INTERNATIONAL League Against Epilepsy



2008 ANNUAL REPORT

OUR MISSION

The International League Against Epilepsy, founded by a group of international neurologists in Budapest in 1909, is a global professional non-profit international organization, and a non-governmental organization in official relations with the World Health Organization.

The ILAE's objectives are:

- O To advance and disseminate knowledge about epilepsy
- O To promote research, education and training
- To improve services and care for patients, especially by prevention, diagnosis and treatment

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IBE PRESIDENT Susanne Lund Stockholm, Sweden

IBE SECRETARY-GENERAL Eric Hargis Maryland, USA

IBE TREASURER Mike Glynn Dublin, Ireland



PRESIDENT'S REPORT



THE EXECUTIVE COMMITTEE

According to our Constitution, the Executive Committee (EC) includes three types of officers: six elected (President, two Vice Presidents, Secretary-General, Treasurer, and the Immediate Past President), three exofficio (the President, Secretary-General, and Treasurer of the International Bureau for Epilepsy (IBE)), and two appointed (Editors-in-Chief of *Epilepsia* and Information Officer). As a result of the last elections, all elected officers came from either Europe or North America, a situation which seemed paradoxical at a time when the ILAE had become a much more global organization than in the past, with 98 Chapters in all regions of the world. It was also somewhat of an anomaly, since previous ECs had often included officers from Asia, Latin America or both.

At the 2005 General Assembly of the ILAE in Paris, an amendment to the Constitution was accepted which says that if after the global elections "any fully operational region of the ILAE is not present on the EC, the Chapters of this region shall elect an additional Vice President (VP). This VP will be a voting member of the EC and not be considered as a regional VP, but unrestrictedly share the global responsibilities of the EC" The EC at its meeting in Paris, using the description of the "Regions" in our Bylaws, agreed that a region would be considered fully operative when it: has a Regional Commission that meets from one to three times per year and submits a budget; is proactive to develop, stimulate and coordinate the epileptological agenda in its part of the world; coordinates local education via formation of a regional academy; and organizes Congresses under the direction of our International Director of Meetings. The Regional Commissions of the regions that were not present on the elected EC were invited to apply for such a VP, and Asia/Oceania was the only region that did so. Since this very active and dynamic region more than fulfils the established criteria, an election was held in the region for an additional VP.

One of the appointed officers, the Editor of *Epilepsia*, decided that he did not want to continue with this office beyond 2005. The position was put out for tender, and many interested and highly qualified candidates applied. At the end of a selection process that involved the EC (including the outgoing Editor), we selected a joint editorship—a basic researcher and a clinician—that also represents the two scientifically most active regions of ILAE, Europe and North America. One of the new Editors was at the time already serving as Information Officer. Therefore, there has been a midterm change in this office; again, a tender was put out, and the EC appointed a new Information Officer from the applications received.

At the end of these procedures, the Executive Committee now consists of:

- Peter Wolf (Denmark), President
- Solomon L. Moshé (USA), Secretary-General
- Martin J. Brodie (UK), Treasurer
- Emilio Perucca (Italy), 1st Vice President
- Frederick Andermann (Canada), 2nd Vice President
- Chong-Tin Tan (Malaysia), Vice President
- Philip A. Schwartzkroin (USA), Co-Editor-in-Chief, *Epilepsia*
- Simon Shorvon (UK), Co-Editor-in-Chief, Epilepsia
- Edward H. Bertram III (USA), Information Officer
- Giuliano Avanzini (Italy), Past President
- Susanne Lund (Sweden), IBE President
- Eric Hargis (USA), IBE Secretary-General
- Mike Glynn (Ireland), IBE Treasurer

THE PRIORITIES

The EC has set three priorities for our term of office: education, the development of epilepsy care worldwide, and translational research.

Education

It is this EC's conviction that education of all professionals who are expected to provide care for patients with epilepsy is the key to any progress, also that the provision of high-quality education attracts and binds young talent to our field. It is in education that we can make the best investment of our resources. It is our ambition to be pioneers in developing the best educational system of all medical specialties. A wide range of approaches has been taken to reach this goal. During the first half of our term of office, the focus of the EC has been on this priority.

- 1. Organization
- Educational Commission: The ambitious horizon we have set requires concentrated and innovative work, and a new commission has been appointed to deal with it. The Commission includes representatives of all regional Commissions/academies, and has subcommissions for education in French and Portuguese languages, for basic research, and for education of professionals allied with medicine. Following a comprehensive review of the present educational landscape, the Commission is now starting to work on a global master plan.
- Academies: In both the European and the Asian/Oceanian regions, the establishment of epilepsy academies (EUREPA 1996 and ASEPA 2003) as educational arms of the regional

PRESIDENT'S REPORT (continued)

commissions has been a very successful approach. The two academies have developed programs that are tailored to the needs of the respective regions and have contributed much to their progress. This success has encouraged the Latin American Commission to start their own academy in 2007 (Academia Latino Americana de Epilepsia, ALADE).

2. Activities

• Residential Courses, Summer Schools: Residential courses are held in retreat settings and extend up to two weeks, during which time a limited number of postgraduate students work with a group of tutors and lecturers. The courses apply a variety of methods of active learning in groups and group design of research projects.

The annual Summer Schools of San Servolo in Venice, under the aegis of the ILAE, have been taking place since 2002. The Commission on European Affairs (CEA) has, since 2005, offered a biennial Summer School on antiepileptic drug clinical pharmacology and pharmacotherapy in Eilat (Israel). In 2007, CEA started an annual "Migrating Course" on epilepsy for secondary care physicians in Central and Eastern Europe. Sub-regional residential courses supported by the CEA include the Baltic Sea Summer School on Épilepsy for young postgraduates (started in 2007) and the Caucasus Summer School that will take place for the first time in 2008. The Latin American Summer School (LASSE), started in 2007, will become an annual course. The first LASSE, near São Paolo, Brazil, brought together young postgraduates from all over Latin America and some Portuguese-speaking Africans. All who became involved in this first LASSE consider it a key event that has opened a new era for the development of epilepsy in the region.

- Educational seminars in underserved locations: Offerings of special seminars in underserved locations is an approach that has successfully been taken by the Asian/Oceanian Commission and Academy. Groups of senior epileptologists address primary and secondary care physicians, especially in countries without ILAE chapters. These seminars provide state-of-the-art lectures on topics relevant to issues of epilepsy care. ASEPA also offers a course and board certification in EEG.
- Distance education: To make epileptological education accessible more widely, EUREPA has started to establish distance education modules in various fields of epileptology (i.e., Genetics, EEG, Neuroimaging, and Pharmacotherapy). These modules are tutored courses that use advanced methods of interactive distance education. Their superior efficacy, compared with mere self-study using the same educational materials, has been demonstrated by a prospective evaluation with a waiting-list control group (Hézser-v.Wehrs V et al. *Epilepsia* 2007;48:872–879). Via VIREPA (Virtual Epilepsy Academy), a section of EUREPA, this activity is constantly renewed and expanded, and is available globally.

- Fellowships: Fellowships for on-site training in recognized centers and institutes are an integral part of our educational approach in Asia/Oceania. The selected fellows often come from countries without established specialist care for epilepsy, and are expected to take a role in their nation's development of epilepsy care following their training. Fellowship opportunities are also being developed in North America and Latin America (to reach out to underserved sub-regions), and also in sub-Saharan Africa.
- 3. Resources
- Funding: The budgetary responsibility for educational activities is primarily with the organizers of these courses, who are expected to find multiple sources of sponsorship. For selected programs, support is given by the ILAE, typically as bursaries. For this purpose, the ILAE and some regional commissions use surpluses from the international and regional Congresses.
- Faculty: The expanding educational agenda requires many volunteers who are willing to serve as teachers and tutors. The First VP is building up a "Faculty of 1,000" for this purpose.

Epilepsy care

This priority is highlighted by a new commission on which all regions are represented. The main task of the Commission is to develop concrete initiatives to improve epilepsy care, especially in underserved regions. This Commission is also responsible, on behalf of the ILAE, for the Global Campaign against Epilepsy which we conduct together with the IBE and the World Health Organization (WHO). To give the Global Campaign increased momentum, more responsibility has been given to the regions. Each region is expected to establish a regional Global Campaign steering committee, to include the regional Commission Chairs and the regional Mental Health Advisors of the WHO (see below). The EC plans to focus on this priority in the second half of our term of office.

Translational research

Basic research on epilepsy has increasingly become concerned with issues that are related to prevalent clinical topics. This focus has resulted in significant progress, for example in conceptual approaches of molecular genetics and functional neuroimaging. Some of our educational programs are aimed at strengthening this development.

- The above-mentioned summer schools in Venice/San Servolo and Brazil (LASSE) aim at bridging basic research with clinical epileptology.
- Some educational seminars at ILAE Congresses also address translational research. This was the case at the Latin American Congress in Guatemala 2006. An ambitious educational seminar is being planned for next year's Asian/Oceanian Congress in Xiamen (China).

PRESIDENT'S REPORT (continued)

Preliminary talks about possible cooperation have taken place with the Academy of Science of the Developing World (TWAS). It is hoped that this contact will become more substantial at the occasion of the meeting in China.

THE COMMISSIONS

The work of our Commissions is an important and integral part of our activities. Commissions are appointed by the President as recommended by the EC. The ILAE has both regional and problem-oriented commissions.

Regional Commissions

With almost 100 national chapters, the ILAE has reached a size that requires an organizational structure between the Chapters and the global EC. The regional commissions fulfill this need. Each regional commission has a membership that is partly elected by the Chapters of the region and partly appointed by the ILAE President. The regional Commissions now include the following:

- Asia and Oceania
- Eastern Mediterranean
- Europe
- Latin America
- North America

The African region is the last major region with no commission of its own. The number of Chapters is increasing there, and there is reason to hope that an African Commission can be established toward the end of our term of office.

The role of the regional Commissions for the further development of the Global Campaign, in cooperation with the regional structures of the IBE and the WHO, has already been mentioned above. In addition, there are joint activities of some regional Commissions that relate to our general priorities. Thus, the North American and Latin American Commissions have in 2007 initiated: an ambitious plan of exchange programs and networks for the development of underserved areas; an initiative for epilepsy care development in the Caribbean; and a specific project for the island of Hispaniola where our Chapter in the Dominican Republic will assist with developing epilepsy care in Haiti, the neighboring country.

A series of trainer courses in the Portuguese language is a joint activity of the Portuguese and Brazilian ILAE Chapters, and includes the lusophone countries of Africa. It is supported by the Commission on European Affairs and the Educational Commission, and has resulted in a bilateral fellowship program of Brazil and Mozambique.

Problem-oriented Commissions

These Commissions focus on many aspects of the professional work within the ILAE's agenda. Among other tasks, they elaborate reports, guidelines and recommendations that become official documents of the ILAE when they have been accepted by the EC. These Commissions comprise at present:

- Classification and Terminology
- Diagnostic Methods
- Education
- Epilepsy Care
- Genetics
- Neurobiology
- Neuropsychiatry
- Pediatrics
- Therapeutic Strategies

Each of these Commissions has a defined mission, and most of them have established sub-commissions and task forces to address specific problems.

On October 19, 2007, all Commission Chairs met in Brussels for a long-range strategic planning meeting. The progress reports of the Commissions' activities so far provided an exciting comprehensive overview of all our activities and initiatives. What has been reported above is only a selection of highlights. The Commission reports provide exciting examples of the rich, varied, and enthusiastic activities ongoing at all levels, involving many different types of networks, which today are perhaps the most distinctive feature of our organization. We can be proud of this range of activity.

THE CONGRESSES

The ILAE was founded at the occasion of an International Congress, and for many decades, the International Epilepsy Congresses were almost the only occasions of public visibility of the League. Although this situation has changed dramatically — see above for examples of ILAE's active commission work (starting with the international classifications of seizures and syndromes), regional activities, our educational agenda, and the Global Campaign against Epilepsy — our congresses remain one of the most important parts of our activity. They provide the most important forum in epileptology for the presentation of new findings, scientific exchange and update. Global international Congresses occur in odd years, and alternate with a series of regional international Congresses in even years. As a consequence of the introduction of quality control measures in some of these Congresses, these regional events have become increasingly attractive and economically successful. The financial surpluses which some Congresses generate are at present used for two purposes: (1) to support good quality science and education at meetings of the low-budget regions; and (2) for the support of our educational programs (e.g., to provide support for young investigators to attend the future Congresses, for residential courses in the region and beyond, and participation in distance education).

During the present term of office, regional Congresses were held in Kuala Lumpur (Asia/Oceania) 2006, Luxor (Eastern Mediterranean) 2007, Helsinki (Europe) 2006, and Guatemala (Latin America) 2006. The traditional Annual Meeting of the American Epilepsy

PRESIDENT'S REPORT (continued)

Society (AES) in San Diego was for the first time declared a joint meeting with the North American Congress of Epileptology, and will have this label every other year (and thus be in phase with the other regional Congresses). The International Epilepsy Congress in 2007 took place in Singapore. The next International Congress, in 2009, will be the ILAE centenary meeting and will be held in Budapest where the ILAE was founded in 1909. Apart from the European Congress of Epileptology, all the above-mentioned Congresses are joint meetings with the IBE.

ORGANIZATIONAL PHILOSOPHY

The ILAE was founded, in 1909, primarily as an international society that soon established national committees. Today, the national organizations that constitute its membership are all legally independent entities, incorporated in their respective countries. Their individual memberships vary from a handful to over 2,000, and their resources and activities vary widely. Some are more aware than others that they are part of a global organization. Since the establishment of an intermediate organizational level between the ILAE EC and Chapters — the regional Commissions — regional identities have developed in addition, as intended and expected. The challenge we face with this structure is to ensure an optimal balance between EC, Regions, and Chapters, a balance which works best to encourage participation by all those who would like to be involved in our manifold activities. One of the ongoing issues to be addressed is the adequate participation of all regions in our global agenda and in the EC. This balance is not easy to find. It is presently under intense discussion of the EC, and was also part of our dialogue with the Regional Commission Chairs last October.

THE COMING ELECTIONS

In 2008, the procedures to elect the next Executive Committee (EC) will start under the direction of an Election Committee chaired by the Immediate Past President. The first step in this process is the election of the new President from a slate of candidates who must fulfill the precondition of having served at least one term of office on the EC. This requirement is to make sure that the candidates for President have experience with our organization. It is not yet known how many of the possible candidates will actually stand for election, but they all will be given an equal chance to present themselves publically and convince our membership that their performance and accomplishments in the service of epilepsy merit their election to the highest office of our organization.

In the second step of the election process, all Chapters will be invited to nominate candidates for the other offices, and the persons who receive most nominations will then be put to a general vote. We are fortunate that around the world there are now many worthy and dedicated people — men and women — who are willing to serve on the EC. The ILAE, in spite of its dynamism and ability for renewal and progress, is a slightly atavistic organization in one respect: all its officers are, and have been for decades, only men. Therefore, the next President, whoever it will be, will again be a man. I feel strongly that the time has come for a change, and very much hope that the Chapters will nominate some of the excellent women who are active in our Chapters and Commissions to be strong candidates with a good chance to be elected.

> Peter Wolf President

SECRETARY-GENERAL'S REPORT



During the past year, we continued activities aimed at providing outstanding educational programs and opportunities, coordinating effective translational research efforts and delivering the best epilepsy care worldwide.

CONSTITUTION AND BYLAWS: We have composed an amendment to the Constitution and the Bylaws. A summary of the document was published in *Epigraph* (http://www.ilae-epilepsy.org/Visitors/ Publications/Winter2008.cfm) and the full version was posted on the Web site (http://www.ilae-epilepsy.org/ Visitors/About_ILAE/ProposedChanges.cfm). The document was discussed and approved at the Chapter Convention of the 2008 Asian Oceanian Epilepsy Congress (AOEC) and will be discussed at the 2008 European Congress on Epileptology (ECE) and Congreso Latinamericano de Epilepsy (LACE) chapter conventions. The amendment will be presented to the 2009 General Assembly for ratification.

CHAPTER NEWS: One of the main responsibilities of the Secretary-General is to promote Chapter development and support their activities. The following Chapters were accepted by the General Assembly in 2007: Uganda and New Zealand. The following Chapters were provisionally accepted by the Executive Committee: Ghana, Republic of Guinea and Vietnam. The final acceptance will be at the 2009 General Assembly.

We are currently working on the applications from Haiti, El Salvador, Kuwait, Libya, Mozambique, Nigeria, Oman, Puerto Rico, Republic of Guinea, Sierra Leone, Sudan and Yemen, Sri Lanka, Mali, Uzbekistan, Bosnia Herzegovina, Ivory Coast, Luxembourg, Iran, Cambodia, Rwanda and Palestine. In the discussions involving new Chapters, we have included the regional Commissions, as the regional Commissions know better the particulars of the region and may provide guidance and input to issues that may be region-specific. The Asian-Oceanian Commission is very active in this role. Unfortunately, we have had no communication with Burkina Faso and Congo. A disaffiliation warning letter was sent to both.

We have prepared sample letters providing guidelines on how to write a Constitution and Bylaws; these can be used by prospective Chapters when they prepare their application to join our organization. These are available at the Brussels office. **COMMISSIONS:** The League's Executive Committee together with the Commission Chairs has developed the following policies. They can be found on the Web site.

ILAE Policy & Procedures document for the Commissions (http://www.ilae-epilepsy.org/Visitors/ About_ILAE/Resource.cfm)

Procedures and Guidelines regarding commission meetings during Congresses

(http://www.ilae.org/Visitors/ CommissionReportsActivities.cfm)

Conflict of interest policy

(http://www.ilae-epilepsy.org/Visitors/ CommissionReportsActivities.cfm)

There is an active collaboration among the different Commissions. Thus, the North American and Latin American Commissions have established educational programs and improve patient care within the western hemisphere. The Neurobiology Commission and the Therapeutic Commission organized a conference just before the 2007 American Epilepsy Society Annual Meeting to discuss approaches to enhance new drug development, learning from past experiences with failed or successful drugs. The same two Commissions are also working on developing a position paper to better classify cortical dysplasias; a meeting is scheduled to take place in Istanbul, Turkey at the end of October 2008. The Pediatrics Commission is working with the World Health Organization (WHO) for the development of guidelines for the diagnosis and treatment of seizures in infants and children. Participants include League, IBE, and OASI Institute for Research and Mental Retardation and Brain Aging and WHO Collaborating Center for Training and Research in Neuroscience. The Neurobiology Commission is also actively working with the sub-commission of Neurobiology of the Educational Commission to create educational programs across the different regions. There is also a joint ILAE-IBRO project to create a summer school in Africa. Finally, there is an effort, spearheaded by Drs J French and H Cross, to provide an educational course in Africa under the aegis of the American Epilepsy Society (AES), the UK Chapters, Dr Perucca, the ILAE Commissioner for African Affairs and the Global Care Commission. A pre-meeting is scheduled in Berlin in September 2008.

The Executive Committee has approved the following Commission reports from:

- 1. The sub-commission for Pediatric Surgery created by the respective commissions of Therapeutics and Pediatrics from the previous Executive Committee published in *Epilepsia*.
- 2. The Therapeutics commission on AEDs on the 'Best Practice Guidelines for Therapeutic Monitoring'.
- 3. European priorities research document (submitted to *Epilepsia*).

SECRETARY-GENERAL'S REPORT (continued)

TRANSLATIONAL RESEARCH: A Translational Research Workshop took place in Singapore in July 2007 during the Chapter Convention of the 2007 International Epilepsy Congress. The Workshop developed specific recommendations. Currently, various Commissions are working closely with the Executive Committee to identify the means and funds to implement these recommendations.

AED DATABASE: There is a need to update the database on the Web page. Information is being collected from WHO by Giuliano Avanzini and data will be collected at the upcoming Chapter conventions. A printout of each country's current list of drugs will be provided to the Chapters to update and correct errors. Bob Fisher will supervise the project. **STAFF CONTRACT:** A new contract was signed with Peter J. Berry, CAE who has been given the title of Chief Staff Office.

During the past year, I have received tremendous help from the Executive Office: Peter Berry, Nele Devolder, Sofie Peters and Cheryl-Ann Tubby. I am looking forward to another great year.

Finally, the office is working with the International Director of Meetings (IDM) on logistical issues relating to the next series of regional Congresses in 2008 and of course the Centennial Congress in Budapest in 2009. The Centennial Committee is preparing an outstanding program under the visionary leadership of Simon Shorvon. I hope I will see you all there to celebrate our League's achievements.

> Solomon L Moshé, MD Secretary-General



STAFF REPORT



ILAE's professional staff enables the volunteer leaders to focus on the strategic direction of the League and to develop new programs and services. The staff manages and coordinates the League's programs and services – chapter administration, finances, web site, publications, and support to the Executive and Management Committees. The staff operates from two locations – Brussels, Belgium and Hartford, CT, USA.

Leading the team is Peter J. Berry, CAE, Chief Staff Officer. Peter brings to the position more than 30 years of experience in association management.

Peter's role is to oversee all staff services. He works closely with the President and other Officers in the planning of the Executive and Management Committee meetings.

Nele Devolder serves as the Assistant Director and Sofie Peeters as Membership Services Coordinator. In 2008, Nele and Sofie worked to accomplish the following:

Executive Committee and Chapter Administration:

- Executive Committee: Attended the Executive Committee meetings in Brussels, Belgium and Venice, Italy. Coordinated the logistics of these meetings, prepared and shipped the agenda books, and produced the meeting minutes.
- Chapter Development: Worked closely with the Secretary General to develop new chapters. Contacts with following countries were established: Ghana, Sierra Leone, Cameroon, Mozambique, Ivory Coast, Sudan, Haiti, Zambia, El Salvador, Kuwait, Libya, Nigeria, Oman, Puerto Rico, Guinea and Vietnam. Several of these are in the process of being accepted.
- Communication: A core responsibility of the Brussels Office is to be the central point of contact for all chapters. A database of each Chapter's Officers is maintained on the website and the office communicates with the chapters frequently on dues, elections, and on other administrative issues.

Donna Cunard, MBA, is the League's Financial Manager, working closely with the Treasurer. Donna oversees all of ILAE's financial transactions and the production of the Association's monthly financial statements. She also liaises with the Association's accountant regarding the preparation of the tax return and Accountant's Report.

The League's Web Site Project Manager is Cheryl-Ann Tubby. Cheryl-Ann's main volunteer contact is the Information Officer. In addition to her Web site management responsibilities, Cheryl-Ann also coordinates the production and distribution of Epigraph, the League's newsletter and the Annual Report.

We thank the ILAE Officers, Chapters, and Commissions for their support and cooperation during the past year. It is an honor and a privilege to work with the ILAE.

> Peter J Berry, CAE Chief Staff Officer



TREASURER'S REPORT

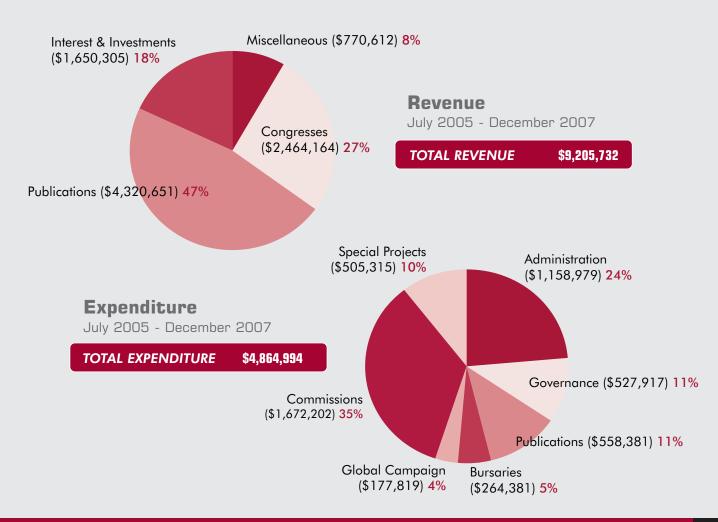


This Annual Report will review two and a half years of financial information from July 2005 to December 2007 reflecting an adjustment in the League's fiscal year. On the advice of our auditor, the fiscal year end was changed from June 30 to December 31st to be consistent with that employed by the International Bureau for Epilepsy (IBE). This accounting adjustment has refined the reporting structure for the League's day-to-day activities as well as facilitating the exchange of joint ILAE and IBE financial information and Congress reports.

Financial information for the entire period is presented in the accompanying two sets of charts. The pie charts consolidate the finances for the 30-month period whereas the bar charts separate this information into three accounting periods. The first accounting period from July 2005 to June 2006 includes the surplus from the successful 26th International Epilepsy Congress held in Paris. The second period from July 2006 to December 2006 represents a shortened analysis to accommodate the change in fiscal year. Three Regional Congresses were held during this time, including the 7th European Congress on Epileptology in Helsinki, the 6th Asian and Oceanian Epilepsy Congress in Kuala Lumpur and the 4th Latin American Congress on Epileptology in Guatemala. This material also includes an accounting adjustment for a full year of *Epilepsia* royalties. During the third accounting period from January 2007 to December 2007, the 1st Eastern Mediterranean Epilepsy Congress was held in Luxor and the 27th International Epilepsy Congress took place in Singapore.

Two policies adopted by the Executive Committee have had an impact on the League's financial operations. The investment policy, focusing on maximizing returns with minimum risk, has provided sufficient funds over the past few years from earnings to support a range of projects. According to the League's spending policy, these earnings are dedicated to new projects and regional development with particular emphasis on epilepsy care and translational research.

(continued on page 14)



CUMULATIVE FINANCIALS

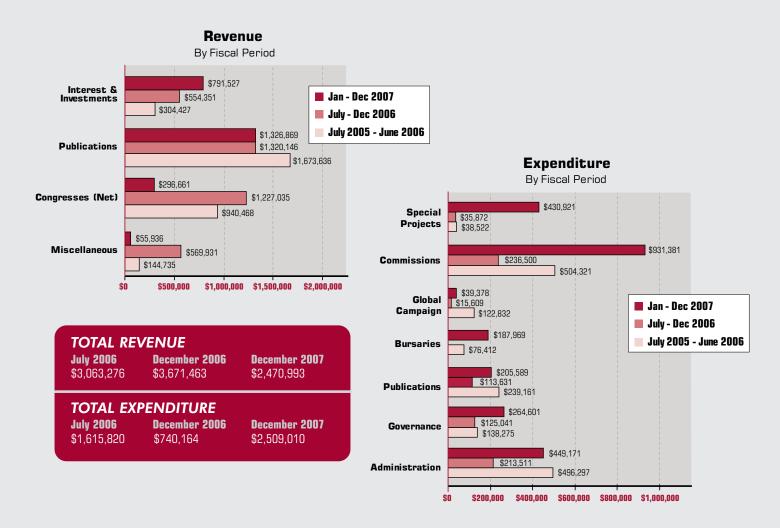
TREASURER'S REPORT (continued)

Although the League has been able to increase its reserves and maintain a solid financial position during this period, a general trend of declining revenue can now be anticipated. As discussed in previous reports, open access publishing and a fall off in pharmaceutical industry support is starting to have a negative influence on *Epilepsia* royalties and Congress returns. This declining revenue presents a major challenge to the League's ability to maintain its current substantial level of activity.

The current uncertain status of global economics will also present an ongoing challenge. While our investments continue to generate earnings, their overall market value has declined. This financial uncertainty will impact decisions that the League must make regarding the extent of future funding and the need for prioritization. Difficult decisions will be necessary to maintain a level of reserves that will ensure the League's financial viability. I'd like to mention just one more item of business the solidarity fund. This is composed of contributions donated exclusively for the use of Chapters in the developing world requesting assistance with payment of their annual dues. My appreciation, therefore, goes to the US, German, Swiss, Taiwanese, Hungarian, Canadian, Slovenian, Cyprian and Italian Chapters for their generous financial support since 2004. Finally, my special thanks go to our Financial Officer, Donna Cunard, for her efficient and sensitive handling of our day-to-day financial affairs.

> Respectfully submitted, Martin J Brodie Treasurer

FINANCIAL INFORMATION BY FISCAL PERIOD



REPORT OF ACTIVITIES – FIRST VICE PRESIDENT



During the last 12 months, I took part in the various activities initiated or supervised by the ILAE Executive Committee, by the Commission on Therapeutic Strategies and by the Commission on Education. Detailed information on these activities is provided in the minutes of the Executive Committee, Management Committee, and relevant Commissions.

In addition to these activities, I continued with my work as Chair of the Faculty of 1,000 Task Force. During the last 12 months, the efforts of the Task Force have been directed to finalizing, in collaboration with the Information Officer and staff, the Faculty database in a format suitable for inclusion in the ILAE Web site. This work has now been completed, and the biosketches of current Faculty members, who at present total 324, have been added to the website for free public access (except for sensitive data, such as Email addresses, for those members who asked for such data not to be publicly disclosed). An important feature of the format is that each Faculty member is provided with a personal password which will allow him/her to edit and update their biosketches as needed. Work is also ongoing to enlarge membership to the Faculty. To this purpose, invitations to join the Faculty have been sent to all non-members who will participate as invited speakers in the 2008 ILAE Regional Congresses, and to all certified EUREPA trainers.

Another activity which has absorbed much of my time is the evaluation and implementation of initiatives aimed at improving access to quality epilepsy care in Africa. These activities involve the gradual build up of a database listing ongoing projects of relevance to people with epilepsy in Africa, initiated or coordinated by governmental institutions, Non-Governmental Organizations (NGOs) and other organizations not necessarily related to the ILAE. Additionally, a number of projects are being planned which are targeted at achieving a self-sustainable improvement in epilepsy care in specific regions. The most advanced of the various projects under consideration, is an initiative aimed at training medical and nursing personnel and in improving infrastructure and access to epilepsy care in Ghana. This effort will develop within the context of the Global Campaign and in close collaboration with the Ghana Health Service and with BasicNeeds, a UK based NGO which focuses on improving the life of people with epilepsy and people with mental disease in underprivileged countries in Africa and Asia. Advanced negotiations are also in progress to obtain support for this initiative from a pool of pharmaceutical companies, and to establish broadly-based fund-raising for the Ghana program in partnership with BasicNeeds. More details on my work in this area are provided on page 65 from the report of the visit that Giuliano Avanzini and I made to Ghana at the end of April 2008.

> Emilio Perucca First Vice President







I mainly see my roles as facilitating and helping to achieve the ILAE mission in the Asia-Oceania region; as well as assisting the ILAE Executive Committee in its decisions with input from the region. The last year has seen steady progress as well as new initiatives in the Asia-Oceania region.

The Asia-Oceania Epilepsy Congress (AOEC) has traditionally been the most important meeting in the region. The 7th AOEC in Xiamen, China in May of 2008 had more delegates (>1,800), and abstracts (>400) than previous Congresses. This is despite the setback of visa problems and the earthquake in Sichuan just before the Congress. Australia has been chosen as the site of 8th AOEC in 2010. The AOECs are now firmly established as an important forum of exchange for the epilepsy community in all Asia.

There has been continuing growth in the educational workshops organized under ASEPA in the last year. Nine workshops were conducted in 2007, and 11 are planned in 2008, with a total of more than 1,000 participants in a year. As compared to the AOECs, the workshops are more comprehensive in the approach to a topic; can be organized in remote places; are affordable for a large number of physicians to attend even in poor countries; cost much less to organize; and are an effective way to reach out to areas where epilepsy care is poorly developed. In my view, it should be viewed as of equal importance to the AOECs.

A period of intensive training lasting from six to 12 months in a mature epilepsy center in the form of exchange fellowships is another important education effort. These fellowships continue to be offered by the Epilepsy Research Foundation of Japan, Japan Epilepsy Society, Epilepsy Society of Australia and ASEPA.

The two-part ASEPA-ASNA EEG Certification examination is being held in Xiamen and Hong Kong in 2008. There is growing acceptance of the certification in Asia. As the examination becomes increasingly popular, I believe this simple process will have an enormous impact on improving EEG reading in the region. There are four countries adjacent to the Mekong River, with a total population of 150 million. They are Vietnam (80 million), Myanmar (50 million), Cambodia (14 million), and Lao (six million). All four countries have a Gross National Product (GNP) of less than \$1,000 USD, with inadequate epilepsy care. I am glad to report some recent progress in the epilepsy movement in these countries. The recently formed Vietnam Association Against Epilepsy has been provisionally accepted as a new ILAE Chapter, making a total of 18 Chapters in Asia and Oceania. An ambitious epilepsy treatment project has been proposed in Lao, involving the one million population in the capital of Vientiane and in Luang Prabang province. The ILAE community hopes to raise about \$30,000 USD yearly from the European Commission, Japan and Taiwan Epilepsy Societies and CAOA, tentatively for three years, with other contributions such as from the Peter Wolf Foundation. An epilepsy association has also been formed in Cambodia, now awaiting official registration. The ASEPA awarded a six-month epilepsy fellowship to Dr Kyaw Linn in 2008. Dr Kyaw Linn is the only pediatric neurologist in Myanmar.

> Chong Tin Tan Vice President

EPILEPSIA REPORT



In the 2006 ILAE Annual Report, we reported on a series of changes that had been made to the Journal. These included the introduction of: themed issues, Online Early, Gray Matters (a section for letters, commentary, ILAE reports, etc), author services, a new style of reviews and editorials, and new Instructions for Authors. These changes were generally welcomed, and a readership survey carried out in late 2006 showed a high level of approval for the Journal. In 2007, we have continued to make further changes that include:

- Full color printing and new page design The Journal has become a full color production, with a specified palette of colours. The new page design, including color headings and more color figures (free to contributors) enhance the aesthetic appeal of the Journal. These changes were absorbed within the production costs of the Journal which did not significantly rise during the year.
- New cover design The cover and cover illustrations, too, have been updated. The cover images continue to be innovative and appealing.
- Online Open –To accommodate the new NIH and Wellcome Trust rules on open access, the Journal has developed an Online Open section, permitting open access (for a fee) of papers from the time of acceptance.
- Online Early We have now reached our target of publishing (online) papers online within 35 working days of acceptance.
- The second Morris-Coole Prize (10,000 euros) has been awarded for what was, in the judge's view, the best paper in the year 2007 (volume 48). The recipient – to receive this award at the European Congress of Epileptology - is Dr Nicola Marchi, (working in the laboratory of Damir Janigro, Cleveland Clinic), for his paper: Marchi N, Angelov L, Masaryk T, Fazio V, Granata T, Hernandez N, Hallene K, Diglaw T, Franic L, Najm I, Janigro D. (2007) Seizure-promoting effect of blood-brain barrier disruption. *Epilepsia*. 48:732-42.
- Legacy Project The Legacy Project has been completed (in 2007). A full set of the back issues of *Epilepsia* the whole Journal since 1909 has been digitized and placed online. This project is a major enhancement to the Journal. *Epilepsia* has for many years published many of the landmark papers in the field of epilepsy, and these back files should be of value to all those interested in the evolution of scientific work in epilepsy over the past 100 years. The back issues are accessible to Journal subscribers, and to other investigators if their institutions subscribe to the Legacy Program.

Our publishers, Blackwell, merged with Wiley, another large publishing house, in February 2007. As a result,

Epilepsia is now published by the new company Wiley-Blackwell. The merger also resulted in a major reorganization of the editorial office in the Boston publishing office with new staff allocated to many of the publishing and marketing functions of *Epilepsia*. The editorial policy of the Journal, set by ILAE, though has not changed.

The team of associate editors continues to provide tremendous expertise and support to the reviewing process and editorial policy. The Associate Editors are: Ettore Beghi, Anne Berg, Edward Bertram, Amy Brooks-Kayal, Mark Cook, Michael Duchowny, Renzo Guerrinii, Bruce Hermann, Philip Patsalos, Michael Sperling, Annemaria Vezzani and Matthew Walker. They have been responsible for the generally very high quality of reviewing and reporting. The Journal continues to receive large numbers of submissions (approx 900 in the year 2007), and the current acceptance rate of papers is about 25%. The impact factor of the Journal rose in 2007 to 3.569, placing the Journal 27th in the list of 146 cited clinical neurology journals.

Publication details for 2007: 483 papers were published and indexed in 2007, including 45 reviews and critical commentaries (23 outside supplements). Excluding supplements, 2,385 editorial pages were published. There were five special reports in these pages, and two sets of commissioned controversies in the Gray Matters section (Internet research, Multi-drug resistance).

Nine supplements were published during 2007: Supplement 1 – AES Merritt-Putnam symposium from 2005

Supplement 2 – Towards closer interactions between bench and bedside

Supplement 3 – Abstracts from the 5th Joint Meeting of the German, Austrian, and Swiss chapters of ILAE Supplement 4 – Imaging approaches to small animal models of epilepsy

Supplement 5 – WONOEP 2005 (ILAE covers costs) Supplement 6 – Abstracts from 2007 AES Annual Meeting

Supplement 7 - Abstracts of the 27th International Epilepsy Congress

Supplement 8 – Proceedings of the London Status Epilepticus Symposium

Supplement 9 – AES Annual Course from 2006 (Problems for people with epilepsy beyond seizures)

> Simon Shorvon and Phil Schwartzkroin Co-Editors-in-Chief Epilepsia

EPILEPSIA REPORT (continued)

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INFORMATION OFFICER REPORT



I was appointed to take over the position of ILAE Information Officer starting July 2007 to follow Dr. Simon Shorvon, who had held the position with distinction since 1997. The Information Officer is a member of the ILAE Executive Committee, and initially was given oversight of three main ILAE comunication activities – the ILAE Web site, the newsletter Epigraph and the ILAE Archive. Because of his great interest in the history of the League, Dr. Shorvon, who is now Co-Editor-in-Chief of Epilepsia, has retained oversight over the maintenance and acquisition of archive material.

ILAE Web site: The ILAE Web site was initiated in 2000, and the Information Officer is responsible for its content and development. The technical management of the Web site is run by the ILAE office in Hartford. The Web site serves a number of purposes: repository of information regarding the League's organization and function, basic information regarding national chapters (officers, contacts, Web site chapter URL's), commission reports, links to meeting web pages, access to educational material (including the latest revisions to the classification system) and archives of current and past publications. One resource on the Web site that members find useful is the database of the names of antiepileptics used around the world. Originally designed and created by Dr. Robert Fisher, this database has proved useful in this era of widespread international travel in which physicians are encountering patients who are taking medicines that have different names in different countries. The database allows a physician or patient to convert names across countries. This service requires ongoing updates and is dependent on information provided by all of the chapters.

Two new features are the Bookstore section and the Farewells section. The first is an area of the Web site in which we will place information on books that are epilepsy related so that members will know what is available. The League does not sell the books, but links to booksellers are provided. In the first steps to provide this service, we have contacted a number of publishers. There has been a cautious response from the publishers regarding the best way to provide the service. We will continue these discussions as we move this service forward.

The Farewells section contains the obituaries of past members and others who were involved in the epilepsy movement across the globe. The intent of this section is to inform the larger epilepsy community about the passing of colleagues, to celebrate their accomplishments in moving epilepsy care forward, and to create an historical archive of people who have helped improve the lives of patients with epilepsy. Although we may solicit obituaries from time to time, we will also depend heavily on our international membership to inform us about the lives and accomplishments of our departed colleagues.

Over the years, the Web site has grown and has attracted increasing traffic and now has over 450,000 visitors each year. The Web site is a key public face for the League, in which its goals and programs are presented. As the goals of the League and the needs of its members change the Web site will also change. In the past year we have been making simple changes to the organization of the sections, primarily to make some parts more obvious and accessible. There have been a few cosmetic changes to reflect the international nature of the League and to remove clutter from several of the initial pages. The most substantive changes took place in the classification section. Although the Commission on Classification and Terminology has been working steadily, the Web site was not up-to-date and did not reflect the League's current position. With the leadership of Dr. Anne Berg, the Commission's chair, the classification section was revamped. Links to appropriate descriptions of syndromes were provided, and we placed a number of key papers over the last 40 years that concern the classification, so that visitors can make easy use of source material. In the coming year we expect further changes and additions of new material.

In the past year we also closed the discussion room, which was initially created for members to ask clinically oriented questions to the greater epilepsy community and to share ideas. Although there was an initial positive response in terms of utilization, over time the interest gradually decreased. There had been no activity for several months before that feature of the Web site was eventually closed. We may consider reopening it in the future, but it will require a new approach to managing the day to day operation.

EPIGRAPH: The newsletter of the ILAE was launched in 1994, and was intended from its inception to provide short summaries of ILAE activities and include occasional features of general interest to an epilepsy audience. Most importantly it is a means by which the ILAE central office could communicate with members worldwide. Since 2006, Epigraph has produced four issues a year (three on-line and one print edition). In the year 2008, which included four regional epilepsy congresses (Asia, Europe, Latin America and North America), four issues were created. The print issue was intended to serve as a general information document about the League and its management to be distributed at each congress. For some of these meetings a special welcoming insert was created to provide congress participants a brief overview of meeting as well as to announce future meetings of potential interest. As 2008 was also the election year for the new League president, the print as well as a number of the electronic issues provided information about the election process as well as the candidates.

In 2009 we will report on two major activities for the League: the beginning of the ILAE's centenary and the election of the remaining members of the Executive Committee. We will also continue to emphasize a number of the League's initiatives around the world such as the Africa project and the development of a new strategic plan for the Centenary period.

INFORMATION OFFICER REPORT (continued)

Issues for the Immediate Future

The nature of the League continues to evolve in scope and in goals, as the membership spreads to more countries and regions, the chapters strengthen and the interaction within the international epilepsy community grows. Although many of the interactions are based on personal contacts, collaborations can be started or enhanced if communication is improved. One of the biggest hindrances to informing individuals about League activities and opportunities for collaboration or development is the inability of the League to communicate with the larger membership. This problem has arisen because of incomplete listings of members of the individual chapters and the lack of email addresses for many names that we do have. Although there are some valid reasons why this information has been difficult to achieve (largely privacy concerns), the ability to communicate with the worldwide epilepsy community is a critical component of a professional society that wishes to move its agenda forward. In the coming year developing a comprehensive database of members names will be a major goal.

> Edward H. Bertram III Information Officer



GLOBAL CAMPAIGN AGAINST EPILEPSY REPORT



1. Global Campaign Against Epilepsy (GCAE) Secretariat

The Global Campaign Secretariat, comprising Giuliano Avanzini, Philip Lee, Tarun Dua and Hanneke de Boer, acts on behalf of ILAE, IBE and WHO with the advice of the ILAE Commission on Epilepsy Care.

2. GCAE in the context of WHO policy

A meeting was held in Geneva on 9 September 2008 with Dr Ala Alwan, the WHO's Assistant Director General for Noncommunicable Diseases and Mental Health. This involved Susanne Lund (President of IBE), Peter Wolf (President of ILAE), Giuliano Avanzini, Philip Lee, Dr Benedetto Saraceno (Head of the Department of Mental Health and Substance Abuse), Dr Tarun Dua (WHO Technical Officer) and Hanneke de Boer. The meeting successfully achieved its purpose of informing Dr Alwan about the Global Campaign, securing his support and commitment for its future and outlining future priorities.

The main GCAE initiatives: declarations, demonstration projects, special projects on legislation, guidelines etc. were developed in strict coordination between ILAE, IBE and WHO. Nowadays the significant dimension of GCAE activities in all the world regions makes it necessary to update it's role in the context of WHO strategies and to match GCAE perspectives with those of WHO. In particular we need a clear view of the numerous WHO related initiatives in the different world regions and of the way they are reciprocally interrelated to avoid duplications and to strengthen any possible synergy.

