

Global Education Agenda

for
EPILEPSY



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Abbreviations, Acronyms and Definitions

Academy	Academies organize and certify educational courses on a regional level.
AES	American Epilepsy Society
ALADE	Academia Latino-Americana de Epilepsia (Latin American Epilepsy Academy)
ASEPA	Asian Epilepsy Academy
Chapter	ILAE has national chapters in 98 countries with over 15,000 members. Each national chapter has elected officers and members who are doctors and other health care professionals interested in epilepsy
CNAR	Commission of the North American Region
EUREPA	European Epilepsy Academy
Faculty of 1000	ILAE international database of professionals with competence, ability and motivation to contribute to ILAE educational initiatives in all areas of epileptology
IBE	International Bureau for Epilepsy, established in 1961 as an organisation of laypersons and professionals interested in the medical and non-medical aspects of epilepsy.
IBRO	International Brain Research organization – an organization which among others provides access to educational materials in neuroscience. The ILAE is affiliated member on IBRO's governing council
ILAE	Founded in 1909, the International League Against Epilepsy is the world's pre-eminent association of physicians and other health professionals working towards a world where no persons' life is limited by Epilepsy. Its mission is to provide the highest quality of care and well-being for those afflicted with the condition and other related seizure disorders (www.ilae.org)
ILAE-EC	Executive Committee of the International League Against Epilepsy consisting of nine officers who are elected for four year terms by the national chapters
PAM	Professionals Allied to Medicine – non-medical health professionals
Summer school	Summer schools are advanced teaching courses under the auspices of chapters and regions
VIREPA	Virtual Epilepsy Academy – ILAE distance education program via internet
WHO	World Health Organization

1 Introduction

Why a global education agenda?

Education is one of the primary goals and purposes of the International League Against Epilepsy (ILAE). Educating their members – professionals in the field of epilepsy – plays a key role in improving care for the people living with the burden of epilepsy. In the meantime, the ILAE educational twig has grown to a notable educational branch, and education has become a “natural” part of ILAE, reflected not only in the International Congresses, which are goldmines also for excellent education.

While the ILAE has a long history of accomplishments in education, it is now necessary to act on the basis of a broader vision, which takes into account the new possibilities and the changing methods of education, and which encompasses the diverse needs of professionals in epilepsy in a wide range of cultural contexts, economic conditions, and health care settings.

With the development to the world wide web, education is potentially available for everyone – for the first time. The question of which education, which quality, and by which methods is therefore of concern to the ILAE and its Commissions, because education of high quality can be a powerful tool for shaping a comprehensive patient-centred approach to epilepsy care.

No less important is the question of who has the opportunity to use the educational courses and at what cost. In many regions of the world, the problems of availability, equitable and sustainable access to education have yet to be solved.

Around 10 years ago, the WHO together with the ILAE and the IBE launched the Global Campaign Against Epilepsy” (http://www.who.int/mental_health/management/globalpilepsycampaign/en/) with an urge on improving public understanding of epilepsy via educational programs throughout the world. On the background of this campaign, the necessity of establishing educational structures with reliable offers is better understood today.

Education is the basis for other issues in the field of epilepsy. It is an indispensable means to unlocking research and development of new treatment strategies.

To support education, the ILAE installed the Commission on Education and Task Forces. The Commission on Education responds to the need of developing education by defining its mission and clarifying its role. The Global Education Agenda is the first result of a workshop in Paris in June 2007 and discussions following this meeting. The Global Education Agenda – currently in development – formulates the agenda until 2012 and addresses priorities and steps.

This report will outline the objectives, strategies, and ways and means of educational activities of the ILAE primarily within a global framework. Future reports may incorporate educational activities within a regional framework (regional academies, summer schools etc.) in more detail drawing a more complete picture of world wide educational activities.

2 Objectives and Strategies

The overall objective is:

**To design and implement an educational system which makes
quality-controlled education in epilepsy globally available
to all professionals dealing with epilepsy**

Objectives

Strategies

Policy development

- To establish standards and guidelines for educational activities within the ILAE
- To identify educational gaps and initiate strategies to overcome
- Assist in developing regional policies
- Support partnerships and exchange of information between academies, countries, educational activities

Increased availability

- To install an educational website within the ILAE with educational material, an overview on activities, as well as support for organizers, and useful information for potential applicants
- To promote educational networks, mentorship / visiting professorship and all additional structural elements of academic education (video conferences, web-based exchanges, telephone conferences etc.)
- To promote staff exchange between centers with an emphasis on epilepsy
- To provide educational material
- To establish and make available a faculty of certified trainers and tutors to enhance education world wide

