

# A Global Agenda

## 2014 ANNUAL REPORT



# OUR VISION

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

# OUR MISSION

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

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### **STRATEGIC PLANNING**

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Sweden



# PRESIDENT'S REPORT



Emilio Perucca

The first year of my presidency passed very fast. We made important progress on several projects initiated in the earlier term and many new initiatives were started. Our ambitious plans are facilitated by the fact that the ILAE community works truly as a team, and I feel privileged to count on the invaluable support of all Executive Committee members, great staff members, and many other dedicated colleagues worldwide.

The first responsibility that an ILAE President faces at the beginning of a new term is the reorganization of Commissions and Task Forces. This was rapidly accomplished, and all Topic-Oriented Commissions were already functional by the end of summer 2013. To ensure continuity with activities conducted in the previous term, Past Chairs are included in the membership of all the new Commissions. Obviously, it is important that Commissions also work in a complementary and coordinated manner. To that purpose, their core work programs were finalized through extensive interaction that took place in Montreal in June 2013, during a meeting that was attended by all past and current Commission chairs as well as by members of the previous and current ILAE leadership.

At the present time, over 300 experts from more than 60 countries worldwide are contributing to the activities of Commissions and Task Forces, and I am most grateful for their dedication and hard work. In line with a commitment that I made prior to my election to the presidency, the membership of all Topic-Oriented Commissions includes at least one talented junior scientist, selected in consultation with individual ILAE Chapters, as part of a mentoring process designed to nurture the epilepsy leaders of tomorrow.

The primary objective of Commission activities is to advance and disseminate knowledge about epilepsy and its prevention and treatment. Education has been a priority for the League since its very foundation and remains very much so in the current term. Our

Education Commission is actively liaising with all other Commissions and Task Forces, and with the Scientific and Organizing Committees of our Congresses, to ensure that the League remains the pre-eminent source of knowledge for scientists and health care providers in all settings. Over the years, our investment into courses, summer schools, workshops, fellowships and visiting professorships has grown significantly, and our distance education programs (VIREPA) has expanded the scope and range of courses provided. We realize that the majority of people with epilepsy across the world do not have access to specialist care and are being managed instead by primary care physicians and other health professionals. It is our duty to reach out to primary care professionals, and we are making new efforts in this direction in collaboration with our Regional Commissions. A recently created Task Force, chaired by our Treasurer Sam Wiebe, is working in strict liaison with the Education Commission and taking a broader look at how we can best diversify our educational activities in a manner which is both compatible with our resources and optimally structured to reach a broader community through efficient use of modern communication media.

In promoting knowledge about epilepsy, our congresses continue to play an important role, not just by providing lectures and courses, but also by supporting the establishment of collaborations and networks. Since Montreal, we have had three very successful regional congresses, the 2nd African Epilepsy Congress in Cape Town, South Africa (22-24 May 2014), the 11th European Congress of Epileptology in Stockholm, Sweden (29 June – 3 July 2014) and the 10th Asian-Oceanian Epilepsy Congress in Singapore (7-10, August 2014). All were well attended and highly rated, and I wish to thank the Organizing-Scientific Committees of these events for a truly superb job. Upcoming Regional Congresses include the 8th Latin-American Congress on Epilepsy in Buenos Aires, Argentina (17-20



Progress and continuity – participants at the meeting of former and newly appointed Commission Chairs in Montreal, June 2013.

# PRESIDENT'S REPORT (continued)

September 2014), the 5th Biennial North American Epilepsy Congress, in conjunction with the AES Annual Congress in Seattle, USA (5-9 December 2014), and the 3rd Eastern Mediterranean Epilepsy Congress in Amman, Jordan (19-21 March 2015). The organization of the next International Epilepsy Congress (IEC) in Istanbul, Turkey (5-9 September 2015) is also already well under way. In the past, surplus from some of the congresses represented an important source of revenue for the League, but in recent years such revenue has declined drastically, due to reduced direct and indirect support from the pharmaceutical industry. In particular, surveys have repeatedly indicated that delegates highly value our congresses, but they are finding it increasingly difficult to obtain financial support for travel and registration. We had predicted that this new scenario would materialize and over the past several years, as explained by our Treasurer in this Report, we have built significant financial reserves to offset the consequences of a continuously decreasing income. Recognizing the difficulties faced by many delegates, particularly younger physicians and basic scientists, to attend our congresses, we made major efforts to decrease registration fees—a policy fully supported by the leadership of the International Bureau for Epilepsy (IBE), whom I thank for being so sensitive to this issue. To make one example, the full registration fee for an ILAE Chapter member went from EUR 655 at the Rome IEC (2011) to EUR 495 at the Montreal IEC (2013) to EUR 400 at the Istanbul IEC (2015). Young delegates are entitled to more discounted rates, and their participation is further facilitated by an increasing number of bursaries which ILAE and IBE are making available.

When it comes to fulfilling the League's mission of advancing and disseminating knowledge about epilepsy, our journals also play a key role. *Epilepsia* remains the most prestigious journal in the discipline, and I was delighted to learn that its 2014 impact factor has risen to 4.584, the highest ever in the history of the journal. Our past and present editors have truly done a superb job in leading the journal to these levels of excellence. You will have noted many innovations in the structure of *Epilepsia* lately, and you can learn more about it in the report written by our current editors, Gary Mathern and Astrid Nehlig, included in this document. Since 2013, *Epileptic Disorders* has also joined *Epilepsia* as an official journal of the League. Its acquisition was motivated by our desire to have a journal dedicated primarily to education, and a new editorial team is actively working under the leadership of Alexis Arzimanoglou in reshaping the configuration of the journal in line with its newly defined objectives.

The League recognizes that to fulfill its mission at best it is necessary to establish and potentiate effective

alliances with other relevant organizations. The alliance with our prime partner IBE has never been stronger—the IBE President Athanasios Covanis and I consult at least because we both recognize that only by working together we can impact the lives of people with epilepsy. For the same reason, ILAE and IBE have strengthened their alliance with the World Health Organization (WHO), with which we collaborate on many matters, from updating and testing ICD codes to coordinating several demonstration projects currently conducted under the aegis of the Global Campaign against Epilepsy. In my inaugural message last year, I emphasized how improving access to epilepsy care in low and middle-income countries must represent a top priority for the League. This objective is being addressed in collaboration with IBE and WHO through the newly established Access to Medicines initiative, a broad-ranging action plan aimed at removing the many barriers which hamper efficient supply and distribution of affordable antiepileptic medications in less privileged areas of the world.

Collaboration with WHO is complemented by other advocacy initiatives aimed at raising the visibility of epilepsy with health authorities and national governments worldwide. Key actors in this process are the joint ILAE-IBE Global Outreach Task Force, chaired by Alla Guekht and Mary Secco, and the newly formed Global Research Advocacy Task Force, chaired by Shichuo Li. The remit of the latter is to sensitize governments and funding organizations about the need to support epilepsy research, taking inspiration from the highly successful Epilepsy Advocacy Europe initiative.<sup>1</sup> Although the League does not have sufficient resources to fund major research projects independently, under special circumstances it can facilitate important research. One example is a recent study published in the prestigious *Lancet Neurology*<sup>2</sup>, where an international group of researchers, assembled by the ILAE Genetics Commission under the leadership of Sam Berkovic, provide new evidence on how susceptibility to develop epilepsy can be determined by the combination of genes that we inherit. Recognizing the important role of the ILAE and IBE constituencies in promoting epilepsy research and in disseminating its findings, the League and the Bureau are also taking steps towards establishing a legal entity in the European Union (EU) to facilitate collaboration with other partners in accessing EU funds and promoting the epilepsy agenda in Europe and other regions involved in collaborative projects with the EU.

The League has continued its fruitful collaboration with other international scientific societies. In particular, I would like to mention our partnership with the International Brain Research Organization (IBRO)

# PRESIDENT'S REPORT *(continued)*

in promoting educational initiatives to advance knowledge about epilepsy in Africa. Two members of our Executive Committee, Amadou Gallo Diop and Marco Medina, hold important positions within the World Federation of Neurology (WFN), and this has helped in further strengthening the excellent collaboration between the two organizations. Along this line, ILAE and WFN have recently agreed to co-fund a project aimed at improving epilepsy care in Zambia, and the League has gratefully accepted WFN's invitation to organize the epilepsy program at the next World Congress of Neurology due to take place in Santiago, Chile, on 31 October - 5 November 2015.

Among the League's many other achievements in the past year, I would like to mention two in particular. The first is the publication of the operational (practical) definition of epilepsy<sup>3</sup>, which complements the 2005 conceptual definition.<sup>4</sup> The operational definition publication is important not only because the topic is so central to our discipline, but also because it represents the first product of the process by which position papers of the League are now prepared, finalized and approved. This process entails involvement of our constituency through an extensive web-based consultation, generating a document that is no longer the product of a group of experts but, rather, incorporates the feedback from the entire epilepsy community.<sup>5</sup> The other major recent achievement which I am especially proud of is the release of the online diagnostic manual of the epilepsies produced by the ILAE Commission on Classification and Terminology.<sup>6</sup> The manual makes available the latest concepts relating to seizures and epilepsies in an easy to understand form, assisting clinicians anywhere in the world to diagnose seizure type(s), classify epilepsy, diagnose epilepsy syndromes and define etiology. I am very grateful to the great team of colleagues who worked for so many years to assemble such a fantastic product.

The past year has brought us exciting developments but also sad moments. An especially emotional event occurred close to last Christmas with the premature disappearance of Harry Meinardi, the only person to have served at different times as president for both ILAE and IBE.<sup>7</sup> We had to bear many other sad losses, including those of John Freeman, Yukio Fukuyama, and Cesare Lombroso—you will find a tribute to these giants in the Farewells section of our website.<sup>8</sup> We will all miss them, but their memory will remain always with us and their example and achievements will continue to inspire our community forever.

Emilio Perucca  
*ILAE President*

- 1 Perucca E. The European Declaration of Epilepsy: Past, present and future. *Epilepsy and Seizure* (Tokyo) 2013;630-7  
<http://www.ilae.org/visitors/farewells/>
- 2 International League Against Epilepsy Consortium on Complex Epilepsies. Genetic determinants of common epilepsies: a meta-analysis of genome-wide association studies. *Lancet Neurology* 2014  
Published Online July 31, 2014  
([http://dx.doi.org/10.1016/S1474-4422\(14\)70171-1](http://dx.doi.org/10.1016/S1474-4422(14)70171-1))
- 3 Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, Engel J Jr, Forsgren L, French JA, Glynn M, Hesdorffer DC, Lee BI, Mathern GW, Moshé SL, Perucca E, Scheffer IE, Tomson T, Watanabe M, Wiebe S. A practical clinical definition of epilepsy. *Epilepsia* 2014;55:475-82.
- 4 Fisher RS, van Emde Boas W, Blume W, Elger C, Genton P, Lee P, Engel J Jr. Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). *Epilepsia* 2005;46:470-2.
- 5 Perucca E. Introduction to the clinical definition of epilepsy by the ILAE president. *Epilepsia* 2014;55(4):473-4.
- 6 <http://www.ilae.org/commission/class/diagnostic.cfm>
- 7 Perucca E, Reynolds EH. In memoriam: Harry Meinardi (February 20, 1932-December 20, 2013). *Epilepsia* 2014;55:621
- 8 <http://www.ilae.org/visitors/farewells/>

# TREASURER'S REPORT

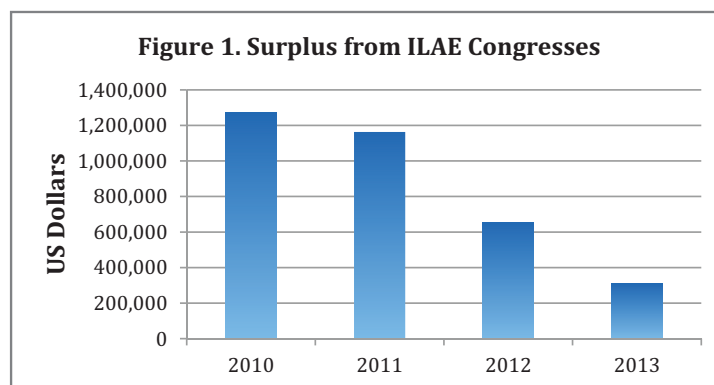


Sam Wiebe, MD

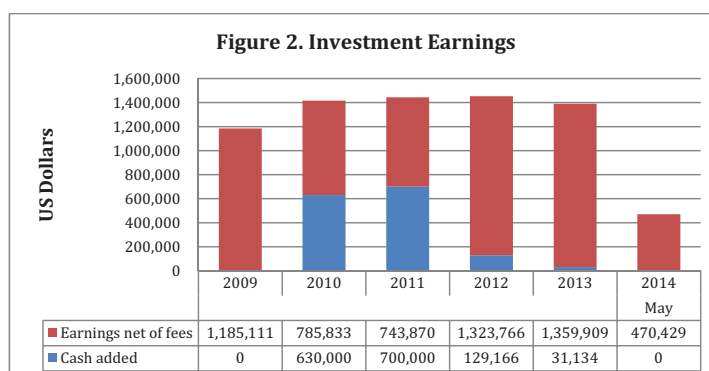
The first year of this Executive Committee has given us many reasons to pause and carefully evaluate our finances. The League, like many other professional organizations, faces significant financial challenges imposed by the new landscape of substantial decrease, in revenue.

