Regional Sub Editors:

- ⊙ Youssouf Noormamode (Africa)
- ⊙ Chahnez Triki (East Mediterranean)
- ⊙ Anastasia Vassou (Europe)
- ⊙ Tomás Mesa (Latin America)
- ⊙ Mary Secco (North America)
- ⊙ P Satishchandra (South East Asia)
- ⊙ Denise Chapman (Western Pacific)

Advisors:

- ⊙ Athanasios Covanis
- ⊙ Sari Tervonen
- ⊙ Mike Glynn
- ⊙ Ding Ding
- ⊙ Philip Gattone
- ⊙ Najib Kissani
- ⊙ MM Mehndiratta
- ⊙ Janet Mifsud
- ⊙ Lilia Núñez-Orozco
- ⊙ Anthony Zimba
- ⊙ Emilio Perucca
- ⊙ Helen Cross
- ⊙ Sam Wiebe

INTERNATIONAL RELATIONS AND PARTNERSHIPS

WHO

IBE is in official relations with the World Health Organisation (WHO).

ECOSOC

IBE enjoys Special Consultative Status on the Economic and Social Council of the United Nations (ECOSOC).

CoNGO

IBE is a member of The Conference of NGOs in Consultative Relationship with the United Nations CoNGO.

EFNA

IBE is a member of the European Federation of Neurological Associations (EFNA).

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In this issue

Dear Readers



Welcome to another news-packed magazine, which I hope you will enjoy. It brings you stories and reports from across the globe.

From Africa there is an interesting report from Gallo Diop on the Epilepsy Caravans Projects, which is bringing epilepsy care to people living in remote districts of the country. In Mongolia, too, there

are ongoing quality of life workshops reaching out to those at a distance from Ulaanbaatar.

In the European Region, you can read about a workshop in the Lithuanian Parliament to alert politicians on the urgent need for improved services and appropriate legislation to support people with epilepsy. Still in Europe, a new epilepsy centre has opened in Scotland, there is a story about a gentle Irish giant, and the Joint Task Force - Epilepsy Advocacy Europe has been very busy.

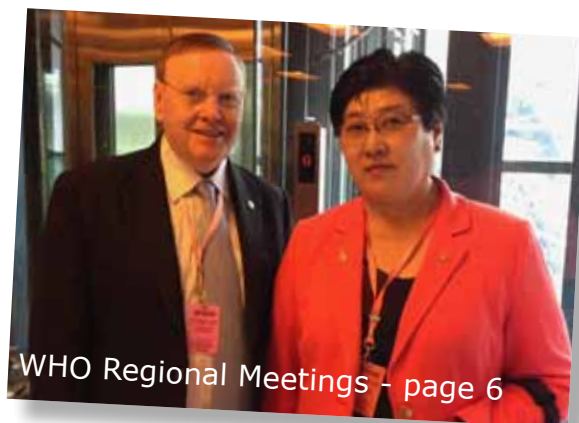
Latin America celebrated its annual Epilepsy Day in September and I thank Tomás Mesa for preparing a report on how this event was marked in Chile and in other countries in the region.

Also on a global perspective, there are reports on the WHO Regional Committee meetings in Europe, Western Pacific and South East Asia regions at which IBE was represented.

Finally, as we near the end of the year, I would like to send you all New Year greetings for 2014!

I wish you happy reading.

Ann Little
Editor



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MONGOLIA - page 14



SENEGAL EPILEPSY CARAVANS
page 4



Latin American Epilepsy Day
page 12

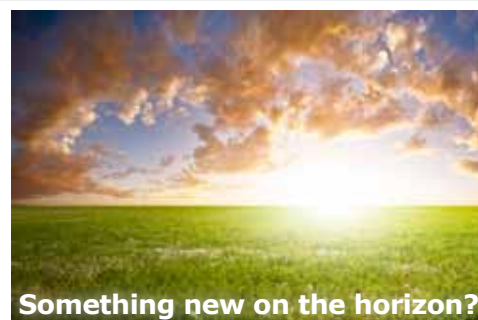
Coming in the next issue



Promising Strategies 2014



European Epilepsy Day 2014



Something new on the horizon?

CARAVANS FOR EPILEPSY

Reaching populations in developing countries

Report by Amadou Gallo Diop, MD, PhD, Department of Neurology, University Hospital of Fann, Dakar, Senegal

- Worldwide 50 million people live with active epilepsy
- 100 million people will experience one seizure in their lifetime
- More than 80% of people with epilepsy live in tropical areas (of this figure, around 10 million live in Africa).
- More than 80% are treated inadequately and/or are inadequately followed up.

INTRODUCTION

Many publications emphasize the insufficiency of health personnel in developing countries, especially in Africa, and, in particular, specialized professionals. There is a huge deficiency in neurology staff.

These last decades, a constant rise in the incidence of non-communicable diseases has been reported, while infectious diseases still remain a major public health problem in Africa, South East Asia and South America. The evolution of the pyramid of ages leads to a progressive rise in the number of people aged up to 65 years.

The large majority of Ministries of Health do not have, as yet, a clear-cut and visible policy for prevention and management of chronic disorders, including diabetes, hypertension, ischemic heart disease, obesity, stroke, cancers, respiratory diseases, epilepsy, dementia, Parkinson disease and other neurological conditions.

So, after years of various efforts to ameliorate accessibility of care for populations

An African person with epilepsy is more likely to receive treatment if:

- they have high income
- they have a high level of education
- they live in an urban area
- they suffered from status epilepticus, encephalitis, or a cranial trauma with loss of consciousness



Above: The 'Caravan' gathers in preparation for the journey to a remote region

Below: Reaching the destination can require hazardous travel



residing far from capital cities and who face great difficulties when they are sick, we created the initiative of "Neuro-caravans" as a possible contributive solution.

BACKGROUND

In 2003, Senegal was chosen as a site for the 1st Demonstration Project set up by the ILAE/IBE/WHO Global Campaign Against Epilepsy.

Different surveys related to epilepsy were conducted (from 2002 to 2005) in the Pikine suburban area of Dakar:

- KAP (knowledge, application and

practice) of health professionals and the general population

- Quality of health services and facilities
- Availability of AEDS and prevalence of the disease

Following this, new initiatives were set up:

- A weekly consultation for people with epilepsy residing in this area, conducted by a specialist who travels to the area each Wednesday;
- Since 2005, a nationwide public health action called 'Caravans for Epilepsy'.