Dr Alwan was keen for the lessons from the demonstration projects to be applied in as many countries as possible. He recognized that this will require significant sums of money and other resources and that the Campaign needed to adopt "resource mobilization" (raising money) as one of its urgent priorities.

There was agreement on the need for enhancing the involvement of the IBE and ILAE regions in GCAE actions. We are establishing regional steering committees for the Campaign, surveying Campaign activities at local levels and encouraging the participation of the IBE Regional Committees, the ILAE Regional Commissions and the WHO Regional Offices and Advisors. Guidance notes on working with WHO regional advisers have been prepared.

The future developments of GCAE have been discussed. Important components of future directions will be focussed on:

- Low and middle income countries with special consideration for sub-Saharan Africa
- Further development of Demonstration projects
- Scaling up care

- The place of GCAE in the context of WHO global and regional strategies
- 3. Regional Activity

Americas

A workshop was organized in Honduras by the WHO Regional Advisor, Dr Rodriguez, in order to discuss the strategy on epilepsy in the AMRO region. Dr Marco Medina and Dr Carlos Acevedo were both involved in the organization of the workshop. The workshop was partly funded by WHO HQ and partly by the WHO regional office. The AMRO Regional Report was finalized with the involvement of the main authors, Dr Carlos Acevedo from Chile and Dr Susan Spencer from the US and was announced at the workshop.

The regional advisor is planning a similar workshop for the English speaking countries in the region.

Europe

The European Regional Report on Epilepsy is complete, subject to final approval by the WHO European regional office.

Africa

The African Regional Report includes a series of recommendations and actions for epilepsy that have been agreed upon by African stakeholders. However, further impetus is required to fashion these into a comprehensible and realistic plan including: identifying specific projects in the region, agreeing on regional priorities and formulating a regional strategy.

Resources are extremely limited, organizations are less well developed and language differences potentially prevent some countries from being involved. All of this makes the idea of an African regional conference less viable. However, a low budget event with a few representatives from each of the African countries, or a workshop similar to the one in the Americas, might be an option.

Eastern Mediterranean

The Campaign Secretariat met with a former WHO EMRO regional advisor in Geneva in September. He offered some useful insights about how to engage with regional advisers generally and about the Eastern Mediterranean region. He reported that Somalia, South Sudan and Afghanistan in particular all experience an acute lack of virtually every resource – from doctors to medications. All were in desperate need of assistance. He further emphasized the importance of patient focused associations working with medical and other professionals. He identified that in many countries in the region, the doctors work in isolation and it is the patient groups that represent the more powerful resource.

GLOBAL CAMPAIGN AGAINST EPILEPSY REPORT (continued)

4. National and Demonstration Projects

Demonstration projects aim to address one or more of the following: reduce the treatment gap and morbidity of people with epilepsy using community level interventions; train and educate health professionals; dispel stigma; identify potential for prevention and develop models of integration of epilepsy control into the health systems of the participating countries. When the project meets the criteria for a demonstration project but two countries in the region have already been selected for demonstration projects these are defined as **National Projects**.

Guidelines have been developed for those interested in applying for a demonstration project and a set of criteria as well as process of project assessment has recently been defined.

Criteria for selection of National and Demonstration Projects are:

- The likelihood that results of the Demonstration Project can be utilized by other countries.
- Availability of political and personal contacts.
- Willingness to participate.
- Availability of a WHO collaborative center or country representative.
- Presence of an IBE and an ILAE member organization, or groups that have the potential to form a member organization.
- A regular supply of basic antiepileptic drugs (AEDs).
- Facility of communication.
- Location in WHO region where demonstration projects are envisaged according to the Campaign's action plan.

During 2008 a new Demonstration Project was started in the country of Georgia led by the two principal investigators, Dr Natela Okujava and Otar Toidze.

The project protocol has been developed and unanimously accepted, involving all stakeholders in Georgia as well as representatives of ILAE and IBE. A project advisory board has been set up, involving all stakeholders in the country and the international leadership of ILAE, IBE and WHO. Three working groups have been set up and terms of reference developed. The groups are: Public Education and Social Intervention; Epidemiological Study; and Elaboration of Training Modules.

A screening questionnaire for the epidemiological study has been drafted based on the WHO screening questionnaire used in the Chinese demonstration project and on the ICBERG screening instrument. To assess specificity and sensitivity, 100 questionnaires have been completed for 50 adult patients suffering from epilepsy and 50 people without epilepsy. Surveyors for the doorto-door investigation have been trained and data collection has been completed. Data of over 10,000 questionnaires has been entered in the data base and is now being analyzed.

The training of trainers and service deliverers took place on 23-26 June 2008 and consisted of the training of half a dozen neurologists and 35-40 family doctors. Supervision and follow-up training will continue throughout the project. Thankfully the project does not appear to be unduly upset or affected by the recent political problems between Georgia and Russia

A proposal for a demonstration project in Honduras is being prepared by Dr Marco Medina. An enquiry has been received from the Ministry of Public Health in Cameroon. This is now being followed up.

Rwanda, Zambia, Bolivia and Hispaniola have all requested Global Campaign recognition for their national projects. Bolivia's application has been assessed and approved. The others are being clarified and processed prior to a decision.

5. Other Projects

Community Based Projects: are initiatives generated by persons or organizations, working in resource poor countries. These projects are concerned with prevention or improvement of care and services or quality of life issues of people with epilepsy and are based on needs expressed by the local community, which is allowed to play an ongoing active role in the work. The projects are much smaller and more limited in scope and duration than Demonstration Projects.

Guidelines and criteria to obtain formal Campaign approval and recognition have been developed. Prerequisite For GCAE approval are that:

- Sufficient medical and social expertise about epilepsy is available, either on the spot or it is easily accessible.
- If pharmacotherapy is part of the project, the procuring of the necessary drugs is safeguarded.
- Sufficient infrastructure is available to enable the project to run smoothly.
- The applicant is considered capable of handling the type of proposed project.
- It is likely that the results of the project will be applied in the region where the project is conducted.
- The project is locally sustainable or can be a future model for other areas in the country.
- The project has a maximum duration of one year.

Awareness raising and public education projects: these vary from small meetings with politicians to organizing big public events, aimed at raising awareness about epilepsy and improve the quality of life of people with epilepsy.

To obtain formal Campaign approval and recognition they should:

- Involve an IBE member and/or ILAE chapter.
- Where and when possible involve the national WHO representative.

6. Special Project: Facing Treatment Gap in Africa This initiative was started in 2007 by Dr Phil Lee and Giuliano Avanzini on behalf of GCAE to facilitate the access to AEDs in Africa and continued in collaboration with Jackie French and Emilio Perucca on behalf of the ILAE Commission on Therapeutics. The plan has been presented to the ILAE EC that considered it as an

GLOBAL CAMPAIGN AGAINST EPILEPSY REPORT (continued)

important initiative and appointed Dr Emilio Perucca as coordinator of the African activities. In 2008 Giuliano Avanzini and Emilio Perucca travelled to Ghana and established several important contacts relevant to GCAE activities in that country.

A partner organization (Basic Needs) has been identified. This organization already has done substantial ground work in the area of mental health and epilepsy. From the experience of Basic Needs and the information collected onsite it was concluded that in order to facilitate the access to AEDs, a comprehensive approach should be considered which would include an educational activity as a first step. A training program is therefore being developed to train nurses, lay individuals and physicians in the medical care of epilepsy. Moreover pharmaceutical partners have been identified, which can contribute to educational efforts and perhaps to medication supply although this is currently provided by government. All of these activities should be ideally linked to a demonstration project whose impact will be assessed correspondingly.

Once validated, the model developed in Ghana could be applied to other African Countries with similar characteristics.

7. Special Project: Neurocysticercosis

This parasitic condition relates to epilepsy and also to the potential for treatment and prevention of an epileptic condition. A working group to look at preventing neurocysticercosis as a cause for epilepsy has been created involving members of the ILAE Commission of Epilepsy Care

8. Communications

This is one area of the Campaign where we need to do significantly better. Efforts are now being focused on improving communication and a comprehensive communications plan is currently being drafted.

Web site

Originally it was agreed by IBE, ILAE and WHO that the IBE Web site would host Global Campaign material on the internet. ILAE and WHO would include whatever Campaign material they wanted on their own sites but otherwise would provide a link to the IBE site. Subsequent technical advice now indicates that the Campaign and its partners would be better served by establishing a separate Web site for Campaign material that all the partners could link to but which would appear as much as possible to be integral to their own sites.

The following tasks have already been completed:

- An updated review of Campaign material already on the internet.
- A content plan and structure for Campaign material.
- An audit and review of Global Campaign publications and written documentation.

The objective is to have the Global Campaign Web site active in the first half of 2009.

9. Manual for medical and clinical officers in Africa

The manual was originally published in 2002. It has been very popular and supplies of the original print run are now exhausted. An updated reprint is now in hand with the active involvement of the IBE African Regional Committee and members of the ILAE Care Commission.

10. Ten Year Publication

The commemorative promotional brochure to mark ten years of the Global Campaign is in preparation.

11. Project on Legislation

A technical workshop to review the outcomes of the legislation survey took place on 18-19 October in Marseille at the conclusion of the IBE Epilepsy & Society conference. The survey report and examples of good practice are scheduled to be completed by 1 January 2009. The workshop produced two significant outcomes.

- 1. A first draft of basic principles for epilepsy legislation – identifying those areas of life where legislation might impact on people with epilepsy.
- 2. A first draft guidelines document designed to assist those looking to introduce or amend legislation affecting people with epilepsy.

Drafts of both of these documents will be distributed to the regional structures of IBE and ILAE and to members of the Epilepsy Care Commission for comment before being finalized. The documents are scheduled to be published in June 2009.

12. Survey of Campaign activities on a national level

The survey was conducted by Phil Lee on behalf of the GCAE to quantify activity undertaken at national/local level in support of or on behalf of the GCAE and to make a limited assessment about the impact of that activity.

Ninety-six ILAE chapters, 88 IBE full members and 20 IBE associate members in 111 countries were contacted by email with an English language questionnaire containing seven closed questions. Seventy-five organizations from 60 countries responded to the survey, 51 organizations (68%) were IBE members, 24 (32%) were ILAE chapters.

Sixteen organizations from 14 countries reported no activity. Inactivity is a consequence of a lack of understanding and awareness about how to access the Campaign. It is not the result of any antipathy toward the Campaign. Fifty-nine organizations in 48 countries reported some sort of activity. 41% of the countries represented are European. The combined population represented by the 48 countries is 3.81 billion people, 56% of the world's population. Thirty of the 48 countries (62%) are classified by the World Bank as high income or upper middle income countries. Only eight (17%) are classified as low income countries.

The types of activity carried out reflect the Campaign's priorities. Public awareness and stigma reduction programs are the most frequently reported activity. Participation in the Campaign has grown steadily but

GLOBAL CAMPAIGN AGAINST EPILEPSY REPORT (continued)

has leveled off since 2005. However, 53 organizations (71%) in 41 countries (68%) report they will be using the Campaign in the future regardless of whether or not they have used it in the past. Only one organization said it wouldn't be using the Campaign. The most popular use of the Campaign is the slogan "Out of the Shadows", used by 71% of actively involved organizations.

Thirty-nine organizations (66%) report their Campaign activity to be either very successful or moderately successful. Only four (7%) report their activity was not very successful and only one (2%) reports no success at all.

> Giuliano Avanzini and Philip Lee Co-Chairs, ILAE-IBE-WHO Global Campaign Against Epilepsy



INTERNATIONAL DIRECTOR OF MEETINGS REPORT



Annual Congress Planning Update

During the year July 2007 to June 2008, the IDM Office has been actively engaged with the management and operation of the Congresses which took place during this period, in addition to the final preparations for several imminent Congresses and the planning for future meetings.

During this time, the IDM Office has seen the successful organization of the 27th International Epilepsy Congress, which was held in Singapore in July 2007 and the 7th Asian & Oceanian Epilepsy Congress, which took place in Xiamen in May 2008. Three further regional Congresses will take place in autumn 2008: the 8th European Congress on Epileptology, Berlin in September, the 11th European Conference on Epilepsy & Society, Marseilles in October and the 5th Latin American Congress on Epilepsy, Montevideo in November. Meanwhile, work is underway on the international and regional Congresses upcoming in 2009, 2010 and 2011.

The 27th International Epilepsy Congress was held in Singapore, from 8-12 July 2007. The Congress took place at Suntec Singapore International Convention and Exhibition Center, a self-contained, state-of-the-art facility. The Congress was deemed a great success, from both scientific and organizational perspectives, and attracted a total of 2,950 participants from 98 countries.

The IDM team spent four years, in collaboration with Dr Shih-Hui Lim, actively preparing for the Congress, in the coordination of the scientific program, the raising of industry sponsorship, logistical on-site planning and Congress promotion.

The seven main topics in the scientific program were selected by the Joint Executive Committee of the ILAE and IBE following suggestions from Chapters and regional Commissions. Topics chosen included "Issues in Developing Countries", "Stigma and Quality of Life", and "Epidemiology and Prognosis" among others. Seven hundred ninety-seven abstracts were submitted via the online system. An ASEPA teaching course complemented a combination of EUREPA Seminars, main sessions and satellite symposia which took place over the course of the Congress. The IDM team would like to record its thanks to Dr Shih-Hui Lim, Co-Chair of the Scientific Advisory Committee for his tremendous support and help throughout the planning of this meeting and Prof Peter Wolf and Mr Mike Glynn for their advice and guidance during preparations.

The 7th Asian & Oceanian Epilepsy Congress (AOEC) was held in Xiamen, China, from 15-18 May 2008. The venue was the Xiamen International Convention & Exhibition Centre (XICEC), located on the east of Xiamen island on the coast, and linked by a covered walkway to the 5 Star Seaside Hotel. The AOEC has been going from strength to strength over recent Congresses, and the 7th AOEC was no exception, with an attendance of 1,650, and the scientific program and general organization was commended widely.

The structure of the scientific program for the 7th AOEC changed from previous AOEC meetings with post main sessions running simultaneously with other parallel and platform sessions. New features of the scientific program included a Chairman's Symposium and a Highlights Session, which summarized the main topics discussed during the 7th AOEC, and a Chinese language session was added to encourage a higher number of local participants. Four hundred thirty-nine abstracts were received for the Congress. Pre-Congress activities included an educational course on translational research and EEG Exams run by the Asian Epilepsy Academy – ASEAN Neurological Association. A subsidiary program was also organized by the regional vice presidents of IBE for people with epilepsy and their caregivers.

The 8th European Congress on Epileptology will take place in Berlin, Germany, from 21-25 September 2008 under the auspices of the German and Israeli ILAE Chapters. The Congress will take place at the ICC Berlin.

Prof Meir Bialer and Prof Christian Elger, Co-Chairs of the SAC, and the Scientific Advisory Committee have worked closely with the IDM team on the programming and scheduling of sessions. The Congress will feature a comprehensive program of main sessions, discussion groups, teaching sessions and workshops, along with various special symposia. The main topics of the Congress are: "Pharmacogenetics & Pharmacogenomics", "Synaptopathies in Epilepsy", "Immune Processes and Epilepsy" and "Predicting the

Response to AEDs". Teaching Sessions and a "How to Do" course will take place each morning, under the academic umbrella of EUREPA.

The European Epileptology Award will be presented during the Congress and the Michael Foundation Symposium will also take place.

Over 750 abstracts were submitted via the online system. Poster presenters have been given the option to submit an E-Poster instead of a traditional poster.

The German Academy Day, organized by the German Chapter of ILAE, will take place on the day before the Congress officially commences.

The 11th European Conference on Epilepsy & Society will take place in Marseilles, France, from 15-17 October 2008. The theme of the Conference is "Active Life and Epilepsy" and each day will focus on different aspects of achieving goals in life and a better quality of life. The Organizing Committee has been very active in constructing and refining the Conference program to be of great interest to people with epilepsy and their carergivers and those who work with people with

INTERNATIONAL DIRECTOR OF MEETINGS REPORT (continued)

epilepsy. The main topics include "Epilepsy on My Mind and in My Brain", "Achieving Goals with an Active Life", "UN Convention on the Rights of Persons with Disabilities", "Epilepsy in Contemporary Literature", "Humor and Epilepsy", "Epilepsy in the Family" and "The Side Effect of Miscommunication". Workshops are connected to the main sessions and are also available in French, for francophones, to complement the English-language workshops. In addition, there will be a special youth session and a EUCARE Seminar.

The 5th Latin American Congress on Epilepsy will take place in the Radisson Victoria Plaza Hotel in Montevideo, Uruguay, from 5 to 8 November 2008.

The Organizing Committee has devised a varied scientific program, consisting of plenary sessions, discussion groups and ALADE (Academia Latinoamericano de Epilepsia) didactic courses, centered around the main themes of the Congress: "Neuroimaging", "Epilepsy Surgery and Etiologies", "Epilepsy Cognition", "Controversies in Pediatric Epilepsies", "Morbi-mortality and Epilepsy" and "Basic Research in Human Tissue". The Congress will end with a Highlights Session. There will be a Bureau Day for people with epilepsy and their caregivers, aimed primarily at teachers and educators. Although the official languages of the Congress are Spanish and Portuguese, authors were requested to submit their abstracts in English as well as in Spanish or Portuguese and 170 abstracts have been received.

Preparations are well underway for the 28th International Epilepsy Congress, which will take place in Budapest, Hungary, from 28 June to 2 July 2009. The venue for the Congress is a new, purpose-built pavilion at Hungexpo Fair Centre.

The main topics of the Congress are: "Autonomic Functions and Biorythmicity", "Remission or Cure? Basic Science and Clinical Outcome", "Comprehensive Care around the World", "Family and Epilepsy", "Brain Development, Plasticity and Epilepsy", "Progress in Imaging and Epilepsy Nosology" and "Non-Specialist Management of Epilepsy".

The Scientific Advisory Committee (co-chaired by Susanne Lund and Peter Halasz) is currently reviewing proposals for sessions and the program should be available online in mid-October 2008.

This Congress will also celebrate the Centenary of the founding of the ILAE, in Budapest in 1909. Several events will be organized to mark the celebration of the ILAE Centenary (private dinner for ILAE officials, Gala Dinner held at the National Gallery, historical exhibit and more). A film festival and competition will also be organized on this occasion. The 2nd East Mediterranean Epilepsy Congress will take place in Morocco in the autumn of 2009. The program and full information on the Congress will be made available after the first meeting of the Program Committee in October 2008.

Arrangements are currently being made for the 9th European Congress on Epileptology, which will take place in Rhodes, Greece from 29 June to 1 July 2010. The Congress Web site will be launched shortly and scientific program information will be included as it becomes available.

The first meeting of the Organizing Committee will take place during the ECE in Berlin. The main topics and members of the Scientific Advisory Committee will be selected by the IOC. The IOC will be co-chaired by George Kostopoulos (Greece) and Michel Baulac (CEA Chair).

The 8th Asian & Oceanian Epilepsy Congress will take place in Australia in 2010. At the time of writing, the city is yet to be chosen with Melbourne, Perth, Sydney and Adelaide all as strong contenders. However, already key members of the ILAE Commission and IBE associations are making plans for the scientific program.

Expressions of interest for the 6th Latin American Congress on Epilepsy have been received from Argentina and Costa Rica. A site inspection trip to Argentina is planned later this year.

The IDM Office is also currently working on arrangements for the 29th International Epilepsy Congress, which will take place in Rome, Italy in 2011.

> Richard Holmes International Director of Meetings

REPORT OF THE CENTENARY COMMITTEE

The ILAE was founded on 30 August 1909, in Budapest. For its Centenary Congress, Budapest was chosen again as the host of its Centenary Congress.

A Centenary Committee has been established to plan and organize events at the Congress. The Committee is comprised of Simon Shorvon (Chair), Howard Goodkin, Peter Halasz, Judit Jerney, Giselle Weiss, and Soazig Daniel.

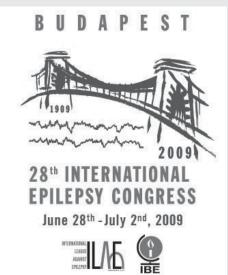
The Committee is currently working on the following provisional program of centenary events, and these are currently in the planning stage.

Centenary reception: A reception will be held which is open to attendees at the Conference on the evening of Wednesday 1st July. The provisional venue is the National Gallery of Hungary and proposed to have a cocktail reception on the Esplanade if the weather permits, followed by a full dining buffet. A program of celebratory entertainments will be provided.

Historical exhibit of ILAE history at the Conference site: A highly illustrated historical exhibit celebrating 100 years of ILAE activity, and 100 years of progress in the battle against epilepsy, will be displayed in the exhibition area in Hungexpo Fair Centre. The exhibition will include a timeline, display cabinets and an 'historical wall' of ILAE events and personnel over the prior 100 years.

Centenary film festival – "A hundred years of epilepsy in film" – and film competition: A Centenary film festival will be run concurrently with the Conference. A different historical feature film will be shown every day, related to the theme of epilepsy. In addition, a film competition has been launched and it is planned to show the winning film on the final day of the conference. Details of the competition are on the ILAE Web site www.ilae.org.

Centenary book: The ILAE will produce a presentation volume, entitled The International League Against Epilepsy – A Centenary History (S Shorvon, F Andermann, H Meinardi, E Reynolds, G Weiss, P Wolf)



published by Wiley-Blackwell. The book is the result of extensive research using personal testimonials, published reports and ILAE archival material, and will provide a detailed history of 100 years of ILAE activity, of *Epilepsia* and of epilepsy and its treatment since 1909. A limited edition of individually numbered and named copies is planned. To ensure that all individuals have the opportunity to own a copy, the ILAE is offering the book at a heavily produced discount to those who reserve a copy in advance (details on the ILAE Web site www.ilae.org or contact Simon Shorvon at epilepsypa@ion.ucl.ac.uk).

Simon Shorvon

On Behalf of the ILAE Centenary Committee





REPORT OF THE ELECTION COMMITTEE

Giuliano Avanzini (Italy) **Chair** Natalio Fejerman (Argentina) Yoshi Mayanagi (Japan)

The Committee duty is to conduct the elections and establish appropriate procedures that are not in conflict with the constitution and bylaws. The Executive Committee shall not interfere with the business of the Election Commission.

According to the procedure established for the election of the 2009-2013 ILAE Executive Committee, 18 months before the end of the current term, the ILAE Election Committee (EC) began to define the potential candidates for the ILAE Presidency, i.e. people who had served, or are currently serving, at least one term on the Executive Committee and who were willing to serve as President of the next ILAE EC. In identifying the potential candidates the commission took into consideration the constitutional rules that "no person may occupy a seat on the Executive Committee for a period exceeding a maximum of sixteen years". Therefore per-sons who were members of ILAE EC for more that two terms were eliminated, as they could not occupy a seat on the Executive Committee for the two next terms as President and Past-President. Out of a list of 29 potential candidates, fulfilling the additional requirement of being ILAE Chapter members, the following three persons declared their willingness to serve as ILAE president and were therefore selected as official candidates:

Martin Brodie Esper Cavalheiro Solomon (Nico) Moshé

A nomination ballot was circulated among the ILAE Chapters to be sent back to the ILAE Notary Office (Attorney Arthur Herold, Washington DC) by 15 July by e-mail (aherold@wc-b.com), or if this was not possible, by fax (1-202-835-0243) or postal mail.

For all the phases of the election each Chapter had from 1-6 votes according to the following sliding scale based on the number of professional dues paying members according to the most recent statement provided by the Chapter:

- up to 50 members: 1 vote
- 51 150 members: 2 votes
- 151 350 members: 3 votes
- 351 750 members: 4 votes
- 751 1500 members: 5 votes
- above 1500 members: 6 votes

Chapters that do not collect dues had one vote.

An e-mail address (election@ilae.org) by which any chapter could put specific question(s) to the three candidates was created. This address sent questions to all three candidates simultaneously as well as to the chair of the election committee and the League's central office. The candidates were committed to prepare responses to the questions within a week of receiving them. Responses were posted on the ILAE website to be accessible to all who might be interested. The system worked well.

Within the deadline the Notary office received ballots

Roger Porter (USA) Simon Shorvon (UK)

from 66 chapters and the results were as follows: Moshé – 74 Brodie – 59 Cavalheiro – 19

Since no candidate received a majority of the votes cast, a second ballot was sent out with the names of the two candidates who received the most votes: Martin Brodie

Solomon (Nico) Moshé

Ballots were to be sent to the notary office by 31 October 2008. By accompanying letter the Chapters were reminded that according to the Constitution the candidate that received the highest number of weighted votes cast in this run-off shall be elected as ILAE president.

Whereas the Election Committee thanked all the Chapters that actively participated in the first phase of the election, dissatisfaction was expressed for the number of Chapters that did not send their vote. It was pointed out in the letter to the Chapters that the election of the governing body is a crucial step of the democratic life of a scientific association. Should a Chapter be unsatisfied about the proposed candidates or about the conduction of the election process it can express this disagreement by sending back a blank form.

Particular care has been put in verifying that all ILAE Chapters would receive the ballot and the related information. In particular the Chapters were asked to send back a notice of receipt, moreover the ILAE Headquarters office was requested:

- to circulate the letter also by regular mail.
- to contact all the chapters that failed to confirm the reception by phone, asking to confirm receipt.
- to notify the notary of those chapters that did not confirm receipt and that the Headquarters Office had been unable to contact (if any) and to work with him to determine a special procedure to contact them.
- to circulate every 20 days a reminder with all the present documentation attached until 20 October 2008.

Also during the second phase, Chapters could ask questions to the candidates up to 15 October 2008 by the same system.

Valid ballots were received by the deadline from 65 chapters with the following results:

Moshé	- 92
Brodie	- 55

Therefore Solomon (Nico) Moshé is the new ILAE president for the period of 2009-2013 and the Election Committee wished him good work.

The next phase of the election process for the ILAE EC Officers for the same term, 2009-2013 is now ongoing

REPORT OF THE ELECTION COMMITTEE (continued)

with the following rules.

- All Chapters are requested to send to the notary a slate of four names from at least three different regions, without any ranking, as candidates for the remaining officer positions.
- The notary will forward the names with the number of votes to the Election Committee, which will choose a slate of fifteen candidates on the basis of non-weighted multiple nominations from the lists submitted by the Chapters. The slate must include candidates from at least three regions. The slate may be smaller if less than 15 people are nominated.
- The Committee shall ascertain that these candidates are available and willing to serve and submit the slate to each Chapter through the Headquarters Office with the request to send to the notary their vote for five candidates from at least three different regions, without any ranking.
- The notary will forward to the Election Committee the final votes that each candidate has received, which will be determined by the sum of the weighted votes received from all Chapters.
- The Election Committee will choose four candidates from at least three regions who received the highest number of weighted votes. If two or more candidates obtain the same number of weighted votes, the candidate(s) from the ILAE region(s) with the least representation among the other elected officers will prevail. If a tie persists after consideration of regional representation, the candidate with the highest number of non-weighted votes will prevail. If a tie still persists, the oldest candidate(s) will prevail.
- The list will be forwarded to the ILAE EC and to the President-Elect.
- The President-Elect with the advice of the Election Committee will appoint the Secretary-General, Treasurer, and the first Vice-President from the newly elected slate.
- In the event that after the global elections of President, two Vice Presidents, Secretary General, and Treasurer, and the appointment of Editor-in-

Chief and Information Officer, any fully operational region of the ILAE (as determined by the Executive Committee) is not present on the Executive Committee, the Chapters of this region shall elect additional Vice Presidents. These Vice Presidents will be voting members of the Executive Committee and not be considered as a regional Vice President but unrestrictedly share the global responsibilities of the Executive Committee

After completing the election process the Election Committee will conclude its activity by sending to the ILAE EC a report with evaluation of the current elections and recommendations for the future. A special concern of the present Election Committee is about the high percentage of ILAE Chapters (about 30%), which did not participate in the election. The analysis of this phenomenon will be part of the final report.

Giuliano Avanzini Chair

On behalf of the ILAE Election Committee

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Regional Commissions

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS

Commission Members

Shih-Hui Lim (Singapore), Chair David Reutens (Australia), Secretary Patrick Kwan (Hong Kong), Treasurer Leonor Cabral-Lim (Philippines) Satish Jain (India) Shichuo Li (China)

Kazuichi Yagi (Japan) Chong Tin Tan (ILAE-VP and ASEPA Chairman), **Ex-Officio**

Sub-Commission Members

Asian Epilepsy Academy (ASEPA) 2007 – 2011 Chong Tin Tan (Malaysia), **Chair** Andrew Bleasel (Australia), **Secretary** Gourie Devi (India) Yushi Inoue (Japan) Weiping Liao (China) Byung-In Lee (Korea) Peter Wolf, EUREPA Representative Shih-Hui Lim (CAOA Chair), Ex-Officio

Aims

To develop, stimulate and coordinate the epileptology agenda in the Asian and Oceanian region.

Missions

- To advance and disseminate throughout the Asian and Oceanian region knowledge concerning the epilepsies;
- To improve education and training in the field of the epilepsies in Asia via the formation of the Asian Epilepsy Academy;
- Epilepsy Academy;
 3. To run the Asian Oceanian Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees;
- 4. To facilitate clinically relevant epilepsy research in Asia;
- To serve as a link between ILAE, IBE, WHO, regional medical organizations to promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders in the Asian and Oceanian region;
- 6. To promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda;
- 7. To review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.

Commission Activities from 1 January 2007 to 31 May 2008

1. Business Meetings

CAOA & ASEPA conducted joint business meetings. There were two meetings conducted during this period.

- a. 10 July 2007, during the 27th International Epilepsy Congress (IEC) in Singapore
- b. 15 May 2008, during the 7th Asian Oceanian Epilepsy Congress

2. Chapter Members

As of June 2008, there are 17 Chapters in the Asian and Oceanian region (including New Zealand Chapter but not including Vietnamese Chapter). The New Zealand Chapter was accepted into the ILAE family during the 27th IEC in 2007. The Vietnam Association Against Epilepsy was formed in early 2008 and has provisionally been accepted as a new ILAE Chapter during the ILAE Executive Committee meeting in San Servolo in July 2008.

3. Chapter Convention

The 2nd Biennial Chapter Convention of the Commission was held on Thursday, 15 May 2008, 11:30 am to 2:00 pm, at the Seaview Hall of the Xiamen International Conference and Exhibition Centre (XICEC), Xiamen, China. National delegates from the 17 ILAE Chapters in this region participated in this Convention. In addition, representatives from non-Chapter countries including Vietnam, Sri Lanka, Myanmar and Laos were invited and/or attended the Convention.

The following items were covered: (1) Presentation by ILAE President Peter Wolf on development in other regions, development in education, including distance education, centenary celebration in 2009 and South-South & North-South Network of Research Cooperation; (2) Update by Dr G Avanzini & CT Tan on the Global Campaign in the Asian and Oceanian region; (3) Briefing by N Moshe on ILAE's Constitutional Amendment proposal; (4) Presentation by M Brodie on financial support of ILAE; (5) Report by CAOA Chair on CAOA activities & plans; (6) Presentation by ASEPA Chair CT Tan on ASEPA development and activities; (7) Report By P Kwan on behalf of CAOA Research Task Force; and (8) Speech by candidates of ILAE Presidential Election.

4. Organization of 7th AOEC

See Accomplishment 1.

5. Selection of the Venue for the 8th & 9th AOEC

Members of the CAOA and the two IBE-Regional Executive Committees have jointly decided that the 8th AOEC will be held in Australia and the 9th AOEC in the Philippines.

With the strong support and enthusiasm of medical and non-medical professionals involved in the care of epilepsy patients, AOECs will remain as the major epilepsy Congresses in this region. These Congresses will continue to provide CME to practicing clinicians and to serve as a platform for young researchers to showcase their research efforts and exchange research ideas.

6. Research Task Force

A Research Task Force was formed under CAOA during 6th AOEC to explore the possibility of joint research. The Task Force is headed by Dr Patrick Kwan of Hong Kong and the Ex-Officio is Dr SH Lim, CAOA Chair. The initial step the Task Force took was to identify research priorities for the region. Members of the Task Force were divided into different subgroups to focus on specific areas within epileptology. Following is a list of names placed under the various subgroups based on expertise and/or indicated area of interest of all members.

Members consist of representatives nominated by each Chapter of the region as indicated in the table below:

Sub-group Epidemiology	Sub-Group Coordinator W D'Souza (Australia)	Members JP Agrawal (Nepal), L Cabral-Lim (Philippines), S Jain, P Kwan (Hong Kong), WP Liao (China), M Mannan (Bangladesh), Z Mogal (Pakistan), A Tovuudorji (Mongolia), A Visudtibhan (Thailand)
Pharmacology	S Jain (India)	JP Agrawal, P Bergin (New Zealand), L Cabral-Lim, P Kwan, BI Lee, WP Liao, M Mannan, DJ Yen
Psychosocial / QOL / Public Health	KS Lim (Malaysia)	L Cabral-Lim, W D'Souza, M Mannan, Z Mogal
EEG	SY Kwan (Taiwan)	S Gunadharma (Indonesia), M Mannan
Surgery Basic Science / Genetics	T Tanaka (Japan) BI Lee (Korea)	Bl Lee, P Bergin S Jain, P Kwan, WP Liao, N Tan (Singapore), T Tanaka

The initial project the Task Force took was to identify research priorities for the region. The Task Force met for discussion in Singapore on 12 July 2007 during IEC, and further on 18 May 2008 during AOEC in Xiamen. It is expected that a unified document would be produced by the end of 2008 or early 2009.

7. Global Campaign Against Epilepsy (GCAE) Activity in Laos

There is progress in reducing the epilepsy treatment gap in Laos. The French Institute of Tropical Medicine in Vientiane, Laos has obtained the support from Sanofi to supply free drugs in Laos. CAOA will assist in this project and aims to raise about \$30,000 yearly (\$15,000 from European Commission, \$5,000 each from Japan Epilepsy Society, Taiwan Epilepsy Societies and CAOA) tentatively for three years. Other financial contributions to this project will come from organizations such as the Peter Wolf Foundation.

8. The Establishment and Delivery of Masakazu Seino Lecture

It was with deepest sadness to receive the news that Dr Masakazu Seino, a distinguished Epileptologist, Past Chairman of CAOA (1996-2001), Chairman of ASEPA (2003-2007), Founding Chairman of the AOEO, and Past Vice President of ILAE, passed away on 7 April 2007. On the day of his death, he was still communicating with one of the CAOA members on the future and financial support of ASEPA.

Dr Seino's family, together with his friends, colleagues and the Japan Epilepsy Society, held a memorial service at Hotel New Ohtani, Tokyo, Japan on 8 April 2007. Dr Solomon Moshé, Secretary-General of the ILAE, Dr Shih-Hui Lim, Chairman, CAOA and Dr Chong Tin Tan, Vice President of the ILAE attended the service.

To perpetuate the memory of the late Dr Masakazu Seino and to recognize his immense contributions to the field of epileptology in the world, CAOA-ASEPA decided to establish a biennial lectureship in the name of Dr Seino. The inaugural "Masakazu Seino Memorial Lecture" was delivered by Dr Yuko Fukuyama during the 7th AOEC in Xiamen. Dr Kazuichi Yagi also spoke on Dr Seino. The memorial lecture is sponsored by Dainipon-Sumitomo and Eisai.

Accomplishments

CAOA-ASEPA had a busy but fruitful period the last 18 months, maximizing the usage of limited human and financial resources. With the commitment and sacrifices of previous and current members of CAOA-ASEPA and the strong support of ILAE and other epileptologists in this region, we are moving closer to achieving our two main aims, (1) to advance and disseminate throughout the Asian & Oceanian region knowledge concerning the epilepsies, and (2) to improve education and training in the field of the epilepsies in Asia.

1. Successful Organization of 7th AOEC

The 7th AOEC was successfully held in Xiamen, China, from 15 to 18 May 2008. The following are members of the International Organizing Committee (IOC) and Scientific Advisory Committee (SAC). Many of them are members of CAOA and ASEPA:

Co-Chair	IOC Shichuo Li (China, CAOA Member) Susanne Lund (IBE President) Peter Wolf (ILAE President)	<mark>SAC</mark> Shih-Hui Lim (CAOA Chair) Wu Liwen (China)
Members	Anchor Hung (IBE Vice-President) Shunglon Lai (IBE Vice-President) Weiping Liao (China, ASEPA Member) Shih-Hui Lim (CAOA Chair) Wu Liwen (China) Chong-Tin Tan (ASEPA Chair) Guoying Xu (China) Wang Yang (China) Yi Yao (China)	Satish Jain (India, CAOA Member) Patrick Kwan (Hong Kong, CAOA Member) Weiping Liao (China, ASEPA Member) Guoming Luan (China) Jiong Qin (China) Ingrid Scheffer (Australia) Tatsuya Tanaka (Japan) Chong Tin Tan (ASEPA Chair)

The Congress was attended by 1,800+ delegates, the largest number of all AOECs. It was felt that if not because of the devastating earthquake in Sichuan, China, the attendance would have been significantly higher. The Congress also received the highest number of abstracts, and it accepted 445. There were 73 regional and eight non-regional speakers. Ms Kathryn Hodgson was the main person from the IDM office to provide all the important secretariat support. CAOA assisted IOC and SAC to award bursaries for those who submitted an abstract as well as those who did not submit an abstract for the AOEC.

The format for the Scientific Program was altered slightly from the previous AOECs. It followed that of the International Epilepsy Congress, with a balance of medical, social and basic science topics. The Scientific Program included a Chairman's Symposium (on stigma), four Main and four Post Main Sessions (epilepsy surgery, pediatric epileptology, epilepsy and comorbidities, and genetics), a Highlight Session, eight Parallel Sessions, the Inaugural Masakazu Seino Memorial Lecture, six ASEPA Didactic Lectures, a Chinese Language Session, five Satellite Symposia and 15 Platform Sessions. Basic science and translational research were emphasized at this AOEC, which included a pre-AOEC teaching course on Translational Research. There were four Tadokoro's Awards, given to the two best oral free paper presentations and two Poster Presentations. In the one-day PWE program, a special session on "Renaming" of the Chinese word for epilepsy was held. There was very active discussion with participation of medical professionals from countries which used Chinese words.

Below were some of the comments made by Dr Peter Wolf, President of ILAE, to members of CAOA and ASEPA: "My most pleasant encounter in Xiamen was with a young generation of future epileptologists from the region. They are highly talented, eager to do research, and committed to contribute to reaching new horizons. It is fantastic that you could get such excellent young people interested in our field. What more can we do together to keep them on board and give them optimal conditions to further develop their talent? They need international contacts and exposure, occasions to meet both peers and seniors on an international level. They need more residential courses like the one conducted in San Servolo. ASEPA

could look into conducting similar courses in Asia. Networking for research is another approach. I had the impression that many groups are now working separately but could perhaps make more progress if they cooperated. This should be of particular interest for the CAOA's Research Task Force".

2. Conduct of Education and Training Activities by ASEPA

The ASEPA was formed in 2003, initially as the educational arm and now a sub-commission of CAOA. Previously majorities of the Executive Committee members were also members of CAOA. For the current Executive Committee of ASEPA 2007-2011, members are different from that of CAOA. The purpose of this is to maximize the use of available human resources in this region to enhance the educational effort of CAOA. The Committee also includes representatives from bigger countries such as Australia, China, and India.

2.1 Teaching Courses and Workshops

The following workshops and teaching courses were conducted under the auspices of ASEPA between January 2006 and May 2008:

Type of Courses and Workshops	Dates	City, Country	Teaching Faculty	Sponsoring Organization
General Epileptology	20 - 21 April 2007	Haikou, China	WP Liao (China), SH Lim (Singapore), CT Tan (Malaysia), K Yagi & Y Inoue (Japan)	ILAE-CAOA
	11 - 12 January 2008	Fuzhou, China	WP Liao (China), SH Lim (Singapore), CT Tan (Malaysia), Y Inoue (Japan)	ILAE-CAOA
EEG	13 - 15 June 2008	Hanoi, Vietnam	SH Lim (Singapore), S Harvey (Australia), CT Tan (Malaysia), H Okada (Japan)	ILAE-CAOA
Neuroimaging	16 September 2007	Bacolod, Philippines	DC Reutens, & JL Freeman (Australia), K Tan (Philippines)	Epilepsy Society of Australia
Pediatric Epileptology	29 September 2007	Kathmandu, Nepal	H Shinichi (Japan), LC Ong (Malaysia), V Udani (India), S Harvey (Australia), N Bajaj (Nepal)	ILAE-CAOA
	2 October 2007	Mumbai, India	H Shinichi (Japan), LC Ong (Malaysia) V Udani (India), S Harvey (Australia), R Kuzniecky (USA)	ILAE-CAOA
Surgery	20 - 22 September 2007	Xian, China	Y Inoue, A Ikeda, T Tanaka, T Otsuki, K Baba & K Terada (Japan), BI Lee & SA Lee (Korea), TT Wong & YH Shih (Taiwan), SH Lim (Singapore), XZ Liu (China)	UCB Japan
Epilepsy Syndrome	27th - 28th April 2007	Bandung, Indonesia	E Somerville, A Bleasel, J Dune (Australia), N Tan (Singapore), A Berroya (Philippines), R Panggabean (Indonesia)	UCB Asia-Pacific
	29 February - 1 March 2008	Dhaka, Bangladesh	E Somerville, J Dunne, W D'Souza, L Nagarajan (Australia), CT Tan (Malaysia)	ILAE-CAOA
Psychosocial Issues	26 - 27 May 2007	Shanghai, China	JJ Tsai & SL Lai (Taiwan), A Tovuudorj (Mongolia), A Hung (Hong Kong), H Kubota (Japan), Z Hong, Wang & Li (China), CT Tan (Malaysia)	IBE-Regional Executive Committees for Western Pacific & South-East Asia Regions and ILAE-CAOA
Basic Sciences	7 July 2007	Singapore (during 27th IEC)	T O'Brien, S Petrou, J Willoughby & G Jackson (Australia), GW Mathern, A Galanopoulou, EH Bertram & SL Moshe (US K Yamakawa (Japan)	ILAE-CAOA SA),
	14 - 15 May 2008	Xiamen, China (during 7th AOEC)	E Cavalheiro (Brazil), BI Lee, HS Shin (Korea), P Wolf (Denmark), I Scheffer (Australia), G Avanzini (Italy), T Tanaka (Japan),T Su (China), P Satishchandra (India)	ILAE's Subcommission on Basic Research of the Educational Commission
Epilepsy Winter School	16 - 20 June 2008	Melbourne, Australia	S Berkovic, T O'Brien, I Scheffer, S Harvey, G Jackson, S Bowden, S Adams, O Alvarez, M Cook, F Vajda (Australia)	Epilepsy Society of Australia & GSK-Australia

The following workshops and teaching courses are being planned, to be held in 2008:

Type of Courses and Workshops	Dates	City, Country	Teaching Faculty	Sponsoring Organization
EEG	25 - 27 September 2008	Tianjin, China	WP Liao (China) SH Lim (Singapore), A Bleasel (Australia), A Ikeda, N Akamatsu (Japan), CT Tan (Malaysia), SY Kwan (Taiwan)	UCB-Japan & CAAE
	3 - 4 October 2008	Colombo, Sri Lanka	SH Lim (Singapore), CT Tan (Malaysia) and others	ILAE-CAOA
	17 November 2008	Hong Kong SAR, China	SH Lim (Singapore), K Terada, (Japan), CT Tan (Malaysia), M Kiley (Australia)	ILAE-CAOA & Hong Kong Epilepsy Society
Neuroimaging	October 2008	New Delhi, India	TBC	TBC
Pediatric Epileptology	17 - 18 October 2008	Chengdu, China	S Harvey (Australia) & Others (TBC)	GSK-Asia & CAAE
Surgery	22 - 23 August 2008	Semarang, Indonesia	Y Inoue, K Iida, K Arita, T Otsuki, (Japan), Z Muttaqin (Indonesia), SA Lee (Korea), SH Lim (Singapore), S Harvey (Australia), CT Tan (Malaysia)	UCB Japan, PERPEI (ILAE Chapter) & Indonesia Neurological Association
AED Treatment	5 - 6 September, 2008	Tagaytay, Philippines	P Kwan (Hong Kong), L Cabral-Lim, MH Ortiz Perez-Gosengfiao, (Philippines), SH Lim (Singapore), M Cook (Australia), CT Tan (Malaysia)	UCB Asia-Pacific

2.2 Fellowship

Four fellowships were awarded in 2006/07 by ASEPA. In addition, ASEPA assisted in the award of two sixmonth fellowships from Epilepsy Research Foundation of Japan and one 12-month fellowship from Epilepsy Society of Australia. These seven candidates were from China (two), Bangladesh (one), India (one), Vietnam (one), Sri Lanka (one), and Indonesia (one). They will undergo training in Shizuoka, Japan (three), Melbourne, Australia (one), Trivandrum, India (one), Singapore (one), and Kuala Lumpur, Malaysia (one).

