



EPI FOCUS



Newsletter of the IBE European Regional Committee

Issue 1-2010



Message from the Chair

Members of the International Bureau for Epilepsy (IBE). You are invited to submit reports, news and photos from your associations to be published in future newsletters. Personal stories are also welcome. The more we know you the closer we are to you.

Europe is a mixture of cultures and with countries of various economical status. However, epilepsy is the same throughout the continent, with similar social problems but with national differences in epilepsy care and state welfare provision. There is an urgent need to harmonize epilepsy issues across Europe and EPI Focus may do just that!

European Epilepsy Day February 14th 2011, a joint activity of EUCARE (Epilepsy Europe), IBE's European Regional Executive Committee and ILAE's Commission for European Affairs should become the chal-

lenging start for joint action. Activities organized by members at national level will complement the major event taking place in Strasbourg, where the European Parliament will be sitting. We hope that many IBE members will also be able to travel to Strasbourg.

For two years EREC has worked to bring together important scientific issues and social activities taking place in Europe, involving many Members and inviting them to participate and present on national activities. The programme of the 12th European Conference on Epilepsy & Society in Porto August 25th-27th 2010 is a reflection of all this effort. We hope to see everyone there!

With best wishes to all.

Thanos Covanis, Chair
IBE Regional Executive Committee

Dear European Members and supporters
It is my pleasure and honor to welcome you to **EPI Focus**. This new initiative of the European Regional Executive Committee (EREC), has been created to facilitate communication between members and supporters in Europe, by reporting on activities in Europe and encouraging new Mem-

European Epilepsy Day



By now, all members will have heard the wonderful news that an annual European Epilepsy Day is to be held for the first time next year, on Monday 14th February. Thereafter, the day will be celebrated annually on the second Monday of February.

Plans are underway to have the launch in Strasbourg, while the European Parliament is in session there, but the IBE European Executive Committee is also

encouraging members in Europe to arrange local events to highlight this special day. During the meeting of the European Regional Committee in Porto there will be discussion on idea for celebrations at national level. We look forward to hearing your suggestions.

In the meantime, over the coming months, you will be hearing a lot more about this great new initiative as plans advance!

EREC Officers

Chair: Thanos Covanis, Greece
Vice chair: Michael Alexa, Austria
Secretary: Aisling Farrell, Ireland
Members: Victoria Dimech, Malta
Seppo Sarkkula, Finland
Ex officio: Janet Mifsud, Malta
Material for EPI Focus should be sent to Aisling Farrell at aisling@epilepsy.ie

- Brainwave wins battle in the war on AED substitution
- Epilepsy awareness in schools in Scotland
- ILAE/IBE/WHO Global Campaign Demonstration Project in Georgia
- IBE Golden Jubilee Photo Competition
- History of Epilepsy in Europe
- Report from Rhodes

IN THIS ISSUE



Advocating for Epilepsy in Europe

Janet Mifsud, Vice President (Europe) IBE provides some practical suggestions

As you have seen in another section of *EPI Focus*, the highlight of 2011 will be the launch of European Epilepsy Day. This forms part of an overall advocacy campaign being undertaken, both by European IBE member associations and by European chapters of the International League Against Epilepsy (ILAE), to advocate for epilepsy in Europe.

As you know – money makes the world go round—and another activity being promoted by ILAE and IBE is to advocate for more epilepsy research funding in Europe. As some of you may know, several funding initiatives are undertaken at European level to improve the health of European citizens. One such is the so-called **Framework programme, FP7, 2007-2014**, which supports the funding of basic and applied research, using collaborative research groups from several European countries. The input of lay organizations, such as IBE member associations, is essential in these actions. Yet the decision to allocate money to epilepsy research is a political one and the message that epilepsy must have European Union (EU) research funding, **MUST** come from several European countries if we are to succeed.