MAIN AVAILABLE DRUGS:

1. Phenobarbital
2. Phenytoin
3. Benzodiazepines
4. Carbamazepine
5. Sodium Valproate

Annual cost ranges from US\$15 to US\$500

PREPARATION

Three months before departure, a member of our team, accompanied by a delegate of the supporting pharmaceutical company (Sanofi), visits the region's administrative, medical and media managers. The date, the organization and the program are discussed and potential venues for training and consultation are visited and evaluated.

ORGANISATION

A team composed of between 12 and 15 people leaves Dakar on Thursday and travels to the capital city of the province being visited. After installing the team, members of the socio-education commission meet with local media, while the rest of the team prepares the sites already selected for training and consultation.

ACTIVITIES

Friday is scheduled for the training session. Weeks before, all Medical Officers and Nurses in the province are informed and invited to travel to the main city for training on different aspects of epilepsy: physiopathology, epidemiology, semiology (including video) of seizures, and management of epilepsy. After each lecture, we have a Question & Answer session.

During this time, some members of the Senegalese League Against Epilepsy meet with primary school teachers and women's associations to educate and sensitize them on epilepsy, its etiologies, life hygiene, social aspects and the support needed by people with epilepsy and their families.

Saturday is reserved for consultations. Pa-

tients come from districts of the province, most having been previously selected by health staff. Many of these patients are seeking modern medical treatment for the very first time. A selected number will have an EEG carried out using a portable machine transported from Dakar.

At the end of each 'Caravans for Epilepsy' journey, it is time for those involved to return to Dakar to start preparing for the following journey.

RESULTS

Between March 2005 and March 2012, we organised 14 "Caravans for Epilepsy" in 12 cities. Two thousand, three hundred and twelve (2,312) patients have had a consultation. Of these, 1,307 (57%) were found to have epilepsy.

One hundred and seventy five (175) doctors and 131 nurses have been trained on the diagnosis and management of seizures/epilepsy.

The number of people suffering from neurological conditions is due to the fact that visits by professionals from the capital city are a unique opportunity to meet specialists. Those who have a neurological condition are accepted and seen. The initiative is becoming so successful that we have had to move from the concept of 'Caravans for Epilepsy' to the concept of 'Neuro-Caravans' by including training topics on stroke prevention and management. During the Question & Answer sessions, questions are also raised about other diseases.

CHARLIE - THE GENTLE GIANT

They are known as the gentle giants of the canine world – but one Great Dane has taken that to a whole new level. An Irish family has come to rely on the family pet, Charlie, who has the ability to alert them when their three-year-old daughter is about to have a seizure.

Brianna Lynch suffers from four different types of seizures, most of which tend to happen at night, explained her mother Arabella.

Twenty minutes before the start of an episode, Charlie can detect that she is about to have a seizure and will hold the child gently to the wall, not leaving her until someone comes to her assistance.

Brianna has had to be hospitalised twice for resuscitation after she stopped breathing and went blue.

"She is quite a complex child; she forgets to breathe and then goes into a seizure. She

has gone through eight different types of medicine and it now looks like she needs brain surgery," said Arabella.

The family has learnt to live with Brianna's condition and is watchful 24-hours a day – however, Charlie has become the real lifeline.

"We know that, when Charlie is acting strange, Brianna is going to have a seizure," Arabella added.

And his gentle protectiveness does not stop at detecting seizures. Charlie also takes care of Brianna when other dogs get boisterous and stands by her side to ensure she doesn't get knocked over.

Arabella describes the dog's sixth sense without any training as "amazing". Of course there are specially trained 'seizure alert dogs', however, Charlie just picked up the skills all on his own. Exactly how dogs can sense that a seizure is about to



occur remains a mystery – however, there are theories.

One is that there may be micro expressions or cues that a dog can pick up which precede a seizure, or a particular scent generated which a dog can be sensitive to.

Or it may be that the dog can sense disturbances in the electric field that are caused by a seizure.

IBE was represented recently at the annual WHO Regional Committee sessions in Europe, South East Asia and Western Pacific. Michael Alexa, Robert Cole and Man Mohan Mehndiratta bring you their reports

66th Session of the WHO Regional Committee for **SOUTH EAST ASIA**

New Delhi, India - 10-13 September 2013

Dr Man Mohan Mehndiratta, IBE Vice President South East Asia reports



In his welcome address, Dr Samlee Pli-anbangchang, Regional Director WHO South East Asia Region, warmly welcomed delegates and thanked His Excellency Mr Pranab Mukherjee, President of India, for his attendance. Dr Salmee also extended a warm welcome to WHO Director General, Dr Margaret Chan.

Dr Nafsiah Mboi, Minister of Health, Indonesia, and Chairperson of the 30th Meeting of Health Ministers, reported that the Yogyakarta Declaration on Ageing and Health had been finalized in May, 2013. She called on health ministers to lay a firm foundation for the future to ensure that equitable, affordable and accessible treatment, care and support became a fundamental component of responsible health-care systems in order to raise the quality of

life of the people of the Region.

Dr Margaret Chan thanked the Government of India, especially His Excellency Mr Ghulam Nabi Azad, Minister of Health and Family Welfare, for hosting the 31st Health Ministers Meeting. The Director General observed that consultations on the place of health in the post-2015

development agenda had been moving forward, and the high-level panel of eminent persons had delivered its report in June 2013. The report's key message was a call to end absolute poverty in the context of sustainable development by 2030. It also proposed 12 global goals, of which goal four was to "ensure healthy lives". She noted the report had stated that achieving goal four "requires universal access to basic health care". Dr Chan said that the debate would continue as Members States negotiated and eventually agreed on the best agenda for sustainable development in the years to come.