The ASEPA has offered two fellowships for 2007/2008, from Bangladesh and Myanmar for further training in India and Malaysia. The ASEPA also helped to select two awards for Epilepsy Research Foundation of Japan and Japan Epilepsy Society, from China and Indonesia; and one for Epilepsy Society of Australia from India.

2.3 ASEPA-ASNA EEG Certification Examination

The ASEPA in cooperation with ASEAN Neurological Association (ASNA) launched a certification examination on EEG in 2005. The purpose of the EEG Certification is to establish and improve standards of training and professional practice of Electroencephalography (EEG) in Asia.

The examination format of the American Board of Clinical Neurophysyiology was adopted but simplified so that the examination could certify those who have met the "minimal" standard for the practice of Routine EEG. To be certified as a qualified Electroencephalographer, candidates have to pass both Part 1 and 2 of the Examination. Part 1 is the Written Examination in multiple-choice question format in English, testing the knowledge of EEG instrumentation, normal and abnormal EEGs. Candidates have to answer 150 multiplechoice questions in three hours. Part 2 is the Oral Examination, testing the skills of routine EEG recording, reporting and interpretation. The oral examination is also conducted in English, by a panel of Examiners who are either ABCN-certified EEGers and/or have extensive experience in using routine and long-term EEG monitoring. Dr Akio Ikeda from Japan and Dr Andrew Bleasel from Australia have been instrumental in setting up and running this EEG Certification Examination.

To date, 55 candidates from Hong Kong, Indonesia, India, Japan, Malaysia, Singapore, Thailand and Vietnam have taken the Part 1 Examination, conducted during ASNA Conventions (in Jakarta, Indonesia 2005 and Cha Am, Thailand 2007), Asian Oceanian Epilepsy Congresses (AOEC in Kuala Lumpur, Malaysia 2006 and Xiamen, China 2008) and the International Epilepsy Congress (Singapore 2007). The passing rate was approximately 60%.

Fifteen candidates have taken the Part 2 Examination, conducted during AOECs (Kuala Lumpur, Malaysia 2006 and Xiamen, China 2008) and IEC (Singapore 2007) and 14 have been certified as qualified Electroencephalographer (one candidate retook the Part 2). Of these, three were EEG technologists.

Another two Part 1 Examinations will be conducted in 2008: (1) Hong Kong on 22 November 2008, and (2) Kuala Lumpur, April 2009. The next Part 2 Examination will also be conducted in Kuala Lumpur in April 2009.

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (continued)

2.4 Publications

The proceedings of the 6th AOEC, which consist of presentations of the plenary sessions, symposia, and 40 selected abstracts from the free papers, were published in 2007 as a supplement of *Neurology Asia*.

Another proceeding on the "Current status of epilepsy surgery in Asia" was published in 2007. This is based on presentations during the workshop on epilepsy surgery in Shizuoka, Japan, 2006. This volume is edited by Y Inoue and M Seino. It is also published as a supplement of *Neurology Asia*. The publication is sponsored by UCB Japan. Both supplements can be accessed online in www.neurology-asia.org.

2.5 ASEPA Web site

It is proposed that the ASEPA set up a Web site, to provide information on educational courses/workshops, fellowships and publications. The lecture-slides of various ASEPA workshops can also be made available in PDF format. The proposed address is: www.asepa.epilepsy-academy.org, to be consistent with academies from other regions.

Future Work

As of June 2008, there are 17 Chapters in the Asian and Oceanian region. The Vietnam Chapter will officially be the 18th Chapter in this region, if accepted at the General Assembly during the 28th IEC in 2009. However, many countries in the Asian and Oceanian region are without a national epilepsy organization and/or an ILAE Chapter. This reflects slow development of epilepsy care in these countries which have diverse political and economical backgrounds. Even in those countries with ILAE Chapters, varying degrees of knowledge, research and/or treatment gaps still exist.

The Commission will provide necessary assistance to form an ILAE Chapter in Sri Lanka and other countries in this region. CAOA-ASEPA will continue to do its part to minimize knowledge gaps by increasing its educational effort in as many cities/countries as we could. It also hopes that the Research Task Force could help to narrow the research gap, thereby indirectly improving patient care. Cooperation and collaboration with IBE-RECs', regional offices of the World Health Organization, and regional neurological organizations needs to be increased to further reduce treatment gaps in this region.

> Shih-Hui LIM Chair



COMMISSION ON EASTERN MEDITERRANEAN AFFAIRS (CEMA)

Commission Members

Hassan Hosny, <mark>Chair</mark> Chahnez Triki Hanan Mostafa El Shakankiry Ahmad Beydoun Sonia Khan

Aims

- Promote epilepsy education by organizing epilepsy courses
- Epilepsy care and patient education
- Translational research
- Increase the number of Chapters in the region

Commission activities from 1 January 2007 to 31 May 2008

Activities in 2007

- Epilepsy course Tripoli, Libya 19-20 January 2007
- Epilepsy course Jeddah, Saudi Arabia 26 January 2007
- Epilepsy course Dubai, UAE 6-8 March 2007
- Epilepsy course Doha, Qatar 5-7 April 2007
- Epilepsy course Sanaa, Yemen 20 June 2007
- Epilepsy course Latakia, Syria 5-7 September 2007
- Epilepsy course Hamamat, Tunisia 25-28 October 2007

Activities in 2008

- Epilepsy course on TLE, Jeddah, Saudi Arabia, January 2008
- Epilepsy course Cairo, Egypt 12 February 2008
- Epilepsy course Tripoli, Libya 22-24 February 2008
- EEG course in Jeddah, Saudi Arabia, 20-22 March 2008
- Epilepsy course Tunis, Tunisia 27-28 March 2008
- Epilepsy course Sanaa, Yemen 20 April 2008
- Epilepsy course Muscat 21 May 2008

Accomplishments

New Eastern Mediterranean Chapters are being established. Currently the Libyan, Yemeni and Omani Chapters are being formed.

Recommendations for Future Work

Establishment of the Eastern Mediterranean Academy for the region; bi-yearly Congresses should be organized to raise the standard of the local doctors; publication of a regional newsletter.

> Hassan Hosny Chair

COMMISSION ON EUROPEAN AFFAIRS (CEA)

Commission Members

Michel Baulac, Chair Cigdem Ozkara, Secretary Meir Bialer, Treasurer Prof Alla Guekht, Chair of EAC Svein I Johannessen, Secretary of EAC

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.

Commission activities from 1January 2007 to 31 May 2008

CEA meetings: three in 2007 (Roma, February 2007; Istanbul, June 2007; Antalya, October 2007). Three are planned in 2008; the first one was held in February 2008 in Roma.

1. Congresses:

The preparation of the next 2008 European Congress on Epileptology, in Berlin, is progressing very well. The organization is shared by Germany and Israel. The first financial projections, as given by IDM, are excellent, even though the total Congress budget may remain a little bit inferior to Vienna 2004, probably comparable to Helsinki 2006.

Greece was selected last year to be the host country for the 2010 ECE, and the island of Rhodos will be the Congress site. The IOC/SAC will be determined at the beginning of 2008.

The selection process for the 2012 ECE will take place at the beginning of 2008.

2. Educational activities:

Years 2006, 2007, 2008, 2009 Clinical Pharmacology Eilat, Eilat Migrating Course Serbia, Lithuania, Czech Republic. Contribution to other courses San Servolo, Baltic Sea, San Servolo EPODES (surgery) Brno (March 2008)

This program has the ambition of being well diversified in terms of topics as well as in terms of geographic distribution across the region: in 2007, two events were run by the CEA (Eilat and the Migrating Course), and two others were financially supported.

• EUREPA activities: The CEA continued to financially support some EUREPA activities, and to encourage a close collaboration with EUREPA in the CEA-run educational activities as well as in the ECE. The Francophone and Lusophone programs received particular interest. Several major adaptations of the legal relationships between EUREPA and the ILAE are underway, and will certainly lead to a renovated mode of collaboration between the CEA and EUREPA. Federico Vigevano Milda Endziniene Bettina Schmitz Péter Halász

- ILAE Commission on Education activities: The CEA is represented in this Commission by Bettina Schmitz and Milda Endziniene. A guideline for requesting a CEA support to educational projects is in development.
- Miscellaneous contributions

3. Care Standards – Antiepileptic Drugs:

- Generics: a follow-up of the discussion group that was initiated in Helsinki took place at the Convention of European Chapters in Singapore IEC. This topic will be carried on in 2008 at the Berlin ECE. The CEA will liaise with the sub-commission on Generics of the Commission on Therapeutic Strategies.
- Rare epileptic diseases: No major development in 2007, but this action will be pursued next year.
- Contribution to the colloquium on Status Epilepticus (London, April 2007) and to the elaboration of European guidelines for the treatment of SE. This guideline was also presented and discussed with neurologists at the EFNS meeting in Brussels (August 2007).
- European Project on Development of Epilepsy Surgery Program (EPODES), coordinated by Cigdem Ozkara
- Contacts with the European Drug Agency (EMEA) CEA is an official correspondent of the EMEA for exchanging views on AEDs. Discussions on specific issues like orphan drug development and use.

Revision of the EMEA guideline on AEDs in 2007-2008 by the Efficacy Working Party of the CHMP (decision-making Committee for EU Drug approval): Holland and France will be the rapporteurs of this new guideline to be elaborated in 2007-2008. The CEA is involved in the organization of a specific symposium, to take place just after the Eilat AED Conference in Sitges, in June 2008. This symposium will be a forum discussion between European experts, US experts, and EMEA and FDA regulators. The main points of discussion are the monotherapy approval, the IV formulations and status epilepticus, as well as trials in childhood populations, including those with epileptic encephalopathies.

4. Research and Scientific activities:

• A political action in favor of epilepsy research was undertaken in order to promote and facilitate epilepsy research across the EU grant procedures, and to defend the presence of epilepsy-related topics in the calls for EU grants (*FrameWork* Prog 7, 2006-2013).

COMMISSION ON EUROPEAN AFFAIRS (CEA) (continued)

A CEA workshop will be held at the beginning of 2008 for defining and expressing our research objectives and priorities. An output document will be issued and published "Epilepsy research priorities for the next decade: A representative view of the European Community". This document is intended to serve at different political and scientific levels for diverse lobbying actions.

- A specific project on Mortality in Epilepsy, called "Mortemus", co-directed by Ph Ryvlin and T Tomson, will benefit from CEA financial support, because of its scientific interest, and its European "added-value" (Europe-wide survey of the cases of cardio-respiratory failures — death or near-death situations — that occurred during EEG-VIDEO monitoring).
- Miscellaneous: Financial support to the Zurich Meeting (state-of-the-art on selected research topics) and to the "Idiopathic generalized epilepsies" Symposium, Bridging basic and clinical sciences, Antalya-Turkey (2007)

5. Communication:

The CEA organized a convention of European Chapters at the Singapore IEC (July 2007), and financially supported the participation of several Chapter representatives, in particular from Eastern Europe. Thereby the CEA provided an indirect financial contribution to the IEC. The CEA contributes to the ILAE Web site, is active in the Global campaign, and participates in EUCARE activities. **6.** Rules and Statutes: The Bylaws of the CEA have been updated and will be coordinated with the other region's statutes.

Accomplishments

See above in the activities section.

Recommendations for Future Work

The main objective is to achieve an excellent ECE 2008 in Berlin, and to secure substantial income for the ILAE, the CEA, and the organizing Chapters. These surpluses may not match what was obtained in Vienna 2004, the objective to be comparable to Helsinki 2006.

Other objectives include:

- The continuation of the educational course program
- A renovated partnership with EUREPA
- A fruitful Chapter Convention at the Berlin ECE
- An improved collaboration with the other regional Commissions
- Lobbying actions in favor of European research in epilepsy

Michel Baulac Chair



COMMISSION ON LATIN AMERICAN AFFAIRS

Commission Members

Marco T Medina, Chair Patricia Campos Marcelo Devilat Barros, Secretary Salvador Gonzalez Pal, Treasurer

Aims

- To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America;
- 2. To coordinate academic activities among the ILAE Latin American region Chapters;
- 3. To improve the health care of people with epilepsy in Latin America.

Commission Activities from 1 June 2007 to 31 August 2008

ILAE Commission on Latin American Affairs members: Marcelo Devilat (Secretary), Salvador Gonzalez Pal (Treasurer), Patricia Campos, Elza Yacubian, Alejandro Scaramelli, Henry Stokes, Marco T Medina (Chair)

- 1. Latin American Epilepsy Academy [Academia Latino Americana de Epilepsia] (ALADE)
- a) ALADE Executive Committee: On 8 February 2008 during the Second Latin American Summer School on Epilepsy (LASSE II) in São Paulo, Brazil, the Latin American Epilepsy Academy (ALADE) Executive Committee was elected by the ILAE Commission on Latin American Affairs. The members of the ALADE Executive Committee are: Elza Yacubian, Patricia Campos, Silvia Kochen, Francisco Rubio Donnadieu, Alejandro Scaramelli, Esper Cavalheiro (Secretary) and Marco T Medina (Chair).They will serve from 2008 to 2011.
- b) ALADE Legal Status: In February 2008, Dr Esper Cavalheiro, Dr Marco T Medina and Dr Elza Yacubian signed the ALADE legal status document in São Paulo. ALADE will have a permanent address in São Paulo, Brazil as a non-profit organization, an educational arm of the ILAE Commission on Latin American Affairs (below a picture with the Brazilian attorney during the signing).



c) ALADE Inaugural Educational Activities: During the 5th Latin American Epilepsy Congress in Montevideo, Uruguay 5 – 8 November 2008, ALADE will inaugurate the following Educational Activities: Alejandro Scaramelli Henri Stokes Elza Márcia Targas Yacubian

- 1) Neurobiology (Coordinator: Rafael Gutierrez),
- 2) Epilepsy Surgery (Coordinators: Americo Sakamoto and Manuel Campos),
- Fundamentals in Electroencephalography (Coordinator: Salomon L Moshé),
- 4) Video-EEG in Children and Adults (Coordinator: Hans Lüders) and
- 5) Clinical Trials: design and review (Coordinator: Samuel Wiebe).
- 2. Second LASSE Latin American Summer School On Epilepsy

Increasing knowledge and decreasing treatment gap, Santa Monica Hotel and Convention Center in Guarulhos, São Paulo, Brazil, from 7-17 February 2008

Director: Esper A. Cavalheiro

The Second Latin American Summer School on Epilepsy was again a major success. The atmosphere was excellent and students were delighted with the experience. The factors that contributed to LASSE success were: (a) the hotel location; (b) teacher's dedication, commitment and generosity; (c) the program covered different aspects of basic and clinical epileptology allowing a closer interaction of students from these two areas and (d) the open discussion with contributions of all teachers present.

3. Epilepsia en Español

Editor: Natalio Fejerman

This important activity was started three years ago. During 2008 the distribution of Epilepsia en Español has been improved significantly and, according to the feedback received from the Chapters, the Journal is being received regularly by the members of the Chapters in Latin America, including Brazil. Novartis is doing quite well in the distribution. Regarding the selected papers and the overall quality of the Journal, we received favorable comments from many colleagues from the Chapters of Latin America and Spain. The 2nd volume has been sponsored by the ILAE as part of the budget of the Latin-American Affairs Commission. Drs Marco Tulio Medina and Elza Márcia Yacubian have been included as Co-Editors representing the mentioned Commission and the ILAE. At this time, we are now finishing the 3rd issue of Volume 2 which corresponds to the papers published in Epilepsia during the last months of 2007. We will have a meeting within the Latin American Commission in Montevideo (November 2008) to try to find new ways to keep the Journal running.

COMMISSION ON LATIN AMERICAN AFFAIRS (continued)

4. Latin American Epilepsy Surgery Subcommittee

The ILAE Commission on Latin American Affairs with the approval of the ILAE President Dr Peter Wolf appointed a new Latin American Epilepsy Surgery subcommittee. The members: Americo Sakamoto (Chair), Dr Manuel Campos (Secretary), Dr Mario Alonso, Dr Jaime Fandiño, Dr Juan Bulacio and a member from Central America (Costa Rica). The term of this subcommittee will be the same as the ILAE Commission on Latin American Affairs. The main goals of this subcommittee will be to improve the epilepsy surgery gap in Latin America and to promote the education and research on epilepsy surgery, working in close contact with the Latin American Academy of Epilepsy (ALADE). This subcommittee will also work with other ILAE Commissions: Therapeutics (Dr Gary Mathern),

North America (Dr Samuel Wiebe) and Epilepsy Care, mainly on the epilepsy surgery gap project.

5. Education Project with the ILAE North American Commission (joint report from the North American and Latin American Commissions)

Members: Sheryl Haut (Leader), Jean Gotman, Nizam Ahmed, Juan Ochoa, Jose Cavazos, Marco T Medina (Latin American Commission), and Elza Yakubian (Education Commission). The North American and the Latin American Commissions of the ILAE have joined forces in their commitment to improve the quality of epilepsy care in Latin America. The primary vehicle used is improvement in the transfer of knowledge.

Status of the 2008 Visiting Professorships (based on the reports from Dr Jose Cavazos, Dr Marco T Medina and Latin American ILAE Chapters):

- a) Jorge Burneo, MD University of Western Ontario Dr Burneo gave an epilepsy educational course in Lima, Peru in close coordination with Dr Lizardo Mija and Dr Patricia Campos. A Neurocysticercosis workshop took place in Tumbes, Peru, with the participation of Dr Hector Hugo Garcia, Theodore Nash, Marco T Medina, Antonio Delgado Escueta, Gustavo Roman, among others. Dr Mija and Dr Garcia reported it was an excellent meeting.
- b) Greg Krauss, MD John Hopkins University He went to Panama and has done several educational courses in coordination with the ILAE Panamanian Chapter. Excellent results were received according to Dr Ernesto Triana.
- c) David Labiner, MD University of Arizona He partnered with neurologists in Costa Rica (Dr Alexander Parajeles as local Coordinator), and plans to establish teleconferencing later this year. He plans to return next year. Excellent report according to Dr Parajeles.
- d) Patricio S Espinoza, MD Brigham & Women's Hospital of Harvard Medical School He participated in a Neurological Update program (IV Seminario Internacional de Neurosciencias) in Quito, Ecuador at the Universidad San Francisco de Quito on 1-3 April 2008. He also performed a teleconference with six sites from different regions within Ecuador.

e) Dr Jose Cavazos – University of Texas Health Science Center

The visit is scheduled for 20-27 November 2008 for the Hospital Infantil de Mexico, which is the main pediatric hospital in Mexico City. There is an epilepsy program there and we are establishing a partnership between our Epilepsy Centers.

Funds for the Visiting Professorships from 2008, 2009, 2010, 2011 and 2012 have been received and are in an account at the AES. Overall, the programs have been very successful. Dr Jose Cavazos will present a report at the AES International Affairs Committee in December 2008 and at the NA Task Force meeting.

6. Island of Hispaniola Project (report from Lionel Carmant)

Members: Lionel Carmant (leader, Canada), Marco Medina (Latin American Commission), Diogenes Santos-Villorio (Dominican Republic), Michel Baldy Mouliner (EUREPA), Alex Elie (Haiti), and Dr Marcel Severe (Haiti).

On 4 June 2008, la Clinique d'épilepsie de Port-Au-Prince was up and running. Haiti and the Dominican Republic constitute the Island of Hispaniola. But unlike the Dominican Chapter, which is well structured, Haiti had no neurologist, no trained electroencephalographers, and it only had access to two conventional EEG machines (one of which is 8channels), to serve a population of eight million. Recordings were reviewed outside of the country.

The Task Force is chaired by Lionel Carmant, Past President of the Canadian Chapter, and includes Diogenes S Viloria, President of the Dominican Chapter, Alix Elie, a neurosurgeon from Haiti who follows most of the patients with epilepsy, Marco T Medina, President of the Latin American Commission and Michel B Moulinier, Past President of the French League who had agreed to share with us his experience in the African Region.

The Task Force rapidly identified the most significant needs of the Island. First, help provide access to proper epilepsy care to the Haitian population. Second, help was needed to eradicate neurocysticercosis from the Island of Hispaniola. Finally we could support the development of an epilepsy surgery program. To reach these objectives, we enriched the Task Force by inviting collaboration from three additional individuals, Dr Marcel Sévère, a young Haitian pediatrician eager to learn how to interpret EEGs, Dr Hector Hugo Garcia from Peru, a world leader in neurocysticercosis epidemiological research, and Dr Diones Rivera, a prominent Dominican neurosurgeon leading the effort in epilepsy surgery development in Dominican Republic.

7. Educational Activities in Congresses: Epilepsy Educational Symposium supported by the ILAE Latin American Commission during the Panamerican Neurology Congress Dominican Republic and the International Epilepsy Congress in Singapore.

COMMISSION ON LATIN AMERICAN AFFAIRS (continued)

During the Pan-American Neurology Congress on 7 to 13 October 2007, the Latin American Commission, the North American Commission and the Dominican Republic Chapter organized an Educational Epilepsy Course (on 10 October 2007), with the participation of: Samuel Wiebe (North America Commission, Canada) Lionel Carmant (Canadian ILAE Chapter), Henry Stokes (Latin American Commission, Guatemala), Salvador Gonzalez-Pal (Latin American Chapter, Cuba), Marco T Medina (Latin American Commission), Diogenes Santos Viloria, Jose Cabrera and Rosario Gomez (ILAE Dominican Republic Chapter), Franz Chaves-Sell (ILAE Costa Rican Chapter), Antonio V Delgado-Escueta and Diana Kraemer (USA). The educational symposium was a success. After this symposium a meeting on the Hispaniola project took place.

During the International Epilepsy Congress, in Singapore on 10 July 2007 the IBE and the ILAE Latin American Commission organized a successful session on: Complementary and Alternative Therapy for Epilepsy with the participation of Dr Lilia Nunez (Mexico), Alicia Bogacz (Uruguay), Franz Chaves-Sell (Costa Rica) and Marco T Medina (Honduras).

8. Global Campaign and WHO/PAHO Central American Regional Meeting Representatives from the Pan American Health Organization/World Health Organization (Dr Victor Aparicio, Dr Jorge Rodriguez, Dr Jose Bertolote), ILAE (Dr Marco T Medina, Henry Stokes), IBE (Dr Carlos Acevedo) and Central America, Cuba, Dominican Republic and Mexico representatives had a meeting in Tegucigalpa, Honduras on 21 – 23 August in order to promote the Epilepsy Global Campaign in the region. Dr Acevedo presented a Latin America Epilepsy Report and Dr Bertolote the Spanish translation of the Neurological Disorders: Public Health Challenges book. During this meeting a demonstrative pilot project was proposed in Honduras and a Regional Consensus on Epilepsy was achieved. 9. Other Activities of the Commission The V Latin American Congress on Epilepsy is going to be held in Montevideo, Uruguay, 5 to 8 November, 2008. The Organizing Committee, including members from ILAE and IBE Latin American Commissions, representatives from the Executive Committees of both ILAE and IBE, the Epilepsy Care Commission as well as members from the local organizing committee, have worked in close collaboration. Several courses organized by the Latin American Academy of Epilepsy were included on the program.

Accomplishments (2007)

- 1. Election of the ALADE Executive Committee, ALADE legal status accomplished and inaugural educational activities in Montevideo.
- 2. Successful collaborative work with the North American Commission.
- 3. Establishment of the Epilepsy Surgery subcommittee
- 4. Successful LASSE II and Epilepsia en Espanol.

Recommendations for Future Work

- Improving the Latin American Epilepsy Academy (ALADE) regional activities (i.e., Mesoamerica and Caribbean, Andean, etc.);
- Improve the epilepsy care in Latin America (i.e., neurocysticercosis project, epilepsy surgery gap and treatment gap);
- 3. Consolidation of LASSE and Epilepsia en Espanol.

Marco T. Medina Chair



COMMISSION OF THE NORTH AMERICAN REGION (NAC)

Commission Members

Samuel Wiebe, (Canada), Chair Sheryl Haut, (USA), Secretary Lionel Carmant, (Canada), Treasurer Jean Gotman (Canada)

Commission Projects

The projects of the North American Commission (NAC) have been outlined in previous reports. Progress has been made in all projects.

Education Task Force

Members: Sheryl Haut (Leader), Jean Gotman, Nizam Ahmed, Juan Ochoa, Jose Cavazos, Marco Medina (Latin American Commission), and Elza Yakubian (Education Commission).

Other participants: Jorge Vidaurre, Arthur Grant, Carly Mann.

The North American Commission of the ILAE is committed to improving the quality of epilepsy care in Latin America by partnering with members and chapters of the Latin American Commission. The primary route to achieve this goal is the transfer of knowledge. The North American and the Latin American Commissions of the ILAE have joined forces to implement a threelevel educational plan:

a) Level One "Partnering Epilepsy Centres in the Americas":

Dr J Cavazos negotiated an \$110,000 unrestricted educational grant from Schwarz Foundation (a subsidiary of UCB Pharma) to fund individual visiting professorships. The Task Force organized a formal process to invite proposals, rate them and provide grants to approved applications. This program chooses faculty from epilepsy centers in North America, to travel to new and/or emerging epilepsy centers in the Caribbean and Latin America, and continue the partnerships via telemedicine. Visiting professors are active in local epilepsy meetings and spend time in epilepsy centers, teaching clinically and didactically, as well as participating in clinical discussions. The initial aim was to have three to four visiting professorships per year with an initial plan for a five-year program. The program has been very successful. To date, the following programs have been completed:

1) David Clarke, MD – University of Tennessee HSC at Memphis, has partnered with the Jamaican Chapter of the ILAE and will extend his participation to the Englishspeaking territories of the Caribbean and also the Dutch Antilles. He also received significant matching funds from the Le Bonheur's Children Medical Center to develop a telemedicine project there. Amza Ali (Jamaica) Robert Fisher (USA) John Pellock (USA) Jeff Noebels (USA, Ex-Officio).

2) Patricio S Espinoza, MD – Brigham & Women's Hospital of Harvard Medical School, participated in a Neurological Update program (IV Seminario Internacional de Neurosciencias) in Quito, Ecuador, at the Universidad San Francisco de Quito on 1 - 3 April 2008. He also performed a teleconference with six sites from different regions within Ecuador.

Photographs of the event are posted online and can be viewed at

http://picasaweb.google.com/PS.Espinosa/IVSeminario InternacioncalEnNeurociencias2008?authkey=Im0QT9 5yXOA.

3) Jorge Burneo, MD – University of Western Ontario, Canada, travelled to Peru in July 2008 and participated in a series of events with the Peruvian Chapter of the ILAE.

4) David Labiner, MD – University of Arizona, partnered with neurologists in Costa Rica quite successfully, is establishing teleconferencing later this year, and he plans to return next year for a second visit.

The following partnerships are being planned in the short term:

1) Greg Krauss, MD – John Hopkins University, partnering with Panama.

2) Jose Cavazos, MD – University of Texas Health Science Center is scheduled to visit the Hospital Infantil de Mexico, which is the main pediatric hospital in Mexico City. Dr Cavazos is establishing a partnership between the Epilepsy Centers of the two institutions. The visit is scheduled for 20 - 27 November 2008.

b) Level Two "Web-based collaboration": Medium-term relationships are being established between North American and Latin American partnering centers for exchange of information, primarily through electronic means, including video conferencing and particularly Web-based exchanges and telephone conferences. This includes clinical aspects, training issues, and other case-based discussions. Some partnerships are beginning to enter this process.

c) Level Three "Long term training":

A long-term relationship will be established between North American and Latin American centers, possibly spanning from one to three years, involving training at the North American center of a number of staff and personnel from the trainee center in Latin America. This stage has not been reached yet, as the projects are at their early stages. Throughout the entire process, the Latin American Commission has been informed and involved, and has provided feedback and assistance in the partnering process.

COMMISSION OF THE NORTH AMERICAN REGION (NAC) (continued)

Disparities in Epilepsy Task Force

Members: Jorge Burneo (Leader), S Wiebe (Canada), A Hauser (USA), D Thurman (USA, Centers for Disease Control), M Jacobs (USA, NIH), K Parko (USA, Public Health Service), C Begley (USA), N Jetté (Canada), J Pellock (USA).

This Task Force has completed its first goal, i.e., a systematic review of the evidence on disparities in epilepsy. The resulting manuscript is being submitted to the ILAE Executive Committee for assessment and approval for submission as an ILAE-sponsored publication. The manuscript encompasses a systematic, critical review of the world literature, and a "call for action" that identifies issues, gaps in the evidence, and areas that need to be targeted for research or future action.

The project exemplifies collaboration of multiple and key organizations, such as the NINDS, the CDC, the Canadian League, the NAC, and experienced researchers in the field. It is expected this will foster future initiatives that explore interventions to address the issue of disparities in epilepsy care more globally. For example, using the experience gained in the NAC disparities Task Force, a new project is being launched through the ILAE Commission in Epilepsy Care to assess disparities in Latin America and Asia.

First Regional Caribbean Epilepsy Congress

Organizing Committee Members: Amza Ali (leader, Jamaica), Robert Fisher (USA), Jeff Noebels (USA), Sharon Whiting (Canada, formerly Jamaica), David Clarke (US formerly from Antigua), Neil Cruz (USVI).

Clinicians from English-speaking Caribbean countries gathered at the First North American Regional Caribbean Congress of Epilepsy, which took place in Montego Bay, Jamaica 30 - 31 May 2008. The event was a truly collaborative endeavor involving the North American Commission of the International League Against Epilepsy (ILAE), the Jamaican League Against Epilepsy (JLAE), the Jamaican Epilepsy Association, the American Epilepsy Society (AES), and the Canadian League Against Epilepsy (CLAE), as well as the international corporations Novartis and Bank of Nova Scotia.

Under the leadership of Dr Amza Ali (President of the Jamaican League Against Epilepsy) and Dr Robert Fisher (North American Commission of the ILAE), Co-Chairs of the Congress, this inaugural and wellattended event marks a new chapter in the development of academic activities focusing on epilepsy in the English-speaking Caribbean region.

The high profile of the Congress was evident by the participation of regional dignitaries and of regional and international speakers. During the official opening ceremony, the Honorable Rudyard Spencer, Minister of Health of Jamaica, eloquently acknowledged the difficulties and stigma facing persons with epilepsy, and pledged his commitment to work with the JLAE to improve the care and quality of life of people with epilepsy in Jamaica. Professor Peter Wolf, President of the ILAE, gave the opening address in which he emphasized the significance of this academic event, and acknowledged the effort of organizers and contributors in bringing the congress to fruition. Although inclement weather impeded the attendance of some of the international and regional speakers, all were able to give their presentations via telecast. International speakers included Drs Robert Fisher (USA), Dennis Spencer (USA, President of the AES), Martin Brodie (UK, ILAE Treasurer), Jeffrey Noebels (USA), William Theodore (USA), Kimford Meador (USA), Eugene Ramsay (USA), Basim Uthman (USA), David Clarke (USA-Jamaica), Franz Chaves Sell (Costa Rica), and Samuel Wiebe (Canada, Chair of North American Commission of ILAE).These speakers covered a wide variety of topics, ranging from basic clinical principles through medical and surgical management, to cutting edge genetic concepts.

Regional speakers and session chairs included Drs Amza Ali (Jamaica, President of the JLAE), Colin McKenzie (University of the West Indies), Hafeezul Mohammed (President of the Association of Consultant Physicians of Jamaica), Professor Robert Gray (University of the West Indies), Judy Tapper (Jamaica), Rainford Wilks (Jamaica), David Corbin (Barbados), Sean Marquez (Barbados), Roberto Rico (Curacao) and Neil Cruz (US Virgin Islands). Speakers in these sessions provided insightful descriptions of their work in the epidemiological, medical and psychosocial aspects of epilepsy in the Caribbean region. The sessions culminated in a lively question and answer period which engaged a keen audience and extended into the evening.

The success of the First North American Regional Caribbean Congress of Epilepsy allows us to envisage an era of new initiatives and collaborations that will lead to better care and quality of life of patients with epilepsy in this region.

Island of Hispanola (Haiti) Project Task Force

Members: Lionel Carmant (leader, Canada), Marco Medina (Latin American Commission), Diogenes Santos-Villorio (Dominican Republic), Michel Baldy Mouliner (EUREPA), and Alex Elie (Haiti).

As of 4 June 2008, la Clinique d'épilepsie de Port-Au-Prince is up and running. Haiti and the Dominican Republic constitute the Island of Hispaniola. Unlike the Dominican epilepsy Chapter, which is well structured, Haiti had no neurologist, no trained electroencephalographers, and it only had access to two conventional EEG machines (one of which is 8-channels), to serve a population of eight million people. EEG recordings were interpreted outside of the country.

The NAC, at its first business meeting in 2006 identified Haiti as a region with some of the most urgent needs for improved epilepsy care. The Hispaniola Task Force was therefore created to assess the needs for Haiti and the Dominican Republic and to help meet these needs. The Task Force is chaired by Lionel Carmant, Past President of the Canadian Chapter, and include Diogenes Santos Viloria, President of the Dominican Chapter, Alix Elie, a neurosurgeon from Haiti who follows most of the patients with epilepsy, Marco Tulio Medina, President of the Latin American Commission and Michel Baldy Moulinier, Past President of the French League who had agreed to share with us his experience in the African region.

COMMISSION OF THE NORTH AMERICAN REGION (NAC) (continued)

The Task Force rapidly identified the most significant needs of the Island. The first priority was to help provide access to proper epilepsy care to the Haitian population. Second, help was needed to eradicate neurocysticercosis from the Island of Hispaniola. Finally, support for the development of an epilepsy surgery program would be highly desirable. To reach these objectives, the Task Force was enriched by inviting collaboration from three additional individuals, i.e., Dr Marcel Sévère, a young Haitian pediatrician eager to learn how to interpret EEGs, Dr Hector Hugo Garcia from Peru, a world leader in neurocysticercosis epidemiological research, and Dr Diones Rivera, a prominent Dominican neurosurgeon leading the effort in epilepsy surgery development in Dominican Republic.

A plan of action was assembled, looking at simple and attainable goals. For the Haiti epilepsy clinic, training for a nurse and an EEG technologist in Haiti was needed. Dr Santos Viloria kindly agreed to provide the training in Dominican Republic. Dr Sévère also needed training in EEG interpretation and he agreed to come to the EEG laboratory in Montreal to train. Finally, the Haiti clinic required modern EEG equipment. To this end, Dr Jean Gotman, owner of the Montreal-based EEG Stellate company, and also a member of the NAC, generously provided an EEG system. He also offered to provide training for the technologist to operate and repair the system. Unfortunately, a Canadian visa could not be obtained for the technologist despite numerous attempts and letters of support.

On 4 June 2008, Dr Carmant and Genevieve Arbour, a Canadian EEG technologist, visited Haiti to launch the newly established Clinique d'épilepsie de Port-Au-Prince, to install the new equipment, to provide support for launching the clinic, and to train the local technologist in the operation of the new Stellate EEG system. During the first week we were able to evaluate 12 patients with a variety of backgrounds. Not only were new diagnoses made, but nonepileptic events were identified and unnecessary medication was discontinued. The clinic remains a success and performs from two to five EEG studies per day.

The Task Force is now ready to tackle the neurocysticercosis project by assessing its prevalence in the endemic region at the border of the Dominican Republic and Haiti. A pilot study has been designed to this end. We also hope to launch the epilepsy surgery program in 2009. We wish to acknowledge the contribution of our two latest additions to the Task Force, Dr Farah Lubin, who helped us look for funding for the Haiti clinic, and Dr Jose Ferreira who at the 2007 AES meeting agreed to provide additional expertise to both the neurocysticercosis and epilepsy surgery projects.

We are extremely pleased with strides made in a relatively short period of time, and we expect this project to develop further as it gains momentum. We wish to thank all the Task Force members as well as the NAC members for their availability, support and devotion to these projects.

Other Activities of the Commission

2nd North American Regional Epilepsy Congress: Seattle, Washington, USA, will host the second North American Regional Epilepsy Congress during the American Epilepsy Society's (AES) 2008 Annual Meeting. This is the second of ongoing biennial North American Regional Epilepsy Congresses that will be hosted at future AES Annual Meetings. Co-hosts will be the Canadian League Against Epilepsy and the Jamaican Chapter of the ILAE.

The keynote event will be the North American Region Symposium, entitled "Epilepsy and the World: Neuroinfections," and it will take place on Monday, 8 December from 7:00 pm to 9:30 pm. Infectious and parasitic disorders of the central nervous system are important causes of epilepsy worldwide. Study of these conditions also provides a unique opportunity to understand the mechanisms of epileptogenesis and ways in which it can be altered. Also, because many of these conditions are treatable and preventable, there is great potential for impacting the burden of epilepsy around the world. A panel of international experts from developed and developing countries will address the mechanisms, impact, management, and current challenges related to the most common neuroinfections in epilepsy. The objectives of the symposium are: A) To obtain up-to-date evidence based information about the mechanisms of epileptogenesis in neuro-infections. B) To review the most common neuroinfections producing epilepsy worldwide. C) To review the challenges of managing epilepsy in the context of anti-infectious agents. D) To obtain an overall view of the impact of neuroinfections on epilepsy. We expect that the program will be of interest to clinicians, trainees, and researchers.

The program includes faculty from China, Peru, Africa, UK, and USA, who are experts in the fields of neurocysticercosis, malaria, HIV-AIDS, pathogenesis of epilepsy in neuroinfections, and therapy. The program is available at http://www.aesnet.org/go/meetingsand-events/annualmeeting.

Other

The North American Commission continues to actively explore interactions with major organizations such as the American Epilepsy Society, Epilepsy Foundation of America, CDC, NIH, as well as Canadian, Caribbean and Latin American Organizations. Opportunities forcollaboration and development are continuously sought. Development of new Chapters and fostering of education and excellence in epilepsy care are goals that the Commission seeks to achieve.

> Samuel Wiebe MD, MSc, FRCPC Chair

Resource and Problem-Oriented Commissions

COMMISSION ON CLASSIFICATION AND TERMINOLOGY

Commission Members

- Anne Berg, Chair Douglas Nordli Ingrid Scheffer Pete Engel Perrine Plouin
- Philippe Ryvlin Sam Berkovic Tracy Glauser Walter von Emde Boas Jeff Buchhalter

Aims

- 1) To revise the concepts and terminology used in classifying epilepsy syndromes and epilepsies;
- To develop methods for objective identification and testing of phenotypes;
- 3) To develop a diagnostic manual.

Commission activities from 1 January 2007 to 31 May 2008

- 1) A proposal for a parallel session in Budapest on an update of classification was accepted. Speakers will be Drs Berg, Glauser, Ryvlin, and Scheffer.
- 2) Ed Bertram (ILAE communications) and Anne Berg have been revising the ILAE Web site for Classification and Terminology. As part of the revisions, we are posting PDFs of many of the earlier discussions and proposals about classification going back to the late 1960s and early 1970s.
- 3) Helen Cross and Anne Berg drafted a definition of epileptic encephalopathy.
- 4) Several Commission members and liaisons attended a meeting organized by Pippo Capovilla and Giuliano Avanzini and held in Monreale, Sicily. The purpose of the meeting was to discuss and better define common terms and dichotomies on which we base much of our thinking in epilepsy. In particular: idiopathic vs. symptomatic and focal vs. generalized. The concept of benign epilepsy was another focus. A summary of the discussions is being prepared for submission to *Epilepsia*. These discussions provided extremely helpful input for the Commission's deliberations.
- 5) Ingrid Scheffer presented our plans for revisions at the regional meeting in China this May.
- 6) An intensive two-day meeting of the Commission and liaisons is taking place in Paris, 28-29 July.

Accomplishments 1) A proposal for a parallel session in Budapest on an update of classification was accepted. Speakers will be Drs Berg, Glauser, Ryvlin, and Scheffer.

Liaisons

Gary Mathern

Ruth Ottman

Jackie French

Helen Cross

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- 5) Ingrid Scheffer presented our plans for revisions at the regional meeting in China this may.
- 6) An intensive two-day meeting of the Commission and liaisons is taking place in Paris, 28-29 July.

Recommendations for Future Work

We are hoping to have a draft for the first goal finished by the end of the year. The other two goals follow from the first.

> Anne Berg Chair

COMMISSION ON DIAGNOSTIC IMAGING

Commission Members

William Davis Gaillard John S Duncan Demetrius Velis Sampsa Vanhatolo, Secretary ILAE Executive Committee, Ex-Officio

Sub-Commission Members

Demetrius Velis, <mark>Chair</mark> Jean Gotman (Canada) Andreas Schulze-Bonhage (Germany) Kyriakos Garganis (Greece) Leopold Gaston Boisy (Senegal)

Neuroimaging Sub-commission: Drs Catherine Chiron and William Davis Gaillard, Co-chairs. Members: Matthias Koepp (UK), Czaba Juhasz (USA), Fernando Cendes (Brazil), Rubin Kuzneiky (USA), Sung Kung Lee (Korea), Fritz Woermann (Germany), and Helen Cross (UK) joined as an Ex-Officio member from the Pediatric Commission regarding our sub-commission mandate on pediatric imaging.

Aims

The charge of the Diagnostic Commission is:

- To provide information-based guides to clinical practice for currently used, selected diagnostic methods; and
- To provide an electronic educational resource to train and educate colleagues around the globe in the appropriate use of selected diagnostic methods.

Commission activities from 1 January 2007 to 31 May 2008

The Imaging E-Education Module was successfully launched (Dr Catherine Chiron) in September 2007 and completed in December 2008. The course ran smoothly and was well received. We have reviewed comments from students and faculty to be incorporated in year two which will begin in the fall of 2009. The guidelines for imaging children with new onset epilepsy have been accepted for publication in *Epilepsia* (WD Gaillard). The working group for evidence-based guidelines for imaging children with chronic epilepsy continues (WD Gaillard). The Singapore meeting provided a basis for WD Gaillard who has also organized a working group to evaluate the role (strength and limitations) of image guidelines. The goal of this group is to establish parameters for future studies.

