

From the President

The last 12 months saw many important developments within our community, including the approval of the *Resolution on the Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications* by the 68th World Health Assembly (WHA). The Resolution calls on Member States to improve epilepsy awareness, care and research. It came almost 20 years after the establishment of the Global Campaign and represents a true milestone in the social history of epilepsy. This event did not occur by chance, but is the result of real teamwork, involving close collaboration between ILAE, the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO). There were contributions from Dr Shichuo Li and the Chinese Association Against Epilepsy and from the Co-chairs of the Joint ILAE-IBE Global Outreach Task Force, Alla Guekht and Mary Secco. Above all, however, the Resolution was primarily the outcome of efforts by ILAE Chapters and IBE Associations in sensitizing their governments about the needs of people with epilepsy. Delegates from as many as 28 countries stood up and made strong motions in support of the WHA Resolution. Our members now have a powerful tool to engage governments and health authorities into stepping up concrete actions to improve epilepsy services, promote awareness and education, and support epilepsy research.

The League would not exist without the dedication of thousands of epilepsy professionals. The many volunteers who contribute to our Commissions and Task Forces have produced 16 published reports over the last two years. The Seizure Type Classification Task Force has finalized a



Emilio Perucca
President

comprehensive report on the operational classification of seizure types. This report will undergo the comprehensive approval process required for 'official' ILAE position documents. The report will be placed on the League's website for input from the entire community,

and an *ad-hoc* Task Force will be appointed to ensure that the comments are incorporated into the final version as appropriate. A sister ILAE position paper, the report by the Commission for Classification and Terminology, which refines the 2010 proposal on the classification of the epilepsies, already received extensive public feedback and we are aiming at finalizing the document before the end of the current term.

Epilepsia, our research journal, continues to lead all epilepsy journals with an impact factor of 4.571 due to the high-quality research from our members as well as to the efforts of our editors. In early 2015, Michael Sperling joined the team of the Editors-in-Chief, and I thank him for his contribution to the direction of the journal. I also wish to thank Alexis Arzimanoglou, the Editor-in Chief for *Epileptic Disorders*, for his work in reshaping the content and structure of the journal. Recognizing that existing journals do not allow us to fully address the diverse needs of our constituency, we will launch a new open-access journal, *Epilepsia Open*.

The 31st International Epilepsy Congress in Istanbul was attended by over 2,700 delegates. We continue to invest a major portion of our resources into epilepsy courses, training programs and initiatives aimed at supporting young colleagues. These activities are being coordinated by our Education Commission, led by Jaime Carrizosa, and by a newly created Education Task Force led by Sam Wiebe. The Task Force has been specifically asked to improve the reach of our educational efforts. Sam is initiating an agreement between the League and Wikipedia, whereby our organization will gradually take responsibility for supervising Wikipedia's epilepsy-related content. This effort will provide information to the general community, as well as to medical students and health professionals. Our North American Commission has started an effort to

mentor on a global scale the epilepsy leaders of tomorrow. Details on this initiative, that addresses a goal very dear to me, are provided in the report by Sheryl Haut

The League promotes epilepsy research. The Joint ILAE/AES Translational Research Task Force is working to improve the quality and translational value of preclinical research. Two reports published in 2015, one by the ILAE Commission on Asian and Oceanian Affairs, and one by the ILAE-IBE Epilepsy Advocacy Europe Task Force, highlighted regional research priorities. A new Task Force, led by Secretary General Helen Cross and by Philippe Ryvlin, is preparing a consensus document on research priorities from a global perspective, including priorities that could benefit from global networks of researchers. The aim is to sensitize governments and funding agencies about the need for international collaborative epilepsy research.

We value partnering with other organizations and scientific societies. We continue to work in close association with IBE in promoting epilepsy awareness and in advocating for support for epilepsy research through our many joint Commissions and Task Forces, our joint congresses, and our coordinated activities on such projects as International Epilepsy Day. We have an excellent relationship with the World Federation of Neurology (WFN). WFN President Raad Shakir and his team promoted the WHA Resolution and dedicated the 2015 World Brain Day to epilepsy. They also supported a very well-attended epilepsy program at the World Congress of Neurology in Santiago, Chile. The ILAE and WFN again joined forces in providing funding for an epilepsy grant to a multicenter project in four South Asian countries (Bangladesh, India, Pakistan and Sri Lanka) under the sponsorship of the Indian Academy of Neurology. We continue to work with the European Academy of Neurology on courses and congresses, and with the International Federation of Clinical Neurophysiology Societies (IFCN) on the program of the 31st International Congress on Clinical Neurophysiology in Washington DC, USA, in May 2018.

Two great leaders of our community left us in 2015. Jean Aicardi, a much loved physician and scientist who mentored so many leaders in child neurology and epileptology, passed away on August 3. Hanneke De Boer, the advocacy champion who fought for decades for the rights of people with epilepsy in all parts of the world, left us on October 12. These giants are still vividly alive in our memory and will continue to inspire our community for generations to come.

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Delegates from WHO, ILAE, and IBE at the 68th World Health Assembly which took place in Geneva, Switzerland, 18–26 May, 2015. From left to right, Athanasios Covanis (IBE President), Shekhar Saxena (Director, Department of Mental Health and Substance Abuse, WHO), Shichuo Li (Chair, ILAE-IBE Joint Task Force on Global Research Advocacy), Tarun Dua (Medical Officer, Department of Mental Health and Substance Abuse, WHO), Emilio Perucca (ILAE President), Brooke Short (Fellow, Epilepsy Program, WHO), Alla Guekht (Co-chair, ILAE-IBE Joint Global Outreach Task Force), Ann Little (IBE Executive Director), and Mary Secco (Co-chair, ILAE-IBE Joint Global Outreach Task Force).

From the Treasurer

Samuel Wiebe, Treasurer

The ILAE has not been immune to the financial setbacks of our times. Yet, in this climate of financial uncertainty, we took measures that secured the viability of the ILAE and the achievement of its mission. The most effective measures are based on sound financial policies, and we are fortunate to receive optimum advice from our Finance Advisory Committee, a group of top financial experts from around the world who generously donate their time and expertise to the ILAE. As a result, this was a positive year for the ILAE's finances and activities.



Samuel Wiebe

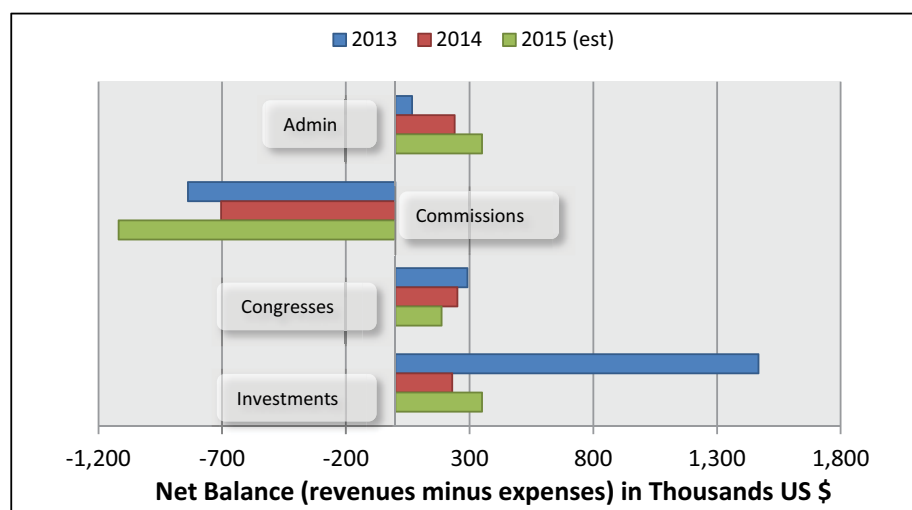
We ended year 2014 with a strong balance sheet that preserved our endowment and allowed us to draw on our investments to maintain and strategically increase our activities. However, over the past five years, reduced congress surpluses (See "Congresses" below) and a volatile stock market have impacted our end-of-year financial statements. Our two main sources of revenue are *Epilepsia* and our Congresses. Our two main expense categories are: a) the costs of running the organization and supporting central activities and b) support for activities of our Commissions and Task Forces. We estimated that our operational revenues would be higher than our operational expenses by about \$400,000. We allocated about \$1.1 million to our Commissions and Task Forces, and we estimated a surplus from Congresses of about \$190,000. Because this resulted in a significant deficit budget, we estimated having to draw about \$350,000 from our investments. This resulted in a final budget with a deficit of about \$230,000.

A major financial decision by previous leadership was to create an Endowment Fund, that is, a core capital investment that will allow us to use the returns to sustain the activities of the League in the future. The intent is to preserve the endowment and use earnings only to supplement the budget.

For the past few years the League anticipated the trend toward open-access publishing. This created opportunities for wider dissemination of our publications, but also a potential threat to our journal, *Epilepsia*, a major source of revenue for the League. Thanks to the relevance and high quality of articles in *Epilepsia*, this threat has not materialized. In fact, the impact factor for *Epilepsia* has increased substantially. This has favorably positioned the League for a new five-year contract with the publisher. This new contract will also include provisions for the League to develop its own open access journal, *Epilepsia Open*, an initiative that is well under way. In addition, the League continues to publish *Epileptic Disorders* as its main educational journal.