Mr Ghulam Nabi Azad thanked WHO for its strong support in India's journey to achieve polio-free status. He said that the key factors for success were strong political will and leadership at the highest levels of government and WHO's technical guidance, financial resources and technological innovations as well as the dedicated efforts of more than 2 million volunteers, partners, and health workers across the country. The Minister added that India produced high-quality and affordable generic drugs that had dramatically reducing the cost of HIV/AIDS treatment. He concluded with a call to Member States of the Region to join hands in developing

and sharing initiatives and technologies to achieve the common goal of providing affordable and accessible health care to the people of the region.

Mr Pranab Mukherjee, President of India, inaugurated the 31st Meeting of Ministers of Health and the 66th Session of the WHO Regional Committee for South East Asia. He noted that although the countries of WHO South-East Asia Region represented a quarter of the global population, the per capita total expenditure on health was the lowest. To achieve universal health coverage it will be necessary to strengthen the primary health care systems through prevention and promotion activities and by optimal utilization of scarce resources. Commending the efforts of Members States in the Region in achieving a number of millennium Development Goals, he stressed the need to define health priorities for the global development agenda beyond 2015.

The President noted that the ministers would consider strategies for further improving public health care and services in the Region, evaluate national experiences, share best practices and set a road map for cooperation in the areas identified.

The meeting was attended by 11 Health Ministers from South East Asia, together with their advisors, and a large number of representatives from non-governmental organizations similar to IBE.

The principal themes of meeting were -

- Elimination of measles and rubella control
- Pandemic influenza preparedness framework
- Progress report on malaria
- Challenges in polio eradication
- A framework for increasing and sustaining immunization coverage

There was also stress on non-communicable diseases and prevention of natural and environmental calamities.



63RD SESSION OF THE WHO REGIONAL COMMITTEE FOR EUROPE Çeşme Izmir, Turkey

Michael Alexa, Vice Chair, IBE Regional Executive Committee Europe

As Janet Mifsud, IBE Vice President Europe, had other commitments and was unable to attend, I had the honour to represent IBE at the annual meeting of the WHO Regional Committee for Europe, in October. These meetings provide a very important opportunity for IBE to network with other NGOs and associations and the meeting in Çeşme was no exception. The first connections were already being made as the shuttle bus took a number of us from the airport in Izmir to the meeting hotel, an hour's drive away in the sea-side town of Çeşme.

Before the official start of the meeting, the NGO representatives attending were given an outline on the structure of the meeting and, more importantly, on the official, and very formal, procedures that we were required to follow. I learned that I was only allowed to speak in the conference when the written statement, which had been submitted by the IBE to WHO, was on the agenda. For the rest of the time I was required to listen to the discussions of the member country health ministers on each of the agenda items. However, one bonus was that I was able to record the written statement so that it would be available on the WHO website.

The evening ended with a reception, hosted by the Turkish Health Minister. The meeting hall was laid out with the health ministers seated in U-shape formation, with their deputies and assistants forming a second row behind them. Each speech and all requests to speak were simultaneously translated into the WHO Europe region official languages: English,

German, French and Russian. There was also translation to Turkish. Papers were available in English and Russian and sometimes in the other official languages also.

I was seated beside two very interesting women, one from the International Nurses Federation, the other from the Turkish Nurses Federation. This was a good opportunity to network and to introduce IBE.

There was also a five member delegation from the International Federation of Medical Students Association. Some of these may well be the neurologists of tomorrow!

An important issue on the agenda, and which was handled during the technical briefings, was WHO budget reform. In the past, WHO was donor driven. In addition the Secretariat budget did not require the approval of the World Health Assembly (WHA). This has now changed and approval is now required.

Targets are also a new introduction to budget procedures. Any changes to the targets set by the WHA for the Secretariat must be approved by the WHA.

Until now there were two funding sources - assessed contributions from member states and voluntary contributions from donors. These have now been merged into one budget, rather than being maintained as separate, and the new single budget must be approved by the WHA. The impact of this is that WHO will no longer be donor driven, but state driven. The role of the WHA is now very significant.

During the first two days, no NGO had the opportunity to speak. With some ministers making long speeches, the time allotted for NGOs ran out - indeed, from the first day the conference was already running behind schedule! Fortunately the problem was recognised and, on the Tuesday evening, before the closing session, it was announced that the Regional Director

of WHO, Mrs Zsuzsanna Jakab, would spend some of her spare time on Wednesday morning talking to the NGOs on how the partnership could be improved.

Mrs Jakab, who is from Hungary, arrived accompanied by the new meeting president, Dr Daniel Reynders, from Malta. The Turkish Health Minister was represented by the Secretary of the meeting Mrs Dagmar Reitenbach, from Germany, and a member of the board Dr Busuttil, from Malta. All four stated that they were pleased that so many NGOs were present and that they would like to have a statement on what the NGOs would like to see done in order to be able to respond to their requests.

I made the proposal that we could use the time on Wednesday afternoon, when a private meeting was taking place to discuss some internal matters, to talk about the possibilities of future collaboration between WHO and NGOs. The WHO Europe board was happy that this proposal came from the NGOs themselves and a drafted statement was agreed.

There was a reception each evening, providing a great opportunity to make new connections. I made many new contacts, especially with the Spanish delegation who were housed in the same hotel as me.

It was very worthwhile to attend the meeting and, in her last speech, Mrs Zsuzsanna Jakab, Regional Director of WHO Europe, mentioned the NGOs three times and the collaboration between civil society and the WHO twice. She also said, in response to the statement drafted by the NGOs, which was read to all the ministers present on Thursday afternoon before the end of the conference, that WHO will have to think about new ways to intensify collaboration between WHO and NGOs.

But that's another story ...

EPILEPSY STRATEGY FOR THE WESTERN PACIFIC

64th Session of the WHO Regional Committee for the Western Pacific Congress
Manila, Philippines October 2013



The 64th Session of the World Health Organisation Regional Committee for the Western Pacific Region was held in Manila, October 2013.

International Bureau for Epilepsy Treasurer, Robert Cole attended the meeting and called for an Epilepsy Strategy for the Western Pacific Region.



Statement by the International Bureau for Epilepsy, Western Pacific Region: Sixty-fourth Session of the WHO Regional Committee for the Western Pacific Region, Manila, Philippines, 21-25 October 2013.