Dr Velis has led implementation of an E-education course in neurophysiology and has also labored to establish recommendations for use of portable EEG in decentralized epilepsy care in countries with limited resources. Dr Velis is also organizing guidelines for MEG. A. The Neuroimaging Sub-commission The Neuroimaging Sub-commission submitted its draft for guidelines in the evaluation of children with recently diagnosed epilepsy and is now working on guidelines for the evaluation of children with refractory epilepsy. The Commission, through WD Gaillard has worked with the AAN Practice Epilepsy Commission (Practice parameter team) and has identified 1,500 papers with MRI, PET, SPECT now being reviewed for pediatric content. A session at the Singapore ILAE meeting will be dedicated to evidence-based use of imaging in the evaluation of children with epilepsy. The Neuroimaging Sub-commission, lead by Dr Chiron, has organized a E-education module and is planning on launching the module in July at the Singapore meeting. Sections and authors have been identified and materials are due in June 2007

B. The Neurophysiology Sub-commission E-Education The Sub-commission on Neurophysiology has made continued progress on the clinical neurophysiology distance learning module which has been successfully launched. Materials are to be made available in Spanish and French in addition to the current English. The sub-commission established recommendations for use of portable EEG in decentralized epilepsy care for countries with limited resources. Early exploration of ambulatory EEG met limited if not disappointing response from many Chapters; but encouraging opportunity appears to be present with West African colleagues and pressing south Asian Chapters with upcoming meeting. Efforts continue to build this program.

Recommendations for Future Work

The primary goal of the Diagnostic Commission and its sub-commissions for the upcoming year is the effective consolidation of the e-education initiative and completion of guidelines.

The Diagnostic Commission will continue to focus on emerging technologies for diagnosis and planning interventions in patients with epilepsy. The Commission plans focus on MEG, Optical Imaging, TMS, and new

COMMISSION ON DIAGNOSTIC IMAGING (continued)

MRI imaging sequences (e.g., DTI). In particular the Neurophysiology Commission is weighing a commission report on MEG with an emphasis on evidencebased review of uses and limitations of MEG for interictal spike localization and source imaging for language. The Diagnostic Commission is also considering mechanisms by which new and recent diagnostic technologies may be evaluated across multiple sites and establishing guidelines for what may be deemed quality imaging studies. This is important given differences in discrepancies between published Class 1-4 evidence and the limitations inherent in imaging epilepsy populations.

Commission and sub-commission meetings are planned for Berlin, AES Seattle and ILAE Budapest.

William Davis Gaillard Chair



COMMISSION ON EDUCATION

Commission Members

Esper A. Cavalheiro, (Brazil) – Basic Science Milda Endziniené, (Lithuania) – East Europe Hassan Hosny, (Egypt) – East Mediterranean Jeffrey Noebels, (Texas) – North America Margarete Pfäfflin, (Germany) Health Care Professionals, Secretary

Perrine Plouin, (France) Francophone

Flyer of the Commission on Education: http://www.epilepsy-academy.org/homepage/de/document_center_1/36.html.

1. Aims

- To design and implement an educational system which makes quality-controlled education in epilepsy globally available to all professionals dealing with epilepsy.
- To promote and make use of all relevant educational methods in a modular system.
- To establish an available faculty of certified trainers and tutors to enhance education world wide.
- To recognize educational activities within the ILAE and establish educational networks, mentorship and all additional structural elements of academic education.
- To establish standards and guidelines for educational activities within the ILAE.

2. Activities and accomplishments (January 2007-December 2008)

2.1 Appreciation

To our great sadness commission member Dr Masakazu Seino passed away on 7 April 2007. The Commission remembers gratefully his excellent contributions.

2.2 Commission Meetings

Three meetings were conducted within the period:

- Workshop in Paris, France, 8-9 June 2007
- Business meeting in Philadelphia, USA, 4 December 2007 (during AES meeting)
- Business meeting in Berlin, Germany, 25 September 2008 (during 8th ECE)

2.3 Joint Meetings and Cooperation within the ILAE

Joint meetings with the American Epilepsy Society (AES) and the Commission of the North American Region (NAC) as well as the European Epilepsy Academy (EUREPA) confirmed mutual aims and resources for the exchange of experience and learning. Joint analysis focused on educational gaps with respect to English speaking countries in Africa and to Spanish speaking countries in Central America. EUREPA, the European Epilepsy Academy is already acting with a strong extra-European outreach. Most well-known are the distance education courses (VIREPA) on EEG, pharmacology, Alejandro Scaramelli, (Uruguay) Latin America, Treasurer Bettina Schmitz, (Germany) – West Europe Chong-Tin Tan, (Malaysia) – Asian-Oceanian Elza Márcia Yacubian, (Brazil) Lusophone, Chair Verena Hézser-v.Wehrs, (Germany) Distance Educ. & Epilepsy Academy Office, Ex-Officio Emilio Perucca, (Italy) Faculty of 1000, Ex-Officio

neuroimaging and genetics and its Trainers' Courses in French and Portuguese speaking Africa. Discussion concentrated on how to finance and how to organize the amount of work in line with the given capacities. The Education Commission concentrates within this discussion on criteria for eligible courses, bursaries and educational tasks.

2.4 Bursary Data Base and Guidelines for educational courses

On behalf of the ILAE and the CEA, the Epilepsy Academy Office programmed a bursary database accessible to all course organizers for verification of grants and identification of especially motivated professionals in epilepsy. The close cooperation between the Commission and the Commission on European Affairs (CEA) led to guidelines for accreditation of educational courses, and guidelines for funding and bursaries.

Application can be done via internet for CEA support and EUREPA accreditation of courses (http://www.epilepsy-academy.org/homepage/de/10.html). The world wide application procedure and the availability for these guidelines globally are pending due to current status problems of the ILAE Epilepsy Academy. Nevertheless, basic aspects can be downloaded with the Global Education Agenda (see 2.8).

2.5 Budget Proposals and educational gaps

With an emphasis on the regions of the world with gaps in epilepsy education, the Commission developed budgets and supported activities in Latin America like the Latin American Summer School in Epilepsy (LASSE), and courses in Africa. African courses were organized under the responsibility of the Francophone Section, the Lusophone Section and the Anglophone Section. Distance education courses included participants from virtually all countries in the world: Asia & Oceanic (China, India, Pakistan, Indonesia, Hong Kong, Australia), Africa (Nigeria), Latin America (Brazil, Uruguay) and the Eastern Mediterranean region (Egypt, Qatar, Kuwait, Kingdom of Saudi Arabia, Tunisia).

2.6 The Epilepsy Academy website - ILAE website on education

The Commission on Education developed an outlined website proposal for an ILAE Epilepsy Academy consisting of two parts:

COMMISSION ON EDUCATION (continued)

- the Information Portal
- the Knowledge Portal

The concept of the Information Portal included objectives, target groups, operational systems, domains, legal aspects, financial aspects and graphic design. Sub-domains for regional epilepsy academies will be offered for regional administration. While the concept of the Information Portal is quite advanced and detailed and is expected to be launched at the latest by summer of 2009, the Knowledge Portal needs further input and discussion in upcoming meetings.

2.7 Design of teaching methods as part of quality improvement

The Commission on Education collects and designs different teaching methods in order to involve learners in the process of acquiring knowledge, skills, and attitudes necessary to become specialists in comprehensive epilepsy care. Therefore trainers are encouraged to make use of a variety of educational methods; a handbook of methods is in preparation. So far specific Manuals on teaching methods used during each of the Trainers' Courses are prepared and distributed to their participants.

2.8 Global Education Agenda

According to the Commission's aims, a global Education Agenda has been set up by the Commission including detailed proposals:

- for a world wide operating ILAE Office and Epilepsy Academy,
- for a Knowledge Portal and Web site,

- for partnerships with other organization active in the field of education, and
- for quality oriented criteria with respect to a large variety of educational.

The Global Education Agenda had been printed and distributed at various congresses. Download the Global Education Agenda:

http://www.ilae-

epilepsy.org/Visitors/Documents/GlobalEducationAgen da07 Website Neu.pdf and

http://www.epilepsy-academy.org/homepage/de/document_center_1/36.html

3. Sub-commission activities and accomplishments:

Different from our last report, sub-commission activity is displayed according to regions. The collaboration between the majority of commission members' has developed to a large extent, therefore this report concentrates on common activities on a regional level. In addition to this report, more information is included in the reports of the "Regional Commissions" available on the ILAE Web site.

3.1 Asia-Oceania

The activities of ASEPA (Asian Epilepsy Academy) includes in average eight courses and workshops per year, fellowship and publications. Furthermore, the ASEPA in cooperation with ASEAN Neurological Association (ASNA) has launched a certification examination on EEG consisting of two parts. Already, 33 persons passed examination part 1 (multiple choice ques-



COMMISSION ON EDUCATION (continued)

tions), and 14 persons passed examination part 2 (oral examination). Educational activity in Asia Oceania is very well established with a large number of participants. On-site trainings are consolidated and distance education courses (VIREPA) are recommended to professionals. There is also an interest to develop a program for "visiting professorship" possibly with the US.

3.2 The American Continent (Latin, Central and North)

Latin America: The Latin American Academy (ALADE) was officially established during the 5th Latin American Congress in Montevideo (November 2008), and provided a number of courses in neurobiology, epilepsy surgery, EEG and clinical trials. The Latin American Summer School on Epilepsy is well recognized in the meantime and will have its 3rd edition in spring 2009. Train-the-trainer courses in Portuguese speaking Africa complement the educational activities and are attended also by Brazilian participants.

Central America: In Central America the First Regional Caribbean Epilepsy Congress in Jamaica was launched in spring 2008, and coordination between epileptologists from the North American Region and the Central American Region have been implemented including visiting professorships.

North America: With respect to the aims of the Commission on Education, the most remarkable development in North America is the growing cooperation with partners throughout the world. Traditionally, the annual meetings of the American Epilepsy Society are highlights in education next to a variety of workshops and conferences throughout the States. Engagement in Africa, Central America and visiting professorships for people from various countries broaden the scope of education.

3.3 Africa and Eastern Mediterranean

The 1st Eastern Mediterranean Epilepsy Congress was launched in Luxor (Egypt) in spring 2007 with promising interest in epilepsy. Africa had been in the main focus for educational activity, and quite a number of courses have been provided in various places in Egypt, Saudi Arabia, Libya, Guinea, Mali, Zimbabwe, South Africa, Senegal, Cameroon and Mozambique. The activities also included first courses for EEG-technicians and other health care professionals. The newly appointed African Commissioner of the ILAE, Emilio Perucca, will help to intensify the educational engagement in Africa - especially with respect to availability of courses and teaching material.

3.4 Europe

A number of new educational courses have been implemented, access and organization is well structured in the meantime. In each year of 2007 and 2008 EUREPA has accredited 21 courses throughout Europe. Migrating courses in Serbia and Lithuania, the Baltic Sea Summer School with its 2nd edition, and shorter educational courses in various European states have attracted a large number of participants. In addition, a European Project on development of epilepsy surgery program (EPODES) has been developed, including training-in-the-field and visiting professorship. A Caucasian Summer School has started in 2008.

Guidelines and application forms for these courses are available via internet (EUREPA Web site:

http://www.epilepsy-academy.org/homepage/de/10.html).

Courses for Health Care Professionals (HCP or PAMs) have been intensified, including train-the-trainer courses for patient education in Lithuania. The translation of the patient program "MOSES" is finished and will be available including training courses.

4. Perspectives

During the period of this Report, negotiations between the ILAE, the CEA and EUREPA have continuously gone on concerning the running of the EUREPA office also as the Epilepsy Academy Office. As experience showed during the period of office and work of this Commission, such a solution proved to be quite inevitable to profit from the long-lasting expertise and existing systems available within EUREPA and its office. Furthermore, the Commission on Education continues to promote the establishment of a world-wide Epilepsy Academy and its office to coordinate, make visible and available ILAE educational activities globally and secure sustainability of achievements, thus fostering education as one of ILAE's continuous main organization purposes.

The project proposal on the Epilepsy Academy Web site (educational website of the ILAE) with its first step of the Information Portal met great interest. ALADE already signed up to use such a sub-domain, to which the Web site manager of the regional academy will have access, administrate and edit using the three languages spoken in their region: English, Portuguese and Spanish. Among other projects still to be developed and implemented like the diversification of the VIREPA program, increased approaches to Africa and the education of Health Care Professionals, the need for a practical educational journal for practicing neurologists was identified, which should be available also online on the Information/Knowledge Portal. Education still is one of the primary goals of the ILAE. The Commission on Education named some steps on the way to promote education and thus improve care for the people living with epilepsy. The final report in April 2009 will present a more comprehensive picture on the achievements and perspectives.

> Elza Márcia Yacubian, Chair Margarete Pfäfflin, Secretary

COMMISSION ON GENETICS OF EPILEPSY

Ruth Ottman, Chair Shinchi Hirose Satish Jain Holger Lerche

Holger Lerche, Chair

Commission Members

Iscia Lopes-Cendes Jeffrey L. Noebels Ingrid Scheffer José Serratosa Federico Zara

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Sub-Commission Members:

Jose Serratosa

Satish Jain

Aims

- 1. To facilitate the identification of human epilepsy genes on a worldwide scale;
- 2. To make the results of genetic research on the epilepsies readily accessible to clinicians;
- 3. To improve the public understanding of genetic factors in epilepsy; and
- 4. To work with related ILAE Commissions to increase understanding of genes that affect risk for epilepsy, including the phenotypes they influence and their role in basic mechanisms of epileptogenesis and antiepileptogenesis.

To advise the ILAE Executive Committee on all questions relating to the genetics of the epilepsies, encourage genetic research that can improve epilepsy diagnosis and therapy, and educate clinicians, individuals with epilepsy, and their families about genetic advances in epilepsy. A specific goal during the current term is to prepare a report on genetic testing in the epilepsies.

Commission activities from 1 January 2007 to 31 May 2008

The Commission held two meetings during this period, in July 2007 (IEC in Singapore) and December 2007 (AES in Philadelphia). Both meetings were devoted primarily to discussion of our report on Genetic Testing in the Epilepsies.

Concerns were raised about medico-legal implications of formal guidelines. Since many Commission members believed it is too early to publish formal guidelines, we decided to change the title of the report to "Genetic Testing in the Epilepsies," omitting the words "Guidelines for." We also decided to restructure the report to make it more accessible to readers, adding a "frequently asked questions (FAQ)" box with questions such as:

- 1. If the gene test is negative, is my diagnosis incorrect?
- 2. When should I perform a genetic test?
- 3. Who should I test in a family?
- 4. When should I test a family member?
- 5. When should I refer for formal genetic counseling?

Another major topic at both meetings was EpiGAD, the Epilepsy Genetics Association Database developed by Nigel Tan and Samuel Berkovic. This Web site is intended to document all genetic association studies in the epilepsies, including both positive and negative studies. Dr Tan attended the Commission meeting in Singapore and Dr Berkovic attended the meeting in Philadelphia. They described the site in detail and requested that the Commission support it, in order to improve visibility and promote its use in the epilepsy community. The Commission agreed to provide support and has created a sub-commission to oversee and monitor the site and specific criteria to be used.

At the IEC Singapore, the Commission co-sponsored (with the Neurobiology Commission) a parallel session entitled: "Epilepsy Genetics in the 21st Century: Building Bridges from the Laboratory to Patient Care."

In addition to our regular meetings, Commission members have communicated regularly by e-mail, and have written, critiqued, and commented on sections on the report on Genetic Testing. They also provided suggestions for a Commission-sponsored symposium at the IEC in Budapest, which were compiled by the Chair, reviewed by all members, and submitted as a proposal.

Accomplishments

Substantial progress has been made in drafting of the report on Genetic Testing in the epilepsies. All of the sections have now been completed, and we are now working on the revisions to simplify its format by adding FAQs. A full-day symposium entitled "Epilepsy Genetics in the 21st Century: Building Bridges from the Laboratory to Patient Care" was held at the IEC in Singapore, co-sponsored by the Genetics and Neurobiology Commissions. The Commission submitted a proposal for a teaching session at the IEC Budapest entitled "Genetic Testing in the Epilepsies," during which we plan to present the final conclusions in our report. We also submitted a proposal to the ILAE Executive Committee detailing our proposed role in providing support for the EpiGAD site, and specific plans for monitoring and oversight.

Recommendations for Future Work

A full Commission meeting is planned for the AES in Seattle (2008), at which time the completed draft of the guidelines report will be reviewed by all members. We plan to submit the report to *Epilepsia* soon thereafter.

> Ruth Ottman Chair

COMMISSION ON NEUROBIOLOGY

Annamaria Vezzani, Chair Heinz Beck Edward H Bertram Christophe Bernard

Commission Members

Marco de Curtis Jerome Engel Yoshiya Murashima Istvan Mody Jeffrey Noebels Magda Lagorhue Nunes Asla Pitkänen Yoel Yaari

Sub-Commission Members

ILAE Neurobiology/Therapeutic Strategies Joint Commission

Annamaria Vezzani, Chair Jacqueline A French, Chair Edward H Bertram Christophe Bernard Gary Mathern John M. Pellock Michael Rogawski Solomon L Moshé

Aims

Our efforts are directed into areas of intervention aimed at improving translational research in collaboration with the ILAE Commissions, in particular with the Commissions on Therapeutic Strategies, Genetics and Pediatrics as well as with the Educational Committee. The three main areas of intervention are:

- 1. Organization of teaching courses to bridge basic and clinical research;
- Organization of workshops and basic science sessions within the scientific program of the main International Meetings on Epilepsy; and
- 3. Initiatives on new therapeutic targets and strategies.

The mission of the Commission is to foster initiatives to improve the transfer of knowledge from basic science to the clinic and back, and to facilitate the translation of basic science discoveries into clinical applications.

Commission activities from 1 January 2007 to 31 May 2008

- 1. Educational activities;
- 2. Organization of workshops and basic science sessions;
- 3. Initiatives on new therapeutic strategies.

Details about these activities are reported in the Accomplishments (2007). A translational research document has been developed and prepared by members of this Commission during the 27th IBE/ILAE International Epilepsy Congress in Singapore. This document is reported in the Accomplishments (2007).

Accomplishments

Accomplished activities in 2007:

1. Educational activities

 In collaboration with the Educational Committee (E Cavalheiro, Chair) we have contributed to "The First Latin-American Summer School on Epilepsy" (LASSE) held in São Paulo, Brazil, 4-14 February 2007. The title of the school was "Epilepsy: Translating basic knowledge into clinical applications". Distinguished epileptologists from different countries (focusing on those working in Latin-American countries) were invited to act as speakers and/or tutors to offer lectures and practical sections to post-graduate students working in Latin-America.

- In collaboration with the Commission on Genetics (R Ottman, Chair) we have organized a Joint Symposium at the 27th IBE/ILAE International Epilepsy Congress, 8-12 July 2007 in Singapore entitled "Epilepsy Genetics in the 21st Century: Building Bridges from the Laboratory to Patient Care". E Bertram and C Bernard were mainly involved in this initiative. The intent of this joint Symposium was to give the clinician an up-to-date review of genetic terminology regarding the types of mutations that have been identified in the epilepsies as well as the consequences of these mutations.
- 2.Organization of workshops and basic science sessions
- Ten basic science scientific sessions have been organized and held at the 27th IBE/ILAE International Epilepsy Congress in Singapore, 2007. A report about these sessions has been published in Gray Matters of *Epilepsia* Vol. 49, No. 2, 2008.
 M de Curtis, Y Murashima and R Sankar organized
- M de Curtis, Y Murashima and R Sankar organized the IX Workshop on Neurobiology of Epilepsy (WONOEP 2007), a satellite event of the 27th IBE/ ILAE International Epilepsy Congress in Singapore. The main topic of WONOEP 2007 was "Transition from the interictal to the ictal state: neurophysiological, cellular, molecular mechanisms". As a novelty of this edition, both proposals for individual presentations as well as panel discussions (involving three or four speakers) have been included in the final program.
- 3. Initiatives on new therapeutic strategies
- In collaboration with the Commission on Therapeutic Strategies (J French and G Mathern, Chairs), we constituted the ILAE Neurobiology/ Therapeutic Strategies joint Commission (A Vezzani, J French, E Bertram, C Bernard, G Mathern, J Pellock, M Rogawski, N Moshé) to promote initiatives to improve the development of new therapeutic strategies. As a first step, this joint Commission organized a one-day meeting in Philadelphia on November 29, 2007 before the 61th AES Meeting, inviting a restricted number of participant representatives of Academia, Drug Companies, NIH/NINDS. The discussion was focused on the current methods of AED screening, with the goal of enhancing the existing screens in a way that will predict ultimate clinical efficacy more consistently.

COMMISSION ON NEUROBIOLOGY (continued)

Report of the Translational Research Workshop Attendees

Facilitator: Nico Moshé, Support: Sofie Peeters, John Swann, Helen Cross, John Duncan, Gary Mathern, Lionel Carmant, Michel Baulac, Patrick Kwan, Francisco Sales, Ljerka Cvitanovic-Sojat, Peter Bergin Annamaria Vezzani, Jacqueline French, Abdullahi Ibrahim, Alicia Bogacz, Cigdem Ozkara, Hans Stroink. Definitions: Translational research can be defined as research efforts aimed at:

- 1. Translating basic discoveries into clinical applications including scientific validation of experimental results, the development and validation of new therapies and prognostic or diagnostic surrogate markers of disease;
- 2. Identifying pressing clinical questions and designing basic science paradigms to test the validity of the clinical concepts and develop new preventive and therapeutic strategies; and
- 3. Developing clinician-scientists that can use emerging technologies in new ways in their unique clinical environments.

Recommendations: The ILAE should create a planning Commission to develop a program to enhance translational research. Suggestions include:

- The creation of International Programs for the development of physicians/scientists, driven by regional needs and emphasizing local training as much as possible. To achieve this, the ILAE, through its regional and specialty Commissions, must identify people within academic centers committed to this endeavor; identify the pool of trainees and match them to the centers; and maintain lists of available opportunities in EU, North and Latin America and Asia and Oceania where such programs thrive.
- The training should be a combination of abroad and local education. The mentors must commit to providing continuous mentoring.
- The mentoring process should follow standard ILAE guidelines with regards to conflict of interest to clarify that this process is not one where the mentor is supposed to end up with some sort of financial gain.
- Address available opportunities with other organizations, i.e., International Brain Research Organization (IBRO), the Academy of Sciences for the Developing World (TWAS), American Epilepsy Society (AES), Foundations, State Ministries, etc.
- Develop symposia in every ILAE-sponsored Congress and in a collaborative effort with other organizations with similar agendas on how to perform research and to monitor the progress of the attendees.
- Consider developing demonstration projects to show the specific local needs.

The deliverables will be:

- Advances in research leading to improvement in local epilepsy care
- Facilitate regional epilepsy centers and programs and individuals
- Promote new advances worldwide Follow up: The suggestions will be discussed at the next ILAE Executive meeting for specific steps to be undertaken by the appropriate Commissions with adequate funding to ensure success.

Recommendations for Future Work Planned activities for 2008-2009:

- Educational activities
- We contribute to organize a Basic Science Session chaired by Dr R Gutierrez (Mexico) at the 5th Latin America Epilepsy Congress to be held in Montevideo, November 2008.
- We contribute to organize the 3rd Advanced International Course: Bridging Basic with Clinical Epileptology, 28 July – 8 August 2008, S Servolo, Venice (M de Curtis, Chair). Seven members of our Commission are tutors or lecturers in this international course.
- 2. Organization of workshops and basic science sessions
- The ILAE Neurobiology Symposium on Neuron-glia signaling and epilepsy will be held during the 8th European Congress on Epileptology, 21-25 September 2008 in Berlin. The topic of this symposium, which will be chaired by C Steinhauser, was inspired by several recent studies clearly indicating that glial cells take an active part in the formation, function and plasticity of synapses. Actually, the contribution of glial cells to CNS signalling can be considered one of the most exciting new fields in the neurosciences. Therefore the aim of the proposed symposium is to present new developments and findings on the neuron-glia crosstalk in the epileptic brain bringing together established scientists with various backgrounds to discuss different aspects of this new, topical field.
- In collaboration with the Commissions on European Affairs, Therapeutic Strategies, and Pediatrics (C Ozkara, G Mathern, H Cross), we organized a meeting on Malformations of Cortical Development and Epilepsy, to be held on 30 October - 1 November 2008 in Istanbul. This symposium will be a two-day open event followed by one day of closed event for further discussions related to the new classification proposals including new basic and clinical information. The scientific organizing committee is composed of C Ozkara, G Mathern, H Cross, I Najm, R Spreafico, A Vezzani.
- In collaboration with the Commissions on European Affairs, Therapeutics, and Pediatrics, we organized two scientific sessions to be presented at the 28th International Epilepsy Congress in 2009, Budapest. The topics of these sessions are: "Cortical Dysplasia and Epilepsy" and "Neonatal Seizures: from the clin-ic to the bench and back". Moreover, our Commission has presented a specific session on "Mechanisms of Aberrant Gene Expression and Regulation in Epileptogenesis" which was prepared by H Beck. These sessions have been accepted by the Scientifc Advisory Committee. Our Commission has also proposed five basic science parallel sessions: Non-conventional mechanisms in epilepsy (A Vezzani); New targets for disease modification and epilepsy prevention (H Potscka); New developments in K+-channel involvement in epilepsy (R Koheling); Depolarizing GABAAergic Signaling: Update on its Role in the Pathophysiology and Therapy of Early Life Seizures (A Galanopoulou); High frequency oscillations (HFOs), what is normal and what is not (J Engel), which are under evalua-

COMMISSION ON NEUROBIOLOGY (continued)

- tion by the Scientific Advisory Committee.
 WONOEP 2009: Istvan Mody was appointed as the main organizer of the next WONOEP which will be held in the city of Pecs in southern Hungary, on 23-25 June 2009, as a satellite event of the 28th IBE/ ILAE International Epilepsy Congress. The topic of the WONOEP will be "New targets for antiepileptic strategies"; the organizing committee includes M de Curtis, C Bernard and E Bertram as former WONOEP organizers, and R Sankar who will also contribute to fund-raising.
- 3. Intitiatives on new therapeutic strategies Deeper insights into the mechanistic hypothesis of epileptogenesis and occurrence of spontaneous seizure have inspired novel approaches of therapeutic intervention that could provide a more efficient seizure control with less side effects, particularly for those types of epilepsy difficult to treat with conventional antiepileptic drugs. Additionally, intervention on the mechanisms envisaged to play a crucial role in disease progression could provide novel means to develop curative, and not merely symptomatic, treatments. Based on these considerations, the ILAE Neurobiology/Therapeutic Strategies Joint Commission is discussing the possibility of organizing a second initiative in the frame of a workshop/discussion group focused on "Novel targets for antiepileptic drug development" where both

academia (basic scientists and clinicians) and representatives of drug companies can contribute to the panel of discussion.

The Commission is also involved in creating educational activities in Africa in collaboration with IBRO (M Bentivoglio, Secretary-General) and the Faculty of 1,000 Task Force (É Perucca, Chair). The first activity is planned to take place in Ghana in 2009.

> Annamaria Vezzani Chair



COMMISSION ON NEUROPSYCHIATRIC ASPECTS

ES Krishnamoorthy, (India), Chair J Trollor (Australia), Secretary Marco Mula (Italy) W LaFrance (USA) A Ettinger (USA)

Commission Members

A Kanner (USA) B DeToffol (France) F Besag (UK) K Kanemoto (Japan) LT van Elst (Germany)

Aims

The Commission on Neuropsychiatric Aspects has had a very dynamic and fruitful period. With four sub-commissions and two task forces, we set off on our journey with a clear agenda, which we are well poised to complete to a great extent. With wide international representation, the commission has taken a truly global approach in its deliberations.

Commission Activities from 1 January 2007 to 31 May 2008

Meetings & Workshops:

A quorum at the very least and in most instances many more than a quorum of members, convened at the following closed door meetings. The work of the subcommissions was discussed and initiated during these meetings and much of the work was completed during the meeting.

July 2007

- Chennai, India TS Srinivasan Centre four days
- Introductory Meeting of Commission/
- Sub-commissions
- Delphi consensus exercise of the clinical practice statement sub-commission
- Piloting educational module
- Initial discussion on epilepsy and disability

December 2007

Philadelphia, USA – AES – four hours Business Review Meeting

February 2008

Chennai, India – TS Srinivasan Centre – three days

- Workshop of task forces: transcultural aspects and psychological therapies (together with Treatment commission members)
- Workshop on Epilepsy and Disability Sub-commission

September 2008 – Berlin, Germany – Charite – 1.5 days Workshop of the sub-commission on research priorities

December 2008 – Seattle, USA – AES – three hours Business Review and Future Planning Meeting

May/June 2009

Budapest (proposed) – ILAE Congress – 1.5 days Wrapping up workshop of all sub-commissions and task forces (subject to approval and release of funds for this activity) M Kerr (UK), **Treasurer** B. Schmitz (Germany), **Past Chair**

Sub-commissions, Task Forces & Output:

Good Clinical Practice (GCP) Statements Chair: Prof. Michael Kerr (UK)

Objectives and Accomplishments

- Using the scientific Delphi method of consensus building, develop a series of good clinical practice statements for neuropsychiatric disorders in epilepsy
- Face-to-face consensus meeting to identify key priority areas needing GCP statements
- Preliminary rounds of priority e-discussion (global)
- Secondary round of e-feedback (global)
- Current Stage and Proposed Outcome
- Tertiary round of statement development is on-going
- A commission report is under preparation by the Chair and will be ready in March 2009 for discussion and finalization among commission members
- The report will be finalized at the time of the International Epilepsy Congress in Budapest and submitted immediately thereafter

Research

Chair: Prof. Ludger T van Elst (Germany) Objectives and Accomplishments

- To develop a position statement on research methods and priorities
- A full 1.5 day workshop dedicated to the development of research priorities was completed in Berlin as a pre-conference activity to the European Epilepsy Congress
- The workshop consisted of several key presentations and interactive discussions by commission members
 Current Stage and Proposed Outcome
- A position statement on development priorities is under development by the Chair based on these presentations and discussions and will be ready for e-discussion by commission members in March 2009
- The report will be finalized at the time of the International Epilepsy Congress in Budapest and submitted immediately thereafter

Epilepsy & Disability

Chair: Prof. ES Krishnamoorthy (India)

- Objectives and Accomplishments
- To develop a clinical construct, classification and health policy paradigm for disability in epilepsy
- Collaboration with the Indian Epilepsy Association (IBE Affiliate) and Indian Epilepsy Society (ILAE Affiliate) working group on the subject
- Two workshops: One for one day (July 2007) and one for two days (February 2008); detailed discussion of cross-national perspectives on disability.

COMMISSION ON NEUROPSYCHIATRIC ASPECTS

(continued)

Current Stage and Proposed Outocme

- A full commission report is under preparation by the Chair and will be ready for e-discussion by commission members in March 2009
- The report will be finalized at the time of the International Epilepsy Congress in Budapest and submitted immediately thereafter

Transcultural Aspects (Task Force)

Chair: Prof. F Besag (UK)

Objectives & Work Accomplished

- To develop a position statement on transcultural
- research priorities in Neuropsychiatry of Epilepsy Half-day closed door meeting in Chennai, India in
- February 2008
- Presentation by chair and brainstorming
 Current Stage and Proposed Outcome
 A summary of the discussions was prepared by Dr. William La France, task force member
- A position statement on transcultural research priorities is under preparation by the chair and will be integrated into the Research Sub-commission report

Psychological Therapy (Task Force) - Jointly with the Treatment Commission

- Co-chairs: Dr. Nandan Yardi (India) and Dr. William La France (USA)
- **Objectives & Work Accomplished**
- To develop a position statement on the role of psychological therapy in epilepsy
- Half-day closed door meeting in Chennai, India in February 2008
- Two representatives of the Treatment Commission, Dr. Nandan Yardi (India)-Chair sub-commission and Prof. SC Schachter (USA) attended this meeting

Current Stage and Proposed Outcome

- A summary of the discussions was prepared by Dr. William La France, task force member
- A position statement on psychological therapy research concerns and priorities is under preparation by the chairs jointly

Accomplishments

- Three commission reports will be submitted to the ILAE Executive in June 2009 with a view to Epilepsia submission and publication
- One task force report will be submitted to ILAE
- The commission has four symposia at the forthcoming Budapest congress and all commission members will be taking part in this effort.

Recommended Future Work

- The Education Sub-commission chaired by Prof. A Ettinger began the process of pooling all committee recent presentations to assemble into a future internet-based core curriculum. This work is ongoing and it is therefore recommended that it be developed by a future commission.
- Prof. F Besag has this year initiated a project together with the ILAE Pediatric Commission and the IBE, examining the life experience of children with epilepsy and their families. This task force activity has true transcultural potential and will provide rich narrative

data about children living with epilepsy across cultures. This being an important activity area, I would recommend that it remains on the agenda that is taken forward by a future commission.

- The commission is proposing a day-long symposium on "Epilepsy & Disability - A Gender and Lifespan Perspective" at a future AES meeting and hopes to develop a full journal supplement on this subject. Prof. Andy Kanner (USA) is leading this effort.
- Commission members are collaborating on and initiating several cross-national projects relating to mood in epilepsy and neurobiology of behavior in epilepsy

In summary:

The present commission on Neuropsychiatric Aspects has been very productive, in the rather short period of its existence. Future directions for this commission will include:

- The development of unified international research protocols to study the neuropsychiatric aspects of epilepsy systematically
- Research efforts linking neurobiology with behavior and the systematic planning of their future study integrating available technology (one session at the Budapest congress will address this theme); a particular focus of study will be mood and anxiety disorders
- The development of integrated international health policy for people with epilepsy and neuropsychiatric co-morbidity (the work on epilepsy and disability is the beginning of this development).

I have no doubt that all the members of this commission, who have worked together admirably, as a welloiled machine, will be delighted to contribute munificently to these future efforts, when called upon to do so. I feel privileged to have been part of this dynamic international group and to have served as its chair and coordinator. My heartfelt thanks are due to every member of this commission for their generosity of time and industry, and to the outgoing President Prof. Peter Wolf and the ILAE Executive Committee for having accorded me this wonderful privilege.

> Prof Ennapadam S Krishnamoorthy Chair

COMMISSION ON PEDIATRICS

Commission Members

Eli M Mizrahi Makiko Osawa James Butler Hanan El Shakankiry

Doug Nordli, Secretary Alexis Arzimanoglou

Sub-Commission Members

Joint Pediatric Surgical Group with Therapeutics commission Chairs: Gary Mathern and J Helen Cross

Aims

Helen Cross, Chair

Tallie Z. Baram

Renzo Guerrini

Nebosja Jovic

- 1. To broaden international understanding of diagnosis and management of epilepsy in childhood;
- 2. To advise the Executive Committee in all questions concerning epilepsy in children, in particular the use of newer AEDs, evidence-based approaches to epilepsy surgery, QOL measurements and psychiatric involvement.

Commission activities from 1 January 2007 to 31 May 2008

- In 2007 the Pediatric Commission was responsible for the 6th International Course on Epilepsy "Clinical and Therapeutic Approaches to Childhood Epilepsy" (Course Directors: H Cross and B Dalla Bernardina) held at the Venice International University, San Servolo 22 July - 3 August. This was a highly successful course involving 68 participants from 40 countries. There were 37 members of the Faculty which included all but two members of the ILAE Commission for Pediatrics. The course covered all aspects of childhood epilepsy moving from diagnosis to treatment including surgery with a high emphasis not only on lectures but also interactive working groups. The course was greatly appreciated by all those who participated.
- The Commission has continued collaboratively working with the World Health Organization with regard to the development of guidelines in the management of seizures in childhood. In particular, although guidelines with regard to the management of neonatal seizures were felt to be completed and provisional guidelines published in June 2007, further discussion has begun regarding the fact that they need to be evidence-based and ultimately require validation. A further meeting was held in Troina, Sicily, in November 2007. This meeting was organized and co-sponsored by the World Health Organization and the IRRCOC in conjunction with the ILAE. A plan for guideline development was reviewed. Ultimately a plan was made for the formulation of key clinical questions, which have subsequently been proposed, for which evidence-base is to be obtained.
- A workshop was organized and held in conjunction with the European Pediatric Neurology Society in Kusadasi, Turkey in September 2007 to initiate discussion about drafting guidelines with regard to management of seizures in infancy. This was attended by six members of the Commission as well as representation from the Commission on Neuroimaging and Commission on Classification as well as other expertise from around the world in

infantile seizures. It has become clear that different levels of guidelines may be required according to resources available. The next proposal as discussed at the Troina meeting in November 2007 would be to formulate a committee to propose key questions from which evidence-based methodology can be secured. This again will be taken forward with the World Health Organization.

• The work of the surgical group is continued jointly between the therapeutic and pediatric Commissions. The results of the retrospective survey of epilepsy surgery around the world in 2004 were published in January 2008.

Accomplishments

Publication of a retrospective study of surgical procedures performed in 20 centers worldwide in 2004 (Harvey et al *Epilepsia* 2008 49:146-155). Successful 6th International Course on Epilepsy July/August 2007. Successful workshop on epilepsy in infancy EPNS Kusadasi September 2007.

Recommendations for Future Work

- Continued working with the WHO on evidencebased guidelines for the management of neonatal seizures and ultimately seizures in infancy.
 - 1. Key questions to be drawn up with regards to neonatal guidelines.
 - 2. Neonatal guidelines to be evaluated and validated in different countries and result presented at the International Epilepsy Congress 2009.
 - 3. Committee to be formed with regard to epilepsy in infancy and key clinical questions evaluated.
- Continued liaison and work with the Therapeutics Commission with regard to epilepsy surgery. Proposed projects include:
 - 1. Outcome assessment of individuals included in 2004 study to validate outcome criteria.
 - 2. Prospect of study to be undertaken of children undergoing epilepsy surgery to review neurodevelopmental and seizure outcome at 12 months.
 - 3. Continued liaison and work with Classification Commission.
 - 4. Assessment of guidelines and information required with regard to transition of care to adulthood.
 - 5. Continued liaison and work with other Commissions with regard to pediatric aspects of ongoing projects.

Helen Cross Chair

COMMISSION ON THERAPEUTIC STRATEGIES

Commission Members

Jacqueline A French, Co-Chair Gary W Mathern, Co-Chair Christoph Baumgartner Martin J Brodie William Harkness Reetta Kälviäinen Giorgio Lo Russo Solomon L Moshé

Emilio Perucca Torbjorn Tomson Nandan Yardi

Aims

The goal of the Therapeutic Strategies Commission is to address a wide variety of international problems in the treatment of epilepsy. Multiple Task Forces have been established to address specific issues.

Mission of the Commission: To advise the ILAE Executive Committee on issues related to the treatment of epilepsy with emphasis on pharmacotherapy, surgery and alternative therapy.

Task Forces and Chairs:

Converting ILAE guidelines to Web Format: Elinor Ben-Menachem

Screening of new antiepileptic drugs (Co-project with Commission on Neurobiology)

Access to AEDs (Co-project with Epilepsy Care

Commission): Emilio Perucca, Giuliano Avanzini and Jacqueline French

Translation of Guidelines to Clinical Practice: Reetta Kalviainen

Definition of Refractory Epilepsy: Patrick Kwan Generics: Barry Gidal

Pregnancy & Epilepsy: Torbjorn Tomson

Pediatric surgery (Co-project with Pediatric

Commission): Gary Mathern and Helen Cross

Epilepsy surgery training in under-developed countries: Gary Mathern

Althernative therapy: Nandan Yardi

Historical control in newly diagnosed: Tony Marson

Commission activities from 1 June 2007 to 31 May 2008

The Commission has been active with several telephone conferences and meetings. A number of subcommissions have been working actively, each of which is making progress toward their respective goals.

Accomplishments

The Task Force on generics has completed a literature search of pharmacokinetic and clinical data related to generic equivalence for major AEDs and several publications and a report are being prepared. The Task Force on guidelines have published the current, accepted AED guidelines (2006), background material in table format and PowerPoint presentation describing the guidelines on the ILAE Web site and an update of the guidelines themselves are being prepared. A separate Task Force is developing a strategy to translate AED-related guidelines to a more useful form for practicing clinicians. The Task Force on defining refractory epilepsy will develop a unified definition that can be used both clinically and for research purposes. The Task Force on pediatric surgery has completed a report on the frequency of epilepsy syndromes and etiologies in pediatric surgical centers. Data were gathered from 20 programs in the USA, Europe, and Australia. The report has been published in *Epilepsia* (2008). The access to AEDs Task Force has worked actively to discuss which drugs should be made available to all countries, even those at economic disadvantage, and has worked with the WHO to improve access. The Task Force on development of epilepsy surgery met in Singapore with plans on future meeting to develop regional needs assessments. Dr Tomson is organizing a meeting of the pregnancy registries that will take place in September funded by the Milken family.

Recommendation for future work

The Commission is involved in defining refractory epilepsy in a closed workshop in July 2008 and organizing a closed meeting with the different pregnancy registries in fall 2008. The task force on alternative therapies will become more active. A meeting about cortical dysplasias in conjunction with the Commission on Neurobiology is going to be held in 2008, emphasizing the importance of translational work needed in all fields of epileptology in future. In addition, the surgical group will work with other Commissions with regard to teaching pre-surgical and surgical evaluations in developing health care systems. Plans also include participation in the Budapest ILAE meeting in summer 2009.

> Jacqueline A French, MD Gary Mathern MD Chairs

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Other Activities

2007 MORRIS-COOLE PRIZE

Excerpted from Epilepsia Volume 49 Issue 9, Pages 1487 - 1650 (September 2008)



Epilepsia and the International League Against Epilepsy (ILAE) are pleased to award the 2007 Morris-Coole Prize, for an outstanding paper in Epilepsia that helps advance knowledge in the field of epilepsy, to Nicola Marchi. The award-winning paper, from Volume 48 (Epilepsia 48:732–742 2007)

is entitled: "Seizure-promoting effect of blood-brain barrier disruption."

The Prize, which carries a 10,000 euros award, was established last year through the generosity of Mr and Mrs Christopher Morris-Coole, with the intention of stimulating epilepsy research and encouraging young researchers in the field. The winning paper is chosen by the *Epilepsia* Editors-in-Chief and the ILAE President, from a short-list of nominations submitted by the *Epilepsia* Associate Editors.

Nicola Marchi is a Research Associate in the Department of Cell Biology in the Lerner Research Institute of the Cleveland Clinic. He received his doc-

toral degree from the University of Pisa in 2000. Dr Marchi then worked as a postdoctoral fellow at the Cleveland Clinic (with Damir Janigro) and at the Institute Mario Negri (with Annamaria Vezzani). In 2005, he returned to the Janigro laboratory at the Cleveland Clinic, where his research focused on inflammation and disruption of the blood-brain barrier associated with seizure activity. According to Dr Janigro, "Nicola was the first to notice focal motor seizures in patients undergoing blood-brain barrier disruption," an observation that suggested "a novel mech-anism for seizure generation" involving changes in vas-cular integrity. Dr Marchi subsequently examined this mechanism in a variety of clinical and basic research investigations. The study for which Dr Marchi has been awarded the Morris-Coole Prize is notably collaborative in its approach, involving a neuroradiologist, a neurologist, a brain tumor expert, and basic and clinical scientists — all working toward "true translation ... into a cure" for epilepsy.

The Morris-Coole Prize was presented to Dr. Marchi at the Awards Symposium at the European Congress on Epileptology (Berlin, 21-25 September 2008), during which Dr Marchi presented a lecture on his research.