In 2015, I was given the charge to lead a new Epilepsy Education Task Force. Its mandate is to work with the Education Commission to assess and prioritize the educational activities of the ILAE. The Task Force has engaged in a comprehensive review of the needs and aims of our educational efforts, and is in the process of designing a core curriculum for epilepsy education with the assistance of educational experts. At the same time, we are focusing energies to develop educational courses that use available media efficiently, while maintaining highly-subscribed distance learning courses like VIREPA.

Financial challenges are our current reality. However, we have achieved stability and growth for the League in the past year. We are committed to continue supporting mission-critical areas through our Commissions and Task Forces, capitalizing on new educational and training opportunities, and increasing scientific value and affordability for our Congresses. To meet financial challenges we will continue to strive for efficiency and innovation. I would like to express my sincere appreciation to the outstanding teams that make all of this possible.



From the Secretary-General

J. Helen Cross, Secretary-General

It has been a relatively busy year for many in our epilepsy community. Two chapters, Myanmar and Belarus, were definitively accepted at the ILAE General Assembly during the 31st International Epilepsy Congress in Istanbul in September. Formal acceptance increased the number of League chapters to 114. Additional countries are going through the process, so we expect this to increase further over the next two years.



J. Helen Cross

With the recognition that a harmonization of rules for election was required to apply to all regions, a Task Force was set up chaired by myself, with membership including all regional commission chairs and Tatsuya Tanaka. A process that applies to all regions has been agreed upon, and the By-laws changed accordingly. 2016 will be the year that the ILAE will hold its elections starting with the election of our new president. The full timetable is as follows:

1. Presidential Election — March 2016
2. Management Committee — September 2016
3. Regional Commission Chair — February 2017
4. Regional Commission Members — March 2017

We now have Guidelines for the Management of International and Regional Epilepsy Congresses. These are guidelines for specific areas within the overall framework of the organization, and management of the International Epilepsy Congresses and regional congresses. These can be found at http://www.ilae.org/Visitors/About_ILAE/documents/GuidelinesMgtEpilepsyCongresses-03_2015.pdf.

As highlighted in the President's Report, many reports have been formulated and published by task forces and commissions on behalf of the League over the past twelve months. Having formulated new guidelines for paper approval as either ILAE position papers, or as papers written by constituents of the League as Commission or Task Force members (<http://www.ilae.org/visitors/Documents/Guideline-PublPolicy-2013Aug.pdf>) a total of 16 papers have been approved over this term. Particularly important topics addressed in the latest reports include the definition and classification of status epilepticus; indications and expectations for neuropsychological assessment in routine epilepsy care; recommendations on minimum requirements for ketogenic diet services in resource-limited regions; recommendations for the management of infantile seizures; guidance on the use of valproate within the context of the recent European Medicines Agency restrictions; recommendations on the participation of people with epilepsy in sport activities; an overview of the work being done for ICD coding for epilepsy; a systematic review of existing epilepsy guidelines; and recommendations for the preparation of ILAE guidelines in the future.

Two of the papers published have been position papers from the European Joint Advocacy Task Force and the

Asian Oceanic Commission on research priorities in their respective regions. NIH has also published benchmarks for epilepsy research (<http://www.ninds.nih.gov/research/epilepsyweb/2014benchmarks.htm>). Recognizing that priorities may differ depending on resources and regions of the world, and different regions may share research-priorities, we have sought your key priorities for research; specifically with relevance to the more global community. The priorities provided have been reviewed and assimilated by the Global Research Priorities and Advocacy Task Force and will be posted on the ILAE website for opinion with regard to ranking, with subsequent incorporation into a report.

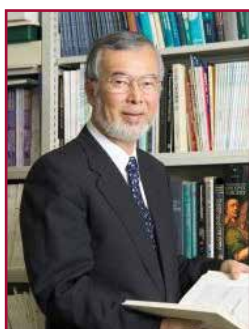
The ILAE is often approached about funding opportunities, both from outside funders who wish to share in projects and from individuals with ideas that would require funding. There have been concerns about possible conflicts of interest. Recognizing the need to capitalize on any opportunity, the Management Committee felt it would be a good way forward to draw up a list of projects that are in accordance with our overall strategy. We therefore sought ideas from the community with regard to possible projects that would be suitable for such an endeavor. Ideas have now been collected together, and a small group will review the next stage of the process. Funding is not guaranteed, but without such ideas we cannot be open when other organizations or individuals approach us.

As the second year of term comes to a close, we look forward to a continued effort on behalf of so many of our community in furthering the care and improving lives of those with epilepsy.

From the Vice President

Tatsuya Tanaka, Vice President

The International League Against Epilepsy has achieved worldwide success over the first century of its existence. This success is reflected by the steady growth of League activities in all of our regions (Europe, North America, Latin America, Eastern Mediterranean, Africa and Asia/Oceania) and the expanded collaboration among the regions with joint multinational educational and research activities. It has been more than two years since the beginning of the current Management Committee at the Montreal International Epilepsy Congress in 2013. One of the important constitutional changes which had been ratified at the Rome IEC in 2011, is the direct election of the Chairs of the regional commission by the member chapters of each



Tatsuya Tanaka

region. This change ended the practice of the Executive Committee appointing the Chairs and has assured that the voice of each region is more reflective of the wishes of the chapters. The elected Regional Chair will also now be a member of the Executive Committee, which will improve communications not only between the leadership of the League and the regions, but also across regions, for the benefit of the ILAE as an international organization. It's a very positive change that I have experienced first-hand because I served under the old and new Constitution and Bylaws. The elected Chairs of six regional commissions are Drs Amadou Gallo Diop (Africa), Byung-In Lee (Asia-Oceania), Hassan Hosny (Eastern Mediterranean), Meir Bialer (Europe), Marco Medina (Latin America), and Sheryl Haut (North America). According to the new constitution, regional chairs are now members of the ILAE Executive Committee. With members of new Executive Committee, it has been an extraordinary pleasure to work with Management Member colleagues Emilio Perucca (President), Nico Moshé (Past President), Helen Cross (Secretary-General) and Samuel Wiebe (Treasurer).

A great aspect of the ILAE is the collaborative work that we have performed with the IBE during past 12 months. There were four specific events that we should all take note of:

1. The recent WHO Resolution on Epilepsy came through the sustained efforts of Emilio Perucca and Thanos Covanis of the IBE. It has energized all of us because we may soon be successful in bringing real benefit to people with epilepsy around the world.
2. International Epilepsy Day was launched on the second Monday of February from 2016. The day was celebrated by the ILAE and IBE together with many people around the world.
3. For World Brain Day, 22 July, 2015, it was decided to focus on epilepsy, with the theme "Epilepsy is More than Seizures." This effort was a great collaboration among the World Federation for Neurology (WFN) the ILAE and the IBE, together with together with the WHO.

(Continued on page 4)

4. Epilepsy Awareness Day in Disneyland, November 5, 2015. This amazing day in Los Angeles was founded to unite the epilepsy community, bring epilepsy out of the shadows and stomp out the epilepsy stigma. This special day was successfully done with many participants with our community for a day of fun with new friends and colleagues in collaboration with the ILAE and the IBE.

As the EC Liaison Officer of the Neuropsychiatry Commission (Kousuke Kanemoto, Chair) and Epilepsy Neurosurgery Commission (Bertil Rydenhag, Chair), I am happy to work with these very active commissions. It is also a great pleasure to have helped plan for the Asian and Oceanian Congress in Hong Kong, our most successful regional congress in Asia yet.

I look forward to even greater successes in the next year.



Friendly gathering: EC members of ILAE and IBE during the Stockholm IEC 2015

2013 - 2017 ILAE Executive Committee Members



Emilio Perucca
President



Tatsuya Tanaka
Vice President



Helen Cross
Secretary-General



Sam Wiebe
Treasurer



Solomon Moshé
Past President



A Gallo Diop
Commission on
African Affairs



Byung-In Lee
Commission on Asian
and Oceanic Affairs



Hassan Hosny
Commission on
Mediterranean Affairs



Meir Bialer
Commission on
European Affairs



Marco Medina
Commission on Latin
American Affairs



Sheryl Haut
Commission on North
American Affairs



Gary Mathern
Epilepsia
Editor-in-Chief



Astrid Nehlig
Epilepsia
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Michael Sperling
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Athanasios Covanis
IBE President



Sari Tervonen
IBE Secretary-General



Robert Cole
IBE Treasurer

Invitees



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Epileptic Disorders
Editor-in-Chief



