

Commission on European Affairs Annual Report 2006

Aims

Include: Congresses; Education; Care standards; Research and scientific activities; Communication; and Rules and Statutes of the Commission.

To stimulate and coordinate all aspects of epileptology across Europe, including organizing the European Congress on Epileptology.

End of Term report Sept 2005 - July 2009

First of all, the outgoing CEA would like to thank the European Chapters for their trust and excellent partnership, the ILAE President Peter Wolf, the ILAE Executive and Management Committees for their support and understanding, the ILAE Financial Office, with a special mention for Dona Cunard, the headquarters in Brussels, as well as IDM for their excellence in Congress preparation and organization. Last but not least, EUREPA was a permanent partner in our Educational activities.

We also would like to express our gratitude to all the persons from our community who helped us at many occasions, in working groups, task forces, scientific advisory and organizing committees for our Congresses or educational courses.

Our Commission was very active in many important domains, as listed below:

1/ Education: at the beginning of our term, we elaborated a comprehensive program of international educational courses, with the preoccupations of offering varied topics, including general epileptology, genetics, surgery, clinical pharmacology, and of trying to cover at best our vast geographical Region. Some of them were entirely organized and financed by the CEA, whilst others were only co-organized and co-financed by the CEA.

| Year | 2006 | 2007 | 2008 | 2009 |
|---|------------------------------|--|--|---|
| The Pharmacological Treatment of Epilepsy | | Israel (Eilat) | | Israel (Eilat) |
| Migrating Course | | Serbia | Lithuania | Czech Republic |
| Contribution to other courses | San Servolo St Petersburg | San Servolo Baltic Sea (Lithuania) | San Servolo Baltic sea (Denmark) Caucasian (Armenia) | Baltic sea (Kiel, Ger) Caucasian (Georgia) San Servolo Moscow-Kazan |
| EPODES (Surgery) | | | Brno | |

General comments and recommendations:

A database of students has been started in collaboration with EUREPA

Regarding the main courses:

A/ Pharmacological treatment of epilepsy: the 2003 San Servolo Course on this topic was successfully replicated by the CEA in Eilat in 2005 and 2007, with the same expectations for 2009. This topic is particularly important in Europe considering all the different new AEDs introduced on the markets, and the site of Eilat has proven to be very attractive to the trainees. Recommendation to keep this important course topic on the CEA agenda

B/ Migrating Course on Epilepsy (MCE): The course takes place once a year in different European Countries in collaboration with the CEA and EUREPA. So far, courses have taken place in Babe, Serbia 2007; Trakai, Lithuania 2008; Pruhonice, Czech Republic 2009. The outgoing commission would like to make the recommendation of Roma for the 2010 MC, and to pursue with this program as a function of the needs. The principle is this of a series of clinically oriented courses targeted to specialists at the second and third level of epilepsy care and focused on comprehensive aspects of diagnosis and treatment of epilepsy. Includes lectures on the clinically relevant aspects on epileptology and interactive case discussions and/or tutorials, including video-EEG sessions.

C/ Advanced Summer School: this international course, taking place usually in San Servolo, has become a major event for the international Epileptology. It has however very strong European roots, as well as a EU financial support, and it seems logical that the CEA remain an active partner.

D/ Baltic Sea Summer Schools on Epilepsy (BSSSE): a success, the contribution from the CEA having been however less substantial so far

Some reflection should be taken perhaps in order to adapt at best our offers in terms of courses to the actual needs of the different parts of the Region

2/ EUREPA: A well detailed and comprehensive business plan was endorsed by the CEA. It includes a program of activities including VIREPA (distance education), information and knowledge web portals, training the trainers, accreditation, certification, bursary database and the financial aspects and implications in the present difficult context.