2008 GORDON CONFERENCE

The 2008 Mechanisms of Epilepsy and Neuronal Synchronization Gordon Research Conference (GRC) was held on 3-8 August 2008, at Colby College, Maine, USA. The meeting was remarkably successful. Presentation and discussion of state-of-the-art, unpublished research findings is the raison d'être of Gordon Conferences. All of our speakers complied with this mandate, and presented very exciting new research throughout the five-day meeting. There were a total of nine Platform Sessions, during which a total of 51 people spoke (including moderators), and four Poster Sessions, where approximately 80 posters were presented. The overall theme of the meeting was Neuroplasticity in Epilepsy, and the themes of the individual Platform Sessions were: Glial Dysfunction in Epilepsy; Acquired Channelopathies in Epilepsy; Genetic and Genomic Approaches in Epilepsy; Genetic Channelopathies in Epilepsy; Early Post-Translational Events in Epileptogenesis; GABAergic Signaling and Epileptogenesis; Imaging Approaches in Epilepsy; Novel Epilepsy Models: Infantile Spasms, Cortical Dysplasias; and Circuit Mechanisms in Epilepsy. Each session was introduced by a knowledgeable moderator, and then was followed by four to six 10-25 minute talks adhering to the overall theme, with ample time for discussion following each presentation. The conference program can be found at the following URL http://www.grc.org/programs.aspx?year=2008&program=epilepsy.

The meeting was fully subscribed, with 147 out of a possible 150 people attending (there were three late withdrawals from the meeting). Talks were uniformly superb, approximately 80% of speakers were new (did not overlap with the previous Epilepsy GRC), and numerous speakers from outside the epilepsy field gave talks that contributed significantly to the meeting, and to potential new directions in epilepsy research. Discussion sessions were active and exciting, and routinely ran over time. Poster Sessions were kept small (20 posters each for four sessions), and were also continued into the evening receptions, allowing large amounts of time both to continue discussions from the day's Platform Sessions, and to present and discuss posters to the entire group of attendees. The only aspect of the meeting that did not go well was the weather, which was overcast and rainy for virtually the entire five-day meeting, with one welcome partially sunny three-hour respite for our canoeing/kayaking outing on a local lake, where we saw eagles and loons, and no one drowned.

Expanded Role of Junior Attendees: We had an explicit goal of increasing trainee participation and visibility at the meeting. We expanded representation of junior/trainee speakers in the Platform Sessions by including eight shorter Platform Sessions gleaned from the poster applicants deemed to be the most meritorious. These included students, postdoctoral fellows, and junior faculty who would not ordinarily be giving platform talks at a meeting of this magnitude. These junior

speakers were: Wolfgang Mueller (University of New Mexico), Jokubas Ziburkus (University of Houston), Joy Sebe (UCSF), Beatrice Marcelin (INSERM, Marseilles), Bin Wang (University of Texas HSC, San Antonio), Dane Chetkovich (Northwestern University), Aristea Galanopoulou (Albert Einstein College of Medicine), and Julia Brill (Stanford University). In addition, we increased the contribution of junior attendees to discussions by having a rule (first inaugurated in the 2006 Epilepsy GRC) that the first two questions of each discussion had to be asked by a student or postdoctoral fellow, and also, at the end of the meeting, awarding two, one-year *Neuron* subscriptions to the junior attendees who contributed most to the discussions. These went to Chris Dulla from Stanford, and Caren Armstrong from UC Irvine.

Although I have not as yet received a summary of the feedback sheets collected from conference attendees from the GRC organization (this should come in the next month or two), I did peruse the feedback questionnaires prior to providing them to the GRC site staff, and, in a rough quantification I conducted informally on the more than 130 responses, >80% of those attending viewed this as the best conference they had attended all year.

Budgetary Report for ILAE funds: Of the 147 scientists/epileptologists at the conference, there were 18 foreign speakers and/or attendees, including five from the United Kingdom, three from Canada, two from Turkey, two from Germany, four from France (one of which had to withdraw at the last minute due to health issues), and one each from Italy and Australia. All of these foreign attendees received at least partial support for their travel costs. The ILAE contribution of \$20,000 directly supported 12 foreign attendees at the meeting, including five foreign trainees (postdocs/students) and seven foreign speakers (one of which was also a trainee, Beatrice Marcelin, a student from Christoph Bernard's laboratory in Marseilles). In addition to direct support (the number of supported attendees was limited by the weak dollar and high airfares, with support costing \$2,000-\$3,000 each), the ILAE funds provided indirect leverage, and allowed us to provide additional foreign travel awards, so that every foreign trainee attending the meeting was supported at least in part. In addition to augmenting the number of foreign trainees attending this conference, speaker representation from Europe, Canada, and Australia increased 30% over the previous Epilepsy GRC. We are deeply grateful for the ILAE support of this important meeting, and clearly, these funds accomplished the goals of increasing foreign representation at the Epilepsy GRC, both in terms of speakers and trainees.

Additional Note: I feel that one additional point is important to raise. Given the success of the first two Epilepsy GRCs, it is likely that this meeting will be removed from probation, and be chartered as an ongoing Gordon Conference. This will mean that the

2008 GORDON CONFERENCE (continued)

Epilepsy GRC Conference will occur every two years (on even years), more than likely remaining in its present time slot of the first week in August. The GRC is not a particularly flexible organization in terms of changing meeting formats, locations, or times, due to the fact that it schedules and coordinates 300-400 meetings in its portfolio. I view the Epilepsy GRC as a significant contribution to Epilepsy meetings worldwide, and one that should be nurtured. Although I understand that there were some unavoidable local logistical issues which contributed to the conflict, it was extremely unfortunate that the ILAE chose to schedule a meeting (the Venice Epilepsy School) in an exactly overlapping time slot to the Epilepsy GRC meeting this year. This siphoned off a significant number of attendees from the GRC (more than 20 in my estimation) as well as several potential speakers, and clearly it is not in the best interest of either meeting to allow this to happen again. Extreme care should be taken to ensure that we do not have conflicting epilepsy meetings making our lives more difficult, and precluding us from attending important conferences due to this kind of overlap. I will pass on the word to future Epilepsy GRC Chairs to take care to ensure that no such conflicts occur, and I would encourage those persons organizing the Venice Epilepsy School to do the same. Explicit efforts should be made to coordinate the timing of these two important epilepsy meetings. It is in everyone's best interests. We have already explicitly scheduled the Epilepsy GRC for even years, to avoid it overlapping with WONEP meetings, which occur in odd years, but the Epilepsy School conflict was not anticipated.

> Douglas A. Coulter, PhD Chair



INTERNATIONAL LEAGUE AGAINST EPILEPSY

REPORT ON THE GHANA INITIATIVE

On 27 April - 3 May 2008, Giuliano Avanzini, Co-Chair of the ILAE-IBE-WHO Global Campaign Against Epilepsy, and I travelled to Ghana to survey conditions for establishing a program to improve the care of people with epilepsy in collaboration with BasicNeeds Ghana, a British non-governmental organization, and with the Ghana Health Services. Our visit had several objectives:

- 1. Become personally acquainted with key professionals responsible for the care of people with epilepsy in Ghana;
- Understand the organization of the local health care system with special reference to addressing the needs of people with epilepsy;
- Survey the logistics and understand the functioning of BasicNeeds Ghana and their respective programs;
- 4. Identify areas where ILAE could assist in improving the quality of care for people with epilepsy in Ghana, and the best modalities by which such assistance could be provided; and
- 5. Determine whether the creation of an ILAE Chapter in Ghana can be made possible in the near future.

Over a period of seven days we had the privilege of meeting with the Deputy Minister of Health (Dr A Dwuma Odoom), the General Director of Ghana Health Services (Dr E Śorey), the Chief Psychiatrist for Ghana Health Services (Dr A Osei), in addition to many other health officials in different parts of the country. We also interacted with key medical professionals involved in the care of people with epilepsy, and we spent considerable time in particular with Dr S Ohene and Dr A Akpalu, who have been actively working towards establishing an ILAE Chapter in Ghana. We visited BasicNeeds facilities in Accra and Tamale, the Korle Bu Teaching Hospital in Accra, the Accra Mental Hospital, the Ghana Institute of Management and Public Administration in Accra, and the offices of the Regional Health Services for the Northern Region in Tamale and for the Upper West Region in Wa. We also had the opportunity to visit community clinics, poor city neighborhoods and rural villages and to interact personally with epilepsy patients and their families. All persons we spoke to were very hospitable and eager to establish collaborative links. All health officials showed a remarkable knowledge of the medical and social problems associated with epilepsy, and a keen interest in supporting initiatives to reduce stigma and improve the quality of epilepsy care in the country.

There are no data on the prevalence of epilepsy in Ghana, though all the physicians we spoke to commented that epilepsy is a major health problem not only in terms of medical/social burden but also in terms of epidemiological dimension. Epilepsy in Ghana is treated almost exclusively by psychiatrists, partly because the boundaries between psychiatry and epilepsy are blurred in the traditional culture, but mainly because the local health system favors the channelling of people with epilepsy (and patients with other neurological disorders) to psychiatric services. Medical practitioners and health workers are fully aware of the distinction between epilepsy and mental disease, but they have not encouraged a differential approach to the care of these conditions, for at least two reasons. First, people with mental disorders and people with epilepsy share similar challenges with respect to stigma and discrimination, and it makes sense to have comprehensive advocacy and educational programs for both conditions. Second, an integrated approach for both conditions allows people with epilepsy to benefit from important resources which have been allocated to psychiatric care, including the establishment of dedicated health centers and personnel, and a provision whereby all patients registered at psychiatric centers receive free medical care and free medications. Therefore, for people with epilepsy, being treated within this framework provides special benefits which are not available to the general population.

In terms of medical personnel, Ghana faces significant shortages and a continuous brain drain, since many medical specialists tend to emigrate to wealthier regions. This implies that the care of people with epilepsy rests primarily on general practitioners, assistant medical officers (non-medical but well-trained health personnel supporting the activities of physicians in rural areas) and, most importantly, psychiatric nurses. The latter consist of health personnel who underwent at least three years of training in nursing plus at least six months of specialized training in psychiatry. Health care in rural areas is a special challenge, and for many people with epilepsy the nearest facility for accessing physicians and obtaining a supply of medications may be as far as 30 kilometers away. Although antiepileptic drugs are provided at no cost to all patients attending psychiatric health centers, there are frequent shortages. Availability of laboratory services, such as EEG, is also very restricted. The size of the treatment gap has not been investigated, but it is estimated that most people with epilepsy have not been reached by the health services and have no access to medical treatment. The gap is largely filled by traditional healers. Misperceptions about epilepsy are highly prevalent. We met women with severe burns who had fallen into fires because of seizures (a common event, as fire is used for cooking) without being



REPORT ON THE GHANA INITIATIVE

(continued)

rescued by bystanders. In fact, many believe that epilepsy is contagious and can be transmitted simply by touching an affected person.

The primary objective of BasicNeeds programs in the country is to give voice to people with epilepsy and people with mental disease, and to support initiatives to address the medical and social needs of these persons. BasicNeeds' main strategy is to liaise closely with national-, regional- and community-level health authorities, to provide complementary services by addressing shortcomings in the health system, and feedback to authorities on their experience in order to upgrade the quality of health care. A key aspect in these activities is to reach out to neglected communities to inform them about the nature of epilepsy and mental disease (thus fighting stigma and discrimination through education), and about the services which exist to address the medical and social needs of affected people. This is done initially by approaching local community leaders, by setting up community meetings and by recruiting networks of volunteers who help in locating needy people and channelling them to health clinics. This is followed up by establishment of support groups and regular monitoring of all people who become enrolled into the program.

BasicNeeds also supports the health care system by stimulating motivation in all parties involved and by addressing directly any dysfunctions. Examples of such activities involve: (i) direct and indirect support of medical and nursing personnel; (ii) taking responsibility for the transportation of physicians to health clinics throughout the regions covered by the program, including rural areas; (iii) making regular bulk purchases of medications to cover for recurrent shortages in the distribution system; (iv) provide modest funding for infrastructure, such as the construction or the upgrade of community clinics; (v) liasing with local authorities and other non-governmental agencies to address specific needs, including the professional training of people with epilepsy and their reintroduction into society and restitution to productive activities. This may include the granting of microloans to start small businesses.

Based on this background, there was general agreement among all parties involved that the ILAE, by linking with BasicNeeds personnel and infrastructure, could provide an important contribution to improve the lives of people with epilepsy in the country. One way in which the ILAE could contribute usefully is in assisting with the training of health care workers. This is of great importance because the primary deliverers of health care to people with epilepsy (general practitioners and community psychiatric nurses) have limited expertise in epileptology. Initiatives which were discussed, and which are now being planned, include the organization of intensive courses targeted at highly motivated physicians and nurses from all regions of Ghana, using a train-the trainer model whereby attendees will be subsequently expected to provide the training of other health personnel in their geographical area. These courses must take into account the peculiarities of epilepsy care in Ghana, i.e. differential diagnosis of seizures and epilepsies without laboratory resources, recognition of treatable causes, psychiatric issues in epilepsy, and basic management principles.

Information on epidemiological methods will also be included in preparation for a demonstration project to be carried out in a second phase, in order to determine the prevalence of epilepsy in representative districts as well as the size of the treatment gap, and to establish intervention programs to improve access to care and social support services. An epidemiological study would also be important to provide health authorities with sound data concerning the size of the epilepsy problem and related unmet needs, and to stimulate the required interventions.

At present, further discussions are ongoing with BasicNeeds and Ghana health officials to determine how these initiatives could be organized into a comprehensive, long-term self-sustainable program. These developments will be facilitated by the establishment of a Ghana ILAE Chapter, which is virtually completed, and by involvement of local advocacy groups. Although we did not succeed yet in establishing a contact with the Ghanaian IBE office, we count on IBE's collaboration in this program as part of a future Global Campaign initiative. The dedication of so many local people to the cause of fighting epilepsy and its consequences was something that touched us, and makes us optimistic that our program will become reality and be successful.

I cannot close this brief report without saying a few words about the hospitality of the BasicNeeds personnel and volunteers, and the Ghanaian people in general. "Akwaaba", which means "welcome" in the Akan language, and its English equivalent were the words that met us everywhere, and we always felt at home in environments which were strikingly different from our real home. Ghana is a beautiful country with a remarkable variety of landscapes, from the lush green South to the bushlands of the North. Giuliano and I brought home a bag of tiny wild mangoes which were donated to us by a group of children in a rural village, and tasted sweeter than any other fruit that we had so far.

> Emilio Perucca First Vice President, ILAE and Coordinator for ILAE activities in Africa

ILAE Chapters

CHAPTERS LIST AND REPORTS

AMERICAN EPILEPSY SOCIETY

Publications

Epilepsy Currents, AES News

Meetings

Annual Meeting and Biennial North American Regional Epilepsy Congress

Summary of Activities

The American Epilepsy Society held Annual Meetings in December (San Diego in 2006 and Philadelphia in 2007). The 2006 meeting was the 1st Biennial North American Regional Epilepsy Congress. Both meetings were very well-attended and provided many thoughtprovoking sessions. Most of the presentations from the AES Annual Meeting are available on the AES Web site (http://www.aesnet.org/go/professionaldevelopment/ed ucationalopportunities/online-education/online-education).

- AES has launched the Resources in Epilepsy Research site (http://epilepsyresearchresource.org) which is designed to help match researchers with the proper funding opportunities. This online database is a comprehensive listing of all available funding from nine organizations with instructions on how to apply for funding consideration as well as links to more information. The site also keeps an inventory of all currently-funded research in order to encourage project collaboration and to avoid duplication in research.
- AES has also launched an effort to educate lay people and professionals about post-traumatic epilepsy. This included Web-based materials as well as advocacy efforts.
- The Society updated the look and navigation of its Web site.
- AES has begun an effort to develop a clinical trial to collect data on the bioequivalence of generic drugs.

Research Funding

The Society funded in 2007-2008:

- Milken Family Foundation Early Career Physician-Scientist Awards (7)
- AES-funded Postdoctoral Research Training Fellowships (3)
- AES and Grass Foundation Robert S Morison Fellowship (1)
- Postdoctoral Research Training Fellowship funded by the Lennox Trust Fund (1)
- Postdoctoral Research Training Fellowship funded by UCB Pharma (1)
 AES and Lennox Trust Fund Pre-doctoral
- AES and Lennox Trust Fund Pre-doctoral Fellowships (4)
- Research Initiative Program (1)
- Research Infrastructure Program (2)
- AES-sponsored Workshops (4)
- Research Recognition Awards (2)
- Targeted Pediatric Partnership (1)

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- Research Initiative Program (2)
- Research Infrastructure Program (3)
- AES-sponsored Workshops (4)
 Research Recognition Awards (2)
- Targeted Pediatric Partnership (1)

Educational Activities

- The educational pinnacle of the year is the Society's Annual Meeting, held in December, which provides a myriad of educational opportunities for clinicians, researchers and other epilepsy professionals. In addition, the Society repurposed most of the sessions from the 2006 and 2007 Annual Meetings and put them on the Web site (www.aesnet.org) free of charge. These include Merritt-Putnam Symposium, Presidential Symposium, Annual Course and the AET Symposium, to name a few.
- The Society also offers Audio- and Web-training sessions free of charge, directed to non-physician epilepsy professionals.
- The Society offered a regional "Epilepsy 101" program directed to non-epileptologists in five cities across the country in 2007 and is exploring other models to bring this education to more physician audiences.

Activities in Conjunction with Local IBE Affiliate

- AES leadership and staff participated in the Epilepsy Foundation's 1st and 2nd annual National Walk For Epilepsy raising money for research.
- Several members also participated in the Epilepsy Foundation's Public Policy Institute learning about advocating to Congress and participated in visits to congress people. The Society is participating in Webbased advocacy efforts of the Epilepsy Foundation.
- Many members are active in national and state Professional Advisory Boards of the Epilepsy Foundation.
- Several research funding vehicles are partnerships with the Epilepsy Foundation.

Future Plans

- This December, the Society will be hosting the 2nd North American Regional Epilepsy Congress in conjunction with the Canadian League Against Epilepsy and the Jamaican League Against Epilepsy.
- New educational efforts include a case study publication that will be distributed several times a year and a Visiting Professor Program where volunteers will deliver education to community hospitals.

Officer Election Date

December 2008

Report By: M Suzanne C Berry, MBA, CAE

CHAPTERS LIST AND REPORTS

EPILEPSY SOCIETY OF AUSTRALIA (ESA)

Meetings

22nd Annual Scientific Meeting, 7-9 November 2007, Adelaide

Summary of Activities

- A new Committee and Melbourne-based Executive took over from the Perth-based Executive in 2007. In 2007, the ESA had 242 members the membership base primarily consisted of neurologists, nurses, technologists, scientists and psychologists.
 In July 2007, a New Zealand ILAE Chapter, separate
- In July 2007, a New Zealand ILAE Chapter, separate from the ESA, was formed. Close working relationships between Australian and New Zealand epileptologists are expected to continue through reciprocal arrangements between the two Chapters.
- The East Timor Epilepsy Project, established in 2004, continued to train East Timorese health workers in diagnosis and management of epilepsy. This project is led by Ernie Somerville with the assistance of several neurologists and epilepsy nurses from Australia. The project is funded by grants from the pharmaceutical industry, the ESA, AusAID and Epilepsy Action.
- After extensive negotiations with national and statebased driver licensing authorities, several states have agreed to pilot a standard form and computer-based decision tree developed by the ESA and ANZAN to assist with determination of fitness to drive in patients with epilepsy, first seizures, and syncope. This is a major step towards removing the onus and potential liability on neurologists for certifying fitness to drive, as well as developing a consistent, nationwide application of the national guidelines for driving and epilepsy.
 The ESA held its Annual Scientific Meeting in
- The ÉSÁ held its Annual Scientific Meeting in November 2007. The meeting featured four international speakers and many local presentations. It was highly successful, with over 200 delegates in attendance.

Educational Activities

- In the financial year 2007, several neurologists from Asia (Jithangi Wanigasinghe from Sri Lanka, Josephine Gutierrez from the Philippines, and Parampreet Kharbanda from India) commenced or finished an ESA-funded 12-month Asian-Oceanian Fellowship in Epilepsy.
- With sponsorship from UCB Pharma and the Molly McDonnell Foundation respectively, the ESA awarded one 12-month Clinical Scholarship and one 12month Research Scholarship in 2007.
- Six Travel Scholarships were awarded to young investigators to present their research at international epilepsy meetings during 2007.
- Formal training guidelines for neurologists learning EEG were accepted by the Australian and New Zealand Association of Neurologists and the Royal Australasian College of Physicians.
- Several Australian epileptologists participated in epilepsy and EEG workshops in Asia conducted by the Asian Epilepsy Academy in 2007.

Future Plans

- The 23rd Annual Scientific Meeting will be held in Sydney in November 2008.
- The 3rd Epilepsy Master Class will be held in Melbourne in August 2008.

Officer Election Date

The present Executive Committee's three-year term ceases at the end of 2009.

Report By: Dr A Simon Harvey

AUSTRIAN LEAGUE AGAINST EPILEPSY

Publications

Mitteilungen der Österreichischen Sektion der ILAE www.medicalnet.at/oe-sektion-ILAE (4 issues per year)

Meetings

Annual Meetings: 16-18 November 2006 Vienna; 16-19 May 2007

5th Joint Meeting of the Austrian, German and Swiss Section of the ILAE in Basel

Summary of Activities

The Austrian Chapter held their annual meeting 2006 in Vienna and 2007 as a joint meeting of the Austrian, German and Swiss Chapters in Basel. The joint meetings of the German-speaking countries take place every second year, with 700 to 1,000 participants. The Austrian Chapter donated the Herbert Reisner Prize for Clinical Epileptology in 2006 to Lydia Urak and Ekaterina Pataraia (both Vienna) and Ernst Niedermeyer Prize in 2007 to Giorgi Kuchuchidze (Innsbruck). In addition, two young epileptologists received financial support for a research fellowship in 2006-2007.

Summary of Activities in Relation to Global Campaign

After a disappointing result of a representative survey reporting the attitudes of the Austrian population against epilepsy (Spatt et al. *Epilepsia* 2005, 46:736-742), the Chapter planned several activities to improve the situation. An educational program in close collaboration with the Austrian Ministry of Health was started in schools, to promote knowledge of epilepsy and improve the opportunities for special educational needs of learning-disabled children with epilepsy.

Educational Activities

Regular state-of-the-art lessons on hot topics in epilepsy are held at the Annual Meetings. A patient information brochure is in press and a book with guidelines on diagnosis and treatment is in preparation.

Future Plans

Certification for specialized epilepsy centers and outpatient clinics will be fostered and a new mode of qualification will be introduced this year. The finalization of the guidelines on diagnosis and treatment can be expected 2008/2009. Elections of the Executive Board will take place in autumn 2008.

CHAPTERS LIST AND REPORTS

Officer Election Date 29 November 2008

Report By: Eugen Trinka

BANGLADESH EPILEPSY FOUNDATION

Summary of Activities

Bangladesh Epilepsy Foundation (BEF) had an excellent year last year. We have arranged six seminars on epilepsy care and treatment, two national level training programs for general practitioners and one epilepsy workshop with international teaching faculty. This workshop was jointly organized by BEF, ASEPA and Society of Neurologist of Bangladesh. One hundred doctors from all over Bangladesh participated. Dr C T Tan, Dr John Dunna, Dr Lakshmi Nagaragan, Dr Wendyl D' Souza and Dr Ernie Somerville made up the international faculty for this two-day training course. A total of 1,487 new patients and 2,879 old patients were seen by the BEF at the free Friday clinic last year. You all know that Cyclone Sidr slammed the highly vulnerable low-lying, densely populated coastal areas of Bangladesh with heavy rain, winds of up to 220 miles/hr in November 2007. Approximately 31 of Bangladesh's 64 districts were affected by the storm. The storm caused extensive damage to the southern districts as it moved north across central Bangladesh. The Government of Bangladesh (GoB) official reports indicated that more than 10 million people were affected by Cyclone Sidr, with a death toll of 3,469 (unofficially 27,000) people, with a further 18,596 missing and 34,508 injured. Material damage is severe, with over 566,000 homes destroyed and a further 845,000 houses were partially damaged. The GoB estimates more than 1.7 million acres of crops are damaged. Over 465,000 livestock are confirmed killed, which represents loss of critical household assets. Extensive damage to roads and public buildings was also reported, including 1,355 educational institutions destroyed and another 7,847 partially damaged. Bangladesh Epilepsy Foundation sent two medical teams to the disaster area to help the victims with treatment, free medicine and other relief materials jointly collected by other local NGOs. A total of 2,145 patients, mostly children and old people, were treated in those medical camps.

Report By: Dr. Muzharul Mannan

BRAZILIAN LEAGUE AGAINST EPILEPSY

Publications

Journal of Epilepsy and Clinical Neurophysiology

Meetings

Annual national meetings and regional meetings

Summary of Activities

 Publication: Journal of Epilepsy and Clinical Neurophysiology – ISBN 1676-2649 – Available online at: http://www.scielo.br/scielo.php?script=sci_serial&lng =en&pid=1676-2649.

- Official Web site : http://www.epilepsia.org.br.
- Annual Meetings: XXXI reunião da Liga Brasileira de Epilepsia (XXXI Annual Meeting of the Brazilian League Against Epilepsy) held in conjunction with the XXI Brazilian Congress of Clinical Neurophysiology – 11-13 October 2007, in São Paulo – SP.
- XXXII Congresso da Liga Brasileira de Epilepsia from 11-15 June 2008 in Campinas – SP. National meeting with 600 delegates. During this meeting (as occurred in the previous meetings) there was also a symposium of the Brazilian Chapter of IBE (Associação Brasileira de Epilepsia – ABE) with participation of patients and family members.
- During the period between 2006 and 2008 there were several regional meetings in different parts of the country, focusing on continuous education activities.

Summary of Activities in Relation to Global Campaign

There have been several actions to support the Global Campaign including activities of ASPE (http://www.aspebrasil.org/) which is in charge of the Demonstration Project in Brazil, and for a Permanent Educational Program for Educators. We participated in several activities during our National Epilepsy Week (first week of September), which included sites for information in public places, such as Shopping Centers; interviews and educational ads about epilepsy in newspapers, radios and TVs; among many other activities. The Brazilian Chapter of IBE (Associação Brasileira de Epilepsia – ABE) also has been very active in promoting educational activities for the general public. More information can be found in our periodic publication: Journal of Epilepsy and Clinical Neurophysiology -ISBN 1676-2649 – Available online at: http://www.scielo.br/scielo.php?script=sci serial&lng= en&pid=1676-2649 or at the official Web site of Brazilian League Against Epilepsy: http://www.epilepsia.org.br which also contains information for the general public and for health professionals.

Educational Activities

In addition to the activities described above, the Brazilian League Against Epilepsy gave support to the very successful LASSE – Latin American Summer School on Epilepsy, first held in February 2007 and the second LASSE in February 2008. The third LASSE is scheduled for next February. Below is an excerpt from the report prepared by the organizer of the LASSE, Dr Esper Cavalheiro: 1st LASSE – Latin American Summer School on Epilepsy "Epilepsy: translating basic knowl-edge into clinical applications" Santa Monica Hotel and Convention Center in Guarulhos, São Paulo, Brazil, from 4-14 February 2007. Director: Esper A Cavalheiro. Organizers have selected 22 students from Spanish-speaking Latin American countries (Mexico-3, Honduras-1, Guatemala-2, Cuba-2, Venezuela-1, Colombia-3, Peru-3, Argentina-4, Uruguay-3), 22 stu-dents from Brazil, three students from Angola and two students from Mozambique totaling 49 students. All but one student (from Honduras) joined the meeting. Their expenses (travel and hotel with full board) have been paid. Air tickets for African students have been provided by their governments. Others: four students from

Brazil, one from Uruguay and one from Peru attended the meeting as they have paid their personal expenses and no registration fee was claimed. Results: The global impression is that LASSE has exceeded its objectives. The atmosphere was excellent and students have been delighted with the experience. Some have even expressed the feeling that LASSE has given a new direction to their professional life. Several factors contributed to LASSE's success and among them it is important to mention: (a) the hotel location (far from appealing tourist attractions but with good services); (b) teacher's dedication, commitment and generosity; (c) the program that covered different aspects of basic and clinical epileptology allowing a closer interaction of students from these two areas and (d) the open discussion with contributions of all teachers present at the conference room. Some points need to be modified in future LASSE editions: (a) increase time for discussion between each conference; (b) provide more free time for students' interaction and preparation of the research project.

Activities in Conjunction with Local IBE Affiliate

See above on the Summary of Activities in Relation to Global Campaign.

Future Plans

To continue to support the local IBE Affiliate (ABE) and the Global Campaign, and the educational activities for the general public and health professionals

Officer Election Date

14 June 2008

Report By: Fernando Cendes

CANADIAN LEAGUE AGAINST EPILEPSY

Publications

The scientific content of the 2007 CLAE Annual Meeting in Vancouver will be published as a supplement to the Canadian Journal of Neurological Sciences in 2008.

Meetings

- a) The 2006 CLAE Annual General Assembly was held on 16 June 2006 at the Palais des Congrès de Montreal during the 2006 Canadian Congress of Neurological Sciences;
- b) The 2006 3rd Canadian Epilepsy Research Initiative meeting was held from 29 September to 1 October 2006 in Markham, Ontario. The theme of the conference was "Contentious Issues in Epilepsy: A Canadian Perspective";
- c) The 1st North American Regional Epilepsy Meeting was held from 1-5 December 2006 in San Diego;d) The 30th Anniversary 2007 CLAE Meeting was held
- d) The 30th Anniversary 2007 CLAE Meeting was held from 2-4 October 2007 in Vancouver. During this occasion, Dr Juhn Wada – a founding member of CLAE, was honored;
- e) The 2007 CLAE General Assembly was held 4 October 2007 during the 2007 CLAE Annual Meeting.

Summary of Activities

- New Board: At the General Assembly in June 2006, a new Board was elected: Dr S Wiebe (Past President), Dr L Carmant (President), Dr R Wennberg (President-elect), Dr D Nguyen (Secretary-Treasurer), Dr M Sadler (Education Director), Dr Moeller (Trainee Representative).
- 2. Meetings: The Canadian Epilepsy Research Initiative (CERI), a branch of our CLAE, met in 2006 and is preparing another meeting in 2008. The goal of CERI meetings is to develop research projects aimed at answering questions which will have an impact on stakeholders. They also promote collaborative research across the country. The 2007 CLAE Annual Meeting took place in Vancouver with a well-appreciated scientific program.
- 3. Membership: Our list of members and their coordinates was updated.
- CLAE Web site: Payment of membership dues is now available online using Pay Pal services. Our Web site was completely rearranged with an improved look and ease of use.
- 5. Fundraising: In order to support community work, research and educational programs, the CLAE has been working on a major fundraising campaign entitled "Don't turn your back on epilepsy". Our first step was to join forces with the Canadian Epilepsy Alliance. With seed money from the Savoy Foundation and donations from Board members and Past Presidents, we have worked on creating a permanent fundraising infrastructure to support our national and international programs, to help develop Canadian National Priorities and to increase the visibility of epilepsy across Canada. We hired a public relations person who has worked with her Web-based team to improve our Web site and promote our 2008 "Out of the Shadows Campaign". Malvina Klag has initiated a fundraising campaign which will first target selected significant donors.
- 6. Task Forces: Four Task Forces were created which will provide us with reports that can be used for lobbying to Provincial Governments across the country. Dr Taufik Valiante is in charge of Regional Epilepsy Networks, Dr Jorge Burneo of Disparities in Epilepsy Care, Dr Nizam Ahmed of Telemedicine, Dr David Steven of Standards for telemetry care and access, and Dr Lorie Hamiwka of Educational Needs for Children with Epilepsy.

Summary of Activities in Relation to Global Campaign

- 1. The CLAE has been able to help create an ILAE Chapter in Haiti.
- 2. Through the Hispaniola project, CLAE in conjunction with the North American Commission, is working hard to open an epilepsy clinic in Port-au-Prince Haiti. In addition to the \$6,500 support given by the ILAE to the cause, the CNSF Foundation agreed to support our efforts with another \$6,000. The clinic will be operated by a neurosurgeon from Haiti, as there is no neurologist in Haiti. A pediatrician will be trained in EEG at Sainte-Justine Hospital and an EEG technologist will be trained in the Dominican Republic and will do an additional month at Stellate, where she will become familiar with the EEG machine given to this project by Stellate.

3. The CLAE is also supporting a project to eradicate neurocysticercosis in the Dominican Republic and the development of the first Epilepsy Surgery Center in Santo Domingo, scheduled to open in March 2008.

Educational Activities

- 1. The 2006 3rd Canadian Epilepsy Research Initiative meeting was held from 29 September to 1 October 2006 in Markham, Ontario. The theme of the Conference was "Contentious Issues in Epilepsy: A Canadian Perspective".
- 2. The 42nd Annual Congress of the Canadian Neurological Sciences Federation was held in Edmonton on June 2007. The CLAE epilepsy course was held in Edmonton on 20 June 2007
- 3. The 30th Anniversary 2007 CLAE Annual Meeting was held from 2-4 October 2007 in Vancouver. It contained oral platform presentations and invited speakers. Dr Juhn Wada, a founding member of the CLAE, was honored for his significant scientific contributions.

Activities in Conjunction with Local IBE Affiliate

- 1. The Canadian Epilepsy Alliance was voted as our representative on the IBE. CEA officials had a first meeting with IBE officials at the ILAE meeting in Singapore.
- 2. We have organized a CEA-CLAE patient information day prior to the 2007 CLAE meeting on 1 October 2007
- 3. On 2 October 2007 both boards met to discuss further collaborations in patient education, research, fund-raising, advocacy, and lobbying.
- 4. CLAE and CEA are working together on the "Out of the Shadows Campaign" which will be launched in 2008 as well as the First National Concert for Epilepsy to take place in 2009.

Future Plans

- 1. Following the success of our 2007 CLAE scientific meeting in Vancouver, it was decided to organize a bi-annual CLAE scientific meeting which would alternate with the North American Regional Epilepsy meeting
- 2. Our "Out of the Shadows Campaign" will be launched in 2008. The approach to fund-raising will be first to sensitize patients and families to the campaign by posters and a pin fundraiser at epilepsy clinics across the nation. Once we have Canadians across the country talking about our efforts, we will hold a National Epilepsy Concert.
- 3. The 2008 Canadian Neuroscience Federation meeting will be held in Victoria, BC in June 2008. In addition to the epilepsy course and the video session, we will be holding our general assembly in Victoria.
- 4. The report from Dr Ahmed was published. We are hoping to publish in 2008 our first two Task Force reports: Regional Epilepsy Networks (Taufik Valiante) and Disparities in epilepsy care (Jorge Burneo)
- 5. The next CLAE biannual meeting planned for 2009 will be held in Calgary.

Officer Election Date

Elections will take place at the next General Assembly on 18 June 2009 in Victoria, BC.

Report By: Dang Nguyen Secretary-Treasurer

CHINA ASSOCIATION AGAINST EPILEPSY

Publications

Clinical Guidelines: Epilepsy fascicule (Chinese); Comprehensive Textbook of Epilepsy (Engel): Chapter 291

Meetings

Three academic meetings and training courses

Summary of Activities

- 1. Compile Clinical guidelines epilepsy fascicule;
- 2. Organized celebration of "International Epilepsy Caring Day" in 36 cities;
- 3. Social awareness activities in ten provinces;
- 4. Compile "Proper technique in managing epilepsy patients in urban communities";
- 5. International exchange activities (WHO HQs; Italy; Netherlands; and Singapore);
- 6. Academic meetings and training courses supported by ASEPA;
- 7. WHO collaborative projects in Suburb Beijing;
- 8. Government supported project in rural area of 15 provinces (free treatment of about 20,000 GTCS patients with phenobarbital).

Summary of Activities in Relation to Global Campaign

Government supported project in rural area of 15 provinces (free treatment of about 20,000 GTCS patients with phenobarbital)

Educational Activities

- Three training courses supported by ASEPA on:
- 1. Advances in diagnosis and treatment of epilepsy;
- 2. Quality of life with epilepsy patients;
- 3. Pre-operation evaluation.

Activities in conjunction with local IBE-affiliate social awareness activities in ten provinces.

Future Plans

- 1. 7th AOEC in Xiamen, China;
- 2. Clinical guidelines publicities in another ten provinces together with social awareness activities;
- 3. WHO 2008-09 biennial collaborative project in Tibet;
- 4. Continue rural project in 15 provinces;
- 5. Three training courses supported by ASEPA;6. National EEG/Electrophysiology Conference in September 2008;
- 7. Second "International Epilepsy Caring Day";
- 8. Second Asian Epilepsy Conference on Epilepsy Surgery in October 2008 in Shijiazhuang, Hebei Province.

Officer Election Date

October 2009

Report By: Shichuo Li President, CAAE

COLOMBIAN LEAGUE AGAINST EPILEPSY

Summary of Activities

The Colombian League Against Epilepsy changed the Board of Directors. The new President is Dr Daniel Nariño, from Bogotá. The Secretary is Dr Orlando Carreño from Medellín. These new dignitaries are organizing the XV National Congress that is scheduled for 28-30 September 2008 in Medellín. We invite everybody to visit our page:www.epilepsiacolombia.org for full information.

We initiated the preparation of the Law Project against discrimination to people with epilepsy. There is a nice reception in the Colombian Parliament for this transcendental step. Hanneke de Bour (Global Campaign Against Epilepsy) and Carlos Acevedo (Executive Director for Latin America) have been invited and kindly accepted to chair the parliamentary session. Colombia will be the first country around the world that has this dreamed initiative.

We continued the education program in epilepsy around the country through conferences to many students.

The Colombian League Against Epilepsy, that owns a Neurological Hospital devoted to epilepsy surgery, must transfer this organization in order to separate the new Board of Directors. For this reason, it was necessary to create a new organization with the same philosophy (non-profit institution, a Foundation): Fundación Centro de Epilepsia. So we are working hard.

Jaime Fandiño-Franky, MD Past President

CROATIAN LEAGUE AGAINST EPILEPSY

Summary of Activities

- 1. Epilepsy: can children live as others.
- 2. Postgraduate course: Preventions in pediatrics, Proceedings, *Slavonski Brod* 16-18 March 2007; 48-57.

CYPRUS EPILEPSY SOCIETY

Summary of Activities

We have participated as co-organizers in the 2nd and 3rd Panhellenic Epilepsy Congresses.

Summary of Activities in Relation to Global Campaign

Presented the topic of SUDEP during the Panhellenic Congress 2007.

Educational Activities

Booklet on epilepsy for patients

Future Plans

Epilepsy Day to be organized around the International Day with a distinguished speaker to be invited

Officer Election Date

January 2009 Report By:

Savvas Papacostas President

DANISH EPILEPSY SOCIETY

Publications

www.epilepsiselskabet.dk

Meetings

Two scientific meetings per year

Summary of Activities

Two scientific meetings per year. Report of working group on recommendations regarding treatment with vagus nerve stimulator. Working on national database about epilepsy treatment. Referee for national guidelines on antiepileptics.

Educational Activities

Two annual scientific meetings. Lecture competition for young researchers at the Annual meeting. Epilepsy course for junior doctors in collaboration with the Danish Epilepsy Center.

Activities in Conjunction with Local IBE Affiliate

Regular meetings (twice a year) attended by the Board of the local IBE and the Board of the Danish Epilepsy Society

Future Plans

National guidelines for the treatment with vagus nerve stimulator, Baltic Epilepsy Sumer School in Denmark in 2008. Extended collaboration with the Epilepsy Societies in the Nordic Countries involving Finland

Officer Election Date

March 2008

Report By: Noémi Becser Andersen Chairman

FINNISH EPILEPSY SOCIETY

Summary of Activities

Our main activity in 2006 was the 7th European Congress on Epileptology which was organized in Helsinki 2-6 July. Our Society worked together with the Scientific Advisory Committee to create a scientific program, which concentrated, among other issues, on epileptogenesis and brain maturation in epilepsy evolution. Finnish Epileptology Symposium focused on "Unverricht-Lundborg disease: in Finland and elsewhere." Progressive myoclonus epilepsy of Unvericht-Lundborg type, EPM1, is most prevalent around the Baltic Sea, especially in Finland, but is also relatively frequent in the western Mediterranean region. This symposium addressed the current knowledge of the

molecular genetics, phenotype variation, clinical evolution and update on treatment of this rare disease. Wider overview of rare or so-called 'orphan diseases' in epilepsy and the possibility to treat these rare disorders with specifically developed 'orphan drugs' was given in this Congress in a unique symposium dedicated to this important issue.

This Congress provided Finnish epileptology with a unique opportunity to increase general knowledge about epilepsy, as together, with the Finnish Epilepsy Association (FEA, the Chapter of IBE) we made a very successful publicity campaign during the Congress and gained lot of visibility in media. The population of Finland is 5.2 million inhabitants, and we have 56,000 persons who have diagnoses of epilepsy (38,000 on active medication). During the Congress and directly after we gained 126 hits in media with the circulation of 7.5 million (July-September 2006).

In 2007 the Finnish Epilepsy Association (the Chapter of IBE) with the support of experts of the Finnish Epilepsy Society arranged education for health care professionals and panel discussions for audiences in collaboration with a Finnish film about epilepsy (A year of a Wolf) done by a famous Finnish movie company. The focus in the film is in experiences of epilepsy as an illness. These activities are a part of the WHO/ILAE/IBE Global Campaign Against Epilepsy: Out of the Shadows in Finland. During this activity 149 hits were in media with circulation of 11.2 million (January-February 2007).

In 2006 we re-started the educational tours around the country. Ten educational meetings were arranged locally as evening meetings. These tours were continued during 2007. The whole neurology and pediatric neurology team working in the district was invited and each meeting gained an audience of 30-80 people. Two national educational meetings were arranged in 2007. In March the topic was "Epilepsy and mental retardation" in Helsinki and in October the topic was "Epilepsy beyond seizures" in Tampere dealing with cognitive and other co-morbid problems of epilepsy and also progression of epilepsy.

Summary of Activities in Relation to Global Campaign

The Chapter has focused to increase professional awareness of epilepsy as a treatable disorder. All our educational meetings are part of the Global Campaign and in major meetings we arrange press conferences to increase public awareness.

Members of the Chapter participate in the national effort to create guidelines for the treatment of epilepsy in Finland. In 2006, "The Treatment of Prolonged Seizure and Status Epilepticus," and in 2007, "The Treatment of Epilepsy in Children and Adolescents" and "The Treatment of Febrile Seizures" were published and are available on the Internet in Finnish.

The Chapter has also been an active participant in the discussion of reimbursement policies of new antiepileptic drugs and epilepsy surgery in Finland. The goal is to increase the equal availability of the new drugs and surgery for epilepsy patients regardless of their economic situation or community they live in.

Educational Activities

Described in the Summary of Activities

Activities in Conjunction with Local IBE Affiliate

Collaboration between ILAE and IBE Chapters in Finland is close and each year at least one of the educational meetings is arranged together.

Most of the Global Campaign activities and other public activities arranged by the IBE Chapter always have experts invited from the ILAE Chapter.

Future Plans

The Finnish Epilepsy Society and the Finnish Epilepsy Association are going to improve knowledge of epilepsy and equal access to high-quality care by joining their forces in building a new Web site.