Epilepsy is one of the world's most common chronic neurological disorders with approximately 50 million people diagnosed worldwide. The prevalence rate is between 0.5% and 1%, which means that up to one in every hundred people has epilepsy¹. Epilepsy is more prevalent than most other conditions, and most people living with epilepsy choose to hide it because of the associated stigma. In the Western Pacific Region there are approximately 17 million people living with epilepsy.

It is important to note that, while medical advances have improved the understanding and management of epilepsy (70% of people with epilepsy are seizure-free with appropriate treatment), 70% of people with epilepsy in the Western Pacific Region still do not receive such treatment. In addition, they experience high levels of unemployment and are exposed to stigma and prejudice, with huge physical, psychological and social burdens imposed on them and their families.

This is the right time for the WHO Regional Committee for the Western Pacific to make epilepsy a priority. Epilepsy has already been selected as a priority in other WHO regions such as the Region of the Americas² in 2011. The Global Campaign Against Epilepsy "Out of the Shadows", which is a three-way partnership of WHO, the International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) has undertaken activities in the Western Pacific Region and in Africa for the past fifteen years. Moreover, in September 2011, the European Parliament, with an overwhelming majority of Members of the European Parliament in favour, approved the Written Declaration on Epilepsy³. In North America, a pivotal report on epilepsy "Epilepsy across the Spectrum" was published by the Institute of Medicines of the National Academies (IOM) in early 2013.

The International Bureau for Epilepsy, Western Pacific Region, calls for the WHO Regional Committee for the Western Pacific to agree to the preparation of a strategic plan for epilepsy. This plan will prioritize an integrated response to promote:

- prevention of epilepsy
- treatment of epilepsy
- research on epilepsy

This plan can only be executed by facilitating and promoting technical cooperation among WHO Western Pacific Member States, and partnerships with key stakeholders and NGOs, in order to formulate the best response possible for the implementation of this strategy.

The time has come to develop sustainable capacity for epilepsy care and support throughout the Western Pacific community. Epilepsy is a highly complex condition and requires both medical and non-medical management.

The psychosocial, educational and economic impacts outweigh the clinical symptoms, creating particular challenges for the delivery of social, community and health services. Building on principles of social inclusion, we urge the WHO Regional Committee for the Western Pacific to foster realistic, creative strategies to ensure that those affected receive equitable care and access to services throughout our Region.

References: 1. Eric Healy, 2. Resolution CD50.R8, 3. EU Written Declaration on Epilepsy 22/2011



*Excerpt from the main address by
Dr Shin Young-soo,
WHO Regional Director
for the Western Pacific,
21st October, Manila*

"In many ways, this is a special year. It is the fifth time I have come before you to talk about WHO's work in the Region.

With my nomination, we have had the opportunity to reflect not only on our shared accomplishments over the past five years, but also on unfinished business and new challenges going forward.

The global public health landscape is changing, perhaps nowhere more rapidly than in this Region. We deal with everything from rapid ageing and urbanization to the consequences of environmental degradation, including climate change.

With these dynamic trends and emerging challenges, the important question for me is: How can I best spend the next five years as Regional Director?

Of course, important technical priorities will be decided in consultation with Member

States and by this Regional Committee.

Based on my experiences over the past five years, however, I have identified **5** principles to guide my work and that of the Secretariat over the next five years.

First: we must be people-centred and country-needs oriented.

Member States are our clients. Their needs always come first.

Second: we should build on successes and tackle emerging challenges while continuing to address unfinished business. Now is no time for complacency.

Third: we must be flexible and adaptable. We have to be ready for the health consequences of emerging challenges in the Region.

Fourth: we have to continue to break down boundaries and engage all actors in health and beyond health. In particular, we must strengthen our convening role to include all sectors.

My **fifth** and final key principle is based on self-analysis: We at WHO must be more effective managers — of both financial and human resources. As the world's leading

health authority, we have to provide value for money at every level of engagement.

Our work will focus on enabling areas — that is, finding better ways to deliver WHO support — and technical priorities.

Many of these priorities are set already by Member States, including universal health coverage, NCDs, ageing and health in the post-2015 development agenda, to name a few.

Our work will continue on the important issues in communicable diseases, antimicrobial resistance, artemisinin resistance, hepatitis B, TB, measles and malaria — as well as our push to fulfil MDGs 4 and 5 and International Health Regulations core capacities.

The opportunity to serve another five years will provide the continuity and commitment necessary to achieve these goals, and to stand ready to address new challenges. I am - and always will be - your advocate.

In closing, I want to stress how grateful I am for the opportunity I have had to work with you over the past five years. Without a doubt, this is the most challenging job I have ever had. But the challenges are worth facing. Indeed, we are all very proud of what we have accomplished together. And with your support and guidance — and that of my staff and colleagues throughout WHO — I am confident we can accomplish even more during a second term.

I am eager to spend five more years taking on the Region's health challenges — and bringing us even closer to attainment of the highest possible health for ALL the 1.8 billion people of the Western Pacific Region.
Thank you."



Left: Robert Cole at the WHO offices in Manila, where the annual session took place.

Above: Robert Cole with newly elected Vice-chairperson, World Health Organisation Regional Committee for the Western Pacific, Dr Natsag Udval, Minister of Health, Ulaanbaatar, Mongolia

A VISIT TO VILNIUS

Report: Ann Little,
IBE Executive Director



Main photo: Gediminas' Tower, the original of which dates back to the 15th century. The white building is the recently renovated Royal Palace of Lithuania.

Above left: Hanneke de Boer, Danutė Murauskaitė and Ann Little discuss the LESIA Integrated Programme plan in the association's offices.

Above right: Danutė Murauskaitė, Hanneke de Boer, Ann Little and Inga Palauskienė

LESIA - Lithuanian Association for the Integration of People with Epilepsy - was created in 2001 and is an Associate Member of IBE since 2007. The association is a federation of seven regional branches located around the country. The President of the Association is Dr Danutė Murauskaitė, a doctor of science and mother of an adult daughter with epilepsy.

LESIA operates from an office close to the city centre of Vilnius and staff members include Inga Palauskienė, who has a degree in special education and works as head of Vilnius Society of People with Epilepsy (Vilnius branch of LESIA); and Aiste, who supports Danutė in the day to day running of LESIA. Mr Juozas Vytas Jacevičius, a lawyer, is also very supportive of the association, providing support and information on a voluntary basis.