Quality improvement

- To promote and make use of all relevant educational methods in a modular system
- To support the development of curricula for various target groups and courses for distance education
- To establish measures for quality
- To establish standards and guidelines for funding and bursaries in education

2.1 Policy development

The provision of high quality education is essential to the goals and mission of the ILAE. Standards and guidelines for educational activity exist partially within regional or national activities or organization but have never been made to an overall issue. The predominant task will be to seek consensus on international standards and quality and to develop a dialogue between representatives of different regions. This is done already at various occasions including the International Regional and National Epilepsy Congresses, Conferences and Workshops, and now it will be the task to assemble and sum up these achievements.

In addition to initiate dialogue and seeking international consensus, the Commission will provide assistance in the form of training and advice to overcome identified gaps in education. With the help of ILAE Epilepsy Academy Office the Commission will assist in developing regional policies wishing to develop new or strengthen current initiatives for education.

2.2 Increased availability

Still there are many areas of the world where there is limited access to education, libraries and even electricity.

Education for professionals in epilepsy has to consider a variety of tools. Wherever possible, educational activities should be published on the website to enhance chances for participation. Furthermore a faculty of trainers and teachers is organized within a task force to provide teaching capacity. Yet, most important for acquiring new skills are educational networks, mentorship or visiting professorship which allow direct experience and insight in different modes of diagnostic and treatment especially for professionals from developing countries.

Accessibility of educational material and their effective use in learning environments requires concerted action and special effort. Shortages of material in languages other than English are an obstacle. The Commission on Education is aware of the necessity to pay attention to special cultural aspects of epilepsies. Therefore it is promoting the extension of language groups to further develop ideas and gain experience, especially with respect to Africa. Also the experience of the colleagues from ASEPA and the other regional academies (ALADE, EUREPA) are evaluated. The Commission is attentive towards education in minority languages.

2.3 Quality improvement

Traditionally advanced education for professionals in epilepsy is composed of a series of lectures. A more current and comprehensive view identifies quality seminars as those which actively engage the learners in the process of acquiring knowledge, skills, and attitudes necessary to become specialists in comprehensive epilepsy care. The Commission promotes and encourages the trainers to make use of a variety of educational methods including those which challenge the active participation of learners.

In the long run the Commission will develop core curricula for various target groups and for various forms of teaching (distance education as well as face-to-face education).

A system of accreditation and standards as well as guidelines for funding and bursaries will promote quality improvement through criteria and serve as a basis for transparency.

3 Ways and Means of Operation

The ILAE seeks to integrate and expand its modalities for training and capacity building for the education of professionals and production of materials. In the area of training the promotion of innovative methods, the use of the internet and the dissemination, sharing and exchange of information (partnership) and best practices are essential ways and means of operation.

To develop these ways and means of operation the ILAE decided to concentrate its educational activities and to clarify the roles of different layers. The Commission on Education has the tasks to develop models and structures in order to ensure that these tasks and goals are reached within the next years.

In addition, partners outside the ILAE are sought with educational experience. The ILAE was incorporated this year into IBRO and became affiliated organization in IBRO's Governing Council.

3.1 ILAE Office and Epilepsy Academy

Within the framework of the ILAE and in tight co-operation with the President and the Executive Committee, the Commission on Education is asked to establish an educational system globally available to professionals dealing with epilepsy.

