

OUR VISION

International League Against Epilepsy's vision is a world in which no person's life is limited by epilepsy.

OUR MISSION

International League Against Epilepsy's mission is to ensure that health professionals, patients and their care providers, governments, and the public worldwide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy.

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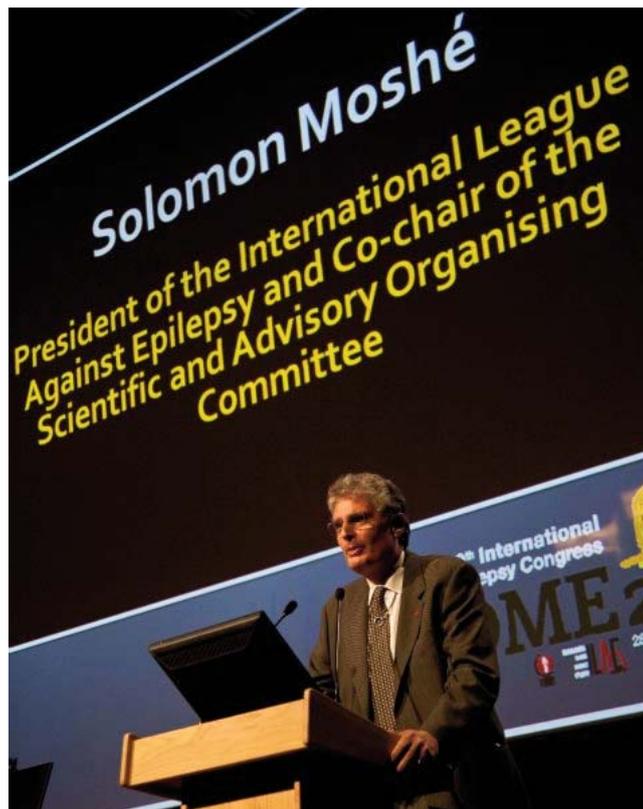
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PRESIDENT'S REPORT



In July 2009, the International League Against Epilepsy (ILAE) developed its four-year Strategic Plan. This is the second year progress report, prepared by the Management Committee and the Chair of the Strategic Task Force, with input from several key leaders, to highlight progress toward achieving the Plan's goals. Additional information regarding our activities can be found at our renovated website (www.ilae-epilepsy.org).

Goal 1: ILAE shall serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.

As the major international epilepsy organization, ILAE is taking the lead in developing practice guidelines for clinical questions faced by clinicians managing people with epilepsy. A new Task Force on Guidelines, chaired by Tim Pedley, has been asked. The aims are: to compile and review existing epilepsy guidelines; identify those that can be adopted world wide or in specific parts of the world; assess the needs of the League's Chapters around the world; identify the most important areas for new guideline development; determine whether a topic or question is best served by a formal clinical practice guideline (which may be hindered by the paucity of methodologically rigorous evidence) or by a position paper representing the consensus of experts supported by the available evidence. Because the development of guidelines is time-consuming and expensive, the League may partner with organizations such as the World Federation of Neurology (WFN), the American Academy of Neurology (AAN) and the European Federation of Neurological Societies (EFNS) in this project.

The Epidemiology Commission and Marco Medina continue their work with the World Health Organization (WHO) to develop the epilepsy-related codes for the ICD-11.

The 29th International Epilepsy Congress was held in Rome, 28 August to 1 September 2011. Nearly 4,000 delegates attended this highly successful Congress. Its program aimed at integrating all aspects of epilepsy (including medical, research, social and novel therapeutic approaches) in each session. A prime example was the Presidential symposium entitled "Avoiding Deaths in Epilepsy". During the 29th Congress the IBE celebrated its 50th anniversary with two exceptional events: A get together of the Ambassadors of Epilepsy, a highly prestigious honor initially conceived by IBE and now conferred by joint deliberations of the IBE and ILAE Executive Committee every two years; and a magnificent concert. Work is ongoing for the preparation of four Regional Congresses scheduled for 2012, including the first

African Congress organized jointly by the ILAE and the International Epilepsy Bureau (IBE) and represents a major component of the educational activities targeted to the African continent by our newly formed Commission on African Affairs. The 30th International Epilepsy Congress will be held in Montreal, Canada.

During the 29th International Congress held in Rome, Dr Jerome Engel Jr received the Life Achievement Award and Dr Pravina Shah the Social Accomplishment Award. Dr Eleonora Aronica was the Michael Prize winner and Dr Laura Jansen was the recipient of the Morris-Coole Epilepsia Award. Twelve new Ambassadors for Epilepsy were elected (Table 1).

The Regional Commissions are establishing bi-annual awards that recognize regional accomplishments. The Commission on European Affairs (CEA) established the European Epileptology Award in 2002. The latest awards were bestowed on Drs Yehezkiel Ben-Ari and Martin Brodie during the 9th European Congress in Rhodes in 2010. The CEA plans to expand the number of awards starting in 2012. During the 2012 London Congress there will be up to two European Research (clinical and basic) Awards for Young investigators, one for Education and one for Service to Europe. The Asian-Oceanian Commission granted their first awards during the 8th AOEC in 2010. The recipients of the Asian and Oceanian Outstanding Achievement Epilepsy Awards included Drs Hasan Aziz, Tatsuya Tanaka, Kazuichi Yagi, P Satish Chandra and Xun Wu.

The League solidified the organizational and financial stability of the long distance education program by acquiring direct supervision of this initiative, and by investing in the expansion of the Virtual Epilepsy Academy (VIREPA) to promote teaching courses under the coordination of Regional Academies. Plans are underway to organize a course for primary caregivers in Sub-Saharan Africa in collaboration with the Task Force on Seizures and Epilepsy in the Tropics, the African Commission and the WHO.

The Education Commission led by CT Tan is developing ways to make educational material generated during our Congresses freely available through the League's website. This was started with a trial run of voice/power point slides captured during the Melbourne AOEC, and the "How to" education session during Rome IEC. In Rome, through an effort coordinated by our Information Officer, many presenters addressing timely topics were also interviewed to produce videos which are currently posted on the League's website. This will be a regular feature of future Congresses. The Education Commission is creating an open access, online Textbook of Epilepsy (Shi Hui Lim, Editor), housed on

PRESIDENT'S REPORT *(continued)*

the ILAE website. We expect the first edition to be available in the first quarter of 2012. We plan translations of the textbook into Spanish, and Chinese.

Congresses are being reorganized to promote translational research venues that allow for better communication between basic scientists and clinicians.

The Neurobiology and the Education Commissions are developing proposals for further training of professionals, including a combination of residential courses with hands-on tutoring of research proposals that are likely to impact resource-poor regions favorably. This initiative may include guidance in preparing grant applications, provision of seed grants, and monitoring research progress. The Academies of the Regional Commissions have developed year round, 1 to 2 day teaching courses in various parts of the regions. For example, the Asian Academy (ASEPA) organizes about 10 such courses yearly. These reach out to diverse populations, address different needs, and are generally more cost effective than traditional large Congresses. The longer and more in depth "summer schools" continue to be organized in Europe and Latin America, and have also been launched in Asia. Other projects by the Regional Commissions/Academies include visiting professorships between the North America and the Caribbean/Latin America; fellowships by the Asian and Latin American Commissions, EEG certification examination and publication of congressional proceedings by ASEPA.

Vital partners in basic research collaborations are the International Brain Research Organization (IBRO) and the Society for Neuroscience. An important aim is to identify and publicize possible funding sources for such programs, and increase public and government awareness of the needs of people with epilepsy.

Discussion is underway with the WFN and the International Child Neurology Association (ICNA) to develop collaborative visiting professorships for Africa. The key aim is to create a long-term relationship between institutions. This initiative will involve the Education, North American and African Commissions.

Goal 2: ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care.

We continue our Global Campaign efforts together with IBE and WHO. Because several additional initiatives do not fall under the collaborative efforts of the Global Campaign, together, with IBE, we created the Global Outreach Task Force, chaired by Helen Cross and Shichuo Li with expert assistance from Hanneke De Boer. Its primary aim is raising awareness

of global educational and service initiatives in epilepsy throughout the world. The Task Force has identified a new slogan, initially proposed by Mike Glynn, President of IBE: **Stand Up for Epilepsy.**



The second SUDEP, A Global Conversation book was launched in Rome six years after the first edition with forewords by the ILAE and IBE Presidents. Much has changed since the earlier edition was launched at the Paris IEC and almost all of it for the better in relation to epilepsy deaths. However, much remains to be done especially in the area of prevention and in regard to people at risk of SUDEP being warned of it together with their loved ones. This book brings together contributions on the subject of SUDEP from all around the world, including pieces from many developing countries.

ILAE and IBE are engaged in several regional activities to highlight the public health dimensions of the epilepsies, and to prioritize allocation of resources to epilepsy healthcare and research. These initiatives include the production of an epilepsy report by the U.S. Institute of Medicine (IOM).

The IOM report will specifically address the following questions: How can the public health burden of epilepsy for patients and families be more accurately assessed? What priorities for future population health studies could inform treatment and prevention? How can the access to health and human services and the quality of care for people with epilepsy be improved? How can the education and training of professionals who work with people with epilepsy be improved? How can the understanding of epilepsy in patients and the general public be improved to create supportive communities? The report will be released in 2012.

The 51st Directing Counseling of the Pan American Health Organization (PAHO), which includes representatives from countries of North, Central and South America), approved and endorsed the Action Plan on Epilepsy for the Americas on 29 September 2011. The Action Plan was prepared by Dr Jorge Rodriguez from PAHO and Drs Carlos Acevedo and Marco Medina as part of the Global Task Force of the ILAE and IBE. The Action Plan highlights the problems associated with epilepsy care throughout the developed and developing countries of the Americas and lists

PRESIDENT'S REPORT *(continued)*

specific goals and anticipated deliverables that would positively impact epilepsy care in the region, with a 10-year focus on epilepsy.

In Europe, efforts are ongoing to advocate for political actions in the fight against epilepsy. The executive body of the European Union (EU) is its Commission. The two key Commissioners who can influence healthcare and research in epilepsy are European Commissioner John Dalli, Commissioner for Health and Consumer Policy and European Commissioner Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science. During European Epilepsy Day, both Commissioners held meetings with delegations from IBE and ILAE led by the two Presidents at the European Parliament in Strasbourg. A Joint Task Force of ILAE and IBE, Co-Chaired by Emilio Perucca and Mike Glynn and including members of the ILAE and IBE regional governing bodies (CAE and EREC respectively), has also been established under the name Epilepsy Advocacy Europe (EAE). EAE aims at making epilepsy care and research a priority in the agenda of the European Union (EU) and national governments in the European Region. Its first action was to obtain the endorsement of the Written Declaration of Epilepsy by the European Parliament. This was achieved with a majority vote of the European Parliament on 15 September 2011. The Declaration calls for the EU to support research and innovation in the prevention and early diagnosis and treatment of epilepsy; to prioritize epilepsy as a major disease that imposes a significant burden of illness across Europe; to encourage Member States to ensure equal quality of life, including education, employment, transport and public healthcare, for people with epilepsy; to encourage effective epilepsy health impact assessments on all major EU and national policies; and to introduce appropriate legislation to protect the rights of all people with epilepsy. The next steps will be to capitalize on the Declaration by ensuring that its recommendations are adopted by the European Commission and by national governments. A European Conference on Epilepsy is being planned with participation of all major stakeholders from the European Commission, the European Council, national governments, funding organizations, lay organizations and the medical and research community.

Our collaborative efforts are beginning to bear fruit. In November 2010, the Colombian Congress passed a law establishing special measures of protection for people with epilepsy with principles and guidelines that call for comprehensive care of people with epilepsy.

The ILAE's Strategic Plan includes a role as the global leader in epilepsy education. To this end, under the

leadership of Ed Bertram, the League developed a series of short, patient-oriented videos dealing with common issues faced by patients (what is epilepsy?, symptoms, diagnosis, treatment, surgery, pregnancy, stigma, where to find treatment, causes and prevention). Although most of the 3-minute videos were designed for Web use, two shorter videos with a clear concise message will be used for public news broadcasts (pregnancy and living with epilepsy).

The League has undertaken a campaign to draw attention to the successes of members of our constituency and the importance of epilepsy. Letters have been written to appropriate authorities (deans, regional and national health ministers) about important contributions made by our colleagues (awards, organization of successful events, publication of important documents, elections to leadership positions, celebrations). Authorities will receive the message that epilepsy-related work provides much positive publicity for their institution or country and that epilepsy is an important health problem. We encourage further interaction with the national Chapters in these initiatives. As with any such effort, the results can be slow in appearing and require regular reinforcement, but feedback from some members suggested that these efforts have resulted in first contacts with health ministers as well as positive responses from deans.

Goal 3: ILAE shall work to ensure its ongoing organizational and financial viability.

In 2013, the League will be electing its new officers. The dates for each step will be communicated to all Chapters by the Chair of the Elections Committee, Past President Peter Wolf.

The new Conflict of Interest policy is also available on the website.

To enhance communication among Commissions and with the leadership, a Commission Chair meeting is held annually. Here, Regional and Task-Oriented Commissions present their work and identify synergies for collaboration. The Commission Chairs will meet again in December 2011 to identify projects congruent with the 2009 ILAE Strategic Plan that can be completed in 2012 and 2013. In addition, the League's leadership has asked Commissions to include plans to disseminate reports and activities to stakeholders and to implement action items.

As discussed in the Year 1 report, steps have been taken to enhance the management of our financial resources and improve transparency in reporting and disclosing financial data. Our Finance Committee and

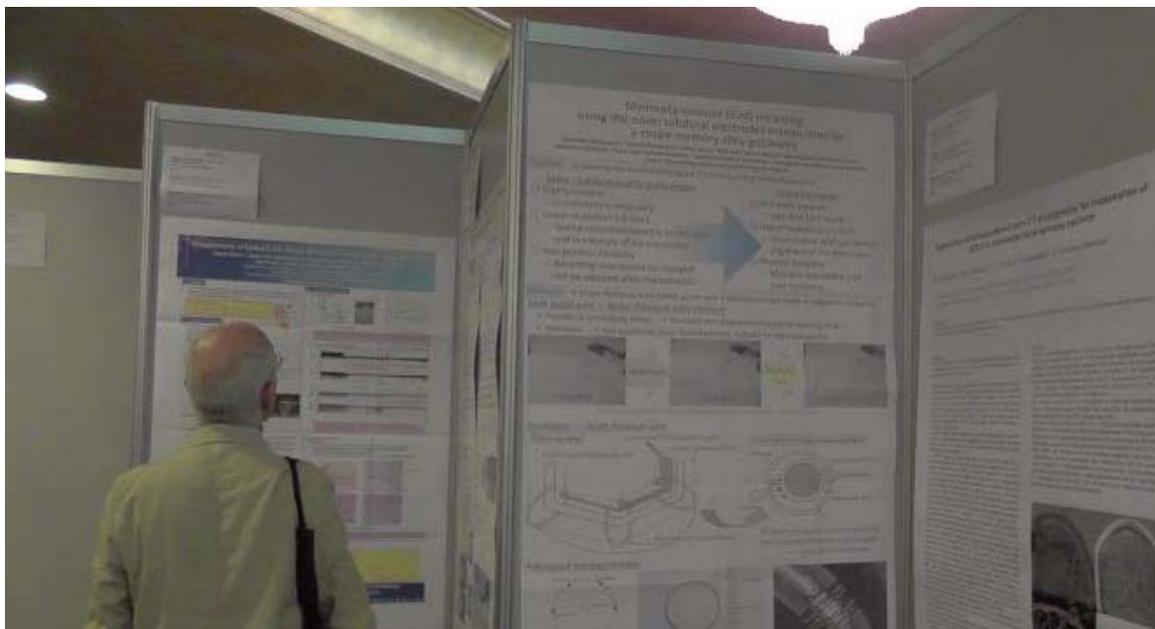
PRESIDENT'S REPORT *(continued)*

Financial Advisory Subcommittee, which include members of the financial and corporate world, have worked effectively to this end. The most important product of these activities has been the finalization of a new Investment Policy intended to improve returns on the League's investments while maintaining a conservative approach consistent with the organization non-profit status and goals. One of the goals will be for the League to be able, within the next 10 years, to derive a sufficient return from investments to support activities at the current level, thereby compensating for a projected loss in revenue from Congresses and other sources. The new Investment Policy also recognizes the international scope of our activities by making provisions for diversification in currency and world markets. To this end, the Executive Committee endorsed the recommendation of the Finance Committee and the Financial Advisory Subcommittee to switch the management of the League's investment to a new Financial Manager with expertise in operating at the international level. The performance of the latter will be monitored closely according to predefined

benchmarks. Finally, the new Investment Policy recognizes potential conflict of interest issues by forbidding direct investments into industries which develop/market pharmaceutical products and medical devices.

We again thank the many volunteers who contribute their time and energy toward accomplishing the League's strategic aims and overall mission to improve the lives of people with epilepsy throughout the world. We also thank our administrative staff, in Hartford: Peter Berry (Chief Staff Officer), Donna Cunard (Financial Manager), Priscilla Shisler (Leadership Liaison) and in Dublin (in close collaboration with the IBE) Gus Egan and Carla Glynn (Chapter Services Coordinators) under the direction of Richard Holmes, International Director of Meetings.

Solomon L Moshé
President



IEC 2011 Poster Session

TREASURER'S REPORT



According to the Strategic Plan created in Budapest at the beginning of this Executive's term, my mandate as the League's Treasurer was to secure and diversify our main sources of income; to ensure that income and expenses are in line with our goals and aims; to ensure high professional standards in terms of financial management and internal control; to reduce the organization's fixed costs, including streamlining our various administrative offices; and to monitor ILAE's financial business plan, reserve policy, and investment portfolio.

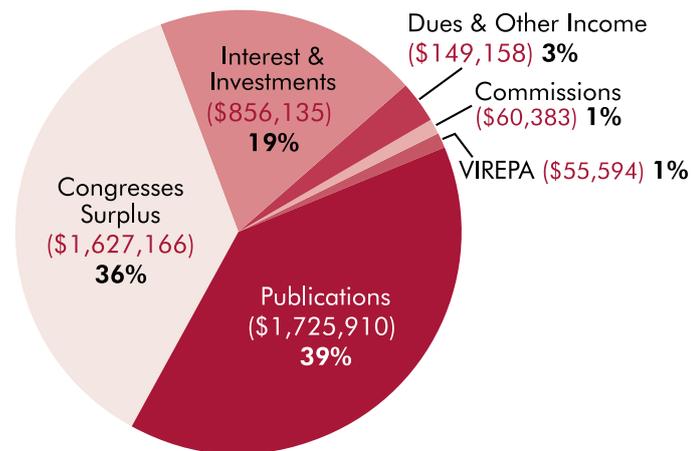
The actions taken for the past 2½ years to fulfil this mandate are as follows:

- League assets have increased \$3 million due to recovering investment gains after the economic crisis of 2009, reducing administrative costs by 30% and negotiating a favorable contract with the publishers of *Epilepsia*
- Support to Commission activities increased 21% from 2009 to 2010. At the same time, we created a Budget Review Committee that includes colleagues from all regions of the world. This Committee assists the League's Finance Committee and the Executive Committee in evaluation projects/budget applications from each of the League's Commissions
- A Finance Advisory Subcommittee was established. This group is comprised of volunteer professionals from the international corporate and banking world, with top-level expertise on financial matters. Their remit is to assist the Finance Committee and the Executive Committee in ensuring that our investment policy is optimally adjusted to address the League's mission. The Advisory Subcommittee also assists the Treasurer and the Financial Manager in monitoring the day to day performance of the League's investments
- The Investment Policy was revised and a separate Cash Management Policy created to address currency and regional diversification in line with the League's global mission
- A new investment firm (UBS AG, New York) has been selected to implement the League's investment policy.

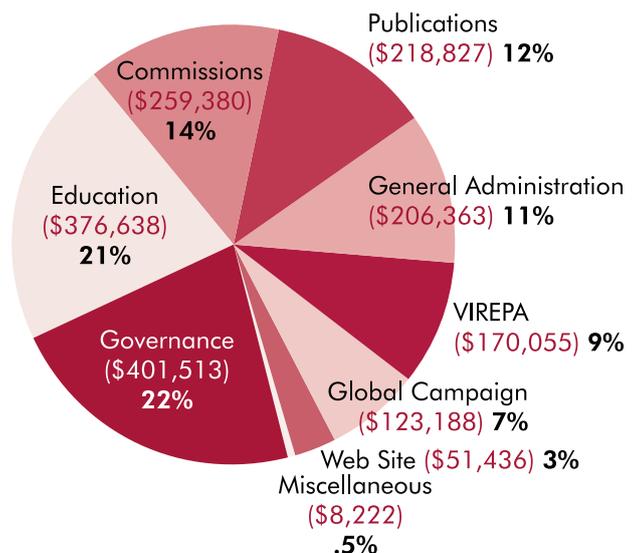
Summaries of revenue and expenses for 2010 (actual data) and 2011 (budgeted data) are presented in the pie charts. The year 2010 was exceptional in terms of revenue, due to A) receipt of a one-time only \$500,000 signing bonus for renewing our contract with the *Epilepsia* publisher, B) a peak surplus from Congresses (which typically show high variation in surplus from one year to the next), and C) high return from investments related to a striking rebound of financial markets in that year. For 2011, projected revenue is conservatively expected to be about 40% lower than 2010. Between 2010 and 2011, we also increased substantially our expenditure to support the expanding activities of our Commissions and a wide range of educational projects.

2010 FINANCIALS

TOTAL 2010 ACTUAL REVENUE \$4,474,346



TOTAL 2010 ACTUAL EXPENSES \$1,815,622



TREASURER'S REPORT (continued)

With respect to ensuring long-term financial viability of the League, the Investment Policy revision and the selection of a new investment firm are the result of an extensive one-year review by the newly established Finance Advisory Subcommittee. After careful consideration and analysis of the League's current financials and anticipated future revenues and expenditures, the Committee submitted a series of recommendations to the Finance and Executive Committees. These recommendations emphasized the need to safeguard the League against expected declines in revenues by increasing the investment fund to a level that would generate sufficient earnings to allow the League to continue to operate at current levels. These recommendations were unanimously approved by the Finance and Executive Committees and will be fully implemented in 2012.

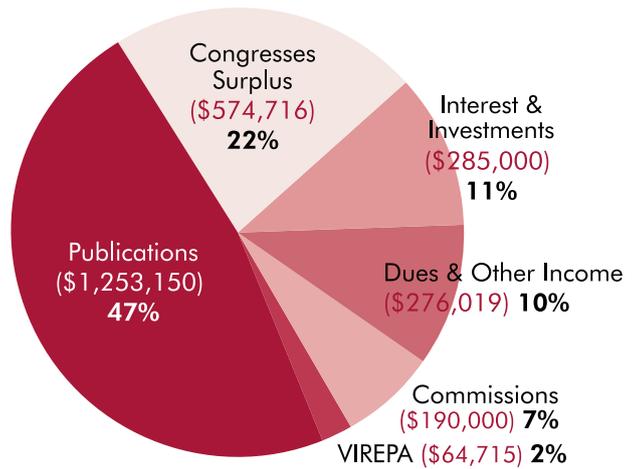
Globally speaking, these are financially challenging times. In addition to anticipated revenue decline, we must also be aware of market volatility and threats of inflation. We are very fortunate to have expert advice to help us navigate through these troubling times. For the remainder of my term, we will continue to assess and evaluate the new policies to ensure that ILAE will now and in the future have the financial means to continue the fight against epilepsy world wide.

Emilio Perucca
ILAE Treasurer

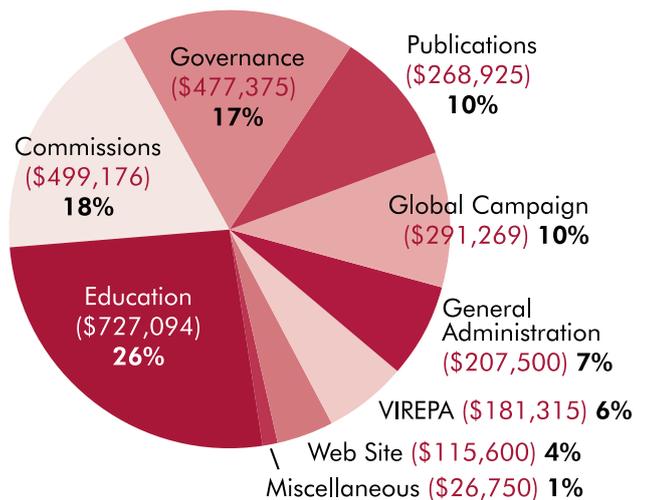


2011 BUDGET

BUDGETED 2011 REVENUE \$2,643,600



BUDGETED 2011 EXPENSES \$2,795,004



SECRETARY-GENERAL'S REPORT



It is a pleasure to report on the activities of the ILAE during the second year of this Executive Committee. A brief glance at the report leaves no doubt that the many accomplishments listed here are the direct result of the vision, commitment and perseverance of our many colleagues and collaborators from around the world. Their work, individually and collectively, makes ILAE what it is, and to them we owe a debt of gratitude.

Some of the highlights during this year include the following:

1. A new Task Force on Guidelines, co chaired by Tim Pedley has been appointed. The ILAE is often looked upon as the international professional organization responsible for producing authoritative practice parameters in epilepsy. This important task force will formally develop the area of practice parameters and related documents for the ILAE. The task at hand is challenging and it will require the help of many volunteers.