Edward Bertrum
Information
Officer



Jaime Carrionsa
Education
Commission



Jean Gotman
Director of
Interactive Media



Torbjörn Tomson
Strategic Plan
Committee



Dieter Schmidt
Epilepsia Open
Editor-in-Chief



Xuefeng Wang
Epilepsia Open
Co-Editor-in-Chief

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 Costa Rica
 Croatia
 Cuba
 Cyprus
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Denmark
 Dominican Republic
 Democratic Republic of Congo
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 El Salvador
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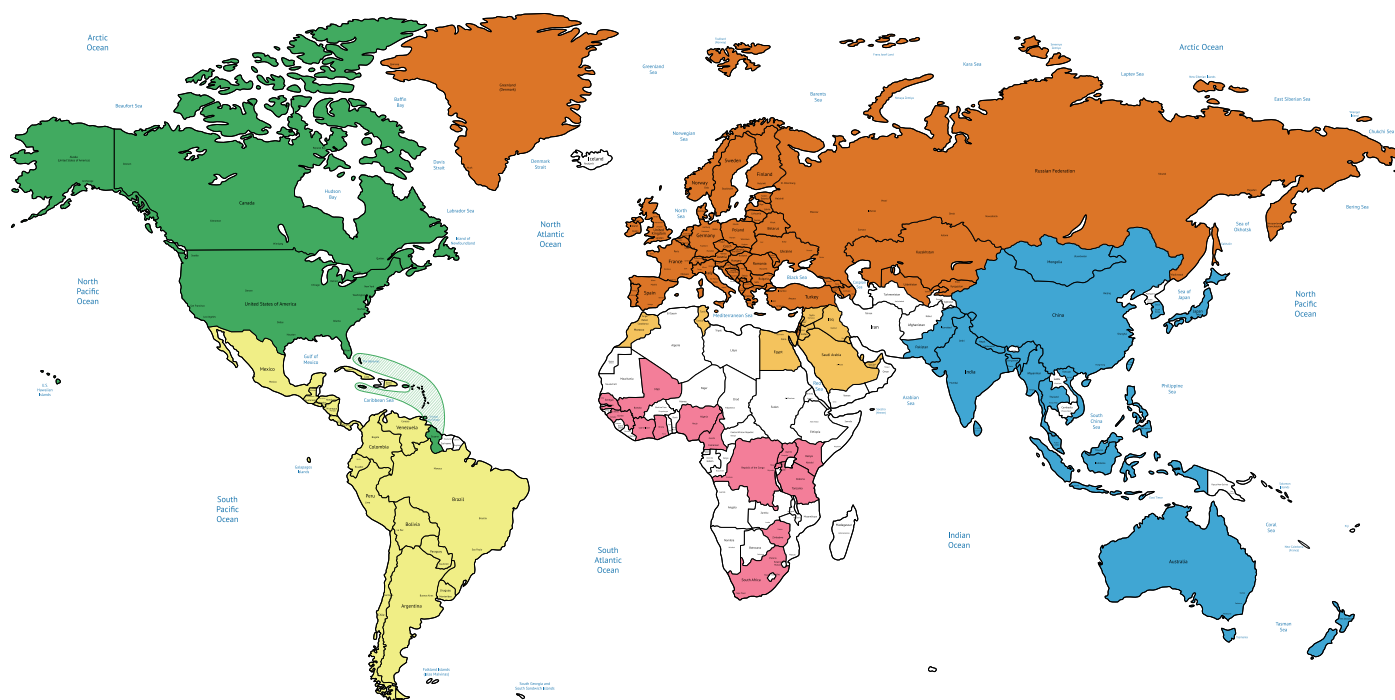
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Sri Lanka
 Sweden
 Switzerland
 Syria
 Taiwan
 Tanzania
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 The Netherlands
 Tunisia
 Turkey
 Uganda
 UK
 Ukraine
 Uruguay
 USA
 Uzbekistan
 Venezuela
 Vietnam
 Zimbabwe

*Antigua, Bahamas, Barbados, Guyana, Jamaica, Martinique, St. Kitts, St. Lucia, Trinidad and Tobago, US Virgin Islands

**New



How to Apply for Chapter Membership

The ILAE is a federation of 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*
- Heavily discounted subscription rates to *Epilepsia*, *Epileptic Disorders* and other epilepsy journals
- Eligibility for membership of ILAE Commission / Task Forces
- Access to the website features

Individual Chapters vary in the 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!

Commission on Diagnostic Methods

Ingmar Blümcke, Chair

The Commission on Diagnostic Methods covers all major diagnostic modalities to 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 a cost-effective diagnosis of epilepsy and their related co-morbidities, as well as use of consensus classification systems for underlying etiologies. We have set up five Task Forces to achieve this goal. They include: Neuroimaging (Andrea Bernasconi, Chair), Neuropathology (Ingmar Blümcke, Chair), Neurophysiology (Philippe Kahane, Chair), Neuropsychology (Sarah Wilson, Chair), and Summer Schools in Diagnostic Methods (Ingmar Blümcke, Chair). These groups place particular emphasis on bridging any validation gap when using technologies for the diagnosis of epilepsy. Another important goal of the commission is to develop teaching courses that address the WHAT? WHY? and HOW? of diagnostic methods, accessible throughout the world. Our work very much depends on interaction with other ILAE commissions for dissemination and training.

The Neuropathology Task Force is addressing tumor-related epilepsies. Neuropathology agreement has shown poor inter-rater agreement in the classification of brain tumors associated with long-term epilepsies (LEAT). LEATs mostly encompass glio-neuronal tumors, i.e. gangliogliomas and DNT (approx. 60-80%), and their frequencies vary largely between regional case series. We have built a collaborative virtual microscopy platform, which allowed us to review large series of LEAT variants



Ingmar Blümcke

by a panel of international neuropathologists and to encourage discussion between WHO and the Intl. Society of Neuropathology to achieve consensus terminology use and acceptance of a revised tumor classification system. To ensure rapid dissemination of the efforts, the Task Force organized a main session on brain tumors and epilepsy at the International Epilepsy Congress in Istanbul and at our International Neuropathology Summer School in Campinas, Brazil. Courses in 2016 will be organized in China (West China Hospital, Chengdu) and Erlangen, Germany.

The Task Force for Neuropsychology is addressing the neuropsychology measures from presurgical evaluations so that they are understandable when interpreting different test domains. Particular topics include measures for assessment of development, effects of antiepileptic drug treatment, effects of single spikes and spikewaves. We are developing consensus protocols for assessment of hemispheric dominance, measures sensitive to surgical treatment, and measures and markers for assessing every day. An official report defining minimum standards for neuropsychology assessment in epilepsy was published in 2015 (Wilson et al. *Epilepsia*, 2015) and a second report on neuropsychological measures in epilepsy surgery is envisaged for 2016. The Task Force organized its first training course on neuropsychology and epilepsy in France. Thirty-six participants took part in lectures, case presentations, and discussions designed to illustrate principles of differential diagnosis and case formulation in epilepsy.

A major goal of the Neurophysiology Task Force is to provide international consensus recommendations on intracranial EEG (IEEG) investigations. The first manuscript is entitled: "Diagnostic Utility of Invasive EEG for Epilepsy Surgery: Indications, modalities and techniques," and it will be published in the near future. Two additional projects will further address 1) recording and stimulation methodologies, and 2) data interpretation and results.

These two papers will accompany similar work from the Translational Task Force of ILAE's Neurobiology Commission aiming to provide methodological standards and functional correlates of electrophysiological *in vivo* depth recordings in rodents. The Task Force also aims at promoting training for surface and intracranial EEG. The European and North American SEEG courses have been active since 2010, and have trained almost 400 neurologists, neuropediatricians and neurosurgeons. A third Asian SEEG training course, as well as two additional summer schools dedicated to EEG in neonates and advanced scalp EEG analysis, are in development.

The Task Force for Neuroimaging is building new standardized parameters for the use of an MRI in epilepsy in order to update current guidelines according to new clinical challenges and research findings. The group has made recommendations broad enough for clinicians working with children and adults. Specific topics include the role of MRI in new-onset epilepsy, the minimum requirements for an epilepsy imaging protocol and optimized imaging for pre-surgical evaluation. There is also the need for specialized evaluation and post-acquisition processing for difficult to identify lesions. The Task Force is also working on a systematic description of common epileptogenic lesions to create a much-needed definition of "MRI-negative" epilepsy. The Task Force is also developing ILAE Summer Schools on Neuroimaging that will migrate across the continents to put the new recommendations into international practice. Our projects will be supported by a web-based collaborative MRI reading and teaching platform. A prototype is available and will be implemented in 2016.

The Commission is working to create standardized approaches to diagnostic test acquisition and interpretation, and then developing educational programs that will facilitate the implementation of these standards internationally.

Commission on Epidemiology

David Thurman, Chair

The Commission on Epidemiology (David J. Thurman, Chair) seeks to promote standard methods for epidemiological research in epilepsy and for describing the epidemiological evidence on the burden of epilepsy and potential preventive measures.

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. Accordingly, the Commission has four main goals.

First it will review available epidemiological evidence and assess its evidence. The Commission will summarize



David Thurman

this evidence to assist the League in the planning and management of its programs. The second task is to identify epidemiological research topics, to promote improvements in research methods, and to strengthen research capacity, including research to inform the League's epilepsy prevention and control programs. Third, the Commission will enhance research and prevention programs in regions where the burden of epilepsy and its adverse consequences are highest. Finally, the Commission will educate the epilepsy community, and health ministries and departments, about the burden of epilepsy in order to promote discussions about the prevention of epilepsy and its adverse consequences.

In the last year, the Commission has pursued its mission through the work of its three Task Forces: Epilepsy Prevention Task Force (Charles Newton, Kenya, and David Thurman, USA, Co-chairs); Burden of Mortality in Epilepsy Task Force (David Thurman and Charles Newton, Co-chairs), and the Comorbidity in Epilepsy Task Force, (Dale Hesdorffer, USA, Chair).