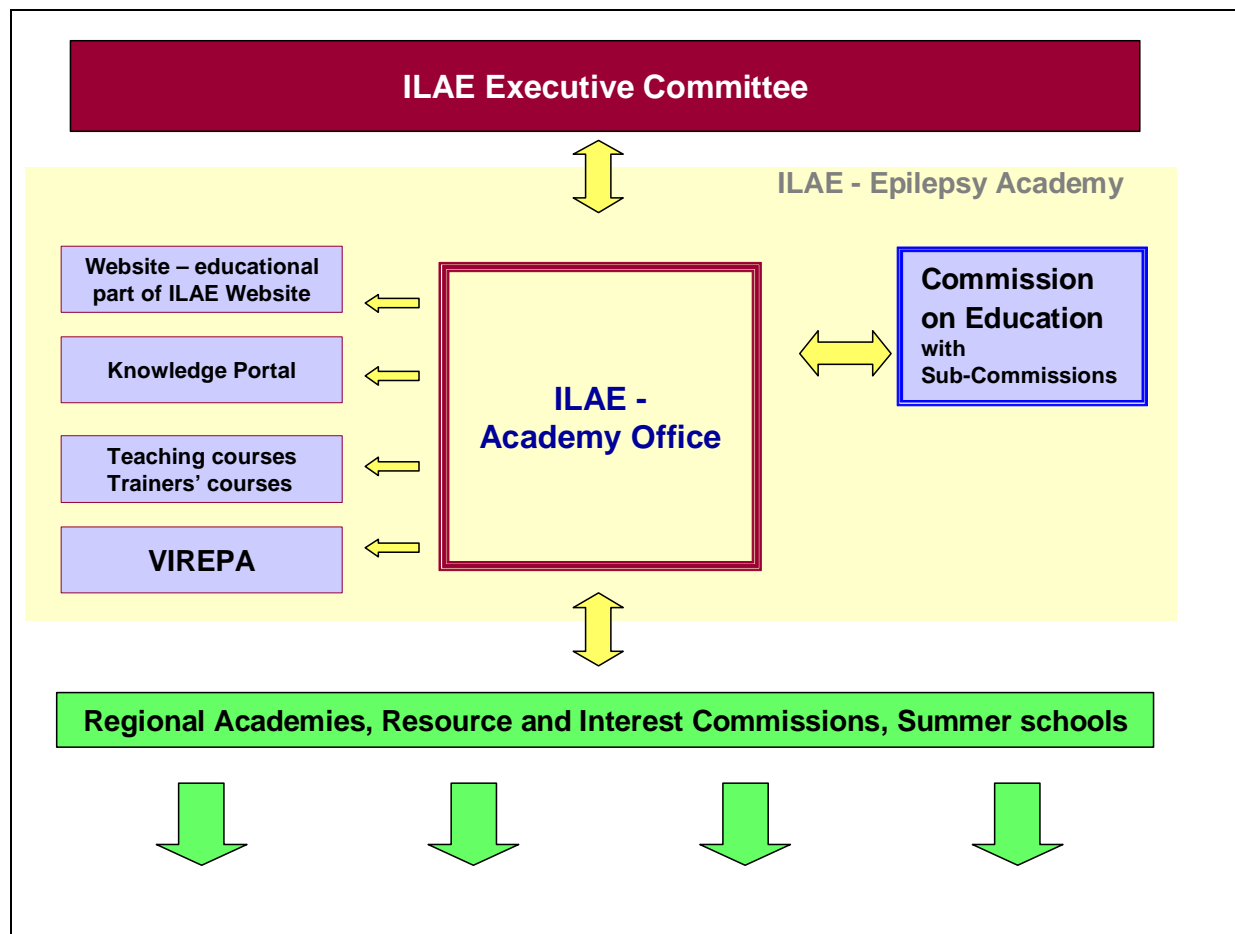
In a first step, an ILAE Epilepsy Academy Office ("OFFICE": office@epilepsy-academy.org) was installed and potential tasks were identified in order to establish durable structures for education and further develop high quality teaching programs. Together with the treasurer of the ILAE Executive Committee a budget together with administrative and organisational details has been set up.

Within the coming year the OFFICE will develop a variety of responsibilities including:

- to create a website to collect and publish all educational activities; to support course organizers with information on didactics, organization and faculty; to provide potential applicants with helpful information, and to update this website regularly,
- to collect information on educational gaps identified by regional organizations and academies, and to report this to the Commission on Education, and to initiate ideas how to overcome educational gaps together with regional academies,
- to provide educational material (Knowledge Portal) to academies, chapters and ILAE members in co-operation with the information officer of the ILAE EC,
- to develop courses in cooperation with the Commission on Education,
- to develop a guide on teaching methods for different course formats,
- to establish standards and measures for quality
- to organize the accreditation demands, collect the evaluation result and report to the Commission on Education,
- to develop a database for keeping records of bursaries (in cooperation with the regional academies) and provide overviews over amount and character of bursaries,
- to support the ILAE respectively the Commission in reaching its mission.

The system of dissemination, sharing and exchange of knowledge, information and material between the ILAE EC (possibly enhanced through an Education Officer), the Commission on Education, various sub-commissions and the OFFICE could be summarized as "ILAE Epilepsy Academy".