2. The League's website has been redesigned under the able direction of Jean Gotman, Ed Bertram and a Web Editorial Team. Each Commission has the responsibility to oversee the content of its section and to create links to ILAE activities including long distance education and global outreach. Plans are underway to provide our chapters access to various forms of ILAE Social Media.

3. *Epilepsia*, the League's journal, continues to develop to meet the needs of our constituencies. The journal is now available on line at no charge to our chapter members in resource-poor countries belonging to the Hinari program. In addition, the League is considering creating a sister on-line journal. Plans are underway for appointment of the next Editors-in-Chief. By 21013, Phil Schwartzkroin and Simon Shorvon, will have completed 8 years of service in this capacity. We anticipate that the new Editor(s) will be appointed by January 2013 and will begin their tenure with the new Executive in 2013.

4. Congresses: The 29th International Epilepsy Congress in 2011 in Rome was highly successful and had nearly 4,000 delegates. Four Regional Congress are scheduled for 2012, including the 9th Asian-Oceanian Epilepsy Congress in Manila (21-25 March 2012), the 10th European Congress of Epileptology in London (30 September-4 October 2012), the Latin American Epilepsy Congress in Quito, (14-17 November 2012) and the 1st African Epilepsy Congress in Nairobi (21-23 June 2012). The 30th International Epilepsy Congress will be held in

Montreal, Canada on June 23-27, 2013.

5. Distance Education: Through direct oversight and expansion of the Virtual Epilepsy Academy (VIREPA), this program is now organizationally and financially stable. The Task Force on distance education, led by Walter van Emde Boas, is increasing the attractiveness and accessibility of ongoing courses, and has add new courses on Pediatric Epilepsies and EEG, Psychiatric aspects, and Sleep and Epilepsy.

6. New Slogan: The Global Outreach Task Force has identified a new slogan, initially proposed by Mike Glynn, the President of IBE: Stand up for epilepsy. The slogan is in the process of being registered.

7. Regional Initiatives: The League and the Bureau have been engaged in a number of regional activities aimed at highlighting the public health dimensions of the epilepsies and raising political support to prioritize allocation of resources to epilepsy health care and research. These initiatives include the production of an epilepsy report by the U.S. Institute of Medicine (IOM) (<http://www.iom.edu/Activities/Disease/Epilepsy.aspx>), the finalization of the Pan American Health Organization (PAHO) Strategy for the Americas, (http://new.paho.org/hq/index.php?option=com_content&task=view&id=5272&Itemid=3841&lang=en), and the support for the European Declaration on Epilepsy to be endorsed by the European Parliament (<http://www.ilae-epilepsy.org/visitors/initiatives/EuropeanDeclaration.cfm>).

8. Five New Task Forces have been established: 1) The Seizures and Epilepsy in the Tropics Task Force (chair P. M. Preux), working in close collaboration with the Global Outreach Task Force, aims to address issues pertaining to seizures and epilepsy in the tropics, in particular as they relate to etiology, socio-cultural aspects and management. 2) The Stigma Task Force (N. Jetté, chair) with support from the North American Commission, aims to determine ways to combat epilepsy-related stigma and its consequences world wide. 3) The Sports Task Force (G.Capovilla, chair), has two main aims: a) To seek out and foster opportunities for interactions with major sports authorities and organizations to increase awareness about epilepsy worldwide. b) To increase awareness and participation of people with epilepsy in sports activities according to their capabilities and not limited by epilepsy. 4) The Task Force on Pre-clinical Drug Discovery (M. Simonato and T. O'Brien, chairs) intends to develop standardized definitions, pathways, techniques and endpoints for pre-clinical drug development for new epilepsy treatments, and to

SECRETARY-GENERAL'S REPORT *(continued)*

enable a stronger evidence base to identify the optimal candidates to take forward to clinical development. 5) The Task Force on ILAE Reports (E. Bertram, chair), will develop guiding principles for writing reports generated by the ILAE, standardize processes for their internal and external review, and develop criteria for their designation as official position statements of the League.

9. Seven New Chapters. During the 29th International Epilepsy Congress in Rome, the General Assembly ratified seven new National Chapters (Bolivia, Cameroon, El Salvador, Kosovo, Kuwait, Nigeria, and Sri Lanka), for a total of 108 active chapters. In addition, applications from 14 countries are being processed. The League's secretariat is reviewing and modifying the rules regarding chapter incorporation to increase participation. Regional commissions have

been asked to facilitate ways in which isolated clinicians can easily interact with the League in countries and territories where formation of an ILAE Chapter is currently unfeasible.

10. Constitutional Amendment. The new Constitution was ratified by the General Assembly at the 29th International Epilepsy Congress held in Rome on August 31, 2011 and is available on the website (www.ilae-epilepsy.org). It ensures that all regions have a voice and a seat in the Executive Committee. In 2013, the League will be electing its new officers.

Samuel Wiebe
Secretary-General



Audience in Scientific Session at 29th IEC in Rome

STAFF REPORT



Staff is pleased to continue to play a role in the development and implementation of new League programs and services.

The following stand out as major accomplishments over the past twelve months:

- Completed the Website Design Project in collaboration with Jean Gotman, Director of Interactive Media. The redesigned site has an improved appearance, streamlined navigation, enhanced search functionality, and video-streaming capability.
- Developed customized websites for the Commissions. The Commissions are now able to create and modify their own content. A training manual was developed to assist in this work.
- Created an online form for the submission of web content material.
- Implemented and enhanced the online system to facilitate the submission and review of Conflict of Interest Disclosure Statements for the Executive Committee, as well as members of Commissions and Task Forces.
- Worked with the Commission Chairs in the development of their plans and budgets for 2012. Staffed the Commission Chair meeting held in Baltimore, Maryland, USA.
- Enhanced the VIREPA distance education web-based application and registration system to support the increase from three to six course offerings.
- Assisted the Constitution Task Force in the revision of the newly ratified Constitution and Bylaws.
- Worked with the Secretary-General in providing background information and assistance to those interested in creating a Chapter. Seven new Chapters were accepted by the General Assembly, bringing the total number of Chapters to 108.
- Coordinated and staffed meetings of the International Chapter Convention and General Assembly held at the IEC in Rome. 89 persons from 60 countries attended the meetings.
- Assisted in the search and selection of a new investment firm.
- Assisted in the revision and implementation of new Investment and Cash Management Policies.
- Organized and staffed meetings of the Finance Committee and Advisory Sub-Committee.
- Assisted the Treasurer in the development of the Operating and Commission Budgets.

Deborah Flower joined the staff team in the position of Web Content Administrator. Deb has ten years of experience as Website Manager at two insurance companies. In these positions, Deb coordinated and created web content for the public, agents, and employees, gaining



experience in web content management, web writing, editing, usability, taxonomy, and testing.

As a project team member, she supported all lines of business by designing, executing, and testing web content and functional enhancements. She wrote system specifications for new or enhanced Web site applications; tested and tracked defects for new applications; and served as business lead on integration of a search engine into the Web site resulting in effective full text search of all content. In addition, she trained content providers throughout company in use of the content management software to enable these subject matter experts to maintain web content in their areas of expertise, resulting in more accurate and timely content maintenance

My sincere thanks to the rest of the ILAE staff team – Priscilla Shisler, Donna Cunard, Gus Egan, Carla Glynn, and Cheryl-Ann Tubby for their hard work on behalf of the League this past year.

Priscilla Shisler serves as Leadership Liaison to the Executive Committee, staffs the Education Commission, and works on projects related to the website, VIREPA, and assists the Commissions with communications and meetings.



Donna Cunard serves as the League's Financial Manager and works closely with the Treasurer. Donna oversees all of ILAE's financial transactions and the production of the monthly financial statements. She also liaises with the League's accountant on the preparation of the annual tax return and Audit report.



Gus Egan and Carla Glynn are based in the Dublin, Ireland, IDM Office. They work primarily with the League's Chapters, coordinate the Chapter Conventions, maintain the Chapter database, liaise with the Secretary-General on the processing of new Chapter applications and promote the League through the use of the booth.



Cheryl-Ann Tubby is the primary staff contact for the League's Information Officer. Cheryl-Ann coordinates the production and distribution of the League's newsletter, Epigraph, and the Annual Report.



Staff looks forward to 2012 and will build upon past efforts in support of the ILAE's Executive Committee, Commissions, and Chapters.

Peter J Berry, CAE
Chief Staff Officer

FIRST VICE PRESIDENT'S REPORT



My activities during the last twelve months can be summarized as follows:

1. Chair of the Constitution Task Force

Through frequent meetings of the Constitution Task Force Members (Drs Michel Baulac, Marco T Medina, Simon Shorvon, Samuel Wiebe and Tatsuya Tanaka) during the past two years, a final amended version has been finalized with a number of changes to the ILAE Constitution. The major amendments were targeted to the structure of the League and responsibilities of its officers. The proposal of Constitution Amendment by the Constitution Task Force was approved by the Executive Committee Meeting on 26 March 2010 in Ghent. At the Rome International Epilepsy Congress, prior to the General Assembly, the final version was discussed in the Chapter Convention on 28 August 2011. Several discussions and confirmations were proposed from the Russia, China, Bangladesh and Great Britain Chapters. Finally, the proposed final version was approved unanimously by all attending Chapters. The General Assembly of the ILAE was held on 31 August 2011. The major part of the Amendment of the Constitution was presented by the Secretary General (Sam Wiebe) and followed by a Motion. The new Constitution was ratified unanimously. Following the ratification of the Constitution, the League's Bylaws were also amended according to the amended

Constitution by frequent ILAE Executive Committee meetings. The final version of the amended Bylaws was ratified by the EC Teleconference Meeting on 2 October 2011. The new Constitution and Bylaws have been uploaded to the ILAE website. The new structure would be implemented for the 2013 Executive Committee Election.

2. Collaboration with the work of Task Forces and Commissions

As a member of the Conflict of Interest Task Force, an EC Liaison Officer of the Diagnostic Method Commission and an EC Liaison Officer of the Commission of Asian Oceanian Affairs (CAOA), many collaborative works were performed during the past twelve months. The next 9th Asian Oceanian Epilepsy Congress (AOEC) will be held in Manila in March 2012. The Organizing Committees of the 9th AOEC have already started activities and finalization of the program is now ongoing. I joined as a member of the Scientific Organizing Committee.

Tatsuya Tanaka
First Vice President



Executive Committee with Chair of Commissions and Task Forces at October 2009 meeting in Newville Bosc, France

THIRD VICE PRESIDENT'S REPORT



Pan American Health Organization (PAHO) Strategy and Plan of Action on Epilepsy

Co-Chairs: Marco T Medina, ILAE and School of Medical Sciences, National Autonomous University of Honduras, Tegucigalpa, Honduras; Carlos Acevedo, IBE, Santiago, Chile; Jorge Rodriguez, PAHO Mental Health, Washington, USA

Health authorities from the countries of the Americas agreed to make epilepsy a priority issue and to strengthen the health sector response to the disorder, with a focus on primary health care for the next ten years (2011 to 2021). Epilepsy is one of the world's most common chronic neurological disorders. Roughly 50 million people suffer from it, five million of them in the Region of the Americas. Nevertheless, it is estimated that over 50% of these people in Latin America and the Caribbean have no access to services (1, 2).

A strategy and plan of action on epilepsy was collectively prepared by PAHO and a team of more than thirty mental health experts of the Region, with the active support and participation of the ILAE, IBE and the WHO in Geneva. Consultations were also conducted in several countries with the cooperation of the health ministries and other national actors. A first meeting in August 2010 was done during the Latin American Epilepsy Congress in Cartagena, Colombia. A PAHO, ILAE and IBE joint commission was established. Jorge Rodriguez, Carlos Acevedo and Marco T. Medina were appointed as co-chairs.

A presentation of the "Strategy and plan of action on epilepsy" at PAHO Executive Committee meeting was done 20 June 2011 in Washington DC. The representatives of the United States, Mexico, Cuba, Chile, Canada, Honduras, Guatemala and Peru enriched the debate with their contributions.

The delegations from the Member States of PAHO officially approved the Strategy and Plan of Action on Epilepsy during the 51st Directing Council in Washington, DC on 29 September 2011 (http://new.paho.org/hq/index.php?option=com_content&task=view&id=6009&Itemid=259)

Under the new strategy, countries will work to:

1. Make epilepsy a national health policy priority, implementing national programs that are adapted to conditions in each country;
2. Strengthen legal frameworks to protect the human rights of people with epilepsy and to ensure effective enforcement of relevant laws;
3. Promote universal and equitable access to medical care for all people with epilepsy by strengthening primary care systems and integrated service networks;

4. Ensure the availability of the four antiepileptic drugs considered essential for treatment of the disorder;
5. Strengthen neurological services to support case detection and management at the primary care level, ensuring adequate distribution of the necessary auxiliary diagnostic media;
6. Support effective participation by the community, patient associations and family members in activities designed to improve care for people with epilepsy;
7. Consider the strengthening of human resources as key to improving national epilepsy programs;
8. Promote intersectorial and educational initiatives to combat stigma and discrimination against people with epilepsy;
9. Close the information gap in the field of epilepsy by improving the production, analysis, and use of information, including research;
10. Strengthen partnerships between the health sector, other sectors, and nongovernmental organizations, academic institutions, and key social actors.

A Launching and Regional Workshop of the Strategy and Plan of Action on Epilepsy was held 19 – 21 October 2011 in Tegucigalpa, Honduras. During the Workshop a PAHO/IBE/ILAE Joint task force was established in order to develop the strategy, this task force will start its work in January 2012.

Marco Tulio Medina
Third Vice President



Participants of the Launching and Regional Workshop, 19 October 2011, Tegucigalpa, Honduras

EPILEPSIA REPORT



This was a good year for *Epilepsia*. During the Volume 51 year, twelve regular monthly issues were published (totaling 2501 pages), with all issues published within the scheduled month; in addition, the following five supplements were published:

Supplement 1: Epilepsy at the Cutting Edge: A Symposium to Honor Fred and Eva Andermann

Supplement 2: 50th Meeting of the German Society Against Epilepsy (Abstracts)

Supplement 3: 10th Workshop on the Neurobiology of Epilepsy (WONOE): Novel Therapeutic Approaches to Epileptogenesis

Supplement 4: Abstracts from the 9th European Congress on Epileptology

Supplement 5: *Jasper's Basic Mechanisms of the Epilepsies*, Fourth Edition

In terms of circulation and readership, there were 669 institutional subscriptions to *Epilepsia* (a renewal rate of 87%), with over 4,000 institutions having access to the Journal. In addition, *Epilepsia* participated in the HINARI program to provide the Journal free of charge to 3,300 public institutions in 108 resource-poor countries. In 2010 there were 779,641 full-text downloads to *Epilepsia*, reflecting an increase of 12% over the previous year. In bibliometric terms, in 2009 *Epilepsia* was ranked 23 out of 167 journals in the Clinical Neurology category, had an impact factor of 4.052, and a 5-Year Impact Factor of 4.299. The average number of days from final acceptance to Early View publication was 35 – 40 days, an excellent record.

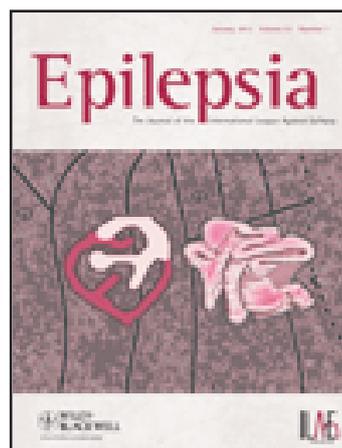
A new Wiley-Blackwell *Epilepsia* website was put online, providing greater access to search engine spiders and thus allowing more extensive indexing. The new site is also more easily accessible for users in libraries, which are significant referrers of traffic to the site. Wiley-Blackwell offered *Epilepsia* the possibility of developing a smart-phone app for accessing/downloading *Epilepsia* articles; implementation of that app was planned for 2011.

During the 2010 year, Laurie Beninsig replaced Alison

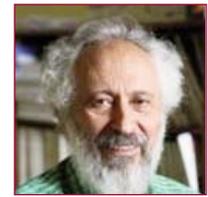
Alsmeyer as Managing Editor. Laurie had experience with the Journal already, having worked in Phil Schwartzkroin's office on Journal projects. She has done an excellent job since her appointment, and the editorial management of the Journal has continued smoothly. The Editors-in-Chief and Managing Editor met regularly (via conference call), consulted with the twelve Associate Editors, and convened an Editorial Board meeting at the annual AES Conference.

In terms of editorial policy, a number of key decisions were made to tighten the criteria for accepting manuscripts for publication (in view of the pressure for space and the increasing number of submissions), to change procedures and criteria for online papers (in particular, publishing all Brief Communications online only), and to add a further stage in the decision-making process that involves active approval by the Editors-in-Chief. These changes are now largely implemented, and have resulted in a lower acceptance rate – but also raised significant issues about how to deal with certain types of articles. Discussions about how to deal with this latter problem continue.

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



INTERACTIVE MEDIA REPORT



The plan to re-do the ILAE website started in 2010. The purpose was to improve the quality of the website, its ease of use, the accessibility of the information, and to make the website more informative and more useful to the community served by ILAE. It was originally expected that the new site would be launched in April-May 2011 but was delayed until 1 August 2011 due in part to technical difficulties related to the complex interactions between the website, Higher Logic and different ILAE databases. The new website has been operating well and was generally well received.

General Operation

It was planned to have a **Web Manager** work an approximately three-day week starting in August to perform the regular maintenance of the website (collecting, posting and organizing new information, removing old information). A person was hired in August and worked for one month but was found to be inadequate. The maintenance has been performed ineffectively by Priscilla Shisler, although some tasks had to be delayed. The website has been dynamic, posting new information frequently. A new Web Manager, Deb Flower started working on November 10. She looks very promising and has already performed important tasks. We have been investigating the most appropriate way of posting **videos**, as many have been recorded during the Rome meeting and at other meetings. This is a relatively complex task (video formats, streaming speed...) but a solution has now been identified. We are also currently working with a firm specializing in improving the **visibility** of the website to search engines; several important weaknesses of our site have been identified and are in the process of being corrected. A web-based form was developed for submission of material to be put on the website.

Commission Sites

A commission-specific site was created for each Commission, with the idea that each Commission would be able to post information on its website and modify it easily. It was intended that Information Officers of each website would be trained to perform these activities after the Rome meeting. Because of our inability to have a Web Manager by then, this training was postponed and will take place in December 2011 and January 2012. A training document explaining every step of the modification procedure is ready. It is expected that the Commissions will be able to manage their own sites during the first quarter of 2012.

Web Editorial Board

A Web Editorial Board was put in place and met in Rome. It consists of the following individuals: A Arzimanoglou, A Kanner, E Bertram, F Chaves Sell, F Lado, G Capovilla, and N Jetté. The Board is asked to provide input on the format of the website and to provide information worthy of putting in the News section.

Plans for 2012

The coming year will be the first year of full operation of the new website. We expect that by the first quarter the Web Manager will be fully operational, allowing more dynamic and useful information to be placed on the website. We also expect that the web search optimization will be largely completed. This should result in a more useful and more frequently used website.

As we have been actively using the website, we have already identified some of its weaknesses and we will probably embark on a "web 2.0" project by mid-2012. The purpose will be two-fold: to improve the website so that it better fits its new dynamic nature and to change the underlying software platform. This platform change is necessary because we built the new site with relatively old software technology because this is the technology that was familiar to the available personnel and we did not want to unduly delay the launch of the new site. Now that we are not in a rush, it is time to plan the move.

In the second or third quarter, we will start investigating the presence of the ILAE on Facebook and Twitter.

Jean Gotman
Director of Interactive Media



GLOBAL OUTREACH TASK FORCE REPORT



Mission

The ILAE/IBE/WHO Global Campaign Against Epilepsy (GCAE) has as a mission statement: *To improve the acceptability, treatment, services and prevention of epilepsy worldwide.* The ultimate goal of the Campaign is to close the treatment gap in epilepsy! To date over 100 countries have developed activities under the Campaign.

In 2009, a Task Force was established with the aim of establishing a Strategic Plan with action points to forward wider development of activities within the GCAE, and raise awareness of achievements. A Strategic Plan was finalized, with four main goals by which certain progress could be tracked over a four year period:

1. *To improve the visibility of epilepsy and the activities of the Global Campaign in all countries;*
2. *To promote activities of all epilepsy projects on a country and regional level;*
3. *To assess and strengthen health care systems for epilepsy;*
4. *To increase partnerships and collaboration with other organizations.*

It has become clear, however, that throughout the world there are many initiatives that could be interpreted as Global Outreach, which need increased awareness, but such activities are not necessarily directed through the collaborative efforts of the GCAE. The Task Force was therefore renamed 'Global Outreach' with a primary aim of raising awareness of global educational and service initiatives in epilepsy throughout the world.

Activities

Regional activities

AMRO – Strategic Plan for Epilepsy

During the 6th Latin American Congress, a meeting was organized involving stakeholders in the Region, IBE and ILAE Presidents, representatives of the Global Campaign and of PAHO with the aim to develop a strategic epilepsy plan for the Americas. The purpose of this plan is for the regional leadership of PAHO, which involves all Ministers of Health of all the Member States, to include epilepsy as a health priority for the next 10 years. The Strategic Plan was approved on 29 September 2011 by the Ministers of the Health Council of the Americas in Washington, during their Annual Meeting. The plan will lead to the commitment of all countries in the region to develop, based on the national realities, a national plan for epilepsy. Thus epilepsy is now included in Americas Government Health Priorities. All countries will be obliged to submit an annual progress report to WHO/PAHO. This document may be a model which can be used in the

other regions of the world. In October the Strategic Plan was launched in Tigucigalpa, the capital of Honduras. The entire process was initiated under the auspices of the Global Campaign Against Epilepsy.

EURO – Written Declaration on Epilepsy

A Joint Task Force of ILAE and IBE, Epilepsy Advocacy Europe (EAE), was established, aiming at the facilitation of initiatives to enhance public awareness and support for research in epilepsy in Europe. EAE seeks to make epilepsy a priority in political and research establishments across Europe. The first initiative of this Task Force was the establishment of a European Epilepsy Day, which was launched on 14 February 2011 in the European Parliament in Strasbourg, France. Following this, a number of meetings took place between Task Force representatives and Members of the European Parliament (MEPs). A special working group of Members of European Parliament with an interest in epilepsy was formed and the first action of this group was to support a Written Declaration on Epilepsy approved by the European Parliament. This was a major project as it required a minimum of 369 signatures of MEPs which had to be obtained within three months. At the end of the three months a total of 459 MEPs had signed and the Declaration was passed in the European Parliament on 15 September 2011. The Declaration is a very important document to use at local and EU level, for example, in

- advocating for increased research funding
- advocating for improved healthcare facilities and service provisions for people with epilepsy
- building other significant initiatives at European level

Assessment of country needs and resources on epilepsy

In early 2011, a project to conduct a needs and resource assessment specific to epilepsy in Tajikistan was initiated by GCAE in collaboration with the WHO European Regional Office, and WHO Country Office Tajikistan. The first step in this project was to create a standardized data collection instrument for epilepsy, building on other related collection tools and reports, such as the data collection survey used for the WHO Epilepsy Atlas 2005, the WHO tool for mental health systems (WHO – AIMS 2.2), GCAE's "A Questionnaire on People with Epilepsy: Legislation and Human Rights" and World Federation of Neurology Survey on Neurology Education and Training. The instrument development process involved identification of the 'domains' to be addressed, then deciding on the 'areas' that would be evaluated under each domain and finally creation of specific 'indicators' pertaining to each area. For data collection, the WHO Country Office focal point individual identified a group of stakeholders who implemented the tool and provided

GLOBAL OUTREACH TASK FORCE REPORT

(continued)

the responses to questions. Interpretation of the data collected is being completed and the next steps of this project involve preparation of a country report that would be useful to integrate epilepsy diagnosis and treatment into primary care in Tajikistan, and that may also be used as the basis for a demonstration project.

A project has now been proposed to IBE and ILAE with a main objective to improve and replicate administration of the epilepsy need and resource assessment instrument in two European countries over the next two years.

Demonstration Projects

General Objectives are to reduce the treatment gap and the social and physical burden of epilepsy, educate health personnel, and dispel stigma. Demonstration projects have been completed in Senegal, Zimbabwe, Brazil and China. The ultimate goal is to develop a variety of successful models of epilepsy control that will be integrated into the healthcare systems of the participating countries and Regions and, finally, applied on a global level.

As part of an epilepsy Demonstration Project (under the aegis of the Global Campaign Against Epilepsy), carried out in rural areas of six non-contiguous provinces of the People's Republic of China, it was estimated that the number of people with epilepsy in China is almost 9 million with a treatment gap of 63 percent. The Demonstration Project was successful in implementing treatment and management of convulsive forms of epilepsy in rural areas of the country. Physicians with basic training were shown to be able to treat people with epilepsy. This cost-effective approach was successful in reducing the treatment gap by about 13 percent.
Dr Hans Troedsson, WHO Representative
WHO Country Office, China*

The epilepsy project in China is an example of successful partnerships: in the first place, the partnership between IBE, ILAE and WHO, but more importantly the partnership with China's Ministry of Health, national Chapters and Members of IBE, ILAE and other scientific societies, WHO regional and country offices, other NGOs and WHO Collaborating Centers.

Mike Glynn, President, IBE
Solomon L Moshé, President, ILAE
Benedetto Saraceno, Director, Department of Mental Health and Substance Abuse, WHO*

* *Epilepsy Management at Primary Health Level in rural China: WHO/ILAE/IBE Demonstration Project: WHO China Office 2009*

Demonstration Projects are being finalized in Georgia and have been initiated in Honduras whilst the means are being sought to also initiate one in Cameroon.

