

The Benefits of Working in Partnership A Joint Note from the ILAE and IBE Presidents

Despite major advances in diagnostic tools, the introduction of 18 new generation antiepileptic drugs (AEDs) and significant refinements in surgical approaches, many gaps continue to impact negatively on the life of people with epilepsy. In all countries of the world, there are gaps in availability of adequate expertise for diagnosis and treatment, and at times even in the possibility of access to anti-seizure medications. Gaps in public knowledge continue to feed prejudice, stigma, and discrimination. In parallel, gaps in support for epilepsy research hamper the development of safer and more effective treatments. Nowhere are these problems as acute as in the under-privileged regions of the world. Over 85 percent of the global burden of epilepsy occurs among people living in low-income and lower-middle income countries, which typically show a huge disparity in healthcare delivery, particularly between rural and poor urban areas and more affluent urban areas. Over the years, the ILAE and its Chapters have invested significant resources to improve and disseminate epilepsy knowledge among professionals. In parallel, the IBE and its associations have spearheaded similar initiatives among people with epilepsy, their families and the general public. In doing so, the two organizations have become increasingly aware that only by working together, and by opening up to collaboration with other organizations, can those gaps be effectively tackled.

The first important step in the ILAE-IBE collaboration came in 1997 with the establishment of the Global Campaign against Epilepsy (GCAE) in partnership with the WHO. The GCAE demonstration projects using different approaches and methodologies have been conducted in several countries, with three initiatives currently ongoing in Mozambique, Myanmar and Vietnam. These projects have proved to be a valuable learning experience for all partners, as we strive to develop sustained models for improved



Emilio Perucca
ILAE President



Athanasios Covanis
IBE President

epilepsy care adapted to the local infrastructure. Importantly, two large community-based projects in China and Brazil have clearly demonstrated that the treatment gap can be reduced through basic training of health personnel and use of inexpensive medications, with a significant impact on the lives of affected individuals. The GCAE project in China also showed that cooperation of the national government in the intervention is crucial to ensure that benefits are not only sustained, but also up-scaled. After realizing the cost-effectiveness of a GCAE project initially limited to five provinces, the Chinese government has now taken upon itself responsibility for gradually extending and upgrading the intervention to the entire nation. When we consider that the number of people with active epilepsy in China is close to 10 million, the success of such initiatives has been staggering, and encouraged us to engage in similar actions in other parts of the world. At present, a major effort is ongoing in Latin America where the ILAE, IBE and WHO are working together on the Pan American Health Organization (PAHO) Action Plan for Epilepsy. The plan includes the promotion of programs and legislation for the care of people with epilepsy and the protection of their human rights. The plan mandates the establishment of health services networks for people with epilepsy, with emphasis on primary healthcare and the provision of AEDs. The education and sensitization of the general population, people with epilepsy, and their families are also encouraged. As part of this plan, a recently completed survey in 18 Latin American countries and in English-speaking Caribbean nations identified major gaps in public knowledge, legislation and quality of epilepsy care. The survey thereby provided the knowledge base for a comprehensive intervention in partnership with local governments. Another more ambitious project in which the ILAE, IBE and WHO are currently collaborating is a global initiative aimed at improving access to epilepsy medicines. The aim is to characterize the barriers that impact the procurement, pricing,

quality and distribution of anti-seizure medications in resource-poor countries and to enact a global strategy to address such barriers, taking advantage of experience acquired in other therapeutic areas such as tuberculosis control and anti-HIV treatment. To optimize coordination of these efforts, the ILAE and IBE have established the Global Outreach Task Force co-chaired by Alla Guekt and Mary Secco, with active support from Tarun Dua on behalf of WHO in Geneva.

Improving epilepsy care and fighting discrimination is not the only area in which ILAE and IBE collaborate on a day to day basis. The two organizations know very well that their vision of a world where people's lives are no longer limited by epilepsy will not be fulfilled unless epilepsy research provides us with better treatments and, ultimately, a cure. Regrettably, however, epilepsy research has been grossly underfunded in all parts of the world. For example, in a recent survey of non-profit organizations in the United States, funding for epilepsy research was found to lag behind that for multiple sclerosis, Parkinson's disease and cerebral palsy, despite the fact epilepsy affects more people than all those diseases combined. A major reason for such poor level of support to epilepsy research is lack of awareness of the epidemiological, medical and social burden of epilepsy among governments, funding institutions and the general public. Our organizations are making a strong effort to change this situation through concerted political action. Examples include the PAHO Action Plan for Epilepsy in Latin America, support for the production of the influential Institute of Medicine Report on Epilepsy in the United States and, most significantly, the Written European Declaration of Epilepsy which was passed in 2011 by the EU Parliament. The Written Declaration calls for the EU Commission and member states to "encourage research and innovation in the area of prevention and early diagnosis and treatment of epilepsy" and to prioritize establishment of national epilepsy services and legislation protecting the rights of people with epilepsy. The process that led to the Declaration is a fantastic example of team work, made possible by the dedication of several enlightened members of the European Parliament (MEPs), led by Gay Mitchell, and the extraordinary ground work done by ILAE Chapters and IBE associations. This collaboration sensitized the MEPs about the importance of the initiative. In the end, the Declaration was approved with the signature of 459 MEPs (90 more than the required majority), making it the declaration with the highest level of support in the current EU term. The first tangible results of this effort came in 2013, when the EU Commission granted close to 50 million euros to epilepsy research, more than in the previous 20 years combined! These successes are gratify-

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ing, but there is no room for complacency as we must keep the momentum going. To this purpose, the ILAE and IBE have established a Joint Global Task for Research Advocacy, chaired by Shichuo Li, with the remit of synergizing the many advocacy initiatives which are now taking place in several regions of the world.

None of the achievements discussed above could have been reached without the vision, dedication and hard work of so many colleagues and friends working within the ILAE, the IBE and our partner organizations. We are immensely grateful to them all, and we look forward to continue to work together with them on our common mission.

Emilio Perucca
President, ILAE

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President, IBE

2013-2017 ILAE Executive Committee Members



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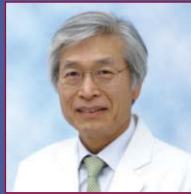
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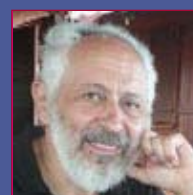
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Message from the Treasurer

Samuel Wiebe, Treasurer

And sweet are the
uses of adversity...
(Shakespeare)

The current financial realities of many professional organizations such as the International League Against Epilepsy are all too clear: dwindling revenues and external support, uncertainty in the financial markets, and growing needs worldwide. The consequences are felt by all, and no less by our hard-working colleagues in charge of ILAE Commissions, Committees, and Task Forces who must adapt to lower budgets while attempting to stay on course. These are some of the rather cheerless financial news I have conveyed more than once over the past year.



Samuel Wiebe

And yet, it is equally important to note that despite financial difficulties, this year the ILAE allocated \$1.27 million dollars to support the activities of its Commissions and Task Forces to ensure that the important work of the ILAE not only continues, but also thrives. We accomplished this together through a judicious review of all expenditures of the organization, and also through the collaboration and creativity of the leaders of our Commissions, Committees, and Task Forces comprising over 300 high caliber volunteers. In addition, we were able to increase access to our Congresses by reducing registration fees for those that need it most. Throughout this process, we have managed to stay on course towards our goal of achieving financial independence from declining external revenues.

It would be a great injustice not to share with you equally the great display of resourcefulness and single-mindedness we have witnessed among our colleagues around the world in response to our new reality. Good people shine in difficult times. And this is what we have seen time and again among the many volunteers who offer their

time, energy and talents to make a difference in the life of people with epilepsy. Our colleagues have confronted difficult times with creativity, collegiality, a keen sense of what is essential, a renewed sense of collaboration, and a sharper focus on our vision as an organization. Adversity can indeed make us wiser.

As we learn to navigate the rough waters of financial constraint, we must more than ever bring into focus the vision and ultimate goal of the collective – A world in which no person's life is limited by epilepsy. This is the time to recalibrate priorities and to choose wisely, to maximize synergies, to build together. Big ideas can be amended to match circumstances; challenging times call for a sharper focus on the large vision, not for a smaller or weaker vision.

Adversity is the good person's time to shine. The ILAE is its people, and we are privileged to count among our ranks some of the most outstanding people in the world, leading remarkable teams and projects. I am confident that we will emerge from this phase stronger and better. This is the time to shine.

Secretary-General Report

Helen Cross, Secretary

A key responsibility of the Secretary-General is to process and maintain reports of Commissions and Task Forces. As all will be aware the proposed refinements to the Organization of the Epilepsies were available for comment by the Community during the early part of this year. Many interesting and useful comments were received. It is evident that the feeling about the proposals is very mixed, and wider debate required. As per the new initiated process with regard to approval of such pro-



Helen Cross

posals, a Task Force has been formed, of existing authors as well as new members, to review all comments made in addition to reviewer's comments from *Epilepsia*. It is proposed that the Task Force will identify the key issues, both where there is general agreement as well as those requiring further discussion, with the plan to formulate a road map of how we should proceed. The Task Force will take this forward over the next six months

The elections for the Commission of African Affairs took place later than those for other Commissions owing to the late formation of the Commission during the last term. The elections are now complete, and we congratulate Amadou Gallo Diop as Chair, as well as the remaining members, Jo Wilmshurst (South Africa), Angelina Kakooza (Uganda), BirinusEzeala-Adikaibe (Nigeria) and Mapoure Njankouo Yacoubou (Cameroon) on their election, and wish them all success for the coming term. They will be joined by Sammy Ohene (Ghana) and Pierre Luabeya (De-

mocratic Republic of Congo) as appointed members. Now that these elections are complete it will be important for us to move forward on harmonizing rules for the election process across Regions where possible, and a Task Force will take this forward over the coming months

The Executive Committee of the ILAE, together with the IBE have been putting serious thought to the possibility of defining an International Epilepsy Day. Although overall it is thought this will raise awareness of epilepsy as well as the respective organizations, there are many things to consider, not least which day to choose and how this should be launched. All ILAE Chapters and IBE associations have been asked their opinion on the development of this in principle, with a view to further consideration dependent on results.