The Educational Branch of the ILAE



ILAE Executive Committee (Term 2005-2009):

President: Peter Wolf, Secretary-General: Solomon Moshé, Treasurer: Martin J. Brodie, Past President: Giuliano Avanzini, 1st Vice President: Emilio Perucca, Vice President: Chong Tin Tan, 2nd Vice President: Fredrick Andermann, Epilepsia Editors-in-Chief: Philip A. Schwartzkroin and Simon D. Shorvon, Information Officer: Edward H. Bertram, IBE President: Susanne Lund, IBE Secretary-General: Eric Hargis, IBE Treasurer: Mike Glynn

ILAE-Epilepsy Academy OFFICE: :

Verena Hézser-v.Wehrs, Petra Novotny, Heiko Holtkamp

Commission on Education:

Elza Márcia Yacubian, Sao Paulo, Brazil (Lusophone) - Chair -; Esper A. Cavalheiro, Sao Paulo, Brazil (Basic Science); Milda Endzinienė, Kaunas, Lithuania (Eastern Europe); Hassan Hosny, Cairo, Egypt (East Mediterranean); Jeffrey Noebels, Houston, Texas (North America); Margarete Pfäfflin, Bielefeld, Germany (PAM) - Secretary -; Perrine Plouin, Paris, France (Francophone) ; Alejandro Scaramelli, Montevideo, Uruguay (Latin America) - Treasurer - ; Bettina Schmitz, Berlin, Germany (Western Europe) ; Chong-Tin Tan, Kuala Lumpur, Malaysia (Asian-Oceanian) ; Ex officio, Verena Hézser-v.Wehrs, Bielefeld, Germany (Distance Education) ; Ex officio: Emilio Perucca, Pavia, Italy (Faculty of 1000) ;

Sub-Commission "VIREPA":

Catherine Chiron, Walter van Emde Boas, Jacqueline A. French, William Gaillard, Verena Hézser-v.Wehrs, Youshi Inoué, Najib Kissani, Holger Lerche, Emilio Perucca, C.T. Tan, Demetrios Velis, Elza Márcia Yacubian

Sub-Commission „Curriculum“ :

Selim Benbadis, Maria Paola Canevini, Greg Cascino, Shih-Hui Lim, Margarete Pfäfflin, Elza Márcia Yacubian

3.1.1 Virtual Epilepsy Academy (VIREPA)

VIREPA is the acronym for an international initiative offering and developing e-learning courses via an internet platform. It is administered and hosted by the OFFICE and runs under the ownership of the ILAE. An international expert group of lecturers was composed with respect to different topics. Resource and interest groups and Commissions of the ILAE were involved to provide courses of high quality. A controlled and prospective evaluation study proved the efficacy of this way of learning with the example of the first course in genetics (Wehrs et al. 2007; *Epilepsia* 48(5) 872f). Currently (2007/2008) the following courses can be booked:

- Genetics of epilepsy
- EEG in the diagnosis and management of epilepsies
- Neuroimaging
- Clinical pharmacology and pharmacotherapy

3.1.2 Teaching courses and Trainers' courses

The OFFICE is based on the expertise of the regional academy EUREPA which in the past has developed substantial structures for the international educational initiative. Teaching courses at International Congresses as well as courses for trainers in different languages and for different regions in the world build a background for setting up guides on teaching methodology and develop further courses together with the Commission on Education.

3.1.3 Knowledge Portal and Website

The provision of learning material easy accessible is one mean to overcome educational gaps. As a rule, learning material is provided by regional academies or commissions in their prevailing languages. The OFFICE will concentrate on educational gaps and on material with high impact. As substantial parts of the world especially African countries do not have easy access to internet, printed learning materials such as textbook or videos have to be produced taking into account different cultural values and approaches to epilepsy on a broader scale. Knowledge Portal and educational website – integrated into the website of the ILAE – are means not only to provide information but also to promote quality controlled standards in which case the material becomes an opportunity for exchanging experience between users and experts.

3.2 The Commission on Education and Partnerships

In contrast to other resource commissions of the ILAE, the Commission on Education is composed of members who represent regions, sub-commissions, academies or other educational organisations from around the world. Commission's members rely thus on an operative structure, and are fully engaged in education. The Commission works closely with the ILAE-Executive Board and with the regional academy EUREPA. The latter forms the seedbed for the ILAE-Epilepsy Academy and the OFFICE thus extending long-lasting structures for education.

Further tasks of the Commission are to develop high quality modular teaching programs and to support and monitor the OFFICE with the above mentioned priorities. Commission's report is published on the ILAE website.