The League depends entirely on revenue from two sources: its journal *Epilepsia*, and its Congresses. Although revenue from *Epilepsia* has been unchanged thanks to a contract with the publisher that expires in 2016, there are challenges on the horizon that we need to address. These include increasing competition from a growing number of journals, the changing landscape in publishing, especially electronic media, and a decrease in revenue from advertising. Fortunately, under the wise guidance of and hard work from our Editors, the Impact Factor of *Epilepsia* is at its strongest level this year, which increases its value to subscribers and to publishers.

As noted in our President's report, direct and indirect industry support to our congresses has resulted in a drastic and steady decline in revenue from these sources over the last four years (See Figure 1). Unfortunately, we see no reason to believe that this trend will reverse any time soon. This is the new normal.



As a result, our ability to contribute to our reserves has not only declined, but we are now drawing from the League's investment income to meet our financial obligations and to carry out our mission (See Figure 2).



A brief glance at our operating budget for 2014, as presented in the table below, is informative. Our operating expenses are met this year by corresponding revenue. However, we project a relatively small surplus from our Congresses. On the other hand, we are committed to continue to strongly support the activities of our Commissions and Task Forces throughout the world. To this, we allocated over US \$1.3 million in 2014. As can be appreciated, even projecting a US \$500,000 return from our investments (which might be optimistic), this required us to draw half a million US \$ from our reserves, and despite this injection of funds, we still project a deficit of US \$127,000.



# TREASURER'S REPORT (continued)

Budget Categories	Revenue	%	Expenses	%	Net
Operating	1,599,625	28%	1,435,688	25%	163,937
Commissions	80,000	1%	1,357,609	23%	(1,277,609)
Congresses	3,550,137	62%	3,013,860	51%	536,277
Investments	500,000	9%			500,000
Other			50,000	1%	(50,000)
TOTAL	\$5,729,761		\$5,857,157		\$(127,396)

The new financial reality demands that we scrutinize carefully all of our expenses and also explore other sources of revenue. And this is what we are doing. We need to re-think all our congresses to make them more efficient without compromising, but actually enhancing, our educational goals; similarly, our operational expenses are being trimmed everywhere possible; finally, we are undertaking a global assessment of our educational activities, which is aimed at designing an overall strategy that incorporates efficiency and creativity to fulfill our mission in the current environment.

Fortunately, the League has been proactive in preparing for the new tough reality. Informed by the wise counsel of our Finance Advisory Committee, an endowment has been built over the last several years that allows us not only to continue functioning in the face of dwindling revenues, but also to expand our mission and to undertake new initiatives. In recognition of the importance of providing support to those who need it most, we have been able to increase the number of bursaries and to reduce the registration fees for our congresses, making them more accessible (see President's report). We also continue to support a large diversity of educational initiatives, such as fellowships, courses, workshops, academies, and online education. Our scientific and educational journals (*Epilepsia* and *Epileptic Disorders*) are thriving, and we are developing new collaborations with the World Health Organization, regional health organizations such as PAHO, and international societies such as IBRO and the WFN.

Our role as the prime source of authoritative materials on epilepsy continues to flourish with the publication of educational tools such as [epilepsydiagnosis.org](http://epilepsydiagnosis.org), Clinical Definitions, Practice Guidelines, and Commission Reports. We intend to continue and increase our support to these activities and to explore ways to increase the type and quality of our educational resources.

To all who have heard our message of fiscal constraint and have responded by donating their time and talent, we owe a debt of gratitude. We continue to move forward thanks to our colleagues around the world who devote the best of their time and energy to make a difference in the lives of people with epilepsy.

Samuel Wiebe, MD  
*Treasurer*

# SECRETARY-GENERAL'S REPORT



Helen Cross

My first year as Secretary-General of the League has been very busy with consolidation of my responsibilities, including the oversight of official records of the ILAE, promotion of chapter development as well as the processing and maintenance of reports of Commissions and Task Forces, submitting them for approval to the Executive Committee. This has been the first term of an inclusive Executive Committee including all Chairs of regional commissions. This has included regular meetings, predominantly by telephone but also face to face, and the commitment shown to our cause with contribution from around the globe has been enlightening.

The League continues to grow. The Executive Committee has granted provisional acceptance to two further chapters: Myanmar and Belarus. Definitive acceptance will be submitted to the vote of the General Assembly of the ILAE, the next to take place during the 31st International Epilepsy Congress. Formal acceptance will increase the number of League chapters to 114, which, because we have interest from other countries about application, we expect will increase further.

Over the last twelve months we have tested a new system to ensure feedback and comment from the membership is taken into consideration on position documents produced by the League. The paper outlining an operational clinical definition of epilepsy was put out for public consultation on the ILAE website. This attracted over 300 comments; a Task Force was then set up, chaired by Robert Fisher whose remit was to edit the document based on the comments raised. A final draft was then agreed on and submitted for publication, published in *Epilepsia* in April of this year. The proposed refinements to the Organization of the Epilepsies were also available for comment on the website during the early part of the year. This attracted comments from 128 people in 43 countries. It was evident that the feeling about the proposals was very mixed and wider debate was required. A Task Force has been formed, chaired by Ingrid Scheffer, and a roadmap is subsequently being set out with regard to a way forward. These two initial consultations demonstrated that the web is allowing the engagement required of the community on important issues for wider discussion. We will continue to assess whether this process can be further improved going forward. In addition to these two areas, there have been a further 10 reports submitted to the Executive Committee for approval from Commissions and Task Forces, highlighting the amount of ongoing work being undertaken on the League's behalf despite this being only the first year of their term.

In addition there have been frequent requests for ILAE endorsement of congresses and scientific meetings,

not necessarily fully organized by commissions or chapters of the League. Guidelines have therefore been formulated and agreed, now available on the ILAE website, for submission on and assessment for support from Regional and Topic-Orientated Commissions.

Now that we have Regional Commissions established to cover all regions of the world, election processes have developed to some degree, varying according to the region concerned. It is now recognized that a degree of harmonization is required of processes for election of officers. A Task Force including all Regional chairs has been working to develop such guidelines, following which the bylaws will be adjusted accordingly.

The League has collected much archived material over time; over the past twelve months we have used the Wellcome Trust library to archive collected material to date. Under the supervision of Simon Shorvon (to whom we are extremely grateful), an archivist was employed who has done an excellent job in fully cataloguing material; a full report was produced and the catalogue is fully available on the Wellcome Trust website for which we are extremely grateful. It is clear there will be other materials and a system for collecting such material and disseminating awareness of their availability will be sent out over the next twelve months.

Earlier in the year, the IBE approached the League about formalizing an International Epilepsy Day. It was felt the time was right to do this, despite the emergence of other activities over time. A poll was therefore circulated to determine regional preference of one of three days. Ultimately a decision was made on the second Tuesday in February. We recognize that unfortunately one day is not going to suit all regions of the world, in view of variability of holiday seasons and other celebrations. However we also acknowledge that the development of such a day should not detract from existing local epilepsy days continuing to be celebrated. Accepting all these factors, this day held the majority of agreement. The next phase will be the launch planned for February 2015.

The initial year of my term has passed quickly; much is moving forward in the League on a global level aiming to improve and empower the lives of people with epilepsy. It is a privilege to be part of it, and I look forward to the next twelve months.

Helen Cross, ILAE  
*Secretary-General*

## EDITORIAL



### From the Editors: Our paper (first) anniversary and launching *Epilepsia*'s new look

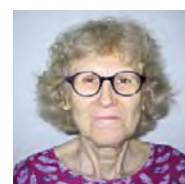
*Epilepsia*, 55(7):949–955, 2014  
doi: 10.1111/epi.12684



Gary Mathern, *Epilepsia* Co-Editor in Chief



Laurie Beninsig, *Epilepsia* Managing Editor



Astrid Nehlig, *Epilepsia* Co-Editor in Chief

It is probably a bit ironic that “paper” is the traditional gift for a first anniversary, as it symbolizes strength from the interlacing of individual threads. That symbolism is germane for the Editors-in-Chief of *Epilepsia* as we celebrate our first year at the Journal. *Epilepsia*'s success relies and depends on the concerted effort of many individuals working voluntarily and together with the common goal of producing a high quality medical journal devoted to epilepsy care and research with an international point of view. The nonprofit International League Against Epilepsy (ILAE), not a commercial interest, owns *Epilepsia*, so we represent and serve professionals in epilepsy care and their patients around the world.

It does not seem like a year has gone by, but it has. This editorial focuses on what has been accomplished since we took over in July 2013, and, just as importantly, highlights our vision for the future of *Epilepsia*. As always, the Editors are open to new ideas for the development of any topics, and we encourage you to send them to [epilepsia@epilepsia.com](mailto:epilepsia@epilepsia.com).

#### CONTENT DEVELOPMENT AND ENHANCEMENT

The core of any medical journal is its content, and *Epilepsia* strives to be the most respected medical subspecialty journal in the field of original clinical and basic science

research in epilepsy and its related disciplines. This is our core mission. We receive >1,100 articles per calendar year—submissions continue to increase—and publish ~200+ original research articles (print and electronic) and Brief Communications (electronic only). Each new submission is screened by the Editors-in-Chief, and often by one or more of our Associate Editors, and is assessed for originality, novelty of study content, and potential impact to the field. If the subject matter is seen as having high significance (even if a negative study), we conduct a secondary assessment, looking at the study design, sample size, and statistical methods to determine if the report is credible and meets our quality standards. This initial screen results in 40–45% of submissions being editorially rejected without peer review. The usual reasons for editorial rejection involve low impact studies or studies with clearly evident flaws in sample size and experimental design. These problems are not new, as discussed in a recent commentary by Phil Schwartzkroin, immediate past Editor-in-Chief, on how to get an article published in *Epilepsia*.<sup>1</sup> If a submission clears the initial assessment and goes out to reviewers, there is about a 1 in 3 chance that it will be eventually accepted for publication in *Epilepsia*. Acceptance rates are likely to remain competitive, and to understand what editorial staff is looking for, we encourage authors to review Dr. Schwartzkroin's article when thinking of writing a paper for *Epilepsia* or any other epilepsy-related scientific journal.