In October of this year a symposium/workshop was organized to evaluate the consequences of the project for epilepsy care in Georgia with the participation of

both IBE/ILAE Presidents; the Chairs of the Global Outreach Task Force; Hanneke de Boer; principal investigators of most Demonstration Projects (completed, ongoing and future projects); Tarun Dua, representing WHO Headquarters; Matthijs Muijen, the WHO Regional Advisor for Mental Health and Neurological Disorders; representatives from SEIN; politicians, including the Minister of Health for Georgia; professionals from Georgia, Armenia and Azerbaijan. The workshop and symposium were held in Tbilisi, Georgia. This event marked the official closure of the ILAE/IBE/WHO Global Campaign Against Epilepsy Demonstration Project on Epilepsy in Georgia. The results of the project were presented at the symposium; the workshop focused on the concept of the demonstration projects. Reports on all projects were presented, and their consequences, outcome assessment and lessons learned. A full report on this workshop will appear shortly.

Project on the burden of epilepsy

The Global Burden of Disease, Injuries, and Risk Factors Study (GBD) (1990) provides a complete systematic assessment of the data on all diseases and injuries. Within a new GBD project, comprehensive estimates of the burden of epilepsy, its disabling sequelae and its role as a risk factor for other diseases and injuries will be developed.

Specific aims:

1. To generate comprehensive estimates of the burden of disease due to idiopathic epilepsy;
2. To generate comprehensive estimates of the burden of disease due to epilepsy;
3. To generate comprehensive estimates of the mortality and burden of disease due to epilepsy.

The Global Campaign Against Epilepsy continues to contribute to the above process.

Development of guidelines on the treatment of epilepsy in children and adolescents

An algorithm was developed for diagnosis and treatment of neonatal seizures especially in resource limited settings, aimed at clinicians in developing countries in collaboration with the WHO Department of Child and Adolescent Health and Development and published in *Epilepsia*. The guidelines will be published shortly.

Project on legislation

The results of this project will be useful for policy makers, health planners, administrators, legislators, lawyers, health professionals and patient groups at a national, regional and international level. A document on the subject has been developed and is ready for publication. Even during its execution the project served as a source of information and offered support to IBE/ILAE members involved in the development of anti-discriminatory legislation in connection with epilepsy. For instance, the Campaign Co-ordinator and others have been instrumental in the development and approval process of a law for the protection of the rights of people with epilepsy in Colombia, which was signed for approval by the President.

GLOBAL OUTREACH TASK FORCE REPORT

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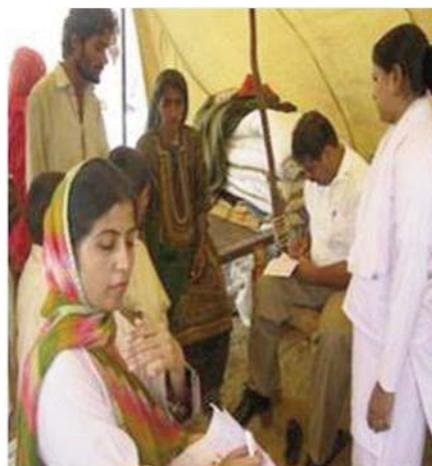
mhGAP Forum

In all countries throughout the world, there is a wide gap between the high prevalence of mental, neurological and substance use disorders and the low proportion of affected individuals that receive adequate care. This gap is particularly wide in low- and middle-income countries. To assist Member States in addressing this gap, WHO launched the mental health Gap Action Program (mhGAP) in 2008: a technical assistance program aimed at supporting Member States in scaling up care for priority mental health conditions, within the context of overall health system strengthening, with a particular focus on low- and middle-income countries.

The “mhGAP Forum” is an informal and evolving group of Member States, intergovernmental and non-governmental organizations, including UN Agencies, international development agencies, philanthropic foundations, research institutes, universities and WHO Collaborating Centers. In October of this year the 3rd meeting of the mhGap Forum took place in Geneva. Emilio Perucca, Mike Glynn and Hanneke de Boer participated as representatives for the world of epilepsy. One of the sessions of this meeting focused on learning from the experiences of a wide variety of organizations and experts working in low- and middle-income countries. The mhGAP is being implemented by WHO in collaboration with a large number of partners. These include governments, civil society including NGOs, professional associations, academic institutions, including WHO Collaborating Centers, and others. The list of participants for the 2011 mhGAP Forum demonstrated the wide range of partners who are contributing to the objectives of mhGAP. This session illustrated and highlighted some of these contributions. Partners briefly described their

activities with the objective of making others aware and contributed to identifying factors that lead to success and failure in scaling up services for priority conditions. Both Mike Glynn and Emilio Perucca were invited to present a brief report on various aspects of the work of IBE and ILAE and highlighted respectively the successful activities in EURO and AMRO.

Hanneke M de Boer
Helen Cross
Shichuo Li
Global Campaign Coordinators



¹In 1997 the ILAE, IBE and WHO joined together to launch the Global Campaign Against Epilepsy: “Epilepsy: Out of the Shadows”. The objective of the Global Campaign is “To improve the acceptability, treatment, services and prevention of epilepsy worldwide”. The Demonstration Projects initiated by the Global Campaign are to improve accessibility to epilepsy care in the developing countries. A Demonstration Project illustrates good practice in providing services to people with epilepsy and will be used as models of what can be achieved.

WHO: The World Health Organization, leading international public health agency

ILAE: The International League Against Epilepsy, representing medical professionals

IBE: The International Bureau for Epilepsy, on behalf of people with epilepsy and their families, non-medical professionals and the general public



**International League
Against Epilepsy**



**International Bureau
for Epilepsy**



**World Health
Organization**

INTERNATIONAL DIRECTOR OF MEETINGS REPORT



Annual Congress Planning Update

The IDM Office has been assiduously managing and operating the Congresses which took place during the year July 2010 to June 2011, in addition to the planning for future meetings. The year has seen the successful organization of the 6th Latin American Congress on Epilepsy in Cartagena in August 2010; the 12th European Conference on Epilepsy & Society in Porto in August 2010; the 8th Asian & Oceanian Epilepsy Congress in Melbourne in October 2010; and the 29th International Epilepsy Congress that took place at the end of August 2011. Meanwhile preparations are ongoing for international and regional Congresses in 2012, 2013 and 2014.

Gus Egan from the IDM Office team is also overseeing ILAE membership services to assist the ILAE office in Hartford. The IDM Office has provided some administrative support as required in co-coordinating the activities of the Global Campaign Against Epilepsy with the GCAE secretariat office.



The 6th Latin American Congress on Epilepsy took place in Cartagena, Colombia, from 1 to 4 August 2010. The venue for

the Congress was the Cartagena Hilton Hotel, close to the city center and the airport. The Scientific Advisory and Organizing Committee, co-chaired by Manuel Campos, Carlos Acevedo and Daniel Nariño, created a scientific program aimed at stimulating research in the field of epilepsy, enhancing patient care throughout Latin America and raising the profile of epilepsy in the region. The main topics of the Congress were: "Neurocisticercosis"; "Legislation and epilepsy"; "Epilepsy surgery"; "Pediatric epilepsy"; "Reproduction and epilepsy" and "Neuroimaging". The scientific program included six plenary sessions, six discussion group sessions, two satellite symposia and three breakfast sessions supported by industry. Five ALADE courses (Academia Latinoamericana de Epilepsia) were also incorporated into the program. In addition, two Platform Sessions took place and over 155 posters were presented. A 'Highlights' session closed the Congress, giving an overview of the presentations. For the first time, all session audio and slides were captured for publication on the Web page of the ILAE Commission on Latin American Affairs. An IBE Day organized by the local IBE association took place on 31 July at the FIRE Centre which attracted a good number of local attendees. Six hundred and ninety-two participants attended the Congress from all parts of the Central and South American Regions, resulting in the highest attendance to date at a Latin American Congress on Epilepsy.



The 12th European Conference on Epilepsy & Society took place in Porto, Portugal, from 25 to 27 August 2010. The venue for the Conference was the Sheraton Hotel Porto. The theme of the Conference was "Epilepsy: so what?" which analyzed different aspects of living with epilepsy. The Conference also featured a EUCARE session. The Organizing Committee was chaired by Thanos Covanis and comprised the IBE European Regional Executive Committee. One of the most significant events at the 12th ECES was the launch of the European Report on Epilepsy of the Global Campaign Against Epilepsy, which was very successful and well-attended. Eighteen posters were presented during the Conference. Travel bursaries were awarded to four recipients. Attendance at the Conference was 233.



The 8th Asian & Oceanian Epilepsy Congress took place in Melbourne, Australia, from 21 to 24 October 2010. The venue was the Melbourne Convention & Exhibition

Centre (MCEC) in the center of Melbourne. Simon Harvey (Australia), Shih Hui Lim (Singapore), Shunglon Lai (Taiwan), Terence O'Brien (Australia) and members of the Scientific Organizing Committee (SOC) and Scientific Consultative Committee (SCC) were responsible for creating a compelling scientific program. The quality of the scientific program received high praise and there was a higher rate of attendance at the 8th AOEC sessions than at previous AOECs. The main topics of the Congress were: "Epilepsy surgery – who and when?", "Outcome in newly-diagnosed epilepsy", "Prevention of symptomatic epilepsy" and "Psychological well-being in epilepsy". Changes to the program included fewer sessions in parallel, an opportunity for a late-breaking news session and more interactive workshops. The Epilepsy and Society Program (IBE) took place on Thursday, 21 October in conjunction with the Congress and received its highest attendance to date, with 234 delegates. Over 320 abstracts were submitted via the online system and attendance totalled 1,436. There were four prizes for the Tadokoro Awards presented to the two best platform presentations. The inaugural Asian & Oceanian Outstanding Achievement Epilepsy Award was presented to five worthy recipients during the opening ceremony.



The 29th International Epilepsy Congress took place in Rome, Italy, from 28 August to 1 September 2011. The venue was the Rome Marriott Park Hotel. The

INTERNATIONAL DIRECTOR OF MEETINGS REPORT *(continued)*

Scientific Advisory & Organizing Committee (SAOC) comprised Mike Glynn (Ireland), Co-Chair; Solomon L Moshé (USA) Co-Chair; Emilio Perucca (Italy), Congress Director; Federico Vigevano (Italy), Scientific Program Director; Giovanni Battista Pesce (Italy) and Janet Mifsud (Malta). The SAOC identified the following main topics (each session incorporated scientific and social components): “When do we consider epilepsy cured?”; “Impaired consciousness in epilepsy”; “Epilepsy during puberty – the wonder years”; “Predicting the unpredictable: the adverse effects of treatment”; “Older, slowing down and seizing up – epilepsy strikes again” and “Challenges in developing a new approach for classification in epilepsy”. The Presidential Symposium was entitled “Avoiding epilepsy deaths”. Each day of the Congress featured Parallel Sessions and Teaching Sessions. A total of 870 abstracts were received via the online abstract submission system. There was a strong emphasis on posters with poster tours at lunchtime led by key experts. Abstracts were available online before the Congress on the *Epilepsia* website. The 29th IEC in Rome marks the high point of a year of activities planned by the IBE to celebrate its Golden Jubilee in 2011, including the ‘Epilepsy Without Words’ photography competition, a poster display highlighting the initiatives and achievements of IBE’s member associations, a publication of *The History of IBE* and a Milestones Walkway – an exhibition of significant moments in the history of IBE. In addition, a special event concert with the world-renowned Carabinieri Band took place at the Auditorium Conciliazione, which was the venue of the Epilepsy Congress in 1961 when the IBE was founded. A number of bursaries were granted and a reduced registration fee was also available for delegates coming from lower income countries. Prizes awarded during the 29th IEC included the Lifetime Achievement Award, the Social Accomplishment Award, Ambassador for Epilepsy Awards, the Michael Prize and the Morris-Coole *Epilepsia* Prize.



The 9th Asian & Oceanian Epilepsy Congress will take place in Manila, Philippines, from 22 to 25 March 2012. The venue is the SMX Convention Center. A strong scientific program has been put together by Josephine Casanova-

Gutierrez (Philippines); Byung-In Lee (Korea), Robert Cole (Australia), members of the Scientific Organizing Committee (SOC) and the Scientific Consultative Committee (SCC). The main topics of the Congress are: “Epileptic networks and seizure propagation”, “Epilepsy genes and beyond”, “The impact of epilepsy”

and “Epilepsy and the developing brain”. The Epilepsy and Society Symposium will take place on Saturday the 24th of March. The abstract submission deadline was set for 11 November but is extended to 25 November due to demand. Over 1,500 participants are expected to attend the Congress.



The 1st African Epilepsy Congress will take place in Nairobi, Kenya, from 21 to 23 June 2012. This will be the first ILAE-IBE Epilepsy Congress in the African Region. The venue is the Crowne Plaza Hotel which is located in Upper Hill, the new financial district of Nairobi, only 25 minutes away from Jomo Kenyatta International Airport. The scientific program has been compiled by Samuel Wiebe (Canada), Anthony Zimba (Zambia), Amadou Gallo Diop (Senegal) and Jo Wilmshurst (South Africa), together with the members of the Scientific Advisory and Organizing Committee (SAOC). More than 40 local, regional, and international speakers will present a range of topics throughout the Congress. The Congress will have a different theme on each day, with day one focusing on diagnosis, management and special epilepsy populations, day two covering the management gap and comorbidities as well as research in Africa and day three concentrating on primary healthcare and on the way forward in the African Region. The sessions have been divided into plenary sessions, topical lectures, interactive sessions and workshops. A poster display will complement the scientific program. Congress bursaries kindly provided by the ILAE will assist successful applicants with Congress expenses.



The 10th European Congress on Epileptology will take place in London, UK, from 30 September to 4 October 2012. The Congress will take place in the ICC London ExCeL, after the London Olympics and Para Olympics. The four main topics selected by the ILAE Commission on European Affairs are: “Imaging and pre-surgical evaluation”; “AED clinical pharmacology in adults and children”; “Basic and translational epileptology”; and “Epileptology and psychiatric problems in adults and children”. More than 300 presentations will be given over four days and a coordinated teaching course on the “Causes of epilepsy” will be held at the end of the Congress. Other highlights of the week will comprise the Nobel Lectures (daily talks given by a Nobel Laureate or Field Medallist), the Olympiad (an Epilepsy Challenge tournament) and the Chairs’ Symposium entitled “The

INTERNATIONAL DIRECTOR OF MEETINGS REPORT *(continued)*

borderland of epilepsy". Registration and abstract submission will be available online at www.epilepsylondon2012.org in December 2011. The full scientific program and local information is already accessible via the Congress website.



The 7th Latin American Congress on Epilepsy will take place in Quito, Ecuador, from 14 to 17 November 2012. The venue for the Congress is the Hilton Colon Quito Hotel. The Scientific and Organizing Committee,

comprising the following members — Patricio Abad (Ecuador); Lilia Núñez Orozco (Mexico); Marco Tulio Medina (Honduras); Carlos Acevedo (Chile); Manuel Campos (Chile); Silvia Kochen (Argentina) and Galo Pesantez (Ecuador) — is planning a varied and interesting scientific program incorporating scientific and social topics presented by a wide range of speakers. The program will include the main topics: "Diagnosis of non-refractory epilepsies"; "Treatment of non-refractory epilepsies"; "Epilepsy and the elderly"; "Brain development disorders and epilepsy"; "Reflex epilepsies"; "Refractory epilepsy"; "Antiepileptic drugs, beyond seizures"; "Extra-temporal epilepsy"; "National epilepsy plans"; "Clinical guides and consensus"; "Temporal lobe, memory and epilepsy"; "Status Epilepticus"; "Transition in the treatment of epilepsy"; and "Epilepsy and women throughout life". There will be a focus on poster tours which are always well attended. Five ALADE (Academia Latinoamericana de Epilepsia) courses will be included in the program. An IBE day will take place on 14 November. The program will cover "Schooling and epilepsy" as well as a seminar on "Neuropsychomotricity". The online registration and abstract systems will open in early 2012. A bursary fund will be established to assist young investigators and doctors in the region to attend the Congress. In addition, the Ministry of Health is expected to provide some bursaries.



The 30th IEC will take place in Montreal, Canada, from 23 to 27 June 2013. The convention center, Palais des Congrès de Montréal, is located in a downtown area, 20 minutes

from the city's international airport. Work has already begun on the creation of the scientific program, which will be of international interest and relevance.

The IDM Office is also currently working on arrangements for the Regional Congresses in 2013 and 2014, including the 13th ECES, 3rd EMEC, 11th ECE, 10th AOEC, and 8th LACE.

Richard Holmes
International Director of Meetings

EUROPEAN DECLARATION



The endorsement on 15 September 2011 of the Written Declaration on Epilepsy by the European Union (EU) Parliament was a major milestone in a concerted effort to have epilepsy recognized in the European political agenda. The Declaration originated from the vision of several members of the European Parliament (MEPs) acting in close synergism with Epilepsy Advocacy Europe (EAE), a Joint Task Force of ILAE and IBE, and with European ILAE and IBE Chapters.

What Is a Written Declaration in the EU?

A Written Declaration is a summary statement on a matter which falls within the remit of EU policies. To be officially endorsed by the EU Parliament, a Declaration has to be signed by a majority of MEPs over a specified time window. Since there are 738 MEPs in the EU Parliament, at least 369 signatures are required.

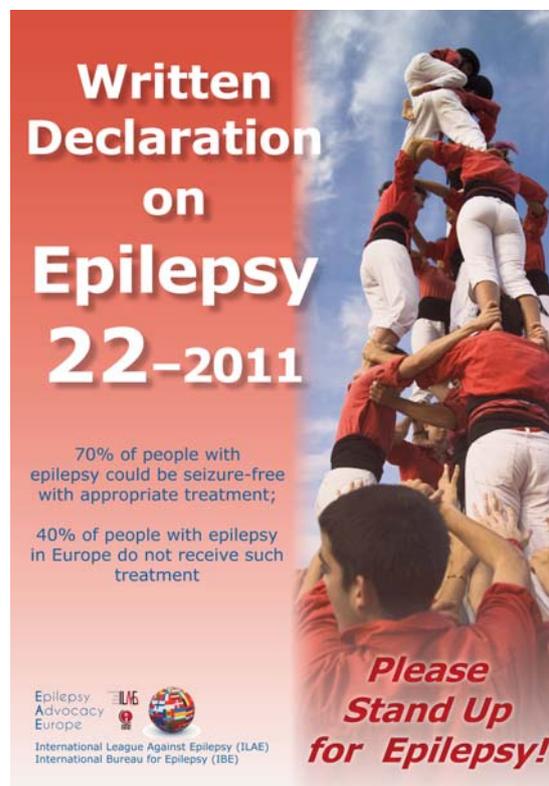
Specifically, What Is the Declaration on Epilepsy?

It is a document submitted to the EU Parliament by Mr Gay Mitchell, Chair of the European MEP Advocates for Epilepsy Working Group, and four fellow MEPs, Nirj Deva, Marian Harkin, Peter Skinner, and Angelika Werthmann. The Declaration highlights the following key facts about epilepsy in Europe:

- 6 million people affected and 300,000 new cases each year
- severe consequences in terms of physical, psychological and social burdens for individuals and families
- barriers caused by stigma and prejudice
- inappropriate management in a large proportion of affected individuals.

The Declaration calls for the European Commission and Council to:

- encourage research and innovation in the prevention, early diagnosis and treatment of epilepsy
- prioritize epilepsy as a major disease that imposes a significant burden across Europe
- take initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice
- encourage effective health impact assessments on all major EU and national policies.



Finally, the Declaration calls on Member States to introduce appropriate legislation to protect the rights of all people with epilepsy.

How Was the Declaration Approved?

Approval was the result of remarkable teamwork. The European Advocates for Epilepsy Group worked very hard to encourage fellow MEPs to support the Declaration. This was done in close collaboration with the ILAE-IBE Joint Task Force, who had representatives present in Strasbourg and Brussels when the Declaration registers were open for signature. Success, however, could not be achieved without the help of ILAE Chapters and IBE associations in each of the EU countries, who did a fantastic job in sensitizing MEPs from their countries about the importance of this initiative. The contribution of national Chapters to this effort was truly a most gratifying experience.

On the final signing session, a total of 459 MEPs had signed the Declaration, e.g. 110 more signatures than the minimum required! This made the Declaration on Epilepsy the one with the highest number of signatures in the current EU term, and among the top three health-related Declarations since records exist!

EUROPEAN DECLARATION (continued)

What Happens Next, and what Impact will the Declaration Have?

The Declaration was forwarded to the EU Commission, the EU Council and the governments of all EU Member States. It demonstrates that the EU Parliament recognizes the need for improved services for epilepsy and provides a mechanism by which people with epilepsy, their families and caregivers, together with ILAE and IBE Chapters and associations, can approach national governments and advocate for improved allocation of resources to epilepsy care. This already happened in some countries, including European countries outside the EU, resulting in national action plans along the lines recommended by the Declaration.

At a central level, the ILAE-IBE Joint Task Force is already working towards ensuring that the European Commission, which funds a major portion of medical research in Europe, recognizes the need to support research on the mechanisms of epilepsy and the development of better treatments. The Declaration will also be crucial in establishing a European-wide awareness program to address stigma and prejudice and to improve legislation, schooling, employment, and living conditions for people with epilepsy.

This is a great moment in our effort to step up political actions against epilepsy. The European Declaration comes at the same time as the Pan American Health Organization (PAHO) and the US Institute of Medicine (IOM) epilepsy initiatives, as well as successful new projects run by ILAE and IBE in collaboration with the World Health Organization (WHO). Let's keep the momentum up!

Emilio Perucca
*on behalf of the members of the Epilepsy Advocacy Europe (EAE), a joint ILAE-IBE Task Force**

*EAE members: Mike Glynn and Emilio Perucca (Co-Chairs), Michel Baulac, Hanneke De Boer, Christian Elger, Mike Glynn, Ann Little, Reetta Kalviainen, Janet Mifsud, Asla Pitkanen





Task Force Reports

CONSTITUTION TASK FORCE



Chair Tatsuya Tanaka
Members Michel Baulac
 Marco Medina
 Simon Shorvon
 Samuel Wiebe

Aims

Amendment of ILAE Constitution and Bylaws

The International League Against Epilepsy (ILAE) has achieved world wide success over the first century of its existence. To better represent its constituency, the League is considering amending its Constitution and Bylaws to ensure participation of all ILAE Regions (Europe, North America, Latin America, Eastern Mediterranean, Africa and Asia/Oceania) in the governance of the League at the highest level with membership to the Executive Committee and its acting branch, Management Committee.

Task Force Activities 2010-2011

Through frequent meetings of the Constitution Task Force Members during the past year, a final amended version has been finalized with a number of changes to the ILAE Constitution. The proposal of Constitution Amendment by the Constitution Task Force was approved by the Executive Committee Meeting on 26 March 2010 in Ghent. In Rome at the International Epilepsy Congress, prior to the General Assembly, the final version was discussed in the Chapter Convention on 28 August 2011. Several discussions and confirmations were proposed. Finally, the original final version was approved unanimously by all attending Chapters.

Accomplishments (2011)

The General Assembly of the ILAE was held on 31 August 2011. The major part of the Amendment of the Constitution was presented by the Secretary-General (Sam Wiebe) and followed by a Motion. The new Constitution was ratified unanimously. Following the ratification of the Constitution, the League's Bylaws were also amended according to the approved Constitution, by frequent ILAE Executive Committee meetings. The final version of the amended Bylaws was ratified by the EC Teleconference Meeting on 2 October 2011. The new Constitution and Bylaws have been uploaded to the ILAE website and can be found on page 80 of this report. The new structure would be implemented for the 2013 Executive Committee Election.

Recommendation for Future Work

During the last 18 months of the term, the Constitution Task Force should carefully check and verify the usage of the new Constitution and Bylaws. It is very important to verify whether the amendment of the Constitution or Bylaws goes well or is helpful in practical use.

Especially, the League will be electing its new President and Executive Committee Officers in 2013. Also during this period, the Constitution Task Force should carefully check and verify the amended articles, and particular care should be taken to detect any remaining inconsistencies or ambiguities.

INSTITUTE OF MEDICINE (IOM)



The League is engaged in regional activities aimed at highlighting the need for support of the epilepsies and raising political and public awareness to prioritize allocation of resources to epilepsy healthcare and research. In North America, one of these initiatives is an anticipated report by the United States (US) Institute of Medicine (IOM). The IOM is the health arm of the US National Academy of Sciences, and is an independent nonprofit agency that provides unbiased advice for policy makers and the public to improve health. The US Congress commissioned the IOM to create a report on the public health dimensions of epilepsy. As part of this process, patient advocacy groups and professional organizations, like the ILAE, were asked to co-sponsor the IOM's activity. The ILAE is one of over 20 sponsoring organizations, including the American Epilepsy Society, for the report. The IOM Committee was formed in late 2010 and was charged to address the following general questions about the epilepsies:

- How can the public health burden of epilepsy for patients and families be more accurately assessed?
- What priorities for future population health studies could inform treatment and prevention?
- How can the access to health and human services and the quality of care for people with epilepsy be improved?
- How can the education and training of professionals who work with people with epilepsy be improved?
- How can the understanding of epilepsy in patients and the general public be improved to create supportive communities?

To address these questions there have been three public meetings and numerous non-public sessions that mixed testimony from patients, with reports from advocacy groups and medical experts in this field. The first meeting, in Washington DC in January 2011 charged the Committee and included discussions on comorbidities, epidemiology, and access to care by representatives from patient advocacy groups including the ILAE.