In the last year, the Prevention Task Force began to assess the need and opportunities for primary and early secondary epilepsy prevention, and to recommend steps toward prevention. The Task Force commenced a systematic review of databases for studies of epilepsy incidence that address causes and modifiable risk. The citations and abstracts retrieved for this search have been screened, of which 255 have been judged potentially relevant. The full articles are being reviewed for the quality of data. Publication of findings and recommendations based on these reviews is anticipated in 2017.

The Mortality Task Force is systematically reviewing the mortality risks and causes of death among people with epilepsy and recommending strategies to prevent premature death in epilepsy. Separate teams are addressing mortality in high-income countries (HIC) and in lower- and middle-income countries (LMIC). During 2014-15, the Task Force completed its systematic review of articles and drafted a manuscript report for HIC,

(Continued on page 7)

while nearing completion of the systematic review and manuscript preparation for LMIC. The Task Force anticipates submitting both manuscripts together to the ILAE Executive Committee in Spring 2016.

The Comorbidity Task Force also continued from the previous Commission term with the purpose of assessing the burden of psychiatric comorbidities among people with epilepsy. The Task Force has made substantial progress toward the completion of its systematic literature review in preparation for a manuscript report. The publication of this report will enable further work, described as follows.

The three Task Forces of the Commission on Epidemiology serve to promote the primary and secondary prevention of epilepsy and its adverse consequences. The work of both the Mortality and Prevention Task Forces will yield published assessments and recommendations that the Commission will promote in collaboration with other ILAE Commissions, WHO, and other governmental and non-governmental agencies to promote research and public health interventions for epilepsy. Similarly, the findings of the Comorbidity Task Force will be translated into prevention work in several ways: first, to increase

awareness through publication, educational symposia, and dissemination of materials to health ministries, and also by the development of assessment and training materials for clinicians to help them identify comorbidities, understand their impact, and improve their treatment.

Continued public health surveillance and research in the epidemiology of epilepsy will be important to monitor and assess the effectiveness of current and future prevention programs addressing epilepsy.

Commission on Classification & Terminology

Sameer Zuberi, Chair

The mission of the Commission on Classification and Terminology, chaired by Sameer Zuberi (United Kingdom) is to develop a scientifically-based approach to the classification of seizures and the epilepsies, and to improve diagnosis of epileptic seizures and syndromes. To that end, the Commission oversees the work of four Task Forces.



Sameer Zuberi

clinical seizure types and the ILAE glossary of terms, and it has written a paper entitled *“Operational Classification of Seizure Types by the International League Against Epilepsy.”* There are several reasons for this new classification. Some clinical seizure types can have either a focal or generalized onset, and a failure to determine which would have made a seizure unclassifiable with the 1981 system. There is also a need to move away from preservation or alteration of awareness as the only descriptor of a focal seizure, although it remains an important descriptor. Some important seizure types were not included in previous classifications. The proposed classification will be put on the ILAE website for comment before eventual publication of a revised version.

The first is the Task Force on Classification, which is chaired by Ingrid Scheffer (Australia). This group is developing a classification framework for the epilepsies, taking into account the epilepsy community’s feedback on classification proposals over the previous four years. A paper, *“Classification of the Epilepsies: New concepts for discussion and debate. Special Report of the ILAE Classification Task Force of the Commission for Classification and Terminology,”* was circulated and discussed in Istanbul, and at the AES in 2015. The developing classification emphasizes considering etiology at all stages of classification. It proposes encompassing seizure type, epilepsies classified by seizure types, epilepsy syndromes and etiology. The term “Classification” has been re-instituted, replacing “Organization.” The Task Force included etiology to reflect increasing scientific knowledge and the wider aim within medicine to encourage the practice of personalized or precision medicine. There are many areas within the document which will produce debate within the epilepsy community. The paper will be published in 2016 to solicit immediate comment.

The Task Force on Seizure Types is led by Robert Fisher (USA) and is working on updating the classification of

The third Task Force is on EpilepsyDiagnosis.org & Syndromes and is chaired by Kate Riney (Australia). EpilepsyDiagnosis.Org is a major educational initiative of the ILAE to make available, in an easy to understand form, the latest concepts relating to seizures and the epilepsies. The principal goal is to assist clinicians to diagnose seizure type(s), classify epilepsy, diagnose epilepsy syndromes and define the etiology of the epilepsy. The site is principally designed for clinicians in primary and secondary care settings, and for others caring for people with epilepsy. It is also a useful teaching aid. The site works on a smartphone, a computer or a tablet, and contains useful videos of seizures. Usage has increased to more than 27,000 page views per month. Feedback from users has been uniformly positive. A major new section on epilepsies with a structural etiology went live in the second quarter of 2016. The text can be shared with Wikipedia’s epilepsy pages to help ensure Wikipedia’s content is current and further promote epilepsy education. The Task Force is working with Translators Without Borders on translations of the content of EpilepsyDiagnosis.Org into other languages. The website will be showcased at the 12th ECE in Prague in September 2016.

The Neonatal Seizures Task Force is under the lead of Ronit Pressler (UK) and has developed a Framework for Classification of Neonatal Seizures. It takes into consideration factors specifically relevant to this age group. The group has undertaken collaborative video – EEG review exercises to facilitate the development of relevant terminology. This effort has guided a seizure type classification which reflects the Task Force on Seizure Types work but does not separate seizures into generalized and focal.

Although the Commission is pleased with the progress that has been made, there is more to do. We will continue the work on the Classification of the Epilepsies and Seizure Type Classification through ongoing engagement with the epilepsy community. We will further develop EpilepsyDiagnosis.org to increase its use by any professional treating epilepsy, as well as to make it a core component of epilepsy education. We will revise the ILAE Glossary of Terms to align it with the evolving scientific understanding of epilepsy. Finally, in the near future, we will develop a glossary of terms to describe and classify clinical and electrographic seizures in the neonate.

INTERNATIONAL
LEAGUE
AGAINST
EPILEPSY



Established 1909

EpilepsyDiagnosis.org
Diagnostic Manual

Commission on Education

Jaime Carrizosa, Chair

The Commission on Education is chaired by Jaime Carrizosa (Colombia). Education has been a cornerstone of League activity from the beginning, with Congresses continuing as the main educational venue. During the 31st International Epilepsy Congress in Istanbul, educational courses had a privileged place in the program. They were organized in five series that covered very current, as well as controversial, topics. The courses were guided by recognized experts on the topics. During the five days, 66 teaching sessions with 39 speakers were held, and they provided a total of 33 educational hours. Several types of courses were especially interesting to the meeting attendees, including the case-oriented series and the sessions that were open to discussion, such as those about the classification system, about diagnosis and about therapeutic approaches. The success of these programs



Jaime Carrizosa

came through the tireless efforts in the planning of these exceptional educational courses under the leadership of Walter van Emde Boas and Sandor Beniczky.

A pilot educational project in epilepsy started in October, 2015 in Latin America. The goal is to reach general practitioners working in primary health care in rural and urban places. The National University and the Neurologic Institute of Uruguay gave their logistical experience and support to a program that reached nearly 50 physicians from several countries of Latin America. During eight weeks, the course themes included epidemiology, semiology, diagnosis, pharmacology, referral systems, and social and legal aspects of epilepsy (such as international drafts or local laws about epilepsy). The courses included discussions under the guidance of recognized professors of several universities of Latin and North America. The evaluation of the course is in process at the moment of this writing, but we hope that these comments about the value of the outreach, as well as the quality of the material and instruction, will lead to further development of the project so that it can be repeated during 2016. If successful, we hope that this effort can serve as an example for implementation in other parts of the world with a wide possibility to reach distant areas.

A survey regarding epilepsy-training opportunities was developed and sent out to ILAE Chapters in October and November, 2015. The survey covers issues regarding opportunities for physician training programs in epilepsy and neurophysiology, a number of University Hospitals with an identified epilepsy department or with epilepsy units, training hours, as well as the contents of epilepsy instruction for under and postgraduate medical trainees. In addition, there were questions about continuous medical education opportunities in epilepsy, including the availability of resource training materials. There were also requests for information about the accessibility of research opportunities in basic, clinical social sciences. Finally, we wished to know the nature and extent of ILAE Chapter contact with universities and hospitals. The analysis and final report is planned for September, 2016.

The Commission continues to look for new ways to improve and expand educational opportunities for epilepsy to the members of our community, as well as for professionals who treat epilepsy. The Commission is always looking for new ideas.

ILAE Commission on Genetics

Daniel Lowenstein, Chair

The ILAE Commission on Genetics (Daniel Lowenstein, Chair) was created with several goals. Its first goal is to organize the search for human epilepsy genes on a worldwide scale, including the complex epilepsies that require for multicenter collaboration. Secondly, it will make the results of genetic research on the epilepsies readily accessible to clinicians, and improve the public understanding of genetic factors in epilepsy. Finally, the Commission will work with other ILAE commissions to increase understanding of how these genes cause epilepsy.

In the last several years, the Commission has worked on several initiatives. The first is to facilitate access to information about the identification and interpretation of gene mutations associated with epilepsy. The Epilepsy Genetic Association Database (EpiGAD) is growing and is being used regularly. However, to simplify an investigator's search, it will be merged with Epilepsio, which is a more comprehensive database on epilepsy and genes that will allow professionals, patient organizations and families to gather relevant information on epilepsy-related genes. Epilepsio will integrate with other available online resources (ClinGen, GeneReviews), but will have "trusted expert opinion" and regular updates as distinguishing features. Forty scientific volunteers are fully engaged in the gene curation efforts of this project. The Epilepsio project is currently in a beta phase and the commission is coordinating efforts with other initiatives to provide a new visually oriented web.