We expanded our editorial content over the last year to complement our usual Invited Reviews, Regular Articles, and Brief Communications. One of *Epilepsia*'s new article categories is our recently introduced Controversy in Epi-

**Table 1. Controversy in Epilepsy series (through May 2014)**

Is it time to replace the Wada test? (May 2014, Print Edition)
The case for medical marijuana in epilepsy (June 2014, Print Edition)
Prevalence of epilepsy—An unknown quantity (July 2014, Print Edition)
Consciousness as a useful concept in epilepsy classification (August 2014, Print Edition)
Epilepsy: Asia versus Africa (September 2014, Print Edition)
When to tell epilepsy patients about SUDEP (in development)
Corpus callosotomy versus vagus nerve stimulation for epilepsy (in development)

**Table 2. My Epilepsy Story**

Organization/individual	Published issue
Gay Mitchell	October 2013
RE Children's Project	December 2013
The Hemispherectomy Foundation	January 2014
Dravet Syndrome Foundation	February 2014
Korea Name Change	March 2014
Tuberous Sclerosis Alliance	April 2014
Kristin Seaborg	May 2014
Michael Foundation	June 2014
The PCDH19 Alliance	July 2014
Hope for Hypothalamic Hamartomas	August 2014
Sophie's Story	September 2014
Muir Maxwell Trust	October 2014
An Interview with: Jorge J. Rodriguez, SUDEP Aware	November 2014
Epilepsy South Africa	December 2014
Ring Chromosome 20 Syndrome	January 2015
We are actively seeking other nominations at <a href="mailto:epilepsia@epilepsia.com">epilepsia@epilepsia.com</a> .	

lepsy series. Peer-reviewed original research studies and reviews follow a well-established pattern of organization and presentation, with a reference point of previously published literature. As Editors we realized that from a content perspective we were missing cutting-edge and developing ideas in the epilepsy field, where concepts were ahead of the

peer-reviewed literature. In other words, in emerging fields there is more opinion than fact available, as ideas often precede experimental data. To gain access to this content, *Epilepsia* offers the opportunity for authors to pitch an idea or position to the world epilepsy community that can be more conceptual, but at the same time meet quality and scholarly standards. Because these submissions are more conceptually driven, we balance these articles by inviting others to critique the ideas in the form of a civilized academic debate. This series was introduced in the May 2014 print edition of *Epilepsia*, with a debate on whether the Wada test is absolutely necessary before surgery. Other topics have been or are being developed (Table 1). We hope *Epilepsia's* readership finds this series of interest, and we encourage anyone with ideas for the Controversy in Epilepsy series to contact us ([epilepsia@epilepsia.com](mailto:epilepsia@epilepsia.com)).

The other new series introduced in our first year is My Epilepsy Story. This series provides an opportunity to highlight individuals and organizations that may not be well known outside their local communities or countries, but have made a substantial contribution to people with epilepsy. In addition, this series is designed to let our readership know about the expanding list of nongovernmental and nonprofit organizations that are taking ownership of epilepsy phenotypes, syndromes, and conditions that provide resources to diagnose and treat these epilepsy-related conditions (Table 2). If you know of individuals or organizations interested in this feature, please contact the Editors.

To further enhance *Epilepsia's* content and access greater involvement of our international professional and nonprofessional readership, we developed the capability for electronic polling. For important ILAE position papers and reports, such as the 2014 ILAE Definition of Epilepsy and Controversy in Epilepsy series, we include an editorial introducing the topic with links for our readers to tell us what they think about key questions and opinions raised by the papers (Table 3). Although not as scientifically valid as it could be, this information provides important feedback to our readership and leadership; results of the polls will be

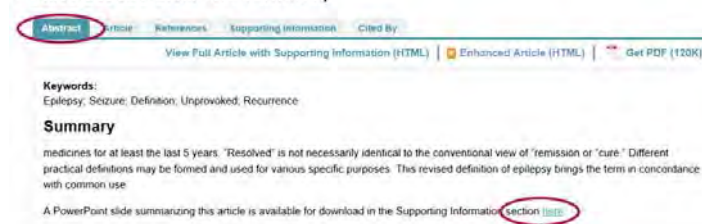
**Table 3. Use of medical marijuana in treating epilepsy—June 2014**

To participate please go to <a href="http://surveys.verticalresponse.com/a/show/1539433/4235ab9776/0">http://surveys.verticalresponse.com/a/show/1539433/4235ab9776/0</a>
Based on the information from the Invited Review, Pro- and Con- position do you believe:
• There are sufficient SAFETY data to allow for open nonprescription use of medical marijuana in treating epilepsy.
• There are sufficient SAFETY data for use of medical marijuana in treating epilepsy but only with prescription and under medical supervision.
• The SAFETY data are insufficient and medical marijuana should not be used for treating epilepsy without more studies.
Based on the information from the Invited Review, Pro- and Con- position do you believe:
• There are sufficient data showing EFFICACY to allow for uncontrolled use of medical marijuana in treating epilepsy
• There are sufficient EFFICACY data for use of medical marijuana in treating epilepsy but only with prescription and under medical supervision
• The EFFICACY data are insufficient and medical marijuana should not be used for treating epilepsy without more studies
What is your opinion about having pharmacologic grade compounds containing cannabidiol available to use in patients with epilepsy?
• Yes, such compounds should be available
• No, such compounds are not needed as growers can provide the medicals
Would you advise patients with severe, catastrophic epilepsy who have not responded to approved therapy to try medical marijuana?
• Yes
• No
If you wish to pitch an idea for the Controversy in Epilepsy series, please contact the Editors at <a href="mailto:epilepsia@epilepsia.com">epilepsia@epilepsia.com</a> .



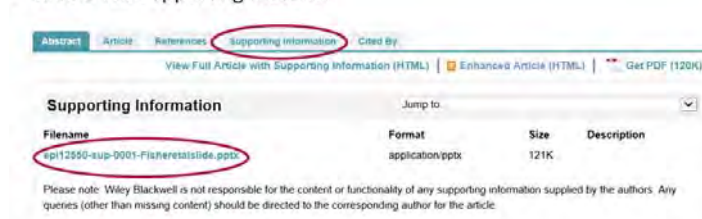
Location on Epilepsia/Wiley web site where slides summarizing the findings of a study can be found and downloaded

## • Abstract tab after the summary

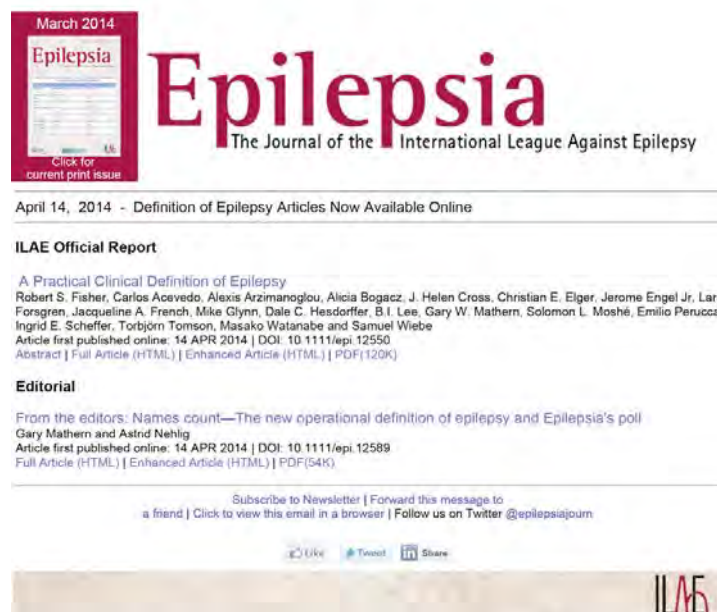


**Figure 1.** Location on *Epilepsia*/Wiley website where slides summarizing the findings of the study can be found and downloaded under Supporting Information. See circled areas. *Epilepsia* © ILAE

## • Article Tab Supporting Material



## Epilepsia Weekly Newsletter



**Figure 2.** Example of *Epilepsia*'s e-Newsletter announcing before-print articles and special articles of interest to our readership. Individuals who are interested in receiving the e-Newsletter can make a request to [epilepsia@epilepsia.com](mailto:epilepsia@epilepsia.com). *Epilepsia* © ILAE

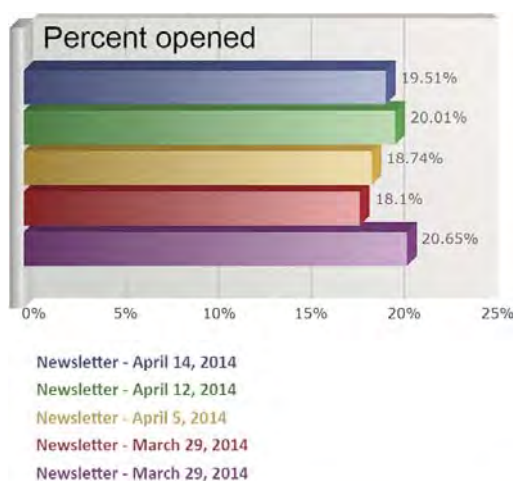
published in future editions of *Epilepsia*. Depending on readership response, we hope to make this feature a permanent component in *Epilepsia*'s content.

Another way to enhance content and its visibility is for readers to have access to PowerPoint slides that summarize the major findings of our published work. This feature was added over the last 6 months; authors are asked to prepare one or two slides, and these are made available on the *Epilepsia*/Wiley website under Supporting Information (Fig. 1). We hope that readers avail themselves of these summary slides, which can be used for educational purposes.

## BETTER ACCESS AND VISIBILITY OF EPILEPSIA CONTENT

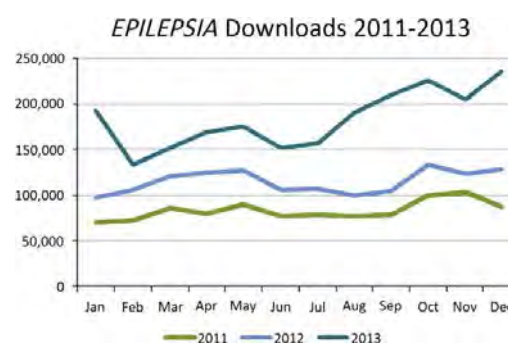
Great content related to epilepsy is of limited value unless it is disseminated and people know about it. To that end, *Ep-*

*ilepsia*'s editorial team has developed improved ways for the journal's content to be disseminated to a wider readership. Perhaps the most visible and successful of these enterprises has been our free e-Newsletter started in September 2013 (Fig. 2). Released on most Friday's, *Epilepsia*'s e-Newsletter is sent to >17,000 e-mail addresses and contains up to six new articles available before the print edition. Other e-Newsletters are sent announcing important League position papers and reports, and announcements, such as the winner of the annual prize for best published paper in *Epilepsia*. On average, about 20% of recipients open the e-mail, and from 5% to 7% click to download articles (Fig. 3). This is an efficient and cost-effective way to get new information to our international readers; if you do not already receive

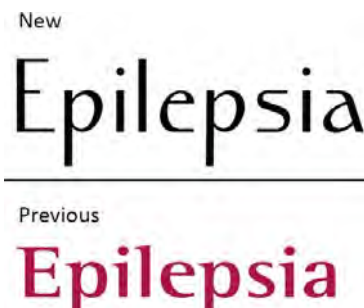


**Figure 3.** Graphs showing the percent of *Epilepsia*'s e-Newsletters opened (top graph) and studies viewed (bottom graph) from March 22 to April 14, 2014. *Epilepsia* © ILAE

*Epilepsia*, 55(7):949–955, 2014  
doi: 10.1111/epi.12684



**Figure 4.** Number of *Epilepsia* articles downloaded per month for calendar year 2011, 2012, and 2013. Each year the number of downloads increase, with a larger increase in late 2013 after the introduction of the e-Newsletter. Data provided by Wiley. *Epilepsia* © ILAE



**Figure 5.** New (top) and old (bottom) logo for *Epilepsia*. Carlos Burges a calligrapher from Grangel Studio in Barcelona, Spain drew the new logo by hand for a more contemporary and unique look. *Epilepsia* © ILAE

# EPILEPSIA REPORT *(continued)*

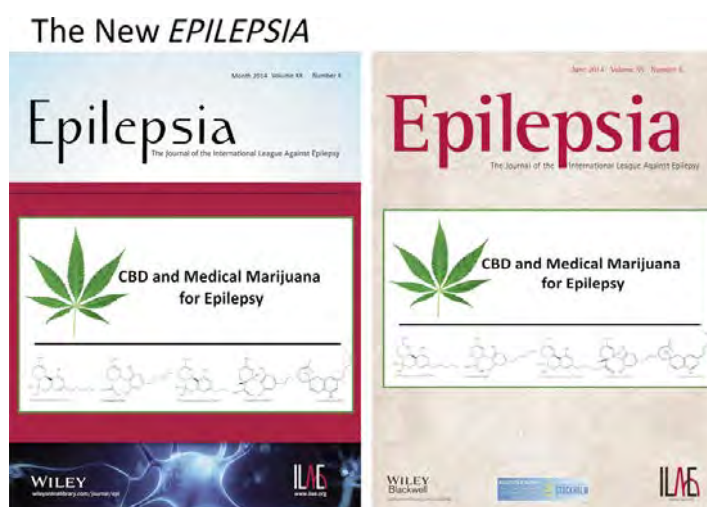
953

*Our Paper Anniversary*

**Figure 6.**  
Carlos Burges (left), Jorge Grangel  
(middle), and Carlos Grangel (right)  
together with some of their creations  
as part of Grangel Studios.  
*Epilepsia* © ILAE



**Figure 7.**  
Old and new cover design for  
*Epilepsia*.  
*Epilepsia* © ILAE



**Figure 8.**  
Icons for different article types in  
*Epilepsia*.  
*Epilepsia* © ILAE



*Epilepsia*, 55(7):949–955, 2014  
doi: 10.1111/epi.12684



the e-Newsletter and would like to, please contact us at [epilepsia@epilepsia.com](mailto:epilepsia@epilepsia.com).