Report By: Reetta Kälviäinen

LFCE – LIGUE FRANCAISE CONTRE L'EPILEPSIE (FRENCH CHAPTER)

Publications

EPILEPSIES (www.revue-epilepsies.fr)

Meetings

Journees Françaises De L'Epilepsie – JFE Lyon 13-15 November 2008

Summary of Activities

- In 2006 the LFCE organized its Annual Meeting in Strasbourg (Prof Hirsch) as a joint meeting with the German Chapter. In 2007 the Annual Meeting (JFE 10th anniversary) was organized in Nice (Prof Thomas) and was preceded by the "Claudio Munari workshop" organized in collaboration with the Italian Chapter.
- The "Henri Gastaut Prize" (LFCE with the support of Sanofi-Aventis) was attributed in 2007 to Prof Pierre Jallon.
- The Journal of the French Chapter EPILEPSIES (Editor-in-Chief Dr Michelle Bureau) was indexed in 2007 and became the official vector of several French-speaking ILAE Chapters.
- The Web site www.lfce-epilepsies.fr was further developed.

Summary of Activities in Relation to Global Campaign

In 2006 the LFCE in collaboration with several associations, all grouped within the Comité National d'Epilepsie (CNE) organized the National Epilepsy Day. Several activities took place in a number of regions. The operation will be repeated in 2008.

- The LFCE, via its journal *EPILEPSIES* edited in French, actively contributes to the dissemination of current knowledge in the field of clinical epileptology.
- The LFCE actively supported the actions of the Commission on European Affairs and the EAC.

Educational Activities

- The LFCE together with the University of Nancy (Prof Vespignani, in charge of the Education Committee) and in collaboration with all main universities organizes a two-year teaching course (Diplôme Universitaire d'Epileptologie) that includes training courses in university hospital departments as well as several options (pharmacology, epilepsy surgery, psychosocial issues, fundamental research). During the last two years the course was again very well attended.
- The LFCE in collaboration with the pharmaceutical industry offers every year a number of grants for research in clinical and fundamental épileptologie and the "J. Roger Medico-Social Grant".

Activities in Conjunction with Local IBE Affiliate

Collaboration with IBE affiliates (Association Française pour les Epilepsies and EPILEPSIE-FRANCE) is mainly accomplished via the CNE. IBE affiliates and the FFRE are systematically invited and represented at the Annual LFCE Meeting.

Future Plans

- The LFCE is currently conducting a prospective evaluation of the needs for epilepsy care in France. The project was initiated by Prof de Toffol (President 2006-2007).
- The Scientific Commission (Coordinator Prof Ryvlin) is conducting a research project on Mortality and Epilepsy. The LFCE will use part of the 26th IEC income to fund research projects in the field of epilepsy.
- Late 2007, following the elections of the LFCE Executive, the Commission for French-speaking countries was reinforced. The Commission develops a number of projects and works in close collaboration with EUREPA.
- The Executive Office of the LFCE was elected in November 2008, following the election of the Administration Council.

Alexis Arzimanoglou President of the LFCE

GERMAN LEAGUE AGAINST EPILEPTOLOGY

Publications

Zeitschrift für Epileptology

Meetings May 2007

Summary of Activities

In 2007, the German Society for Epileptology gave substantially more financial support for young investigators in the field of Epileptology. Also the project of EURAP will be supported over the next years. The Otfried-Förster-Stipendium was newly created: This bursary can be applied for by individuals wishing to link clinical and experimental work. The DGfE will fund proposals of theoretical epileptologists wishing to expand their clinical knowledge, and conversely, clinical epileptologists aiming to gain experimental experi-

ence. Costs for 50% of personnel expenses (up to 35,000 euros) will be covered for up to one year, provided the home institution will cover the other 50%. The German Society discussed the problems with aut-idem antiepileptic medications and published recommendations. New financial systems for outpatient clinics for epilepsy patients have been implemented by the government; the German Society produced certification rules for those outpatient clinics. The Otfried-Förster-Prize was dedicated to Professor Erwin-Josef Speckmann from Munster for his work in the field of experimental epileptology. Mrs Gisela Schüler and Mr Rupprecht Thorbecke have been nominated as new honorary members of the Society for their work in social topics of epileptology. The German Society for Epileptology moved from its office in Bielefeld to Berlin and now resides together with the German Society of Neurology in Berlin, sharing both logistics and lobbying power. The German "Tag der Epilepsie" in October 2007 in Dresden was supported by the German Society. A number of local actions were organized in the center of Dresden and many people were attracted to the event, being interested in different aspects of epileptology The German Society for Epileptology celebrated its 50th birthday in 2007.

Officer Election Date 2009

Report By: Dr Thomas Mayer

GREEK LEAGUE AGAINST EPILEPSY

Meetings

Panhellenic Congress of Epilepsy once per year

Summary of Activities

- 2nd Panhellenic Congress of Epilepsy "Epilepsies: diagnostic and therapeutic approach" 10-12 November 2006, Hyatt Regency Hotel, Thessaloniki;
- 3rd Panhellenic Congress of Epilepsy "Epileptic and non-epileptic events in children and adults" 09-11 November 2007, Ledra Marriott Hotel, Athens, Greece. Participants: 600.

Summary of Activities in Relation to Global Campaign

Global Campaign 2006, "Out of Shadows" Greek League Against Epilepsy organized a special session on the 12th of November 2006 within the framework of the 2nd Panhellenic Congress of Epilepsy. Chair: Athanasios Covanis, Konstantinos Sitzoglou. Topics included: SUDEP – Speaker: Savvas Papacostas; Global Campaign "Out of the Shadows" – Speaker: Philip Lee; Epilepsy and Quality of Life – Speaker: George Zacharakis.

Educational Activities

In 2007, the Greek League Against Epilepsy decided to establish the organization of educational workshops in order to promote the advancement of education and practice in the field of epilepsy.

practice in the field of epilepsy.
1) 1st Educational Workshop, "Epilepsies and Pharmacoresistance" 9-11 February 2007, Montana Hotel, Karpenisi, Greece. Participants: 50. The scientific program of the aforementioned workshop

included a variety of lectures on the subject of "Epilepsies and Pharmacoresistance" and managed to bring together a scientific group of distinguished speakers in order to exchange views and ideas on the field of epilepsy.

2) 2nd Educational Workshop, "Epilepsies: Basic Rules Regarding Classification and Management" 21-23 September 2007, Le Meridien, Limassol, Cyprus. Participants: 50. Greek League Against Epilepsy in cooperation with Cyprus Epilepsy Society organized the 2nd Educational Workshop on Epilepsy. The scientific program of the aforementioned workshop included a variety of lectures on the subject of "Epilepsies: Basic Rules Regarding Classification and Management." This workshop was a fruitful opportunity for professionals in both countries to meet together and discuss current issues in the field of epilepsy.

Activities in Conjunction with Local IBE Affiliate

Global Campaign 2007, "Out of Shadows" Greek League Against Epilepsy organized a special session on the 11th of November 2007 within the Employment legislation framework of the 3rd Panhellenic Congress of Epilepsy. "Across the member states for people with disabilities with reference to any statistics concerning prejudices against employment opportunities for people with disabilities across Europe," Speaker: Gay Mitchell. "When there is a will there is a way," Speaker: Marion Clignet, Chair: Giuliano Avanzini, Philip Lee. "Parental needs of children with epileptic seizures and family management issues," Speaker: Thalia Valeta and Athanasios Covanis.

Future Plans

- 3rd Educational Workshop, "Frontal Lobe Seizures" 29 February-2 March 2008, Xenia Palace Hotel, Portaria, Pilion, Greece. Participants: 50;
- Educational Workshop, "Epilepsies of parietal and occipital lobes" 4th Panhellenic Congress of Epilepsy 14-16 November 2008, Alexandroupolis, Greece and 4-6 July 2008, Dolphin Bay Hotel, Syros, Greece. Participants: 50.

Officer Election Date

10 November 2007

Report By: A Covanis President

GUATEMALA LEAGUE AGAINST EPILEPSY

Summary of Activities

- 1) First Session of the programming of the activities of the whole year 2007.
- 2) Approval of the year 2007 Plan.
- 3) First Scientific activity basic and academia aspects of epilepsy.
- Organization of the different subchapters of the Chapter Guatemala International League Against Epilepsy.
- 5) General programming of the yearly activities of each subchapter of ILAE.
- 6) Manufacturing of the educational materials for patients.

- 7) Manufacturing of educational materials for patients and their families.
- 8) Manufacturing of educational materials for school teachers and students.
- 9) Creation of video materials for patients, relatives, teachers and general practitioners.
- 10) Production of audio material for patient and physician education on epilepsy.
- Production of video material for the general public about epilepsy.
- 12) Special planning for activities for elementary school teachers, materials about epilepsy.
- 13) Inauguration in all the subchapters in Guatemala in different status or departments of specialized clinics for the attention of patients with epilepsy.
- 14) Special training courses about epilepsy diagnosis and management of Neurology Residents in the areas of Pediatric Neurology, Adult Neurology and Clinical Neurophysiology; these activities with the support of State University of San Carlos de Guatemala.
- 15) Once per month activities in the subchapters and in the headquarters of the League scientific meetings with specialists in the neurological branches; topics covered different aspects in the management, treatment and research in epilepsy.
- 16) Joint meeting once a month with the neurological associations and epilepsy organizations with the support of the Continuum of the World Federation of Neurology discussing topics about epilepsy and other related topics of the neurological sciences.
- 17) Monthly meeting of the Commission of Continuous Medical Education of the College of Physicians of Guatemala projecting to all the organized medical community of Guatemala in topics of epilepsy management and guidelines in epilepsy for the physicians that are not neurologists.
- Participation in electronic teaching courses for physicians through the country of Guatemala through Internet and through the Web page www.Neurologiaparatodos.com.
- 19) Participate in courses given at a distance on our Web page about epilepsy topics and increase awareness about the prevalence, incident and importance of the correct management of the epilepsies.
- 20) At monthly intervals members of the League and the Bureau delivers lectures about epilepsy and related basic neuroscience topics in the subchapters spread all over the country of Guatemala.
- 21) Active participation in research projects about social, academia and clinical aspects of epilepsy in different areas of interest.
- 22) Participation in courses for the neurological residents and other professionals interested in electrophysiology, specially supporting the knowledge in interpretation of electrodiagnostic tests in the field of the neurosciences.
- 23) Jointly with the Neurology and Neurophysiology Residency programs of the University of San Carlos participating in a joint effort for developing protocols for treatment and management of epilepsy.
- 24) Direct participation through the Neurology residency program.
- 25) Our organizations are deeply involved in the development of the epilepsy surgery programs in Guatemala.

- 26) Joint participation with the School of Psychology of The University of San Carlos in the development and support in the area of Neuropsychology.
- 27) Planning of the monthly activities about epilepsy for the general population that are not medical physicians.
- 28) In the subchapter of Coban Alta Verapaz at 250 kms from Guatemala City, the local committee with the help of the city government and local organizations is involved at the present in the construction of a multi-clinic facility in the area of epilepsy with practical and modern facilities. It is expected, once finished, to be a pioneer project in Guatemala and Central America. Expected to be completed in the last trimester 2008.
- 29) With the Guatemala Red Cross we have an agreement of mutual cooperation for joint projects in the field of epilepsy and neurological diseases, the organizations involved are Chapter Guatemala ILAE, Chapter Guatemala IBE, Neurology training program of the University of San Carlos of Guatemala. The League runs an epilepsy clinic in the headquarters of the Red Cross to attend epilepsy patients. The Neurology residency program provides a medical Neurology Resident, the Red Cross provides the facilities and modern equipment of Brain Mapping and EEG also supplies para-medical personnel.
- 30) The Red Cross has this year purchased first class equipment for Brain Mapping and EEG.
- 31) A cooperation agreement has been signed between the Chapter Guatemala, International League Against Epilepsy, the International Bureau for Epilepsy, The Neurology-Clinical Neurophysiology Residency programs of the University of San Carlos, and the Guatemala Red Cross. The main general objective is to pursue an integral concept of health. Health is not just the absence of disease but a complete sense of wellbeing socially, medically and economically according to WHO.
- 32) Guatemala is a multilingual pluricultural society; 21 languages are spoken in addition to the official language Spanish less than half of the population know to read and write. A very innovative process was started with Dr Henry B Stokes who for the first time in the country made a set of audio CDs in ten different languages with the help of local communities. This material is instrumental for teaching epilepsy to many rural communities in their own languages. A large number of CDs were produced and distributed with a special grant of \$5,000 that was awarded by the IBE International Bureau for Epilepsy. A second phase of this process is being implemented for the near future. This is also a joint venture between IBE and ILAE national Chapters.
- 33) Meetings: Each year for the last 25 years the Chapter Guatemala of ILAE and the Chapter Guatemala IBE and the Guatemalan Association of Neurological Sciences organizes with its fellow societies from Spain the Iberocentroamerican Congress of Neurological Sciences and Epilepsy with the participation of professionals from Central America, Latin America, USA, and Europe.
- 34) Local organizations of the subchapters all over the country are made up of: physicians, teachers, prominent members of the community, social work-

ers, patients and relatives of patients. Monthly meetings are scheduled.

Officer Election Date January 2009

Report By: Dr Henry B. Stokes

HONG KONG EPILEPSY SOCIETY

Summary of Activities

Scientific meetings:

- 26 January 2007, 2nd HKES-UCSF Video Conference Prince of Wales Hospital
- 5 March 2007, "New Challenges in the Management of Pediatric Epilepsies," Professor Lieven Lagae, University Hospital Leuven, Marco Polo Hotel, Kowloon
- 5 July 2007, The Epilepsy Awareness Day Symposium on Quality of Life in Childhood Epilepsy Queen Mary Hospital
 6 July 2007, "Improving quality of life - beyond
- 6 July 2007, "Improving quality of life beyond seizure control," Professor Steve Schachter, Harvard Medical School Sheraton Hotel, Kowloon
- 14 July 2007, Symposium on advances in medical and surgical treatment of epilepsy, Sheraton Hotel, Kowloon
- 10 November 2007, Joint symposium with The Hong Kong Neurological Society Ltd, Hotel Shangri La, Kowloon
- 10 November 2007, Seminar on Neuropsychological Aspect in Epilepsy: Theory and Practice, Tuen Mun Hospital

Details of individual symposium are as follows:

Scientific symposium on advances in medical and surgical treatment of epilepsy was on 14 July 2007. Speaker was Prof Christian Elger. The meeting was sponsored by Pfizer. Program included: "Advances in medical treatment of epilepsy" by Christian E Elger; "Case presentation I (four cases)" by Jason Fong, Howan Leung, WK Chak and Colin Lui; "Workup and outcome of surgery for non-lesional refractory epilepsy" by Christian E Elger; and "Case presentation II (four cases)" by Eva Fung, Ada Yung, Howan Leung, and WK Chak .

Joint symposium with The Hong Kong Neurological Society Ltd A joint symposium with The Hong Kong Neurological Society Ltd. in the annual scientific meeting of HKNS, was held on 10 November 2007 at Hotel Shangri-La, Kowloon. The Chairpersons were Dr Jason Fong, Dr Patrick Kwan. The program included: "Individualizing antiepileptic drug therapy for patients with epilepsy" by Prof Kore Liow of Via Christi Comprehensive Epilepsy Center, University of Kansas School of Medicine – Wichita, US; "Epilepsy Pharmacogenomics – Promises and Challenges" by Dr Patrick Kwan of Prince of Wales Hospital, Hong Kong; and "Acupuncture and traditional Chinese medicine for the treatment of epilepsy" by Dr Danial KL Cheuk of Queen Mary Hospital, Hong Kong.

Seminar on Neuropsychological aspects in Epilepsy, Theory & Practice on 10 November 2007. This seminar was co-organized by Tuen Mun Hospital and Hong Kong Epilepsy Society and chaired by Dr NS Kwong and Dr TS Fong. Neuroimaging of epilepsy and pediatric epilepsy surgery were also covered in the topics. The meeting was sponsored by Janssen Cilag. The program included: "Opening Ceremony" by Dr Albert Lo, Dr NS Kwong and Dr TS Fong; "Neuropsychological model of brain function" by Prof Tatia Lee; "Neuropsychological assessment" by Ms Florence Kwok; "How imaging detects brain function in epilep-sy" by Dr YC Wong; "How epilepsy affect developmen-tal brain? How epilepsy surgery affects cognitive outcome?" by Dr WK Chak; "Psychiatric problems in epilepsy protocol of psychiatric assessment for epilepsy surgery" by Dr TS Lai; "Case Discussion" presented by Dr Kate Leung, Ms Florence Kwok, Ms Eliza Lau and Dr Lucia Tsang.

Educational Activities

First Neurophysiology course was offered for neurology trainees. It was co-organized with The Hong Kong Neurological Society Ltd. The course was on 17, 18 and 31 March 2007. For the Electroencephalography session on 31 March, there were 31 individuals registered. Drs Jason Fong, Patrick Kwan, Howan Leung, Andrew Hui and Colin Lui were the speakers. The course was welcomed by the audience. Course materials were uploaded onto the Web site of HKNS Ltd. The program, chaired by TH Tsoi/ KK Lau included: "Basic principles Montages/localization" by Jason Fong; "Normal variants" by Patrick Kwan; "Application & different patterns of epileptic disorders" by Jason Fong; "Non-epileptiform patterns" by Howan Leung; "Brief introduction to video EEG" by Andrew Hui; and "Quiz" facilitated by Colin Lui, Patrick Kwan, and Jason Fong.

Activities in Conjunction with Local IBE Affiliate

The Epilepsy Awareness Day – Symposium on Quality of Life in Childhood Epilepsy – was a single day symposium organized by Department of Pediatric & Adolescent Medicine, QMH and Community Rehabilitation Network and co-organized by Hong Kong Epilepsy Society and was held at the Underground Lecture Theater 2, New Clinical Building, QMH on 5 July 2007. The program included: Prof Gabriel Ronen, Department of Pediatrics, McMaster University; Dr Winnie Yam, Private Pediatrician; Dr CW Fung, Specialist in Pediatrics, Department of Pediatrics & Adolescent Medicine, QMH; Ms Anchor Hung, Medical Social Worker, The Hong Kong Society for Rehabilitation Community Rehabilitation Network.

Future Plans

Participation in global research and more collaboration with IBE Chapter to promote public awareness of epilepsy

Officer Election Date

January 2009

Report By: Colin Hiu-Tung Lui

HUNGARIAN EPILEPSY LEAGUE - (HEL)

Publications

The frontal lobe, as the common structure of neurology and psychiatry, by P Halász (eds.). 2006, Guideline of Epilepsy Care, by P Rajna (eds.). 2007.

Meetings

In 2006: Meeting of HEL, Pécs

In 2007: Meeting of HEL, as a Section of the Hungarian Clinical Neurophysiologic Society Conference, Pécs

Summary of Activities

In 2007, we published the detailed form of the Epilepsy Protocol (Guideline of Epilepsy Care). The protocol contains the diagnostic, therapeutic, rehabilitation and care giving recommendations, and defines the rules of personal and institutional conditions of epilepsy care. The officer election process was held in 2007. J Jerney President, Z Szupera Secretary, J Janszky Presidentelect, P Rajna Past President. The ILAE passes the organization of the 28th International Epilepsy Congress to the HEL in 2009 in Budapest.

Summary of Activities in Relation to Global Campaign

Patronizing and supporting the Valentine Epilepsy Days every year on 14 February. Publications for patients and their families about epilepsy. The Richter Pharmaceutical Company, in cooperation with the HEL announces a competition for award of new methods to improve the quality of life for people living with epilepsy, every year.

Educational Activities

- Regular educational courses and workshops on epilepsy in Győr (yearly).
- Richter Academy about the modern diagnostic and therapeutic methods in epilepsy, Budapest.
- Brain Day, with focusing on epilepsy, Zalaegerszeg.
- Teaching course for different specialties about the brain areas involved in epilepsy, Budapest.

Activities in Conjunction with Local IBE Affiliate

The IBE General Assembly ratified the membership application of the Association for the Future of People with Epilepsy in Hungary in 2007. HEL Continues helping with the organization by having an umbrella function and coordinating the local societies as well as patronizing the Valentine Epilepsy Days.

Future Plans

To continue the regular educational courses. The 28th International Epilepsy Congress will be held 28 June – 2 July in 2009 in Budapest. It is a great challenge for the HEL to help organize a successful and memorable Centenarian Congress, in association with the ILAE.

Officer Election Date

2011

Report By: J Jerney and Z Szupera

INDIAN EPILEPSY SOCIETY

Publications

EPILEPSY INDIA (Newsletter)

Meetings

Annual Conference

Summary of Activities

The Indian Epilepsy Society (IES) held its Annual Conference on 3 and 4 October 2007 in Hotel Taj President, Mumbai. It was attended by over 400 persons. There was an Oration given to Prof Ruben Kuzniecky, USA, who spoke on cutting edge neuroimaging. There was a mini-symposium on interesting case presentations by Drs R Kuzniecky, Simon Harvey, K Radhakrishan and P Satishchnadra followed by a quiz. There were invited lectures by Prof Martin Brodie and Prof Ong Lai Choo. There was a pre-conference update on pediatric epilepsies which was sponsored by ASEPA. Nearly 200 pediatricians/physicians/neurologists attended a full day program where the notable speakers were Drs Simon Harvey, Shinichi Hirose and Ong Lai Choo. After deliberations of over two years the IES has formed a core group of 16 members to finalize 'Guidelines for Epilepsy Management in India (GEMIN)'. The group has had two separate meetings in January and April, 2008. The first draft of the guidelines was reviewed in the meeting held in April, 2008. We propose to finalize the guidelines in the next three months and hopefully the guidelines will be formally released during the next Annual Conference of the IES in October 2008.

Summary of Activities in Relation to Global Campaign

International Epilepsy Day celebration each year on 17 November

Educational Activities

The IES has formed a core group of 16 members to finalize "Guidelines for Epilepsy Management in India (GEMIN)". The group has had two separate meetings in January and April 2008. The first draft of the guidelines was reviewed in the meeting held in April 2008. We propose to finalize the guidelines in the next three months and hopefully the guidelines will be formally released during the next Annual Conference of the IES in October 2008.

Activities in conjunction with local IBE affiliate

Annual Conference International Epilepsy Day each year on 17 November

Officer Election Date

October 2008

Report By: Satish Jain Secretary-General, IES

ISRAELI CHAPTER OF ILAE

Summary of Activities

Conferences: Two national conferences: January 2007, keynote lecture: D Schmidt (Berlin); April 2007 – guest

lectures: H Weiner, R Kuzniecky, D Yoshur, A Kanner, R Goodman. Case presentation meetings twice a year.

Activities in Conjunction with Local IBE Affiliate

- Assistance for the Israeli patients association: consultations
- Web: Q & A, editing the scientific part
- Lectures in patients' association meetings
- Activities to help inclusion of new AEDs/devices/procedures into the "medical basket" (Levetiracetam; VNS, Video-EEG Monitoring)

Officer Election Date

January 2008

Report By: Prof Uri Kramer

ITALIAN LEAGUE AGAINST EPILEPSY

Publications

Bollettino della Lega Italiana contro l'Epilessia

Meetings

Chapter's National Congresses: Pisa 3-6 June 2006; Reggio Calabria 29 May to 1 June 2007

Summary of Activities

The Italian Chapter has been mainly involved in organizing activities devoted to the improvement of knowledge, medical care and specialist training in the field of epileptology. These activities have been pursued by the Commissions and working groups of the LICE, as detailed below:

- Commission for the guidelines, with the elaboration and publication (*Epilepsia* Vol 47, Suppl 5, 2006) of three guidelines concerning the therapy of status epilepticus in adults, the diagnosis and treatment of the first seizure, and the generic products of antiepileptic drugs. Further documents prepared during the last two years concern the guidelines on febrile seizures and a consensus statement on epilepsy and pregnancy.
- Commission for genetics, with the organization of two meetings per year devoted to the presentation of families and discussion of the research projects (on familial temporal lobe epilepsies, severe myoclonic epilepsy, familial cavernous angiomas with epilepsy, pharmacogenomic study of pharmacoresistance, familial juvenile myoclonic epilepsy, familial eyelid absence epilepsy, etc.), gathering the interest and collaboration of many epileptologists and geneticists at a national and international level.
- Commission on surgery for epilepsy, with the organization of a forum for the discussion of the anatomoelectro-clinical characteristics of clinical cases of possible neurosurgical interest and elaboration of guidelines on the different aspects of surgery of epilepsy.
- Commission on videos, with the collection of informative videos on different seizure types and elaboration of appropriate tools for the didactic presentation of the material (DVD on neonatal seizures, DVD on parieto-occipital seizures).

- Working group on epilepsy and pregnancy, supporting the prospective European study on pregnancies in epileptic women (EURAP study).
- Working group on quality of life, with the elaboration and validation of an original questionnaire for patients and caregivers, and publication of the results of the study.
- Working group on basic sciences, promoting the organization of meetings with the aim to fill the gap between basic scientists and clinicians in the field of epilepsy.
- Working group on neonatal convulsions, with the organization of a network among interested clinicians with the aim to collect information about specific etiological problems (e.g., neonatal vascular pathology).
- New working groups have been also instituted (neuropsychology with the elaboration of a protocol on neuropsychological testing of epilepsy in adults and children, epilepsy and the elderly, psychiatric aspects of epilepsy, neurophysiological techniques in epilepsy).

The Italian League has also promoted a competition among the students of the Experimental School of Cinematography of Rome to carry out four short movies on epilepsy, which will be used to promote the knowledge of epilepsy in the next Campaigns Against Epilepsy. The Italian Chapter has also confirmed under its authority a number of centers for epilepsy. More information on the Chapter's activities can be found on the Web site www.lice.it.

Summary of Activities in Relation to Global Campaign

The Italian Chapter has supported the Global Campaign in 2006 and 2007 by promoting a number of activities concentrated around the first Sunday of May, declared Epilepsy Day by the Italian Ministry of Health. The activities in different regions were prepared in conjunction with patient associations and focused on correct information on the disease through the media and a direct contact with the citizens in the city squares and schools. The aim was to improve knowledge about epilepsy and increase public awareness of the disease. We also devoted a specific section in our Web site containing any information on the disease and the various events taking place in each region and town. A press office was also created to coordinate the relationships with the media and the different activities and events. In detail: 2006: organization of a specific meeting with press conference in Rome (5 May 2006), 2007: organization of the first "Maratonina" in April 2007 at the presence of testimonials from the sporting world.

Educational Activities

- The Italian Chapter has promoted a number of educational activities including: Annual multicenter meeting in Rome (20 September 2006 and 8-19 January 2007), gathering epileptologists (mostly young doctors training in neurology) from different epilepsy centers with a program focused on the interactive discussion of clinical cases and scientific papers (journal club).
- Annual video-EEG course for technicians and epileptologists (Catania, 29-31 October 2007).
- Claudio Munari workshop: Verona, September 2006 and Nizza, (in conjunction with the French Chapter) November 2007.

- Production of an interactive atlas of electroencephalography in epilepsies.
- Course on medical writing (Rome, 21-22 June 2007).
- Other educational activities have been performed in conjunction with the regional sections, which operate in the various administrative areas of the country under the leadership of a regional coordinator.

Activities in Conjunction with Local IBE Affiliate

In 2006 the Epilepsy Day was organized in conjunction with the local IBE affiliate (Italian Association Against Epilepsy).

Future Plans

Future plans of the Italian Chapter include:

- Strengthening of the research into the causes and treatment of epilepsy.
- Further support for young doctors and specialists interested in improving their knowledge of epilepsy.
- Promotion and support of the epilepsy services in the country.
- Promotion and support of legislation and regulations in favor of people with epilepsy.
- Collaboration with the health authorities to develop high standards for epilepsy care throughout the country.
- Elaboration and diffusion of guidelines aimed to improve the diagnosis and treatment of epilepsy.
- Organization of the national Congress.
- Organization of courses, meetings and conferences on epilepsy.
- Encouragement of contributions and donations to be used for the statutory aims of the Society.
- Strengthening of the relationships with the International League Against Epilepsy and other national and international organizations involved in the care of people with epilepsy.

Officer Election Date

5 June 2008

Report By: Dr Roberto Michelucci

JAPAN EPILEPSY SOCIETY

Publications

Epilepsia (3 publications a year) *Epilepsy* & Seizure (annual publication)

Meetings

Congress of the Japan Epilepsy Society

Summary of Activities

- 1. Membership and Public Relations Affairs Chair: Eiichi Maru. By using e-mails, it became possible to communicate more effectively and interactively.
- 2. Committee of English journal *Epilepsy & Seizure* Chair: Kousuke Kanemoto. Since we only had the official journal in Japanese, the members had less opportunity to introduce their activities to the world. In January 2008, we launched a new publication *Epilepsy & Seizure*, the new medical online journal of epilepsy. It allows open access to all to review/submit articles from the moment of publication. To achieve a high academic standard of journal, *Epilepsy &*

Seizure welcomes international editors from all over the world.

- 3. Drug Investigation Affairs Chair: Makiko Osawa. In cooperation with the Japan Society of Child Neurology, Japanese Society of Clinical Neurophysiology and Epilepsy Surgery of Japan, we have been trying to make a formal request for the approval of new antiepileptic drugs and introduce the new tests in a social insurance system.
- 4. International Affairs Chair: Sunao Kaneko. A number of our members participated in the 27th Congress of International Epilepsy Society held in July 2007. The representatives of each Chapter had the Chapter Convention. We submitted several proposals and confirmed Japan-Asia cooperation. As a result of our efforts, JES Scholarship was inaugurated for the young researchers in Asia-Oceania and the 1st candidates were selected. In 2008 they start their internship programs in Japan.
- their internship programs in Japan.
 5. Practice Guideline Chair: Tateki Fujiwara. Practice Guideline has established eight guidelines on Epilepsy; each of them is on the JES Web site.

Summary of Activities in Relation to Global Campaign

Cooperation with Japan Epilepsy Association

Educational Activities

Activity promotion and education of young researchers, Chair: Yoko Ohtsuka. At the 41st Congress of the Japan Epilepsy Society in Fukuoka, we had the 2nd ceremony for the Best Poster Awards for the young researchers.

Activities in Conjunction with Local IBE Affiliate

JES Regional Groups were organized and they started operations in Tohoku, Kanto-Koshinetsu, Kinki, Chugoku Shikoku, Kyusyu and Hokkaido districts.

Future Plans

Cooperation with AOEO and ILAE

Officer Election Date

18 October 2008

Report By: Masako Watanabe Secretary-General Japan Epilepsy

SOCIETY OF EPILEPTOLOGISTS OF LITHUANIA

Meetings

Chapter meetings: "Generalized idiopathic epilepsies: rarity or commonness?" in Vilnius, Feb 2006; "Partial epilepsies – classical facts and controversies" in Kaunas, Nov 2007; "Neurophysiologic diagnosis of intractable epilepsy" in Kaunas, May 2007".

Summary of Activities

 Organization of annual conferences with participation of experts in the field from other countries. In 2006 President of ILAE Professor Peter Wolf was invited to visit a Chapter and to participate at the Annual Meeting. The Lithuanian Chapter was the host and co-organizer of the 1st Baltic Sea Summer School on Epilepsy (BSSSE, organized by ILAE Commission of European Affairs) on 19-23 August in Druskininkai with 33 participants from 12 countries.

- Chapter has initiated establishment of Lithuanian Society of Clinical Neurophysiology and Neurosonology in May 2007.
- Regular contacts with the health authorities regarding availability of antiepileptic drugs. New President and Chapter Board was elected in October 2006.

Summary of Activities in Relation to Global Campaign

Promotion of epilepsy-related problems by inviting mass media to the organized events and publishing in press.

Educational Activities

- Annual conferences with participation of experts from Europe.
- Practical course for EEG technicians with participation of colleagues from Finland.
- Participation at BSSSE.
- Regular postgraduate courses on epilepsy for neurologists and child neurologists at university hospitals.

Activities in Conjunction with Local IBE Affiliate

Conference "Challenging psychosocial rehabilitation for epilepsy patients" in Vilnius, November 2006, organized by Lithuanian Association for Integration of People with Epilepsy (LESIA) which is a new IBE associate member in collaboration with Epilepsie-Zentrum Bethel, Germany. Joint Conference organized by Lithuanian Chapter and IBE Chapter for patients and caregivers on different aspects of comprehensive management of epilepsy in Kaunas, May 2007.

Future Plans

Co-organization and hosting of 2nd Migrating Course in Epilepsy in June 2008. Annual conferences of the Chapter. Further development of epilepsy rehabilitation, EEG services, surgery and education.

Officer Election Date

October 2006

Report By: Nerija Vaiciene

MACEDONIAN LEAGUE AGAINST EPILEPSY

Publications

Epilepsy (journal of Macedonian League)

Meetings

Seminar on Diagnosis and Treatment of Epilepsies with Regional Participation, September 2007 in Ohrid

Summary of Activities

Educational courses on EEG, June 2006 in Dojran and October 2006 in Skopje

Seminar on Diagnosis and Treatment of Epilepsies with regional participation, September 2007 in Ohrid.

Summary of Activities in Relation to Global Campaign

Publishing informative brochures on different aspects of epilepsies

Future Plans

Congress of Macedonian Neurological Association with regional participations, one of major topics being epilepsy and EUREPA seminar, September 2008 in Ohrid

Officer Election Date 2008

Report By: Emilija Cvetkovska

MALAYSIAN SOCIETY OF NEUROSCIENCES (ECM)

Publications

Epilepsy Council of Malaysia

Meetings

May 2006, August 2006, November 2006, January 2007, March 2007, May 2007, July 2007

Summary of Activities

In line with ECM's objectives of 1) promoting education, training of health professionals in care of epilepsy patients, 2) promoting research in epilepsy and 3) continuing to improve care in epilepsy management, ECM conducted a series of educational lecture tours to health professionals all over Malaysia, embarked on two research studies. One study was entitled "Epilepsy Registry: An epidemiology, descriptive study of epilepsy in tertiary neurology clinics in Kuala Lumpur" and the other study was "Socioeconomic and psychological impact of quality of life in Malaysian patients with epilepsy". ECM is also in continuous discussion with the Ministry of Health on the need for HLA-B*1502 screening. ECM initiated a school epilepsy awareness program in conjunction with the Ministry of Education to educate the school counselors on epilepsy.

Summary of Activities in Relation to Global Campaign

- 1. School epilepsy awareness campaign initiated in mid 2007;
- 2. Educational lecture tours to health professionals throughout 2006 and 2007;
- 3. Epilepsy Awareness campaign via public forum, media campaign, epilepsy newsletter and Web site www.epilepsy.org.my.

Educational Activities

Year 2006 – a total of 13 lectures to health professionals were conducted.

Year 2007 – a total of 15 lectures delivered to health professionals. The topics of lecture are:

- 1. Current medical management of epilepsy
- 2. Management of epilepsy in pregnancy
- Seizure semiology
 Long-term treatment of epilepsy
 How to stop antiepileptic drugs
 Fits of faints?

- Differentiation of seizure types: have you made 7. the right diagnosis?
- 8.
- Epilepsy: pre-surgical evaluation Unusual and atypical features of epilepsy
- 10. Management of partial epilepsy
- 11. Management of status epilepticus
- 12. Optimizing the management of epilepsy
- 13. Management of idopathic generalized seizure
- 14. Managing epilepsy in children
- 15. Epilepsy in special populations

Activities in Conjunction with Local IBE Affiliate

- 1. School epilepsy awareness program
- 2. Epilepsy Awareness campaign

Future Plans

- 1. Continue the educational lecture tours to smaller district hospitals.
- 2. School epilepsy awareness program to follow through. The plan is to have the program throughout Malaysia.
- 3. Epilepsy Awareness campaign to reach wider public.
- 4. Setting up a Task Force to discuss the issue of HLA-B*1502 allele and recommendations.
- 5. To embark on a prevalence study of HLA-B* allele among Malaysians.

Officer Election Date

29 June 2006

Report By: Annie Tan ECM Secretariat

EPILEPSY SOCIETY OF MALTA

Summary of Activities

- Participation in seminars and awareness-raising activities on epilepsy.
- Lectures on epilepsy for various healthcare professional students and social workers.

Summary of Activities in Relation to Global Campaign

- Invited to speak on radio and TV media on reducing stigma associated with epilepsy.
- Printed new ID cards and diaries for persons with epilepsy.

Educational Activities

- Poster Presentation at Malta Medical School Conference, December 2007.
- Multi-Disciplinary Conference in Epilepsy for general practitioners February 2008 with over 200 participants.

Activities in conjunction with Local IBE Affiliate

- In-service training course for teachers in conjunction with Caritas Malta Epilepsy Association and Ministry for Education, July 2007.
- Epilepsy for Nurses in conjunction with Caritas Malta Epilepsy Association and Malta Union of Midwives and Nurses, November 2007.
- Participation in Grundtvig project Education in Epilepsy for PAMS – Malta concluding meeting, April 2007.

Future Plans

Promote better access for persons with epilepsy in primary healthcare. Promote better diagnostic facilities and therapy in tertiary health care.

Officer Election Date 2010

Report By: Janet Mifsud Secretary

MONGOLIAN EPILEPSY SOCIETY

Publications

"The current situation of the Epilepsy care in Mongolia" for the scientific meeting, held on the occasion of 60th Anniversary of Department of Neurology of Health Sciences, University of Mongolia, Ulaanbaatar, 2007. "The status of health education on epilepsy in some provinces of Mongolia" 27th International Epilepsy Congress, *Epilepsia*. "The Mongolian plan to overcome epilepsy treatment gap and improve epilepsy care" *Neurology* Asia 2007;12 (Supplement 1): 48-50. "Mongolian experience and contribution" Workshop in Psychosocial Issues of Epilepsy, Shanghai, 2007.

Meetings

In March 2008, Mongolian Epilepsy Society and National Epilepsy Center of Japan (with participation of Dr Yushi Inoue) organized a workshop on "Epilepsy in Children – clinical and therapeutic approach" in Ulaanbaatar for neurologists, psychiatrists and child neurologists of rural and urban area of Mongolia.

Summary of Activities

In 2006, the Mongolian Epilepsy Association, with the Epilepsy Center and Mongolian Epilepsy Society started an enhanced health education workshop on epilepsy among the general public and the professionals who looked after epilepsy in the district levels ("Quality of Life"). In March 2007, Mongolian Epilepsy Society and National Epilepsy Center of Japan (with participation of Dr Yushi Inoue) organized workshop on "Diagnosis and treatment of Epilepsy" in Ulaanbaatar for neurologists, psychiatrists and child neurologists of rural and urban area of Mongolia.

Summary of Activities in Relation to Global Campaign

As a follow-up of the recommendations, made from the study conducted by MES and MEA with the support of WHO in 2004 on "Present situation health care for people with epilepsy in Ulaanbaatar," Mongolian Ministry of Health included epilepsy in the list of diseases that is treated free-of-charge in 2006. Whereas previous to the study, the AEDs were given free only to patients under the care of psychiatric hospitals, the neurologists in provincial and district hospitals are now also allowed to prescribe the free AEDs to patients with seizures. The issue of free treatment was ratified by the Parliament of Mongolia in 2006 and was included in the Renewed Health and Insurance Law of Mongolia. The renewed law provided new opportunity and assistance in improving quality of life and better epilepsy care for people with epilepsy.

Educational Activities

Dr B Munkh-Och (young doctor) from MES and MEA trained in the Department of Neurology, Kaohsiung Chang-Gung Medical Center, College of Medicine, Chang-Gung University of Taiwan with the support and supervision of Dr Shung-Lon Lai (2007-2008). MES and MEA are implementing "Quality of Life" program and have organized training in three provinces of Mongolia and provided the assistance to the people with epilepsy and their family members and doctors and nurses on the aspect of health education and training. The Quality of Life program involved eight lectures with drama and video presentations and consulting to the patients.

Activities in Conjunction with Local IBE Affiliate

In 2007, the Mongolian Epilepsy Association started the Promising Strategies Program of the IBE. The aim was to improve public health education on epilepsy among the population.

Future Plans

Expansion and development of Epilepsy Care; continuation of "Quality of Life" Charity action for all provinces and major settlements; elaboration of the epilepsy clinical guidelines; develop epilepsy surgery in Mongolia.

Officer Election Date

June 2006

Report By: A Tovuudorj MD

NEPAL EPILEPSY SOCIETY

Meetings

- Executive Board meeting every month
- CME on various aspects of epilepsy every three months

Summary of Activities

- Regular CME every three months
- Executive Board meeting every month
- Pediatric Epilepsy workshop sponsored by ASEPA in 2007
- Many members of Society attended AOEC in Kuala Lumpur in 2006 and recently in Xiamen, China

Educational Activities

- Awareness program in the form of FM radio talk program
- TV talk program
- Regular CME for the update of the members and others on epilepsy related matters

Activities in Conjunction with Local IBE Affiliate

Work in harmony with Nepal Epilepsy Association (IBE affiliate) regarding awareness programs and management of epilepsy patients.

Future Plans

- To develop a national protocol for management of epilepsy
- To conduct EEG workshop in early 2009
- To develop a chapter Web site with full information

Officer Election Date

January 2009

Report By: Dr J P Agrawal President

NEW ZEALAND LEAGUE AGAINST EPILEPSY (NZLAE)

Meetings

November 2007

Summary of Activities

Officially recognized as national Chapter at the 27th International Epilepsy Congress in Singapore, July 2007. Article promoting NZLAE in the NZ Medical Journal.

Summary of Activities in Relation to Global Campaign

Successfully obtained funding for vitamin supplements for children on the ketogenic diet. New Zealand (NZ) does not have access at present to Levetiracetam. We have been working with the funding arm of the NZ Ministry of Health and UCB Pharma to get the drug made available.

Educational Activities

Promotion of buccal midazolam as a treatment option for out of hospital seizures. Teaching session held at the NZ annual pediatric meeting November 2007. Further teaching activities planned for 2008.

Activities in Conjunction with Local IBE Affiliate

Collaboration with the lay organization "Epilepsy New Zealand" to raise the profile of epilepsy in NZ. We have met with the National Executive and agreed to check information booklets and provide a medical opinion on epilepsy whenever it is requested. Joint promotion of buccal midazolam with production of a DVD promoting its use.

Future Plans

Promotion of research into the management of epilepsy; in particular, the use of the Internet to enroll patients for trials comparing antiepileptic drugs in specific syndromes. Further collaboration with the lay organization "Epilepsy New Zealand" to raise the profile of epilepsy in NZ. Further efforts to obtain access to Levetiracetam for NZ patients.

Officer Election Date

November 2009

Report By: Peter Bergin President

NICARAGUAN LEAGUE AGAINST EPILEPSY

Meetings Annual symposia with doctors

Summary of Activities

Every year an Epilepsy Symposia took place in Managua, Nicaragua. Participation in the 4th Latin American Congress of Epilepsy in Guatemala, 2006

Summary of Activities in Relation to Global Campaign

One member of the Chapter is involved in the Health Department Commission with the choice of antiepileptic drugs. Epilepsy is officially recognized as a chronic condition allowing patients to get antiepileptic drugs by health national services and social security services.

Educational Activities

The organization of periodic symposia on epilepsy diagnostic and treatment with participation of pediatric, internist and general doctors. Regular participation in national and international Congresses. Conferences and meetings for medical students.

Future Plans

To continue educational activities with general doctors and specialists focusing in primary medical attention. To promote epilepsy surgery in Nicaragua.

Officer Election Date

Every four years in February

Report By: Jorge Martinez Cerrato

NORWEGIAN LEAGUE AGAINST EPILEPSY

Summary of Activities

The Norwegian Chapter of ILAE has about 200 members – mainly neurologists, pediatricians, neurophysiologists, nurses and neuropsychologists.

The Board has 11 members and the Executive Committee consists of the President, Vice President, Secretary and Treasurer. The Board has three meetings each year.

The Annual Meeting took place at Lillestrøm (near Oslo) in September with about 130 active participants.