With a population of three million, it is estimated that there are 24,000 people with epilepsy in Lithuania. LESIA has

been working on an extremely ambitious plan since 2002, looking at a systematic approach to solving the problems of people with epilepsy in Lithuania. The association is hoping that the government will support 'an integrated health and rehabilitation services network model'. The aim is to ensure decentralisation of services so that people with epilepsy can avail of the support services they need closer to where they live and with improved service quality.

Lithuania has 376 neurologists but their geographical distribution within the country is uneven. The largest number of neurologists and people with epilepsy are concentrated in two of the main cities of Lithuania. In Vilnius and Kaunas there are just 40 persons with epilepsy for each neurologist, while in other areas of the country there are too few neurologists for the population they serve. There are no epileptologists in Lithuania.

LESIA would like to see the government

adopt the plan within the government programme for the period 2014-2018, requiring the government to do the following:

1. Improve and develop continuing professional development programmes for neurologists, GPs and nurses;
2. Improve EEG training for neurologists;
3. Train neuropsychologists for tertiary care university hospitals;
4. Include psychologists in healthcare teams providing services to people with epilepsy;
5. Develop an algorithm for medical rehabilitation and also create and validate procedures (descriptions) for organising work in all the stages of healthcare;
6. Develop close cooperation between healthcare institutions at all levels and NGOs providing social rehabilitation for people with epilepsy;



Among the participants at the Meeting in the Parliament were, from left: Juozas Vytas Jacevičius, a lawyer who provides information and support to LESIA; Jonas Bartlingas, Acting Director, Personal Health Care Department at the Ministry of Health; Genovaitė Paliušienė, Director of Department for Disability at the Ministry of Social and Labour; Ann Little, IBE Executive Director; Saulius Ročka, Manager, Neurovascular Surgery Center; Hanneke de Boer, SEIN, Netherlands; Arvydas Gabrilavičius, Head of General Medical Care Division at the Ministry of Health; Dangutė Mikutienė, Chair, Committee on Health Affairs; Danutė Murauskaitė, President, LESIA; Regina Labiniene, Non-Formal Education and Education Support Division at the Ministry of Education and Science.

7. Develop a database of all healthcare and rehabilitation services received by people with epilepsy living in the country.

The plan was first submitted to the relevant government departments - SAM and SADM - in 2004, but the response was disappointing. However Danutė and her association were determined to carry on with their efforts. Work continued on the programme and IBE support was provided through the Promising Strategy Programme in 2012 to help progress the work.

In September, I was invited to travel to Vilnius to represent IBE and to speak about the EU Written Declaration, the European Advocates for Epilepsy special interest group of Members of the European Parliament (MEPs), and the success of European Epilepsy Day. Hanneke de Boer, representing SEIN in the Netherlands, was also invited to speak at the meeting on the Global Campaign legislation project. This was a very opportune time, with Lithuania holding the Presidency of the European Union for the second half of 2013.

The two and a half hour meeting was chaired by Mrs Dangutė Mikutienė, who is Chair of the Committee on Health Affairs, Parliament of the Republic of Lithuania. Representatives from a number of government departments were also

present. At the meeting Danutė also spoke about the plan she has been trying to have adopted for over ten years.

In presenting the work of IBE, I outlined the importance of combining the efforts of IBE and ILAE to work together on joint initiatives. I also highlighted the importance of presenting a united voice when sending out messages about epilepsy and outlined the background to the Global Campaign and its relevance as a three-way partnership of ILAE, IBE and WHO.

Hanneke de Boer spoke about the survey that had been carried out under the banner of the Global Campaign to establish what kind of legislation already existed to safeguard the rights of people with epilepsy and how a document on how to go about drafting legislation had been crafted.

Regina Labiniene, from the Non-Formal Education and Education Support Division, Ministry of Education and Science, told of phone calls she receives from mothers looking for disability provisions for their children with epilepsy but who want to keep their children's condition hidden. The stigma connected to epilepsy is still a huge problem in Lithuania. Much of this problem has its roots back to the time Lithuania was part of the Soviet Union and when people with epilepsy were treated as psychiatric patients.

It was clear that the government recognises the need for improved services but the funds available are very limited; Lithuania has been independent from the Soviet Union for a little over 20 years and is still in the process of developing new services. It is one of the less well-off countries in the EU with very high unemployment figures and very low wages.

The meeting in the parliament went very well and, it was astonishing that so many government representatives attended given how busy the parliament was with EU Presidency events. Those who attended were aware of the need to improve services and noted the case made by LESIA. It was obvious that the presence of IBE, as an international body for people with epilepsy, was recognised and appreciated.

Apart from the meeting in the parliament, it was also very worthwhile to be able to visit the association's office and to discuss all of their other activities. LESIA is making great strides in the services it provides for people with epilepsy and their families, thanks to the determination and hard work of Danutė and the conscientious support of Inga, Aiste and Juozas. They made Hanneke de Boer and me most welcome and looked after us extremely well during our time in their city.



Latin American Epilepsy Day Día Latinoamericano de la Epilepsia

Report by Tomás Mesa, Chair, IBE Latin American Regional Executive Committee

Latin American Epilepsy Day is the oldest of the regional days promoting awareness and understanding about epilepsy. It was officially launched at the 1st Latin American Epilepsy Congress, in Santiago de Chile in 2000. Since then it has been celebrated annually on this date. Thirteen years later, it is now embraced by epilepsy associations throughout the Latin American Region.

CHILE

It is probably no surprise that the biggest celebrant of Latin American Day - Día Latinoamericano de la Epilepsia - is the Chilean League against Epilepsy and this year they pulled out all the stops (quite literally as you can see in the photo above) to bring public attention to the event. To celebrate a week of epilepsy awareness, a number of activities were arranged by the

CHILE

Para conmemorar la semana de la epilepsia, la Liga realizó diversas actividades orientadas a fortalecer la relación con los pacientes y sus familias, entre ellas, la visita por parte del Voluntariado de la Institución a niños internados en el Hospital de Neurocirugía; Un concurso de cuentos y dibujos, el cual buscó fomentar la creatividad en los participantes y exponer distintos puntos de

First meeting of epilepsy surgery patients



Chilean League to strengthen the relationship between people with epilepsy and their families. For instance through the Volunteers group, visits were made to children in the Neurosurgery Institute. The young people were encouraged to show their views on epilepsy through a range of creative activities, including art and a literature contest.