Associated with the release of the e-Newsletter, the number of downloads per month of *Epilepsia* articles has increased (Fig. 4). You can find the link for the e-Newsletter at *Epilepsia*'s website and Scholar One for those submitting new papers for review. Delegates registering for the ILAE's International or Regional Congresses will also have

the opportunity to request *Epilepsia*'s e-Newsletter. In addition, *Epilepsia* also tweets and assesses Facebook use of our content, and we will be looking at ways to expand the use of social media and presence on these sites to announce new content in the Journal.

Another important way to enhance the dissemination of *Epilepsia*'s content for our international audience, and a topic for development, is for non-English readers to have

## *Epilepsia* Associate Editors



**Figure 9.**  
Names, photos, and country of the Associate Editors for *Epilepsia* 2013–2014.  
*Epilepsia* © ILAE



access to *Epilepsia*'s content in their native language. As an example, an opportunity presented itself over the last year through one of ILAE's chapter, the Chinese Association Against Epilepsy (CAAE). The CAAE asked if articles from *Epilepsia* could be translated into Chinese and made available through the newly created Chinese Epilepsy Journal for the many clinicians in that region who have trouble reading English. After several months of negotiations, an agreement has been reached and our Chinese colleagues should be seeing selected *Epilepsia* content in the coming year. *Epilepsia* and the ILAE are looking forward to working with others in a similar model to provide content in other languages through one of our chapters or regional commissions. If chapters have an interest in *Epilepsia* content for translation, please contact the Editors.

## NEW LOOK

A principle well known in the world of communication is that for material to be seen as trustworthy and fresh, the manner in which a topic is presented is as important as the content itself. Therefore, it is not a bad idea to regularly assess the "look" and image of the journal with the goal of improving our ability to communicate with our readers. An important example of this improvement is seen in this print edition of *Epilepsia*, where we introduce several new features.

The most visible is our front cover, where we have a new logo and a new design. The new *Epilepsia* logo (Fig. 5) was designed and hand drawn by Carlos Burges, who has > 40 years of experience creating logos, movie posters, and corporate letterheads. Jorge and Carlos Grangel assisted him, and they are from the world-renowned character and animation Grangel Studio in Barcelona Spain (Fig. 6). They initially prepared about 15 ideas that were evaluated by our editorial team. The final one was selected for its visual appeal, and modern, elegant, and functional look. With the new logo, we also thought it was time to take a look at our cover design, which now has been redesigned for a more modern look, with the help of the design team at Wiley, Inc. (Fig. 7). We hope our readers find this new look fresh and exciting, and that it helps brand *Epilepsia* as the world leader in medical publishing in epilepsy-related research and care.

Changes to the Journal are not all external. As many may have already noticed, the Editors have made changes to the internal look of the Journal over the last year. For example, articles are accompanied by pictures of the first author, so

readers can attach a name with a face and identify new investigators in the field of epilepsy. In addition, we are introducing icons to help readers visually identify quickly what type of article they are reading, whether it is My Epilepsy Story, Controversy in Epilepsy, Invited Review, Regular Article, or Brief Communication (Fig. 8).

## ASSESSMENT AND FUTURE DIRECTIONS

As mentioned at the start of this Editorial, our work as Editors would not be possible without the tireless support and contributions from our Associate Editors, Members of the Editorial Board, and our production staff at Wiley. Special thanks go to our Associate Editors who are instrumental in helping us assess submissions, and communicate often several times per week with the Editors and Managing Editor. In addition, they actively participate in monthly telephone conference calls, often at unfriendly hours of the day, given our global representation (Fig. 9). They are as much a part of the *Epilepsia* team as the Editors-in-Chief.

As we look toward the future, *Epilepsia* will continue to strive to improve content, expand distribution and access, and improve our functionality for our readers and all others interested in the care and treatment of people with epilepsy. In the coming months, expect a new rollout of the annual *Epilepsia* prize for the best paper on clinical and basic research published in the previous calendar year. We will also be looking at ways to improve the synergy between *Epilepsia*, *Epileptic Disorders* (our new sister journal), and the ILAE website, with an eye toward creating a strong portfolio of content for the epilepsy-related international community. As we identify ways to improve the Journal, if you have comments or suggestions, we as Editors would like to hear from you. Thank you for our first year, and we look forward to year 2 and beyond.

Gary W. Mathern  
Co-Editor in Chief, *Epilepsia*  
Laurie Beninsig  
Managing Editor, *Epilepsia*  
Astrid Nehlig  
Co-Editor in Chief, *Epilepsia*

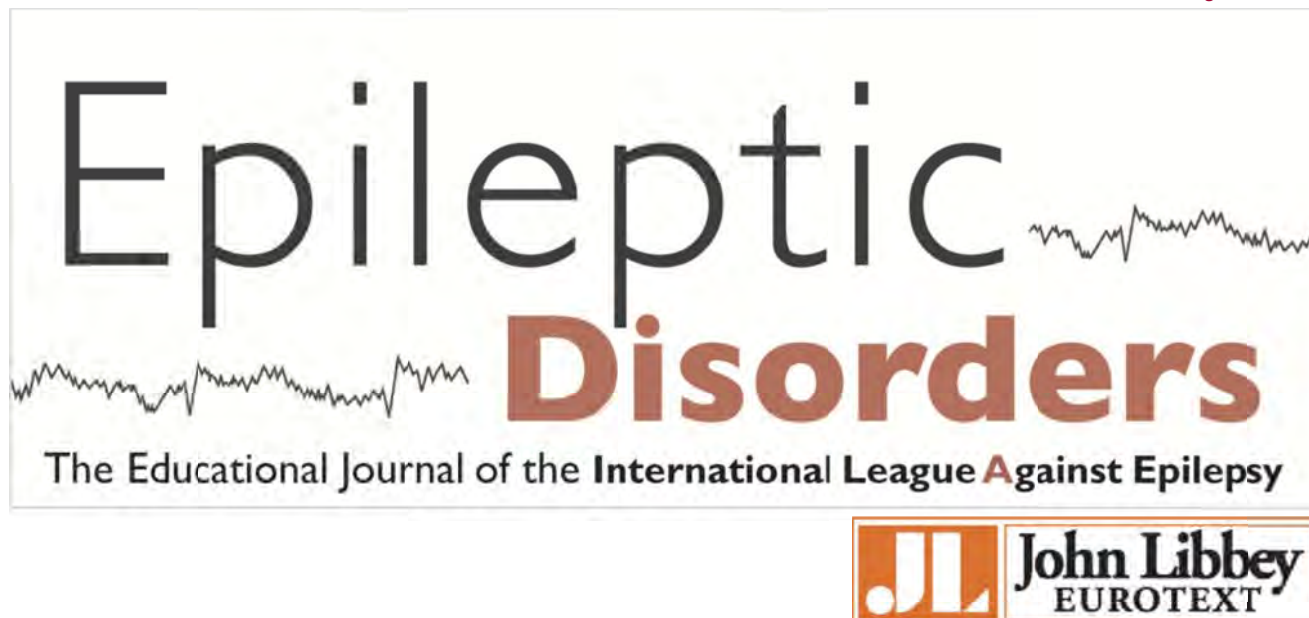
## REFERENCES

1. Schwartzkroin PA. Getting a scientific paper published in *Epilepsia*: an editor's perspective. *Epilepsia* 2013;54:1852–1854.

# EPILEPTIC DISORDERS



Alexis  
Arzimanoglou



## June 2013 – August 2014 Report

# EPILEPTIC DISORDERS *(continued)*

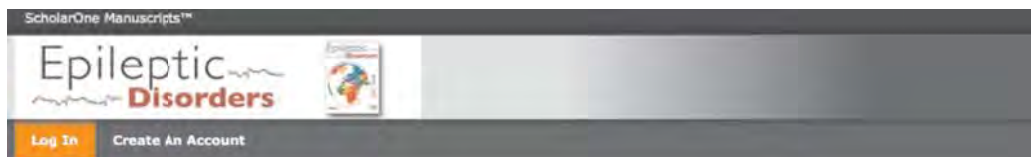


## Appointment of a new and fully operational team of Editors and Production Staff

EDITOR-IN-CHIEF			FOUNDING EDITOR	
<b>Alexis A. Arzimanoglou</b> Director, Epilepsy, Sleep and Pediatric Neuropsychology Dpt. University Hospitals of Lyon, France Consultant, Hospital San Juan de Dios, Barcelona, Spain			<b>Jean Aicardi</b> Paris, France	
ASSOCIATE EDITORS				DEPUTY EDITORS FOR EPILEPSIA
<b>Ingmar Blümcke</b> Erlangen, Germany	<b>Alexander Hammers</b> Lyon, France	<b>Carla Marini</b> Florence, Italy	<b>Pierre Thomas</b> Nice, France	<b>Gary W. Mathern</b> Los Angeles, USA
<b>François Dubeau</b> Montreal, Canada	<b>Yushi Inoue</b> Shizuoka, Japan	<b>Silvia Kochen</b> Buenos Aires, Argentina	<b>Torbjorn Tomson</b> Stockholm, Sweden	<b>Astrid Nehlig</b> Paris, France
<b>Michael Duchowny</b> Miami, USA	<b>Philippe Kahane</b> Grenoble, France	<b>Doug Nordli</b> Chicago, USA	<b>Sarah Wilson</b> Melbourne, Australia	
<b>Aristea Galanopoulou</b> New York, USA	<b>Michael Kerr</b> Cardiff, UK	<b>Graeme Sills</b> Liverpool, UK		
EDITORIAL & PRODUCTION STAFF				
<b>MANAGING EDITOR</b> <b>Oliver Gubbay</b> epileptic.disorders@gmail.com	<b>PUBLICATIONS DIRECTOR</b> <b>Gilles Cahn</b> gilles.cahn@jle.com	<b>DESK EDITOR</b> <b>Marine Rivière</b> marine.riviere@jle.com	<b>PRODUCT MANAGER</b> <b>Jiriane Kouevi</b> jiriane.kouevi@jle.com	<b>MEDICAL MANAGER</b> <b>Sylvie Vercken</b> sylvie.vercken@jle.com

# EPILEPTIC DISORDERS (continued)

## From *Fontis* to ScholarOne platform



### Log In

Welcome to the *Epileptic Disorders* manuscript submission site. To Log In, enter your User ID and Password into the boxes below, then click "Log In." If you are unsure about whether or not you have an account, or have forgotten your password, enter your e-mail address into the "Password Help" section below. If you do not have an account, click on the "Create Account" link above.

The image shows a screenshot of the login and password help form. It is divided into two main sections: "Log In" and "New User?". The "Log In" section has fields for "User ID:" and "Password:" with a "Log In" button. The "New User?" section has a "Register Here" link. Below the "Log In" section is a "Password Help" section with an "E-Mail Address:" field and a "Go" button. The "Log In" section also includes a small globe icon and the journal's logo.

