International Bureau for Epilepsy

European Region

European Regional Executive Committee (EREC): Report 2009-2011

IBE European Regional Executive Committee (EREC)

Chair                                         Athanasios Covannis; acovanis@otenet.gr
Vice chair                                 Michael Alexa; michi19691@yahoo.de
Secretary:                                  Aisling Farrell; afarrell.brainwave@epilepsy.ie
Members:                                  Victoria Dimech; mvdimech@gmail.com and
                                      Seppo Seppo; seppo.sarkkula@kolumbus.fi
Vice President Europe                Janet Mifsud; janet.mifsud@um.edu.mt

Since 2009 the EREC has engaged in several activities. The main aims of those activities are to
improve understanding, diagnostic, nursing facilities and treatment care for PWE and therefore
improve quality of life for the patients and their families. Furthermore, the EREC participates in
various lobbying activities, together with researchers, for funding or raising money for research
projects.

Background
Early in 2009, elections were held to determine the IBE International and Regional Executive
Committees for the term 2009-2013 which began after the 28th IEC in Budapest, June 27th to July
2nd 2009. On Wednesday July 1st 2009 ((in Hungexpo Budapest at 10.30-12.00, Gallery Room)
there was a meeting between the incoming and outgoing EREC which was followed by a meeting
of the new EREC on Thursday July 2nd. During their first meeting, the EREC discussed the
location for the next ECES and decided it would take place in Porto August 2010. It was further
decided that the IBE European Committee Travel Bursary Fund – in memory of Jonina Björg
Gudmundsdottir (a decision previously taken by the outgoing committee) should be allocated to
the next three ECES starting with the 12th ECES in Porto 2010.

The committee met again in Dublin, 25th September 2009, where the dates for the 12th ECES were
confirmed - August 25th to August 27th 2010 - and the structure of the programme including
speakers and chair persons was laid-out. Other issues discussed were: the possibility of an
IBE/EREC logo, the review of poster procedure and the creation of an “EREC Epilepsy News” as
a way of reporting and communicating with all our IBE European Members.

Goal 1: improve the visibility of epilepsy and the activities of the Global Campaign in all
countries
A. In 2010 much of EREC activities were focused on the organization of the 12th European
Conference on Epilepsy and Society that took place in Porto, Portugal from 25th to 27th
August. The theme for the conference was “Epilepsy: So what?” The conference was
attended by more than 300 delegates with participants from as far afield as Australia,
USA, South Africa and Sierra Leone. The conference programme covered a wide range
of topics including ethics, genetics, AEDs and lifestyle issues, policy influencing as well
as some topics of a more scientific nature. Photosensitivity and new advances in epilepsy
treatments were also featured in the programme. A series of Discussion Groups addressed
issues such as epilepsy and disability, driving and insurance problems, epilepsy
emergency cards and warning devices, best practice in twinning of IBE members,
training and personal development opportunities, and advocacy work. Presentations for
most of the speakers were available for download after the conference. The Youth Session was a huge success. The conference also saw a strong participation in the poster presentation section. For this Conference 3150 dollars were offered to bursaries.

B. During the opening ceremony of the Epilepsy and Society Conference, August 25th, Dr Matthijs Muijen WHO Regional Advisor for Mental Health and Brain Disorders gave a short presentation on the occasion of the launch of the European Regional Report: Epilepsy in the WHO European Region-Fostering Epilepsy care in Europe, which took place on Thursday August 26th, at 08.00 AM, with the title: Meeting European Stakeholders in Epilepsy. The report provides a) an overview of the state of affairs of epilepsy and epilepsy care in Europe b) the activities that have taken place or are being planned & c) the challenges we face when trying to improve the situation for PWE in our region. The EURO report received much publicity from the press and medical journal namely Epilepsia (Gray matters), Lancet (editorial) and World Neurology (WFN Newsletter).

C. The EREC met in Porto and a decision was made to move the 13th European Conference on Epilepsy & Society to 2013. To date the EREC has received expressions of interest from Ireland, Slovenia, Austria and Georgia. A positive decision for Slovenia was taken.

D. Recently two questionnaires were sent by the EREC to all European Members regarding Membership and the implementation of the New Driving Directive.

Travel Bursary Fund
A working group has been established to discuss the selection and criteria for the travel bursary and poster guidelines.

EpiFocus
A questionnaire was sent to European members in 2009 asking for feedback and recommendations. The results of this questionnaire were discussed in Hungary. One recommendation was the development of a communication tool where members would be informed of the work of the EREC and would also provide an opportunity for members to share their work. The first EpiFocus was launched in Porto and was very well received. The EREC plans to continue to produce this newsletter in the future and plans to publish three editions each year. Members are encouraged to write articles for the newsletter. In addition, EpiFocus is also a forum for the EREC to inform members of the work the committee has been involved in. The EpiFocus 1, 2011 was already sent to all IBE/EU Members and it is also available on the European section of the IBE website.