Daniel Lowenstein

The Commission also posts new messages weekly on the ILAE Genetics Commission Blog on topics related to genes and seizures. These posts are well received by the professional community, as the blog receives 5,000-7,500 views per month and has had more than 60,000 visitors since it started. In addition to the blog, we issue "The Channelopathist," a weekly email newsletter for the epilepsy community. For the Genetics Commission, the blog has been proven extremely valuable as an outreach tool for the community.

The second initiative is to assist in the creation of a centralized database of complete sequence data with variants that are paired with clinical information for as many patients as possible throughout the world. Formally known as the "Epilepsy Genetics Initiative (EGI)," it has been launched through a collaboration of the NIH-sponsored "Epi4K Center Without Walls" and the Chicago-based "Citizens United for Research in Epilepsy." The website <http://www.cureepilepsy.org/egi/index.asp> allows people to track this project and to help patients learn about the benefits of participation.

The third initiative continues the work of the ILAE Consortium on Complex Epilepsies. *Lancet Neurology* (Sept 2014; <http://www.ncbi.nlm.nih.gov/pubmed/?term=lan-cet+neurology++++consortium+on+complex+epilepsies>) published the consortium's first meta-analysis of GWAS data from nearly 9,000 subjects, which demonstrated risk alleles for the combined epilepsy cohort and for genetic generalized epilepsy. The Consortium is now undertaking sub-analyses of more specific phenotypes and of the relationship of loci influencing brain structure to those raising risk for epilepsies. Further collaborations are planned on epilepsy comorbidities by combined analyses investigating migraine and neuropsychiatric disorders.

Finally, the commission is working to increase genetics literacy among patients and clinicians. There are two primary efforts: the creation of educational brochures and the development of a Genetics Literacy Series for clinicians. The educational brochures include "Epilepsy and Genetics: Things You Want to Know," and were designed by Alica Goldman and other Commission members for patients and family members. It is available through the ILAE Genetics Commission website. Culturally sensitive Spanish and Arabic translations (<http://www.ilae.org/Commission/genetics/>) are on the ILAE website. A Japanese translation is under the review of the Japanese Epilepsy Society and the approval is planned for early 2016. Similar brochures in Chinese and other languages are a high priority by the ILAE. The Genetic Literacy Series targets clinicians who are often uncertain about or uncomfortable with genetic testing in epilepsy. The Genetics Commission, under the leadership of Nigel Tan, has a new series on Genetic Literacy in *Epilepsia*. These 12 papers aim to update and educate practicing clinicians about clinically relevant epilepsy genetics. The first paper was published in November 2015, and we anticipate this series will run to mid-2017.

Looking forward, there needs to be further effort in helping clinicians stay up-to-date on the latest findings in epilepsy genetics, given that we are now beginning to see the emergence of individualized therapies based on the patient's genomic profile. We will encourage patients and family members to understand the role that genetic testing may play in epilepsy evaluation and the value of involvement in the Epilepsy Genetics Initiative. Finally, we intend to explore the potential value of a global registry of patients with defined epilepsy gene mutations, with the goal of expediting observational studies and treatment trials.

Neurobiology Commission

Marco de Curtis, Chair

The Neurobiology Commission (NBC) focuses on the development of research strategies that address clinically relevant issues in the field of epilepsy. The Commission organizes and promotes international and regional educational and public outreach initiatives to enhance the interaction between neuroscience and the clinic.



Marco de Curtis

The Commission strategic plan has five main initiatives implemented by *ad-hoc* Task Forces. The Commission reports and new documents generated by Commission activities are updated on the ILAE web-site every three months by Katja Kobow. A website section dedicated to advertise jobs, and postdoctoral positions will be soon implemented and highlighted on the NBC web page.

To strengthen the interaction between the clinical and laboratory world, the NBC regularly organizes symposia for the League's congresses. In Istanbul, the symposium "The Best of Two Worlds: Translational Epileptology" was well-attended. Other sessions looked into the future, such as the "Neurobiology Symposium on Optogenetic to Cure Epilepsy: Facts and Feasibility" and the summary session from the "Workshop on the Neurobiology of Epilepsy," which emphasized the highlights of the meeting held just before the Congress. In Istanbul, the inaugural Young Neuroscientist Award, supported by a generous donation from the Harinarayan family, was awarded to Cristina Ruedell of Dublin and Ping Zheng of Melbourne for the best neuroscience contribution to the Congress. For future ILAE meetings, the applications for this Award will be advertised on the Congress registration form. At the 12th European Congress on Epilepsy in Prague, the NBC is sponsoring the Neurobiology Symposium on *Learning about focal ictogenesis from patients (and animal models)*. The Commission also keeps epilepsy visible to the neuroscience community by offering the translational course on San Servolo and supports the Gordon Conference on Epilepsy. The Commission wants to enhance the participation of basic scientists at the Congresses because the more that they are part of the epilepsy community, there will be faster progress in developing new treatments for the disease. Participation rates have ranged from 1 to 7.5%, and ideally it should be at 10% or greater.

The Commission was active in opposing the initiative from the European Citizen's Initiative, "Stop Vivisection." A letter by Aristeia Galanopoulou on behalf of the ILAE-AES Translational TF and the NBC was sent to the President, Martin Schulz, and to all members of the European Parliament. Multiple academic institutions were mobilized against this initiative. The ILAE letter, co-signed by ILAE and IBE Presidents, supported the existing directive to provide for the ethical and justified use of animals for biomedical research, that has significantly benefited human and veterinarian care. The EU Parliament supported the research community's opposition to the proposal. However, a debate and conference by the end of 2016 to

emphasize the importance to address and discuss animal experiments in scientific meetings and on publications was mandated by the Parliament.

The Commission wants to encourage the development of translational programs in all of the League's regions. As a first step, the NBC Chair met with the European Commission CEA, following the initiative of CEA member Annamaria Vezzani, to evaluate potential interactions between the two Commissions on the issues of supporting translational neurobiology topics at regional meetings and to assist young scientists to participate at WONOE, and on encouraging the participation of neurobiologists at the Congresses. In light of the positive response, the NBC will start to work with all regions to develop regionally appropriate neurobiology programs.

One of the major goals of the Commission is to create conditions that enhance the discovery process for new therapies. One of the important steps will be to develop research consortia that can generate reproducible data that are predictive of clinical efficacy. The Translational Task Force and the Multicenter Preclinical Animal Research Team are working to facilitate opportunities for preclinical multicenter studies in epilepsy. To improve the meta-analysis of existing data, the Task Force is working with a group led by Dr. David Howell with broad experience in the field, to develop a teaching platform to instruct the group on the theory and practice of systematic reviews and meta-analyses.

To make the interpretation of results across laboratories and models easier, the Task Force is working with the NINDS for the effort to generate preclinical common data elements (CDEs). In addition, the group started discussions with the European veterinarian consortium to create consistent classification systems for seizures in both rodents and companion animals. The Translational TF has been in contact with the NC3R group and has provided feedback on the recent NC3R report on "Outlining opportunities for improving animal welfare in rodent models of epilepsy and seizures" (Lidster

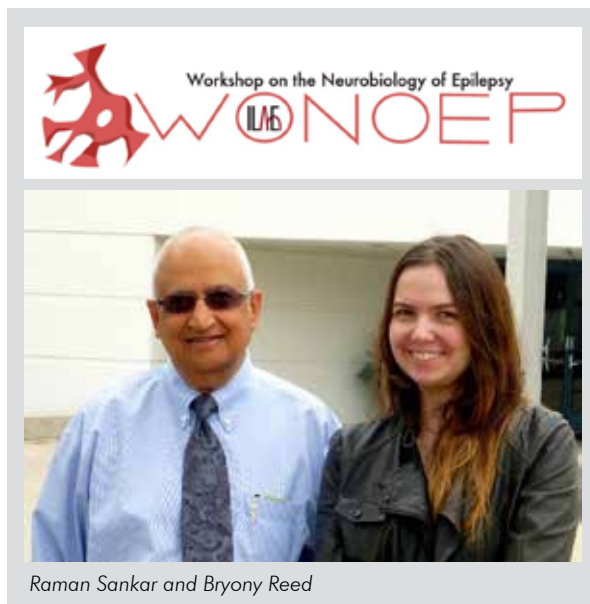
K et al, J Neurosci Methods, 2015).

The first set of reports from the Translational TF are currently in preparation and are planned for submission for an Epilepsia Supplement (2016). These will discuss methodological, technical, and interpretation standards of video-EEG recordings in adult and immature rodents used as experimental controls, using surface or depth electrodes; methodological standards for in vitro electrophysiological studies; and standards involved in the signal analysis of electrophysiological recordings using computerized methods and specific software. This will be a first step before addressing the classification of seizures in rodents and interpretation of controversial or abnormal patterns.

WONOE Task Force activities update

A new WONOE logo was created by Bryony Reed (shown with Dr. Raman Sankar) and was utilized for the first time at XIII WONOE.