On September 25th, there was an official ceremony to launch Latin American Epilepsy Day, with the President of the Chilean League against Epilepsy, Dr. Tomás Mesa, explaining the relevance of epilepsy day and the achievement attained by the League in its 60-year history.

Participants included Dr Javier Uribe, PAHO representative; Dr María Cristina Escobar, Chief of the Non-transmissible Diseases Department; and Dr Lilian Cuadra, who has charge of the National Program of Epilepsy in the Ministry of Health.

On September 29th, a first meeting of patients who had undergone epilepsy surgery was organised through the epilepsy surgery program. The meeting was attended by 29 such patients.

A major event was a Bikeathon, which also took place on Sunday 29th and attracted about 600 participants. This was the first bike event in Santiago de Chile to be organised for a good cause: epilepsy. The initiative's aim was to show that most people who have epilepsy can live a normal active life; that the real problems still existing for people with epilepsy were stigma and discrimination.

COLOMBIA

Latin American Epilepsy Day was celebrated in Colombia with an art exhibition and a speech given by the President of the Rehabilitation Institute for People with Epilepsy (FIRE), Dr Jaime Fandiño. National awards for Young Researchers were presented by Mrs Margaret Mertz de Fandiño of the National Award Foundation.

GUATEMALA

The Epilepsy Day of the fight against epilepsy was celebrated on September 8th in the "obelisco", located in the city of Guatemala. Medical students at the University Rafael Landívar and neurologists from San Juan de Dios Hospital were in charge of organizing the event, together with Dr Henry Stokes. A number of volunteers also attended and collaborated. At the start of the event Dr Stokes gave a lecture on some of the basic concepts of epilepsy.

At the end of September, Dr Stokes together with psychologist Elizabeth Stokes attended the First National Seminar of Epilepsy. Dr Stokes was appointed to be in charge of international relationships of the ILAE Guatemala Chapter.

HONDURAS

The Honduras Foundation of Epilepsy celebrated Latin American Epilepsy Day on September 9th in Tegucigalpa, with the attendance of more than 200 people, as well as the media. The foundation took the opportunity to arrange a commission to review the new National Law of Epilepsy in Honduras.



Left to right: Mrs Luz Madrid, President of the Volunteers of the Chilean League against Epilepsy (LICHE); Dr Lilian Cuadra, Chief, Program of Epilepsy in the Ministry of Health (MINSAL); Dr Jorge Förster, Vicepresident LICHE, Dr María Cristina Escobar, Chief of Non-communicable Diseases MINSAL, Dr Javier Uribe, PAHO Representative, Mrs Nora Signé, Vicepresident of the Volunteers LICHE; Dr Tomás Mesa, President LICHE, Dr Keryma Acevedo, Director LICHE.

vista en torno a la epilepsia a través del arte y la literatura; El 25 de septiembre se llevó a cabo la celebración del Día Latinoamericano de la Epilepsia, en una ceremonia en la cual el Presidente de la Institución, Dr Tomás Mesa, se refirió a la importancia del día de la epilepsia y a los logros alcanzados por la Liga en sus 60 años de historia. Asistieron el Dr Javier Uribe, representante de la OPS;

la Dra María Cristina Escobar, Jefa Departamento Enfermedades No Transmisibles; y la Dra Lilian Cuadra, Encargada Programa Nacional de Epilepsia Ministerio de Salud.

El 29 de septiembre se llevó a cabo el 1er Encuentro de Pacientes Operados del programa de la Liga, de cirugía de epilepsia, programa que contabiliza 29 pacientes operados.

Ciclotada: con una masiva concurrencia, se realizó el domingo 29 de septiembre la primera ciclotada familiar por la epilepsia. La iniciativa tuvo como objetivo demostrar que, quienes tienen esta condición, pueden hacer una vida normal, así como evidenciar el estigma y la discriminación que aún viven quienes la padecen. Asistieron alrededor de 600 personas.

COLOMBIA

El Día Latinoamericano de la Epilepsia se celebró con una exposición de obras manuales y una conferencia por parte del Presidente del Instituto de Rehabilitación para personas con epilepsia, Dr Jaime Fandiño. En aquella ocasión, se entregó el Premio Nacional de Epilepsia, que otorga la Fundación Premio Nacional de Epilepsia Margaret Merz de Fandiño, para investigadores jóvenes.

GUATEMALA

El Día internacional de lucha contra la epilepsia fue llevado a cabo el 8 de septiembre en el obelisco, ubicado en la ciudad de Guatemala. La organización estuvo a cargo de alumnos practicantes de la Universidad Rafael Landívar y médicos de neurología del Hospital San Juan de Dios, junto con la colaboración del Dr Henry Stokes y de voluntarios. Al inicio del evento el Dr Stokes llevó a cabo una conferencia introductora, la cual tuvo como objetivo brindar conceptos básicos de la epilepsia a los participantes.

A fines de septiembre, el Dr Stokes, junto a la psicóloga Elizabeth Stokes, participaron del Primer Seminario Nacional por la Epilepsia. El Dr Stokes es nombrado como encargado de las relaciones internacionales del Capítulo de Guatemala de la ILAE.

HONDURAS

El día 9 de septiembre se celebró en Tegucigalpa el día Latinoamericano de la Epilepsia, bajo la dirección del Capítulo del IBE de Honduras (Fundación Hondureña de Epilepsia) con la asistencia de más de 200 personas, así como medios de prensa. En aquella ocasión se conformó una comisión de dictamen del Congreso para la nueva Ley Nacional de epilepsia de Honduras.



Improving Quality of Life in Mongolia

Dr Tovuudorj, Mongolian Epilepsy Association, reports on a successful program, supported by the IBE Promising Strategies Program and IBE's Regional Executive Committee Western Pacific

The Mongolian Epilepsy Association, through its “Quality of Life” program for improving health education on epilepsy in the general population, has organized several training seminars in Bayanzurkh district of Ulaanbaatar, Dundgovi Aimag and Zamyn Uud county of Dornogovi Aimag during 2013.