It is up to you all to inform your Member of the European Parliament (MEP) and policy makers that:

- **Epilepsy is a common multifactorial neurological disorder affecting 6 million people in Europe. The total European health cost associated with epilepsy has been estimated to be €15.5 billion.**
- **About one third of all epilepsy patients remain refractory to current therapy of this devastating and disabling disease, implying an urgent need for novel treatment strategies.**
- **Epilepsy research is needed if we are to have real developments in therapy and quality of life of persons with epilepsy and their families.**

We need **YOUR** help and so we suggest these practical points:

- Contact your local MEP and inform him/her about epilepsy <http://www.europarl.europa.eu/members.do?language=EN>
- Visit http://cordis.europa.eu/fp7/ncp_en.html, See who your national contact point for Health research is, find out his/her name and contact him/her –and try to get a few concrete suggestions from them with respect to epilepsy in FP7.

With one voice we can do a lot! **Epilepsy needs you!!**

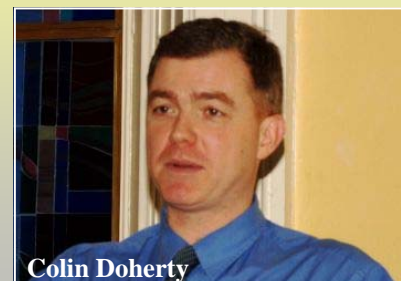
GCAE Taskforce

During a meeting in October 2009 of the IBE and ILAE Presidents in Geneva with the WHO leadership, the future direction of the Global Campaign Against Epilepsy (GCAE) and potential future activities were discussed. It was agreed that, for the Campaign to maintain its current success and aim for an expansion in activities, “more hands on deck” would be imperative. Resulting from these discussions, the IBE and ILAE Presidents established a Global Campaign Taskforce to help in achieving this goal. The Taskforce, co chaired by Dr

Helen Cross, UK and Dr Sichuo Li, China, has had two meetings and has now finalised a Strategic Plan. One of the recommendations of the plan is to identify regional representatives who can work closely with the Taskforce in providing a direct link between the regions and the campaign Secretariat and Task Force. In Europe, the regional representatives are Dr Janet Mifsud, Malta and Dr Colin Doherty, Ireland. In future issues of *EPI Focus* we will have more news about the GCAE Taskforce.



Janet Mifsud



Colin Doherty

A History of Epilepsy in Europe

Part One of a series of articles written by Thanos Covanis, Chair, IBE European Regional Executive Committee

Introduction

Epilepsy is a disorder of the brain and, therefore, it may be assumed that as far as its manifestations are concerned, there should not be much difference amongst members of the same species e.g. human beings. However, causes of epilepsy may be different or occur with different frequencies depending on where one lives. Also, the ways epilepsy can be eliminated or at least its consequences can be minimised will differ depending where in the world the person with epilepsy lives and the social situation that affects his or her life.

According to studies about its prevalence, one in twenty or thirty people in certain areas of the world with poor health conditions has epilepsy, but in other parts—Europe for example—it is only one in 150, or at most one in 100 persons. Based on epidemiological studies at least 50 million people world wide have epilepsy, but the actual figure is probably much higher, and 85% live in developing countries¹ Epidemiological studies also have shown that epilepsies are more frequent in childhood and adolescence².

A general practitioner in Europe will have roughly 10 – 20 persons with epilepsy in the list of patients registered in his practice. Access to who has the best knowledge about epilepsy depends on the way Health Care is structured where the person lives. One section of this paper will try to show the situation in Europe.

History

Epilepsy or the “falling sickness” has been recognised as a disease for more than 4000 years. There are references in the Codex Hammurabi (2080 BC) laws regarding marriage of epileptic persons and their validity as witnesses in court testimony. The oldest account of epilepsy dates back to the Babylonians (2000 BC) as indicated on a tablet exhibited in the British museum. The word “epilepsy” was first used by Hippocrates (460-357 BC) and Aristotle (384-322 BC): the word means that something is falling over you or catches you. Many expressions have been used throughout history such as “sacred disease”, “black disease” and “Herakles’ disease”.