Prior to the meeting the satellite symposium "Gender Issues in Epilepsy" was arranged with outstanding international speakers. The symposium collected about 160 participants and resulted in a theme number in *Seizure* in March 2008.

The symposium "Cognitive Function in Refractory and Easy-to-Treat Epilepsy" took place during the Annual Meeting of the Norwegian Neurological Association in November.

Report By: Dag Aurlien Secretary

EPILEPSY ASSOCIATION OF PAKISTAN

Summary of Activities

The Epilepsy Association of Pakistan, through the auspices of the Comprehensive Epilepsy Control Program of Pakistan (CECP) focuses on provision for quality 'holistic' treatment to patients with epilepsy and creating epilepsy awareness among the masses. This was achieved through the various indigenously devised CECP projects.

National Epilepsy Center (NEC):

The National Epilepsy Center is the landmark project of CECP which started functioning in April 2007. This epilepsy care center, built through the gracious donation of a philanthropist family, is providing quality 'holistic' services at a token cost to patients with epilepsy in Pakistan. This center is expected to become a center of excellence in epilepsy management, research and public health education in the country.

- The outpatient clinics were started in April 2007. New patients registered: 580 Follow-up patients: 677
- Consultation Charges
 April November 2007: Free
 December 2007 to date: Registration =
 Rs 20/-(USD 0.28)
 Consultation = Rs 30/-(USD 0.43)
 All consulting doctors provided free services.
- Drug bank established in October 2007 through donations. Fifteen days of medicines for a token cost of Rs. 30/-(USD 0.43). This is only 8% of the actual cost. Remaining is paid through donations received. A total of 766 patients were given medication.
- Two EEG laboratories set-up through gracious donation of a philanthropist family started functioning in November 2007. EEGs done on 132 patients.

Charges: NEC registered patients Rs 300/-(USD 4.28) Outside referal: Rs 1000/-(USD 14.28)

Summary of Activities in Relation to Global Campaign Satellite Epilepsy Centers

These centers provide near-home epilepsy care and facilitate epilepsy awareness in the neighborhood. In 2007, eight new health care facilities were given the status of a Satellite Epilepsy Center bringing the total to 63 in Pakistan.

Free Epilepsy Camps:

In 2007, Free Epilepsy Camps (FEC) were held in eight cities and towns. Free consultation and counseling by the volunteer doctors was provided to 1,230 patients with epilepsy. This field event is also an important epilepsy awareness activity. One week prior to a FEC an intensive awareness campaign is launched via banners, handbills, print media, cable TV and a loudspeaker-mounted vehicle in the area of the camp.

School Awareness Posters:

These posters have been specially designed to spread awareness about epilepsy among school children. A total of 1,659 school awareness posters were placed in schools in various cities/towns of all four provinces of Pakistan. This task was undertaken by a courier company.

Epilepsy Awareness through graffiti:

A pedestrian bridge in the main market area of Karachi was painted with the slogan 'Epilepsy is a treatable disorder' in Urdu with the kind support of the Town Counselor. Many previously untreated epilepsy patients and family members were motivated to come and seek advice at the NEC after reading this message.

Educational Activities

Epilepsy CME Workshops:

In 2007, two-day intensive epilepsy management workshops were held in Rawalpindi and Lahore in which leading primary care physicians participated. Workshops were also held in four more cities/towns of Punjab, training local GPs of the region in diagnosis and management of epilepsy.

Future Plans

In a developing country like Pakistan lack of awareness is the major reason for a significant treatment gap. As in the past, we will continue to focus on activities to reduce the existing treatment gap through public health education. We have through our various indigenously designed health education projects addressed this issue very successfully but have yet a long way to go.

Officer Election Date:

November 2008

Report By: Prof Hasan Aziz President

PANAMANIAN LEAGUE AGAINST EPILEPSY

Summary of Activities

The activities of the Panamanian League Against Epilepsy are confined to the aspects of physician practice, education for patients and their families and to their doctors, and activities of operation for the center of surgery of epilepsy in Colombia.

Summary of Activities in Relation to Global Campaign

The League Against Epilepsy was reorganized in Panama, with two new members: Dr David Dondis and Dr Nelson Novarro. Multiple activities related to the education of patients and relatives throughout the country and education participation in radial mass media have been realized. In some regions welfare donations of antiepileptic medicine have been received for needy patients. Educational activities directed to the doctors focusing in diagnosis and treatment have been programmed. Also the qualification-training of a neurosurgeon in functional neurological surgery was coordinated in Argentina. The cases of symptomatic epilepsy that deserve surgery are sent to the group of epilepsy surgeons in Bogota, Colombia, with good results.

Educational Activities

The educational activities were oriented toward three areas: patients and relatives, doctors of primary and secondary attention, and Congresses with national and international guests. A hospitable educational activity was held to commemorate the Latin American Day of Epilepsy with conferences for patients and relatives. The exhibitors were the neurologists who work in our institutions of the Box of Social Insurance. The participation of the patients and their relatives was very active. In the city of Panama, a Latin American Congress of Neuropediatrics was held 25-27 April 2007. Dr Brown Noris of Flagge had active participation. In this event, local physicians and non-physicians participated as much as international physicians. International participants included representatives from the United States, Chile, Spain and Central American countries. The event agenda varied in medical and surgical aspects, and included much discussion and interaction among participants. In the Hospital Santo Tomás/Ministry of Health, administrative and educational activities have been held with clinical application. The educational activities were mainly focused on patients and their families. From January to December 2007, eleven weekly programs were held with approximately 480 people attending. These were held in waiting rooms of the neurology offices and educational information was distributed to the public. As far as the education for the doctors, this was emphasized in the clinical direction – welfare. The Panamanian participation in the celebrated days of epilepsy in Guatemala was accomplished in 2007.

Future Plans

Our emphasis has been organizing an educational agenda for patients and their families and local conferences for the doctors. These activities will be accomplished in the month of September 2008, in the capital city and the more important rural areas. We also plan to participate in Congresses related to epilepsy to continue to promote the medical welfare activities in our clinics of epilepsy of our hospitals. Also we wish to create a center of epilepsy of reference, where a specialized medical evaluation can be accomplished in the standard more recent diagnoses and to be able to offer a surgical alternative.

Officer Election Date

May 2008

Report By: Dr David Román Dondis Camaño Neurologist

PERUVIAN LEAGUE AGAINST EPILEPSY

Meetings

National Congress 1-4 November 2007 Cuzco

Summary of Activities

- Epilepsy Course for residents with Cayetano Heredia University, four credits from April to September 2007
- Epilepsy Course for patients Ins. Neurological Sciences December 2007

Summary of Activities in Relation to Global Campaign

It will be scheduled in September 2008

Educational Activities

For residents and patients

Future Plans

Reorganized the IBE-Perú; we just elected a new Delegate Dr Luis Deza.

Officer Election Date

18 December 2008

Report By: Patricia Campos General Secretary

PHILIPPINE LEAGUE AGAINST EPILEPSY (PLAE)

Main Goals of the Year

- Update membership and encourage active participation of all members in all PLAE activities.
- To strengthen the National Support Group, the EAAI.
- III. To appoint the following chairpersons to the following committees:

Regular Committees

- Ways and Means Dr Josephine Gutierrez
- II. Membership Dr Herminigildo Gan III. Research and Epilepsy Registry
- Dr Leonor Cabral-Lim
- IV. Continuing Medical Education Dr Anna Berroya
- Lay Education Dr Glicerio Alincastre
- VI. Advocacy and Support Group Dr Ana Javelosa and Dr Lourdes Ledesma

Activities

- I. National Epilepsy Awareness Week 2006
 - Chair, Dr Marlyn Ortiz A. "Pinoy Olympics" -
 - Dr Godfrey Robeniol, Chair
 - B. Epilepsy Poster Making Contest -Dr Martha Lu-Bolaños, Chair
 - C. 2nd Epilepsy Exemplar Awards Dr Hazel Paragua, Chair D. Health Forum – PLAE members

 - 1st National Epilepsy Camp in Iloilo City -Ε. Dr Cynthia Demaisip, Chair
- II. National Epilepsy Awareness Week 2007
 - "Epilepsy Ko, Sagot Ko To"
 - 1 September Evaluation of Epilepsy i.
 - Manager Program 2 September First Search for the "National Epilepsy Idol" ii.
 - 4 September Health Forum Conference iii. with Trimedia
 - 7 September "MD's Chefs on Display" iv.
 - Lay Fora in the following institution V.
 - 1. Philippine General Hospital
 - 2. University of the East Ramon
 - Magsaysay Memorial Medical Center
 - 3. Jose R. Reyes Memorial Medical Center
 - 4. Philippine Children's Medical Center

Special Projects

- A. Epilepsy Manager Program (EPM)
- 1. EMP Pilot: Pampanga
- 2. EMP Iloilo 200 Done in four towns, Graduated four Epilepsy Managers
- 3. EMP Negros Occidental 2007 Done in four towns, Graduated three Epilepsy Managers
- B. Epilepsy Exemplar Awards
- 1st Epilepsy Exemplar Awards given to six Awardees
- 2nd Epilepsy Exemplar Awards given to six Awardees
- C. Epilepsy Partners: Chairs, Drs Ana Javelosa and Hazel Paragua Launched during the Epilepsy Awareness Week 2007 with benefit dinner (1,000 per Plate) "MD's Chefs on Display": This aims to raise funds for buying antiepileptic drugs for deserving indigent patients.

Epilepsy Friendly Institution

• A merger between PLAE, EAAI and Pharmaceutical Companies initially done in Iloilo City. This is the brainchild of Dr Cynthia Demaisip

Ongoing projects

- BRIDGES (PAVES)
- Lay Education (PAVES)
- PLAE Epilepsy Registry and Research
- Biennial Epilepsy Congress
- PLAE Webpage Updates

Prepared by: Herminigildo H. Gan, MD Secretary 2006-2007

POLISH SOCIETY OF EPILEPTOLOGY

Publications

Our members published their studies mostly in the official journal of the Polish Society of Epileptology (PSE), edited quarterly with an English summary. Each issue includes two to three original studies of Polish or foreign authors, case reports, review papers, and a chronicle about PSE activities and pieces of information. Studies on epilepsy were also published in neurological and pediatric journals edited in 2006 and 2007 in Poland: Polish Journal of Neurology and Neurosurgery, Child Neurology, Pediatrics, Neurological Current, Practical Neurology, Neurology (Polish edition), Pol. J. Environ. Stud. and European Journal of Neurology, Epilepsy and Behavior, Brain.

Meetings

The V Congress of the Polish Society of Epileptology Warsaw 21-23 September 2006. The XXth Conference on Epilepsy of the Polish Epilepsy Society 24 -26 May 2007 Warsaw

Summary of Activities

In 2006 and 2007, the Polish Chapter of ILAE (Polish Society of Epileptology) continued its activities in four directions: scientific, educational, organization and supporting patients and their organizations in Poland. The Polish Chapter has been mainly involved in organizing activities devoted to the improvement of knowledge and specialist training in the field of epileptology. These activities have been pursued by the working groups of the Polish Society of Epileptology, as detailed below:

- Working group on epilepsy and pregnancy, supporting the prospective European study on pregnancies in epileptic women (EURAP study).
- Working group on quality of life, with the elaboration and validation of an original questionnaire for patients and caregivers.
- Working group on videos, with the collection of informative videos on different seizure types and elaboration of appropriate tools for the didactic presentation of the material.

The V Congress of the Polish Society of Epileptology – Warsaw 21-23 September 2006. This meeting, in which outstanding Polish epileptologists and invited guests from abroad gave lectures on leading topics, presented the current state of the art and highlighted the perspectives and hopes for the near future. During this Congress the new Board of PSE was elected.

The XXth Conference on Epilepsy of the Polish Epilepsy Society. This was held in Warsaw between 24 and 26 May 2007 with international contributions. The national experts on various fields of epilepsy were invited to give lectures. The topics covered were: "Epilepsy and pregnancy," "Video-EEG diagnostic values in different types of epileptic syndromes" and "Non-epileptic events". A very important session was devoted to quality of life problems especially the impact of communication between the medical doctor and patient. Other topics were: "Are the benign epileptic syndromes really benign, optimalization of AED treatment" and "New radiological techniques and their use in patients with epilepsy". The Conference was quite a success – over 400 participants, very interesting lectures and platform presentations, livable and substantial discussion.

Summary of Activities in Relation to Global Campaign

An important part of our activities in 2006 and 2007 were contacts with the Ministry of Health and National Health Fund. The main problem was the reimbursement for patients of new AEDs in refractory epilepsy. Finally in November 2007 Levetiracetam is free for patients with epilepsy.

Educational activities

The Polish Chapter created the program of Polish Epileptology School which held its first session at the beginning of 2008. Its aim is to provide young trainees in epileptology with principles of basic and clinical epileptology. Polish members of ILAE were involved in collaborative research enterprises including EURAP on pregnancy registries and surveys on mortality.

Activities in Conjunction with Local IBE Affiliate

The cooperation with patients' organizations, e.g., the organization of Polish People Suffering from Epilepsy was intensified in 2006 and 2007. At the moment in Poland, there exist 14 organizations of patients (nine of them are district Chapters of Polish People Suffering from Epilepsy established in 1985).

Future Plans

- Future plans of the Polish Chapter include:
- Organization of the National Congress.
- Organization of courses, meetings and conferences on epilepsy. The extensive preparations for the XXIst Conference in Warsaw in 2008 are now in progress.
- Further support for young doctors and specialists interested in improving their knowledge of epilepsy.
- Promotion and support of legislation and regulations in favor of people with epilepsy.
- Collaboration with the health authorities to develop high standards for epilepsy care throughout the country.

Officer Election Date

September 2006

Report By: Joanna Jędrzejczak

PORTUGUESE LEAGUE AGAINST EPILEPSY (LPCE)

"Liga Portuguesa contra a Epilepsia"

Summary of Activities

- 1. 2007 was the first year of independence between the LPCE and the EPI – Associação Portuguesa de Familiares, Amigos e de Pessoas com Epilepsia (EPI), the Portuguese patient association, which took its place as the Portuguese Chapter in the IBE, in Singapore. The LPCE kept its financial and technical support to the EPI contributing to its work. The LPCE did participate in the first "Jornadas de Epilepsia" of the EPI and in several other initiatives of the EPI.
- 2. The newsletter Notícias da Epilepsia is now a joint adventure between both organizations and has increased its publication from two to three times a year.
- 3. The Livro Básico de Epilepsia, a reference comprehensive book made exclusively by Portuguese authors, was presented in our meeting in March and it's an instrument to disseminate the knowledge on epileptology to all general practitioners and all other technicians with interest in improving their expertise in this area.
- 4. A second workshop on epilepsy surgery was organized in September, with all the five groups interested in developing epilepsy surgery, with the publication of two documents: one concerning the financial aspects of the future activity in this area and the other with the minimum conditions determined to implement a center for this activity. The LPCE also tried to influence the development of a National Program for Epilepsy Surgery, contacting the different involved authorities at a regional and national level, including contacts with the Portuguese Ministry of Health.
- 5. The process of certification of the Portuguese Centers and Professionals was developed with the inclusion of the Serviço de Neurologia of the Hospital de Santa Maria in Lisbon, in the support network of EUREPA and the application of the Consulta Multidisciplinar de Epilepsia do Centro Hospitalar do Porto – Hospital de Santo António, Porto.

- 6. The second part of the "Training the Trainers" course and the Basic Epilepsy Course on Epilepsy, supposed to be held in Maputo, Mozambique, integrated with the activity of the Lusophone Section of EUREPA, was postponed to 2008, due to local difficulties.
- 7. The site of the LPCE is being reorganised with the support of Pfizer and we hope to have it in full activity during 2008.

Educational Activities

- 1. Active support to all the education initiatives of the EPI
- 2. 19th National Meeting of the LPCE in Vale de Lobo, Algarve, in March, with the participation of more than 250 technicians in this area and together with the 2nd Meeting of the Portuguese and the Brazilian Leagues.
- 3. Participation in an educational activity in the National Congress of Primary Care Medicine, in Vilamoura, Algarve, in March.
- 4. Several Regional Meetings took place during the year as the "Epilepsia na Ordem", organized by Epicentro of Porto or the "Epilepsia ao Café" and the 2007 edition of the "Curso de Epilepsia da Unidade de Monitorização de Epilepsia e de Sono dos HUC", organized by the Epicentro of Coimbra.
- 5. In October we had the 3rd Hispano Luso Meeting of Epilepsy, in Sevilhe.

Report By: Prof José Manuel Lopes Lima President

SLOVAK LEAGUE AGAINST EPILEPSY (SLAE)

Publications

Five articles in Slovak/Czech language

Meetings

Two meetings

Summary of Activities

- Annual Congresses on epileptology in cooperation with Czech League against Epilepsy.
- Postgraduate courses on epilepsy.
- Postgraduate courses on child neurology epilepsy.

Summary of Activities in Relation to Global Campaign

- Appearances on TV.
- Articles on epilepsy.
- Press conference on epilepsy.
- Direct input into newly prepared legal regulation on the driving license for epilepsy patients.

Educational Activities

- Postgraduate courses on EEG under Slovak Medical University.
- Weekend courses on epileptology.

Activities in Conjunction with Local IBE Affiliate

Name of local IBE branches is AURA. SLAE is cooperating with their educational activities – questions and answers.

Future Plans

Cooperation with health and medical board of the Parliament

Officer Election Date May 2005

Report By: Vladimir Donath

SLOVENIAN LEAGUE AGAINST EPILEPSY

Summary of Activities

The League's activity in 2007 has been rich and in a certain way different compared to previous routine: lowered level of comprehensive care in the country related to the untoward blend of longlasting poor staffing of doctors and new political moves in the organization of medical care reached a point where the League's EC and patients' representatives felt responsible to raise alarm in the media and to contact and pressure politicians in order to stop further deterioration. This activity represents an additional burden on the Chapter's members.

- a) Comprehensive Care deteriorating situation in Slovenia: several meetings with Ministry of Health, followed by a professional/organizational focal group meeting: On Comprehensive Care in Slovenia (one-day workshop for ten professionals, ten service users writing their basic views to approach the media and politics on the issue), open public meeting stressing alarming and unacceptable deterioration of epilepsy care in the state tertiary hospitals (worsened access to care, waiting lists, fragmentation of professional services, absence of tertiary adult epilepsy program). In addition: delays in accepting legislation on epilepsy and driving, needed coordinated project on employment by Ministry of Labor and Ministry of Health, needed coordinated project with Ministry of Education (teaching teachers about epilepsy, administering AEDs to stop seizures at schools with no nursing staff). Result: A Task Force nominated by the Ministry of Health, mainly comprising members of the League's Executive Committee, National Board of Neurology and Institute of Occupational Medicine to produce proposals on further development of epileptology in the country
- b) Teaching seminars, workshops, postgraduate courses under the auspices of EUREPA and Slovenian Medical Chamber (30 participants from Slovenia, Croatia, Macedonia, France, Germany, Czech Republic)
 - Pharmacoresistant temporal epilepsy, VNS, epilepsy and migraine (international), two days (guest: D Parain)
 - Seizure semiology workshop (international), two days (guest: C Elger)
 - 2nd Practical Epilepsy Summer School (international), thee days (guests: P Chauvel, JP Vignal, P Marusič)
- c) Planning European accreditation of the tertiary Center for Epilepsy (two closely linked units for pediatric/adolescent and adult age), including invitation to the League's President to participate in the Task

Force at the Department of Neurology nominated to prepare proposals to stop further deterioration of services for PwE at the tertiary facility

d) Promoting epilepsy research: visits to research units, clinical and basic neuroscience, discussion of possible common projects, preparing future common research

Other Ongoing Projects of the League

- a) Education about epilepsy: for schools, chronic institutions (for the severely handicapped, for the elderly), for patients, parents (newly diagnosed, children with special needs, legal aspects)
- b) Tutoring and mentorships to undergraduate students on topics about epilepsy
- c) Psychosocial counselling work (weekly telephone hotline)
- d) Publishing: flyers (about the League, on First Aid), Epilepsy Identity Card, The Focus (Žarišče) Bulletin Quarterly, e-Forum
- e) Self-help groups, coordination and logistics/financial support to local programs
- f) Volunteer project: student/lay accompanying for patients with epilepsy travelling for health abroad, well supported by professionals often acting on volunteer basis themselves
- g) "Counselling Unit of the League" in development: individual personal and anonymous e-mail counselling (medical, psychological, legal, social issues); needs not covered in psychosocial issues and cognitive rehabilitation
- h) Epilepsy and driving, epilepsy and public transportation: Task Force active on the League's initiative and participation (lay and professionals)
- Working with media, and with public (The Brain Awareness Week), presenting the League with other non-governmental humanitarian and professional associations
- International activity (Report on Epilepsy and Social Isssues in Eastern Europe, sending juniors to international epilepsy schools, proposing a new candidate for a certified EUREPA trainer from Slovenia, EU research proposals)
- k) Cooperation with and support for the IBE activities and common projects
- Miscellaneous: reacting to actual events in public sphere, in the media, on the market (AED availability), claiming and supporting new drug registrations

During 2007, new statutory connections have been created with the Associations of Chronic Patients, with the Slovenian Brain Council (observer status). The League was approached by other associations of neurological patients (MS, Parkinson's) claiming better care in a common endeavor before the Department of Health. Creation of a more formal link was discussed with the Slovenian Medical Society (in order to represent more widely the League's activity among doctors).

Report by: Igor M Ravnik President

SPANISH LEAGUE AGAINST EPILEPSY

The meetings provided by Liga Española Contra la Epilepsia in 2007:

- Annual Meeting LECE, Madrid
- Epilepsy Conference by ALAMCE Foundation
- Epilepsy Course, Madrid 2007
- Epilepsy Conference by AELCE Foundation

SWEDISH EPILEPSY SOCIETY

Educational Activities

- Annual Course: Status Epilepticus, Lund 9-10 November 2006
- Seminar: Cognitive Behavioral Therapy and Epilepsy, Uppsala 16 April 2007
- Workshop on Cardiac Symptoms and Epilepsy, Linköping 18 October 2007
- Workshop on Pre-surgical work up, in collaboration with Lund and the Cleveland Clinics, 10 October 2007
- Annual Course: Pharmacotherapy of Epilepsy: From Present Practice to Future Prospects, Stockholm 8-9 November 2007
- Symposium: Epilepsy and Children: School and Learning, Göteborg, 23 November 2007
 Activities in conjunction with other ILAE Chapters
- Meetings with Board members from Finnish, Danish and Norwegian Chapters
- Participating with tutors and students in the Baltic Sea Summer School, Lithuania 2007

Activities in Conjunction with Local IBE Affiliate

Members of the Society have participated as speakers in the local IBE campaign "Epilepsy Train".

Future Plans

- Workshop "Infantile Spasm State of the Art" 17 October 2008.
- The Annual Course 2008 will be held in Gothenburg 13-14 November with the purpose of making an inventory of ongoing scientific projects in Sweden and to promote translational research. There will also be a one-day course with the theme "Who benefits from epilepsy surgery?"

Officer Election Date

14 November 2008

Report By: Eva Kumlien

SWISS LEAGUE AGAINST EPILEPSY (SLGE)

Publications

- Journal "Epileptologie" (Epileptology), publication four times a year, 52 pages each, with information about new developments in epilepsy research and treatment (for professionals, 2,000 copies).
- Newsletter "Epilepsie News", publication four times a year, six pages each, with information about the activities of the League and about epilepsy (for laymen, 32,000 copies in German, 7,000 copies in French and 4,000 copies in Italian).
- Brochure on "Epilepsy and Insurance" in German (9,000 copies), French (3,000) and Italian (2,000).

One new information leaflet on "Epilepsy and Driving Fitness" in German (7,500), French (2,000) and Italian (1,000 copies).

- Annual report in German and French (1,000 copies) in 2006, 1,300 copies in 2007).
- Brochure on events of the Swiss League Against Epilepsy in German and French (7,000 copies). Joint Annual Meeting of the Swiss League against Epilepsy and the Swiss Society for Sleep Research, Sleep Medicine and Chronobiology in Tschugg, 10-11 May 2006.
- Ten new information leaflets about epilepsy in German (8,000 copies each), French (2,000 each) and Italian (1,000 copies each).
- One new information leaflet on "Epilepsy in the Elderly" in German and French.
- Brochure on events of the Swiss League against Epilepsy in German and French (4,000 copies).

Meetings

- Joint Annual Meeting of the Swiss League Against Epilepsy and the Swiss Society for Sleep Research, Sleep Medicine and Chronobiology in Tschugg, 10-11 May 2006.
- 5th Joint Meeting of the German, Austrian and Swiss Chapters of the International League Against Epilepsy (ILAE) in Basel, 16-19 May 2007, organized by the Swiss Chapter. With 1,100 participants a very successful event.

Summary of Activities

- Three annual events in different cities, for laymen, with several lectures by epilepsy experts. Main Topic: "Life with Epilepsy"
- Special day for patients and their relatives. Topic: 'Epilepsy and Complementary Therapies".
- TV-Spot "Mitenand" for the German part of Swiss TV
- Giving away of the award for the best dissertation of the year in the field of epilepsy research. • Giving away of the grant for the most promising
- study in Switzerland in the field of epileptology. • Awarding Professor Kazimierz Karbowski with the first
- Tissot medal, offered by the Swiss League against Epilepsy.
- Special day for patients and their relatives. Topic: "Epilepsy and Relationships".
- TV-Spot "Ensemble" for the French part of Swiss TV

Summary of Activities in Relation to Global Campaign

2006

Main event on the "Day of Epilepsy", 5 October, in Zurich. Topic: "Epilepsy and Art". Open to laymen and professionals, accompanied by a campaign in the media.

2007

Main event on the "Day of Epilepsy", 5 October, in Berne. Topic: "Epilepsy and the Elderly". Open to laymen and professionals, accompanied by a campaign in the media.

Educational Activities

2006

Three annual events in different cities for professionals, with several lectures by epilepsy experts. Lectures for the staff of the pharmaceutical industry.

2007

Three annual events in different cities, open to professionals, with several lectures by epilepsy experts. Lectures for the staff of the pharmaceutical industry.

Activities in Conjunction with Local IBE Affiliate

2006

Main event on the "Day of Epilepsy", October 5, in Zurich. Topic: "Epilepsy and Art". Open to laymen and professionals, accompanied by a campaign in the media.

- Special day for patients and their relatives.
- Topic: "Epilepsy and Complementary Therapies". 2007

Main event on the "Day of Epilepsy", October 5, in Berne. Topic: "Epilepsy and the Elderly". Open to laymen and professionals, accompanied by a campaign in the media.

• Special day for patients and their relatives. Topic: "Epilepsy and Relationships".

Future Plans

Publication of a series of DVDs for professionals and laymen.

Officer Election Date

Spring 2010

Report By: Daniela Erb

TAIWAN EPILEPSY SOCIETY

Meetings

Annual meeting of Taiwan Epilepsy Society (TES)

Summary of Activities

- Annual meeting of Taiwan Epilepsy Society. The 3rd & 4th annual "Care about patients with epilepsy" essay contest awards ceremony.
- Joint annual meeting of Taiwan Neurology Society and TES on antiepileptic drugs.
- Symposium of optimizing treatment for patients with epilepsy (Northern, Middle, Southern Taiwan).
- Summer camp for children with epilepsy and their families
- The 11th & 12th annual drawing contest of patients with epilepsy and going for an outing.

Summary of Activities in Relation to Global Campaign

- Participation of the 6th Annual Meeting of AOEC-2006.
- Participation of the 7th Annual Meeting of ILAE-2007
- Participation of AES-2006 & 2007.

Educational Activities

- Epilepsy training course for young neurologists (adult and child).
- Epilepsy education for school teachers and administrator (Northern, Middle, Southern Taiwan).

- EEG teaching workshop (Northern, Middle, Southern Taiwan). Epilepsy education for nurses (Northern, Middle, Southern Taiwan).
- Educational program of common neurological problems focusing on epilepsy for general physicians.

Activities in conjunction with Local IBE Affiliate

The 11th & 12th annual drawing contest of patients with epilepsy and going for an outing. Summer camp for children with epilepsy and their families.

Future Plans

Active participation of promoting education program including EEG training and epilepsy surgery in Asian area. Promote "Epilepsy Ambassador" participation in local educational program for patients and public to remove stigma of the disease.

Officer Election Date

24 March 2007

Report By: Ching Shiang Chi

EPILEPSY SOCIETY OF THAILAND

Publications

Epilepsy Digest

Meetings

24-25 July 2008

Summary of Activities

During the past two years, The Epilepsy Society of Thailand had various activities involving physicians and patients with epilepsy. These activities were

- 1. Annual Scientific Meeting 2006 and 2007
- 2. A two-day EEG Workshop in July 2006
- 3. One-day epilepsy conference for general practitioners in provincial hospitals, four times in 2006 and five times in 2007
- 4. Consolidation of the third version of Epilepsy Guideline in 2006
- 5. EEG Textbook in Thai language 1st edition, 2006
- 6. Epilepsy Day for parents and patient in January of each year
- 7. School visit and teacher education program

Summary of Activities in Relation to Global Campaign

Epilepsy Association of Thailand, which is the main organization in association with The Epilepsy Society of Thailand, set up an education program and school visits in 2006 and 2007. In addition, Annual Meeting with the patients and parents with the main objective in improving knowledge to the patients and parents was organized in January of each year. Epilepsy Day for parents and patients in January of each year. School visit and teacher education program.

Educational Activities

Annual Scientific Meeting in 2008 and 2009 EEG Workshop in 2008. Epilepsy Lecture trip to provincial hospitals.

Activities in Conjunction with Local IBE Affiliate

Parents and Patient Education Conference annually in January

Future Plans

- 1. Annual Scientific Meeting in July 2008
- 2. A two-day EEG Workshop in July 2008
- 3. Epilepsy Day in five provincial hospitals
- Reorganization of the Editorial Board of the Epilepsy Digest (Official bulletin of the Epilepsy Society of Thailand)
- 5. Newsletters and Advice for self care to the parents and patients.
- 6. Research in Epilepsy Care in Thailand by questionnaire survey by July 2008

Officer Election Date

15 June 2009

Report By: Anannit Visudtibhan, MD

TURKISH EPILEPSY SOCIETY

Publications

Epilepsi, quarterly journal

Meetings

6th National Congress on Epilepsy, 4-7 June 2008 (www.epilepsi2008.org)

Summary of Activities

- "Epilepsy Days" organized every two years by the Society was held on 4 May 2007, in Istanbul. The topic of this year was "Epilepsy and the Legal Issues". Legal issues, the laws, social issues and the rights of patients with epilepsy were discussed by physicians and legal practitioners.
- 2. Monthly scientific "Armada" meetings of the Society have continued during 2006-2007 and 2007-2008 academic year periods. We celebrated the 10th year of these meetings in 2007. Speakers from abroad or from various Turkish universities have given talks on clinical and basic science topics related to epilepsy.
- 3. The official scientific journal of our chapter, *Epilepsi*, continued to be published as it has been since 1995.
- 4. The 6th National Congress on Epilepsy is organized to be held in Izmir-Çesme, 4-7 June 2008, with international contributions. The scientific program of this Congress is available on our Web site (www.epilepsi2008.org). Awards will be given to the best poster and oral presentations to support young scientists working on basic or clinical sciences doing research on epilepsy.
- 5. The Epidemiology Commission of the Society launched the "Epilepsy Incidence Study in Eskişehir" under the supervision of Prof Dr Oğuz Erdinç from Eskişehir Osmangazi University.

- 6. The Commission on Epilepsy Genetics started a study on "Linkage analysis in absence epilepsies in Turkish population" and this study will be completed in 2008.
- 7. A "Working Group on Status Epilepticus" was set up this year to develop a national protocol for the interventions and treatment in status epilepticus. The working group aims to create a platform for neurologists and physicians from anesthesiology and emergency medicine departments that are involved in the treatment of status.
- 8. Supports: Three young researchers were supported by Turkish Epilepsy Society funds to attend the 27th International Epilepsy Meeting in Singapore that was held in 2007.
- 9. Awards: The Turkish Epilepsy Society has decided to give awards for the best original research articles on epilepsy in basic and clinical sciences that were carried out in Turkey. The awards will be presented at the National Meetings. The first awards will be given this year, at the 6th National Congress on Epilepsy, 6 June 2008. To support young scientists working on basic or clinical sciences doing research on epilepsy. Best poster and oral presentations have been given during National Meetings.

Summary of Activities in Relation to Global Campaign

- A national campaign was organized during National Epilepsy Week in June 2007. Our members talked in live radio and TV broadcasts to give information about epilepsy. Brochures and posters were distributed throughout the country. The Web site (www.turkepilepsi.org.tr) was redesigned so that patients and families can get detailed information about epilepsy. The documentary film CDs were distributed
- 2. The national campaign will be repeated this year. Radio spots on epilepsy will be broadcast several times a day to get attention on the subject. Posters will be displayed in buses and subways in Istanbul and Ankara.
- 3. A painting competition for children with epilepsy was organized with the support of Sanofi Drug Company. Awards were presented at the "Epilepsy Days" meeting on May 2007. This competition was repeated this year with the support of the drug company and awards will be presented during the National Epilepsy week in June 2008. Paintings will be posted on the Web site and will be displayed in different locations through out the country.

Educational Activities

- An original comprehensive textbook on epilepsy in Turkish written by Turkish experts under the supervision of the Turkish Epilepsy Society was recently published.
- 2. Regional meetings in Anatolia (e.g.: Eskişehir, Van) were held for the clinicians working in different cities and nearby. Seminars and interactive case discussions constituted the contents.
- 3. Two documentary films on epilepsy, named *Epilepsy* and *Against the Storm*, were prepared by the Society with the support of drug companies. One targets the public and includes general information about

epilepsy. The other is about the history of epileptology in Turkey. They were copied onto CDs and distributed throughout Turkey.

Activities in Conjunction with Local IBE Affiliate

Members of Executive Committee joined the local seminars organized by the patient groups.

Future Plans

We expressed our interest to host the 10th European Congress of Epileptology in 2012 in our country.

Officer Election Date

5 June 2008

Report By: Rezzan Gülhan Aker General Secretary

EPILEPSY SOCIETY UGANDA (EPISOU)

Meetings

We have held a series of local meetings since the inception of the Society in 2006.

Summary of Activities

- 1. EPISOÚ was formed in February 2006. Members formulated the Bylaws and the Constitution.
- 2. We were formally registered as a non-governmental organization with the National Board of Non–Governmental Organizations of the Republic of Uganda on 2 February 2007.
- 3. We were officially inaugurated as a Chapter of the ILAE in Singapore on the 11 July 2007 at the ILAE General Assembly.
- The President of the Chapter, Dr Kakooza, presented a poster on epilepsy and HIV/AIDS at the 61st Annual Meeting of the American Epilepsy Society in Philadelphia, Pennsylvania, 30 November – 4 December 2007.

Summary of Activities in Relation to Global Campaign

- As a Society we endeavor to correct misinformation about epilepsy and increase its awareness and how it can be treated through radio talk shows and print media (local newspaper articles and regular bulletins).
- 2. We have held meetings with the principal medical officer in charge of mental health in the Uganda, Ministry of Health to explore ways of addressing the treatment gap. Currently the drugs Phenobarbitone and Carbamazepine are available in some health units.
- 3. The President of the Society made contacts with colleagues in the United States who helped set up links with Abbott Pharmaceuticals. This company has donated Depakote tablets to the Pediatric Neurology Clinic at Mulago National Referral Hospital.

Educational Activities

 We hold continuing medical education sessions, tutorials and case presentations with medical students and staff at Makerere University Medical School and Butabika Regional Mental Hospital. 2. We have occasional talk shows on local FM radio stations on epilepsy patient care and management.

Activities in Conjunction with Local IBE Affiliate

- We conducted a joint media conference meeting on 29 June 2007 in which we educated journalists and the public about epilepsy, its causes, challenges of people living with it and how to care for a person with an epileptic fit.
- 2. We are planning to run a mobile clinic caring for patients with epilepsy who are members of the Epilepsy Support Association of Uganda (ESAU) the local IBE affiliate. Members of EPISOU will provide free medical consultation.

Future Plans

- To create awareness about epilepsy and encourage the public to be supportive to Patients with Epilepsy. We plan to target ten primary schools within Kampala, have talks with the teachers and pupils on epilepsy types, causes, prevention, management and referrals.
- 2. To develop information, education and communication materials on epilepsy. We plan to print posters and stickers on key messages about epilepsy sources of funding.
- 3. To run regular affordable community outreach clinics in Kampala and its suburbs in conjunction with ESAU, the local IBE affiliate. We intend to have two outreach clinics targeting 100 patients per station. Drugs will be provided through a drug bank run by ESAU and the EPISOU members will provide free medical consultation.
- 4. To conduct research studies to identify the needs of Ugandan people with epilepsy at the national and professional levels. Application for funding of proposals will be sought from Makerere University and Ministry of Health.

Officer Election Date

February 2010

Report By: Dr Angelina Kakooza-Mwesige

UK CHAPTER

Summary of Activities

The UK Chapter held a very successful Annual Scientific meeting in Southampton in 2008. Over 300 health professionals with a special interest in epilepsy attended. The Chapter has developed a basic science flavor to the meetings, whereby young basic scientific investigators present their work. A prize of £1000 is awarded to the best presentation. The ILAE UK Chapter Teaching Weekend for Specialist Registrars (SpRs) was held in October 2007. As usual it was oversubscribed, with over 150 SpRs attending. The next Teaching Weekend will take place in October 2009.

Educational Activities

Under the aegis of the ILAE UK Chapter a primary care interest group has been set up which held its inaugural meeting in Leeds in June 2007. The meeting was a success and the interest group plans to meet twice yearly – once at a stand alone meeting and once at a

session during our annual scientific meeting. The ILAE UK Chapter has been in discussion with other UK epilepsy groups to set up a UK-wide epilepsy research network.

Future Plans

The next ILAE UK Chapter Annual Scientific Meeting will be held in October 2009 in Sheffield. Further development of the Chapter's Web site.

Officer Election Date

Autumn 2008

Report By: Secretariat

URUGUAYAN LEAGUE AGAINST EPILEPSY (LUCE)

Publications

Revista Uruguaya de Epilepsia Vol 17(1) - 17(2)

Summary of Activities

During 2006 and 2007 our Chapter basically continued its regular activities both in the scientific and medical area (local publication, adviser of Neurological Institute on the field, support to the Epilepsy Surgery Program, promotion of training for interested colleagues, participation in local, regional and international epilepsy meetings) and those included in our social program devoted to patients with epilepsy (information and practical guides, social assistance, groups for patients and relatives coordinated by psychologists). Some additional effort has been devoted to the organization of the next Latin American Epilepsy Congress that will be held in Montevideo, 5-8 November 2008.

Summary of Activities in Relation to Global Campaign

Besides our already mentioned social program, members of our Chapter participated in radio and TV activities explaining different aspects related to the life of people dealing with epilepsy and the yet unsolved problem of myths and prejudice.

Educational Activities

We started to organize, together with National Education authorities, a specific program directed to train and update secondary school professors on the management of adolescents with epilepsy. Some of our members participated in regional educational activities (LASSE) either as faculty or assistants.

Activities in Conjunction with Local IBE Affiliate

In 2007 both LUCE (ILAE Chapter) and AUCLE (IBE Chapter) organized charitable activities and participated in public diffusion programs, seeking support for the Project of a "House of People with Epilepsy", where we are planning to add educational and training activities to our social program.

Future Plans

Our future plans include the development of some specific educational and research activities in coordination with other countries (USA, Belgium) specially devoted

to improve our Epilepsy Surgery Program and to introduce Vagal Nerve Stimulation in the country. In the social area, we expect to achieve our goal of improving our social program, increasing the number of patients and including new activities.

Officer Election Date

31 May 2008

Report By: Patricia Braga

YUGOSLAV UNION OF LEAGUES AGAINST EPILEPSY

Publications

Series of Proceedings "Selected Epilepsy Topics VIII-X" dedicated to the educational cycle of Epilepsy School; Guidelines and Recommendations of epilepsy treatment with brand name and generic AEDs.

Summary of Activities

- Educational cycle of Epilepsy School courses (two, lasting 3-4 days in Serbia and Montenegro).
- EEG-epilepsy workshop (three days, targeted to the neurophysiologists of Serbia and regional countries).
- Participation to the Project of EURAP.
- Series of lectures, workshops and round-tables on brand-name and generic AEDs resulting in Recommendations issued by YU Chapter on that topic
- Collaboration with a number of other national ILAE Chapters, especially with regional Leagues.

Summary of Activities in Relation to Global Campaign

- Educational and public-awareness activities of Leagues in press and visual media (local, country, region).
- Lectures on a) Epilepsy and sporting/physical activities b) Stigmatization of school children c) Difficulties in professional occupation and driving license procedure.
- Summer camp for leisure, sporting activities and friendship of patients with epilepsy.
- Work on the national Epilepsy Register.

Educational Activities

- 8th Epilepsy School, has taken place in Niška Banja (Serbia), on 1-4 June 2006.
- 9th Epilepsy School, was organized in Becici (Montenegro) during 5-7 October 2007. 10th Epilepsy School has taken place in Divcibare
- (Serbia) during 27-29 June 2008.
- All courses cited above are accredited in EUREPA.
- Regional EEG workshop: "Clinical EEG in the diagnosis and treatment of epilepsies" Vršac (Serbia), 29 September – 1 October 2006. (sponsored by
- Sanofi-Aventis, Hemofarm concern) 1st Migrating Course on Epilepsy, Babe (Serbia), 27 May 3 June 2007 (ILAE, EAC, Yugoslav ILAE Chapter).

Activities in Conjunction with Local IBE Affiliate

Selection and supervision of epileptic children and adolescents participating in "Episport" project targeted to patients who are interested in sporting activities. There were no activities of the local IBE affiliate.