The heart of educational activities lies at regional level. Regional educational activity has a long tradition in the ILAE, especially in some parts of the world. Arising from needs and gaps within regions, a variety of programs and structures were developed by regional/national chapter of the ILAE, by com-

missions or related institutions. Educational courses and supplementary academies were founded last not least with the aim to develop certified and accredited education in epileptology responding to demands of participants. The Commission will support and strengthen ties between educational groups or academies of regions or chapters which promote quality education. Hopefully within the next years, regional activities will open up to participants from all over the world and regions will develop mutually beneficial partnerships.

At the present time and for this edition, the global educational agenda limits itself to current regional activities which follow joint supra-regional activities and which are tracked through the OFFICE. A more complete evaluation of regional and world wide educational activities requires the functioning structure and communications proposed with this agenda in the first hand.

3.2.1 Strategic meetings

The annual meeting of the AES gives a background for the first and possibly future exchange between representatives of regional commissions and academies and the Commission on Education. The need for a comprehensive strategy became apparent when addressing the need of Southern American countries as Peru, Honduras and Santo Domingo. The Northern American Region will stimulate educational projects in these regions starting with Santo Domingo as pilot.

3.2.2 Epilepsy Collaboration Projects ECOP

The mutually beneficial partnership between those active in education is an ideal and as a rule a non-expensive way for disseminating education.

The ECOPs between the Commission of the North American Region and the Latin American ILAE Commission and the Latin American Academy ALADE are examples for such a partnership. Within one year a joint educational program was set up. Furthermore, a joint plan is followed with the aim to support the Caribbean, especially Haiti. As a result, the North American Commission started an initiative with the Latin American Commission for a joint educational program that includes visiting professorships, training fellowships and bilateral cooperation between chapters from both regions. These commissions have also started to work on a joint development plan for the Caribbean with the establishment of a Haitian Chapter as the first aim.

3.2.3 EUREPA

EUREPA plays a somewhat special role within the global education agenda. Founded by members from worldwide in 1996, EUREPA became involved in supra-regional activities such as teaching courses at European and International ILAE Congresses, Trainers' courses in different languages, some of them in cooperation with the French and Lusophone Section in different regions beyond Europe like in Brazil and in Africa, both with African participants. The main objectives of these trainers' courses are to improve teaching in the given settings of the participants and on networking within the group of trainers to strengthen their educational input in their regions.

VIREPA – the distance education program started some time before it was linked to the ILAE. EUREPA can be seen as nucleus of the OFFICE of the ILAE-Epilepsy Academy providing its expertise in international education. On the background of current structural changes, the Commission on Education takes responsibilities towards EUREPA. In a first step, criteria for responsibilities and tasks will be developed in accordance with the EUREPA Executive Board.

3.3 Establishing measures of quality

Taking into account the growing number of educational activities and courses, the Commission's forthcoming activities will focus on assisting trainers in their endeavours to define and implement standards for quality both in content and design based on outcomes that are responsive to local needs.

The Commission expects an ongoing process in reaching consensus on fundamental principles for monitoring participants and courses quality from a broader perspective.

3.3.1 Guidelines for accreditation of ILAE educational activities

Trainers who wish to use the ILAE logo and obtain certification for their educational courses are asked to pursue the following steps:

1. The program must be submitted to the ILAE-Epilepsy Academy OFFICE including faculty, title of lectures, detailed time schedule and source of funding. The target group, the learning objectives, and the teaching methods to be used must be clearly defined.
2. The application form is available online www.epilepsy-academy.org (/document center / forms)
3. The application will be submitted to the OFFICE which contacts the relevant bodies for approval. If it is an industry-sponsored course, any promotional part of the program must be clearly identified and is excluded from accreditation.
4. Courses can be accredited only if directed by an independent scientific program committee, at least one member of which must belong to an ILAE chapter.
5. There must be a procedure for evaluating the quality of the event. Aims and evaluation procedure must be clearly explained. The evaluation form must include the following question: "Was this course promotional for any pharmaceutical product or company? Yes/No. If yes, please provide details".
6. ILAE accredited courses will be published on the ILAE website www.ilae.org (education)

3.3.2 Guidelines for funding of courses

Although the quality of courses has the highest priority, the lack of finances can obstruct taking place and quality. Generally, all attempts should be made to mobilize financial sources outside the ILAE. For the term 2005-2009, the ILAE will only support transnational educational activities from its central funds, which are organised by own ILAE Commissions and Academies in particular:

- Summer schools and similar advanced courses
- Distance education programs and
- Exchange programs.