Hippocrates may be considered to have described epilepsy as a clinical entity for the first time. He based his medical practice on observations and on the study of the human body. He held the belief that illness had a physical and a rational explanation. He rejected the views of his time that considered illness to be caused by superstitions and by possession of evil spirits and disfavor of the gods. He accurately described disease symptoms and was the first physician to accurately describe among other the symptoms of epilepsy in children and stated that epilepsy was caused by a blockage in the brain. A revolutionary aspect that was invented by Hippocrates was the concept of

cleanliness. When the plague broke out he recommended that people burn their clothes and boil water before drinking it. It was to take over 2000 years before this was rediscovered. The Hippocratic Oath is still sworn by new doctors in many parts of the world and is the basis for the code of ethics of the World Health Organization (WHO).

To the ancient Greeks, medicine was a gift from the gods. Greek mythology is full of symbolic legends and allegories explaining the nature and origins of the art of healing. In these myths, and the gods and goddesses associated with them, we can find the basic, fundamental archetypes that have guided and shaped the art of healing in Western civilization from its very inception.

Asclepius, was the god of medicine and was worshipped in special sites called Asclepieia. Pilgrims flocked to asclepieia to be healed. They slept overnight and reported their dreams to a priest the following day. He prescribed a cure, often a visit to the baths or a gymnasium. One of the most important Asclepieia in antiquity was based in Kos.

Hygeia (meaning health), the goddess of health, sanitation and hygiene, was the stepdaughter of Asclepius. She was worshipped alongside Asclepius in all his healing sanctuaries.

Continued in the next issue

References

1. Epilepsy : epidemiology, etiology and prognosis. Geneva, World Health Organization, 2001 (WHO Fact Sheet No 165; available on internet at <http://www.who.int/inf-fs/en/fact165.html>).
2. Hauser WA, Kurland LT. The epidemiology of epilepsy in Rochester, Minnesota 1935 through 1967. *Epilepsia* 1975; 16: 1-66



The statue of the father of Medicine, Hippocrates, in Latissa, Greece, the place where he died

ILAE/IBE/WHO Global Campaign Against Epilepsy Demonstration Project in Georgia

Report by Hanneke de Boer

Georgia has 5,000,000 inhabitants of whom one third live in the capital city, Tbilisi. More than 40 nationalities with different religions and culture live in Georgia, 60% of the population consists of Georgians who speak the Georgian language.

Georgia belongs to the very few European countries that are recognised as developing countries; a monthly salary fluctuates from 15 to 50 US dollars.

The state support for epilepsy fully covers inpatient treatment of children under 3 years of age and the treatment of status epilepticus (only convulsive). The costs for epilepsy care for children under 14 years are supported for 50%, other age groups are without support.

It is against this background that the Global Campaign Secretariat, in consultation with the Regional Advisor for Mental Health in Europe (Dr Wolfgang Rutz and his successor, Dr Matthijs Muijen) decided to investigate the feasibility of initiating a Demonstration Project in Georgia (2004).

The protocol

During a meeting of stakeholders in the country with participation of the Campaign Secretariat the protocol for the Demonstration Project was discussed and finally unanimously agreed upon by all stakeholders in the country.

The development of such a protocol is essential for the development of a demonstration project. In Georgia the

aim of the project is to test the feasibility of diagnosis and treatment of convulsive forms of epilepsy at a primary care level using phenobarbital, carbamazepine and valproate as the first options. The long-term prospect of the project would be to integrate epilepsy management into the existing primary health delivery system of Georgia.

Organisation of the project

Dr Tarun Dua and Hanneke M de Boer will act as monitors of the Project on behalf of the Global Campaign, while Dr JWAS (Ley) Sander will be its Scientific Project Leader. The Ministry of Labour, Health and Social Affairs of Georgia is responsible for the demonstration project and has delegated this to the Centre for Epilepsy Management, Research and Education and to the Centre of Epilepsy Control and Prevention the tasks of ensuring concerted action. The responsibility for the activities will rest with the local neurologists of the National Learning Centre of Family Medicine, the Healthcare, Prophylactic Centres and various out-patient clinics.

The project will be carried out in 4 main districts of Tbilisi. The epidemiological investigation will cover 10,000 inhabitants. Educational, social and community intervention will be performed through the entire population of Tbilisi.

Progress

In the mean time an epidemiological phase has been completed to estimate the prevalence of active epilepsy and the treatment gap.