As I write this the Regional Congresses are almost upon us. I look forward to taking part and meeting with many of you around the world.

Topic-Oriented Commissions Reports:

The Commission on Classification and Terminology Activity Report

Sameer Zuberi, *Classification and Terminology Commission Chair*

The ILAE Commission on Classification and Terminology has had the charge for a number of decades to review our concept of epilepsy and its pathophysiology and make changes to how we view the different epilepsies as new information becomes available. It has been from the earliest days of the Commission — a fluid and dynamic area — that has always engendered much interest and discussion within the international epilepsy community, as evidenced by the recent development of the new definitions of epilepsy and the proposed new organization of the epilepsies.

The development of a new organization for epilepsy has been the major focus of the last two Commissions. It is a mark of the importance of this task and the active debate it has generated that this process continues into the 2013-17



Sameer Zuberi

term. Many of you will have read and commented on the “The Organization of the Epilepsies: Report of the ILAE Commission on Classification and Terminology” which was posted for a period of consultation on the ILAE website. An ILAE Management Committee-appointed Task Force will meet at the ECE in Stockholm to review comments from the epilepsy community with the aim of developing the Commission Report into a final ILAE Position Paper for publication in *Epilepsia*.

It is important that the International Classification of Disease reflects modern practice and an ILAE Task Force, Chaired by Donna Bergen is developing a paper on how the new organization relates to ICD-10 and ICD-11 coding schemes. The latter reflects the more aetiological perspective of the new organization.

A new Commission Task Force on Neonatal Seizures, Chaired by Ronit Pressler, began its work this year. The aim of this Task Force is to develop ways in which neonatal seizures and epilepsies can be integrated into the new organization of the epilepsies taking into account the particular complexities in this age group including acute aetiologies, high electrographic seizure burden and management within the intensive care setting.

An online ILAE Diagnostic Manual, reflecting the new organization approach of attempting to describe seizure type, syndrome and aetiology in every individual with epilepsy, will go live in the next few months. The manual includes descriptions of syndromes and incorporates video clips of seizure types. We anticipate this will be an important, authoritative, educational and diagnostic resource for the worldwide epilepsy community. Access to videos requires a simple registration procedure, so we can record who is using the resource, but the site will be freely and immediately accessible to anyone with an internet connection. This major development has been driven forward by Kate Riney and colleagues in the current and past commission. The site will require ongoing development and has great potential for expansion over coming years. The ILAE Glossary of Terms will be updated during the Commission term by a Task Force on Syndromes and the Diagnostic Manual.

Commission Members: Nerses Bebek, Robert Fisher, Jacqueline French, Edouard Hirsch, Nobukasu Nakasato, Jukka Peltola, Eliane Roulet Perez, Kate Riney, Muhammad Salisu, Ingrid Scheffe, and Sameer Zuberi.

Bridging the Validation Gap in Diagnostic Methods — Future Plans of the Commission on Diagnostic Methods

Ingmar Blümcke, *Diagnostic Methods Commission Chair*

Our Commission covers major diagnostic modalities to clinically characterize a patient’s epilepsy, namely electro-/neurophysiology, neuropsychology, imaging and neuropathology measures. Our objective is to provide standardized protocols, terminology use and guidelines for an cost-effective diagnosis of epilepsy and their related comorbidities as well as consensus classification systems for underlying etiologies. We have set up four Task Forces to achieve this goal, and to bridge the validation gap of increasingly available technologies in the community of clinical epileptology.

Consensus terminology use, protocols, and guidelines for minimum requirements to apply neurophysiology meas-



Ingmar Blümcke

ures are a major topic for our Commission (Task Force for Neurophysiology, Chaired by Philippe Kahane, Grenoble, France). Increased interest for invasive EEG methodologies also requires practice parameters or criteria that determine clinical indications for intracranial EEG monitoring and will be shared with the ILAE community. However invasive EEG recordings are increasingly used in patients with “MRI-negative” focal epilepsies. This term needs a better definition to allow comparison between different centers and published patient series (Task Force for Neuroimaging, Chaired by Andrea Bernasconi, Montreal, Canada). Our Commission follows the strategy to validate any new definition using a pathology-based approach and consensus classification systems. Good examples are our recent Focal Cortical Dysplasia and Hippocampal Sclerosis classification systems proposed by the Commission in 2011 and 2013.

Our next term’s challenge in Neuropathology addresses tumor-related epilepsies (Task Force for Neuropathology, Chaired by Ingmar Blümcke, Erlangen, Germany). Neuropathology agreement studies have shown dramatic inter-rater variance in the classification of these specific group of

brain tumors associated with long-term epilepsies (LEAT). LEATs mostly encompass glio-neuronal tumors, i.e. gangliogliomas (GG) and Dysembryoplastic Neuroepithelial Tumors (DNT) (approx. 60-80%). Despite their histopathologic definition in the WHO classification of brain tumors (2007), the frequency of DNT and GG vary largely between individual case series. We have built a collaborative virtual microscopy platform, which allows us to review unlimited series of LEAT variants by a panel of international neuropathologists and to encourage discussion between WHO, Intl. Neuropathology, and ILAE communities to achieve consensus terminology use and acceptance of a revised tumor classification system.

An important aspect of our Commission’s work will address neuropsychology measures during presurgical evaluation to be understandable for epileptologists when using or interpreting different test domains (Task Force for Neuropsychology chaired by Sarah Wilson, Melbourne, Australia). Particular topics will address measures for assessment of developmental hindrance, measures sensitive to antiepileptic drug treatment or sensitive to EEG pathol-

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ogy (electrophysiological epileptic activity, single spikes & spikewaves, grouped activity, nonconvulsive (cognitive) seizures). Consensus protocols for assessment of hemispheric dominance (IAT, fMRI, functional Doppler, dichotic listening), measures sensitive to surgical treatment, and measures and markers for assessing every day functioning are other important topics of this Task Force.

Our work will very much depend on interaction with other ILAE Commissions, dissemination and training. All Task Force members are actively engaged in setting up

training facilities, such as the new International Summer School for Neuropathology and Epilepsy Surgery (INES), first held in 2013 in Erlangen, Germany under the auspices of CEA-ILAE. INES. This course will make available an advanced microscopy training facility for the diagnostic evaluation of surgical specimens, with particular emphasis on mTLE-HS, epilepsy-associated tumors, cortical dysplasias, vascular malformations, and encephalitis. It will help to disseminate new and up-coming clinico-pathologic classification systems among the neuro / pathology communities

as well as validate existing and up-coming consensus classification systems by a larger cohort of practicing neuro-/pathologists. The successful launch of INES in Erlangen 2013 with more than 70 applications from 29 different countries was encouraging.

Commission Members: Ingmar Blümcke, Chair, Fernando Cendes, Andrea Bernasconi, Philippe Kahane, Callixte Kuate Tegueu, Riki Matsumoto, Donald Schomer, Sarah Wilson, and Sam Wiebe, MC Liaison.

The Education Commission Activity Report

Jaime Carrizosa, Education Commission Chair

The Commission on Education was established to support and enhance the education of healthcare professionals with accurate and up to date information about epilepsy, its causes and care that is appropriate for the geographic setting in which it is given. In addition the Commission works to bring advanced skills such as clinical neurophysiology to areas where it doesn't exist. One of the main working areas of the Education Commission for this term is the collection and analysis of the projects and results of different educational efforts at every level of education. We will evaluate objectives, contents, didactic strategies and impact, so that the experience of one group could serve as an example to help guide educational efforts for other groups and regions that have interests in epilepsy education.



Jaime Carrizosa

Appropriate education about epilepsy for the general community, families, and persons with epilepsy as well as undergraduate and postgraduate students is a major concern for the Education Commission. Of equal importance is the continuous education for clinicians and paramedical personnel. We hope that at the end of the analysis of our programs that the best experiences in education could be identified, and that minimal contents or standards for specific educational programs can be established.

The acquisition of *Epileptic Disorders* and its designation as the educational journal of the ILAE is being reinforced. One approach to fulfilling its mission is presenting illustrative case studies and topics that can be helpful for clinicians in every day work.

The courses of VIREPA have been well received and are ongoing during this year. The development of new courses that will be designed to the members' interests will be considered in the near future. It is possible that we will see courses on Status Epilepticus, basic sciences and epilepsy in primary healthcare. ASEPA (Asia) and ALADE (Latin America) activities in their respective regions are of utmost importance. Their courses and overall involvement during Regional Congresses, summer schools on epilepsy, educa-

tion courses for general clinicians in several countries with topics of primary health care, semiology and EEG, have been maintained and are rated as high quality activities by attendees and faculty. Educational postgraduate programs in epilepsy with important funds from ILAE have benefited three clinicians in Latin America during 2013 and will do so for another three persons. These professionals have the commitment to enhance education activities and to work in public institutions in their country of origin after fulfillment of their professional training. It is the mission of the Education Commission to stimulate the construction of educational opportunities making the access easier for those caring for people with epilepsy. At this point the Commission will have special emphasis on projects of underserved regions in Africa, Asia and Latin America.