Commission activities, updated by Katja Kobow, can be viewed at the ILAE NBC website, <http://www.ilae.org/Commission/neurobio/index.cfm>



Raman Sankar and Bryony Reed



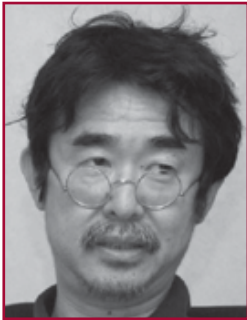
Group photograph at the 2015 WONOE XIII

Commission on Neuropsychiatry

Kousuke Kanemoto, Chair

The main aim of the Neuropsychiatric Commission is to develop, stimulate and coordinate research and medical education in the field of the neuropsychiatry of epilepsy. To meet its goal, the Commission is working to ensure that health professionals, as well as patients and their care providers, have the educational and research resources essential for understanding, diagnosing and treating various psychiatric manifestations in patients with epilepsy. The Commission also is working to reduce prejudice, as epilepsy patients with psychiatric co-morbidities are easily exposed to a double prejudice that can affect medical personnel involved in their treatment.

One of the important research and clinical needs is to standardize evaluation and diagnostic tools across countries and cultures. To move this important area forward, the Depression Task Force (chaired by Park Sung Pa) has led an effort to create translations of the Neurological Disorder Depression Inventory for Epilepsy (NDDIE) and the Generalized Anxiety Disorder scale. So far, validations of the French (McGonigal) and Chinese (An) translations have been completed. Translations and validations are in



Kousuke Kanemoto

different stages for Danish, Thai and Polish. In addition, Sung Pa Park has completed a study investigating the relationship between perceived stress and depression in PWE that showed that depression exerted direct effect on perceived stress regardless of seizure control.

The Psychosis Task Force (chaired by Bertrand DeToffol) has been examining the awareness gap about psychosis in patients and medical personnel. A preliminary investigation has been published (Kanemoto K, et al., Delusional experience awareness gap between patients and treating doctors - Self-reported EPDS questionnaire. *Epilepsy Behav.* 2015). In addition, the Task Force is working on validation for EPDS as a simple screening tool for psychosis in patients with epilepsy, as well as on recommendations for pharmacological treatment of psychosis in patients with epilepsy. Finally, the Task Force is recommending the creation of an ILAE supported definition of psychoses in patients with epilepsy. A survey to evaluate the knowledge of psychiatrists about psychosis in epilepsy may be useful.

The Education Task Force (chaired by Marco Mula) is working to highlight psychiatric comorbidities. Task Force members have been active in promoting knowledge about psychiatric comorbidities in regional and local meetings, and educational events. The 9th Latin America Summer School on Epilepsy in São Paulo was dedicated to comorbidities in epilepsy, with several sessions dedicated to psychiatric comorbidities in children and adults with epilepsy. Alla Guekht organized two workshops in Russia and in Kazakhstan, with special attention to somatic and

psychiatric comorbidities of epilepsy. The Task Force has also worked on two online courses. The first focused on psychiatric aspects in adults with epilepsy (Co-Chaired with Andy Kanner). The second covered psychiatric challenges in children (Co-Chaired with David Dunn). Finally the Task Force is surveying neurologists and psychiatrists about psychiatric comorbidities of epilepsy, with the goal to present the initial results later this year.

The Task Force on Psychogenic Non-Epileptic Seizure is performing a survey about the treatment of PNES around the world. The ultimate goal of this project is to allow more patients to gain access to appropriately trained and equipped diagnostic and treatment services. An international ILAE PNES Task Force formulated plans for two surveys. The first is a detailed survey of health practitioners in a number of countries, and the second is a brief survey of all ILAE chapters. The chapter survey has been completed by 53 chapters so far. These surveys will allow the Task Force to define different levels of PNES treatment compare the range of diagnostic and therapeutic options for people with PNES.

The Commission is also working on the issues of preoperative psychiatric evaluations and the neuropsychiatric issues faced by children. These are major issues that have not been extensively addressed and may have major implications for long term quality of life of people with epilepsy. These efforts are in the organizing phase but will become a significant area of activity in the future.

Commission on Pediatrics

Jo Wilmsburst, Chair

The Pediatric Commission aims to develop tools to guide care for children with epilepsy. These tools should be relevant across all settings, from resource-equipped to resource-limited settings.

These tools should consist of collected treatment guidelines that are viable in the many settings of the world, methods of circulating the recommendations widely, and identifying the appropriate epilepsy teams that can educate and activate all levels of healthcare workers, from rural settings to major medical centers. Finally, there should be support of lobbying governments for the implementation of essential aspects of the guidelines.

Under the leadership of Chair Hans Hartmann (Germany), the Subcommittee on Neonatal and Infantile Seizures is urging the adoption of existing neonatal and infantile seizures to ensure that they are viable for use at local levels. The Pediatric Epilepsy Training programs (PET) (established by the British Pediatric Neurology Association (BPNA)) may be adopted for broader use. The courses are directed to all medical professionals working at first and secondary levels of care and who have reached an international level. Commission members will take



Jo Wilmsburst

part in train-the-trainer courses in order to build up an international faculty before launching the courses. In order to make the 2011 WHO/ILAE/IBE guidelines on Neonatal Seizures more widely known, the Task Force has started updating the guidelines in collaboration with the neonatal task force of the Commission on Classification and Terminology.

The Task Force for Co-morbidities in Pediatric Epilepsy, Chair Stephane Auvin (France): The aim for this Task Force is to develop a "user friendly text" that documents the known data, identifies what is not known and highlights red flags where interventions are needed. After extensive debate surrounding this large and challenging area, the working group agreed that the Task Force should focus on key common and high-impact conditions, and to use this protocol as a template to potentially address parallel scenarios. The neuropsychiatry group has been active compiling a report focusing on the behavior problems in people with epilepsy and intellectual disability, and members of the Pediatrics Commission are part of this project.

The rights of the child to access consistent and reliable AEDs has been aided by the resolution on the Global Burden of Epilepsy that was approved by the World Health Assembly in May, 2015. The resolution addressed the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications. Some of the key points include the introduction and implementation of national health care plans, the integration of epilepsy management into primary health care, and improving accessibility to

and promoting affordability of safe, effective and quality-assured antiepileptic medicines. The Advocacy Task Force has formed a working group with additional members from the IBE and the Advocacy TF to address how the above resolution relates to children with epilepsy and what must be in place to ensure it is effective.

The pediatric neuropsychology Sub-commission, led by Dr Madison M Berl, completed their survey of pediatric neuropsychology presurgical evaluation practices. This survey was conducted in conjunction with a subcommittee of the Neuropsychology Sub-commission of the Commission on Diagnostics. The survey examined the use of tests employed in presurgical assessments and found comparable domains are routinely assessed across sites, and that several measures are commonly used. Smaller centers in resource-challenged countries have expressed a view that such data would be very helpful for petitioning for resources and training. Initial responses from show bias towards North America: efforts are being made to expand geographic participation in the survey. To understand changes in epilepsy surgery practice, in patient selection, diagnostic testing and surgical techniques that have occurred over the past ten years, the Task Force plans a survey of sites from the 2004 and 2008 surveys (all based on surgical cases in 2004) for 2014. In all, the Task Force is establishing the range of training and practices to help establish consensus to improve assessments, treatments, and outcomes of pediatric epilepsy surgery and to evaluate advances in practices in epilepsy surgery care and outcomes.

Commission on Medical Therapies

Patrick Kwan, Chair

The Commission on Medical Therapies (Patrick Kwan, Australia, Chair) is involved with seven different aspects related to the treatment of patients with epilepsy. Its mission has always been to improve the care of patients with epilepsy by facilitating collaboration among clinicians, scientists and other professionals. The Commission has a broad mandate to review current treatments, and to advocate for improvements related to drug therapies and other non-surgical interventions. Its seven areas of activity include AED trials and regulatory affairs (Jackie French, Chair), dietary therapy (Eric Kossoff, Chair), the use of natural products and botanicals (Steve Schachter, Chair), efficacy outcomes (Mark Cook, Chair), emergency treatments (Eugen Trinka, Chair), Emergency treatments (Eugen Trinka, Chair) and psychobehavioral therapy (Rosa Michaelis and Markus Reuber, Co-chairs).



Patrick Kwan

The AED Trials and Regulatory Affairs Task Force worked on three targeted areas. The first was to harmonize the extrapolation of efficacy in adult add-on trials in focal seizures to the pediatric age group. The EMA had already accepted that drugs that are approved in adults for add-on therapy of focal epilepsy should also be approved in children down to the age of two. The PEACE initiative (Pediatric Extrapolation Academic Consortium in Epilepsy), a group led by Jack Pellock, submitted a white paper that suggested a similar extrapolation for FDA approvals. This effort was also a part of the FDA critical path. As a result

of these efforts, the FDA has accepted extrapolation down to the age of four. This is a momentous decision, based on a substantial PK/PD modeling effort. As a result, new drugs will reach pediatric patients faster and fewer children will need to be exposed to placebo in clinical trials. The second area of activity was to facilitate monotherapy approvals. The Task Force submitted a white paper to the FDA suggesting that drugs should be approved for indications (e.g., focal epilepsy, Lennox-Gastaut syndrome) for both monotherapy and polytherapy use, irrespective of the way the trials were performed (i.e. as monotherapy or polytherapy). A paper was subsequently published in *Lancet Neurology* supporting the arguments in the white paper (Mintzer, French et al. Is a separate monotherapy indication warranted for antiepileptic drugs? 2015 *Lancet Neurology*, 14: 1229–40). The FDA is considering the arguments. The final topic concerned using time to event as a new approach to clinical AED trials. Drs. French and Bagiella have accumulated evidence suggesting that regulatory studies can be performed using time to event rather than parallel arm designs. This would shorten placebo exposure times. The FDA and EMA are considering the approach.