The second phase – the intervention phase (service delivery) started and is ongoing. Over 400 patients who were not treated appropriately were identified and are now well treated.

The third phase: the Educational, Social and Community Intervention also has been initiated and it ongoing: all local investigators and primary health care physicians in each of the 4 study areas received basic epilepsy training.

Target groups for educational activities include all professional groups, which may have dealings with people with epilepsy (school teachers, employers, police) and also professional groups dealing with the community (priests, journalists etc).

An educational programme aimed at decreasing social stigma, in areas of social relations, employment, leisure activities, schooling, etc. has been developed. The programme aims to decrease social stigma in areas of social relations, employment, leisure activities, schooling, etc.

Social intervention will be provided at 10 "Inclusive Schools". These types of schools provide education to healthy as well as disabled children. Finally a number of evaluations will be carried out to measure the effectiveness of this project.

The project will be completed by the end of 2010, with a second epidemiological survey, measuring the results of the project. The data should be analysed during the first quarter of 2011.

From left to right: Sofia Kasradze, Natela Okujava, Hanneke de Boer, Ley Sander, Tarun Dua





Generic Substitution in Ireland

Brainwave – The Irish Epilepsy Association wins major battle

The introduction of generic substitution has been on the Irish government's agenda since health services were re-structured in the early-mid 2000's and throughout that period Brainwave has been advocating for the protection of people with epilepsy against harmful switching of anti epileptic drugs (AEDs). A new system of generic substitution was deemed necessary to promote price competition and to reduce the costs of medications for both the State and patients. Currently, there are far less generic medications prescribed in Ireland (<20% of all drugs dispensed) compared to the UK (>80%) and other European countries.

In 2005, Brainwave received assurances from the Minister and the Department of Health & Children that its concerns would be taken on board. Nevertheless, in 2006, Brainwave made a presentation to the Joint Oireachtas Committee on Health & Children, an influential Parliamentary committee made up of members of both the lower and upper houses. A strong argument was made favouring the exclusion of AEDs from substitution based on international evidence and best practice.

Brainwave kept up its campaign in the intervening years, raising awareness at every opportunity regarding the body of evidence showing that generic substitution can lead to the recurrence of seizures in some people whose epilepsy was otherwise controlled.

Mike Glynn, CEO, spoke on the dangers of switching between branded AEDs and generic and, even more so, on switching between different generic versions of a drug, both in Ireland and abroad. In 2007, he presented in Paris, spoke again at a congress in 2008 and presented a poster in Budapest 2009.

In early 2010, Brainwave's work was rewarded. In March, Brainwave was invited to a meeting organised by a working group of experts set up by the Minister for Health & Children. At the meeting, Brainwave received assurances that epilepsy medications would

be specifically exempted from the working group's proposed system of reference pricing and generic substitution, based on the weight of evidence supporting such an exclusion.

In June, the Minister published the working group's report on implementing generic substitution. The new system will allow pharmacists to substitute medicines which have been designated as "interchangeable". Pharmacists will only be able to substitute interchangeable medicines, and substitution will only be allowed where it is deemed safe to do so.

Crucially, the report specifically states that medicines will not be regarded as interchangeable "where there is a difference in bioavailability between brands of the same medicines, particularly if the medicine has a narrow therapeutic index. (AED) products in this group include Carbamazepine, Gabapentin, Lamotrigine, Phenytoin, Sodium Valproate)".


The exclusion of epilepsy from the proposed system protects thousands of people with controlled epilepsy from breakthrough seizures and can rightly be regarded as an important victory for the Association and for all Irish people

with an interest in the condition.

Key to our lobbying success has been the consistent stance we maintained, which can be broken down into the following key messages:

- *Epilepsy is the only common serious condition for which the substitution of drugs presents a problem.*
- *The prescribing of generic epilepsy drugs per se is not a problem when prescribed for new patients and presuming that there will continue to be an adequate supply of the generic available in the long term.*
- *However, a problem exists when an individual's epilepsy medication is **switched**. Switching can lead to seizure recurrence not only when it takes place from the brand to the generic, but also vice-versa or even between two different generic versions.*
- *Seizure recurrence can cause loss of driving privileges, serious injury, disruption to employment and education and can even cause death.*

Drafting of legislation to introduce the new system will now begin. A significant PR campaign will also be launched to inform the public about generic substitution later this year.