Commission Members: Jaime Carrizosa, Chair, Chong Tin Tan, Alexis Arzimanoglou, Patricia Braga, Lionel Carmant, Amina Gargouri, Guenter Kramer, Shih Hui Lim, Daluwanga, Hiba Mahmud, Walter van Emde Boas, and Sam Wiebe, MC Liaison.



ILAE Commission Chairs

Commission on Epidemiology Activity Report

David Thurman, *Epidemiology Chair*

As the new term of the Commission on Epidemiology commenced with a meeting on 8 December 2013, when the Commission affirmed its mission as follows:

"The principal responsibility of the Commission on Epidemiology is to develop and disseminate knowledge of the global burden of epilepsy and its risk factors from a public health and prevention perspective."

In general, we understand that this mission involves continuing assessments of the best available epidemiological evidence, identifying epidemiologic research needs, helping to promote epidemiologic research capacity through guidelines and other means, and helping to promote program development toward the prevention of epilepsy and its adverse consequences. Toward these aims, the Commission currently supports three Task Forces: Prevention, Mortality and Comorbidity.

The purpose of the Prevention Task Force is to assess opportunities for epilepsy prevention and to develop strate-



David Thurman

gies toward implementing prevention measures. This is a newly formed Task Force; it will address both primary prevention (i.e., the prevention of epileptogenic brain insults such as injury, stroke, or infection), early secondary prevention (i.e., the interruption of epileptogenesis following a brain insult), and secondary prevention (i.e., timely access to appropriate care following the onset of epilepsy). To this end, activities of the Task Force will include systematic reviews of: (a) studies of incident epilepsy, addressing causes and modifiable risk factors in both higher and lower income countries; (b) studies of epilepsy treatment gaps and treatment non-adherence; and (c) studies of effectiveness of epilepsy prevention strategies. Based on the results of these studies, the Task Force intends to offer recommendations identifying prevention priorities, as well as identifying major research needs to close gaps in understanding causes and risk factors in different world regions. As its work progresses, the Task Force anticipates collaboration with other ILAE Commissions, WHO, PAHO, and other relevant agencies.

The purpose of the Mortality Task Force is to describe the risk and causes of death among people with epilepsy, and to assess and recommend strategies to prevent premature death in epilepsy. The work of this Task Force continues from the previous Commission term. It is currently completing systematic reviews of studies to identify the incidence, risk factors, and causes of death in epilepsy, both

in high-income and lower income countries. Based on these, the Task Force intends to better quantify risk among subgroups of people with epilepsy and to recommend prevention strategies appropriate to different world regions.

Finally, the purpose of the Comorbidity Task Force is to identify and assess the burden of comorbidities among people with epilepsy, with a primary focus on psychiatric comorbidities, and as time and resources permit, cognitive comorbidities. This Task Force was initiated during the previous term. Through publication of its work and other means of disseminating its findings, the Task Force intends to increase awareness of the scope of epilepsy comorbidities, to promote and propose instruments and research to better assess epilepsy comorbidities, and to create training materials for clinicians to help identify comorbidities and improve understanding of their impact on epilepsy prognosis and quality of life.

At the end of this term it is our hope that the Commission will provide better insights into the scope, severity and impact of epilepsy on the global burden of disease, and that our work will help provide new approaches to alleviating that burden.

Commission Members: David Thurman, Chair, Dale Hesdorffer, Ettore Beghi, Arturo Carpio, Jakob Christensen, Wendyl D'Souza, Sandra Helmers, Jie Mu, Charles Newton, Kamadore Touré, and Emilio Perucca, MC Liaison.

The Genetics Commission Activity Update

Dan Lowenstein, *Genetics Commission Chair*

The Genetics Commission is pleased to report major progress on a number of initiatives developed over the past few years, along with two, entirely new concepts to be launched in the coming year.

First, in the domain of public education, Alica Goldman has overseen the development of an educational brochure entitled "Epilepsy and Genetics: Things You Want to Know," which addresses the essentials of human inheritance. The pilot educational material, designed for the English speaking population of the North America, was first beta tested in a focus group that included epilepsy patients, parents, and healthy individuals. The final document was then approved by the ILAE in 2013. Positive public reception of the material prompted Spanish translation aimed at the Spanish speaking Latin American population. This next version has been finalized and will be beta tested in a focus group and then submitted for review and approval by the ILAE by the end of 2014. At the same time, we plan to pursue the same strategy for creating similar brochures in Chinese, Japanese and other languages considered to be high priority by the ILAE.



Dan Lowenstein

Second, the ILAE Consortium on Complex Epilepsies, sponsored by the Genetics Commission and led by Sam Berkovic, has achieved a major milestone in completing a genome-wide meta-analysis of almost 9,000 patients with epilepsy and over 26,000 controls. This effort, the first of its kind in epilepsy, brought together nine research groups from throughout the world under the aegis of the ILAE, and the initial results (currently submitted for publication) demonstrate the tremendous value that comes from open, large-scale, generous collaboration within the epilepsy research community.

Third, and in the new initiatives category, Ingo Helbig is developing an online communication strategy to share and discuss recent findings in the field of epilepsy genetics and related areas. To this end, the "Beyond the Ion Channel — the Channelopathist" blog of the European EuroEPI-NOMICS consortium (channelopathist.net) will be continued under the leadership of the Genetics Commission. This platform will be enhanced by the "Epilepsioime" database, an online knowledge base for constant, concise and expert-reviewed information on epilepsy genetics that will be generated during the term of the current Genetics Commission. Our hope is that this novel approach will allow the ILAE Genetics Commission to reach out to clinicians and scientists and make epilepsy genetics more accessible for professionals and lay persons."

Finally, recognizing that healthcare professionals have difficulty keeping up with advances in epilepsy genetics, the Genetics Commission, under the leadership of Nigel

Tan, has planned a new series on Genetic Literacy in Epilepsy. The goal of this series, to be published in *Epilepsia*, is to provide a concise, readable resource on genetic testing in epilepsy for the clinician on the ground so that he/she can apply that knowledge at point-of-care. The series will begin with a primer on genetics, and then progresses to cover frequently encountered epilepsies or epilepsy syndromes, e.g., genetic testing in epileptic encephalopathies, in progressive myoclonic epilepsies, or in IGEs / GGEs. We plan for each paper to start and end with a clinical scenario or case to ensure a strong and consistent clinical slant. The core of each paper will be a discussion centered around the case — who to test, why test, and what to do with the test result. Finally, the discussion returns to the case and a clinical conclusion is made. Each paper will also end with a short online multiple-choice test, with answers and feedback provided at the end of the test to reinforce learning.

Commission Members: Dan Lowenstein, Chair, Sam Berkovic, Peter de Jonghe, Alica Goldman, Ingo Helbig, Yuwu Jiang, Mitsuhiro Kato, Heather Mefford, Steve Petrou, Parthasarathy Satishchandra, Nigel Tan, and Helen Cross, MC Liaison.

Activities of the Neurobiology Commission

Marco de Curtis, Neurobiology Commission Chair

The long-established objective of the Neurobiology Commission (NBC) is to support, develop and promote activities related to the neurobiology of epilepsy within ILAE and to collaborate with neuroscience organizations to support epilepsy research. The Commission is composed of Task Forces (TFs) that will develop specific actions for the period 2013-2017, in continuity with the program of the previous NBC chaired by Astrid Nehlig and Jeff Noebels. Whenever possible, TF's activities defined in agreement with the ILAE Executive Committee are fostered in collaboration with other Commissions. In keeping with NBC mission and objectives, six initiatives coordinated by specific TFs are planned. The progress of TF activities is regularly monitored by TF Chairs and is discussed at yearly NBC meetings scheduled during major International Epilepsy Congresses.



Marco de Curtis

The goal of Initiative 1 is to formulate recommendations for preclinical epilepsy drug discovery. A joint ILAE and American Epilepsy Society Translational Research TF will devise a plan to revise terminology and to identify optimal methods and strategies for the discovery, validation, and translation of new therapies into the clinics. Since 2011, the work of the TF recognized that changes in traditional pre-clinical development pathways for anti-epileptic therapies are needed (*Epilepsia* 2013; 54,S4). Future steps include the development of i) standards for seizure and comorbidity classifications in animal models, ii) central repositories of video-EEG recordings from animal models and of software/methods for the analysis of large EEG dataset, iii) central infrastructures for undertaking multicentre pre-clinical studies based on the analysis of common data elements and iv) higher quality evidence of efficacy of new treatments and targets.

Initiative 2, run by the Resource Mapping TF, aims at keeping a record of techniques, resources and equipment available worldwide for basic epilepsy research. A questionnaire distributed among epilepsy centers will contribute to the development of a geographical mapping of available resources that should help to point out where there are critical needs which ideally would lead finding assistance to help correct the lack of equipment and other research resources.

The Education and Beyond TF is responsible for Initiative 3, which is focused on the identification of training activities to be supported by NBC. Recommendations and assistance to improve and enhance the neurobiology content of the training events will be provided. Funding requests will be received and evaluated by NBC through a call for application (to be developed).

The Education and Beyond TF will also work on a Beyond Training project (Initiative 4) that aims at seeding neurobiology activities in less advantaged geographical areas, in particular Africa, South America and Asia. The project seeks to advance professional training in epilepsy in countries with limited resources, by promoting and launching a competitive call for new research developments aimed at solving specific regional epilepsy issues. Projects and international networks will be evaluated during ILAE-sponsored training courses (LASSE and San Servolo), and selected international teams will be given the opportunity to compete for funding provided by ILAE and other funding agencies. This challenging project aims at funding two proposals per year starting from 2016-17.