As of the current situation, the relationships between EUREPA, ILAE and CEA have not been fully clarified. Particularly the respective responsibilities from the CEA and from the ILAE regarding the functioning of EUREPA in the future should be refined. EUREPA is in a transition period, and on the other hand, the current EC and CEA are at the end of their term, therefore it was felt that the CEA was not in position of making major decisions, and that any major decision concerning the future of EUREPA should be made through a close cooperation between the next upcoming EC and CEA. The budgetary issues, namely what would be the financial contribution from the CEA to the EUREPA budget (running budget in particular), will be crucial.

3/ Congresses (European Congress on Epileptology -ECE)

Two ECEs took place during our term

The 2006 Helsinki ECE (although prepared by the precedent CEA) and the 2008 Berlin ECE. Both were a great scientific success, and generated substantial surpluses. The important role of the SAC and their Chairs, R. Kalviainen, and C. Elger together with M. Bialer, should be emphasized

Two innovations:

1/ the satellite in St Petersburg in 2006, inspired by the geographic proximity from Helsinki, which was an occasion to run a two-day course in Russia, very largely attended.

2/ The joint organization between the Israeli and the German chapter in Berlin (2008)

Our commission took in charge two selection processes: selection of Greece with Rhodos in 2010, and UK (city to be finalized between Glasgow and London). At these two occasions Turkey (Istanbul) finished in second position..

Recommendation:

1/ Turkey is encouraged to bid again for ECE organization, and the high quality of the Turkish project will be emphasized to the next upcoming CEA. Of note Greece was in the same situation at the beginning of the present CEA term, and ended up successfully for the 2010 ECE organization.

2/ The CEA tried to encourage joint organization by two Chapters. The joint (equally-partnered) Israeli-German organization in Berlin was a good example. Other possibilities exist. For instance UK (selected for 2012) and Ireland are planning to cooperate in the 2012 ECE. In the current difficult financial context, however, the outgoing CEA would recommend that any type of joint organization should not lead to increased costs or plethoric IOC/SAC

3/ Communication with Chapters: this was mainly done at the occasion of the European Chapter Conventions, in Helsinki 2006, Singapore IEC 2007, Berlin 2008. The European Advisory Council chaired by Alla Guekht and Svein Johannessen, together with the Commission, suggested to organize the Convention of European Chapters on a yearly basis, including therefore convention at the IEC. Care was taken not to overlap onto the global ILAE activities, and on the contrary, we encouraged our Chapter representatives to take actively part to the ILAE activities during the IEC. The fact of providing financial assistance to representatives from the less advantaged countries should also be regarded as a CEA contribution to the global ILAE activities.

In the present period, 2005-2009, the priorities in the EAC activities have been:

- Education (in close cooperation with EUREPA and the ILAE Commission on Education)
- Improvement of epilepsy care targeting on the adequate management being accessible to all patients in all countries
- Regional and interregional cooperation between the European Chapters, forming the “European working networks” in specific areas of epilepsy care and research
- Special attention to the particular needs of different Chapters

Attendance:

- Madrid , 2002 : 20 Chapters
- Vienna ,2004 : 26 Chapters
- Helsinki, 2006 – 40 Chapters
- Singapore, 2007 (IEC): 31 Chapters
- Berlin, 2008 : 39 Chapters

4/ CEA rules and statutes

Two working groups have permitted to elaborate an update of CEA rules and statutes, and a guideline for seeking a CEA support for educational activities. The constitutional amendment proposed by Nico Moshé, if voted in Budapest, may lead to make some substantial changes in the CEA / EAC rules, and to harmonize to some extent the CEA rules and Statutes with these of the other Regional Commissions. The process for the CEA election in May 2009 will follow the same principles as before, with some improvements regarding the safety and follow-up of the ballots sent by the Chapters. The largest participation is encouraged.