The second meeting, in Los Angeles, in March 2011 focused on population health research, and data collection for the epilepsies. There were individual sessions directed toward understanding the impact of epilepsy on patients, families, the healthcare system and society, which included direct and indirect costs of epilepsy to society, epilepsy surveillance systems to track epilepsy care gaps and where improvements are necessary, and risk factors and prevention in epilepsy care.

The third meeting, back in Washington, in June 2011 addressed the theme of healthcare quality and access and education of patients, families, and providers who treat those with epilepsy. Sessions were directed to address existing models and opportunities for improvement in healthcare systems and pathways, quality of care, access and barriers, education of providers, patients and families, and public education and awareness campaigns about epilepsy stigma.

The sessions were further directed toward answering specific questions including:

- What experiences do people with epilepsy and their families have when entering and moving through the healthcare system?
- What are the current models of care for specific populations with epilepsy, including children, women, older adults, and racial and ethnic minorities?
- How is quality of care measured?
- What is known about health outcomes for people with epilepsy?
- What international models of care delivery exist for people with epilepsy?
- What comparative effectiveness research exists for best practices?
- What are the barriers to access and care?
- What is known about whether the current workforce is adequate to provide quality healthcare for people with epilepsy?
- What are the approaches being used to educate and test knowledge and competence of healthcare professionals about the epilepsies?
- What are the healthcare (psychosocial as well as medical) educational needs of patients and families?
- How are employers educated about epilepsy?
- How can public education and awareness campaigns be used to increase knowledge and understanding about the epilepsies, change attitudes and perceptions, and reduce stigma?
- What is the role of the media in educating the public and how can this role be leveraged to better educate the public about the epilepsies?

INSTITUTE OF MEDICINE (IOM) *(continued)*

The final IOM report is expected to be released in early 2012, and it is hoped that many of these questions will be addressed. For more information and to contribute to the discussion about international needs in epilepsy care please visit <http://www.iom.edu/Activities/Disease/Epilepsy.aspx> where you can e-mail the IOM Committee with your thoughts and experience. ILAE will be involved in the distribution of the IOM findings to the international community where the report can be used by any country to inform the public and Ministry of Health about the urgent need for improved epilepsy care around the world.

Gary W. Mathern, MD
Chair Strategic Task Force

The screenshot shows a web browser window displaying the IOM website. The page title is "The Public Health Dimensions of the Epilepsies - Institute of Medicine - Windows Internet Explorer". The URL is <http://iom.edu/Activities/Disease/Epilepsy.aspx>. The page features the IOM logo and the tagline "Advising the Nation. Improving Health." The navigation menu includes "ABOUT THE IOM", "REPORTS", and "ACTIVITIES". The main content area is titled "Activity" and contains the following information:

- Activity:** The Public Health Dimensions of the Epilepsies
- Type:** Consensus Study
- Topics:** Diseases, Public Health
- Boards:** Board on Health Sciences Policy
- Activity Description:** Epilepsy is one of the most common neurologic conditions in the United States, affecting at least 1 in 100 adults and 1 in 20 children. There are more than 40 types of epilepsy—referred to collectively as the epilepsies—that cause recurrent seizures and that can be responsible for brain damage, neurological, cognitive, or psychiatric impairment, and death. Advances in research are improving our understanding of the scope of epilepsy and its public health impact. However, current approaches do not fully take into account either the broad range of epilepsy disorders and their comorbidities or their consequences for health and quality of life. The IOM is undertaking a new study that will consider the public health dimensions of the epilepsies in the United States—including health care and human services, health literacy, and education. The IOM will recommend priorities in these areas in order to better understand the public health impact of the epilepsies and to meet the needs of people with epilepsy and their caregivers. Specifically, the IOM will focus on the following questions:
 - How can the public health burden of epilepsy for patients and families be more accurately assessed?

On the right side of the page, there are several sidebar sections:

- Stay up to date!** Receive regular emails about the IOM's work. Sign Up Now
- Committee Members**
 - Mary Jane England, Chair
 - + View Full Committee Roster
- Study Staff**
 - Cathy T. Liverman, Study Director
 - Andrea M. Schultz, Study Director
 - + View Full Study Staff Roster
- Activity Sponsors**



Regional Commissions

COMMISSION ON AFRICAN AFFAIRS

Members

Chair	Pr Amadou Gallo Diop (Senegal)
Secretary-General	Dr Callixte T Kuate (Cameroon)
Treasurer	Pr Angelina Kakooza (Uganda)
Education Officer	Pr Bryan Kies (South Africa)
Research Officer	Pr Paul Kioy (Kenya)
Communication Officer	Dr Birinus E Adikaibe (Nigeria)
Outreach Officer	Pr Baba Koumare (Mali)

Task Force on Access to Care:

- Dr Sammy Ohene (Ghana)
- Pr Amara Cisse (Guinea)
- Par Ait-Kaci (Algeria)
- Dr Eris Aris (Tanzania, Zimbabwe)

Aims

Training

- Identify centers with training capacity
- Identify teaching resources
- Hold educational meetings
- Visiting professor initiative

Communication and Advocacy

- Quarterly news report
- Update GCAE document in French, English, Portuguese

Research

- Via the working committee generate publications addressing the current challenges facing Africa
- Communication across centers managing large groups of patients with epilepsy which allows focused research studies to be undertaken, e.g.
 - o genetics
 - o etiology and epidemiology
 - o differing treatment regimens, e.g. Status Epilepticus
 - o development of epilepsy surgical centers
 - o neurobiology
- Monitor progress from the various interventions
- Network of doctors actively involved in the care of patients with epilepsy
 - o The "Directory of Neuro-Staff in Africa" country by country, including people involved in epilepsy care (currently being updated)
 - o 1st draft done (shared with PAANS, SONA, WFN)
- Develop a research database

Commission Activities July 2010 through July 2011

Public Health Interventions: "Caravan for Epilepsy" or "Where there is no Neurologist"

- Interactive media intervention on epilepsy
- Training of MDs and Nurses
- Meeting with Women Associations and Teachers
- Consultations and portable EEG
- Patient Book; Information leaflets; Training Book; Posters; T-shirts

Interface with other organizations complementing and working with other groups with common interests/agendas

- IBE especially Kenya 1st AEC
- IBRO/SONA Training meetings
- EFNS Training meetings
- Pan Arab Union of Neurological Societies "PAUNS" training meetings
- WFN/PAANS Visiting professor program training meetings
- ICNA/ACNA Target groups/workshops
- WHO lobbying/1st AEC

A plan is being developed for a two-day meeting with many of these organizations to discuss project coordination and avoid gaps and redundancy of efforts.

Future Work

- Developing appropriate resources to accomplish the Commission's mission
 - o Lack of specialists in Africa
 - o Need to develop a support mechanism for primary healthcare (PHC) workers who currently are unskilled, unsupported and untrained
 - o Need to teach and train practitioners from primary healthcare (PHC) workers through to specialists
- Effectively communicating with and coordinating and integrating the efforts of the different groups mentioned above.



COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA)

1. List of Members and Officers

As of November 2011, CAO A takes charge of 19 Chapters in the Asian and Oceanian Region, which includes Australia, Bangladesh, China, Hong Kong, India, Indonesia, Japan, Korea, Malaysia, Mongolia, Nepal, New Zealand, Pakistan, Philippines, Singapore, Sri Lanka (formally accepted September 1 at the 29th IEC in Rome), Taiwan, Thailand, and Vietnam.

Nomination and election of the CAO A 2009-2013 Officers was carried out in the second quarter of 2009. New members of CAO A took office officially in July 2009 and a member representing India (V Nadkarni), Chair of CAO A-Research Task Force (P Kwan), and Chair of Regional Committee of GCAE (E Somerville) joined the Commission as Ex-Officio.

Table 1. Officers of CAO A (2009-2013)

Chairman	Byung In Lee (Korea)
Secretary	John W Dunne (Australia)
Treasurer	Jing-Jane Tsai (Taiwan)
Information Officer	Sunao Kaneko (Japan)
Members	Hasan Aziz (Pakistan)
	Shi Chuo Li (China)
	Chong Tin Tan (Malaysia)
	Shih-Hui Lim (Singapore)
Ex-Officio	Tatsuya Tanaka (Japan, ILAE- First Vice President)
	Vrushali Nadkarni (India)
1. Research Task Force	Patrick Kwan (Hong Kong)
2. Global Campaign Task Force	Ernest Somerville (Australia)

The Asian Epilepsy Academy (ASEPA) was formed in 2003, initially as the educational arm and now a sub-commission of CAO A. The composition of ASEPA is shown in Table 2.

Table 2. Officers of ASEPA

	(2007-2011)	(2011.9.-2015)
Chair	Chong Tin Tan (Malaysia)	Shih Hui Lim (Singapore)
Secretary	Andrew Bleasel (Australia)	
Members	Gourie Devi (India)	Man Mohan Mehndiratta (India)
	Yushi Inoue (Japan)	Yushi Inoue (Japan)
	Weiping Liao (China)	Weiping Liao (China)
	Shih Hui Lim	Dede Gunawan (Indonesia)
		Josephine Gutierrez (Philippines)
Ex-Officio	Byung In Lee (Chair, CAO A)	Byung In Lee (Korea, Chair of CAO A)
		Chong Tin Tan (Malaysia, Immediate Past President, ASEPA)

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) *(continued)*

2. Aims and Missions of CAO A

a. Aims

Aims of CAO A, the Regional Commission of ILAE, is to develop, stimulate, and coordinate the epileptology agenda in the Asian and Oceanian Regions

b. Missions

- i. To advance and disseminate knowledge concerning the epilepsies throughout the Asian and Oceanian Region
- ii. To improve education and training in the field of the epilepsies in Asia via the formation of the Asian Epilepsy Academy
- iii. To organize the Asian Oceanian Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees
- iv. To facilitate clinically relevant epilepsy research in Asia
- v. 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
- vi. To promote the activities of local Chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda
- vii. To review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.

3. Action Plans of CAO A: 2009-2013

Plans formulated in the CAO A business meeting at Seoul, 26 September 2009, and presented/accepted at the Commission Meeting of ILAE in Paris, 22 to 23 October 2009

- a. Construct CAO A and ASEPA website with its link with ILAE Web and Regional Chapter's Web, and publish newsletter
- b. Enhance education and training efforts and activities
 - i. Continue to provide teaching courses and workshops in regions in need

- ii. Provide epilepsy fellowship (~6 months) for the nurturing of future epilepsy specialists of the Region

- iii. Continue to conduct EEG certification examination for the purpose elevating the standard of EEG recording and interpretation skills.

- c. Organize the Asian and Oceanian Epilepsy Congresses every two years

- d. Stimulate clinical and translational research

- e. Promote new Chapter formation

- f. Facilitate Global Campaign Against Epilepsy (GCAE) activities

- g. Facilitate interactions and communications among Chapters and Commissions

- h. Initiate the "Asian and Oceanian Outstanding Achievement Epilepsy Award"

4. Commission Activities

a. Communication and Business Meetings

- i. Communication amongst members of CAO A and ASEPA were mainly through e-mails and during teaching courses/workshops/Congresses in the region. In addition, the CAO A business meeting was held in Bangkok, Thailand, on 13 May 2011. The discussion points included:

- (1) Budget

- (2) Progress reports of CAO A

- (3) Report of Information Committee (S Kaneko)

- (4) GCAE TF (E Somerville)

- (5) Research TF (B Lee for P Kwan)

- (6) ASEPA (CT Tan) and EEG Exam (SH Lim)

- (7) Summary of 8th AOEC and progress of 9th AOEC (BL)

- (8) JES activities against National Disaster in Japan (S Kaneko)

- (9) Constitutional Amendment (T Tanka)

- (10) Chinese Summer School (SC Li)

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) *(continued)*

- (11) General discussions on
 - (i) Global Campaign and Outreach
 - (ii) Support for the 5th AESC in Hong Kong, Mongolian Project raised by Dr Tovudorjii of MES
 - (iii) Infantile Spasm Society
 - (iv) Epilepsy Outstanding Achievement Award
 - (v) Travel support for Chapter Convention in Rome
- ii. Communications with ILAE are also being made mainly through e-mail and during Congresses on local, regional, or international levels
 - (1) Commission Meeting at the AES in San Antonio, TX, 3 December 2010
 - (2) 29th IEC at Rome, Italy, 27 August to 1 September 2011
- iii. Interactions with Independent Epilepsy Activities in the region
 - (1) First Advanced Clinical Epileptology Courses in Chengdu, China, on 7 to 14 August 2011
 - (a) Organized by CCAE, CAO, and ILAE, 65 students participated in the course
 - (b) CAO supported two speakers (BI Lee and T O'Brien)
 - (2) 5th Asian Epilepsy Surgery Congress (AESC) in Hong Kong, 10 to 12 November 2011
 - (a) First Joint Symposium of CAO and AESC on "Surgery of Frontal Lobe Epilepsy" P Kwan (Hong Kong); supported by CAO
 - (b) Pharmacological Treatment of Drug-Resistant, Frontal Lobe Epilepsy BI Lee (Korea); supported by CAO
 - (c) Presurgical Evaluation of Frontal Lobe Epilepsy JW Chang (Korea); supported by AESC
 - (d) Surgery of Frontal Lobe Epilepsy
 - (3) Infantile Spasm Society Annual Congress in Tokyo 18 to 19 February
 - (a) Planning to have a joint symposium of CAO and ISS
 - (b) Title is under development and CAO is going to support two speakers
- iv. Proposal from Mongolian Epilepsy Society (MES; Dr A Tovudorj)

Mongolian Epilepsy Society asked help from CAO for the project of MES focusing on reduction of treatment gap in Mongolia; discussion at the Bangkok Business Meeting was to support an educational course in Mongolia through ASEPA
- v. New Chapter Formation
 - (1) Sri Lanka; approved as the 19th Chapter of Asian and Oceanian Region
 - (2) Inaugural Congress, 19 September 2011, in Colombo
- b. Information Committee and CAO-Website
 - i. CAO Information Committee meeting (S Kaneko, Chair)
 - ii. CAO website (<http://www.cao-epilepsy.org>) opened with excellent feedback
 - (1) Linked to ILAE and IBE websites as well as local Chapter websites of Asian and Oceanian Region
 - (2) Uploaded most recent documents; need to be updated every six months.
 - (3) Contents include
 - (a) Nature of CAO, including membership structure and contact details
 - (b) Proceedings and abstracts of AOEC
 - (c) Profiles of outstanding award winners and its process
 - (d) History of epilepsy in the Region, local Chapter activities, global campaign activities, ASEPA materials and educational resources from workshops and Congresses

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) *(continued)*

c. CAO A — RTF

Scope of Actions of RTF

- i. Improve research infrastructure
- ii. Understand etiologies and epileptogenesis
- iii. Lessen psychosocial comorbidities
- iv. Achieve better treatment outcome

One whole day meeting on 1 July 2011 at Taipei, Taiwan

Attendants: P Kwan (Chair), W D'Sourza, BI Lee, L Cabral-Lim, SH Lim, S Jain, CT Tan

- i. All agreed that the priority document should emphasize research being relevant to the dynamic socioeconomic changes occurring in the Region
- ii. It was agreed that the priority document should include a new dimension to cover the burden of epilepsy, which will include epidemiology, aging, and etiologies. – CT Tan will lead this dimension
- iii. The moderator of each topic will draft the relevant section for the priority document
- iv. The timeline is to get an approval of the priority document at the 9th AOEC in Manila

d. GCAE — TF (E Somerville, Chair)

Meeting of GCAE-TF at 8th AOEC in Melbourne provided an excellent opportunity for gathering information regarding the activities, initiatives and programs of the different Chapters, including diverse and creative strategies relevant to local situations

Role of TF

- i. Compile a register of what was available in neighbor Chapters to avoid reinventing the wheel
- ii. Provide a means of activating communications among different Chapters to be aware of what was being tried, what had worked and what had not worked
- iii. Closer interactions with Global Campaign website and CAO A website

- iv. Provide service for the diagnosis and education of epilepsy in selected Regions with severe treatment gaps

Report of Laos Project by CT Tan

- i. Supported by CAO A and JES
- ii. Primary role in training of neurologists — 3rd neurologists had training in epilepsy

GCAE TF; action plans on 2012

Forum on "How to Reduce Treatment Gap in Asian and Oceanian Region?" in 9th AOEC in Manila, Philippines

e. ASEPA

Four major activities: workshops/teaching courses, fellowships, EEG certifications, publications of proceedings

- i. Workshops and Teaching Courses in 2011

	Workshop	City	Funding	Month	Coordinator
1	Syndrome	Harbin, Heilongjiang, China	ASEPA	Jan 13-15	Dunne
2	Focal epilepsy: concept, diagnosis and treatment.	Karachi	JES	Jan 29-30	Inoue
3	Paediatrics and syndrome	Dhaka, Bangladesh	ASEPA	Mar 25-26	Deepak
4	Video-EEG monitoring.	Penang, Malaysia	Janssen-Cilag	Mar 4-5	Lim
5	EEG conference, localization.	Guilin, China	JES	Apr 7-9	Inoue/ Lim
6	Neonatal seizures and related disorder	Tokyo	ISS	Apr 9	Fukuyama
7	ANZAN format EEG course.	Bangkok	Orient Pharma/ UCB	May 12-14	Somerville/ Lim/Yotin
8	Management of seizures in systemic diseases.	Solo, Indonesia	ASEPA	June 10-11	Lim
9	Drugs.	Taiwan	GSK	July 2-3	Kwan
10	Summer school	Chengdu, China	CAAE-Janssen	Aug 7-14	Dong Zhou
11	EEG Refresher Course	Bali, Indonesia	ASEPA	Nov 2 nd	Lim

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) *(continued)*

ii. ASEPA EEG Certification Examinations

Part 1 Exam: A total of 145 candidates took the part 1 exam with pass rate of 62 percent

- (1) Karachi, Pakistan, 29 January 2011
- (2) Guilin, China, 8 April 2011
- (3) Solo, Indonesia, 11 June 2011
- (4) Taipei, Taiwan, 3 July 2011
- (5) Bali, Indonesia, 3 November 2011

Part 2 Exam: A total of 40 candidates took the Part 2 exam with passing rate of 55 percent

- (1) Penang, Malaysia, 5 March 2011
- (2) Guilin, China, 9 March 2011
- (3) Solo, Indonesia, 11 June 2011
- (4) Bali, Indonesia, 3 November 2011

There will be two Part 2 Examinations:

- (1) 25 to 26 November 2011 in Xiamen (62 candidates)
- (2) 18 December 2011 in Taipei (15 candidates)

iii. Published Proceedings of 8th AOEC in Neurology Asia

Electronic version is available:
www.neurology-asia.org

iv. Fellowship — for 2012

- (1) Chunhong Chen (China) to Shizuoka, Japan under Epilepsy Research Foundation of Japan (ERFJ)
- (2) Shouwen Zhang (China) to Shizuoka, Japan under Epilepsy Research Foundation of Japan (ERFJ)
- (3) Nguyen Thai (Vietnam) to Kuala Lumpur, Malaysia under ASEPA
- (4) Abdus Salam (Bangladesh) to Trivandrum, Kerala, India under ASEPA

f. 9th AOEC

22 to 25 March 2012, SMX at Manila, Philippines

i. SOC members: Josephine Casanova-Gutierrez, Byung-In Lee, Simon Harvey, Tatsuya Tanaka, Patrick Kwan, Robert Cole, Vinod Saxena, Ding Ding, Andrew Pan

ii. Scientific Consultative Committee of the 9th AOEC
Chairs: John Dunne (Australia) and Leonor Cabral-Lim (Philippines)

Members

Australia: John Dunne (CAOA), Ernest Somerville (CAOA), Andrew Bleasel (ASEPA), Terry O'Brien, G Shears (IBE), D Chapman (IBE), Ingrid Scheffer
China: SC Li (CAOA), WP Liao (ASEPA), J Qin, G Luan
India: V Nadkarni (CAOA), MM Mehndiratta, K Radhakrishnan, S Jain,
Japan: S Kaneko (CAOA), Y Inoue (ASEPA), A Ikeda, M Watanabe, S Hirose
Korea: HD Kim, SB Hong
Malaysia: CT Tan (CAOA)
New Zealand: P Bergin
Pakistan: H Aziz (CAOA)
Philippines: Leonor Cabral-Lim, M Ortiz, Felicidad Soto, V Bael, Jeannie Desiree Khgonhun (IBE), Imelda David, Benilda Sanchez
Singapore: SH Lim (CAOA and ASEPA), Grace Tan (IBE)
Thailand: Y Chinvarun, A Visudiphan
Taiwan: Jing-Jane Tsai (CAOA), Yung Yang Lin, Yuan-Fu Tseng (IBE)
Vietnam, Mongolia, Nepal, Bangladesh, Indonesia, Hong Kong: None

iii. Progress

First SOC meeting in Manila, Philippines on 25 February 2011 at SMX in Manila

Timeline for preparation

January 2011 –
First Announcement; Print and post

May 2011 –
Second Announcement; Print and post

June 2011 –
Online registration and abstract submission

November 2011 –
Abstract submission deadline;
11 November (extension — 25 November)

December 2011 –
Abstract reviewed

February 2012 –
Design of final program and abstract book

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (CAOA) *(continued)*

- iv. Scientific Programs
- 5. Summary of Action Plans of CAO A and ASEPA for 2012**
- a. 9th AOEC in Manila, Philippines
 - i. Chapter convention
 - ii. CAO A and ASEPA Business Meeting
 - iii. Asian and Oceanian Epilepsy Outstanding Achievement Award
- b. Continuing ASEPA activities with
 - i. Promotion of Affiliated Programs in collaboration with individual Chapters
 - (1) ANZAN and ESA, (2) Korean ES, (3) Taiwan ES, (4) Mongolian ES, (5) Nepal ES, (6) Sri Lanka ES, (7) Bangladesh ES, (8) Thailand ES, (9) Chinese AAE
 - ii. Joint program with another epilepsy organization
 - (1) Infantile Spasm Society, (2) Asian Epilepsy Surgery Society (AESCS)
 - iii. Support for Indian Epilepsy Summer School in Trivandrum, India
- c. Research TF
 - i. Approval and distribution of Research Priority Document at the 9th AOEC
 - ii. Plan for future action plans at the Business Meeting at the 9th AOEC
- d. Information Committee
 - i. CAO A website: promotion to advanced website by timely review and revision
 - ii. Organize Information Committee representing each Chapter for promotion of communication among Chapters
 - iii. Publication of Newsletters
- e. GCAE TF
 - i. Workshop and Committee meetings at the 9th AOEC
 - ii. Registration of various Campaigns in each Chapters
 - iii. Reduction of Treatment Gaps; Dx and treatment in resource-poor countries
 - iv. Education programs in collaboration with ASEPA
 - v. Continue the support for the Lao Project for training and education of epileptologists
- f. Promotion of New Chapter Formation
 - i. Candidate Chapters: Myanmar, Cambodia, Bhutan, Laos, Papua New Guinea
 - ii. Invite delegates to the Chapter Convention for planning of new Chapter formation

COMMISSION ON EASTERN MEDITERRANEAN AFFAIRS (CEMA)

The Commission on Eastern Mediterranean Affairs (CEMA) consists of members from different countries in the Eastern Mediterranean Region who have expertise in care and education in epileptology.

List of Members

Chair	Ahmad Beydoun
Members	Adel AL Jeshi Hassan S Hosny Jihad S Inshasi Ahmad Khalifa Sonia Khan Chahnez Triki Saoudi Zemrag Michel Baulac, MD, EC Liaison

Aims

- To identify research and education priorities in epilepsy for the Eastern Mediterranean Region (EMR)
- To establish standards and guidelines for research activities within the EMR
- To support partnerships and exchange information between academics in different countries in research and educational activities
- To improve the quality of research and education in the EMR

Commission Activities from July 2010 to July 2011

The Region is clearly in great political turmoil and so the activities of the Commission are greatly hindered. There are, however bright spots and achievements including:

- Successful implementation of the 1st Annual Saudi Epilepsy Society Symposium
- Some attendance from the Region at WFN
- New Chapter request from Kuwait
- Evolution in the UAE Chapter; Chair has changed (Pr Saadi)
- Survey in Lebanon on New Onset Epilepsy Lebanon

It was noted that Turkey is in a crucial place for reaching out to the Region through education.

Charge: Develop an alternate way to provide education that doesn't exclude the Regional Commission but uses countries close by, like Turkey.



ILAE 2011 Ambassadors at 29th IECD in Rome

COMMISSION ON EUROPEAN AFFAIRS (CEA)

List of Members:

Chair	Meir Bialer
Secretaty	Alla Guekht
CEA Treasurer	Eugen Trinka
Past Chair	Michel Baulac
Communication Liaison	Alexis Arzimanoglou
Global Campaign Liaison	Athanasios Covanis
EAC – European Advisory Council – Secretary	Reetta Kalviainen
EAC – European Advisory Council – Chair	Torbjorn Tomson
Ex-Officio, Basic Sciences Liaison	Asla Pitkanen
Ex-Officio, Educational Liaison	Helen Cross
Ex-Officio, EC liaison	Solomon L. Moshé
Ex-Officio, EC liaison	Emilio Perucca

List of Sub-commissions and Members (indicating the Chairs) See above

Aims

1. Articulate internationally applicable guidelines for diagnosis and treatment of patients with epilepsy in Europe;
2. Stimulate and enhance education on the prevention, diagnosis and treatment of epilepsy;
3. Stimulate and enhance basic and clinical research in epilepsy in Europe;
4. Work with European organizations to catalogue current epilepsy care in Europe and determine its needs;
5. Prompt and facilitate initiatives that improve standards of comprehensive care (diagnosis, treatment and social care). Reduce the treatment gap throughout Europe;
6. To help ensure that ILAE's organizational structure is efficiently and effectively dedicated to fulfilling ILAE mission.