**New submissions platform, similar to the one used by Epilepsia, to facilitate collaboration between the 2 journals**



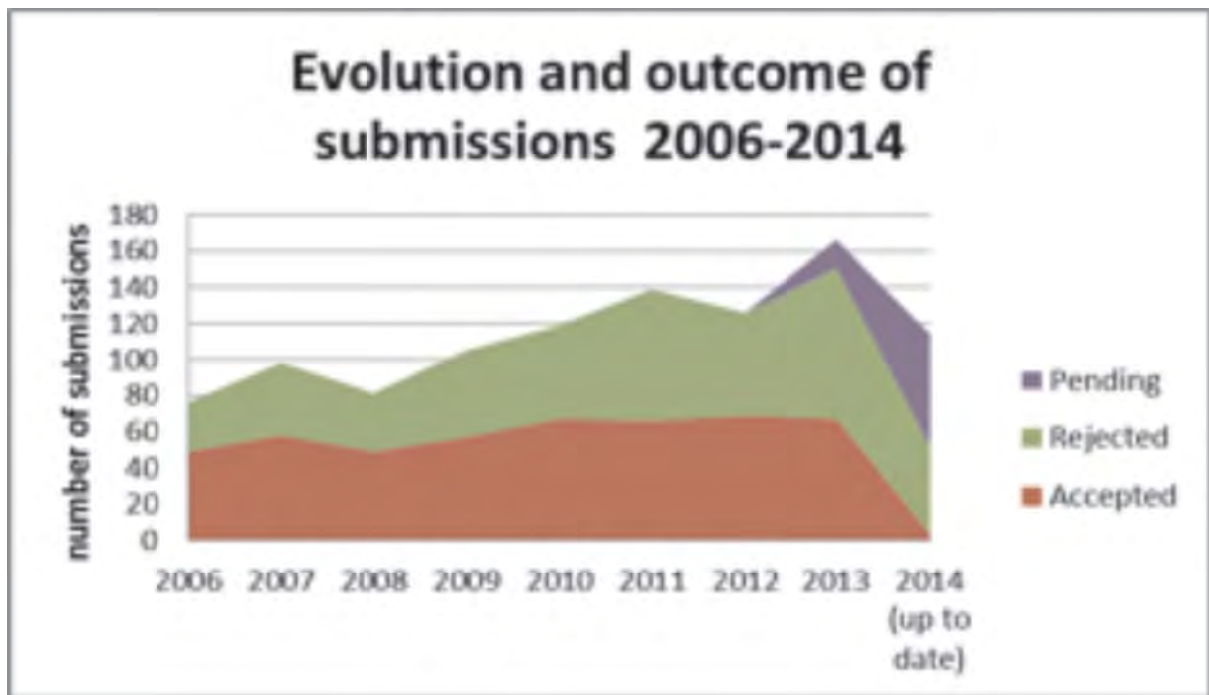
## EPILEPTIC DISORDERS (continued)



### From *Fontis* to *ScholarOne* platform

- All templates have been reviewed and modified;
- New instructions to authors;
- Management of submissions using the 2 platforms progressively moved to ScholarOne only;
- Training of Associate Editors to ScholarOne;
- Updated Instructions to Authors integrating the newly created sections of the journal.

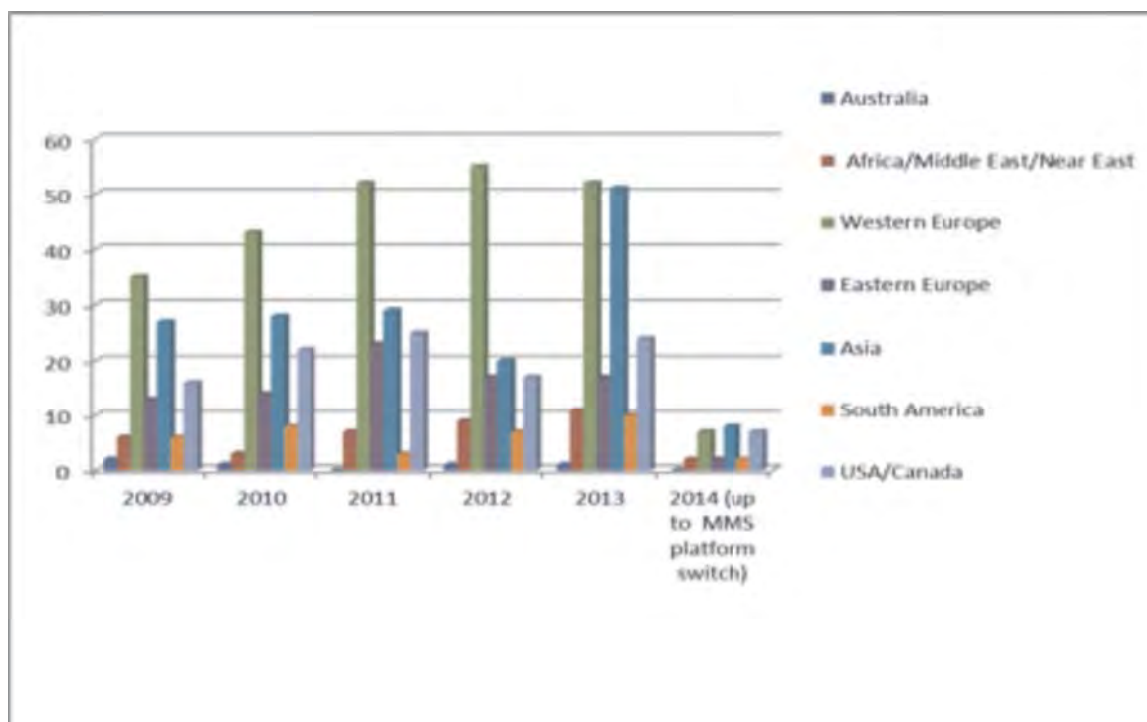
## EPILEPTIC DISORDERS *(continued)*



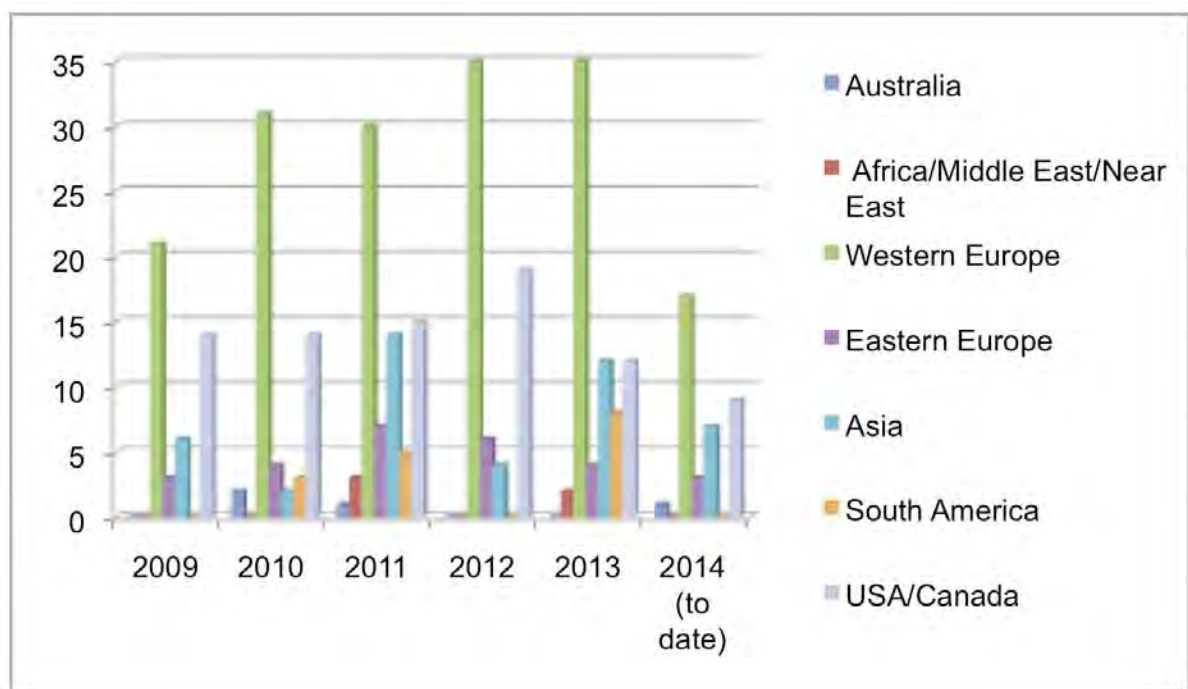
Number of submissions steadily increased during the last five years. Based on the outcome of the years completely reviewed, the acceptance/rejection rate is on average **57% of acceptance vs 43% of rejection**.

# EPILEPTIC DISORDERS *(continued)*

## Geographical distribution of **submissions** 2009-2014



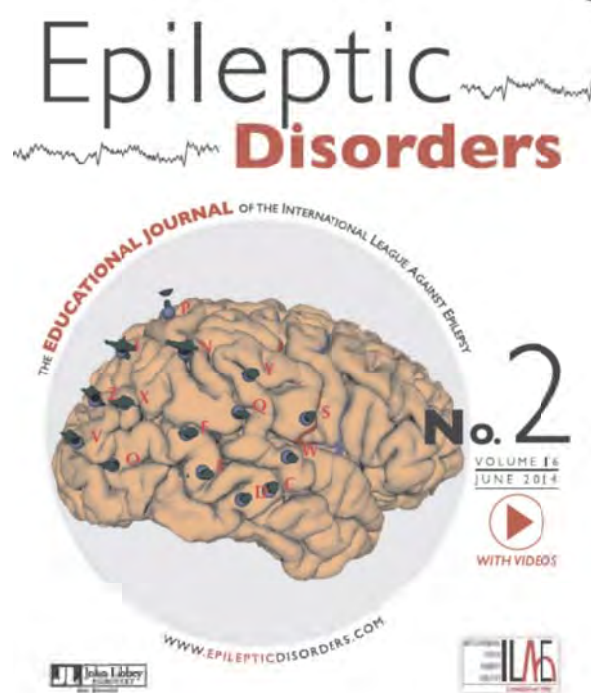
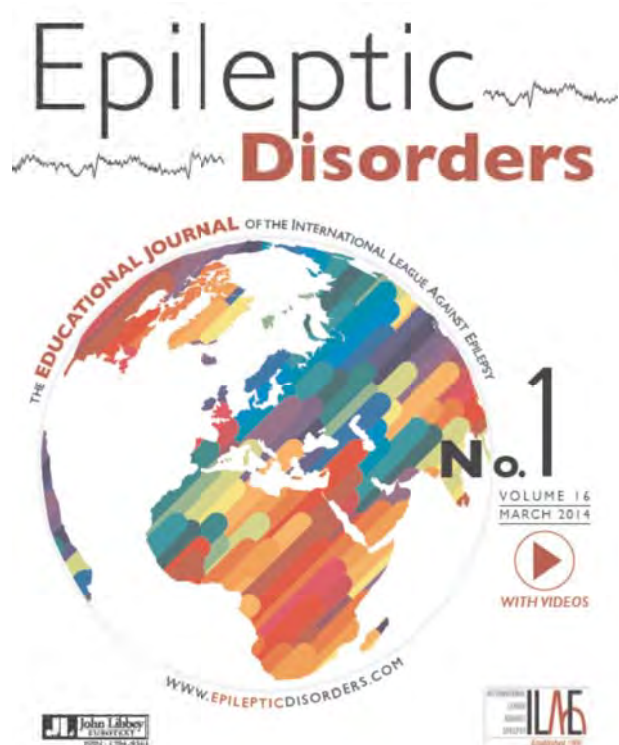
## EPILEPTIC DISORDERS *(continued)*





# EPILEPTIC DISORDERS *(continued)*

**A newly designed cover page better displaying the educational mission of the journal**



## EPILEPTIC DISORDERS *(continued)*



Creation of a **Newsletter** regularly diffused by the John Libbey Eurotext team

Creation of an “**Editors’ choice**” commentary, coordinated by M. Kerr (Associate Editor), published through

- . ILAE Website
- . Epileptic Disorders website
- . Newsletter

The Comment remains online during a 3-4 weeks period, during which the commented manuscript becomes Open Access.