The Botanicals Task Force has finalized the content of “Epilepsy Naturapedia,” a wiki, to be hosted on the ILAE website, which will be the most comprehensive, current and customizable central research hub for bench- to bedside scientific information on the use of natural products for the treatment of epilepsy. Among its many features, Epilepsy Naturapedia enables users to search for information using common names, scientific names and names of compounds. Visitors may also search for names of historical neurologists, historical use, pharmaceutical information and any published evidence for use in the treatment of epilepsy.

The Dietary Therapy Task Force published a monograph in *Epilepsia* (Kossoff et al, What are the minimum requirements for ketogenic diet services in resource-limited regions? Recommendations from the International League Against Epilepsy Task Force for Dietary Therapy 2015, 56:1337–42). The Task Force also maintains a webpage: <http://www.ilae.org/Commission/medther/keto-index.cfm>. The Psychobehavioral Therapy Task Force is working to update Cochrane reviews of psychological treatments for people with epilepsy, with a focus on health-related quality of life. The literature search and risk of bias evaluation of identified studies has been concluded. This Task Force is also creating treatment recommendations on psychological management for adults and children with epilepsy based on Cochrane reviews, systematic review and the clinical experience. Key intervention strategies and components will be presented as they seem suitable to address various treatment targets that arise in epilepsy. A detailed description of the intervention elements will be published in a glossary as supplementary material online. A brief overview of treatment modalities including options for resource-poor settings, service evaluation measures, and implications for training and facilities offering psychological services for people with epilepsy is provided. To increase comparability and reproducibility of future studies, the inclusion of outlined key intervention elements should be clearly referenced and the standard use of the QOLIE-31 as primary or secondary outcome parameter is recommended.

Epilepsy Guidelines Task Force

Nathalie Jetté, Chair, and Khara Sauro

The Epilepsy Guidelines Task Force (Dr. Nathalie Jetté, Chair) was established to perform a systematic review of existing published epilepsy related guidelines to identify gaps in these guidelines, and to make recommendations regarding the guidelines in need updating. To assist in the development of new guidelines, a working group was created to evaluate the process of clinical guideline development. This working group was charged with examining guideline development processes that currently exist (e.g. the American Academy of Neurology and the National Institute of Health and Care Excellence (UK)). As part of their efforts, this group examined what



Nathalie Jetté

grading systems are available to evaluate the evidence. In addition, they were asked to develop a framework for epilepsy-related clinical guideline development that can be used by the League.

In the last year, the Task Force completed its systematic review that included seven databases and six grey literature sources (which includes the reports and publications from governmental and non-governmental organization) to identify epilepsy- and seizure-related clinical guidelines in all languages. The Task Force reviewed 10,926 abstracts, as well as 410 full text articles (13 languages) in duplicate for eligibility. Sixty-three guidelines were identified for inclusion in the systematic review. The systematic review was published in *Epilepsia* (Volume 57, pages 13–23, 2016). The group met at the International Epilepsy Congress in Istanbul in September, 2015 to plan the next steps for the Task Force.

The Process Working Group reviewed the clinical practice guidelines development frameworks from key organizations (e.g. American Academy of Neurology, Institute of Medicine and the World Health Organization, among others). The

group has reached consensus on which aspects from each guideline development framework should be incorporated into the future ILAE guidelines development toolkit. Tools to evaluate the quality of the evidence were also reviewed and the group agreed to adopt the GRADE. A number of educational resources were developed to guide ILAE chapter members on the process involved in developing high-quality guidelines. The resulting document and associated toolkit are published in *Epilepsia*.

The original tasks of this Task Force have been completed. Future efforts for the Epilepsy Guidelines Task Force will include the identification of the gaps in guidelines and highlighting key areas for future guideline development. It will also systematically review on an annual basis published epilepsy guidelines and evaluate the quality of these guidelines. It will continue to review protocols for future guideline development, and develop a certification and training module for use with the toolkit that will be developed, to facilitate the creation of high-quality epilepsy guidelines.

Distance Education Program 2016–2017

- 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 are received from May to August each year. Courses start in October/November.

<p>EEG in the Diagnosis & Management of Epilepsy Basic Course (2016) (14th edition) Basic Course (2017) (15th 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. Course Directors: Walter van Emde Boas, Sándor Beniczky Duration: 7 learning units of 3 weeks each and 10 days for final task Course fee: \$1080 for self payment; \$270 for approved bursaries</p>
<p>EEG in the Diagnosis & Management of Epilepsy Advanced Course (2016) (3rd edition)</p>	<p>The Advanced course will focus on more specific aspects of EEG in epilepsy, including long-term monitoring, seizure documentation and computer-assisted signal analysis. Course Directors: Sándor Beniczky, Michalis Koutroumanidis Duration: 8 learning units and 10 days for final task. Course fee: \$1080 for self payment; \$270 for approved bursaries</p>
<p>EEG in the Diagnosis & Management of Epilepsy in Neonates & Children (6th 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: 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>

Important for bursary applicants:

Bursary applicants must submit a letter of recommendation from their 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 their 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.

An Introduction to ILAE

The ILAE is constituted as an international nonprofit organization and is registered in the United States. The ILAE is the premier 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 114 countries with over 10,000 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 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, Atstrid Nehlig and Michael Sperling), *Epileptic Disorders* (Alexis Arzimanoglou) and *Epilepsia Open* (Dieter Schmidt, Xuefeng Wang and Gary Mathern) 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 have 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 to the Constitution. The Constitution was updated in 2011. The Bylaws were updated in 2015.

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, as well as membership eligibility vary from Chapter to Chapter, within stipulations defined in the ILAE Constitution. 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 the League's 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 – G Diop), European Commission (Chair – M Bialer), Asian and Oceanian Commission (Chair – B-I Lee), North American Commission (Chair – S Haut), Latin American Commission (Chair – M Medina), Eastern Mediterranean Commission (Chair – H Hosny).

Commissions and Task Forces

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 Blümcke), 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 Classification Roadmap, Communications, Elections Commission, Epilepsy Education, Finance Committee/Financial Advisory Sub Committee/Budget Review Committee, Global Outreach, Guidelines, Past President Advisory Commission, Publications, Global Research Priorities and Advocacy, Stigma, Seizures and Epilepsy in the Tropics, Sports and Epilepsy, and Strategic Planning Committee.

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 also 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; Deborah Flower, Web Content Administrator; Gus Egan, Chapter Services Coordinator; and Verena Hészser-v.Wehrs, MA, VIREPA Coordinator.

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 national scientific conferences as well. 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 national 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 WileyBlackwell and edited by Editors-in-Chief (G Mathern, A Nehlig and M Sperling) who appoint an editorial board and the Associate Editors (current: A Arzimanoglou: H Beck, E Bertram, R Caplan, F Cendes, M Cook, W Gaillard, A Goldman, A Hartman, D Hesdorffer, A Ikeda, N Jette, D Loring, P Patsolos, H Potschka, A Poduri, D Schmidt, P Siddarth, R Tuchman, and J Wilmshurst.)

Epilepsia Open

Epilepsia Open is the League's new open-access journal scheduled for its first articles this fall. Its peer-reviewed articles will cover the entire breadth of basic, translational and clinical research in epilepsy and will include negative, failure to reproduce, and confirmatory studies. Because it is open-access and freely available, *Epilepsia Open* will enhance the access to basic research findings for clinical scientists and health professionals. It is published by Wiley Blackwell and with D Schmidt, XF Wang and G Mathern serving as Editors in Chief.

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 Arzimanoglou) who also appoints an editorial board and Associate Editors (currently: I Blümcke, F Dubeau, M Duchowny, A Galanopoulou, A Hammers, Y Inoue, P Kahane, M Kerr, S Kochen, C Marini, D Nordli, G Sills, P Thomas, T Tomson and S Wilson).

Epigraph and the Website

In 1994, the ILAE launched its own newsletter, *Epigraph*, sent individually to all members. The online version premiered in 2006. The newsletter is designed to facilitate
(Continued on page 14)

communication of ILAE news to individuals in the greater epilepsy community. ILAE also has a website at www.ilae.org. This has grown in size and complexity, and in 2015 there were over 200,000 visits. *Epigraph* and the website are overseen by Information Officer, Ed Bertram, and Director of Interactive Media, Jean Gotman, respectively.

Finances

With the assistance of the Headquarters Office, ILAE finances are overseen by the Treasurer, who reports to the Executive Committee on all financial and budgetary matters. Membership of the Executive Committee, Regional and Topical Commissions and Task forces is voluntary, and members are not paid for their work. Salaried staff are 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, sponsorships, *Epilepsia* royalties, international and regional Congresses, and investment income. The annual dues of each chapter to the 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 may be supported by a solidarity fund.