Future Plans

- 1. 11th Epilepsy School, Subotica (Serbia), June 2009
- 2. Initiation of the national Journal of Epilepsies, edited by League
- 3. Further work on the National Epilepsy Registry
- 4. 3rd YU Epilepsy Congress Belgrade, 23-26 April 2009
- 5. Summer camp for leisure, sporting activities and friendship of children and adolescents, lasting 7-10 summer days in 2009 (Divcibare, Serbia)
- 6. Series of one-day meetings on brand-name and
- generic AEDs in Serbia and regional countries 7. 12th Epilepsy School

Officer Election Date

25 April 2009

Report By: Prof Dr Nebojsa J Jovic Chapter President

Directory

DIRECTORY

(As of December 2008)

Azerbaijan League Against Epilepsy

Albanian League Against Epilepsy

•••			
President	Jera Kruja	President	Sharif Magalov
Secretary	Ali Kuqo	Vice President	Zakir Aliyev
Treasurer	Mira Kapisyzi	Secretary-General	Vafa Magalova
		Treasurer	Nailya Abasova
Officer Election Date	13 August 2008	neusorer	rianya / ibasova
	10 //09031 2000	Officer Election Date	
Algerian League Agair	st Epilopsy	Chicer Election Dale	
Algenun Leugue Agun		Bangladesh Epilepsy F	oundation
President	Mahmoud Ait-Kaci-	bungiouesii Epilepsy i	oondahon
riesideni	Ahmed	President	MA Mannan
Comptone.	Annea Amar Lebiod	1st Vice President	Quazi Deen Mohammad
Secretary	Saadi Ibrahim	2nd Vice President	
Treasurer	Sadai Ibranim		AKM Anwar ullah
	A	Secretary-General	Muzharul Mannan
Officer Election Date	August 2007	Treasurer	Shaheen Akhter
	•		
American Epilepsy Soc	iety	Officer Election Date	August 2006
D 11 1			
President	Dennis Spencer	Belgian League Agains	st Epilepsy
Past President	John Swann	B	
1st Vice President	Steven Schachter	President	Paul Boon
2nd Vice President	Jaideep Kapur	Vice President	Patrick Van Bogaert
Treasurer	John Pellock	Secretary-General	Eric Schmedding
Officer Election Date	December 2008	Officer Election Date	31 March 2008
Argentinean League A	gainst Epilepsy	Brasilian League Against Epilepsy	
D 11 1			
President	Roberto Caraballo	President	Fernando Cendes
		Secretary	Carlos Alberto Mantovani
Officer Election Date	1 October 2009		Guerreiro
		1st Secretary	Kette D R Valente
Armenian National Leo	ague Against Epilepsy	Treasurer	Luiz Eduardo Betting
D 11 1			141 0000
President	Gayane Melikyan	Officer Election Date	14 June 2008
Vice President	Tatyana Stepanyan		A
Secretary-General	Yegiazaryan Nune	Bulgarian Association	Against Epilepsy
Treasurer	Irena Shadyan		
		President	Dimitar Borisov Chavdarov
Officer Election Date	9 July 2008	2nd Vice President	Dimitar Minchev
		Secretary-General	Melania Radionova
Epilepsy Society of Aus	tralia	Treasurer	Veneta Bojinova
B 11 .			
President	Simon Harvey	Officer Election Date	1 September 2008
Vice President	Terence O'Brien		
Secretary	Jillian Bicknell-Royle	Burkina Faso League A	Against Epilepsy
Treasurer	Mark Newton		
0.00		President	Kapoune Karfo
Officer Election Date	2009		
		Officer Election Date	
Austrian League Again	st Epilepsy		
D 11 1			
President	Martha Feucht		
Secretary-General	Eugen Trinka Martin Graf		
Irodeliror	addrtip L-rot		

Martin Graf

Officer Election Date 29 November 2008

Treasurer

Canadian League Against Epilepsy

President	Lionel Carmant
President-elect	Richard Wennberg
Past President	Samuel Wiebe
Secretary/Treasurer	Dang Nguyen
Board Member	Mark Sadler
Officer Election Date	18 June 2009

Chilean League Against Epilepsy

President	Juan Salinas
Vice President	Marcelo Devilat
Secretary-General	Daniela Avila
Secretary	Perla David
Treasurer	Daniela Trivino
Treasurer	Daniela Trivino

Officer Election Date 8 July 2008

China Association Against Epilepsy

President	Li Shichuo
Vice President	Jion Qin
Vice President	Guoming Luan
Vice President	Xiaoying Zheng
1st Vice President	Hong Zhen
2nd Vice President	Liao Weiping
Secretary-General	Wu Liwen
Treasurer	Wu Jianzhong

Officer Election Date October 2009

Colombian League Against Epilepsy

President	Jaime Fandino-Franky
Vice President	Sicard Valencia
Secretariat	Judith Herren
Board Member	Margarete Fandino
Board Member	Cesar Manjares
Board Member	Artur Matson
Board Member	Adolfo Bemudez de Leon

Officer Election Date 31 August 2006

Congo League Against Epilepsy

President	Kazadi Kayembe		•
Vice President	Samuel Mampunza	President	Noémi Andersen
	Da Miezi	Vice President	Helle Hjalgrim
Secretary-General	Mutombo Lukusa	Secretary	Ioannis Tsiropoulos
Treasurer	Maria Haag	Treasurer	Jesper Gyllenborg
Officer Election Date		Officer Election Date	1 March 2008

Costa Rica Chapter of the ILAE

President Vice President Secretary-General Secretary Treasurer	Franz Chaves Sell Dennis Chinchilla Weinstock Alexander Parajeles Rocio Quesada Quesada-Roman Roberto Brian Gago
Officer Election Date	9 October 2008

Croatian League Against Epilepsy

President		
Vice President		
Past President		
Secretary-General		
Treasurer		

Danilo Hodoba Igor Prpic Vera Durrigl Ljerka Cvitanovic-Sojat Davor Sporis

Officer Election Date 1 December 2008

Cuban League Against Epilepsy

Secretary-General

Salvador Gonzalez Pal

Officer Election Date

Epilepsy Society of Cyprus

President	Savvas Papacostas
Vice President	Andriani Flourentzou
Secretary-General	Goulla Stylianidou
Secretariat	Marina Chryseliou
Treasurer	Elena Kkolou

Officer Election Date

1 January 2009

Czech League Against Epilepsy

President	Jan Hadac
Vice President Secretary	Milan Brazdil Jana Zarubova
Treasurer	Miroslav Kalina
Officer Election Date	12 February 2008

Danish Epilepsy Society

President	Noémi Andersen
Vice President	Helle Hjalgrim
Secretary	Ioannis Tsiropoulos
Treasurer	Jesper Gyllenborg
Officer Election Date	1 March 2008

Dominican Republic League Against Epilepsy

President Vice President Secretary	Diogenes Santos Viloria Jose Silie Ruiz Milagros Gomez
Treasurer	Cristian Damsa
Board Member	Guillermo Jimenez
Board Member	José Cabrera
Board Member	Evelyn Santos

Officer Election Date 1 January 2008

Dutch League Against Epilepsy

President	Gerrit-Jan de Haan
Past President	Steven A J de Froe
Secretary-General	Monique Christen
Secretariat	Joke Boogaard
Treasurer	Hans Bersinger
Officer Election Date	23 May 2007

Ecuadorian League Against Epilepsy

President	Patricio Abad
Vice President	Fausto D Cuesta Compán
Officer Election Date	15 July 2009

Egyptian Society Against Epilepsy

President	Farouk Koura
Vice President	Tarek Tawfik
Secretary-General	Ahmed El-Ghonemy
Treasurer	Mahmoud Allam

Officer Election Date 3 July 2008

Emirates League Against Epilepsy

President	Jihad Inshasi
1st Vice President	Mohd Saadah
2nd Vice President	Khalid Alshamsi
Secretary-General	Hanan El Shakankiry
Treasurer	Ahmad Samir

Officer Election Date 2 July 2008

Estonian League Against Epilepsy

President	Valentin Sander
Secretary-General	Andre Oppliger

Officer Election Date

Finnish Epilepsy Society

President Secretary-General Treasurer Tapani Keränen Reetta Kälviäinen Reina Roivainen

Officer Election Date 1 October 2008

French League Against Epilepsy

President Past President 1st Vice President 2nd Vice President Secretary-General 2nd Secretary Secretary/Treasurer Treasurer Vice Chair	Alexis Arzimanoglou Bertrand DeToffol Philippe Ryvlin Franck Semah Arnaud Biraben Laurent Vercueil Elisabeth Landre Suzanne Trottier Serge Chassagnon	
Officer Election Date	21 November 2008	
Georgian Society Again	st Epilepsy	
President Vice President Secretary-General	Tina Geladze Otar Toidze Nana Tatishvilli	
Officer Election Date	July 2008	
German League Against Epilepsy		
President Vice President Secretary-General Secretariat 2nd Secretary Treasurer Board Member Board Member	Rüdiger Köhling Bernd Neubauer Thomas Mayer Petra Gehle Hajo Hamer Dieter Dennig Bettina Schmitz Bernhard Steinhoff	
Officer Election Date	2009	
Greek League Against B	Epilepsy	
President Vice President Secretary-General Treasurer Board Member	Athanasios Covanis Vasilis Kimiskidis Kyriakos Garganis Stylianos Giannakodimos Stefanos Tsounis	
Officer Election Date	10 November 2007	
Guatemala League Against Epilepsy		
President Secretary-General	Henry Stokes Jose M Perez Cordova	
Officer Election Date	January 2009	
Hong Kong Chapter of the ILAE		

Hong Kong Chapter of the ILAE

President Vice President Secretary Treasurer

Officer Election Date

Gardian CY Fong January 2009

Jason KY Fong

Patrick Chauvel

Colin Lui

Honduran Epilepsy Society

President	Claudia Amador	President	Ettore Beghi
Vice President	Heike Hesse	Secretary-General	Giuseppe Capovilla
Past President	Marco T Medina		
Secretariat	Reyna Duron	Officer Election Date	5 June 2008
1st Secretary	Aleyda Rivera	In the Charles of L	
2nd Secretary Treasurer	Rosa Palencia Lazaro Molina	Jamaican Chapter of I	LAE
neusorer		President	Sheik Muhamad Amza Ali
Officer Election Date	23 October 2007	Secretary-General	Charles Thesiger
		,	-
Hungarian Chapter of	the ILAE	Officer Election Date	10 July 2008
President	Judit Jerney	Japan Epilepsy Society	
Secretary-General	Zoltan Szupera	Jupun Epilepsy Jociely	
		President	Tatsuya Tanaka
Officer Election Date	2011	Secretary-General	Masako Watanabe
	2011	Secretary	Kiyotaka Hashizume
Indian Epilepsy Society	,		
		Officer Election Date	18 October 2008
President	M Devi		
Secretary-General	Satish Jain	Jordanian Chapter of	Epilepsy
Treasurer	Man Mehndiratta		
		President	Ziad Nuseir
Officer Election Date	October 2008	Vice President	Ali Alrefai
		1st Vice President	Majed Habahb
Indonesian Society Age	ainst Epilepsy		
		Officer Election Date	30 November 2008
President	Lina Soertidewi		A 1 1 1 1 1 1
Past President	Dede Gunawan	Kazakhstan National L	eague Against Epilepsy
Secretary-General	Suryani Gunadharma	President	Roza Aldundarova
Officer Election Date	26 July 2007	Treasurer	Orazul Arinova
	20 July 2007	neusorei	
Iraq Society Against Ep	oilepsy	Officer Election Date	
President	Sarmed Al-Fahad	Kenya Society For Epile	epsy
Secretary-General	Abdul Mutaleb Al-Skeikly		
		President	Max Okonji
Officer Election Date	25 June 2008	Vice President	Romi Grammaticas
Labor strategies and		Secretary-General	Paul Shillito
Irish Epilepsy League		Officer Election Date	12 August 2008
President	Joe McMenamin	Officer Election Date	13 August 2008
Secretariat	Mike Glynn	Korean Epilepsy Societ	N .
Secretary	Brian Sweeney	Rorean Epilepsy obcier	7
Treasurer	Bryan Lynch	President	Sang Doe Yi
	bryan Lynen	Secretary-General	Yong Won Cho
Officer Election Date	13 August 2008	Treasurer	Myeong-Kyu Kim
	0		, , ,
Israeli Chapter of the I	LAE	Officer Election Date	20 June 2009
D. I.I. I			E 11
President	Uri Kramer	Kyrgyz League Against	Epilepsy
Secretary-General	Meir Bialer	Desitive	
Board Member	Ilan Blatt	President	Valery Solozhenkin
Board Member Board Member	Nathan Watemberg Miri Neufeld	Secretary	Albina Pankratova
bourd member		Officer Election Date	13 August 2008
Officer Election Date	January 2008		
Shiel Liechon Dule	Junioury 2000		

Italian League Against Epilepsy

Latvian League Against Epilepsy

President	Eglis Vitols
Officer Election Date	10 July 2008

Lebanese League Against Epilepsy

Ahmed Beydoun
Mohamad Kassem
Fadi Abu Mrad
Ramzi Hilal
Salim Atrouni
Hasan Saad

Officer Election Date 17 June 2008

Society of Epileptologists of Lithuania

President	Nerija Vaiciene
Vice President	Milda Endziniene
Secretary-General	Jurate Grigoniene
Treasurer	Arunas Zobakas
Board Member	Ruta Mameniskiene

Officer Election Date October 2006

League Against Epilepsy of Republic Macedonia

President	Mihail Pashu
Vice President	Dijana Nikodijevic-Kedeva
Secretary-General	Emilija Cvetkovska
1st Secretary	Ana Doneva
Treasurer	Igor Kuzmanovski

Officer Election Date 1 March 2008

Malaysian Society of Neurosciences

President	Raymond Ali
Secretary-General	Raihanah Abd Khalid
Treasurer	Azmi Abdul Rashid

Officer Election Date 29 June 2006

Epilepsy Society of Malta

President
Vice President
2nd Vice President
Secretary-General
Treasurer

Anthony Galea Debono Doriette Soler Norbert Vella Janet Mifsud Josanne Aquilina

Officer Election Date 2010

Mexican League Against Epilepsy

President	Juan Carlos Resendiz
Secretary-General	Eduardo Barragán
Treasurer	Gerónimo Aguayo

Officer Election Date 12 July 2006

Moldavian League Against Epilepsy

Moldavian League Agai		
President Vice President Vice President Secretariat Treasurer	Stanislav Groppa Ion Artemi Constantin Turcan Lilia Zaporojan Gabriela Panchaud	
Officer Election Date	2 October 2008	
Mongolian Epilepsy Soc	iety	
President Secretary-General Secretary	G Tsagaankhuu A Tovuudorj P Tsogtsaihan	
Officer Election Date	June 2006	
Moroccan League Against Epilepsy		
President Vice President Secretary-General Treasurer	Hamid Ouhabi Reda Ouazzani Fettouma Moutawakkil Saoudi Zemrag	
Officer Election Date	25 June 2008	
Nepal Epilepsy Society		
President Vice President Secretary-General Treasurer Board Member	J P Agrawal Rabindra Shrestha Saroj Ojha Pawan Kumar Manen P Gorkhaly	
Officer Election Date	June 2009	
New Zealand League Against Epilepsy		
President Vice President Secretary-General Treasurer Board Member	Peter Bergin Lynette Sadleir Elizabeth Walker Claire Spooner Richard Frith	
Officer Election Date	November 2009	
Nicaragua Chapter of the ILAE		
President 1st Vice President 2nd Vice President Secretary-General Treasurer	Jorge Martinez Cerrato Foad Hassan Morales Rigoberto Castillo Walter Diaz Octavio Duarte	
Officer Election Date	22 January 2008	

Norwegian League Against Epilepsy

President	Leif Gjerstad
Vice President	Geir Bråthen
Secretary	Dag Aurlien
Treasurer	Torunn Erichsen

Officer Election Date 14 October 2008

Epilepsy Association of Pakistan

President	Hasan Aziz
Secretary	Muhammad Abdullah
Treasurer	Syed Akhtar

Officer Election Date November 2008

Panama League Against Epilepsy

President	Luis Carlos Castillo
Secretary-General	Evelia Gomez Wong
Secretariat	Ernesto Triana Bernal
Treasurer	Fernando Garcia

Officer Election Date May 2008

Paraguayan League Against Epilepsy

President	Carlos Arbo Oze de Morvil	Tr
Vice President	Ana Quintana	
Secretary-General	Marta Cabrera de Abente	C
Treasurer	Alicia Aldana	
		D

Officer Election Date 15 May 2008

Peruvian League Against Epilepsy

President	Alberto Díaz Vásquez
Past President	Juan Altamirano del Pozo
Secretariat	Patricia Campos Olazaba
Board Member	José Carlos Delgado Rios
Board Member	Daniel Koc Gonzáles
Board Member	Lizardo Mija Torres
Board Member	Isabel Tagle Lostaunau
Board Member	Hugo Umeres Cáceres

Officer Election Date 18 December 2008

Philippine League Against Epilepsy, Inc.

President	Victoria Bael
1st Vice President	Josephine Gutierrez
2nd Vice President	Cynthia Demaisip
Secretary-General	Glicerio Alincastre
Treasurer	Herminigildo Gan
Board Member	Ma Felicidad Soto

Officer Election Date 8 July 2008

Polish League Against Epilepsy		
President Vice President 2nd Vice President Secretary-General Treasurer Board Member	Joanna Jedrzejczak Ewa Motta Janusz Wendorff Asbena Grabowska-Grzyb Maria Mazurkiewicz- Beldzinska Barbara Steinborn	
Officer Election Date	September 2006	
Portuguese League Aga	inst Epilepsy	
President Past President Secretary-General Treasurer Board Member Board Member	José Lopes Lima Francisco Pinto Francisco Sales Dilio Alves Manuel Goncalves Paula Breia	
Officer Election Date	1 December 2006	
Qatar League Against Epilepsy		
President Vice President Secretary-General Treasurer	Hassan Al hail Belonwar Missroua Tag Eldin Sokrab Mahmoud Fauzi	
Officer Election Date	1 April 2008	
Romania Society Against Epilepsy		
President	Ioan-Radu Rogozea	
1st Vice President 2nd Vice President Secretary-General	Al Constantinovici Al Serbanescu Claudia Portmann	
Officer Election Date	7 July 2008	
Russian League Against Epilepsy		
President Secretary-General Treasurer	Gagik Avakian Alla Guekht Anna Lebedeva	
Officer Election Date	2 October 2008	
Saudi Chapter of Epilepsy		
President 1st Vice President 2nd Vice President Secretary-General Treasurer	Sonia Khan, Suad Al Yamani Hassan Al Ayafi Mohammed Jan Mohammed Dad	

Officer Election Date

30 December 2007

Senegal League Against Epilepsy

Officer Election Date 7 August 2007

Singapore Epilepsy Society

President	K Puvanendran
Vice President	Shih-Hui Lim
Secretary	Hian-Tat Ong
Treasurer	Andrew Pan

Officer Election Date 28 June 2006

Slovak League Against Epilepsy

Vice President	Pavol Sykora
Secretary	Felix Müller

Officer Election Date May 2005

Slovenian League Against Epilepsy

President	Igor Ravnik
Vice President	Bogdan Lorber
Secretary-General	Ljubica Vrba
Secretary	Svetana Simic
Treasurer	Matevz Krzan

Officer Election Date 23 July 2008

South African Chapter of the ILAE

President	Roland Eastman			
Vice President	Bryan Kies	Officer Election Date	15 June 2009	
Secretary-General	James Butler			
Treasurer	J Wilmshurst	Tunisian Association Age	ainst Epilepsy	

Officer Election Date

Spanish League Against Epilepsy

Ines Picornell Darder
Zarza Luciáñez
A Mercado Urdanivia
A Luengo Dos Santos

Officer Election Date

2 October 2008

Swedish Epilepsy Society

President
Vice President
Secretary-General
Treasurer
Board Member

Eva Kumlien Kristina Källén Fredrik Asztely Roland Flink Kristina Malmgren

Officer Election Date 14 November 2008

Swiss League Against Epilepsy

President Günter Krämer Vice President Giovanni Foletti

Officer Election Date Spring 2010

Syrian Chapter of Epilepsy

President	Ahmad Khalifa
Vice President	Kossay Dib
Secretary-General	Sleie Abdulnaser
Treasurer	Imad Eddin Sabbagh
Officer Election Date	12 April 2007

Taiwan Epilepsy Society

President	Ching-Shiang Chi
Secretary-General	Shang-Yeong Kwan
Treasurer Elect	Yang-Hsin Shih

Officer Election Date 24 March 2007

Tanzania Epilepsy Association

President	William BP Mutaja
Officer Election Date	28 April 2006

Epilepsy Society of Thailand

President	Surang Chiemchanya
Past President	Pongsakdi Visudhibhan
Secretary-General	Anannit Visudtibhan
Treasurer	Kanlaya Dhiravibulya

President	Chahnez Triki
Vice President	Najoua Miladi
Secretary-General	Mohamed Fredj
Treasurer	Amina Gargouri
Officer Election Date	6 December 2006

Turkish Epilepsy Society

President	Ibrahim Bora
Vice President	Naz Yeni
Secretary-General	Nerses Bebek
Treasurer	Veysi Demirbilek
Board Member	Berrin Aktekin
Officer Election Date	5 June 2008

UK Chapter of the League

Yugoslav Union of Leagues Against Epilepsy

Ksenija Bozic

Mirjana Spasic

Ksenija Gebauer-Bukurov

President	John Duncan	President	Nebojsa Jovic
Past President	David Basangwa	Vice President	Slavica Vujisic
		Vice President	Dragoslav Sokic

Vice President

1st Secretary

Secretary-General

Officer Election Date Autumn 2008

Ukrainian League Against Epilepsy

		2nd Secretary	Nikola Vojvodic
President	Sergey Kharchuk	Treasurer	Marko Ercegovac
Vice President	Galina Maryek		
Vice President	Oleg Golubkov	Officer Election Date	25 April 2009
Secretary	Natalia Zavyazkina		
Treasurer	George Selyukov	Zimbabwe League Against Epilepsy	
Officer Election Date	15 May 2009	Treasurer	Douglas Mzengi

Officer Election Date 15 May 2009

Uganda League Against Epilepsy

. . .

Officer Election Date

President	Angelina Kakooza
Vice President	David Basangwa
Secretary-General	Augustine Mugarura
Treasurer	Rebecca Wandeka

Officer Election Date February 2010

Uruguayan League Against Epilepsy

President	Isabel Rega	
Vice President	Claudia Portmann	
Past President	Diana Yorio	
Secretary-General	Patricia Braga	
Treasurer	Andrea Rossetti	

Officer Election Date 31 May 2008

Venezuelan League Against Epilepsy

President	Beatriz Gonzalez del
	Castillo
Vice President	Brunilda Garcia de Parma
1st Vice President	Jose Miguel Lopez
2nd Vice President	Luz Marina Rangel
Secretary-General	Maria Gabriela Senior
Secretary	Glenda Sotillo
Treasurer	Jesus Silvera
Vice Chair	Ernesto Muller
Board Member	Maria Haag

Officer Election Date 10 July 2008

INTERNATIONAL LEAGUE AGAINST EPILEPSY

CONSTITUTION

Article I — Name

The name of this international organization, founded on August 29, 1909, in Budapest, is the International League Against Epilepsy (hereinafter called "the ILAE").

Article II — Effective Date

This Constitution is amended and valid as of August 2005.

Article III — Objectives

The objectives of the ILAE are to:

- 1. Advance and disseminate throughout the world knowledge concerning the epilepsies.
- 2. Encourage research concerning the epilepsies.
- 3. Promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders.
- 4. Improve education and training in the field of the epilepsies.

Article IV — Methods

To that end, but without restricting the main objectives of the ILAE, and insofar as the same shall be wholly charitable, the ILAE shall:

- Encourage the establishment and maintenance worldwide of societies with the same objectives as the ILAE which will be members of the ILAE (hereinafter designated "Chapters").
- 2. Seek to establish and maintain effective cooperation with other organizations worldwide active in the field of the medical sciences, public health, and social care, who are, or may become concerned with problems related to the epilepsies.
- 3. Promote publications concerning the epilepsies and arrange for the publication of the journal of the ILAE, *Epilepsia*, and other ILAE educational and informational materials.
- 4. Organize or sponsor international Congresses, symposia, or other meetings, in particular the International Congress of the ILAE, to be held at the time and place as prescribed in the Bylaws.
- 5. Appoint special commissions or individuals for the purpose of studying specified problems related to the aims of the ILAE and making recommendations for implementation of specific activities.
- 6. Develop and apply other methods consistent with the objectives of the ILAE.

Article V — Legal Status

The ILAE is a non-profit, tax exempt, international organization incorporated in the District of Columbia, USA.

Article VI — Membership

 Member Chapters are composed of professionals who are involved in patient care or research in epilepsy and whose primary concern is with the problems of epilepsy. The minimum membership of a Chapter is nine professionals which is deemed to be the minimum number that would allow the rotation of President, Secretary-General and Treasurer. Exceptionally, a Chapter may consist of a mixed professional and lay membership for a period of time. In this situation, only professional members constitute the basis for dues, voting and holding office.

- 2. There shall be only one Chapter in each country defined as any State recognized as a member of the United Nations and/or World Health Assembly. When there is more than one eligible organization in a country, the Executive Committee shall recommend for membership that organization which, in its opinion, can best accomplish the objectives of the ILAE. Organizations in territories/regions that do not fall within the above definition of a State may exceptionally be considered for membership by the Executive Committee and ratified by the General Assembly.
- 3. The Chapters shall be voted into the ILAE upon the approval of the Executive Committee and two-thirds vote of those attending the meeting of the General Assembly. Pending approval by the General Assembly, a prospective Chapter may be provisionally admitted to the ILAE by decision of the Executive Committee which will entitle the prospective Chapter to all rights of membership except the right to vote.
- 4. By applying for membership a prospective Chapter agrees to fulfill all obligations of Chapters as stated in this Constitution and Bylaws. Chapters are autonomous societies, but their Constitutions must not contain articles inconsistent with the Constitution of the ILAE.
- 5. A prospective Chapter becomes a Chapter after approval by the General Assembly, submission to the Secretary-General of a list of names and addresses of its own members, and payment of its dues.
- 6. A Chapter may withdraw from membership by giving notice in writing to the Secretary-General.
- 7. On recommendation of the Executive Committee, membership may be terminated by a two-thirds vote of those attending the meeting of the General Assembly, if the Chapter fails to pay its annual dues or if, for any other reason, it no longer fulfills the stated requirements for membership.
- 8. The Chapters are organized into Regions as determined by the Executive Committee.

Article VII — Governance

The ILAE shall be governed by the Executive Committee and the General Assembly.

Article VIII — The Executive Committee

- 1. The Executive Committee shall conduct the affairs of the ILAE subject to ratification by the General Assembly.
- 2. The Executive Committee shall consist of:
 - a. The President, Secretary-General, Treasurer, Vice Presidents, and the Immediate Past President as elected members. Only elected members shall have the right to vote.
 - b. The President, Secretary-General and Treasurer of the International Bureau for Epilepsy (hereinafter called the "IBE"), as ex-officio, non-voting members.
 - c. The Editor-in-Chief of *Epilepsia* and the Information Officer as non-voting members.

- 3. The term of office for elected Executive Committee members is four years. Candidates for the Presidency must have served, or be in the process of serving, at least one term on the Executive Committee. After serving as President, the person shall automatically serve one term as Immediate Past President. The President and the Immediate Past President shall serve one term. The Vice Presidents, the Secretary-General, and the Treasurer may be re-elected for one additional term to any one of these offices. Thereafter, they may only be elected to the Presidency.
- 4. The Editor-in-Chief of *Epilepsia* and the Information Officer shall be appointed by the Executive Committee and serve at their discretion. The term of office can not exceed twelve years.
- 5. Should any vacancy in the Executive Committee occur it shall be addressed by the Executive Committee subject to ratification by the General Assembly.
- No person may occupy a seat on the Executive Committee for a period exceeding a maximum of 16 years.
- 7. The President shall appoint an independent Elections Commission, of five persons, each representing different regions, and chaired by the Immediate Past President. The Executive Committee shall not interfere with the business of the Elections Commission. The Commission is to conduct the elections and establish appropriate procedures that are not in conflict with the Constitution and Bylaws and respect the following constraints:

The Elections Commission shall be responsible for fully informing all Chapters about the elections process and its procedures eighteen months in advance of the meeting of the General Assembly during which the new Executive Committee takes office.

The election of the President will be carried out first, followed by the election of two Vice Presidents, Secretary-General, and Treasurer.

The geographic distribution of the elected officers, including the President, shall be restricted as follows: Each of the five elected officers must be primary members of different Chapters. Primary membership is defined by the location of where professional activities are performed. No more than two members of the Management Committee shall come from the same region, as defined by the geographical division accepted within ILAE, and no more than three of the five elected officers shall come from the same region.

8. In the event that after the global elections of President, two Vice Presidents, Secretary-General, and Treasurer, and the appointment of Editor-in-Chief and Information Officer, any fully operational region of the ILAE (as determined by the Executive Committee) is not present on the Executive Committee, the Chapters of this region shall elect an additional Vice President. This Vice President will be a voting member of the Executive Committee and not be considered as a regional Vice President but unrestrictedly share the global responsibilities of the Executive Committee.

- 9. The Executive Committee may hold meetings at any time or in any place which may be convenient to its members; it may conduct its business also by other appropriate means of communication. Only business of which minutes have been made, acknowledged by the members of the Executive Committee who participated, will be considered legal business of the Executive Committee.
- 10. Two-thirds of the voting members of the Executive Committee constitute a quorum. Decisions are made by a majority of the voting members attending. In the event of a tie, the President has a deciding vote.
- 11. The Executive Committee shall have the power to formulate at any time Bylaws not in conflict with the Constitution. These Bylaws are legally binding, but a posteriori corrective action may be taken by the General Assembly to revoke or amend these rules.
- 12. The Executive Committee shall approve the annual budget of the ILAE and shall set the dues to be paid by the Chapters.

Article IX — The General Assembly

- 1. The General Assembly consists of all approved Chapters of the ILAE.
- 2. Regular meetings of the General Assembly shall be convened during each International Congress of the ILAE. Participants shall consist of one delegate from each Chapter who carries the total number of votes of that Chapter.
- 3. Representatives from more than fifty percent of the Chapters attending a meeting of the General Assembly shall constitute a quorum. Decisions will be taken by a majority of the votes of those attending.
- 4. The General Assembly shall receive and consider for vote of approval the reports of the President, the Secretary-General, and the Treasurer.
- 5. The General Assembly shall vote on proposals submitted by the Executive Committee.
- 6. The General Assembly shall approve the admission of new Chapters and the termination of membership of Chapters.
- 7. The General Assembly shall set the time and place of future Congresses, after recommendation by the Executive Committee.
- 8. Meetings of the General Assembly are open unless a number exceeding ten percent of the delegates present requests the Chair to close the meeting to observers. Only delegates may speak and vote. Exceptionally the presiding officer with the approval of the General Assembly may invite a non-delegate to speak, but not to vote.
- 9. Between regular meetings of the General Assembly, should urgent business arise requiring General Assembly action, this shall be carried out in writing, using available technology as determined by the Executive Committee. Such business must involve responses from at least fifty percent of the Chapters, and decisions would require a majority of the votes of those responding.
- 10. Chapters whose total votes correspond to a minimum of twenty-five percent of all available votes may request a written consultation by mail of the General Assembly. Reasons for doing so must be sent to the Executive Committee ninety days before the consultation.

Article X — Finances

- 1. The ILAE shall have the authority to accept and administer gifts, legacies, movable or immovable properties, donations, and assets of any kind without any restrictions as to the amount or value and to collect annual dues of its Chapters.
- 2. The assets of the ILAE shall be used to further the objectives of the ILAE as authorized by the Executive Committee.
- No portion of the assets of the ILAE shall be paid directly or indirectly to any Officer, members of its Commissions and Task Forces, or officers of its Chapters, except for payment of expenses made in the interest of the ILAE.
- Proper books of account shall be overseen by the Treasurer and they shall be certified by a qualified auditor at the end of each fiscal year.

Article XI — Epilepsia

- 1. The Editor-in-Chief of *Epilepsia* shall be responsible for editing *Epilepsia* in accordance with the general policies established by the Executive Committee.
- 2. The Editorial Board shall consist of editors appointed by the Editor-in-Chief. The term of office of the editors is four years and editors may be reappointed.
- 3. The editorial Advisory Board of *Epilepsia* shall consist of the Executive Committee and shall approve all contracts related to the publication of *Epilepsia*.
- 4. All financial responsibilities of *Epilepsia* reside with the Treasurer and the Executive Committee of the ILAE.

Article XII — Information and Communication

The Information Officer oversees the collection of relevant information on epilepsy according to a policy agreed by the Executive Committee and ensures its availability to professionals throughout the world.

Article XIII — Commissions and Task Forces

- Commissions and Task Forces in unlimited number may be appointed by the President of the ILAE as recommended by the Executive Committee. The President, Secretary-General and Treasurer of the ILAE shall be ex-officio members of all Commissions and Task Forces, except the Elections Commission.
- 2. No expenses shall be incurred by a Commission or Task Force on behalf of the ILAE without the consent of the Executive Committee.

3. Annual budgets and financial reports of the Commissions and Task Forces must be approved by the Executive Committee.

Article XIV — International Bureau for Epilepsy (IBE)

- 1. A privileged relationship exists between ILAE and IBE as partners for addressing respectively the professional and social aspects of the epilepsies.
- ILAE and IBE will establish appropriate administrative structures that will facilitate the accomplishment of mutual objectives.

Article XV — Amendments

- 1. The present Constitution may be amended by a two-thirds vote of those attending the meeting of the General Assembly.
- 2. Amendments may be initiated by the Executive Committee, or by Chapters whose total votes correspond to a minimum of twenty-five percent of the votes of the General Assembly. Such amendments must be submitted to the Secretary-General at least ninety days before the next meeting of the General Assembly, and due notice of such amendments shall be given to all Chapters by the Secretary-General at least sixty days before the meeting of the General Assembly.

Article XVI — Dissolution or Merger

- The ILAE may be dissolved or merged with another body having similar objectives on proposal of the Executive Committee, ratified by two-thirds of the available votes of the General Assembly as well as two-thirds of the total number of Chapters.
- 2. In the event of dissolution, the assets of the ILAE may not be divided among its members but shall be transferred to one or more other international organizations of similar interests, as agreed by the General Assembly.

BYLAWS

The Executive Committee is empowered by the Constitution (Article VIII, 8) to establish Bylaws as necessary to achieve the objectives of the League, subject to their not being in conflict with the Constitution and to their ratification by the General Assembly.

The Secretary-General shall keep a book containing the current Bylaws, in which all modifications are entered as they are made.

I. Elections

- For each phase of the election, the Elections Commission shall ascertain if candidates are available and willing to serve. Candidates will provide the Elections Commission with appropriate background information on their candidacy. This information will be sent to each Chapter and published in appropriate League publications.
- 2. Each Chapter has from 1 to 6 votes depending on the number of dues paying members in good standing.
- 3. For the election of the President, the Elections Commission shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII, 3), who are available and willing to serve and will ask each Chapter to vote for one of them. If one of the candidates receives more that fifty percent of all possible votes, that candidate shall be elected. If this is not the case, a run-off shall be held between the two candidates that received the highest number of votes. The candidate in the run-off that receives the highest number of votes cast shall be elected. If both candidates receive the same number of votes, the Elections Commission has the final choice.
- 4. Following completion of the Presidential Election, the Elections Commission shall request each Chapter to submit a slate of four names as candidates for the remaining officer positions.
- 5. The geographic representation of the candidates must allow for the eventual election of officers who meet the geographic distribution requirement stated in the Constitution (Article VIII, 6).
- 6. The Elections Commission shall choose a slate of not more than twelve candidates on the basis of weighted multiple nominations from the lists submitted by the Chapters. The Commission shall ascertain that these candidates are available and willing to serve.
- 7. The Elections Commission shall then submit the slate to each Chapter for voting by mail, e-mail, or fax. This is the fourth and final stage in the election process. If two or more candidates obtain the same number of votes the Elections Commission has the final choice.
- 8. The Elections Commission will, with the advice and consent of the President-elect, appoint the Secretary-General, Treasurer, and two Vice Presidents from the newly elected slate.

II. Duties of Officers

- 1. The President shall preside at meetings of the Executive Committee and the General Assembly.
- 2. The President, Secretary-General and Treasurer shall act as Management Committee in between meetings of the Executive Committee. Their actions shall be subject to ratification by the Executive Committee.
- 3. The Vice Presidents shall assist the President, and the First Vice President shall assume the duties of the President in his absence. In case of the inability of the first Vice President to serve, his place shall be taken by the Second Vice President.
- 4. The Secretary-General shall conduct the affairs of the League under the direction of the Executive Committee.
- 5. The Treasurer shall administer the accounts of the League.

III. The General Assembly

Unless otherwise indicated, matters brought before the General Assembly shall be decided by majority of vote of those attending an official meeting or responding to a mail ballot. The number of votes accorded to each Delegate shall depend on the number of professional dues paying members in his/her Chapter according to the most recent statement provided by the Chapter. The number of votes shall be determined by a sliding scale where a second vote is obtained when the membership has passed the number of 50, and where the increase of membership giving an additional vote doubles for every step. There shall be a maximum of six votes for any Chapter:

up to 50 members1 vote
51-150 members
151-350 members
351-750 members
751-1,500 members5 votes
above 1,500 members

Chapters that do not collect dues shall have one vote.

IV. Epilepsia

- The Editorial Advisory Board shall advise the editors on matters of general policies and arbitrate on matters referred to it by the Editor-in-Chief, but shall leave the day-to-day conduct of the journal entirely to the Editor-in-Chief and the Editorial Board consisting of the editors, working with the publisher.
- 2. The Executive Committee shall approve or terminate any contract with the publisher. It shall determine the budget of *Epilepsia*.
- 3. The Editor-in-Chief will take all steps necessary to fulfill the aims of the League through its journal, *Epilepsia*. The Editor-in-Chief shall: conduct the day-to-day business of the journal in conjunction with the Editorial Board and the publisher; have final responsibility for the acceptance or rejection of manuscripts; call meetings of the Editorial Board in special situations; recommend a budget for *Epilepsia* on request of the Executive Committee; and render an account of expenses incurred.

V. Information and Communication

- 1. The Information Officer supervises the publication of *Epigraph* at least twice annually.
- 2. The Information Officer is responsible for the information published on the Web site and serves as Chair of the Web site Task Force.
- 3. The Information Officer oversees the activities of, and the contract with, the Epilepsy Information Center.

VI. Commissions and Task Forces

- 1. Each Commission and Task Force shall have a Chair appointed by the President.
- 2. The term of office of each Commission shall expire at the end of the term of the Executive Committee, but it may be renewed in the same or a revised composition by the new President of the ILAE.
- 3. Task Forces are appointed for specific purposes and their term of office expires when their duties are completed.
- 4. The Chair of each Commission and Task Force shall make interim reports and recommendations to the Executive Committee as deemed necessary and shall submit a final report at the conclusion of their term. Said final report shall be communicated to the Chapters.

VII. Chapters' Obligations

- Each Chapter must send to the ILAE Secretary-General the names and contact information of its officers within thirty days after the Chapter's General Assembly Meeting during which a new Executive Committee takes office. Documentation, such as minutes of this meeting, must accompany the contact information. If changes in contact addresses occur these must be immediately reported to the Secretary-General of the ILAE.
- 2. In March of each year, every Chapter shall send to the ILAE's Secretary-General the names and addresses of its members as of 31 December of the previous year.
- 3. Before 1 July of each year, each Chapter shall pay to the ILAE annual dues which shall be proportional to the number of dues paying members as of 31 December of the previous year, and shall be fixed for each fiscal period of the General Assembly. Dues for a Chapter are 3% of the annual dues that the Chapter charges each member, multiplied by the number of Chapter members, or a minimum payment of \$10 (US), whichever is highest. In countries where exchange regulations do not allow for remittance of funds outside the country, then escrow accounts may be established with the approval of the ILAE Treasurer.
- 4. If a Chapter without consent of the Executive Committee omits paying its dues it will be once warned to do so; if the next year dues are again not paid the Executive Committee will propose disaffiliation to the General Assembly by mail ballot. Two-thirds of votes cast (with at least twothirds of all available votes having been cast) have to confirm disaffiliation.

VIII. Fiscal Year

The fiscal period of the ILAE shall be 1 July through 30 June.

IX. Staff

- 1. The location of the ILAE's Headquarters Office will be determined by the Executive Committee.
- 2. The Executive Committee is empowered to retain such staff and contract for other professional services as may be necessary to carry out the functions of the League.

X. Meetings

- 1. The International Congress of ILAE shall be held ordinarily every two years, in conjunction with the International Bureau for Epilepsy.
- 2. In the year between two International Congresses of the ILAE, the Regional Divisions of the ILAE will organize Regional Congresses with the support of the ILAE.
- The ILAE may sponsor or support, wholly or in part, other meetings relevant to its objectives. Such a meeting shall not be designated as an International Congress of the League.

XI. Regions

- Regional Commissions shall consist of representatives elected by local Chapters together with a Chair and Secretary appointed by the ILAE President. Chapters can belong to only one region.
- 2. Regional Commissions should meet from one to three times a year and must submit an annual budget for approval to the Executive Committee.
- 3. Regional Councils may be established to include members from all local chapters. In some regions, Councils may include non-voting members from countries without Chapters. Councils are expected to meet at least once per year.
- 4. Regional Commissions should aim to develop, stimulate and coordinate the epileptology agenda in their part of the world.
- 5. Regional Commissions should promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda.
- 6. Regional Commissions should coordinate local educational activities via the formation of a regional epilepsy academy.
- 7. Regional Commissions should run their Congresses under the direction of the International Director of Meetings (IDM).
- 8. Regional Commissions should review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.
- 9. Regional Commissions should develop documents with the aim of stimulating local medicopolitical initiatives and improving patient care.

XII.Cooperation with the International Bureau for Epilepsy (IBE)

- ILAE shall cooperate with IBE on all levels international, national, regional, and chapter — to ensure maximum efficiency in promoting quality of life for people with epilepsy.
- Each ILAE Chapter shall promote the establishment and/or assist in establishing a Chapter of the Bureau, if such a Chapter does not exist.

- 3. At least annually, and more frequently if possible, the Executive Committee shall meet jointly with the Executive Committee of the IBE, to consider matters of mutual interest and/or responsibility to both ECs. Such a meeting shall be known in full as a Joint Meeting of the Executive Committees of the IBE and ILAE, and in brief as a JEC.
- 4. A JEC shall have no financial or constitutional power or existence independent of the Executive Committees of the IBE and ILAE. It is a meeting of two separate and independent constitutionally defined bodies, not an entity in itself.
- 5. Matters to be considered by a JEC shall include International Epilepsy Congresses, the Global Campaign, the Epilepsy Web site, the International Resource Center, and such other matters as the IBE and ILAE Executive Committees shall consider appropriate to be delegated to consideration and decision by a JEC.
- 6. A proposed action by a JEC should not be in conflict with the Constitution of the ILAE and must be ratified by the two ILAE and IBE Executive Committees prior to implementation.
- 7. Chairing of each JEC shall be shared equally between the IBE and ILAE Presidents, or their nominees, in a manner acceptable to both. The Chairperson of a JEC shall not have a casting (i.e., tie-breaking) vote.
- 8. A quorum for a JEC shall be the presence of a majority of the members of each of the IBE and ILAE Executive Committees.
- 9. A JEC may be called at any time mutually acceptable to the Presidents of both the IBE and ILAE.
- 10. To be considered by a JEC, a motion must be moved by a member of one Executive Committee, and seconded by a member of the other.
- Members of the Management Committee of each of the IBE and ILAE, although ex officio members of both Executive Committees, shall each have only one vote in a JEC meeting.
- 12. Responsibility for administration, minuting, etc. of JECs shall be shared equally between the Secretaries-General of the IBE and ILAE, in a manner acceptable to both.
- 13. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the IBE and ILAE, in a manner acceptable to both.

A Joint Management Committee, consisting of the Management Committees of each of the IBE and ILAE, is authorized to take actions in the name of a JEC between JEC meetings. Such actions must:

- a. Be approved by a majority (i.e., two members) of each of the Management Committees of the IBE and ILAE.
- b. Be in accord with policies of both the IBE and ILAE.
- c. Involve neither Executive Committee in expenditure exceeding a sum to be set by each Executive Committee.
- d. Be notified to each Executive Committee as soon as possible.
- e. Be ratified by each Executive Committee at its next meeting.

XIII. Indemnification

Executive Committee members, officers, and other authorized staff, volunteers, or agents of the ILAE shall be indemnified against claims arising in connection with their positions or activities on behalf of the ILAE to the full extent permitted by law.

XIV. Amendments

The Executive Committee shall have the power to amend these Bylaws by the affirmative vote of a majority of the voting Executive Committee members then in office, provided that notice of the proposal to amend the Bylaws is provided to the Executive Committee with at least thirty days' notice.