Mission of the Commission

Aim 1– Articulate internationally applicable guidelines for diagnosis and treatment of patients with epilepsy in Europe.

Action: CEA liaisons:

A Arzimanoglou, Communication; A Covanis, Global Campaign; H Cross, Education and EPNS; A Guekht, EFNS; A Pitkänen, Basic science

Aim 2 – Stimulate and enhance education on the prevention, diagnosis and treatment of epilepsy

Action:

- a) EUREPA continues as the European Educational Academy within the CEA
- b) Established an educational agenda available for review on the CEA website with procedures for application for CEA support

- c) Continuing with the Migrating Courses in 2012/13
- d) Coordinating the European Educational Courses. San Servolo, Basic Science, Pediatrics and Pre-surgical; Eilat, Pharmacology and AEDs; Lyon, Stereo EEG alone or with EPODES
- e) Welcome new Regional Courses (e.g., Caucasian, Baltic-Sea Summer School on Epileptology)

Aim 3 – Stimulate and enhance basic and clinical research in epilepsy in Europe

Action:

- a) Extensive dialogue via the Epilepsy Advocacy Europe (EAE) with EU executives (directly and lobbying via various ILAE Chapters) aiming to give epilepsy research priority in EU funding
- b) CEA-EU Symposium (Rhodes and London ECEs)
- c) Support scientific conferences with European added value that publish post-conference proceedings (e.g. Status Epilepticus, inflammation in epilepsy)

Aim 4– Work with European organizations to catalogue current epilepsy care in Europe and determine its needs

Action:

Epilepsy Advocacy Europe (EAE) that is The CEA-EREC Joint Task Force for Epilepsy Advocacy

Aim 5– Prompt and facilitate initiatives that improve standards of comprehensive care (diagnosis, treatment and social care). Reduce the treatment gap throughout Europe

Action:

- a) A CEA-CNA-CTA Joint Task Force (JTF) on regulatory issues of new AEDs (meeting in Rhodes, AES, Rome)
- b) A JTF-EMA-FDA meeting on regulatory issues (Paris – 17 November 2011)

Aim 6– To help ensure that ILAE's organizational structure is efficiently and effectively dedicated to fulfilling ILAE mission

Action:

- a) Continuous update of European Chapters' Chairs and secretaries (via Gus Egan ILAE Dublin office)
- b) Establish ILAE Chapters in the three remaining European countries (Belarus, Bosnia and Iceland)
- c) Update CEA rules in accordance with the ILAE-EC proposed Constitutional Amendment

COMMISSION ON EUROPEAN AFFAIRS (CEA) *(continued)*

Commission Activities from July 2009 through October 2011

- a. 3rd Eilat Educational Course on Pharmacology (8 to 15 September 2009)
- b. 2nd Caucasian Summer School (Tbilisi, Georgia, 4 to 10 October 2009)
- c. 1st & 2nd Training course on Stereo-EEG (Lyon, February 2010 & February 2011)
- d. 4th Baltic Sea Summer School (Oslo, 13 to 18 June 2010)
- e. Symposium on Immunity & Inflammation (Milan, 16 to 18 August 2010)
- f. 9th European Congress on Epileptology (Rhodes, 27 June to 1 July 2010)
- g. 2010-San Servolo Courses on Therapy (Venice, 19 to 29 July 2010)
- h. 2011-San Servolo Courses on Basic Science (Venice, 17 to 29 July 2011)
- i. 4th Migrating Course on Epilepsy (Warsaw, 15 to 22 August 2010)
- j. 5th Migrating Course on Epilepsy (Rome, 29 May to 4 June 2011)
- k. 3rd Colloquium on Status Epilepticus (Oxford, 7 to 10 April 2011)
- l. Comprehensive Epileptology Congress (St. Petersburg, 23 to 25 May 2011)
- m. 4th Eilat Educational Course on Pharmacology (18 to 25 September 2011)
- n. 3rd Caucasian Summer School (Baku, Azerbaijan, 16 to 21 October 2011)
- o. 2nd EPODES Congress (Brno, 25 to 28 January 2012, postponed from 2011)

Accomplishments (2009-2011)

- a. Established the CEA Strategic and Action Plans that served as a model for other ILAE Regional Commissions
- b. Continued the migrating and the Eilat Educational courses as the CEA residential courses
- c. Continued the European Congresses on Epileptology (ECEs) as one of the most successful international scientific epilepsy Congresses
- d. Lobbied through a JTF at EU headquarter (Brussels) via various countries' representatives to promote epilepsy treatment and research in Europe
- e. Established collaboration between the CEA and the ILAE-North American. A joint CEA-CNA symposium at the 2011 AES and 2012 ECE

Recommendations for Future Work

CEA Sponsored Events for 2012-2013

Educational Courses to be supported:

- a. Young Scientists Symposium (Beer-Sheva, 7 to 11 January 2012)
- b. 2nd Stereo-EEG Course (Lyon, 7 to 11 February 2012)

- c. 6th Baltic Sea Summer School (Rostock, 8 to 13 June 2012)
- d. 6th Migrating Course on Epilepsy (Porto, 10 to 15 June 2012)
- e. San-Servolo Course on Pediatrics (Venice, 15 to 25 July 2012)
- f. Dianalund Summer School on EEG & Epilepsy (Dianalund, 23 to 28 July 2012)
- g. VIREPA-EEG SCORE Course (October 2012-February 2013)
- h. 5th Eilat Educational Course on Pharmacology (30 September to 5 October 2013)

Other activities

- a. The European Chapter Convention during the London-ECE (29/9/2012) and thus, having a yearly dialogue between the CEA and the various ILAE-European Chapters
- b. Regional epilepsy educational conferences in European Regions with unmet need for epilepsy training
- c. Scientific conferences with European-added values
- d. CEA is currently waiting for suggestions for items b and c

Additional CEA Targets for 2012-2013

- a. Making the 10th European Congress on Epileptology (ECE, 30 September to 4 October 2012) in London to top or at least match the successful ECEs in Vienna (2004), Helsinki (2006), Berlin (2008) and Rhodes (2010)
- b. Continuous update of European Chapters' Chairs and secretaries
- c. Establish ILAE Chapters in the three remaining European countries
- d. Update CEA rules in accordance with the ILAE-EC Constitutional Amendments

COMMISSION ON LATIN AMERICAN AFFAIRS

List of Members

Chair	Manuel Campos (Chile)
Secretary	Eduardo Barragán (México)
Treasurer	Patricia Braga (Uruguay)
LASSE	Esper Abrao Cavalheiro (Brasil)
	Franz Chaves Sell (Costa Rica)
	Beatriz González del Castillo (Venezuela)
	Salvador González-Pal (Cuba)
	Silvia Kochen (Argentina)
	Magda Nunez (Brasil)
Vice President and EC Liaison	Marco Medina (Honduras)
Ex-Officio	Alejandro Scaramelli (Uruguay)
EC Liaison	Samuel Wiebe (Canada)

Introduction

The Latin American Commission has a mission to improve the prevention, diagnosis and treatment of the epilepsies in Latin-America, within the frame of our ILAE politics and Strategic Plan.

Aims

1. 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 America Region Chapters
- The Commission is composed of 11 physicians, but also all Latin-American ILAE Chapters are involved.

Commission Activities from July 2010 through July 2011

1. Strategy and Plan of Action on Epilepsy

The Pan American Health Organization (PAHO) approved, during the 51st Directing Council and 63rd Session of the Regional Committee (September 2011, Washington, USA), the Strategy and Plan of Action on Epilepsies for the Americas and their implementation under the particular conditions of each country to provide an appropriate response to current and future needs.

It is the main issue for us during 2011 and our duty for the next five years to develop epilepsy programs in all regional countries, and improve the prevention, diagnostic, treatment and quality of life in all people with epilepsy.

The Strategic Plan promotes partnerships with the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE), as well as international agencies, governmental and nongovernmental organizations, and other regional actors in support of the broad multispectral response needed for the execution of this strategy and plan of action. The main persons to reach this plan were Dr Jorge Rodriguez (PAHO), Dr Carlos Acevedo (IBE) and Dr Marco Medina (ILAE). We have a meeting in October 2011 in Honduras to prepare the strategies, with participation of authorities from WHO, ILAE and IBE.

The Strategic Plan urges the Member States to:

- a) Make epilepsy a priority in national health policy by executing specific national programs suited to the conditions of each country to sustain achievements and make progress toward meeting new goals, especially in relation to reducing the existing treatment gaps
- b) Strengthen legal frameworks as appropriate in order to protect the human rights of people with epilepsy and ensure effective enforcement of the laws
- c) Promote universal equitable access to medical care for all people with epilepsy by strengthening health services in systems based on primary healthcare and integrated service networks
- d) Ensure the availability of the four antiepileptic drugs considered essential for treating people with epilepsy, especially at the primary care level
- e) Strengthen neurology services as support for case detection and management at the primary care level, ensuring adequate distribution of the necessary auxiliary diagnostic media
- f) Support effective participation by the community and associations of users and family members in activities designed to secure better care for people with epilepsy
- g) Consider strengthening human resources as key to improving national epilepsy programs, through systematic training geared especially to the personnel in primary healthcare
- h) Promote intersectoral and educational initiatives directed to the population to combat the stigma and discrimination suffered by people with epilepsy
- i) Close the information gap in the field on epilepsy by improving the production, analysis, and use of information, including research
- j) Strengthen partnerships between the health sector, other sectors, and nongovernmental organizations, academic institutions, and key social actors

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

2. V Latin American Summer School on Epilepsy (LASSE) – Escuela de Verano de Epilepsia. February 2010, Sao Paulo, Brazil:

LASSE is organized by Prof Esper Abrao Cavalheiro with the support of many Brazilian colleagues (Drs Elza Marcia Yacubian, Americo Sakamoto, Fernando Cendes, etc). LASSE V received more than 50 young professionals from all of Latin-America for a full 10-day course, who learned through conferences and by working on scientific projects. It is in part supported by ILAE (20%); the rest of the resources came from the Brazilian Government and research agencies.

Also the success of LASSE depends on the generosity of many faculty (epileptologists) in great relationship with our ILAE.

The previous LASSE were:

- a. The First Latin American Summer School on Epilepsy: "Epilepsy: Translating basic knowledge into clinical applications", was held from 4 to 14 February 2007
- b. The Second Latin American Summer School on Epilepsy: "Increasing knowledge and decreasing treatment gap", was held from 7 to 17 February 2008
- c. The Third Latin American Summer School on Epilepsy: "Epileptogenesis in the developing brain: Basis for treatment and prevention", 4 to 14 February 2009
- d. The Fourth Latin American Summer School on Epilepsy: "Epilepsy and Time", was held from 1 to 10 February 2010

LASSE V was held 20 February to 1 March 2011, at the Santa Monica Hotel and Convention Center in Guarulhos, São Paulo, Brazil. The main topic was "Epilepsy, Behavior And Cognition." A special event, during the LASSE V, was a special award to Prof Carlos Medina-Malo a great neuro-pediatrician from Colombia for his work devoted to the development of epilepsy treatment in Colombia and Latin-America.

3. Latin American Academy of Epilepsy (ALADE)

ALADE Mission: To provide and promote epilepsy education and research with excellence, quality, efficient and humanistic approach for medical and non-medical professionals in Latin America.

ALADE Vision: To promote and provide epilepsy education and research, aiming to improve the healthcare of people with epilepsy in the Region.

Goal: The goal of ALAE is to promote epilepsy education and research in the Latin American Region in order to improve healthcare of people with epilepsy.

ALADE depends on our Commission and is its academic arm. The new members added in February 2011 were: Elza M Yacubian (President, Brazil), Jaime Carrizosa (Secretary, Colombia) and Roberto Caravallo (Delegata, Argentina). During the next few months we will include new members.

We would like to thank all colleagues, who worked and served to ALADE from 2008 to February 2011: Elza M Yacubian (Brazil), Patricia Campos (Perú), Silvia Kochen (Argentina), Francisco Rubio Donnadieu (México), Alejandro Scaramelli (Uruguay), Esper Cavalheiro (Secretary, Brazil) and Marco T Medina (President, Honduras).

ALADE provided courses at the LACE 2011 with the support of a local Committee:

1. Organization and participation of the V LASSE, February 20 to March 1 2011, Guarulhos, São Paulo, Brazil.
2. Participation and distribution of the book *Las Crisis Epilépticas* during the II Symposium on Epilepsy, at Clínica Las Condes, Santiago, Chile, 27 to 28 May 2011 (local support by Dra Loreto Ríos)
3. Organization of one Educational Course in Caracas, 12 November 2011; 200 copies of the book are being printed in Venezuela (sponsored by Abbott). The local support is by Dra Guilca Contreras.
4. Organization of Educational Course in Guatemala, local contact is Dr José Manuel Pérez.
5. The first textbook of ALADE was *Semiología de las crisis epilépticas* (Seizures semiology) edited by Silvia Kochen (Argentina) and Elza Marcia Yacubian (Brazil). Printing of 1,000 copies of the book was completed in Argentina with an academic grant from Abbott. Actually this text is being distributed in all Latin-America.

4. Projects (Fellowship in epileptology and neurophysiology)

Five bursaries and 11 positions were offered in the call for applications after the budget approval (end of February 2011) with a deadline submission for applicants of 15 April 2011. Eleven applications were received and submitted to evaluation by ALADE Commission. Five bursaries were given: Dra María Angélica Uscátegui (Colombia) starting August 2011 at Universidade de Campinas (Brazil); Enrique Ortega (Córdoba, Argentina) starting September 2011 in Hospital de Clinicas de Ribeirao Preto (Brazil); Nicolás Garófalo (Cuba) who will start in November 2011 at the Universidade Federal de São Paulo (Brazil); Angela Pérez (Colombia) starting September 2011 in Ribeirao Preto (Brazil) and Silvia Marca (Bolivia) who started at the Epilepsy Center in Santiago de Chile in September 2011. Further, those applicants not awarded with bursaries were offered the possibility of performing the

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

fellowships in the remaining positions if they could obtain support from other sources. Dr Alberto Castaño (Colombia) started his training this way at the Universidade de Campinas (Brazil). Because of the delayed timeline and further difficulties with visa issues, fellowships started recently, and apart from the enthusiastic messages from the trainees and “lack of problems” informal reports from those responsible at the Centers, formal reports on the experience will have to wait until later in 2012.

5. Latin American Epilepsy Surgery Subcommittee

The ILAE Commission on Latin American Affairs with the approval of the ILAE President, Peter Wolf, appointed a new Latin American Epilepsy Surgery Subcommittee. The members of this Subcommittee are: Mario Alonso (Chair, Mexico), Americo Sakamoto (Secretary, Brazil), Carlos Barzallo (Ecuador), and Manuel Campos (Chile).

The term of this Subcommittee will be the same as the ILAE Commission on Latin American Affairs. The main goals of this Subcommittee are improving the epilepsy surgery gap in Latin America, promoting education and research on epilepsy surgery and, working closely with the Latin American Academy of Epilepsy (ALADE).

May 2011 was the 2nd Regional Meeting in Epilepsy Surgery, in Cordoba, Argentina (Chairman, Dr Adrian Muñoz), with delegates of many Epilepsy Centers of Argentina, Brazil, Chile and Uruguay. This activity will be continuing each year in different countries.

The main achievement of this Subcommittee in 2011 has been the accomplishment of the first Fellowship in Epilepsy Surgery. Due to the underdevelopment of epilepsy surgery in many countries in the Region, we obtained ILAE support for one fellowship in surgical treatment of epilepsies (neurosurgeon), with Dr Mario Alonso at the National Neurological and Neurosurgical Institute of Mexico as coordinator. The first fellowship was for a young colleague from Peru (Dr Carlos Mao Vasquez), who returned to Peru and performed the first epilepsy surgery at Peruvian National Institute of Neurological Sciences (Instituto Nacional de Ciencias Neurológicas de Perú). Actually we have a second fellow (2011-12), a Dr Rafael Leonardo from Honduras.

Also in Lima, Peru, Dr Manuel Campos in February 2011 performed the first two Functional Hemispherectomies in children at the “Hospital Guillermo Almenara” of the Social Security, with the local neurosurgeons (Dr Marco Mejias, Alejandro Rossel, etc.).

6. Relationships with North American Commission

The LA Commission worked together with the North American Commission and her Chair (Jacqueline French, USA) and the Education Task Force of the North American Region.

Our main goal was education, through the program “Partnering Epilepsy Centers in the Americas (PECA)”. This program was developed by José Cavazos (USA) with economic support provided by industry (UCB). It consists of visiting American professors in Latin-American epilepsy centers giving support for the development in specific areas of the epilepsies. Many countries were involved including: Bolivia, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, Mexico, Paraguay, Peru and Uruguay.

We had a meeting at the last International Epilepsy Congress in Rome, September 2011, with participants from the Education Committees of the North American Commission (Sheryl Haut, Jaideep Kapur, Jacqueline French, etc.).

7. ILAE Chapters in Latin-America:

- a) New Chapters: In the Region only two countries did not have ILAE Chapters yet (Bolivia and El Salvador). In the last year, with the participation of Eduardo Barragan (Secretary our Commission) and Samuel Wiebe (Secretary General, ILAE), both countries were accepted during the ILAE Assembly at the International Epilepsy Congress in Rome (September 2011).
- b) Renewal of already established ILAE Chapters: Due to lack of recent and updated information on some Chapters, efforts were conducted to contact them and to help them to give a new impulse on their activities. A good example was Nicaragua: this country is again involved in our ILAE activities. Our tasks on the topic are not finished yet. We would also like to include new physicians in the management of each Chapter, because one of our main duties is identification of new and young colleagues with interest in epilepsy in the Region. These people will be the next generation for the development of epilepsy care in Latin America.

8. Regional Journals in Epilepsy

There are three epilepsy journals in Latin America, where now it is possible to publish local research. The *Neurophysiologic Journal* from Brazil, is published in English, *Revista Chilena de Epilepsia*, is published in Spanish and *Revista Uruguaya de Epilepsia* has been published since the early 90s, but so far it has only a local distribution.

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

9. Work together with IBE (International Bureau for Epilepsy)

Our Commission has an excellent relationship with the Latin American IBE Commission (Lilia Nuñez, Chair, Mexico and Tomás Mesa Secretary, Chile) and the International Vice President (Carlos Acevedo, Chile). We work together in academic and social activities for development of epilepsy in the Region and we jointly organize the LACE. Our next step is to work on the Global Campaign "Epilepsy out of the shadows" together with the World Health Organization (WHO). Another target is to include the epilepsies in the PAHO (Pan-American Health Organization) agenda in the next meeting of the health minister with the PAHO.

Accomplishments (2009-2010)

- Strategy and Plan of Action on Epilepsies for the Americas (PAHO, ILAE and IBE)
- V Latin American Summer School on Epilepsy (LASSE)
- The Latin American Academy of Epilepsy (ALADE)
- Creation of the Fellowship in Epilepsy in Latin-America
- Establishing a Collaborative Educational work with the ILAE North American Commission.

Recommendations for Future Work

- Support the Strategy and Plan of Action on Epilepsies for the Americas
- Support to LASSE as an important educational activity
- Support to the Latin American Congresses, as the main activity in our Region.
- Continuous support to the Latin American Epilepsy Academy (ALADE) and the regional educational activities.

Summary

Based on this team work, the ILAE Commission on Latin America affairs took a big step forward, becoming a mature Region with our main issue the Strategy and Plan of "Action on Epilepsies for the Americas". We must continue with the success of the Latin American Summer School on Epilepsy (LASSE), also with the Latin American Academy of Epilepsy (ALADE); establishment of new targets, like the Epilepsy fellowship; development of a website with the main conferences on LACE and the collaboration with the ILAE North American Commission. We still have several challenges in order to improve the prevention, epilepsy healthcare, education and research in our Region.



Latin American Commission

COMMISSION OF THE NORTH AMERICAN REGION (NAC)

List of Members

Chair	Sheryl Haut (USA)
Secretary, President Canadian League Against Epilepsy	Sharon Whiting
Treasurer	Lionel Carmant
Past Chair	Jacqueline French Amza Ali (Jamaica, Caribbean) Jaideep Kapur (USA) Nathalie Jetté (Canada)
President, American Epilepsy Society AES	Jack Pellock (USA)
International Affairs Committee	Bill Theodore (USA)
ILAE Secretary- General, Ex-Officio	Samuel Wiebe

Sub-commissions and Members

1. Education Task Force:	
Chair	Jaideep Kapur Sheryl Haut (USA) Jose Cavazos (USA) Nizam Ahmad (Canada) Vivian Suarez (USA)
2. Task Force on Regulatory Affairs:	
Co-Chair	Jacqueline French (USA)
Co-Chair	Meir Bialer (Israel)
Co-Chair	Steven Schachter (USA) Michel Baulac (France)
Statistician	Emilia Bagiella Alexi Arzimanoglou (France) Eugen Trinka Scott Mintzer (USA) Emilio Perucca (Italy)
3. Hispaniola Task Force:	
Chair	Lionel Carmant (Canada)
Latin American Commission	Marco Medina Diogenes Santos-Viloria (Dominican Republic)
EUREPA	Michel Baldy Mouliner Alex Elie (Haiti) Marcel Sévere (Haiti) Farah Lubin (USA) Jose Ferreira (USA)
4. Task Force for Caribbean Development:	
Chair	Amza Ali (Jamaica) Sharon Whiting (Canada, formerly Jamaica) David Clarke

(US formerly from Antigua)
Lionel Carmant (Canada)

5. Stigma Task Force:
Chair
Nathalie Jetté and 14 international
members

Aims

The Commission's overall goal is to improve the delivery of epilepsy care throughout the Americas and the Caribbean. The Commission directly addresses this goal through educational and training initiatives, direct clinical interventions, regulatory projects, and research related to disparities, treatment gap and stigma in epilepsy.

Mission of the Commission

The current North American Regional Commission (NAC) was constituted in 2006, comprising English-speaking North American Chapters of Canada, the United States of America, and the English-speaking Caribbean (represented by Jamaica). The Commission's overall goal is to improve the delivery of epilepsy care throughout the Americas and the Caribbean. The Commission also aims to participate globally with partnering ILAE Commissions to share experiences and resources towards the improvement of epilepsy care worldwide.

Commission Activities from July 2010 - July 2011

The Commission established five Task Forces to accomplish the stated goals.

1. The Education Task Force continues to focus on the Partnering in the Americas (PECA) program. A PECA meeting took place after AES in December 2010. Many members of the partnerships attended, and provided feedback about the program. The mission of the PECA program was adjusted accordingly, as indicated below. This mission was further adjusted after a joint meeting of the NAC and the LAC in Rome 2011. Specific activities are described below. The Task Force has been working to develop visiting professorships to Africa, and is sponsoring a Spanish translation of the ILAE symposium at the upcoming AES.
2. The Regulatory Guidelines Task Force met in July 2011 and has planned a meeting between the EMA and FDA to take place in Paris on 17 November 2011. Specific activities are described below.
3. The Hispaniola Task Force has focused on the rebuilding and maintenance of the epilepsy clinic in Haiti, the neurocysticercosis project in the Dominican Republic, and the epilepsy surgery program in Dominican Republic. Expansion of the epilepsy clinic and neurocysticercosis projects have been planned for 2012, as described below. The

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

- epilepsy surgery program in Dominican Republic has continued to be successful.
4. The Caribbean Task Force has focused on formation of an ILAE Caribbean Chapter during 2011, which would serve as a unifying Chapter of the ILAE. As this would be the first Chapter of its kind, the process of writing the Constitution has received much attention from the Task Force members, the Commission and the Executive. Additionally, the Task Force has planned the 3rd Regional Meeting of the Epilepsy Society of the Caribbean, and continued many activities towards the development of epilepsy surgery in Jamaica. Specific activities are described below.
 5. The Stigma Task Force is a new initiative for our Commission in 2011. In a short time, Dr Jetté has convened a large group of reviewers with representatives from the following ILAE Commissions: African, Asian & Oceanian, Latin American, European and North American. These experts are examining thousands of abstracts related to stigma — details below.
 6. North America Regional Congresses: The NAC has continued to sponsor an annual symposium at AES. It was decided to invite other ILAE Commissions to organize this symposium every other year, and this will begin with a symposium organized by the European Commission at the upcoming AES. In return, the NAC was given the opportunity to organize a symposium at the European epilepsy meeting in London, in 2012.

Accomplishments from July 2010 - July 2011 Epilepsy education in the Americas, and around the world:

1. The Education Task Force approved and administrated the following PECA visiting professorships in 2011: Carol and Peter Camfield to Cuba; Barbara Dowertzky Ecuador F/U visit; Ronan Kilbride, Brazil; Selim Benbadis, Dominican Republic; Jorge Borneo, Peru. The following visits are approved and are anticipated to take place between now and Feb 2012: Mohamad Koubeissi to Brazil; David Anshel to Mexico; and Mark Sadler to Cuba.
2. The mission of the PECA program was rewritten with the following new goals: Education and training of epileptologists, neurologists, neurosurgeons, primary care physicians, healthcare extenders, and/or other professionals involved in epilepsy care; education (and advocacy) of local authorities and opinion makers, to enhance community awareness of epilepsy, treatment gap, access to care, cultural and other issues that impact delivery of care; Improve the provision of locally-sustainable patient care; initiate and foster sustainable collaborative research related to epilepsy.