Nevertheless, course directors can ask for funding of otherwise uncovered costs given the following criteria:

1. Only courses that fulfill quality criteria may be entitled to ask for funding.
2. Courses that are not covered by the direction of a regional academy can ask for funding.
3. Courses must have an impact on region (region-added-value) or deal with a special rare topic (topic-added-value)
4. Interactive elements in courses are highly recommended.
5. Minimum duration of courses: one day

3.3.3 Guidelines for bursaries for professionals in epilepsy

Professionals who want to apply for a bursary (e.g. for travel to congresses, costs for courses, onsite-training or fellowship, distance education, visiting professorship) are asked to apply for bursaries. The applicant must be aware that the names are stored in the ILAE-OFFICE database. The body for the decision of bursaries entrusts to the following aspects and takes into account:

1. The economic level of country in which the applicant works and the individual income
2. His/her commitment to epilepsy
3. His/her curriculum vitae
4. His/her age (younger ones should have some priority)
5. The potential impact to others if this person is supported
6. Previous bursaries (not more than one bursary per year)
7. The Chapter's recommendation (if applicable)
8. His/her abstract/formulation of interest/case report (if applicable)

The evaluation of the aspects and the decision about the bursary is taken by at least two persons of the commission in charge. The OFFICE keeps track of provided bursaries, last not least to identify well trained professionals and to include them as educational trainers.

The commission in charge of decision is aware that sometimes the rule no. 6 can be violated: when otherwise places within courses remain vacant or no other applicants are available and the applicant can finish a specific education.

4 Next steps, Priorities for 2008 – 2012

The legal and administrative conditions for implementation of the OFFICE will be clarified within the next year.

If possible objectives should be specified with respect to the number of distant education participants, the number of seminars in Africa and other developing regions, sustaining new and excellent initiatives e.g. in Brazil, Argentine and China, the inclusion of non-medical professionals and patient education programs.

By repeating and diversifying the offers of VIREPA with regard to its course languages, course content and format as well as with the implementation of a Knowledge Portal to be expanded and updated over the years, it is expected to increase the use of VIREPA in the following years substantially.

The Commission on Education will proceed according to the listed responsibility. It will specifically support any quality controlled educational activities in areas with less educational initiatives such as Africa.

The Global Education Agenda, which encompasses objectives and strategies applicable for educational activities on every layer, will be disseminated after formal adoption through the ILAE.

By 2012 the Educational Commission will provide information about the achievements. The Commission should by then have brought its ultimate goals and mission into a steady process.

5 Annex I (Regional educational bodies)

5.1 *Regional Commissions (2007):*

Commission on Asian and Oceanian Affairs

Shi-Hui Lim (Chair), Leonor Carbral-Lim, Shichuo Li, Satish Jain, Patrick Kwan, David Reutens, Chong-Tin Tan, Kazuichi Yagi

Commission on Eastern Mediterranean Affairs

Hassan Hosny (Chair), Chahnez Triki, Hanan Mostafa, El Shakankiry, Mohamad Mikati, Sonia Khan,

Commission on European Affairs

Michel Baulac (Chair), Meir Bialer, Milda Endziniene, Alla Guekht, Peter Halasz, Svein Johannessen, Cigdem Ozkara, Bettina Schmitz, Federico Vigevano, Peter Wolf

Commission on Latin American Affairs

Marco T. Medina (Chair), Patricia Campos, Marcelo Devilat Barros (secretary), Salvador Gonzalez Pal (treasurer), Alejandro Scaramelli, Henri Stokes, Elza Márcia Targas Yacubian

Commission on North American Affairs

Sam Wiebe (Chair), Amza Ali, Lionel Carmant, Robert Fisher, Jean Gotman, Sheryl Haut, Jeffrey Noebels, John Pellock,

5.2 *Regional Academies (2007)*

AES - American Epilepsy Society

ALADE - Latin American Epilepsy Academy

ASEPA - Asian Epilepsy Academy

EUREPA - European Epilepsy Academy

5.3 *Examples of Regional Educational Activities*

Summer schools (San Servolo, Eilat, Baltic Sea Summer School, Latin American Summer School, etc.)

Migration Courses

Francophone Courses

Lusophone Courses

Anglophone Courses

Hispaniola Courses

HCPC – Health Care Professional Courses

PAMs Courses

Fellowship Program

Visiting professorship