Future action plans
- Develop a common message for all countries;
- Allocate bursaries for the 29th IEC in Rome, preferably for countries with no National Association. See above.
- To send a questionnaire in order to verify if the new directive on epilepsy and driving (due to be complied by all European countries by September 2010) has been applied. See above.
Goal 2: promote activities of epilepsy projects at a national and regional level

European Epilepsy Day
A questionnaire was sent out to all IBE European members regarding dates for the European Epilepsy Day and the date has been confirmed to be the second Monday of February every year. The 1st European Epilepsy Day was celebrated in Strasbourg 14th February 2010. The EREC sent letters to the IBE European members and encouraged them to organize activities on February 14th 2010. The European members were also invited to send one representative to Strasbourg February 15th, where they would have the opportunity to get in touch with the National Euro-MEPs. All participants took part in the activities during the launch of the first EUROPEAN EPILEPSY DAY (see EpiFocus1, 2011).

An investigation of the needs of individuals with epilepsy and other learning disabilities and their families
A working group has been established between members of the EREC and ILAE Task force on Epilepsy in Adults with an Intellectual Disability to distribute a survey and investigate the care needs of individuals with epilepsy and learning disabilities and their families. The objectives are: to examine the experiences of families of individuals with epilepsy and Intellectual Disability and of individuals themselves; to identify key issues for service development; to explore apparent deficits; to summarize and communicate this information to the ILAE and other relevant bodies to foster change and development; The survey is currently in the development stage [Aisling Farrell, Mike Kerr and Mike Glynn are on the task force].

Future action plans
- Organise an IBE European Regional Executive Meeting & European Regional Committee Meeting in Rome. In process.
- An EREC delegate to visit Georgia preferably before end of June 2011 & help them to develop first aid for epileptic seizures and also help them to implement the Asian guidelines, and or develop European guidelines for the patients & those who look after them (did not materialized, lack of funds).

Goal 3: Assess and strengthen health care systems analysis for epilepsy by acquiring a better understanding of the conceptual model, magnitude and scope of the coverage gap including the treatment and knowledge gap (definition), measuring the burden of epilepsy and methods for conducting country resource assessments. An instrument for epilepsy resource assessment is been developed (Tajikistan) within the GCAE in collaboration with WHO. This will help for better assessment and planning to improve epilepsy services. We will ask for the report and consider implementing it, if possible, in other countries in the European Region.

Future action plans
- Translate educational materials or “patient” guidelines (e.g. China, India and Japan) in other languages in order to reduce the knowledge gap
- Collect material for the 3rd and 4th EpiFocus

Goal 4: Increase partnerships and collaboration with other organisations
EREC has joined forces with the Alliance for MRI since 2009 when the EREC secretary Aisling Farrell attended their meeting in Brussels. The Alliance for MRI supports the adoption of
guidelines to support the safety standards. One of the main focuses of the Alliance at the moment is the derogation for the medical and research use of MRI from the exposure limit values, which will ensure that this vital technology will continue to be available for all patients. The directive is due to come into force in 2012, having been delayed because of the MRI issue. To ensure this support in May 2010, the EREC sent a letter to all IBE European members urging them to take part on an online petition set up by the Alliance for MRI in order to support its cause. Due to financial constraints Aisling didn’t attend the Alliance for MRI meeting in 2010.

In 2010 IBE European Regional Executive Committee (EREC) and ILAE Commission on European Affairs (CEA) have endorsed the change from EUCARE to a new Joint Task Force (JTF). In this respect the CEA and EREC will be able to work together. The new Joint Task Force for Advocacy & Research will be the political and advocacy arm of the ILAE-CEA and IBE-EREC, promoting epilepsy care across European region, defending the social integration of persons with epilepsy, and facilitating Epilepsy Research funding. Through this Task Force, the EREC will liaise with other international initiatives such as the Global Campaign. The President of IBE appointed Hanneke De Boer, Reetta Kalviainen, and Janet Mifsud to represent IBE on the JTF for Advocacy and Research. Furthermore, the European Advocates for Epilepsy Working Group (cross-party, cross-national MEPs with particular interest in epilepsy) was also created. The first action of this Group is to support ILAE and IBE in having a Written Declaration on Epilepsy approved by the European Parliament. For the Declaration to be approved, we require signatures of 50% plus 1 of all MEPs (369 signatures). EREC has and continues to encourage all EU members to be very active in this process.

Future action plans

- Identify appropriate national groups to disseminate the message
- Join forces with national groups
- Liaise with countries with no IBE-representation such as Armenia, Albania, Ukraine, Monaco and Luxembourg. Albania is in the process of submitting the application to IBE for full membership.
- Identify NGO’s with similar objectives