# EPILEPTIC DISORDERS (continued)



A constantly renewed website:  
[www.epilepticdisorders.com](http://www.epilepticdisorders.com)

**More than 300 video sequences &  
12 years of archives access free**



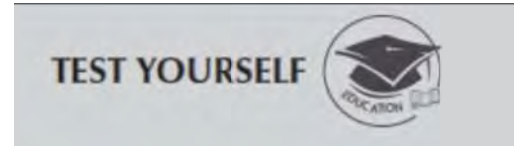
***Further development of an already  
highly performing research tool :***

- Per Etiology
- Per Phenomenology
- Per Localization
- Per Syndrome

**To be used both for diagnostic and  
educational purposes**

**New : Key Words ; Secured Access Procedure**

# EPILEPTIC DISORDERS *(continued)*



## Initiatives to reinforce our “educational” mission

- Each published manuscript will be accompanied by a **series of Power Point slides** illustrating the results and messages the authors wish to deliver. They will be included in the peer reviewing process and then become available for downloading on the website.
- Each published manuscript will include a **set of questions and answers** at the end, in the format of a quiz related to the publication. Questions and suggested answers are part of the peer reviewing process. Answers will be available on the website of the journal;

# EPILEPTIC DISORDERS (continued)



## Initiatives to reinforce our “educational” mission

### **Seminars in Epileptology**

*Seminars in Epileptology* are articles of high didactic value that are relevant to general neurologists and child neurologists, and focus on general knowledge or **everyday clinical practice and care**.

### **Review articles**

*Review Articles* reflect **novel findings and state-of-the-art techniques**, targeting an audience of specialists in epileptology with up-to-date references, including seminal publications.

**Both Seminars and Review articles are published with a "Test Yourself" set of peer reviewed questions & answers**



# EPILEPTIC DISORDERS (continued)



**Next steps  
(Early 2015)**

**[www.epilepticdisorders.com](http://www.epilepticdisorders.com) under complete reconstruction**

**Multimedia Teaching Material** to include  
EEG & MEG plates and figures;  
Neuroimaging (Associate Editor: Alexander Hammers);  
Neuropathology (Associate Editor: Ingmar Blümcke);  
Neurosurgical techniques (videos)  
Exercises (prepared by training colleagues)

**The EpiCentre** to include a selection of  
Review and Seminars articles;  
Electro-clinical reasoning reports  
(Associate Editors: Mike Duchowny & Philippe Kahane;  
Original Clinical Commentaries;

# ELECTIONS COMMISSION



Soloman "Nico" Moshé,  
Chair

## Commission Members

Peter Wolf (Denmark)  
Giuliano Avanzini (Italy)  
Jerome (Pete) Engel (USA)  
Natalio Fejerman (Argentina)  
Paul Kioy (Kenya)  
Soloman "Nico" Moshé, Chair  
Chong Tin Tan (Malaysia)

## RESULTS OF COMMISSION ON AFRICAN AFFAIRS ELECTIONS FOR THE 2013-2017 TERM

### Commission on African Affairs Chair



Amadou Gallo Diop

### Commission Members 2014-2017

The following have accepted election to the Commission on African Affairs for the 2014-2017 term:



Birinus Ezeala-Adikaibe  
(Nigeria)



Angelina Kakooza  
(Uganda)



Mapoure Njankouo Yacoubou  
(Cameroon)



Jo Wilmshurst  
(South Africa)

The following candidates have been appointed to the Commission on African Affairs



Pierre Luabeya  
(Democratic Republic of  
the Congo)



Sammy Ohene  
(Ghana)

# DIRECTOR OF INTERACTIVE MEDIA



Jean Gotman

## Interactive Media Annual Report 2014

Jean Gotman, Priscilla Shisler, Deb Flower, Steve Shane

### Highlights

The ILAE web site is a major window to the world, reflecting the diversity of the activities of ILAE. We have continued toward our goal of providing useful information about epilepsy to the diverse groups accessing the web site. We primarily target two types of visitors: those who know about ILAE and who come to the web site searching for information related to ILAE activities, and those who are searching the web for information about epilepsy and who end up on the ILAE site. The survey we performed in 2013 indicated that the latter group is the larger one. It is a challenge, however, to present information to such a diverse group.

In 2014, we began implementing an important new aspect of the web site: presenting as much information as possible in languages other than English. We do not plan to translate what is currently on the web site, but rather, to find information that is available in other languages, and post it or place links to it.

In May, we debuted a new home page feature, "Chapter Spotlight," in which we highlight a new chapter each month, using information obtained from national chapters. We began the series with Nigeria, and announce the featured chapter each month in the monthly e-Newsletter.

We transferred the Commission sites out of the Higher Logic web system and integrated them into the ILAE web site. This has saved money and simplified operations. Our original plan of having the Commissions manage their own web site failed and we are now effectively managing the Commission sites in response to their requests.

The number of visits to the ILAE web site has increased continuously in the last 5 years from 118,000 in 2010 to 203,000 in 2014 (Figure 1), and all other visitor metrics continue strong. Graphs and details about web activity are shown in Appendix 1.

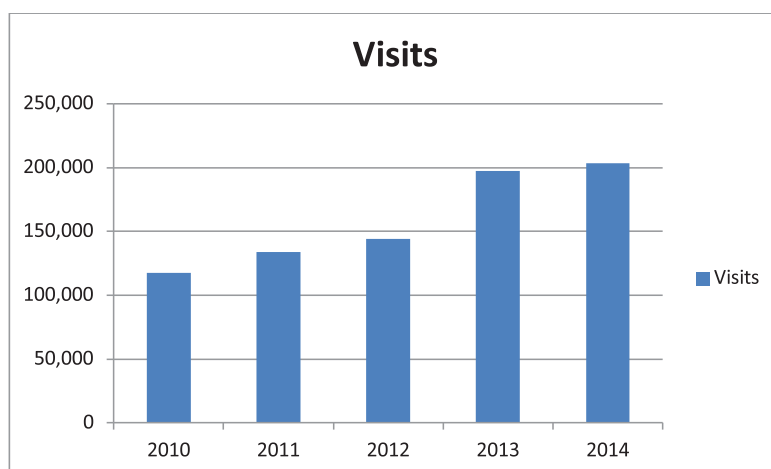


Figure 1

# DIRECTOR OF INTERACTIVE MEDIA (continued)

Our presence on social media has continued to increase with regular posts to Facebook and Twitter. Our Facebook “likes” jumped 143%, to 1,179, and Twitter followers increased 62%, to 374.

We sent monthly e-Newsletters to the ILAE mailing list. During discussions at the meeting of the Communication Task Force, it was decided that occasional mailings from ILAE, for particularly important issues, could also be sent to the Congress (IDE) mailing list and to the *Epilepsia* mailing list. This process has started.

## Operations

Our Web Manager Deb Flower has continued to take care of the many updates and changes we make to the web site. There are updates almost every day, and more important changes to the structure of the site occur frequently. This position is critical for having a responsive, up-to-date and accurate web site. The programmer Steve Shane has provided support for the structural changes to the web site. The daily supervision of activity is provided by Priscilla Shisler. The web team meets for a weekly conference call.

## Major Changes to the web site

### Home page features

We continued our policy of changing the center section of the Homepage approximately every month. We implemented a system of generating reports on regional and international ILAE congresses and have featured these reports after each congress. The following were posted:

6/21/13	New EC members, with links to of the reports of each of the MC members
7/31/13	Stockholm
8/21/13	Montreal post-congress report and photo gallery.
Fall 2013	Upcoming Regional Congresses
12/31/13	Meinardi Farewell
2/4/13	Educational Activities of the ILA 1 <sup>st</sup> education feature: International Congress on Epilepsy, Brain & Mind and Dianalund Summer School (DSSEE)
2/12/14	2 <sup>nd</sup> Education feature: BSSSE and EPODES
3/5/14	3 <sup>rd</sup> Education feature: INES, CAA (Francophone Dakar) & San Servolo.
3/20/14	Revert to showing all 4 regional congresses
5/6/14	Definition of Epilepsy 2014:: Photos, links to commentaries
6/25/14	2nd African Epilepsy Congress (AEC), Cape Town post congress report and photos

### Commission Site Redesign and Platform Migration

- Moved the sites out of Higher Logic to maintain consistency of appearance and ILAE branding, and to promote links between ILAE.org and commission sites, ensure regular reviews of content, and reduce cost by not paying for unused services.
  - Redesigned all 16 commission sites for a consistent, cleaner appearance
  - Automated appearance of photos on members pages, requested more photos from commission members
  - Commissions and Task Forces have begun to actively use and update their pages. Examples include:
-

# DIRECTOR OF INTERACTIVE MEDIA *(continued)*

- **Ketogenic Diet** (Medical Therapies Commission): Has created a microsite of resources for the ketogenic diet for an international audience in several languages. For the 2014 calendar year, two pages of the Ketogenic Diet site, its home page and Centers, were the sixth and seventh most visited Commission site pages, although not launched until May.
- **Neurobiology Commission**: Has provided content for all Commission site pages, and suggested new pages to feature activities of all task forces. WONOEP is particularly active
- **Genetics Blog**:
  - **After some discussion** about moving it to a new platform, we linked to the Genetics Commission Blog, “Beyond the Ion Channel” from the Genetics Commission site, announced it in the January eNews. Add links to the recent blog posts from the Genetics Commission page

## Reach Out/Create Community

Used the website to engage and inform our members and to engage readers; solicit their opinions; and thereby give them ownership in the content.

### Organization of the Epilepsies – Request for Comments

- 131 comments received (11/13/13 – 2/27/14)

### Communications Survey

- Posted and included in May 2014 eNewsletter

### EEG Equipment Bulletin Board:

- Posted requests for used equipment, solicited offers of donation through eNewsletter, Twitter, & Facebook (January onward)

### Social Media:

- Post at least weekly – and sometimes daily – to Facebook & Twitter.
- As of 11/25/14: 609 Twitter followers and 1,179 Facebook “likes”

## Execute Mission

We believe the website should advance the ILAE’s mission to “ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy.”

### *Epilepsia*

We have established a closer working relationship with *Epilepsia* and now promote it more strongly in a permanent prominent space on the home page that is changed weekly. In addition, we continue to post Editor’s Choice and Gray Matters, and feature articles of special interest in our “News” section.

### *Epileptic Disorders*

Created a new section on the website, modeled after *Epilepsia*, to feature our new journal, *Epileptic Disorders*. Monthly “Editor’s Choice” articles appear in the right hand panel of the ILAE home page.

### Patient and care providers

Consolidated information to create a resource page for persons with epilepsy and caregivers



# DIRECTOR OF INTERACTIVE MEDIA *(continued)*

## **Continual Improvements**

Behind the scenes, we undertook changes to improve functionality and freshen content. A total of 378 revisions/additions were made. Examples include:

### **SUFE**

- Featured new photo each week from January 2013 to May, 2014 in a special area of the ILAE home page, linking to larger photo gallery

### **ILAE in translation**

- Created pages for each of eight other languages. These pages included links to chapter sites that are in the language of the page.

### **Commission and Task Force Members**

- All members were revised to reflect leadership changes 7/1/13

### **Communication with Congress Office (IDE)**

- We have a monthly conference call with the Congress Office to ensure coordination between the communication activities of the two groups.