The main objective of this training was to give to patients with epilepsy, their families, friends, and others concerned, a general understanding about epilepsy, primary knowledge on diagnosis and treatment, and to encourage people with epilepsy to talk about their experiences.

A video showing people with epilepsy in other countries was used for learning purposes and to introduce international organizations working in the epilepsy field.

Additionally, we introduced them to the policies and measures taken by the Ministry of Health with regard to people with epilepsy; listened to the opinions and ideas

of patients and their family members; and discussed and exchanged ideas on future activities and issues to be included in Government policies and decisions.

After each training session, we hold individual meetings for people with epilepsy and their family members and give consultations on diagnosis and treatment.

The following day training is aimed at doctors and medical staff, in which are involved family doctors, neurologists, pediatricians, psychologists, nurses, hospital managers and social workers.

During this training, we strive to provide more detailed information on diagnosis and treatment of epilepsy, consult on how to make diagnosis, on prevention control and on the importance of continued treatment of epilepsy. Finally we have discussions and listen to the opinions of those present on how epilepsy is taken care of in rural areas and on ideas for improving treatment and care.

Training Outcomes

For participants and rural people:

1. The local people are very supportive of the “Quality of Life” program and are very happy to participate;
2. People with epilepsy and their family members have the opportunity to meet together and exchange their opinions and life experiences;
3. Local hospital managers and doctors learn how to continue with training after the seminar has ended;
4. People with epilepsy, their family members and the general public get the opportunity to convey their opinions to local authorities and hospital management and to provide them with an understanding of social issues that they face;
5. Rural dwellers who cannot afford to go to the Ulaanbaatar city can receive consultancy from medical specialists;



Family members and professional health providers attending one of the Quality of Life seminars in rural Mongolia

For organizers:

1. The Mongolian Epilepsy Association has the opportunity to convey the problems and hindrances facing local people with epilepsy to government authorities, concerned professional organizations, medical suppliers and others;
2. The Mongolian Epilepsy Association receives ideas, opinions and evaluations from people with epilepsy and the public on how to improve its activities;
3. The members of a program team have the opportunity to learn about issues and problems experienced by rural neurologists, family doctors and other medical staff;
4. The members of a program team also conduct a survey on the "Understanding, knowledge and attitudes towards epilepsy" among patients, their family members and general public, which serves as an important tool for improving the training programs and elaborating the national program on epilepsy.

The Mongolian Epilepsy Association is pursuing an objective to continuously conduct the "Quality of Life" program for improving health education on epilepsy among populations in all provinces of Mongolia and districts of Ulaanbaatar city and we welcome any individual or organisations interested in cooperating in this endeavour. Finally, we wish to express our thanks to IBE for its financial support through the Promising Strategies Programme and to the IBE Regional Executive Committee Western Pacific, which provided additional support.

STATE OF THE ART EPILEPSY CENTRE OPENS IN SCOTLAND

Deputy First Minister of Scotland, Nicola Sturgeon (*second left*) joined former patient Kelsey Durham (*third left*) to unveil a plaque to mark the opening recently of a new epilepsy centre in Glasgow. The William Quarrier Scottish Epilepsy Centre is the only one of its kind in Scotland, offering assessment for people with complex epilepsy and diagnosis where the condition is uncertain. Around 100 patients will be admitted each year.

A wireless enabled video telemetry system, which has built-in integrated observation and alerts, has been installed in the new centre with technology never before used anywhere else in the world. This allows patients to freely roam the centre while still have integrated video and EEG monitoring.

The majority of Scotland's trainee neurologists will have placements at the centre, which will also deliver training for family doctors, nurses and conduct cutting-edge research into epilepsy. Former patient Kelsey Durham, said that Quarriers had transformed her life. She said: "When I first came to Quarriers four years ago I was a prisoner to epilepsy, and I couldn't take part in any of the usual activities teenagers do with their friends. It was such a relief when I was given a clear diagnosis of my epilepsy at Quarriers. My condition is now managed by medication and I have my life back again".

Chief Executive, Paul Moore (*fourth left*) said: "This marks the start of a new chapter in the history of the charity's services for people with epilepsy which have been going for more than a century. The vision of the charity's founder, William Quarrier, is very much embodied in this new state-of-the-art centre which will truly transform lives."

Also in the photo: Bill Scott, Chair of Fundraisers. Quarriers is an Associate Member of IBE.



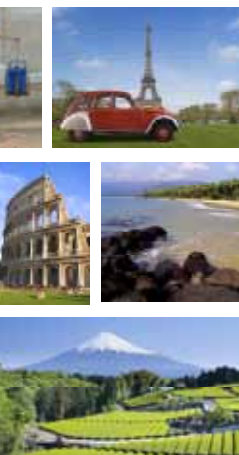


EPILEPSY & SOCIETY WORKSHOP

2nd African Epilepsy Congress

Cape Town - South Africa

A special workshop, focussing mostly on the social aspects of epilepsy and organised specifically for people with epilepsy, their families, caregivers and healthcare providers, will run for the final day of the congress on 24th May. There will be a special reduced registration fee for the day. Further information in the next issue or on www.epilepsycapetown2014.org



The Traveller's Handbook

For people with epilepsy

Visit the Traveller's Handbook website where you will find travel information and tips in several languages. It's the perfect place to go before travelling abroad.

There is also a CD available, free of charge, (although postage charges will apply where more than 3 CDs are requested). To order your copy email ibeadmin@eircom.net. Don't forget to include your full name and mailing address!

SOLIDARITY FUND

In the next few weeks, the IBE Office will be sending out the call to Members for dues payments for 2014. When paying, may we earnestly ask you to consider including a donation towards the IBE Solidarity Fund. The fund is used to finance IBE's Promising Strategies Program. Since 2006, Promising Strategies has allowed Members in 38 countries in developing regions to introduce 81 new projects to improve the lives of people with epilepsy. Donations are vital if we are to continue with this work.

Please help us to make a difference!