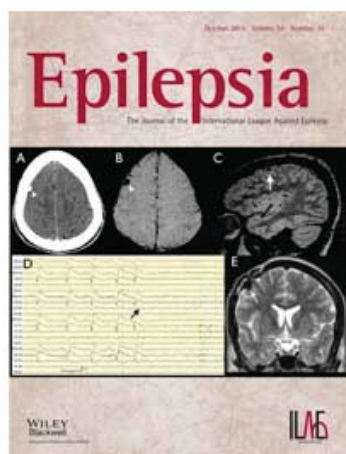
Initiative 5 is focused on the scientific and logistical organization of the Workshop on Neurobiology of Epilepsy (WONOEP), the ILAE discussion arena for novel neurobiology research strategies in epilepsy. The topic of the next edition (WONOEP XIII, satellite of the 2015 Istanbul ILAE meeting) is biomarkers in epilepsy. The meeting is separated into sessions on such subthemes as (biomarkers of epileptogenesis, of seizures, of comorbidities; biomarkers by modality and function). An open call for abstracts will be published in July 2014. WONOEP discussion catalyzes specific reviews on neurobiology of epilepsy that are submitted to *Epilepsia* for publication.

Central to NBC purposes is Initiative 6, pursued by the Neurobiology Dissemination TF. To promote interactions between clinical scientists and neuroscientists and to help dissemination of neurobiology in the clinical setting, the need to include members with neurobiology expertise in ILAE Commissions and TFs is strongly emphasized. Among the specific TF objectives is the enhancement of the participation of neuroscientists to ILAE meetings. A link with WONOEP has been recognized as crucial to achieve this goal. For the 2015 ILAE Congress, the following activities were proposed: training sessions for neuroscientists on specific clinical epileptology issues; debates between neuroscientists and clinicians on specific topics; Young Scientist Awards for the best Neurobiology contribution during the platform presentations; neurobiology-related symposia about a cutting-edge science achievement with a clear-cut educational format. To reinforce interactions with neuroscience societies, translational epilepsy sessions, symposia and satellite workshops are recommended at National and International neuroscience meetings. Finally, new strategies to disseminate NBC activities through the use of new web technologies accessible via cell phones or Pads are planned.

There are many exciting laboratory findings that may be applied to epilepsy that have appeared over the recent decades. It is the task of the NBC to keep the flow of new discoveries that may benefit epilepsy moving to the clinic and to support the continued efforts of neuroscientists that will one day lead to new better treatments.

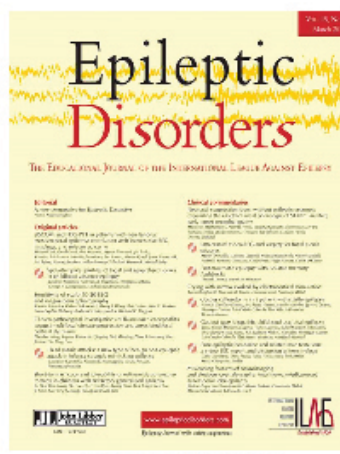
Commission Members: Marco de Curtis, Chair, Astrid Nehlig, Jeff Noebels, Aristeia Galanopoulou, Norberto Garcia-Caraisco, Richard Idro, Damir Janigro, Hoon-Chul Kang, Katja Kobow, Merab Kokaia, Weiping Liao, Terence O'Brien, Vicky Whittemore, and Nico Moshé, MC Liaison.

Research



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Epileptic Disorders

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The Neuropsychiatry Commission Activity Update

Kousuke Kanemoto, Neuropsychiatry Commission Chair

As you know, 20-30 percent of the patients with epilepsy suffer from some kind of psychiatric problem and the impact of this on quality of life is at least as serious as seizures themselves. However, psychiatric issues have not attracted a corresponding level of attention among epilepsy specialists. As John Hughlings Jackson once said, "we need to be botanist and gardener at the same time to take care of patients with such a complex disease as epilepsy." Whilst the botanist side of epilepsy appeals so much to specialists, the gardener aspect of it tends to be unpopular. Psychiatric issues in epilepsy still need a lot of gardener-like coping skills, which awaits a systematic approach from the field of epilepsy.

Since the start of the new Commission on Neuropsychiatry, from 2013 in Montreal, we have planned a number of initiatives covering all areas of psychiatric impact in epilepsy: depression, psychosis, epilepsy surgery, childhood issues, discussion between neurologist and psychiatrist, and educational matters. We have established Task Forces specializing in each of these topics. All the members of the Task Forces are now striving hard to get visible achievements on the relevant issues.

In the first half of our Commission's time, we are focusing on two tasks. I am going to address these issues first and then briefly summarize the other activities.

The first is about behavioral problems in adults with an intellectual disability and epilepsy. This subgroup of patients has a wide range of clinical backgrounds such as epileptic encephalopathy as a primary cause resulting in



Kousuke Kanemoto

intellectual problems and underlying brain damage leading both to epilepsy and intellectual disability. The size of this subgroup is large but attention given so far has been not always sufficient. Mike Kerr and I are holding an international symposium titled "Epilepsy, behavior and intellectual disability: a time for change. An international ILAE conference" at Tokyo in 1 October 2014. The purpose of the meeting is to discuss key areas of need, and solutions to these needs, to reduce the burden of psychological and behavioral problems around the world especially in this subgroup. The planned speakers and Chairs include Christine Linehan (Ireland); Mike Kerr (UK); Kenji Sugai (Japan); Christian Brandt (Germany); Sara Wilson (Australia); Kousuke Kanemoto (Japan); Jun Kawasaki (Japan); Hirano Keiji (Japan); Yukari Tadokoro (Japan); Mbewe EK (Zambia); and Jo Wilmshurst (South Africa). Jo Wilmshurst is the current Chair of the Commission on Pediatrics of the ILAE. A close co-operation between both Commissions is in prospect. Our Child Task Force chair, David Dunn, will also promote this cooperation.

The second primary target is Psychogenic Nonepileptic Seizures (PNES). Markus Reuber now leads this Task Force. The precise goal of this Task Force is entitled "PNES around the world." This Task Force will explore the present status of PNES around the world, especially different therapeutic approaches depending on different cultural backgrounds. At Stockholm in association with the 11th European Congress of Epilepsy, an international meeting on this issue is planned. Markus Reuber (UK); Kousuke Kanemoto (Japan); Alejandro De Marinis (Chile); Curt LaFrance (USA); Ali Akbar Asadi-Pooya, (Iran); David Gigineishvili (Georgia); Ravi Paul (Zambia); and Kette Valente (Brazil) are intended attendees and will discuss this. Based on these discussions, an international symposium will be held on this matter at Nagasaki, Japan on 29 October 2015.

During the term of the last Commission, the Task Forces on Education and Depression made remarkable achievements. Marco Mula continues his leadership of the Educa-

tion Task Force, promoting VIREPA e-learning and plans to publish a textbook on neuropsychiatric issues in epilepsy. The Task Force on Depression under the leadership of Sung Pa Park, with the help of Andres Kanner, is promoting further dissemination of the Neurological Depression Disorders Inventory for epilepsy (NDDI-e) in nations where it has not yet been done. Because of the remarkable time-saving nature of NDDI as a screening tool for depression, dissemination of this is expected to heighten awareness of depressive states in patients with epilepsy around the world. Aileen McGonigal and Dongmei An are now translating the scale into French and Chinese, respectively.

The Task force on the Psychiatric Aspects of Epilepsy Surgery, chaired by Gerardo Filo, is working on identifying minimum requirements for psychiatric evaluation before surgical intervention, which should help clinicians who work in facilities where psychiatrists' involvement is not currently available. The Task force on Psychoses, Chaired by Robert Kuba, plans to investigate gaps in our knowledge about mild psychotic experience both in health professionals and patients. Initially, a pilot study will be performed in Japan and the Czech Republic.

There are many other experts, who have kindly decided to become part of the Task Force and have not been listed here. Many new initiatives concerning psychiatric issues in patients with epilepsy will come out during our remaining term. I sincerely ask you all to help us to heighten the awareness of this important, but still relatively neglected area, and to kindly pay attention to our activities as gardeners directly confronted with patients with the doubly difficult situation that is epilepsy and psychiatric difficulties.

Commission Members: Kousuke Kanemoto, Chair, Andres Kanner, Marco Mula, Mike Kerr, David Dunn, Gerardo Filho, Robert Kuba, Sung-Pa Park, Markus Reuber, José Francisco Tellez-Zenteno, and Tatsuya Tanaka, MC Liaison.

The Pediatric Commission Report: Activities for 2014-2016

Jo Wilmshurst, Pediatrics Commission Chair

The child suffering with epilepsy has many unique needs. Some of these needs are linked to the cause of the epilepsy and others are tied to societal attitudes about epilepsy and to the impact that epilepsy may have on the family and the child's development. Many of these needs go unaddressed because the children often don't have a voice to call attention to these age specific and critical medical and psychosocial issues. The Commission on Pediatrics has selected three key areas specific to children with epilepsy that will be targeted during the next three years. These areas are to assure that



Jo Wilmshurst, Chair

children have a reliable access to medications, to develop an approach to the many comorbidities of epilepsy specific to children and to adapt seizure guidelines that are focused on neonatal and infantile seizures.

1. Advocacy Task Force for the rights of the child to consistent and reliable AED supply (Chair: Jo Wilmshurst)

The rights of the child with epilepsy are abused worldwide by the limitations on access to effective antiepileptic drugs that are often driven by pharmaceutical companies, who can withdraw or limit access to AEDs based on revenue and by the local limitations set by financial restraints. Children, especially from resource poor settings, either have no access, unreliable access, or are managed with a combination of antiepileptic drug (AED) generics of different bioavailability. Legislation exists in Europe, which states that changing a child who is stable on one brand of a drug to another is unethical. A working document will be com-

pleted based on the current practice and policies relating to access to and supply of AEDs (withdrawal of "essential" agents), and the prescribing behavior of AEDs (generic, changing over of brands), for children with epilepsy. Ideally this document will evolve into a position statement, under the auspices of the ILAE, relating to recommended good practice. Key members from the therapeutics and the Advocacy Task Forces will be invited to be part of this work.