5/ Care standards

- The relationships between EMEA (European Medicine Agency) and CEA: Through our contact group and during the post-Eilat conference workshop on regulatory issues (June 2008), the views of our scientific community have been well received by the EMEA regulators. We can hope that some of our suggestions will be implemented in the next revision of the EMEA guidelines on AEDs (Several changes are expected regarding paediatrics syndromes in particular). This revised draft will be available through internet for consultation soon, and, then, there will be a few months for further comments. The EMEA regulatory rules and procedures are influencing drug availability and epilepsy therapy throughout Europe
- Colloquium on Status epilepticus: our commission invested in the two Colloquium, London 2007 and Innsbruck 2009, and its members participated actively in these enterprises aiming not only at refining knowledge on SE, but also at harmonizing treatment guidelines and drug availability across the Region. A guideline for treatment recommendation was published (*Epilepsia*2008;49:1277-285). The CEA could play a coordinating role in future pan-European clinical trials in SE.
- Generics: Discussion groups on this topic were held at the occasion of the Chapter Conventions, with a very active participation showing that the issue of generics is global throughout our Region, with various interests however.
- EPODES is a program designed to facilitate the development and the availability of epilepsy surgery programs in the less advanced parts (in this regard) of the Region. This program features courses, professorships (they will visit centers and train on site candidate Centers) and fellowships for training young epileptologists abroad. The registrations so far have suggested a high level of interest, and this activity should be pursued in 2010 (because of budgetary restrictions, some amount of the budget has been postponed from 2009 to 2010).
- Our Commission initiated some action in the domain of the “Rare Diseases Programs”, on the premises that several governmental, European, and WHO programs are progressively implemented. It would be important for our community to take part, to defend the cause of the rare epileptic diseases, and to try to benefit from these multilevel actions. The IBE has been contacted on this subject.

6/ Research: our commission had to restrain all budgets dedicated to scientific meetings and tried to invest in actions of “European added value”

- A project on the mechanisms of SUDEP, “MORTEMUS” was supported financially: it is based on the collection of data across Europe on the largest possible number of cases of SUDEP or near-SUDEP that occurred in the EEG-video monitoring settings

- Our commission has undertaken a concerted action to promote Epilepsy research at the European level. The key role of Asla Pitkanen should be particularly underlined. The goal is to identify the Epilepsy Research Priorities in Europe for the coming decade. Research efforts on these priorities should guarantee that European epilepsy research stays and strengthens its position at the cutting edge of the world epilepsy research, has a potential for decreasing the economical and social burden of epilepsy in Europe, and will lead to significant changes in diagnosis, treatment, and quality of life of patients with epilepsy. To achieve these ambitious goals, it was necessary to elaborate a representative opinion of the research areas that should be investigated. A workshop took place in Brussels, Jan 17th -18th, 2008, and a consensus document was elaborated, then published in *Epilepsia*, under the title: Epilepsy research priorities for the next decade: a representative view of the European scientific community. (*Epilepsia*2009;50:571–583).

This document was distributed to all European chapters with some recommendations on how to use it for lobbying purposes. (European deputies, EU national contact points, etc). It was also proposed to organize a follow-up meeting in 2010, that would update the research priorities. This could be done in collaboration with Günter Kramer in Zurich: this opportunity may bring some European added value to this Zurich meeting which theme is revolving around the “State of the art in Epilepsy research”. The importance of giving a higher importance in the future to clinical research and social issues was emphasized by the CEA. The European Brain Council will utilize this document for elaborating its neuroscience program.

7/ Budgets

Due to the global economic crisis which affects the whole world, ILAE had to reduce its expenses to a certain amount. Following a letter circulated by the ILAE-EC, we revised our 2009 budget, and reduced it by a substantial percentage. Budgetary adjustments were made, trying to apply fairly similar percentages of reduction to every activity, but also taking into account the proximity in time of the event, its other financial supports, and suggesting that some events can be postponed to 2010. The revised budget, with about 35% overall cut, was approved by the ILAE-EC in April 2009, with the hope that these CEA efforts will be appreciated.

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Chair