Epilepsy Advocacy Europe

Introducing the new members of the ILAE/IBE Joint Task Force in Europe for the term 2013-2017

IBE Representatives



Athanasios Covanis
Co-chair



Sari Tervonon



Gay Mitchell MEP



Philip Lee
Secretary

ILAE Representatives



Philippe Ryvlin
Co-chair



Hannah Cock



Meir Bialer
Treasurer



Christian Elger

The members of the Joint Task Force met for the first time on 1st September in Ljubljana, at the time of the European Conference on Epilepsy & Society. This was the occasion for the group to review the achievements of the previous term and to set its direction for the coming four years.

Strategic Plan

As a first step, it was agreed that it was important to document a Strategic Plan, for which a Business Plan would be required, in order to '*plan the work and work the plan*', as Gay Mitchell so nicely put it.

Thanks to Gay Mitchell, a Business Plan is now being drafted on a pro bono basis by the fifth largest accountancy firm in the world - BDO International. Members of the task force were first interviewed by Frank van der Lee and Rik van Brederode from the BDO Amsterdam office and this

was followed by a meeting in Brussels in mid-November. The next meeting takes place in December, at which time it is hoped to sign off on the plan. This will facilitate the work of the Task Force as it endeavours to play an active role in the next phase of the European Union funding programme - Horizon 2020 - which begins in January 2014.

Stockholm 2014

In the meantime, the task force is in the process of finalising a symposium to take place at the 11th European Congress on Epileptology in Stockholm next June. The title is *A political agenda for supporting epilepsy care and research in Europe* and the speakers will address three important issues:

- The ILAE-IBE roadmap in advocating for epilepsy care and research

- A summary of the epilepsy projects financed by FP7
- An update on initiatives at national level

EED 2014

Early next year, we will be celebrating European Epilepsy Day (EED) with events in the European Parliament in Strasbourg on 4th February and with the official day on Monday 10th, when member associations across Europe will celebrate the day with their own activities. The theme for 2014 is *Epilepsy is more than Seizures*.

On the following pages you can read more about preparations for EED and see a poster designed to promote it. The poster is available on the joint task force website www.epilepsyadvocacyeurope.org in several translations and other European languages can be provided on request.

Getting ready for European Epilepsy Day 2014

Associations across Europe are planning activities to celebrate European Epilepsy Day (EED) on Monday 10th February. EED will be launched in the European Parliament in Strasbourg a week earlier, on Tuesday 4th February, when the Joint Task Force - Epilepsy Advocacy Europe - is organising an evening reception. EU Health Commissioner Tonio Borg has been invited to speak at the reception and has accepted the invitation. We are keeping our fingers crossed that an official duty or meeting, requiring his attendance, will not change things at the last moment. Gay Mitchell MEP has also agreed to host the event once again.

The Joint Task Force is arranging a poster display and members of the IBE European Regional Executive Committee (EREC) will also attend the event and have private meetings with MEPs. This is an opportunity to alert MEPS to the need for improved treatment and information on epilepsy.

We know that, since its launch in 2011, EED has been marked by a number of very interesting initiatives across Europe. The IBE office has already gathered information on some past events and several have been reported on in the IE News. However, EREC plans to survey members to get the full picture so that we can collate these into a Users' Manual that we will provide to all members. We believe this will provide a great source of inspiration to members for future events!

In the meantime, you will all have seen the logo for EED 2014 and the poster that has been drafted to mark the theme 'Epilepsy is more than Seizures'. The logo is now available in most European languages and the poster has also been translated on request.

If you would like to have the poster produced in your language, please send the translated text to Ann Little at the IBE Office ibedublin@eircom.net who will pre-

pare the poster within a few days. In the meantime, you will find all of the logos, together with a number of posters, on the website of the Joint Task Force www.epilepsyadvocacyeurope.org.

As plans for EED are progressed, the Joint Task Force will be circulating up to date information. This will be the 4th EED and we believe it is now a successfully established event, which is celebrated not only by IBE and ILAE member associations across Europe but also by epilepsy centres and support groups and by the pharmaceutical industry.

With Horizon 2020 now, literally, on the horizon, any means of raising awareness on the problems faced by people with epilepsy and the need for increased funding to address these problems, is important. So, let's all celebrate EED 2014 as widely and as loudly as possible!

IBE rejoins the European Federation of Neurological Associations



IBE has rejoined the European Federation of Neurological Associations - EFNA - as a full voting member. The ratification announcement was made at the EFNA General Assembly in Vienna on 18th September, with Ann Little, IBE Executive Director, representing the Bureau.

Following a lapse in membership, IBE is pleased to be once again involved. EFNA is a federation of European patient associations working in the field of neurology and currently has twenty voting members, which includes Stroke Alliance for Europe, the Motor Neurone Disease Association, International Brain Tumour Alliance,

European Multiple Sclerosis Platform, and the European Headache Alliance. The current President of the association is Mrs Audrey Craven.

EFNA is represented on a number of European bodies, including the European Brain Council - EBC. The EBC is a powerful force in Europe and this connection is valuable.

EFNA plans for 2014 include:

- A campaign in the lead up to, during and after the European Parliament elections to bring to the attention of election candidates the need for increased funding and programmes for neurological diseases;

- Efforts to identify and develop a network of national contact points (NCPs) in EU Member States

A final activity for 2014 relates to ongoing efforts for a European Year of the Brain. While the EU had designated the month of May this year as the European Month of the Brain, there was disappointment that the designation was not for a full twelve months. However, without the endorsement of the EU, it is still planned by the EBC to have 2014 as the European Year of the Brain.

The next assembly of EFNA will take place early in 2014.

EPILEPSY IS MORE THAN SEIZURES

Stigma in epilepsy causes



TO IMPROVE QUALITY OF LIFE WE NEED



FUTURE CONGRESSES



2nd AFRICAN EPILEPSY CONGRESS
CAPE TOWN, SOUTH AFRICA
22nd – 24th May 2014



11th European Congress on Epileptology
STOCKHOLM
29th June - 3rd July 2014
ILAE-CEA



10TH ASIAN & OCEANIAN
Epilepsy
CONGRESS
SINGAPORE 2014
7 - 10 AUGUST



17-20 Setiembre 2014
BUENOS-AIRES
VIII CONGRESO LATINOAMERICANO DE EPILEPSIA



31st International
Epilepsy Congress
06-10 September 2015
ILAE
Istanbul 2015