2. Task Force for comorbidities in Pediatric Epilepsy (Chair: Stephane Auvin)

The aim for this Task Force is to develop a "user friendly text" that documents the known data (epidemiology, regional variations, etiologies), identifies what is not known, and highlights and red flags where interventions are needed for children with epilepsy. Where data are lacking, explanations for this will be sought, such as challenges from lack of resources, from the effect of stigma, and failure to disclose the presence of the disease. Known etiolo-

(Continued on page 10)

gies for comorbidities will be sought, differentiating them by such factors as when they are part of the “overall brain makeup” or are the result of parallel processes such as tuberous sclerosis. Other comorbidities may be the result of insults to the brain and as such are secondary or acquired, such as post meningitis. Etiologies will vary regionally, for example in resource poor countries there will be higher prevalence of acquired insults (neuroinfections, trauma, poor nutrition, lack of interventions). Knowledge of other potential influences will be investigated for example, nutritional state, social access and bonding among other influences. Clues will be used to identify when a behavioral trait is purely behavioral and when it is in fact the epilepsy. The task force will also recommend which AEDs should be avoided to minimize drug induced adverse behaviors. The evidence will be documented to support the current interventions, as well as the controversial issues such as “treating” the EEG. Red flags will be noted so as to identify patients for early intervention. A syndromic approach will also be undertaken examining comorbidities which are prevalent with specific seizure types.

3. Task Force for adaptation of recommendations for neonatal and infantile seizures

Chair: Hans Hartmann; Regional experts: Pauline Samia (Africa), Vinayan Puthenivill (Asia), and Marilisa Guerreiro (South America)

The aim of this Task Force will be to adapt existing pediatric guidelines and recommendations into user-friendly formats for neonatal and infantile seizures and epilepsies. These templates will be further adapted to be useful at a local level (i.e. in settings with different resources). Where existing programs exist, they will be recruited to avoid duplication. Various tools will be used to translate the information in these recommendations (e.g. web, direct teaching, visiting expert programs). The regional experts will undertake pilot studies for applying these guidelines (ideally as part of established teaching programs), and will explore the best way to translate and adapt the information. Simple flow diagrams will be developed, as will leaflets, card lists and mobile “apps”. Monitoring will be incorporated to measure the success, effectiveness and usefulness of these recommendations on such things as neonatal morbidity rates on units, long term outcomes, duration of stay and improved seizure

control. There will be collaboration on this project with the Education Committee.

It is the goal and hope of the Commission on Pediatrics that these efforts will bring added attention and action to address the needs of children with epilepsy and their families. As our work progresses we will bring these issues to our colleagues for their advice on how best to improve this dire situation.

The working committee consists of Jo Wilmshurst, Chair, Patrick van Boegart, Hans Hartman, Perrine Plouin, Petia Dimova, Stephane Auvin, Amy Brooks-Kayal, Makiko Osawa, Vinayan Puthenivill, Pauline Samia, Marilisa M Guerreiro, and Helen Cross, MC Liaison. There are affiliations with key Commissions and Task Forces with complementary interests namely; epilepsy surgery (pediatric advisor - Bill Gaillard), education (Jaime Carrizosa, Lionel Carmant), neuropsychiatry (David Dunn), and neonatal classifications (Ronit Pressler, Perrine Plouin).

Commission for Surgical Therapies

Bertil Rydenhag, *Surgical Therapies Commission Chair*

Epilepsy surgery is worldwide an underutilized option for people with medically intractable epilepsy that is surgically remediable. Strategies to gain seizure freedom through surgery differ depending on local resources and traditions. As is usually the case in most of medicine there are several paths to reach the same goal. The ultimate goal for epilepsy surgery whenever possible is seizure freedom without consequences imposed by the treatment or by the presurgical evaluation. It is important not to forget that in many cases seizure freedom is not possible and that a significant reduction of seizures may be a substantial gain for many patients. In this term the Commission for Surgical Therapies has several issues that it will emphasize.



Bertil Rydenhag

Patient oriented outcomes – relating seizure outcome to safety

The goal of the Commission on Surgical Therapies is to develop and support new strategies in the presurgical evaluation and actual surgery that minimize the risks for the patient and optimizes the outcomes. This statement does not mean that we must standardize the surgical approach, as there are so many causes and surgical possibilities. In pursuing this goal, the Commission of Surgical Therapies will work together with other relevant League Commissions.

The importance of education

With the rapid spread of epilepsy surgery worldwide it is of great importance to train and to educate the new teams in all that is needed to diagnose, localize and remove the seizure focus. Different efforts should be planned in respect to local resources and experience. Courses in epilepsy surgery need to encompass not only technical surgical aspects, but the multidisciplinary team work which is the basis for optimizing presurgical evaluations. Fellowships may make it possible for younger colleagues to gain experience by education in experienced centers and with the evolving techniques it is increasingly possible to build networks, have internet consultations and discussions and to find international support. This is also strongly supported by the ILAE’s strategic plan: to make it easy to find and seek knowledge in epilepsy worldwide!

The surgical treatment and procedures

The surgical decision and recommendations to the patient and family must be based on multidisciplinary evaluation and discussions, including not only the surgical risks, but also possible or expected cognitive deficits or in some instances even neurological deficits. Trade-offs between the therapeutic effects of surgery and the risks for adverse effects and complications must be discussed with all who will be affected by the outcome.

Long-term follow up and further randomized studies

An increasing number of reports are published on the long term results of epilepsy surgery. It is important that observational long-term follow-up studies are comprehensive and with sound methodology. Patients and their relatives need information on the long-term outcomes as part of the counseling process when they are considering resective brain surgery. One goal for the Commission will be to en-

courage and support centers worldwide to focus on the immediate as well as the longer duration consequences for the operated patients and use these outcomes to improve these results.

The importance of support to developing countries and countries with minimal resources

Some epilepsy surgery procedures and programs may be handled well in countries with minimal resources and in developing countries. It is, however, important for these teams to get support and educational resources from the well established epilepsy surgery centers. The development of transnational partnerships may be a key goal for our Commission.

Summary of Commission Goals:

- To continue the international collaboration to spread knowledge of techniques for evaluation and surgery of patients with epilepsy
- To emphasize good long-term results
- To create a culture of maximal safety for the patients in both evaluation and treatment
- To promote and assist in evaluation of new techniques
- To foster education in epilepsy surgery
- To support the creation of epilepsy surgery programs in developing countries and countries with minimal resources.

Commission Members: Bertil Rydenhag, Chair, Bernhard Steinhoff, Kristina Malmgren, Mike Sperling, Christine Bulteau, Pavel Krsek, Andrew McEvoy, Sanford Hsu, Mario Alonso, Serege Vuillimoz, and Taisuke Otsuki.

ILAE/AES Translational Task Force of the Neurobiology Commission: An Update on the Translational Initiatives

Aristea Galanopoulou, Jackie French, Michele Simonato and Terrence O'Brien, Joint ILAE-AES Translational Research Co-Chairs

The newly assembled ILAE / AES Translational Task Force of the Neurobiology Commission of the ILAE has been tasked to continue the work of the ILAE working group for preclinical epilepsy drug discovery and pursue the next steps that were set as priorities following the 1st Joint ILAE/AES Translational Workshop in London (2012). The Co-Chairs of the new Translational Task Force (Jacqueline French, Aristea Galanopoulou, Terence O'Brien, and Michele Simonato) along with the elected members (Amy Brooks-Kayal, Marco de Curtis, Akio Ikeda, Frances Jensen, Solomon (Nico) Moshé, Asla Pitkanen, Helen Scharfman) are currently in the process of selecting working group members that will address the following next steps.



Aristea Galanopoulou



Jackie French



Michele Simonato



Terrence O'Brien

Infrastructure to harmonize video-EEG interpretation and analysis in rodents

At present, there is significant heterogeneity in the recording, interpretation, and analysis of electrophysiological recordings of neuronal activity in vivo and in vitro animal models of seizures. This heterogeneity in interpretation of animal EEG has created significant hurdles in the comparison of studies describing epilepsy development in animal models and is a major obstacle in the evaluation of anti-epileptogenesis treatments. The co-leaders of this Step (Aristea Galanopoulou, Marco de Curtis, Akio Ikeda) have been tasked with four goals:

- (1) Develop standards for recordings and interpretation of rodent EEGs (cortical and depth) across the life span.
- (2) Develop standards for the interpretation of in vitro seizure models.
- (3) Enhance and optimize depositories of annotated video-EEG data and analysis software to permit the analysis and interpretation of studies from different laboratories using the same tools and standards.
- (4) Generate publications that will disseminate the products of our working groups.

We hope that the products of our working groups will provide working definitions, classification systems, and analysis methods that will facilitate the translation and comparison of studies from different laboratories, and will set the foundations for the generation of common data elements for electrophysiological studies and multi-center anti-epilepsy therapy multi-center trials (below).

Review of animal model data for particular clinical syndromes, including treatments, biomarkers, and comorbidities

In basic and preclinical research, reviews are always descriptive and never systematic, meta-analysis of the data is difficult, because of varying approaches, models and tech-

niques. Organizing and coordinating databases and systematic reviews on regarding animal research in epilepsy is needed. The goal of this Step is to establish means to generate, publish and periodically update (in journals and / or websites) these databases and reviews. Creating a Cochrane-like collaboration will facilitate identification of what is strong and what is weak, what is promising for clinical application and what would benefit from in-depth analysis. Systematic reviews could pave the way for large, multi-center studies with appropriate characteristics and statistical power; in addition, the reviews will provide material for common data elements (see other Steps below). The co-leaders of this Step are Michele Simonato, Amy Brooks-Kayal and Frances Jensen.