## **Plan for 2014-2015**

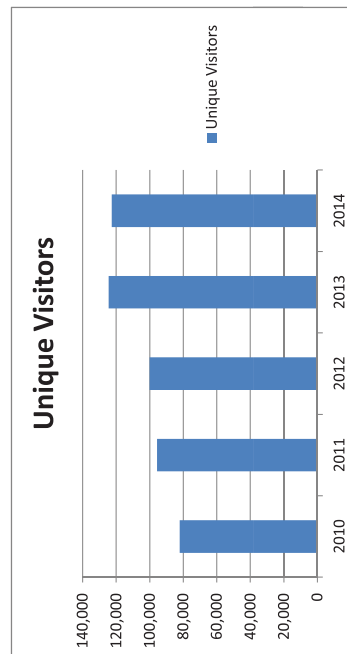
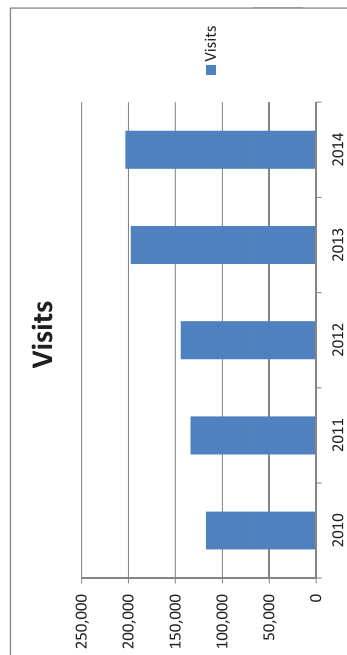
We plan to continue our various activities to provide useful information about ILAE and reach a broad community through the web site, social media and e-newsletters. Particular effort will be placed on increasing the multilingual content of the web site. We will also undertake a revision of the structure of the web site, which has grown in a way that is not sufficiently well-structured. This will not be a major revision but a partial restructuring. We will work in close collaboration with the Communication Task Force. We will continue our efforts to work closely with the publications of ILAE (*Epilepsia*, *Epileptic Disorders*, and *Epigraph*).

# DIRECTOR OF INTERACTIVE MEDIA (continued)

## Appendix 1: Web Statistics

### 2014 Year End Analytics 5 Year Overview

	Site Overview: 5 Years				
	2010	2011	2012	2013	2014
Visits	117,578	133,958	144,360	197,597	203,420
Unique Visitors	82,084	95,662	100,135	124,535	122,634
Page Views	406,796	391,217	426,175	689,009	691,465
Unique Page Views	297,427	291,702	283,901	381,438	409,478
Pages/Visit	3.46	2.92	2.95	3.49	3.40
Avg Visit Duration	0:03:00	0:02:41	0:02:41	0:02:47	0:02:36
Avg time on page	0:01:13	0:01:22	0:01:21	0:01:06	0:01:04
Bounce Rate	49.09%	56.64%	46.54%	31.30%	32.65%
index/home page views	67,871	75,213	83,212	95,281	97,018



**Sessions** (formerly, Visits) represent the number of individual sessions initiated by all the visitors to the site. If a user is inactive on the site for 30 minutes or more, any future activity will be attributed to a new session. Users that leave the site and return within 30 minutes are counted as part of the original session.

**Unique Visitor:** Unique visitors refers to the number of individuals requesting pages from the website during the reporting period, regardless of how often they visit. When an individual goes to a website on Tuesday, then again on Wednesday, this is recorded as two visits from one visitor

**Pageview:** view of a page on the site. A new view for a particular page is counted each time a visitor lands on a page or returns to the page after navigating to a different page.

**Unique page view:** Aggregation of all views of a single page by a single user during a single session. In other words, each page that a user views within one session is counted once, no matter how many times they return to that page.

**Bounce Rate:** The percentage of visitors who enter the site and "bounce" (leave the site) rather than continue viewing other pages within the same site. Visitors who "bounce" only look at the page on which they entered the site.

# DIRECTOR OF INTERACTIVE MEDIA (continued)

## Appendix 1: Web Statistics 2014 YE Analytics Detailed Report

Most Viewed Pages			Page Views		
Page Name	2013	2014	2013	2014	
Home Page	95,438	97,018	68,373	71,695	
Guidelines	33,849	60,908	15,879	27,403	
Congresses	19,077	40,565	11,729	19,283	
Classification & Terminology Reports*	56,792	38,944	25,479	26,290	
2014 Definition	-	24,829	-	11,170	
Epilepsia	20,106	21,272	7,935	9,356	
WIREPA	20,165	16,519	8,892	7,465	
ILAE Sponsored Meetings and Courses	15,984	16,106	7,451	7,103	
Classification -ILAE Index page	9,680	15,684	7,236	10,829	
Definition of Epilepsy (Draft/request for comment	30,010	14,820	13,785	7,926	
CEA home page	11,012	13,177	4,513	9,095	
Chapter landing page & Select Chapter	11,959	10,460	5,705	5,154	
Site search	11,336	10,398	8,461	7,610	
ILAE Congresses	7,845	9,194	6,575	7,759	
Organization of the Epilepsias	3,708	7,162	1,670	3,310	
<b>Total page views for ALL pages</b>	<b>689,009</b>	<b>691,465</b>	<b>381,438</b>	<b>409,478</b>	
Most Viewed Commission Site Pages			Page Views		
Page Name	2013	2014	2013	2014	
Classification Reports*	56,792	38,944	25,479	26,290	
European Commission home page	11,012	13,177	4,513	9,095	
Classification Commission home page	19,786	5,634	7,715	2,936	
Latin America home page	7,572	4,430	3,160	3,124	
Diagnostic Commission: Epilepsy/Diagnosis.org	-	4,232	-	3,503	
Ketogenic Diet (home page)	-	3,992	-	2,275	
Ketogenic Diet (Centers)	-	2,995	-	2,731	
Asia & Oceania home page	5,175	2,319	2,280	1,982	
North America home page	4,119	2,279	1,790	1,681	
Sessions (formerly, visits) by Location (as % of total)			Sessions (formerly, visits) by Location		
	2013	2014	2013	2014	% Change
United States	17.81%	16.31%	35,193	33,181	-5.72%
United Kingdom	8.32%	8.12%	16,438	16,524	0.52%
India	4.98%	5.30%	9,838	10,779	9.56%
Mexico	3.48%	3.70%	6,884	7,532	9.41%
Italy	3.18%	3.18%	6,278	6,472	3.18%
Canada	4.26%	3.08%	8,426	6,258	-25.73%
Germany	3.28%	3.06%	6,473	6,231	-3.74%
Brazil	3.41%	3.05%	6,744	6,197	-8.11%
Australia	2.43%	2.56%	4,798	5,211	8.61%
France	1.83%	1.88%	3,807	3,824	0.45%

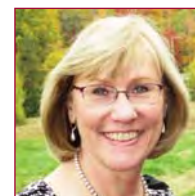
Most Viewed Documents			Views		
Document Name	2013	2014	2013	2014	Unique Views
Practical Clinical Definition of Epilepsy	-	6,127	-	6,127	-
Organization of the Epilepsias (2010)**	7,263	**2,542	7,263	**2,542	6,730
ILAE evidence review of AED efficacy 2013	3,165	2,280	3,165	2,280	2,893
Updated ILAE review of AED efficacy ...	3,165	2,280	3,165	2,280	2,893
New classification proposal (brief 2011)**	6,136	**2,106	6,136	**2,106	5,660
Definition Draft (2013)	5,868	1,664	5,868	1,664	5,402
WIREPA EEG Basic Course Details	1,081	1,430	1,081	1,430	1,549
Organization of the epilepsias-Quick	2,102	1,592	2,102	1,592	1,081
ILAE Treatment Guidelines (2006)	4,197	1,444	4,197	1,444	3,829
WIREPA EEG Basic - Schedule	1,929	1,312	1,929	1,312	1,776
ILAE Org. of the Epilepsias - short talk**	3,049	**898	3,049	**898	664
ILAE Treatment Guidelines PPT	1,290	870	1,290	870	828
Organization of the Epilepsias (2013)	746	845	746	845	1,200
WIREPA Pediatric EEG course detail	84	776	84	776	695
Org. of the Epilepsias 2010 - Spanish**	2,413	**679	2,413	**679	78
Guidelines on Neonatal Seizures	379	663	379	663	78
San Servolo School announcement 2014	113	612	113	612	2,193
Treatment Guidelines Excel spreadsheet	895	590	895	590	347
Guidelines for imaging infants and children	548	501	548	501	102
WIREPA - EEG Advanced Course announcement	-	492	-	492	570
<b>Total document views for ALL documents</b>	<b>59,394</b>	<b>42,763</b>	<b>59,394</b>	<b>42,763</b>	<b>837</b>
					<b>516</b>
					<b>422</b>
					<b>25,752</b>

\* When the commission sites were converted, the classification reports were all moved to the commission site having two almost duplicate pages.  
 \*\* Tracking not available for all of 2014; document tracking wasn't added to commission sites upon conversion;

**Pageview:** view of a page on the site. A new view for a particular page is counted each time a visitor lands on a page or returns to the page after navigating to a different page.

**Unique page view:** Aggregation of all views of a single page by a single user during a single session. In other words, each page that a user views within one session is counted once, no matter how many times they return to that page.  
**Visits** represent the number of individual sessions initiated by all the visitors to the site. If a user is inactive on the site for 30 minutes or more, any future activity will be attributed to a new session. Users that leave the site and return within 30 minutes are counted as part of the original session.

# HEADQUARTERS REPORT



Priscilla Shisler

The first year of the 2013-2017 term has seen the start of many important initiatives and the continuation of others with many successful achievements. All this has been accomplished by incredibly passionate individuals around the world who give their time and expertise daily in service to the mission of the League. The ILAE Headquarters and Chapter Services staff members are equally as dedicated and passionate in their support of the important work of the League. We have had the opportunity and privilege to be involved with many projects, including those listed below.

- Provided assistance to the incoming Commission and Task Force Chairs with invitations for new members and support for business meetings held in Stockholm and via conference call.
- Worked with the Secretary-General to develop the League's newest Chapters in Belarus and Myanmar, both of which will be presented for membership to the General Assembly in Istanbul. Several other Chapter applications are ongoing or nearing completion.
- Maintained the membership database with current Chapter member lists to ensure all Chapters and Regions receive League communications and that all members can have access to Member Registration Rates at League Congresses. We encourage each Chapter to continue to update Gus Egan [gegan@ilae.org](mailto:gegan@ilae.org) at the Chapter Services Office with their member lists.
- Coordinated the largest number of VIREPA courses (9) since the distance education program's inception, including providing support for over 50 Tutors and Course Directors and over 200 students.
- Organized Chapter Conventions for:
  - Commission on African Affairs (2nd African Epilepsy Congress, Capetown, May 2014)
  - Commission on European Affairs (11th European Congress on Epileptology, Stockholm, June 2014)
  - Commission on Asian and Oceanian Affairs (10th Asian and Oceanian Epilepsy Congress, Singapore, August 2014)
  - Latin American Commission (8th Latin American Congress on Epilepsy, Buenos Aires, September 2014)
- Continued to develop the Chapter Poster displays at each of the Regional Congresses, giving all Chapters the opportunity to promote, share and describe the work they are doing on national, regional and international levels.
- Designed and staffed the ILAE booth in Stockholm, which provided a meeting point for Chapters and an opportunity to meet with the staff, pay dues, learn about Congresses and VIREPA courses, and about other Chapters and what's happening in the regions. Note that if there are any suggestions about how the booth

experience can be improved let us know by contacting Gus Egan [gegan@ilae.org](mailto:gegan@ilae.org)

- Worked in close collaboration with Jean Gotman, Director of Interactive Media, to engage readers and solicit opinions via monthly e-Newsletters, periodic reader surveys and requests for comments.
- Continued commitment to keep the website current by refreshing content on a continuous basis, including updating the home page monthly, featuring a new *Epilepsia* article (with illustration) weekly and monthly *Epileptic Disorders* updates, posting regular features on activities and research of note, as well as Chapter Spotlights.
- Redesigned the Regional and Topical Commission websites for a consistent, branded appearance, to promote links between the League's website and the Commission sites and to encourage more active review and updating of content.
- Coordinated and made available translations of select materials into eight languages on the League website.
- Increased the League's presence on social media sites such as Facebook and Twitter.
- Assisted and advised the Treasurer, the Budget Task Force and the Commission Chairs in the development of the annual budget.
- Coordinated with and assisted the Finance Committee and Finance Advisory Committee to ensure compliance with the League's Investment and Cash Management Policies.

I would like to express a heart-felt thank you to the Headquarters and Chapter Services staff with whom I have the privilege to work—Donna Cunard, Gus Egan, Deborah Flower and Verena Hézser-v.Wehrs.



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



Gus Egan is based in the Chapter Services Office in Dublin, Ireland. Gus works with the League's Chapters, coordinates the Chapter Conventions, maintains the Chapter database, liaises with the Secretary-General on the processing of new Chapter applications and promotes the League through the use of the booth.