3. Dr Bigelow performed a first visiting professorship to Haiti in August 2011 and will return multiple times per year as he is completing his fellowship.
4. The proposed African fellowships have not yet begun, however members of the NAC have been working closely with the African Commission to institute this program for the upcoming year. Additionally, Dr Haut has been working with both the African Commission and the World Federation of Neurology on a similar professorship program to Africa.
5. The NAC met with the LAC to discuss optimizing educational opportunities for Latin American providers. As a first step in this partnership, the NAC has approved funding for Spanish translation of the ILAE symposium at the upcoming AES meeting in 2011.

Regulatory Guidelines

The Regulatory Guidelines Task Force has planned a meeting between the EMA and FDA to take place in Paris on 17 November 2011. Two key issues that will be discussed at the meeting are the concept of abolishing the need for a monotherapy indication for epilepsy, and acceptance of a novel trial design (time to event). A meeting was held in July to address the proposal for a unified (both monotherapy and polytherapy) claim. A white paper supporting this concept is underway. For the time to event initiative, eight letters have been sent to pharmaceutical companies, requesting a post-hoc analysis of existing trial data to determine whether this approach would have been successful, and to determine the optimal outcome measures for the trial. So far, three companies, (representing trials from five drugs) have approved the proposal, and the others are considering the proposal.

Hispaniola projects

1. The epilepsy clinic in Haiti is administering phenobarbital to patients. Biannual visits by Dr Bigelow and Dr Carmant have continued to support this clinic. A mobile clinic expansion is planned for 2012.
2. Following a successful conclusion of Part I of the neurocysticercosis project in 2010, analysis this year revealed the need for establishing the prevalence of neurocysticercosis in a control population. The study design has been planned this year, with this portion of the project expected to begin in early 2012.
3. The epilepsy surgery program in the Dominican Republic remains in operation. Surgeries have been performed following video-EEG recordings read by Dr Diogenes Santos Vilorio.

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

Epilepsy in the Caribbean

1. The proposed constitution for the ILAE Caribbean Chapter is well developed and moving towards completion, having undergone review by Dr Wolf. Many issues of membership and administration of a Caribbean ILAE Chapter were discussed and decided upon at the in-person NAC meeting in March 2011. It is anticipated that a provisional approval may be obtained by the 3rd NARCCE meeting in Antigua in February 2012, followed by full approval by the assembly in 2013.
2. A telemedicine facility in Jamaica was launched in July 2011. A number of issues must be addressed prior to initiation of the program.
3. The 3rd NARCCE meeting was organized to take place in Antigua, February 2012. Many members of the NAC will participate as speakers, and the NAC will hold a meeting at that venue.
4. The Task Force has begun discussions with the Ministry of Health in Jamaica about two projects:
(i) An educational program in schools about epilepsy, and (ii) An educational program about epilepsy directed at nurses, with the ultimate goal of developing a program for training specialist epilepsy nurses. The Ministry is very receptive. Funding will become important as this moves forward next year.

Stigma

The newly established Stigma Task Force began in January 2011. Four conference calls have been held already (each with detailed minutes, with one more call scheduled in November 2011), and one face to face meeting in Rome (August 2011). An extensive literature search strategy was developed with input from an expert librarian and feedback from the Task Force members to ensure all key articles would be identified for this work. The literature search strategy was tested and refined. All Task Force members were involved in abstract review. An initial training exercise was done to ensure everyone was in agreement with the eligibility criteria and the procedure, where all members reviewed the same 40 abstracts identified from the search strategy. A conference call was then held to discuss agreement between reviewers for these 40 abstracts and discuss why some abstracts were selected and others not. In total, 8,142 abstracts were identified from the following databases: MEDLINE, Cochrane Central Register of Controlled Trials, PubMed, EMBASE, PsychINFO, CINAHL, Cochrane Database of Systematic Reviews, Health and PsychoSocial Instruments, Social Services Abstracts, Sociological Abstracts, SocINDEX, LILACS and Web of Science. Removal of duplicates resulted in 4,123 abstracts for review. These were divided and each abstract was reviewed by two Task Force members. Abstracts with disagreements were discussed. All articles where agreement was reached were pulled. Review is nearly complete.

North America Regional Congresses

The NAC organized a symposium at the AES meeting 2010 entitled "Epilepsy Treatment in North America and Around the World: Can We Learn From Each Other?" The NAC has worked with the European Commission to plan the NAC-sponsored symposium at the upcoming AES meeting entitled "Research Network in Europe and the USA: How Results Apply to Clinical Practice."

Recommendations for Future Work PECA partnership program:

We met with the LAC in Rome, and have further revised the plan for the 2012 PECA programs. The new programs will include a new focus on reverse visits of LAC faculty to North American centers to obtain specific epilepsy training. The LAC will work closely with the Education Task Force to issue the call for applications, review and select applications. The NAC will continue to administer the program, request applications, review and award the visits.

Translation

The NAC is conducting a pilot trial of Spanish translation for the ILAE symposium at the AES meeting in 2011. Based on the success of this project, future translation projects are planned, including expansion to more courses and a greater number of languages.

African partnerships

African partnerships are planned for 2012. We anticipate the funding of three to five partnerships between faculty and African sites. In addition, we plan to continue to collaborate with the African Commission and the World Federation of Neurology towards planning professorships to Africa. This will be discussed further at the upcoming WFN meeting in Marrakesh.

Regulatory guidelines

We anticipate that at the upcoming meeting of the Regulatory Task Force, FDA and EMA will lay the groundwork for changes in trial design for epilepsy studies going forward. A follow-up meeting is planned for 2012.

Hispaniola Mobile clinic in Haiti:

A mobile clinic is planned for Haiti, with the goals of providing care in rural areas of Haiti, educating health providers, patients and families about epilepsy, and eventually train local nurses and technologists to develop their own Level One epilepsy clinic. We will travel using a mini-van equipped with the portable EEG system donated by Grass Instruments after January 2010. Visits will include four communities located within two hours of Port-Au-Prince: Jacmel, St-Marc, Léogane and Mirabelais. A partnership has been established with the local Rotary Clubs to provide offices to perform clinical evaluations. Over the

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

ensuing year, we will try to establish partnerships in each Region to make the project sustainable. Jacmel and Léogane with the Canadian Red Cross, Mirabelais with Partners in Health and St-Marc with a Chicago city foundation where one of our members Dr Serge Pierre Louis is involved.

Neurocysticercosis (NC) project

Two years ago, we screened 100 people with epilepsy in the endemic region of neurocysticercosis to determine the prevalence of the disease. We realized that 29 percent of the population tested were positive. In line with these findings we will start a second phase to test the prevalence of NC in the control population to better determine the impact of NC on the epileptic population. In partnership with the LAC, 100 controls will be tested using brain imaging and blood tests for neurocysticercosis. A questionnaire will also be filled and neurological examination completed to ensure that these controls have not experienced seizures, especially subtle focal seizures.

Caribbean

Caribbean chapter of the ILAE:

We anticipate completion of the Constitution for the Chapter, with the hope of obtaining provisional approval during 2012, and full approval of the assembly in 2013.

Telemedicine and epilepsy surgery

The teleconferencing project with the Caribbean, initially planned for 2011, is now planned for 2012. This project aims to establish an infrastructure for teleconferencing between North American and Caribbean epilepsy centers. A telemedicine facility in Jamaica was launched in July 2011, but is not yet in use due to technical issues to be resolved. Dr Ali is working with others in an activity of the International Affairs Commission of the AES, chaired by Professor Dennis Spencer, toward developing a telemedicine facility to be physically sited in the Department of Neurosurgery at the University Hospital of the West Indies in Kingston. This initiative has been greatly facilitated by the interest and support of Professor Ivor Crandon, Head of the Department of Neurosurgery at the University of the West Indies. It will link Yale and the EPSEG in Jamaica for regular case conferences, towards the development of a mentored epilepsy surgical program in Jamaica for the Caribbean.

Stigma

The Stigma Task Force has nearly concluded the selection of abstracts. The next step is a systematic review focusing on stigma in epilepsy, specifically addressing:

1. Available tools to measure stigma in epilepsy;
2. Frequency and nature of stigma towards epilepsy;
3. Determinants/predictors of stigma;
4. Impact of stigma on other outcomes (e.g. QOL, employment, etc);
5. Existing effective interventions to reduce epilepsy-related stigma.

Results of the systematic review will be available by the end of 2012 with recommendations regarding what is needed to move the field forward and to address this important issue. A final report will be submitted to the ILAE summarizing the results of the systematic review and the recommendations. A shorter report will be prepared for peer review submission (*Epilepsia*) as well.

PAHO

The Commission plans to establish a new Task Force chaired by Dr Haut, and take an active role in addressing the recently approved PAHO epilepsy initiative. The NAC plans to work on implementing the North American segment of the four strategic aims of the PAHO initiative, where applicable, and to expand our existing partnership with the Latin American Commission to assist with the implementation of PAHO in Latin America. We will address PAHO initiatives which concur with the strategic goals of the ILAE including education and training on local, regional and distance levels towards improvement of the care of persons with epilepsy, and reducing the treatment gap in epilepsy. As an initial step, the PAHO Task Force of the NAC will meet with the Latin American Commission at AES in 2011 to identify areas of potential collaboration.

Institute of Medicine report

The NAC plans to participate in the dissemination of recommendations of the IOM Committee on the psycho-social aspects of the epilepsies in partnership with the other Vision 20/20 Committee members. Dr Carmant will continue to represent the ILAE on the IOM Committee. Further steps will be taken pending the results of the report.



Topic-Oriented Commissions

COMMISSION ON CLASSIFICATION AND TERMINOLOGY

List of Members

Chair	Ingrid Scheffer (Australia)
Secretary, Past Chair	Anne Berg (USA)
Information Officer	Pippo Capovilla (Italy)
Finances	Mary Connolly (Canada)
Education Officer	Sameer Zuberi (UK)
	Laura Guilhoto (Brazil)
	Edouard Hirsch (France)
	Helen (Yue-Hua) Zhang (China)
Ex-Officio – Pediatrics	Doug Nordli (USA)
Ex-Officio – Genetics	Sam Berkovic (Australia)
EC Liaison	Sam Wiebe

Aims

1. Education regarding revisions of terms and organization of the epilepsies;
2. Translation of teaching slides/package into other languages;
3. Web resource of Controlled Vocabulary, Videos, EEG, MRI for use in diagnosis and phenotyping in epilepsy;
4. Diagnostic manual for the six most common electroclinical syndromes (BECTS, CAE, JAE, JME, West, LGS).

Mission

To develop a scientifically-based approach to the classification of the epilepsies. To improve diagnosis of epilepsy seizures and syndromes globally.

Commission Activities from July 2010 through July 2011

The new organization of the epilepsies has been disseminated via *Epilepsia* and education globally (live and electronic) resulting in much debate and some modification in response to feedback. The Commission is seeing acceptance of the new terminology in papers using the new terminology and reviewers requesting the information.

Classification of Epilepsy Syndromes Task Force

- Diagnostic manual development for common and new syndromes with videos for each syndrome and EEG correlates

Classification of Status Epilepticus Task Force

- Document to be developed from workshop at Status Colloquium at Oxford

Challenge/Charge

- Listen for refinement input
- Encourage people/other countries to work with the new organization
- Interplay of new organization and ICD coding (further discussion during Epidemiology Commission presentation)

Recommendations for Future Work

- Further refinement of organization in response to comments, translation to more languages, more education, encouraging each Region to have a classification activity
- Develop and go live with Diagnostic Manual Website
- New status classification to be published

Ingrid E Scheffer
Chair

COMMISSION ON DIAGNOSTIC METHODS

Commission Members

Chair	Fernando Cendes (Brazil)
Past Chair	William Davis Gaillard (USA)
Secretary	Matthias Koepp (UK)
Translational Research	Ingmar Blümcke (Germany)
Educational Officer	Prassana Jayakar (USA)
Information Officer	Bruce Hermann (USA)
Treasurer	Friedrich G Woermann (Germany)
Members	Catherine Chiron (France)
	William Theodore (USA)

Task Forces

1. Neurophysiology:

Chair	Prassana Jayakar
Past Chair	Demetrios Velis
Secretary	Herman Stefan
	Francois Dubeau
	Eli Mizrahi
	Aristea Galanopoulou
	Akio Ikeda
	Roberto Caraballo
	Paolo Tinuper

2. Neuroimaging:

Chair	Matthias Koepp
Past Chair	William Davis Gaillard
Secretary	Friedrich G Woermann
	Catherine Chiron
	William Theodore
	Donald W Gross
	Seung Bong Hong
	Dennis Spencer
	Masako Watanabe

3. Neuropathology:

Chair	Ingmar Blümcke
Secretary	Roberto Spreafico
	Eleonora Aronica
	Hajime Miyata
	Andre Palmi
	Maria Thom
	Harry Vinters
	Guenther Sperk

4. Neuropsychology:

Chair	Bruce Hermann
Secretary	Michael Saling
	Maryse Lassonde
	Isabelle Jambaqué
	Christoph Helmstaedter
	Urvashi Shah
	Ronit Pressler

5. Focal Cortical Dysplasias:

Chair	Ingmar Blümcke
	Eleonora Aronica
	Maria Thom
	Harry Vinters
	Andre Palmi
	Roberto Spreafico
	Guiliano Avanzini
	Scott Baraban
	Jim Barkovich
	Giorgio Battaglia
	Albert Becker
	Carlos Cepeda
	Helen Cross
	Nadia Colombo
	Olivier Delalande
	Francois Dubeau
	John Duncan
	Renzo Guerrini
	Ajay Gupta
	William Harkness
	Philippe Kahane
	Giorgio LoRusso
	Joseph Loturco
	Gary Mathern
	Imad Najm
	Cigdem Ozkara
	Charles Raybaud

Aims

The major challenge is the proper evaluation and use of technology and other diagnostic methods to improve care of patients with epilepsy when there is such a broad range of available technology and expertise across the globe. At one extreme is the optimal best practices in developed societies, the other is optimal use of limited resources in underdeveloped economies. These issues touch upon education as well as assessments and utilization of diagnostic methods, and emerging diagnostic methods and disciplines.

Mission of the Commission

To give ILAE all support necessary in order to ensure the optimal use of technology and other diagnostic methods to improve care of patients with epilepsy world-wide.

Commission Activities from July 2010 through July 2011

In conjunction with the Education Commission, the Commission is supporting the planning and implementing of e-learning imaging and EEG courses, as well as other educational activities in different parts of the world, such as in activities during Regional Congresses and Latin-American School of Epilepsy (LASSE).

COMMISSION ON DIAGNOSTIC METHODS *(continued)*

FCD Task Force – proposal for a new neuropathological classification system for FCD

Neuropathology Task Force – proposal for a semi-quantitative ILAE scoring system for HS in epilepsy patients

Neuropsychology Task Force

- Summarize and advance evidence-based neuropsychological practice
- Focus on relevance for clinical practice and directions for the future
- What are the important evidence-based outcomes and their implications for improving diagnosis and clinical care?
- What remains to be determined through future research to advance treatment?

Neurophysiology Task Force

- Proposed Task Force to develop optimal guidelines for “MRI negative” cases in conjunction with the Pediatric Surgical Task

- Working on a retrospective study to define the utility of various tests in this cohort
- Hope to incorporate some of the “MEG guidelines” and integrate our efforts with the imaging Task Force

Neuroimaging Task Force

- Consensus paper on the use of advanced and functional imaging methods
- Define the role of advanced structural and functional imaging methods in pre-surgical evaluation guidelines for children and adults, jointly developed and led through the Neuroimaging and Neurophysiology Task Forces and the Paediatric Commission

Fernando Cendes
Chair



IEC 2011 opening reception

COMMISSION ON EDUCATION

List of Members

Chair	Chong Tin Tan Tallie Z Baram Walter van Emde Boas Maria Canevini Hassan Hosny Angelina Kakooza Ruediger Koehling David Labiner Shih Hui Lim Karupath Radhakrishnan Marcia Elza Yacubian
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Task Force on Distance Education

Chair	Walter van Emde Boas Dimitri Velis Perrine Plouin Jackie French Holger Lerche Catherine Chiron Kuate Callixte Magda Nunes Verena Hézser-V.Wehrs Priscilla Schisler Li Kuo Tan Chong Tin Tan
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Task Force on e-Textbook

Editor	Shih Hui Lim Solomon Moshé Emilio Perucca Chong Tin Tan Li Kuo Tan
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Mission and Aims

The role of the Education Commission is to coordinate the education efforts by the various Regional and Topic-oriented Commissions, and to be directly responsible for the online educational activities. It also works with non-ILAE partners in joint education efforts.

For 2011, members of the Commission, Distance Education and e-Textbook Task Forces met face to face in March in Brussels, and in August in Rome during the IEC.

The Regional Epilepsy Academies and Commissions

The ASEPA, EUREPA, ALADE, North America, Eastern Mediterranean continue with their various efforts in education. The African Commission was formed in 2010. We are sad to hear of Dr Bryan Kies, the Education Officer, who passed away in July after a period of illness. We are glad to see the appointment of Jo Wilmshurst, a pediatric neurologist from Cape Town, South Africa as the new Education Officer. We look forward to a fruitful time of working together.

There are various education activities being carried out in the different regions. They are summarized as follows:

I. Workshops and summer schools

There were nine stand-alone workshops organized by ASEPA in 2011. Various education programs were also conducted during the IEC in Rome. The Neurobiology Commission organized the 11th WONOE in Grattaferrata.

As for the longer duration training courses, other than Eilat in September, a summer school was successfully held for the first time in China in Chengdu – the gateway city to West China.

II. Visiting professorship

This is mainly by the North American Commission with emphasis on building of long lasting academic and clinical relationship between centers in Latin America, Caribbean and North America. Discussion is now underway to organize similar scheme in Africa, with World Federation of Neurology (WFN) and International Child Neurology Association (ICNA).

III. EEG certification

This is mainly by the ASEPA, conducting a two-part EEG certification examination. There are six each of Part I and Part II examinations being conducted in various parts of Asia in 2011. To date, there are 384 candidates who have sat for Part I examination with passing rate of 63 percent, and 138 candidates in Part II with passing rate of 62 percent.

IV. Fellowships

This is mainly by the ASEPA and Latin American Commission. In ASEPA, this was started in 2003. By the end of 2010, there were 34 candidates who have benefited from the fellowship. Other than one candidate, the others have all returned to serve in their own communities. Many of the fellows are now in leadership positions in the various national Chapters. It is hoped that the visiting professorship program in Africa will be followed by fellowships.

V. Publications

The proceeding for the Melbourne AOEC in 2010 was published in May 2011, with the online version available as open access in the ILAE website.

VI. Research mentorship and grant

The Neurobiology Commission under Marco de Curtis and the Education Commissions are discussing the proposal to build on the residential courses with hands-on tutoring of practical research proposals that are likely to create an impact in resource-poor regions, including guidance to grant application. The proposal also includes providing a seed grant, and mentoring of its implementation and progress.

COMMISSION ON EDUCATION *(continued)*

Distance-Learning Courses

The League solidified the organizational and financial stability of the long-distance education program by acquiring direct control and investing in the expansion of the Virtual Epilepsy Academy (VIREPA) and by creating a Task Force on Distance Education led by Walter van Emde Boas within the Education Commission. It is organizing and conducting the various teaching courses with the Regional and Topic-oriented Commissions. In order to increase the attractiveness and accessibility, ongoing courses have been shortened and either divided in basic and advanced parts (Imaging and Pharmacotherapy) or split in a general course (EEG) to which now a totally new course on Pediatric EEG and Epilepsy has been added. The course on Genetics is being remodelled along the same line. For 2012-2013 new courses on Psychiatric Aspects and on Sleep and Epilepsy are in development. Preliminary discussion has been undertaken to organize a course for primary caregivers in Subsaharan Africa in collaboration with the Task Force on Seizures and Epilepsy in the Tropics and with the African Commission.

e-Textbook

This project is led by Shih Hui Lim. The editors for various sections have also been appointed. About 50-100 common topics will form the first edition. Hopefully we can keep the timeline of uploading the first edition in first quarter of 2012. There is also plan to translate the textbook into Spanish, and proposal to translate to Chinese.

Recorded Presentations

Other than the workshop in Melbourne AOEC, some of the education sessions in Rome IEC were also recorded. These recaptured voice/power point slides are being uploaded to the "recorded presentations" of the ILAE website. Similar recapturing of the presentations are being proposed for the various Regional Congresses in 2012.

CT Tan
Chair



IECD 2011 opening reception

COMMISSION ON EPIDEMIOLOGY

List of Members

Co-Chair	Dale Hersdorffer
Co-Chair	Ettore Beghi
	Giancarlo Logroscino
	Ding Ding
	Josemir Sander
	Torbjorn Tomson
	Allen Hauser
	Charles Newton
	David Thurman
	Marco Medina

Sub-commission Members

Reliability Task Force	
Chair	Ettore Beghi
	Dale Hesdorffer
	Donna Bergen
	Allen Hauser
	Peter Bergin
	Jacqueline French
	Marco Medina
	Charles Newton
	Douglas Nordli
	Giuseppe Capovilla

Comorbidity Task Force	
Chair	Dale Hesdorffer
	Ettore Beghi
	Roberto Tuchman
	Andres Kanner
	Michael Trimble
	Paola Torelli
	Christoph Helmstaedter

Mortality Task Force	
Co-Chair	Giancarlo Logroscino
Co-Chair	David Thurman
	Dale Hesdorffer
	Allen Hauser
	Ley Sander
	Charles Newton
	Torbjorn Tomson

Status Epilepticus Task Force	
Chair	Shlomo Shinnar
	Giancarlo Logroscino
	Others TBD

Aims

The Commission on Epidemiology's work is focused on providing standards for the conduct of epidemiological research in epilepsy and for describing the epidemiological evidence on the burden of epilepsy and potential preventive measures.

Mission

The Commission on Epidemiology's work is focused upon the burden of epilepsy. The work that stems from this focus includes: the development of standards for the conduct of epidemiological research in epilepsy in order to best study the occurrence and burden of epilepsy; the burden of mortality in epilepsy with a specific focus upon potentially preventable causes of death; the spectrum of comorbidity in epilepsy; development of an epidemiological definition of Status Epilepticus; and assessment of the reliability of epilepsy classifications.

Commission Activities from July 2010 through July 2011

A meeting was held in London (16 March 2011) for the Task Force on Comorbidity. A Commission meeting was held in Rhodes (1 July 2011). Two teleconferences and some informal meetings with members of the Task Forces were held during this period.

Accomplishments

1. Completion of the Standards in Epidemiology document, now published as a supplement to *Epilepsia*.
2. Completion of a combined analysis of SUDEP risk factors and preparation of two scientific reports, now in publication.
3. Finalization of questions for a systematic review of epilepsy comorbidities and selection of search terms for MEDLINE.
4. Preparation of the material (case reports and case record forms including the 1989 ILAE classification, the ICD-10 and ICD-11 codes) for the study, testing the reliability of the epilepsy classifications.

Recommendations for Future Work

We are proposing no new tasks. We will continue the current tasks to completion as indicated in the work plan. This also includes the preparation of workshops to disseminate and implement the results of the Task Force activities.

Dale Hesdorffer and Ettore Beghi
Co-Chairs

COMMISSION ON GENETICS OF EPILEPSY

Members

Chair	Sam Berkovic (Australia)
Past Chair	Ruth Ottman (USA)
	Shinichi Hirose (Japan)
	Thomas Sander (Germany)
	Peter DeJonghe (Belgium)
	Nigel Tan (Singapore)
	Sanjay Sisodyia (UK)
	Dan Lowenstein (USA)
	Marcello Kauffman (Argentina)
	Alica Goldman (USA)
	Carla Marini (Italy)

Recommendations for Future Work

- Completion of SCN1A testing report
- Completion of information pamphlet
- Rapid development of the ILAE Consortium now that the 'political' aspects have been dealt with

Sam Berkovic
Chair

Aims

- Improve genetic literacy of members of the League to ensure up to date information can be provided in their professional roles
- Develop information sources regarding genetics of epilepsy for the public, taking into account regional sensitivities, cultural factors and possible stigmatization related to epilepsy and genetics
- Assist in coordination of international efforts to understand the basis of complex epilepsies that will require large multinational cohorts.

Mission

Improve knowledge among professional and public regarding genetics and facilitate collaborative research.

Commission Activities from July 2010 through July 2011

Commission met in Rhodes July 2011 and at AES in San Antonio, December 2010.

A teleconference was held in June 2011. Met in Rome, August 2011

Accomplishments from July 2010 through July 2011

1. Genetic literacy
 - EpiGAD website has been maintained and is under regular review
 - Guidelines for SCN1A testing in mature draft stage
 - Negotiations with "GeneTests" website successful
 - VIREPA course – clarification of its viability and ongoing support from Commission
2. Public information
 - Document for public education being developed
 - Awaiting advice from Global Campaign
3. International Research Coordination
 - A Consortium for Genetics of Complex Epilepsies has been formed
 - The Consortium Charter has been finalized and all key groups have signed on
 - A meta-analysis of published and unpublished GWAS data is in planning stages.