Common data elements (CDEs) in preclinical research

CDEs standardize the collection of investigational data and facilitate comparison of results across studies. They allow more effective aggregation of information into significant metadata results. The NINDS has spearheaded an effort to create a group of CDEs for > 10 neurologic diseases (<http://www.commondataelements.ninds.nih.gov/default.aspx#page=Default>). Epilepsy has been one of the areas for which CDEs have been created, and they are now in common use. Preclinical CDEs for epilepsy ensure that important data elements (e.g., experimental conditions, collection of EEG or behavioral data) are obtained in all studies in a similar fashion. CDEs will provide a tool that can be applied in multiple ways in preclinical research. They will serve the needs of individual laboratories as well as the large scale research consortia to standardize the study protocols. Implementation of preclinical CDEs may influence design of studies for grant applications and the preparation of scientific articles. The co-leaders of this Step include Jackie French, Asla Pitkanen, and Helen Scharfman.

Develop infrastructure for multi-center preclinical studies

Because preclinical studies can be resource intensive partnerships among government-related funding organizations (NIH, European Community), industry, philanthropic foundations and academia is necessary. These studies will represent a "Phase II" of preclinical studies, similar to clinical Phase II/III multicenter, randomized, double-blinded studies, and the goal is to generate more rigorous pre-clinical data for efficacy than is currently generated from single laboratory "Phase I" studies. These single lab studies are usually underpowered, are often unrepliated and suffer from significant experimental limitations. The ultimate goal is to improve the evidence from pre-clinical studies for investigational new drugs that show strong promise in initial "Phase I" studies and thus to increasing the chances that clinical studies will be successful. More predictive preclinical results may encourage industry and government to invest in a prospective therapy's clinical development. The co-leaders of this Step include Terry O'Brien, Nico Moshé, and Akio Ikeda.

Dissemination

Finally, the Translational Task Force has undertaken an intense dissemination activity to inform epileptologists as well as the broader scientific and medical community about its mission while at the same time seeking feedback and suggestions. The summaries and recommendations of the proceedings of the "Joint AES / ILAE Translational Workshop to Optimize Preclinical Epilepsy Research", held in London in 2012, have been published in a special supplement in *Epilepsia* (Volume 54, Supplement s4, 2013), and a brief critical summary of the work performed to date is in press as a "Personal view" in *Lancet Neurology*. Moreover, a workshop has been proposed and accepted at the 17th World Congress of Basic and Clinical Pharmacology (Cape Town, South Africa, July 2014). In this workshop, entitled "Optimizing anti-epilepsy drug discovery", Michele Simonato, Terrence O'Brien, Aristea Galanopoulou, Asla Pitkanen and Jerome (Pete) Engel will present and discuss the ongoing work of the Task Force to an audience of pharmacologists.

An Introduction to ILAE

The ILAE is constituted as an international nonprofit organization and is registered in the United States. The ILAE is the premiere international professional association of physicians and other health professionals in the field of epilepsy. It was founded in 1909 and has grown greatly in size and influence in recent years. From its earliest years, it has been organized in the form of a federation of national Chapters. Currently there are Chapters in over 100 countries and over ten thousand members worldwide. The mission of the ILAE is to work towards a world where no person's life is limited by epilepsy. Its mission is to provide the highest quality of care and well-being for those afflicted with the condition and other related seizure disorders. For more details, readers can consult the ILAE website at www.ilae.org.

Executive Committee

The ILAE is overseen by an Executive Committee, currently of 16 persons (current members in brackets). The President (E Perucca) is elected by a ballot of national Chapters for a four-year term. The Secretary-General (H Cross), Treasurer (S Wiebe), and the Chair of each recognized ILAE Region are also elected by a ballot of national Chapters for a four-year term. The Editors-in-Chief of *Epilepsia* (Gary Mathern and Astrid Nehlig) are appointed by the President and the Executive Committee. The Past President (S Moshé) serves for a four-year term. The President (Athanasios Covanis), the Secretary-General (Sari Tervonen) and the Treasurer (Robert Cole) of the sister organization, the International Bureau of Epilepsy (IBE), are Ex-Officio members of the Executive Committee.

Constitution and Bylaws

The ILAE is governed by a written Constitution and Bylaws which are posted on the ILAE website. The Constitution has fifteen articles, and the Bylaws gave thirteen sections, and these cover the objectives, membership, governance and the range of the ILAE activities and its structure. The Constitution can be amended at the General Assembly of the ILAE. There is a standing Constitutional and Elections Task Force to oversee changes in the Constitution. The Constitution was updated in 2011. The Bylaws were updated in 2013.

Chapters

Each national Chapter has its own Constitution and Bylaws and its own President and officers, elected by individual members of each Chapter. The constitutional and leadership arrangements vary from Chapter to Chapter, within stipulations defined in the ILAE Constitution, as do the details of membership eligibility. However, generally speaking, membership is open to any doctor and health professional interested in epilepsy.

There are currently 114 Chapters in the ILAE, which is the greatest number in history. National Chapters range in size from 3,000 to just seven voting members. The role of the national Chapters is generally to establish and maintain good communication between persons active in the field of epilepsy, assist in the care of epilepsy and maintain standards of this care in their own countries, promote publications in the field of epilepsy, organize or sponsor national meetings, appoint Commissions or individuals for specific problems, and develop or apply other methods for the furtherance of the objectives of the ILAE.

Regional Bodies

ILAE is also divided into six Regions (North America, Latin America, Europe, Eastern Mediterranean, Asia and Oceania, and Africa). Each Region is made up of a grouping of national Chapters — the largest is Europe with 46 Chapters and the smallest is North America with three national Chapters. Fully developed Regions each have a Regional Commission and a Regional Council, and regional scientific conferences are held every two years. Active Regions also conduct research and education and have a role in influencing public policy in epilepsy at a regional level. The currently constituted Regional Commissions are: African Commission (Chair — A Diop), European Commission (Chair — M Bialer), Asian and Oceanian Commission (Chair — B Lee), North American Commission (Chair — S Haut), Latin American Commission (Chair — M Medina), Eastern Mediterranean Commission (Chair — H Hosny).

Commissions and Task Forces

In every four-year term, the President and the Executive Committee appoint Topic-Oriented Commissions and Task Forces to carry out work for the ILAE. These bodies involve individual members transnationally. Currently, the following Topic-Oriented Commissions are: Classification and Terminology (Chair — S Zuberi), Diagnostic Methods (Chair — I Blüemcke), Education (Chair — J Carrizosa), Epidemiology (Chair — D Thurman), Genetics (Chair — D Lowenstein), Medical Therapies (Chair — P Kwan), Neurobiology (Chair — M de Curtis), Neuropsychiatry (Chair — K Kanemoto), Pediatrics (Chair — J Wilmshurst), Surgical Therapies (Chair — B Rydenhag).

Task Forces include Conflict Elections Commission, Finance Committee / Financial Advisory / Sub Committee / Budget Committee, Global Outreach, ICD-11 Task Force, Past President Advisory Commission, Strategic Planning Committee, Task Force on Epilepsy in the Tropics, Task Force on Stigma, Task Force on Guidelines, Task Force on Sports and Epilepsy, Communications Task Force, and Publications Task Force.

Staff

ILAE Headquarters is located in Hartford, CT (USA). Headquarters staff performs services related to leadership support, financial and website management, and publications coordination. The League provides services to its 114 Chapters from the IDM Office located in Dublin, Ireland. The following individuals serve on the staff of the ILAE: Priscilla Shisler, MEd, Administrative Director; Donna Cunard, MBA, Financial Manager; Simone Upsey, Communications Liaison; Deborah Flower, Web Content Administrator; Steve Shane, Web Programmer. Gus Egan, Chapter Services Coordinator; Verena Hézser-v.Wehrs, MA and Mary Anne Lynch, MA, VIREPA Coordinators.

IDM Office

ILAE holds a global scientific conference once every two years (International Epilepsy Congress). Each Region holds a regional scientific conference every two years, in the years when there is no global Conference, and every national Chapter holds a national scientific conference every year. At the national Conferences, the Chapters hold their Annual General Meetings, and at the International Congresses, the ILAE holds the General Assembly of all its na-

tional Chapters. The regional and international Conferences of the ILAE are organized by its own conference organizer (R Holmes, International Director of Meetings) and his office.

Global Outreach

This is a joint ILAE, IBE and WHO initiative, launched in 1997. The first phase of the Global Campaign Against Epilepsy was devoted primarily to increasing public and professional awareness of epilepsy as a universal treatable brain disorder, and raising epilepsy to a new plane of acceptability in the public domain. The second phase of the Global Campaign Against Epilepsy was launched in 2001 and was devoted primarily to activities that promote public and professional education about epilepsy, identify the needs of people with epilepsy on a national and regional basis, and encourage governments and departments of health to address the needs of people with epilepsy. The third phase was launched in 2005 and is focused on special projects in different parts of the world and on assisting healthcare authorities worldwide in the field of epilepsy.

Epilepsia

Epilepsia is the scientific journal of the ILAE and the leading journal in the field of epilepsy. It is published by Wiley-Blackwell and edited by Editors-in-Chief (G Mathern, A Nehlig) who also appoint an editorial board and Associate Editors (currently: H Beck, E Bertham, R Caplan, J French, W Gaillard, A Hartman, D Hesdorffer, A Ikeda, N Jette, D Loring, P Patsalos, A Poduri, H Potschka, D Schmidt, P Siddarth, M Sperling, R Tuchman, T Velasco, and J Wilmshurst). *Epilepsia* was started in 1909, and currently is published monthly.