32ND INTERNATIONAL EPILEPSY CONGRESS 2ND - 6TH SEPT 2017



BARCELONA



Epilepsia Open

Aristea Galanopoulou, Dieter Schmidt, Gary Mathern, Xuefeng Wang, Editors-in-Chief, Epilepsia Open

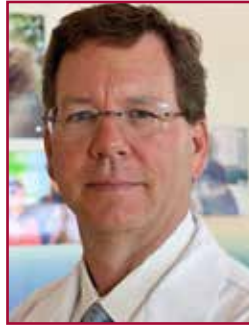
The International League Against Epilepsy is launching *Epilepsia Open*, a peer-reviewed, online open-access journal dedicated to epilepsy. The first issue is scheduled for release at the 2016 European Epilepsy Congress in Prague.

Epilepsia Open has been created for rapid publication of high-quality papers on any aspect of epilepsy. These peer-reviewed articles will cover the entire breadth of translational and clinical research in epilepsy. They will range from basic science to clinical, social, public and global health research, including negative, failure to reproduce, and confirmatory studies. *Epilepsia Open* will also publish communications from the ILAE and its Chapters. A priority for this journal is to enhance the access and application of basic research findings for clinical scientists and health professionals, and promote a better understanding of clinical challenges for biomedical researchers. *Epilepsia Open* is creating a unique forum for the open publication of epilepsy research and epilepsy care.

The League is excited about this new venture that will increase access to new knowledge for our field. Please look for coming announcements about submitting manuscripts to *Epilepsia Open*.



Aristea Galanopoulou



Gary Mathern



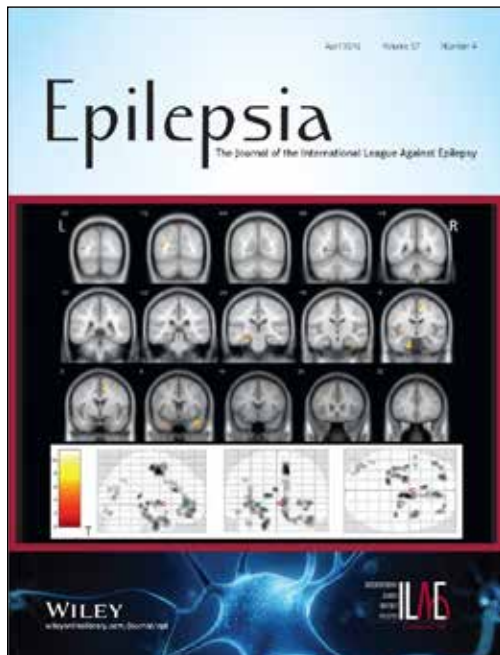
Dieter Schmidt



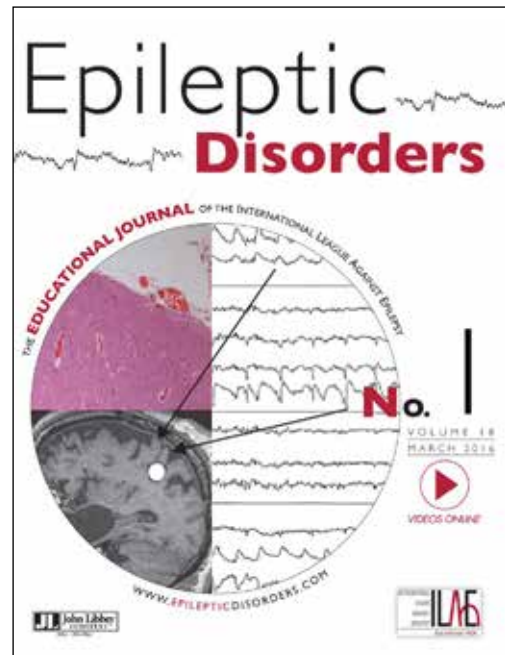
Xuefeng Wang

Journals

Research



Education



Open Access



For subscription information, visit www.ilae.org

Meetings of Interest - 2016

18 – 21 August 2016

15th Asian Oceanian Congress of Neurology (AOCN 2016)
Advanced Education in Neurology in Asian Oceanian Region
Kuala Lumpur, Malaysia
Website: aocn2016.com



21 – 26 August 2016

Mechanisms of Epilepsy & Neuronal Synchronization
Aberrant Circuits to Impaired Function in Epilepsy
PGA Catalunya Business and Convention Centre,
Girona, Spain
Website: <https://www.grc.org/programs.aspx?id=13762>

26 – 27 August 2016

Fundamental Mechanism of Epilepsy International Conference:
Excitatory-Inhibitory Signaling Balance as Therapeutic Target in Epilepsy
Montreal Neurological Institute of McGill University, Canada
Website: <http://neuroevents.mcgill.ca/index.php?page=mni-epilepsy-conference>

29 August – 2 September

4th International Summer School for Neuropathology and Epilepsy Surgery (INES 2016)
West China Hospital, Sichuan University, Chengdu, P.R. China
Flyer: <http://www.ilae.org/Visitors/Congress/congressinfo/INES-2016-2.pdf>



Website: www.epilepsyprague2016.org

15 – 16 September 2016

14th European Congress on Epilepsy and Society
Prague, Czech Republic
Website: www.epilepsyandsociety.org

16 September 2016

Epilepsy Surgical Techniques
Prague, Czech Republic
Website: <http://www.fmotol.cz/microsite-estm/>

20 – 24 September 2016

5th Global Symposium on Ketogenic Therapies
Treating epilepsy, brain cancer, autism and cognitive disorders
Banff, Alberta, Canada
Website: <http://www.ketoconnect.org/>

29 September 2016

BNA-ABN Joint Symposium: Meeting of Minds
Cardiff University, UK
Congress Website: <https://www.bna.org.uk/events/view.php?permalink=CRFUFU8298>

5 – 7 October 2016

Joint British and Irish Chapters Annual Scientific Meeting
Clontarf Hotel, Dublin, Ireland
Website: <http://ilaebritish.org.uk/events/ilae-british-irish-chapters-annual-scientific-meeting-dublin/>

6 – 9 October 2016

5th International Summer School for Neuropathology and Epilepsy Surgery (INES)
Erlangen, Germany
Flyer: <http://www.ilae.org/Visitors/Congress/congressinfo/INES-2016-Flyer.pdf>
For more information, contact Ingmar Blumcke:
blumcke@uk-erlangen.de

14 – 16 October 2016

Canadian League Against Epilepsy Biennial Scientific Meeting
Quebec City, Quebec
Website: <http://canadianleagueagainstepilepsy.memberlodge.org/2016-Scientific-Meeting>

20 – 22 October 2016

Annual Meeting of the German-Swiss-Austrian Epilepsy Working Group DACH-AK
Excellence discourse epileptology. I: Clinical epileptology, II: Electrophysiology (EEG, MEG)
Meeting Venue: Prien, Germany
Course directors: Hermann Stefan, Margitta Seeck, Eugen Trinka
Registration ends 15 September 2016

2 – 5 November 2016

The 27th International Symposium on the Autonomic Nervous System
San Diego, California, USA
Website: www.americanautonomicsociety.org/

8 – 10 November 2016

Neuro Santiago 2016 Conference of Neurology
Epidemiology of Epilepsy and Childhood Headaches
Santiago, Cuba
Website: <http://www.neurosantiago.org/index.php/convocatoria-2>

24 – 26 November 2016

Video-EEG in pediatric epilepsies: from seizures to syndromes
Madrid, Spain
Information: <http://www.ilae.org/Commission/CEA/documents/CEA-VidEEG-Ped-2016-letter.pdf>
Program: <http://www.ilae.org/Commission/CEA/documents/CEA-VidEEG-Ped-2016-Program.pdf>
Application form: <http://www.ilae.org/Commission/CEA/documents/CEA-VidEEG-Ped-2016-App.pdf>

2 – 6 December 2016

AES 70th Annual Meeting and 6th Biennial Regional American Congress
Houston, TX, USA
Abstract submission deadline is June 8, 2016
Website: https://www.aesnet.org/annual_meeting

2017

16 – 18 February 2017

4th East Mediterranean Epilepsy Congress
Luxor, Egypt
Information: luxor@epilepsycongress.org



23 – 26 March 2017

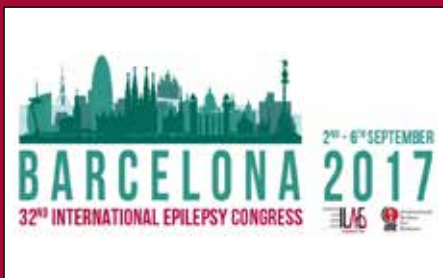
The 11th World Congress on Controversies in Neurology (CONY)
Athens, Greece
Congress website: www.comtecmed.com/cony/2017-8-April-2017

6 – 8 April 2017

6th London-Innsbruck Colloquium on Status Epilepticus and Acute Seizures
Salzburg, Austria
www.statusepilepticus.eu



32nd International Epilepsy Congress



Congress website: www.epilepsybarcelona2017.org

INTERNATIONAL
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AGAINST
EPILEPSY



Epigraph

is coordinated by Edward Bertram with the assistance of staff in the Headquarters office.

All communications should be directed to epigraph@ilae.org or faxed to 860.201.1111.