COMMISSION ON NEUROBIOLOGY

List of Members

Chair	Astrid Nehlig (France)
Co-Chair	Jeff Noebels (USA)
Past Chair	Annamaria Vezzani (Italy)
Treasurer	Christophe Bernard (France)
Chair of the WONOEP	
Commission Liaison to Epidemiology	Marco De Curtis (Italy)
Commission Chair, Education	Edward Dudek (USA)
Commission Chair of the Translational Task Force	Uwe Heinemann (Germany)
Chair, Basic Science Task Force	Terry O'Brien (Australia)
Liaison to Pediatrics	Heidrun Potschka (Germany)
Commission Liaison to Therapeutics	Raman Sankar (USA)
Commission	Matthew Walker (UK) Rafael Gutierrez (Mexico) DS Kim (Korea) Filiz Onat (Turkey) Takao Takahashi (Japan)

Sub-commissions

Sub-commission on Education

Chair	Uwe Heinemann (Germany) Guiliano Avanzini (Italy) Esper Cavalheiro (Brazil) Marco De Curtis (Italy) Istvan Mody (USA) Asla Pitkänen (Finland) Liao Weiping (China)
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Sub-commission on Translational Research

Chair	Terence O'Brien (Australia) Greg Holmes (USA) Pete Engel (USA) Aristea Galanopoulou (USA) Roustem Khazipov (France) Merab Kokaia (Sweden) Holger Lerche (Germany) Matthew Walker (UK)
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Sub-commission on Basic Research

Chair	Heidrun Potschka (Germany) Maria José da Silva Fernandes (Brazil) Alon Friedman (Israel) David Henshall (Ireland) John Huguenard (USA) S Koh (Korea) Filiz Onat (Turkey) Steven Petrou (Australia)
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Günther Sperk (Austria)
Jana Veliskova (USA)

Sub-commission for WONOEP

Chair	Marco De Curtis (Italy)
Treasurer	Christophe Bernard (France) Guiliano Avanzini (Italy) Pete Engel (USA) Uwe Heinemann (Germany) Raman Sankar (USA)

Aims

The overall goals of the Neurobiology Commission are to increase the visibility and impact of basic neuroscience research among the epilepsy community, to bring education to a broader community, to develop specific Task Forces and spread knowledge during diverse meetings.

Mission of the Commission

The mission is the sum of the aims, namely, to provide a forum for neuroscientists involved in epilepsy research to discuss new findings related to the understanding of the basic mechanisms of epilepsy and epileptogenesis. The Commission will also promote the participation of ILAE Chapters and of young emerging scientists in the field of experimental epileptology. It is also to develop basic science and translational approaches to remaining problems such as establishing better guidelines for preclinical research and with the help of other Chapters and Commissions to develop a better interactive network partly related to specific problems linked to epileptic syndromes more common in less developed countries.

Commission Activities from July 2010 through July 2011

- Supported travel for Young Investigators to attend the Gordon Conference on Epilepsy held in New Hampshire, USA (August, 2010)
- Held meeting at AES in San Antonio, TX, USA to organize workshops and Task Forces
- Is actively involved in several international educational projects designed to train young neuroscientists entering the field of basic and translational epilepsy research. These included the support of the fourth Advanced International Course: Bridging Basic with Clinical Epileptology 4, which was held in San Servolo, Venice, 17 to 29 July 2011. This course is aimed at bringing together young clinical and basic epileptologists for an intensive two week program aimed at designing translational research projects
- Organized and held the XI Workshop on Neurobiology of Epilepsy (WONOEP) in Grottaferrata, Italy in August 2011. The topic of this workshop, directed by Marco De Curtis (Milan) and the Commission Chairs, was "Finding Novel Mechanisms for Epilepsy Therapy" and included

structured panel sessions on the following sub-themes: receptors/ion channels and synaptic transmission; anti-inflammatory strategies; metabolic homeostasis; drugs aimed at neurodegenerative targets for epileptogenesis; and strategies for pre-clinical screening and trial design. Each panel session included an introductory talk, data blitz presentations and a long general discussion

- Organized several parallel sessions at the ILAE Congress in Rome, including the WONOEP Report session, a workshop on metabolic mechanisms of epileptogenesis and a session on Brain Tumors
- Created a new Task Force on Translational Research, directed by Terence O'Brien (Melbourne) and Co-Chaired by Michele Simonato (Ferrara), which met with the AES Task Force in Grottaferrata
- Held a Commission meeting in Rome in August 2011 to further plan Translational Task Force, including forthcoming meeting on Pre-clinical Research Guidelines in London, 2012
- Was involved in the preparation of the program of LASSE 2012 in cooperation with Esper Cavalheiro.

Accomplishments from July 2010 through July 2011

The Commission has successfully chaired and participated in the fourth Advanced International Course: Bridging Basic with Clinical Epileptology 4, in San Servolo, Venice 17 to 29 July 2011. This course brings together young clinical and basic epileptologists for an intensive two-week experience in designing translational research projects. It was very successful this year since it allowed electing a high quality research project on malaria and epilepsy with the main leader coming from a less developed country (Ethiopia). This research project is proposed as a new project for the Neurobiology Commission and was included in the budget to be covered for a small part of the cost giving a further incentive to the project if it can be selected by the Bill Gates Foundation.

The WONOEP workshop content and format were highly successful. This will generate four review publications of the Workshop Report in 2012 in *Epilepsia*.

The Task Force on Translational Research helped co-author with the AES Task Force a first organizing framework for development of optimized pre-clinical research practices in response to need for higher quality of pre-clinical evidence. As a result, a

multidisciplinary group of experts in epilepsy drug development, animal models, and human clinical AED trials is finalizing a report entitled "Identification of new treatments for epilepsy: Issues in pre-clinical methodology" which has been submitted for publication in *Epilepsia*. A follow-on publication is planned after the London 2012 Task Force meeting.

The Commission has agreed to move forward on the planning of a project entitled "From Professional Training in Neurobiology to Regional Research Funding", proposed by the Educational Task Force of this Commission, which will be launched with the Educational Commission. The joint project seeks to advance professional training in epilepsy with a focus on new research projects to solve regional epilepsy issues in less advantaged countries. A major goal is to identify resources and mechanisms for research on topics corresponding to specific regional needs. The discussion of this initiative will begin with:

1. identification of specific epilepsy research topics with clinical and social regional relevance,
2. identification of local human resources that will be involved in the project,
3. institutional structures that can host the research activities,
4. an international network that contributes to the development of the initiative, and
5. local and international funding necessary to support the project.

Recommendations for Future Work

The Neurobiology Commission recommends to focus mainly on two goals:

1. Promote further collaboration between the Translational Task Force and the AES Basic Science Committee to elaborate further appropriate guidelines for the design of appropriate and uniform pre-clinical models aimed at the development of new therapeutic strategies for some epilepsy syndromes.
2. Support the innovative research project on neuro-malaria and epilepsy which could achieve two goals: first, ultimately better curing the disease and protecting millions of children exposed to the disease and second, promoting a network of research involving less developed countries and new sites with high quality human resources.

Astrid Nehlig and Jeff Noebels
Co-Chairs

COMMISSION ON NEUROPSYCHOBIOLOGY

List of Members

Co-Chair	Andres Kanner (USA)
Co-Chair	Marco Mula (USA)
Treasurer	Mike Kerr (UK)
Past Chair	ES Krishnamoorthy (India)
Secretary	Frank Besag (United Kingdom)
Educational Officer	Bettina Schmitz (Germany)
	W Curt LaFrance Jr (USA)
	Lilia Nunez Orozco (Mexico)
	Naoto Adachi (Japan)
EC Liaison	Simon Shorvon (UK)

Sub-commissions

1. Task Force on Education

Co-Chair	Andres Kanner (USA)
Co-Chair	William Curt LaFrance Jr. (USA)
Information Officer	Marco Mula (Italy)
	Bettina Schmitz (Germany)
	Alan Ettinger (USA)

2. Task Force on Disabling Epilepsy

Chair	ES Krishnamoorthy (India)
Liaison with IBE	Lilia Nunez Orozco (Mexico)

3. Task Force on Child Neuropsychiatry

Chair	Frank Besag (UK)
	Rochelle Caplan (USA)
	David Dunn (USA)
	Albert Aldenkamp (The Netherlands)
	Thierry Deonna (Switzerland)
	Giuseppe Gobbi (Italy)
	Matti Sillanpaa (Finland)

4. Task Force on Psychoses

Chair	Naoto Adachi (Japan)
	Kosuke Kanemoto (Japan)
	Perminder Sachdev (Australia)
	Bertrand de Toffol (France)

5. Task Force on Mood and Anxiety Disorders

Chair	Andres Kanner (USA)
	Marco Mula (Italy)
	Bettina Schmitz (Germany)
	Mike Kerr (UK)

Liaison with Commission on Epidemiology	Dale Hesdorffer (USA)
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6. Task Force on Intellectual Disabilities in Adults with Epilepsy

Chair	Mike Kerr (UK)
	Marco Mula (Italy)
	Antonio Gil-Nagel (Spain)
	Sameer M Zuberi (UK)
Liaison with IBE	Mike Glyn (Ireland)

7. Task Force on Treatment Strategies

Chair	Marco Mula (Italy)
	Andres Kanner (USA)
	Bettina Schmitz (Germany)
	Michael Trimble (UK)
Liaison with Commission on Therapeutic Strategies	Steven Schachter (USA)

8. Task Force on Psychiatric Aspects of Epilepsy Surgery

Chair	Andres Kanner (USA)
	Sarah Wilson (Australia)
	Marco Mula (Italy)
Liaison with Task Force on Epilepsy Surgery – Commission on Therapeutic Strategies	Bernhard Steinhoff (Germany)

9. Task Force on Psychogenic Nonepileptic Seizures

Chair	William Curt La France
	Markus Reuber (UK)
	Laura Goldstein (UK)
	Gus Baker (UK)
	Roderick Duncan (UK)

Liaison with Commission on Classification and Terminology	Anne T Berg (USA)
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Aims

Major aim of the Commission is to develop, stimulate and coordinate research and medical education in the field of neuropsychiatry of epilepsy.

Mission

Mission of the Commission is to ensure that health professionals, patients and their care providers have the educational and research resources that are essential in understanding, diagnosing and treating psychiatric manifestations in patients with epilepsy.

Commission Activities from July 2010 through July 2011

The main project of the Commission is the translation and validation process of screening instruments for psychiatric disorders in epilepsy.

The translation of the Neurological Depression Disorders Inventory for Epilepsy (NDDI-E) for adult patients with epilepsy is still ongoing. A number of versions in different languages have already been

COMMISSION ON NEUROPSYCHOBIOLOGY *(continued)*

produced and in some cases the validation process has been also terminated (Spanish, Portuguese). The validation of the Italian, German and French versions is terminated and preliminary drafts of the final papers are available in some cases. The Commission is in touch with key members of local Chapters in Asia for the Japanese and Chinese versions.

In conjunction with the Task Force on Psychiatric Aspects of the American Epilepsy Society, a screening instrument for suicidality in epilepsy has been developed and it is being tested in a small group of patients for feasibility.

The Task Force on Child Neuropsychiatry has identified a number of screening instruments for psychopathology in children with epilepsy with special attention to depression, anxiety, hyperactivity, attention problems, and conduct disorder spectrum (CHAOS). Results of feasibility in a test sample are almost ready and a preliminary draft of the document is in preparation.

The Task Force on Intellectual Disability in Adults is collecting information on burden, mortality/life expectancy, hospitalization and access to care of people with epilepsy and intellectual disabilities.

A Web-based survey of IBE members on issues related to learning disabilities is ongoing.

The Task Force on Treatment Strategies is developing a position paper on the FDA warning regarding the issue of increased suicide risk with AEDs.

The Task Force on Education is in touch with the Sub-commission on Virtual Education of the ILAE to start a special educational VIREPA module on psychiatric comorbidity of epilepsy in 2012.

Accomplishments from July 2010 through July 2011

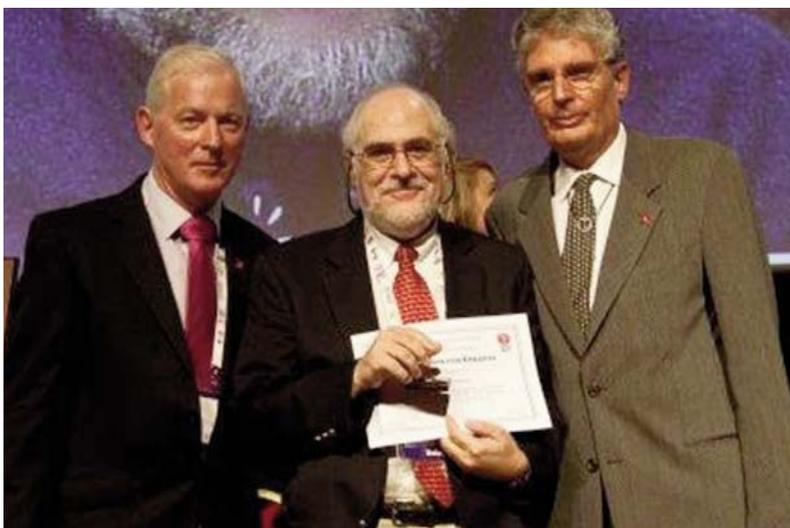
- A number of versions of the NDDI-E in different languages have already been produced and in some cases the validation process has been also terminated (Spanish, Portuguese). The validation of the Italian, German and French versions is terminated
- A screening instrument for suicidality in epilepsy has been developed
- A number of screening instruments for psychopathology in children with epilepsy with special attention to depression, anxiety, hyperactivity, attention problems, and conduct disorder spectrum (CHAOS).

Recommendations for Future Work

We plan to have a two-day Commission meeting in Chicago in 2012. This will be a focused meeting to assess progress and deliver final outcomes.

One of the principal aims of the present Neuropsychobiology Commission of the ILAE is to provide clinicians (neurologists and non-neurologists alike) with practical and user-friendly tools to identify the more frequent psychiatric comorbidities in epilepsy and to provide clinicians with a pragmatic approach to the treatment of these psychiatric comorbidities. Thus, we plan to publish an *Epilepsia* supplement to provide a very practical and user-friendly guide for all health professionals for the pharmacologic and non-pharmacologic treatments of major psychiatric disorders affecting adult patients with epilepsy as well as special populations such as cognitively impaired subjects.

Marco Mula
Co-Chair



Andres Kanner
receives 2011
Ambassador Award
from Mike Glynn and
Nico Moshé

COMMISSION ON PEDIATRICS

List of Members

Co-Chair	Doug Nordli (USA)
Co-Chair	Perrine Plouin (France)
	Jaime Carrizosa (Colombia)
	Donna Craiu (Romania)
	Helen Cross (UK)
	Heung Dong Kim (Korea)
	Hirokazu Oguni (Japan)
	Kevin Sraley (USA)
	Roberto Tuchman (USA)
	Patrick Van Bogaert (Belgium)
	Jo Wilmshurst (South Africa)
	El Yamani (Saudi Arabia)
EC Liaison	Solomon L Moshé

Guidelines for the Evaluation of Infants with Epilepsy Task Force

Committee Members:

Jo Wilmshurst (Chair) (South Africa), Perrine Plouin (France), Doug Nordli (USA), Eli Mizrahi (USA), Helen Cross (UK), Deborah Hirtz (USA), Virginia Wong (Hong Kong), Patrick van Bogaert (Belgium), Jaime Carrizosa (Colombia), Maurizio Elia (Italy), Vinayan Puthenveetil (India), Tracy Glauser (USA), Nebojsa Jovic (Serbia), Bill Gaillard (USA), Dana Craiu (Romania).

This will be a continuation of the algorithm for diagnosis and treatment of neonatal seizures in developing countries. These guidelines would include recommendations for genetic testing, metabolic investigations, electrophysiological studies, imaging and screening for autism in infants in collaboration with the Autism Task Force. The Task Force is making steady progress and met in Rome, 2011 at the ILAE meeting. All the next topics were discussed in Rome with many questions still to be answered:

Key questions identified

- Definitions/non epileptic differentials (Eli Mizrahi)
- Epidemiology (Jo Wilmshurst)
- Febrile seizures – when is it epilepsy? (Nebojsa Jovic)
- Genetic testing – what and when? (Maurizio Elia/ Jaime Carrizosa)
- Metabolic investigations – optimal (Maurizio Elia/ Jaime Carrizosa)
- Electrophysiological studies – role of, type (Perrine Plouin)
- Imaging – role of, type (Bill Gaillard, Patrick Van Bogaert)
- When to treat seizures (asked Tracey Glauser / Deborah Hirtz – no response – Jo will cover for now)

- What AED to treat with (ditto)
- Ketogenic diet – evidence for and indications for use (Dana Craiu/Jo Wilmshurst)
- When to stop therapy (Dana Craiu)
- Screening for autism (Virginia Wong)
- Optimal management of infantile spasms (Vinayan Puthenveetil)
- Diagnostic markers of malignant seizure syndromes (Nebojsa Jovic)
- Diagnostic markers of benign seizure syndromes (Patrick Van Bogaert)
- Which infants should be referred for epilepsy surgery? (Helen Cross, Vinayan Puthenveetil)

The next meeting should be in Paris before the European meeting in London, and could take place on Friday 28 September.

ILAE – Autism Speaks Collaboration Task Force

Roberto Tuchman, Chair
Andy Shih (Vice President for Scientific Affairs Autism Speaks)
Solomon (Nico) Moshé (President ILAE)

Eduardo Barragan (Mexico), Anne Berg (USA), Roberto Caraballo (Argentina), Daniel Coury (USA), Michael Cuccaro (USA), Dana Craiu (Romania), Hatem El-Shanti (Doha – Qatar)
Varda Gross-Tsur, MD (Israel), Marilisa Guerreiro (Brazil), Makiko Kaga (Japan), Daniel Lightfoot (USA), Fernando Mulas (Spain), Eliane Roulet-Perez (Switzerland), Camilla Stoltenberg (Norway), Virginia Wong (Hong Kong), Lonnie Zwaigenbaum (Canada)

Global Awareness of Epilepsy-Autism
AS-CURE-ILAE: [Scientific Research Synergies from a Global Perspective: Key Points](#), Brooklyn, 10 December 2010

Several Key Points were developed

- Identify infants with seizures at risk for autism and those with autism at risk for epilepsy
- Identify genetic and environmental risk factors common to epilepsy-autism
- Explore the underlying mechanisms of convergence between autism and epilepsy
- Coordinate tissue and brain banking efforts in epilepsy-autism
- Develop treatment behavioral and pharmacological models in infants with epilepsy-autism (or at risk for autism).

COMMISSION ON PEDIATRICS *(continued)*

Clinical Resources Survey

A goal for 2011 was to determine what services were available for children with epilepsy and autism.

- Surveys were sent to Task Force members in coordination with the Epidemiology Task Force
- Conclusion from the survey is that there is very little systematic screening of children with epilepsy for autism.

The consensus from the Task Force was that there is a need to develop specific strategies at a local and regional level to address these needs.

Clinical and Research Resources Goals for 2012

- Continue to develop comprehensive clinical resources for children with epilepsy and autism
- Raise awareness of screening for autism and related disorders in epilepsy clinics
- Continue to develop the infrastructure needed for research programs on epilepsy-autism at a local, regional, and global level.

Sub-commission: Adolescent Transition Update On Transition Guidelines In Epilepsy

Jaime Carrizosa M, Colombia

Tania Rodriguez, Chile

Rome, August to September 2011

Mission and Aims

Mission of the ILAE Adolescent Transition Committee:

To establish a program that medical centers can incorporate into existing clinical care to assist patients and families with the transition from pediatric to adult medical care.

Aims

- To raise awareness about the need to support patients as they transition from pediatric to adult specialty medical care
- To provide written recommendations to ILAE regarding transition to adult healthcare for pediatric patients with epilepsy.

Goals of A Transition Program

1. To prepare adolescents and young adults for transfer of care;
2. To provide uninterrupted healthcare, that should be patient-centered, age and developmentally appropriate;
3. To educate on specific and individual issues on epilepsy and related medical conditions;
4. To prepare adolescents and young adults for transfer of care;
5. To provide uninterrupted healthcare, that should be patient-centered, age and developmentally appropriate;
6. To educate on specific and individual issues on epilepsy and related medical conditions;
7. To promote communication, decision-making, self care and self-advocacy skills;

8. To foster personal and medical independence, sense of control over health, healthcare decisions and psychosocial environment;
9. To optimize the quality of life, life expectancy and future productivity.

Transfer

- Transfer of care from the pediatric to adult healthcare system occurs at the successful completion of a thoughtful transition process
- Transition and transfer occur on a predictable manner
- Transition and transfer should be considered as a rule or as a natural process that everyone goes through
- Flexibility has to be considered according psychosocial and developmental characteristics of the individual patient.

Coordination between pediatric and adult services or healthcare professionals.

Transfer Checklist:

1. Complete medical history
2. Family dynamics
3. Individual health supervision issues
4. Genetic counseling
5. Sexuality, pregnancy and reproductive issues
6. Education and career choices
7. Physical activity
8. Driver's license
9. Mortality
10. Insurance

Recommendations for Future Work

- Fall 2010/Winter 2011 – Pilot 5 step transition program at Children's Memorial Hospital Epilepsy Center in Chicago
- Spring/Summer 2011 – Develop educational series via podcasts for providers about transition to adult care
- Summer/Fall 2011 – Recruit 6-10 sites internationally to pilot transition program
- Winter/Spring 2012 – Pilot transition program internationally
- Summer 2012 – Evaluate transition program via survey to providers
- Fall 2012 – Write summary of recommendations for transition to adult healthcare for pediatric patients with epilepsy.

E-Learning program on Neonatal and Pediatric EEG

The first edition started in October; the program has been elaborated with the Sub-commission on VIREPA. The tutors are from around the world.

Technical issues in this age group
Fabrice Wallois
France

COMMISSION ON PEDIATRICS *(continued)*

Normal EEG patterns in premature and neonates
Ronit Pressler
UK

Normal EEG patterns in infants and children
Magda Lahorgue Nunes
Brasil

EEG in Neonatal pathology
Hitoshi Yamamoto
Akihisa Okumura
Japan

EEG in neonatal and infantile epilepsies
Monika Eisermann
Germany and France

EEG in epilepsies in early childhood
Pramote Laoprasert
USA

EEG in epilepsies in late childhood
Christian Korff
Switzerland

Nonepileptic events in neonates and children
Nicola Specchio
Italy

Thirty-one students are participating; many of them had already experienced the VIREPA E-learning course on EEG. Most are neuro-pediatricians. The geographical origin is various: few from Europe, but from Africa, India, South or Central America. The course is going on now with the third unit.

San Servolo Summer School in 2012: Epilepsy in Infancy.

This summer school will take place 12 to 25 July
The budget and the program are in preparation.

Doug Nordli and Perrine Plouin
Co-Chairs



IEC 2011 opening reception

COMMISSION ON THERAPEUTIC STRATEGIES

List of Members

Co-Chair	Steve Schachter (USA)
Co-Chair	Bernhard Steinhoff (Germany)
Information Officer	Guenter Kramer (Switzerland)
Secretary	Carlos Acevedo (Chile)
Treasurer	Patrick Kwan (Hong Kong)
Education Officer	Jack Pellock (USA)
Past Co-Chair	Jackie French (USA)
Past Co-Chair	Gary Mathern (USA)
Members:	JoAnne Dahl (Sweden)
	Hanneke De Boer (Netherlands)
	Jaideep Kapur (USA)

List of Sub-commissions and Members

New Strategies of Clinical Therapeutic Studies: Jackie French (Chair). See North American Regional Commission report for membership.

Behavioral Treatments: JoAnne Dahl, Chair

Treatment Gap: Carlos Acevedo, Hanneke De Boer (Chair); Gretchen Birbeck, Tarun Dua, Ley Sander

Surgery: Bernhard Steinhoff (Chair), Mario Alonso, Gary Mathern, Taisuke Oztuki, Cigdem Ozkara, Steven Roper, Felix Rosenow, Americo Sacamoto

Drugs: Guenter Kramer (Chair)

Natural Products: Steve Schachter (Chair), Robert Orynich, Nikolaus Sucher

Pharmacogenomics: Patrick Kwan (Chair), Martin Brodie, Tracy Glauser, Michael Johnson, Terence O'Brien, Nigel Tan

Aims

To complete efforts begun by the previous Commission and to define and pursue opportunities for progress consistent with the ILAE Strategic Plan in several key therapy-related areas: behavioral treatments, drugs, natural products, new strategies of clinical therapeutic studies, pharmacogenomics, surgery and the treatment gap. A couple of substantial projects were completed. Some of the initiated plans and projects are still ongoing and should be accomplished during the coming years. Some Task Forces did not report any accomplishments during the past year which will be certainly addressed by the Chairs of the Commission.

Mission of the Commission

To improve the care of patients with epilepsy by facilitating collaboration among clinicians, scientists, and other professionals in fulfillment of the relevant aspects of the ILAE Strategic Plan.