Epileptic Disorders

Epileptic Disorders has been designated as the League's educational journal. It publishes articles concerned with the clinical manifestations of epilepsy, but with all aspects of the diagnosis, natural history and management of seizure disorders including neurophysiological, imaging and other ancillary techniques. It is published by John Libbey, Eurotext and edited by an Editor-in-Chief, (A Arzimanoglu) who also appoints an editorial board and Associate Editors (currently: I Blüemcke, F Dubeau, M Duchowny, A Galanopoulou, A Hammers, Y Inoue, P Kahane, M Kerr, D Nordli, G Silla, P Thomas, T Tomson, S Wilson, and F Zara). *Epileptic Disorders* was started in 1999 and currently is published quarterly.

Epigraph and the Website

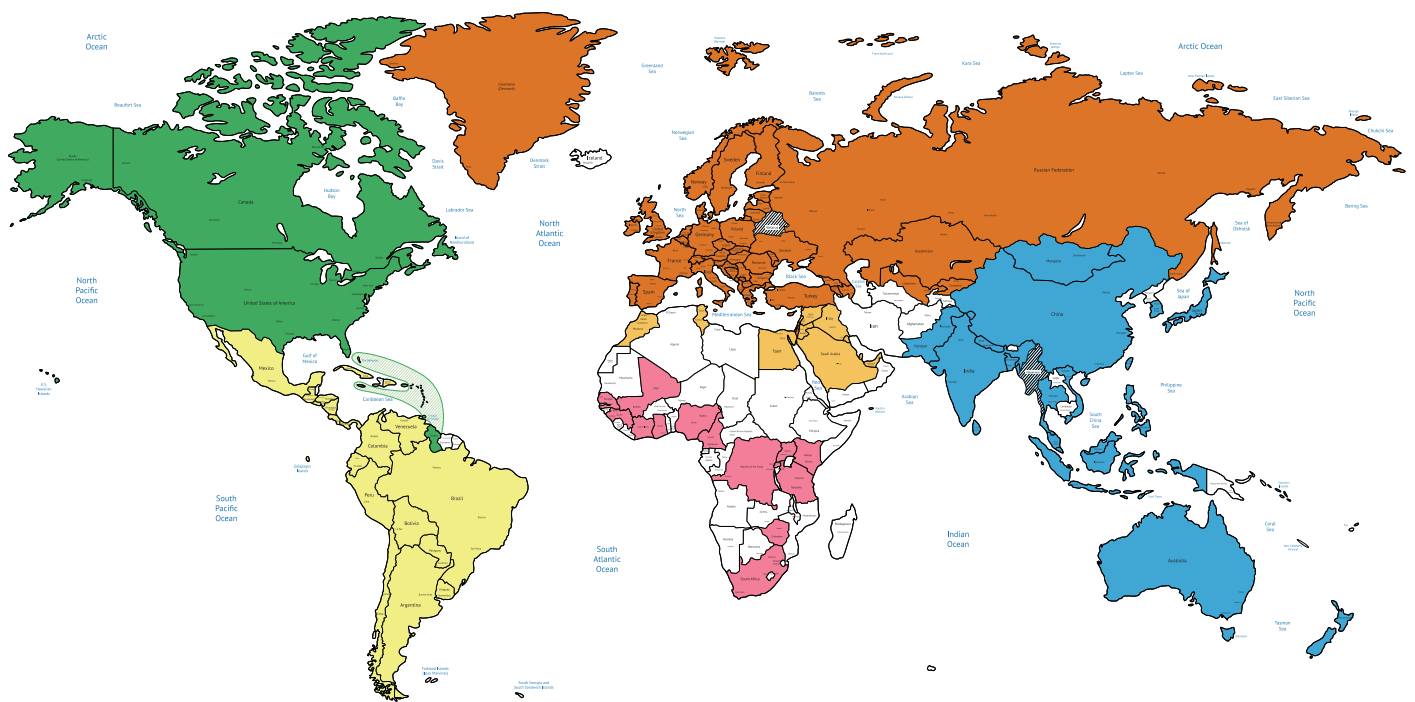
In 1994, the ILAE launched its own newsletter *Epigraph*, to be sent individually to all members. This was initially sent out two to three times a year. Since 2006, four issues a year have been published — three online and one (the current issue) in print. The first online edition in 2006 was mailed to 10,587 persons. The newsletter is designed to facilitate communication of ILAE news from the central bodies to individual members in each country. ILAE also has a website at www.ilae.org. This has grown in size and complexity and in 2013 there were over 197,000 visits. *Epigraph* and the website are overseen by Information Officer, Ed Bertham, and Director of Interactive Media, Jean Gotman, respectively.

(Continued on page 13)

ILAE Chapters

- | | | | | |
|--------------------|------------------------------|-------------|-----------------------|-----------------|
| Albania | Denmark | Ireland | Nigeria | Sweden |
| Algeria | Dominican Republic | Israel | Norway | Switzerland |
| Argentina | Democratic Republic of Congo | Italy | Pakistan | Syria |
| Armenia | Ecuador | Ivory Coast | Palestina | Taiwan |
| Australia | Egypt | Japan | Panama | Tanzania |
| Austria | El Salvador | Jordan | Paraguay | Thailand |
| Azerbaijan | Emirates | Kazakhstan | Peru | The Netherlands |
| Bangladesh | Estonia | Kenya | Philippines | Tunisia |
| Belgium | Finland | Kyrgyzstan | Poland | Turkey |
| Bolivia | France | Kosovo | Portugal | Uganda |
| Bosnia Herzegovina | FYR Macedonia | Kuwait | Qatar | UK |
| Brazil | Georgia | Latvia | Romania | Ukraine |
| Bulgaria | Germany | Lebanon | Russia | Uruguay |
| Cameroon | Ghana | Lithuania | Rwanda | USA |
| Canada | Greece | Malaysia | Saudi Arabia | Uzbekistan |
| Caribbean* | Guatemala | Mali | Senegal | Venezuela |
| Chile | Guinea | Malta | Serbia and Montenegro | Vietnam |
| China | Honduras | Mexico | Singapore | Zimbabwe |
| Colombia | Hong Kong | Moldova | Slovakia | |
| Costa Rica | Hungary | Mongolia | Slovenia | |
| Croatia | India | Morocco | South Africa | |
| Cuba | Indonesia | Nepal | South Korea | |
| Cyprus | Iraq | New Zealand | Spain | |
| Czech Republic | | Nicaragua | Sri Lanka | |

*Antigua, Bahamas, Barbados, Guyana, Jamaica, Martenique, St. Kitts, St. Lucia, Trinidad and Tobago, U.S. Virgin Islands



Commission on North American Affairs	Commission on Latin American Affairs	Commission on European Affairs	Commission on African Affairs	Commission on Eastern Mediterranean Affairs	Commission on Asian and Oceanian Affairs	Provisional Chapters
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An Introduction to ILAE

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Finances

With the assistance of the Financial Office, ILAE finances are overseen by the Treasurer, who reports to the Executive Committee on all financial matters. Membership of the Executive Committee, regional bodies, and Commissions and

Task Forces is honorary and members are not paid for their work. The editorships of *Epilepsia* and *Epigraph* are also unpaid. Salaried staff is located in three administrative offices: Headquarters Office located in Hartford, Connecticut, USA; Chapter Services Office located in Dublin, Ireland; and the Meeting Planning Office located in Dublin, Ireland.

Income is derived from national Chapter dues, sponsorship, *Epilepsia* royalties, international and regional Congresses, and investment income. The annual dues of each Chapter to ILAE are a minimum of \$10 per year per Chapter, except for countries with low GDPs (World Bank categories low and lower middle) for whom membership is supported

VIREPA course format All courses are internet-based, e-moderated courses with downloadable learning material. To earn credits in each learning unit, tasks are successfully completed through active communication among all participants, guided by the experts. The tasks strengthen the theoretical knowledge and enable the participant to transfer this knowledge to his/her clinical practice.

Entry criteria Three years of training in neurology, neuropediatrics, clinical neurophysiology, psychiatry or neurosurgery or combinations of these. See specific entry criteria for each course at www.ilae.org.

Application Applications will be received from May 5 - August 4, 2014. Invitations to register will go to qualified applicants in late August. Courses will start in October/November 2014.