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International Bureau for Epilepsy



Dr Matt Muijen
WHO Regional Advisor for Mental Health

European Report on Epilepsy

Thursday 26th August
08:00—09:00

One of the most significant events at the 12th European Conference on Epilepsy & Society in Porto will be the launch of the European Report on Epilepsy of the Global Campaign Against Epilepsy.

This long-awaited important report, which is being published by the WHO, will be officially launched by Dr Matt Muijen, WHO Regional Advisor for Mental Health.

The report will bring together, for the first time, all available evidence from the region on the epidemiology, etiology and management of epilepsy and will be a valuable tool for those working for change at national level. A copy of the report is included in each delegate bag.

We hope that many of you attending the conference in Porto will be able to attend the launch event.

Promising Strategies Programme 2010

The following two projects, submitted by Members in Europe, were chosen to receive financial support under this year's round of IBE's Promising Strategies Program/

Raising Awareness is the main goal of the Romanian project planned by EpiRomania. Despite the obvious beauty of the architecture and countryside of Transylvanian, stigma, prejudice and ignorance about epilepsy are still widespread in this region—both in people with epilepsy and the general public.

ROMANIA



REPUBLIC

CZECH

Children's Survey

Using existing methodology and verified questionnaires, EpiStop plans to undertake a survey involving school children, their teachers and parents to establish whether the situation has changed for children with epilepsy in the Czech Republic since similar surveys were carried out in 1995 and 2007. Based on the data obtained, the association will inform all those interested how it is possible to improve the quality of life of children with epilepsy. These questionnaires could be a reliable tool for the next investigation in the Czech Republic.

The next plan will be to use the results of the survey to prepare an information brochure or leaflet and to upload the information on websites with a pro link to the website of the Ministry of Education.





Delivering epilepsy awareness programmes to schools communities in Scotland

Shirley Maxwell reports

Epilepsy Connections provides innovative information and support services to people affected by epilepsy in west and central Scotland. A key part of our work is to raise awareness at community level and one of the ways we do that is through our Schools Project.

Set up as a pilot in 2003, this project provides information about epilepsy and living with seizures to students and teachers and promotes open and positive attitudes and behaviour towards people with epilepsy. Project staff Colleen Wilson and Nicola Small deliver fun, interactive education sessions tailored to meet the needs of children and young people of all ages in mainstream and special educational needs settings. Teachers are also offered a session on the possible impact of epilepsy on learning and behaviour, and how this can be managed in the classroom.

Over time we have developed a range of ways of communicating complex information in a meaningful way to

even very young children, and our in-house resources now include a story book, "Sunny's Story"; PowerPoint presentations, quizzes, group exercises, games, worksheets and case studies for group discussion.

The project helps deliver *Getting It Right For Every Child* (GIRFEC), the Scottish Government's policy relating to the wellbeing of children and young people. The introduction last year of a certificate scheme is proving popular. Project Worker Nicola Small says, "The awards scheme is an effective way of recognising schools who have committed time to develop and maintain their epilepsy knowledge".

Satisfaction surveys show that the project delivers relevant, useful information at the right level and represents a valuable and worthwhile use of time. More creative evaluation methods include our annual poster competition organised by Colleen Wilson. "Each year children who have taken part in

the project are invited to design a poster to raise awareness of epilepsy and their drawings and paintings show how much information they have retained, so this is a great way to measure the effectiveness of our sessions", says Colleen.

Epilepsy Connections Executive Director Shirley Maxwell says, "Epilepsy Connections' Schools Project has been running for 6 years, and we've shown it to be a resource-effective way of improving understanding of epilepsy in schools and of supporting individual children. Like every IBE member, we'd like to see epilepsy awareness programmes in every school and every teacher training college.

"Until that happens, Epilepsy Connections is committed to working with individual schools to ensure that inclusion in nurseries, classrooms, playgrounds and campuses is a reality for all children and young people with epilepsy".