Commission Activities from July 2010 through July 2011

- A. Behavioral Treatments. Under the leadership of JoAnne Dahl, the Behavioral Treatments Task Force intends to actively explore opportunities to test the feasibility and preliminary benefits of a behavioral approach to epilepsy treatment in a developing region. In this regard, a potential collaboration with Guangzhou Children's Hospital in Guangdong, China, to study Acceptance and Commitment Therapy for children with epilepsy is under consideration. The Co-Chair of the Commission, Bernhard Steinhoff, encouraged the Task Force to proceed.
- B. Pharmacogenomics.
 1. A teleconference was held on 19 April 2011.
 2. An informal meeting was held during the IEC in Rome.
 3. A meeting to discuss phenotype definitions has been planned for 2 December 2011.
- C. Treatment Gap. Task Force Chair, Hanneke De Boer, is coordinating efforts across ILAE to address the global treatment gap.
 1. A face to face meeting was convened in Heemstede, the Netherlands, followed by a number of teleconferences.
 2. A Plan of Action was prepared including the following activities:
 - i. Re-visit definition treatment gap, and
 - ii. Regulatory issues re: availability of phenobarbital
 3. A proposal was prepared and submitted to the Joint Executive at their request. They decided that this was an issue for a time-limited Task Force consisting of members representing both IBE and ILAE.
 4. Phenobarbital is a clinical and cost effective antiepileptic drug which is recommended by WHO as a first-line drug for the treatment of generalized and partial tonic-clonic seizures in resource-poor countries. A number of barriers, however, impede its widespread use in such settings. These economic, cultural, social and legislative barriers are not fully understood. Of concern particularly are the legislative and regulatory barriers that are often country specific. This proposal is to carry out specific research to identify these regulatory and legislative barriers obstructing the use of phenobarbital in places where treatment is most needed so remedial action can be taken by the epilepsy community.
- D. Surgery. Task Force Chair, Bernhard Steinhoff, convened meetings in Rome. The project to define a consensus on surgical treatment in case of Cavernous Angioma was further worked on and will

COMMISSION ON THERAPEUTIC STRATEGIES *(continued)*

probably be finalized at the next meeting of the Task Force that is scheduled on 3 December 2011. The other project, to develop guidelines regarding minimal standards for presurgical workup and surgical treatment of epilepsy, will be updated by then after having collected global information by the Chapters of the ILAE. Finally, the newly-founded European Epilepsy Monitoring Association will be presented at that meeting by Philippe Ryvlin in order to start an appropriate liaison.

- E. Natural Products. Recognizing the need for reliable information to guide neuroscientists interested in studying natural products as potential treatments for epilepsy, Task Force Chair, Steve Schachter, has guided the development of an extensive and unique Wiki that encompasses the historical, botanical, scientific and medical aspects of plant-derived products that were either discussed by previous neurologists such as Gowere as treatments for epilepsy or other products used for the same purpose over the centuries in Traditional Chinese Medicine. The botanical Wikipedia is now being installed on the ILAE server.
- F. New Strategies of Clinical Therapeutic Studies. The Task Force has planned a meeting between the EMA and FDA to take place in Paris on 17 November 2011. An agenda of the meeting as well as participants and background information is included in the Commission activities. Two key issues that will be discussed at the meeting are the concept of abolishing the need for a monotherapy indication for epilepsy, and acceptance of a novel trial design (time to event). A meeting was held in July to address the proposal for a unified (both monotherapy and polytherapy) claim. A white paper supporting this concept is underway. For the time to event initiative, the group has sent letters to eight pharmaceutical companies, requesting a post-hoc analysis of existing trial data to determine whether this approach would have been successful, and to determine the optimal outcome measures for the trial. So far, three companies, (representing trials from five drugs) have approved the proposal, and the others are considering the proposal.
- G. The Drug Task Force and the Task Force on Treatment Gap did not report any accomplishments during the past year which will be certainly addressed by the Chairs of the Commission.

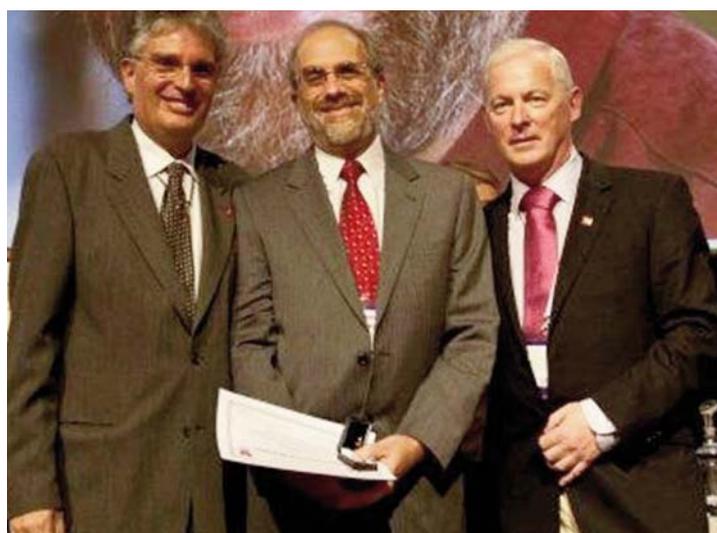
Accomplishments (2009-2010)

See Commission activities.

Recommendations for Future Work

- A. Behavioral Treatments. The Task Force will propose and begin implementation of a feasibility study of Acceptance and Commitment Therapy in the treatment of persons with epilepsy in a developing region.
- B. Treatment Gap. The Task Force is planning a workshop to achieve consensus on the definition of the coverage gap, causes of the treatment gap, indicators to measure the coverage gap, methods for integrating these metrics into existing country-specific information systems, and the need for further epidemiological studies.
- C. Surgery. The Task Force intends to finalize the two major projects outlined above.
- D. Natural Products. The Wiki will be shown to ILAE leadership and, if approved, hosted on the ILAE server and thereby become a widely accessible resource for neuroscientists interested in the potential application of plant-derived products to developing new therapies for epilepsy.
- E. Pharmacogenomics. See above
- F. New Strategies of Clinical Therapeutic Studies. See above.

Steve Schachter and Bernhard Steinhoff
Co-Chairs



Steve Schachter receives 2011 Ambassador Award from Mike Glynn and Nico Moshé



Other Activities

AWARDS

Morris-Coole *Epilepsia* Prize

The Morris-Coole *Epilepsia* Prize is given in recognition of an outstanding research paper published in *Epilepsia* the previous year on any field of epilepsy research, either clinical or basic. Papers are nominated to the Selection Committee by the associate editors of *Epilepsia*. The prize was established to stimulate excellence in epilepsy research as well as rewarding young researchers for outstanding contributions to the field.

In 2011 the Prize has undergone a change. The Trust and the ILAE have combined to ensure the continuing future of this Prize which is widely regarded as being one of the most prestigious accolades for research into epilepsy. It will be called the Morris-Coole *Epilepsia* Prize. What has previously been solely a money prize will now be a money prize of US\$5,000 but will have additionally a Prize Insignia. The Trust appreciates that the award of the Prize should carry with it a personal token to mark the individual achievement. Rather than a certificate, it will be the insignia. All previous winners will receive the insignia.



The 2011 Morris-Coole *Epilepsia* Prize will be awarded to Laura Jansen of the USA for her paper entitled 'Impaired maturation of cortical GABA(A) receptor expression in pediatric epilepsy' *Epilepsia* 2010, 1456:67.



Michael Prize



The Michael Prize, presented every two years by Stiftung Michael from Germany, is an award for outstanding epilepsy research performed by Young Investigators (under the age of 45).

The 2011 Michael Prize recipient is Eleonora Aronica of the Netherlands.



Lifetime Achievement Award

The Lifetime Achievement Award is given every two years by the Joint Executive Committee of the International Bureau for Epilepsy and the International League Against Epilepsy to honor those truly exceptional persons with a record of achievement in work against epilepsy, which exceeds even that of those who have been awarded the Ambassador for Epilepsy Award or the Award for Social Accomplishment

The honoree for 2011 is Jerome Engel Jr, USA, who received the award during the 29th International Epilepsy Congress in 2011 in Rome.



AWARDS

Ambassador Awards

Ambassador Awards are presented in recognition of outstanding international contributions to the cause of epilepsy. These activities have either been performed at an international level or have had international impact.

Twelve people were presented with this honor during the Opening Ceremony of the 29th International Epilepsy Congress in Rome. The award consists of an 'Ambassador for Epilepsy' pin and is intended to reflect peer recognition of individual contributions to the international cause of epilepsy.

Table 1. Ambassador Award Recipients

Axelrod, Susan (USA)	Panelli, Rosemary (Australia)	Liao, Wei-Ping (China)
Loescher, Wolfgang (Germany)	Fandino, Jaime (Colombia)	Van Emde Boas, Walter (The Netherlands)
Aziz, Hasan (Pakistan)	Pitkanen, Asla (Finland)	
Mizrahi, Eli M (USA)	Kanner, Andres (USA)	
Carmant, Lionel (Canada)	Schachter, Steven (USA)	



Jaime Fandino of Columbia



Wei-Pint Liao of China



Asla Pitkanen of Finland



Eli Mizrahi of USA



Hasan Aziz of Pakistan



Rosemary Panelli of Australia



Susan Axelrod of USA



Walter Van Emde Boas, The Netherlands

AWARDS

The International Bureau for Epilepsy and the International League Against Epilepsy gives the Social Accomplishment Award every two years to one person who has accomplished outstanding activities aimed at the social benefit of people with epilepsy. The candidate must have a record of activities promoting improvement in the social circumstances of people with epilepsy.



Pravina U. Shah of India was awarded this honor during the Opening Ceremony of the 29th International Epilepsy Congress in Rome.



Mike Glynn, President of International Bureau for Epilepsy accepts a proclamation from ILAE.

CONSTITUTION

Article I — Name

The name of this international organization, founded on 29 August 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 31 August 2011.

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:

1. 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

1. 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. Chapters are autonomous societies, but their Constitutions and Bylaws must not contain articles inconsistent with the Constitution and Bylaws of the ILAE. A copy of the Chapter’s Constitution and Bylaws must be kept in the League’s main office. Any changes in the Chapter’s Constitution and Bylaws must be submitted to the Executive Committee and the General Assembly

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, or in groups of two or more states, 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. The Chapter must submit to the Secretary-General a list of names and addresses of its own members. After a Chapter is approved, it must pay its annual dues.
5. A Chapter may withdraw from membership by giving notice in writing to the Secretary-General.
6. 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.
7. 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, Vice President, Secretary-General, Treasurer, and the Immediate Past President, and the Chair of each of the recognized ILAE Regions as voting members. Within the Executive Committee, Regional Chairs will work on behalf of, and in the best interests of the ILAE globally.
 - 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* as a non-voting member, appointed by the voting members of the Executive Committee.
3. The Management Committee:
- a. Shall consist of the President, Vice President, Secretary-General, Treasurer, and Immediate Past President.
 - b. The Management Committee will implement the policies approved by the Executive Committee and govern the League between meetings of the Executive Committee.
 - c. The geographic distribution of the elected officers, including the President, shall be restricted as follows: Each of the newly elected Management Committee members must be primary members of different Chapters. Primary membership is defined by the location in which professional activities are performed. No more than two of the newly elected members of the Management Committee shall come from the same Region, as defined by the geographic regions recognized by ILAE.
 - d. The President shall serve one term. Candidates for the Presidency must have served, or be in the process of serving, at least one term on the Executive Committee either as an elected or ex-officio member. After serving as President, the person shall automatically serve one term as Immediate Past President.
 - e. The term of office for any Executive Committee member is four years. The members of the Executive Committee may be re-elected or re-appointed for one additional term to any of these offices. No member of the Executive Committee can serve more than two terms as an elected officer, unless elected as President. No person may occupy a seat on the Executive Committee for a period exceeding a maximum of sixteen years.
 - f. If the current President cannot fulfill the full term of office, a new President will be selected in accordance with the Bylaws. Should any vacancy in the Executive Committee occur it shall be addressed by the Executive Committee subject to ratification by the General Assembly.
 - g. The President shall appoint an independent Elections Commission. The Elections Commission shall be chaired by the Immediate Past President. It will include one person from each of the recognized ILAE Regions and the Immediate Past Chair of the Elections Commission. The Executive Committee shall not interfere with the business of the Elections Commission. The Commission is to conduct the elections and establish appropriate procedures as described in the Bylaws and that are not in conflict with the Constitution.
 - h. 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. The business decisions of the Executive Committee once taken become effective, will be recorded in minutes and the minutes will be approved at the next meeting.
 - i. 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.
 - j. 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.
 - k. 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. Meetings of the General Assembly are open unless a number exceeding ten percent of the delegates present requests to 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.
 8. 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.
 9. Chapters whose total votes correspond to a minimum of twenty-five percent of all available votes may request a written consultation by 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.
 3. 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.

4. 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 for one additional term.
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 — Commissions and Task Forces

1. 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.
4. Regional Commissions must have written rules of procedure that are in agreement with the League's Constitution and Bylaws. A copy must be kept in the League's Headquarters Office. Any changes in these rules must be submitted to the Executive Committee for ratification.

Article XIII — International Bureau for Epilepsy

1. A privileged relationship exists between ILAE and IBE as partners for addressing respectively the professional and social aspects of the epilepsies.
2. ILAE and IBE will establish appropriate administrative structures that will facilitate the accomplishment of mutual objectives.

Article XIV — 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 XV — Dissolution or Merger

1. 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.

Approved August 2011
Rome, Italy

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

1. 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 publicized in the ILAE website.
2. Each Chapter has from 1-6 votes. The number of votes accorded to each Chapter shall depend on the number of professional dues-paying members in that Chapter according to the most recent statement provided by the Chapter. The number of votes shall be determined by a sliding scale as follows:
 - up to 50 members: 1 vote
 - 51 – 150 members: 2 votes
 - 151 – 350 members: 3 votes
 - 351 – 750 members: 4 votes
 - 751 – 1,500 members: 5 votes
 - above 1,500 members: 6 votesChapters that do not collect dues shall have one vote.
3. All votes are secret. To ensure secrecy in all voting processes, the Election Committee shall appoint an independent third party, who shall be responsible for receiving the Chapters' votes. The third party will inform Chapters by e-mail or fax within 72 hours that their vote was received, and will transmit the counts of votes to the Election Committee. The number of votes received by each candidate will be disclosed publicly at the completion of each election stage.
4. 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), who are available and willing to serve. The Elections Committee will ask each Chapter to vote for one of them by e-mail or fax. If one of the candidates receives more than fifty percent of all possible weighted votes, this candidate shall be elected. If this is not the case, a run-off shall be held between the two candidates who received the highest number of weighted votes. The candidate in the run-off that receives the highest number of weighted votes cast shall be elected. If both candidates receive the same number of votes, the candidate with the highest number of unweighted votes will prevail. If the tie still holds after counting unweighted votes, the

candidate who had been in the Executive Committee for 8 years already will prevail. In the event that the tie still holds, the older candidate will prevail.

5. Following completion of the Presidential Election, the Elections Commission shall request each Chapter to submit a slate of five names from at least 3 different Regions, without any ranking, as candidates for the remaining officer positions.
6. 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).
7. The Elections Commission shall 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 3 Regions. The slate may be smaller if less than 15 people are nominated. The Commission shall ascertain that these candidates are available and willing to serve.
8. The Elections Commission shall then submit the slate to each Chapter for voting by e-mail, or fax. In this process, each Chapter shall vote for five candidates from at least 3 different Regions, without any ranking. The final votes for each candidate will be determined by the sum of the weighted votes received from all Chapters. 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 unweighted votes will prevail. If a tie still persists, the oldest candidate(s) will prevail.
9. 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.

II. Duties of Officers

1. The President serves as the chief elected officer of ILAE, and shall
 - a) Preside at meetings of the Executive and Management Committee and the meeting of the General Assembly;
 - b) Call regular and special meetings of the General Assembly, and conduct necessary mail ballots in accordance with guidelines outlined in the Constitution;
 - c) In conjunction with ILAE staff and Executive Committee members, prepare the agenda for the Executive Committee meetings;
 - d) Serve as a spokesperson for ILAE to the public, press, legislative bodies, and other related organizations;
 - e) After consultation with the other Executive Committee Officers, appoint the Chairs and members of ILAE Commissions and Task Forces,

- and outline their purposes and duties consistent with the ILAE Strategic Plan;
- f) Serve as an Ex-Officio member of all Commissions and Task Forces, except for the Election Commission;
 - g) Promote active participation in ILAE activities, and report the activities of the Executive Committee and ILAE to the chapters through E-mail broadcasts, the ILAE website, *Epigraph* and other publications;
 - h) Serve as an ILAE representative on the IBE Executive Committee and maintain liaisons with other related organizations;
 - i) Monitor the activities, programs, and developments of ILAE, supporting and promoting policies and programs adopted by the Chapters, Executive Committee, and Commissions;
 - j) Provide the leadership for monitoring the ILAE Strategic Plan;
 - k) Recommend initiatives, research, and special assistance whenever necessary for Executive Committee approval;
 - l) Assume a key role in the orientation and transition of the President-elect;
 - m) Identify, recruit and cultivate future leaders of the ILAE;
 - n) Assume other duties and responsibilities as may be assigned by the Executive Committee.
2. The Secretary-General ensures that records are maintained of all General Assembly and Executive Committee meetings, and encourages Chapter development. Specifically, the Secretary-General shall:
 - a) Serve as a member of the Executive and Management Committee;
 - b) Oversee the maintenance of the official records of ILAE including (i) minutes of regularly called meetings of the General Assembly and Executive Committee; (ii) affiliated Chapters in good standing; (iii) official correspondence to and from ILAE and other entities;
 - c) Maintain the Constitution and Bylaws, including responsibility for the process of amending the official documents;
 - d) Give timely notice of all meetings of the General Assembly and Executive Committee;
 - e) Conduct a roll call of the members at the meetings of the General Assembly and Executive Committee meetings, assuring that a quorum is present;
 - f) Promote Chapter development and support activities; review applications and supporting documents for the establishment of new Chapters and provide guidance to the Executive Committee regarding the approval process;
 - g) Serve as an Ex-Officio ILAE representative on the IBE Executive Committee;
 - h) Represent ILAE with other associations or entities as assigned by the President or Executive Committee;
 - i) Receive, process and maintain the reports of Commissions and Task Forces, submitting such reports for Executive Committee approval and to *Epilepsia*;
 - j) Oversee the publication of the Annual Report;
 - k) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
 3. The Treasurer ensures the integrity of the fiscal affairs of ILAE. Specifically, the Treasurer shall:
 - a) Serve as a member of the Executive and Management Committee;
 - b) Ensure that the ILAE accounts are maintained according to international accounting standards, assuring the financial integrity of ILAE;
 - c) Exercise prudence in maintaining the assets of ILAE;
 - d) Report on the financial condition of ILAE at the meeting of the General Assembly and the Executive Committee;
 - e) Submit the financial account of ILAE to an annual audit;
 - f) Working with the staff, develop the annual budget for review and approval by the Finance and Executive Committees;
 - g) Monitor the financial performance of ILAE in relation to the annual budget;
 - h) Ensure the timely payment of all ILAE financial obligations;
 - i) Oversee financial long-range planning;
 - j) Serve as an Ex-Officio ILAE representative in the IBE Executive Committee;
 - k) Retain authority and responsibility for the financial activity of ILAE when such activities are delegated to staff or contracted with an external entity;
 - l) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
 4. The Vice President will:
 - a) Serve as a member of the Executive and Management Committee;
 - b) Will assume the responsibilities of the President in his or her absence.
 5. The Immediate Past President assists the President with guidance and advice based upon knowledge of previous Executive Committee policies and past practices. Specifically, the Immediate Past President shall:
 - a) Serve as a member of the Executive and Management Committee;
 - b) Serve as a Chair of the Elections Commission;
 - c) Provide advice and counsel to the President and act as an information source;
 - d) Assist in providing continuity between terms of office;
 - e) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
 6. The Management Committee will meet as needed between meetings of the entire Executive Committee.
 7. The Editor-in-Chief of *Epilepsia* shall be appointed by the Executive Committee and serves at its discretion, and conducts the day to day editorial business of *Epilepsia*, the official journal of ILAE. It may be appropriate for the Executive Committee to appoint more than one Editor-in-Chief of *Epilepsia*.

The editorial content of *Epilepsia* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epilepsia* shall:

- a) Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
 - b) Make recommendations to the Executive regarding number and role of Associate Editors and Managing Editor;
 - c) Appoint the Associate Editors and the members of the Editorial Board, and supervise communication with the Board;
 - d) Call meetings of the Editorial Board as needed;
 - e) Recommend an annual budget for *Epilepsia* to the Executive Committee;
 - f) Liaise with the Publisher and oversee compliance with the contract;
 - g) Assist the Treasurer in supervising expenditures for the *Epilepsia* office;
 - h) Perform other tasks as necessary for the operation of, and maintenance of quality of the Journal.
8. The President, Secretary-General and Treasurer of IBE serve as Ex-Officio, non-voting members of the ILAE Executive Committee. Their function is to facilitate a close and collaborative understanding between IBE and ILAE.

III. The General Assembly

The General Assembly is convened by the Secretary-General and is chaired by the President. All members of the Executive Committee participate in the meeting of the General Assembly as non-voting members. Unless otherwise indicated, matters brought before the General Assembly shall be decided by majority of weighted vote of those attending an official meeting or responding to a mail ballot.

IV. *Epilepsia*

1. The Editorial Advisory Board of *Epilepsia* shall consist of all members of the Executive Committee, except for the Editor(s)-in-Chief. It advises the editors on matters of general policies and arbitrate on matters referred to it by the Editor(s)-in-Chief, but shall leave the day to day conduct of the Journal entirely to the Editor-in-Chief and the Editorial Board. The editorial content of *Epilepsia* is the responsibility of the Editor(s)-in-Chief.
2. The Executive Committee shall approve or terminate any contract with the publisher. It shall determine the budget of *Epilepsia*.
3. The Editor(s)-in-Chief will take all steps necessary to fulfill the aims of ILAE through its journal, *Epilepsia*. The responsibilities of the Editor(s)-in-Chief are described in Article II.7 of the Bylaws.

V. Resource- and Topic-oriented Commissions and Task Force

1. Each Resource- and Topic-oriented Commission and Task Force shall have a Chair appointed by the President in discussion with the Executive Committee. Each Commission and Task Force shall designate a Secretary, Treasurer, Information Officer, and representative to the Global Outreach activities. If appropriate the Commission should

appoint a liaison to the Neurobiology Commission. Liaisons to other Commissions are encouraged. The President will appoint one member of the Executive Committee as the primary contact who serves as an Ex-Officio member.

2. Funds raised by an individual Commission, when not spent within the next fiscal year, may be allocated to the same Commission for the subsequent fiscal year, subject to the Commission providing a plan for the utilization of the funds and approval of the plan by the Executive Committee. At the end of the term of each Commission, any unused funds will be incorporated into the general ILAE assets.
3. 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 ILAE. It is recommended that the out-going Chair be retained as a member of the new Commission, if applicable.
4. Task Forces are appointed for specific purposes and their term of office expires when their duties are completed.
5. 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.

VI. Chapters' Obligations

1. Chapters shall be open for membership to all professionals working for epilepsy in that country, territory or region as defined in the Constitution.
2. 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. If changes in contact addresses occur these must be immediately reported to the Secretary-General of the ILAE.
3. Within thirty days after each Chapter's General Assembly meeting, the Chapter must submit any changes to its Constitution and Bylaws (in English) to the Secretary-General.
4. By March of each year, every Chapter is requested to upload/enter their database, including e-mail addresses, to the ILAE website.
5. Before October 1 of each year, each Chapter shall pay to 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.
6. If a Chapter without consent of the Executive Committee omits paying its dues it will be once invited to do so. If the next year dues are again not paid, the Executive Committee may propose disaffiliation to the General Assembly in writing and/or have its right to vote at the meeting of the

General Assembly revoked. Two-thirds of votes cast (with at least two-thirds of all available votes having been cast) have to confirm disaffiliation.

VII. Fiscal Year

The fiscal year of ILAE shall be 1 January through 31 December.

VIII. 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.

IX. 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.
3. The International Congress of ILAE and the Regional ILAE Congresses will be organized with the assistance of the ILAE-designated International Director of Meetings.
4. 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.

X. Regions

1. Regional Commissions shall consist of:
 - a) representatives elected by the local Chapters comprising the Region (with each Chapter casting one vote) and b) up to two additional members appointed by the President, in consultation with the Executive Committee, among professionals from the Region. The Chair will be elected first, followed by the election of the remaining members. The total number of elected members is five. If more than one candidate receives the same number of votes, the oldest candidate in age will prevail. Each member of the Commission must be a primary member of different Chapters. Appointments to various positions within the Commission are decided by the Commission members based on their rules of procedure. It is recommended that Regional Commissions have education and information officers, and liaisons to global outreach and to neurobiology. Chapters can belong to only one Region. Special arrangements will be made for Regions with fewer than 6 Chapters.
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 Commissions should aim to develop, stimulate and coordinate the epileptology agenda in their part of the world.
4. Regional Commissions should promote the activities of local Chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda.
5. Regional Commissions can have designated funds which they access via the budget process.

6. Regional Commissions should coordinate local educational activities.
7. Regional Commissions should run their Congresses under the direction of the International Director of Meetings.
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.

XI. Cooperation with the International Bureau for Epilepsy (IBE)

1. The 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.
2. 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 necessary, the Executive Committee shall meet jointly with the Executive Committee of the IBE, to consider matters of mutual interest and/or responsibility to both Executive Committees. Such a meeting shall be known in full as a Joint Meeting of the Executive Committees of the ILAE and IBE, 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 ILAE and IBE. 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 co-organized Epilepsy Congresses and the Global Campaign, and such other matters as the ILAE and IBE 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 ILAE and IBE 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 ILAE and IBE Executive Committees.
9. A JEC may be convened at any time mutually acceptable to the Presidents of both the ILAE and IBE.
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.
11. Responsibility for administration, minuting, etc. of JECs shall be shared equally between the Secretaries-General of the ILAE and IBE, in a manner acceptable to both.
12. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the ILAE and IBE, in a manner acceptable to both.

13. A Joint Committee, consisting of the voting members of the ILAE Executive Committees and the Management Committee of IBE, is authorized to take actions in the name of a JEC between JEC meetings. Such actions must:

- a) Be approved by a majority of each of the Committees of the ILAE and IBE;
- b) Be in accord with policies of both the ILAE and IBE;
- 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.

XII. 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.

XIII. 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.

Approved October 2011