<p>EEG in the Diagnosis & Management of Epilepsy I. Basic Course (2014) II. Advanced Course (2014) (9th edition)</p>	<p>The Basic course will cover the basic elements of the practice of EEG in the diagnostic work up and management of persons with suspected or already established epilepsy. The Advanced course will focus on more specific aspects of EEG in epilepsy, including long-term monitoring, seizure documentation and computer-assisted signal analysis. Basic Course Directors: Walter van Emde Boas, Sándor Beniczky Advanced Course Directors: Sándor Beniczky, Michael Koutroumanidis Duration: 7 learning units of 3 weeks each and 10 days for final task Course fee: Each course \$1080 for self payment; \$270 for approved bursaries.</p>
<p>EEG in the Diagnosis & Management of Epilepsy in Neonates & Children (4th edition)</p>	<p>The course will cover the basic elements of the practice of EEG in the diagnostic work up and the management of children with suspected or already established epilepsy. Course Director: Perrine Plouin, Monika Eisermann Duration: 8 learning units of 3 weeks each and 10 days for final task Course fee: \$1210 for self payment; \$300 for approved bursaries.</p>
<p>Epilepsy & Sleep (1st edition) I. Basic Part (2013) II. Clinical Part (2014)</p>	<p>The courses will cover the interaction between epilepsy and sleep in adults and children. In the first year (2013-2014) basic aspects and registration techniques will be the subject. Clinical aspects are the focus in the second year (2014-2015). Participation in the first year course is required to participate in the second year. Course Directors: Al de Weerd, Lino Nobili Duration: 5 learning units of 3 weeks each and 10 days for final task Course fee: \$810 each course. Self payment for approved bursaries will be \$200.</p>
<p>Genetics of Epilepsy (7th edition) I. Basic Science Part (2014) II. Clinical Part (2015)</p>	<p>The course will cover the clinical genetics, i.e. the epileptic phenotypes that are associated with specific mutations, the genetic defects of the different syndromes, and the pathophysiological mechanisms by which these defects can lead to epileptic seizures. These courses give the participants the opportunity to study all three aspects all the way from basic science to clinical practice. Course Directors: Carla Marini, Holger Lerche Duration: Basic - 6 learning units of 3 weeks each and final MCQ test Clinical: 7 learning units of 3 weeks each and final MCQ test Course fee: Basic: \$810 for self payment; \$200 for approved bursaries. Clinical: \$945 for self payment; \$235 for approved bursaries.</p>
<p>Medical Treatment of Epilepsy I. Introductory Course (2014) II. Advanced Course (2015) (6th edition)</p>	<p>The courses will cover the clinical pharmacology of currently available antiepileptic drugs and the principles governing their use in people with epilepsy. (Formerly: "Clinical Pharmacology & Pharmacotherapy" Course) Introductory Course Directors: Janet Mifsud, William Theodore Advanced Course Directors: Steve White, John Pollard Duration: Introductory - 6 learning units of 3 weeks each and 10 days for final task Advanced - 7 learning units of 3 weeks each and 10 days for final task Course fee: Introductory: \$945 for self payment; \$235 for approved bursaries. Advanced: \$1080 for self payment; \$270 for approved bursaries.</p>

<p>Neuroimaging (8th edition) I. Part 1 II. Part 2</p>	<p>The course will cover the methodological basics of neuroimaging techniques and their application to the diagnostic work up and management of adults and children with new onset or chronic epilepsy. Course Directors: Catherine Chiron, William Gaillard Duration: Part 1 - 4 learning units of 3 weeks each and 10 days for final task Part 2 (only available if taking Part 1) – 3 learning units of 3 weeks each and 10 days for final task Course fee: Part 1: \$675 for self payment; \$170 for approved bursaries. Part 2: \$540 for self payment; \$135 for approved bursaries.</p>
<p>Psychiatric Aspects of Epilepsy I. Adults (2014) II. Children (2015)</p>	<p>This year's updated format will provide neurologists an understanding of the importance of identifying and facilitating treatment of the most frequent psychiatric comorbidities in epilepsy in adults and children (mood & anxiety, psychoses, attention deficit disorder, psychogenic non-epileptic seizures, dementia), and the practical tools to achieve these goals. Course Directors: Andres Kanner, Marco Mula Duration: 7 learning units of 3 weeks each and 10 days for final task Course fee: Each course \$945 for self payment; \$235 for approved bursaries.</p>

Important for bursary applicants:

Bursary applicants must submit a letter of recommendation from your current working place or the leadership from the local ILAE chapter or the regional commission stating the expected benefit from this specific VIREPA course for the bursary candidate in the epilepsy care and development in your community.

OR, if such a letter cannot be submitted, bursary applicants must submit a personal letter of motivation outlining the benefit the bursary candidate expects from attending this specific course for his/her daily practice and professional career.

This requirement (letter of recommendation OR personal letter of motivation) is mandatory and is an important part of the decision-making process for the granting of any bursary. Please note that dropping out of a course or having limited participation in one, may impact future bursary eligibility.

Only one ILAE bursary per year per person is possible. Bursaries are partial bursaries involving partial payment. Partial bursaries will only be available for participants living in countries designated by the World Bank as low and lower middle income.

For information and application • www.ilae.org • e-mail: courses@ilae.org

How to Apply for Chapter Membership

The ILAE is a federation of over 114 Chapters and a person can join the ILAE by becoming a member of their Chapter.

Benefits of Chapter membership include:

- Full participation in national and international activities of ILAE
- Chapter conferences and other benefits of individual Chapters
- Complimentary copy of *Epigraph* and *Epileptic Disorders*
- Heavily discounted subscription rates to *Epilepsia* and other epilepsy journals
- Eligibility for membership of ILAE Commission / Task Forces
- Access to the website features.

Individual Chapters vary in exact criteria for membership, but generally speaking, any doctor or health professional with an interest in epilepsy is eligible for membership. To join, write to the Secretary of your Chapter. You can find the contact addresses on the ILAE website at www.ilae.org.

Your membership in the International League Against Epilepsy is vital. Of greatest importance is the fact that membership strengthens the authority of ILAE in its mission to influence and improve epilepsy care worldwide. Your membership counts; become part of the League!

Meetings of Interest

22 - 24 May 2014

4th NARCCCE
(North American Regional Caribbean Conference on Epilepsy)
St. Lucia
www.epilepsycaribbean.org

31 May - 5 June 2014

6th Regional Caucasian Summer School on Clinical Epileptology (RCSSCE)
Bakuriani, Georgia
Contact Email: n_tatishvili@hotmail.com

5 - 7 June 2014

9th International Postgraduate Practical Epilepsy School
Slovenia
Contact Email: epilepsija@epilepsija.org

5 - 7 June 2014

2014 Epilepsy Pipeline Conference
San Francisco, CA, USA
<http://www.epilepsy.com>

12 - 14 June 2014

Korean Epilepsy Congress
Seoul, Korea
www.epilepsykorea.org

27 - 29 June 2014

Cleveland Clinic Epilepsy Review Course
Cleveland, Ohio, USA
www.clevelandclinicmeded.com

29 June - 3 July 2014

11th European Congress on Epileptology
Stockholm, Sweden
www.epilepsystockholm2014.org

4 - 5 July 2014

PES PedEpiSurg Gothenburg 2014
www.ped-epi-surg-göteborg2014.com

3 - 6 July 2014

2014 World Tuberous Sclerosis Complex (TSC) Conference
Washington, D.C., USA
www.tsalliance.org/worldTSCconference

13 - 19 July 2014

Dianalund Summer School on EEG and Epilepsy (DSSEE),
2nd edition
Dianalund, Denmark
www.ilae.org

20 July - 1 August 2014

2014 San Servolo Epilepsy Summer Course:
San Servolo, Italy
www.ilae.org

3 - 8 August 2014

8th Baltic Sea Summer School on Epilepsy (BSSSE 8)
Trakai, Lithuania
www.ilae.org

7 - 10 August 2014

10th Asian & Oceanian Epilepsy Congress
Singapore
<http://www.epilepsysingapore2014.org/>

30 August - September 3 2014

2nd International Summer School for Neuropathology and Epilepsy Surgery (INES)
Erlangen, Germany
www.epilepsie-register.de

31 August - 3 September 2014

12th Eilat Conference on New Antiepileptic Drugs (EILAT XII)
Madrid, Spain
www.eilatxii.com

12 - 13 September 2014

EPNS Research Meeting 2014
Forum for researchers in the area of Pediatric Neurology,
Bucharest, Romania
www.ilae.org

17 - 19 September, 2014

3rd Halifax International Epilepsy Conference & Retreat
(3rd HIECR)
Halifax, Nova Scotia, Canada
Contact Email: b.pohlmann-eden@dal.ca

17 - 20 September 2014

8th Latin American Congress on Epilepsy (8th LACE)
Buenos Aires, Argentina
www.epilepsybuenosaires2014.org
5 - 10 October, 2014
8th Migrating Course on Epilepsy
Dubrovnik, Croatia
Contact Email: Davor.Sporis@davor.sporis@kbd.hr

5 - 11 October 2014

23rd Annual International Epilepsy Symposia
Cleveland Convention Center
Global Center for Health Innovation
www.ccfme.org/epilepsy14

17 - 19 October 2014

Canadian League Against Epilepsy (CLAE) Biennial Meeting
London, Ontario, Canada

5 - 8 November 2014

25th International Symposium on the Autonomic Nervous System
Puerto Rico
Deadline for abstract submission is 2 June 2014.
Contact Email: zeller.anita@mayo.edu
www.americanautonomicsociety.org

2015 Congresses

12 - 16 January 2015

5th Course on Epilepsy Surgery (EPODES)
Brno, Czech Republic
Basic Course
Deadline for bursary applications: 1 November 2014
www.ta-service.cz/epodes2015

22 February - 3 March 2015

Latin American Summer School on Epilepsy (LASSE 2015)
www.lasse.med.br/

2 - 6 September 2015

XIII Workshop on Neurobiology of Epilepsy (WONOE)
2015
Istanbul/Turkey
www.ilae.org
For more information, email: decurtis@istituto-besta.it

4 - 5 September 2015

2nd International Epilepsy Symposium
Bielefeld-Bethel, Germany
Main topics: Epilepsy, cognition, autoimmunity and surgical therapy.
Organizers: Epilepsy Centers Bethel and Berlin-Brandenburg
Information: bbs2015@mara.de

6 - 10 September 2015

31st International Epilepsy Congress
Istanbul, Turkey
www.epilepsyistanbul2015.org

6 - 10 October 2015

6th Eilat International Educational Course on the Pharmacological Treatment of Epilepsy (6thEilat Edu)
www.eilatedu2015.com

31st International Epilepsy Congress
Istanbul, Turkey
6th - 10th September 2015
www.epilepsyistanbul2015.org