Police Training in Malta

After the successful national epilepsy conference in February 2010, Caritas Malta Epilepsy Association (CMEA) was invited by the Police Academy in Malta to deliver a talk to 165 police recruits, on the role of police officers in assisting persons with epilepsy. The lectures were held at the Police Academy in Valletta. The recruits were addressed by Dr Janet Mifsud, advisor CMEA, Frank Portelli treasurer CMEA and Manuel Camilleri, member CMEA.

Dr Mifsud gave an overview of epilepsy, and showed how different kinds of seizures can be recognized. She also described some triggering factors and the steps involved in giving first aid to a person having a seizure. Frank Portelli spoke on the history and aims of CMEA and discussed how CMEA keeps pressure on the Maltese Health Authorities

so that the latest diagnostic equipment and AEDs are made available to Maltese persons with epilepsy. He also described his personal experience as

a father of a child with epilepsy. Manuel Camilleri spoke of the great difficulties encountered by him as a person with epilepsy when looking for a job. He also showed his "SOS Bracelet" which contains information on his medical condition, his contact details and those of his nearest relative, medication and doctor's contact.

Great interest was shown by the re-



cruits, with several questions regarding emergency first aid. Interest was such that even after the lectures were over, several recruits stayed back to ask more questions. These lectures are a large positive step in our awareness campaign and clearly show the importance of providing key information to police officers who are often on the front line in emergency situations.



Report from the 9th European Epilepsy Congress on Epileptology, Rhodes 2010

In late June distinguished basic scientists, researchers and eminent epileptologists throughout Europe and further afield came together to exchange ideas and medical experience, provide the scientific communication with solutions, raise questions regarding the origin and the treatment of all types of epilepsy, connect epilepsy with social and psychosocial issues, unveil new treatments, bring to the foreground a number of hard-to-answer-questions and ensure that scientists continue to research and produce more advanced knowledge.

The 9th European Congress on Epileptology, organised by the Commission of European Affairs of ILAE, which took place in Rhodes, was attended by 2,865 people from 83 countries, with 87% of those registered coming from European countries.

The programme comprised 80 sessions with 173 speakers, including Main Ses-

sions, Workshops, Discussion Groups, Platform Sessions and Video Sessions; Teaching Sessions, EUREPA Teaching Sessions and Courses; sponsored Satellite Symposia; special symposia (Chairs' Symposium, Michael Foundation Symposium, CEA-EU Symposium, Neurobiology Symposium, Bursary Award Symposium, The Symposium of Excellence in Epileptology).

There was a new and innovative emphasis on posters at the congress, with poster tours led by experts in the field taking place each day at lunchtime.

Several awards were presented during the congress. The ILAE Commission on European Affairs presented the European Epileptology Award 2010 during the Opening Ceremony. The prize is awarded to European epileptologists whose achievements are considered to have contributed significantly to the development of epileptology in Europe. The European Epileptology Award 2010

was awarded jointly to Martin J Brodie (UK) and Yehezkel Ben-Ari (France).

The Morris-Cooles Prize, awarded by the ILAE, is the initiative of Mr and Mrs Christopher Morris-Cooles, who have endowed the prize. The annual prize of €10,000 is awarded for the paper published in *Epilepsia* during the preceding year which has, in the judges' opinion, made the most significant advance in knowledge in the field of epilepsy. The 2009/2010 prize was awarded to Yao-Chung Chuang (Taiwan) for his paper entitled "Longterm antiepileptic drug therapy contributes to the acceleration of atherosclerosis".

The sessions were very well attended due to the excellent scientific programme combined with the relaxed atmosphere of the location. Most people were in very good form and happy with the congress. Almost everyone I spoke with is pleased with the success of the Rhodes congress.

Agenda

1. Minutes and matters arising
2. Items not on the agenda
3. European Regional Executive Committee Report
4. Plans and Budgets for 2010/2011
5. Members' reports
6. 13th European Conference on Epilepsy & Society 2012
7. Any other business
8. Date and venue next meeting

Meeting of the European Regional Committee in Porto

13:00–15:00
Wednesday 25 August
Meeting Room Gemini
Sheraton Hotel