# HEADQUARTERS REPORT *(continued)*



Verena Hézser-v.Wehrs has been the Lead Coordinator for the VIREPA distance education program since its inception. We were proud when she was awarded the European Epilepsy Service Award 2014 in Stockholm for her work to develop and implement the program. Working closely with the Education Commission, Course Directors and Tutors, she administers, moderates and evaluates the VIREPA program. Verena also collaborates in the development of new courses and formats.



Deborah Flower supports the League in the position of Web Content Administrator and works closely with Jean Gotman to create, execute and maintain web content and functional enhancements. Deborah reaches out regularly to Chapter and Regional contacts for photos and updates and assists with the monthly eNewsletter, Epigraph, and the Annual Report.

Priscilla Shisler, M.Ed.  
*Administrative Director*



# INTERNATIONAL DIRECTOR OF MEETINGS



Richard Holmes

From July 2013 to June 2014, the Congress Team managed 3 congresses: the European Conference on Epilepsy & Society, the 2nd African Epilepsy Congress and the 11th European Congress on Epileptology.

The 10th Asian & Oceanian Epilepsy Congress and the 8th Latin American Congress on Epilepsy followed in August and September respectively.

These congresses had a total of 4,864 attendees, 564 speakers and Chairs, 1,531 abstracts/posters received and 163 bursaries awarded.



## 13th European Conference on Epilepsy & Society, Ljubljana, Slovenia

28-30 August 2013

The organizing committee, chaired by Athanasios Covanis (Greece), comprised 8 members. The congress venue was the Cankarjev Dom Cultural and Congress Centre. There were 218 attendees and 39 countries were represented.

### Conference program:

- The program comprised 14 sessions, with 47 speakers and Chairs.
- The theme of the conference was "Break Down the Barriers and Stand Up for Epilepsy."
- On this occasion and for the first time, the ILAE-CEA made a contribution to the ECES, for a workshop entitled "Advocates for Epilepsy", which took place on the day prior to the main conference program. The workshop focused on topics to develop strategies to help the audience better understand and support the individual living with epilepsy, using a person-centered approach.
- Session topics included "What are the alternatives when drugs don't work?" "Beyond seizures and medication" "How to apply social media with effect and affection" "Women and epilepsy" "Switching brands: What are the issues?" Epilepsy care in Europe."
- There was a lively debate, "Representations of epilepsy in popular culture break down stereotypes" while Group Discussions on "Joining Forces" and "Employment and Epilepsy" completed the program.

### Other highlights:

- All delegates under 35 years of age and delegates from Albania, Estonia, Georgia, Macedonia, Serbia, Russia, Moldova, Ukraine and Bulgaria were entitled to free registration.
- 35 posters were received and 6 bursaries were awarded.



## 2nd African Epilepsy Congress, Cape Town, South Africa

22-24 May 2014

The organising committee, chaired by Amadou Gallo Diop (Senegal) and Anthony Mulenga Zimba (Zambia), comprised 10 members. The congress venue was The Westin Cape Town. There were 287 attendees and 59 countries were represented.

### Congress program:

- The programme comprised 18 sessions, with 62 speakers and Chairs.
- The Main Session "Bridging the Gap in Africa" provided delegates with an overview of epilepsy in Africa, strengthening the epilepsy organisations in Africa, the UNCRPD and continental plan of action, as well as epidemiology of epilepsy in Africa. Session topics included: "Diagnosis of epilepsy"; "Causes of epilepsy"; "Treatment options"; "Childhood epilepsy"; "Management of epilepsy."
- Interactive Round Table Discussions took place on "Epilepsy surgery in resource-poor settings"; "The role of EEG"; "Educational programmes in epilepsy" and "Epilepsy management guidelines and their implementation".
- An information session "How to get your paper published" provided an insight into how to get published in the two leading epilepsy journals, *Epilepsia* and *Epileptic Disorders*.
- A joint ILAE/IBE session addressed what is being done to target improved care for patients with epilepsy in various African regions.
- The Epilepsy and Society Day Seminar took place on Saturday, focusing on topics such as "Epilepsy and the family", "Traditional healers" and "Anti-epileptic drugs – availability, affordability, continuity of supply."

# INTERNATIONAL DIRECTOR OF MEETINGS *(continued)*

## Other highlights:

- Two sessions in particular were especially innovative for Africa. The theme on the ketogenic diet illustrated that the diet is possible and effective even in a resource-limited setting. The session on education programs was most important: Without finding innovative and relevant ways to raise awareness of epilepsy, affected persons are not able to access care.
- 103 abstracts were received and 25 bursaries were awarded.



## 11th European Congress on Epileptology, Stockholm, Sweden 29 June-3 July 2014

The organizing committee, chaired by Meir Bialer (Israel) and Kristina Malmgren (Sweden), comprised 7 members, and the scientific committee, chaired by Torbjörn Tomson (Sweden), comprised 10 members. The congress venue was Stockholmsmässan. There were 2300 attendees and 91 countries were represented.

## Congress program:

- The program comprised 100 sessions, with 263 speakers and Chairs.
- 4 main themes: basic science; epilepsy surgery; pharmacotherapy; pediatric epileptology. Chairs' Symposium dedicated to prevention in epileptology in its broadest sense.
- Interactive session on the use of the proposed ILAE Classification and organization of seizures and epilepsies; ILAE-CEA / European Sleep Research Society joint symposium; Epilepsy Advocacy Europe symposium.
- Two sessions with a special historical perspective: Unverricht-Lundborg Disease from 1891 to 2014 and Carbamazepine 50th Year Anniversary Symposium.
- Teaching sessions featured three attractive morning series run over three days.
- ECE teaching day on last day of congress—full day course Pharmacological treatment of epilepsy; 2 courses targeting epilepsy nurses and EEG technicians; ECE Forums for interactive discussions focusing on new topics or projects of special interest.

- More time allocated to platform presentations and poster sessions with guided tours and poster highlight sessions.

## Other highlights:

- Nobel theme followed from the London ECE to the home town of Alfred Nobel, with a lecture about the man behind the Prize during the Welcome Ceremony and an exhibit from the Nobel Museum.
- Awards presented: European Epileptology Award; European Epilepsy Education Award; Young Investigator Awards; European Epilepsy Service Awards.
- 807 abstracts were received and 51 bursaries were awarded.



## 10th Asian & Oceanian Epilepsy Congress, Singapore

7-10 August 2014

The organizing committee, chaired by Byung-In Lee (Korea), Shih Hui Lim (Singapore) and Vinod Saxena (India), comprised 9 members. The venue was the Grand Copthorne Waterfront Hotel. There were 1,305 attendees and 51 countries were represented.

## Congress program:

- The programme comprised 47 sessions, with 105 speakers and Chairs.
- Broad range of topics selected from recommendations from Asian & Oceanian ILAE chapters and IBE members. Main session topics: The Chairman's Symposium: "AED tolerance and resistance"; "Epilepsy burden"; "Neurostimulation in the treatment of epilepsy"; "Electrophysiological markers of the epileptogenic zone."
- The Masakazu Seino Memorial Lecture: Recent advances in molecular genetics of epilepsy.
- The main sessions were complemented by a comprehensive mix of post main and parallel sessions, didactic lectures, video quizzes, debates, forums, workshops and teaching courses. The Tournament of the Brainwaves quiz was a new feature.

# INTERNATIONAL DIRECTOR OF MEETINGS *(continued)*

- The day-long Epilepsy & Society Symposium covered topics ranging from anticonvulsants to stigma at work and school, and the truth about reflexology and stem cell therapy for epilepsy as well as heartfelt sharing from people with epilepsy and caregivers. The day was rounded off with an innovative mini fair.

## Other highlights:

- Awards presented: The Tadokoro Prize (for the 2 best poster and platform presentations), the Asian and Oceanian Outstanding Achievement Epilepsy Awards, the Outstanding Persons with Epilepsy Awards.
- 400 abstracts were received and 45 bursaries were awarded.



## 8th Latin American Congress on Epilepsy, Buenos Aires, Argentina

17-20 September 2014

The organizing committee comprised 5 members. The venue was the Hilton Hotel Buenos Aires. There were 754 attendees and 37 countries were represented.

## Congress program:

- The program comprised 30 sessions, with 87 speakers and Chairs.
- The scientific program took place over 3½ days with courses taking place on the first day.
- In parallel with the courses, an IBE day organized by the local IBE association took place on the first day.
- In addition to courses, the program included 21 sessions, 2 platform sessions, 2 sponsored sessions (included 1 satellite symposium) and poster tours on 2 days.
- Topics covered included epilepsy surgery, epilepsy and women, genetics, special epilepsy syndromes, pediatric syndromes, social issues, antiepileptic drugs, basic science, classification, and epilepsy and physical activity.

- The program also included the Academia Latinamericana de Epilepsia (ALADE) courses on pharmacotherapy, Epilepsy EEG and Seizure Semiology; an "Update in Epidemiology in Latin America"; "The new ILAE proposal for classification of seizures and epilepsies"; "How to get published in *Epilepsia* and *Epileptic Disorders*"; "Epilepsy in the tropics: current impact"; "Castells and Mendilaharsu Symposium: advances in juvenile myoclonic epilepsy."

## Other highlights:

- The congress opened with a Presidential Symposium followed by the Welcome Ceremony.
- A workshop Epitango was held one evening, exploring the connection between the tango, an important part of Argentinian culture, with neuroscience, especially the brain mechanisms involved in the synchronization of brainwaves and its therapeutic effects in neurological diseases.
- 186 abstracts were received and 36 bursaries were awarded.

## Future Congresses

The Congress Team is currently working on arrangements for the upcoming congresses in 2015 (3rd EMEC Amman, 31st IEC Istanbul), in 2016 (12th ECE Prague, 3rd AEC, 11th AOEC, 9th LACE), as well as the IECs in 2017 and 2019.

Richard Holmes  
*International Director of Meetings*  
*October 2014*



# Task Force Reports 2013 – 2017

# COMMUNICATIONS TASK FORCE



Jean Gotman

## Chair

Jean Gotman (Canada)

## Members

Alexis Arzimanoglou (France)  
Ed Bertram (USA)  
Fernando Correia (Portugal)  
Phil Gattone (USA)  
Kheng Seang Lim (Malaysia)  
Gary Mathern (USA)  
Mark Morton (UK)  
Astrid Nehlig (France)  
Torbjörn Tomson (Sweden)

## MC Liaison

Helen Cross (UK)

## Identification of the Situation

The Task Force (TF) came into existence in the Fall of 2013. It held a teleconference in November 2013, then a short face to face meeting at the AES in December 2013, followed by more teleconferences and a full day of meeting at the European Epilepsy Congress in June 2014 in Stockholm.

The TF first identified the following as the current means by which the ILAE communicates with the outside world:

- The Epigraph Newsletter
- The ILAE website
- The Congress website
- The Congress-related electronic newsletters
- The ILAE electronic newsletters
- The letters sent to government officials (part of specific projects)
- In a special category, the journals (*Epilepsia* and *Epileptic Disorders*)
- The Gray Matters section of *Epilepsia*

The TF also identified a few important points regarding the communication needs of the League. A survey of users of the ILAE website was conducted in early 2013 and one of its main findings was that a diverse public accessed the website, including a significant proportion of medical professionals and lay individuals not related to the League's chapters. The Management Committee indicated that the League is the primary source for information on epilepsy for experts. Knowing that persons with epilepsy and caregivers are also accessing this information meant that some of it should also be provided in lay format, both in the journals and on the website. It was agreed that the League should overtly project the message that it is the primary source of information on epilepsy for health care professionals, and this is likely to lead non-professionals to the site as well. It was noted that the League generates a lot of content, some of which could be very useful to patients,

but not in a way that is optimal for communication, particularly for para-professionals and lay people. Collaboration with IBE may be sought in this respect. The issue of presenting information in languages other than English was raised. The question of coordination of communication activities between our various branches (website, congress organization, journals, different newsletters) was raised.

## Actions by the Task Force

A survey on the current use of the main ILAE communication channels was sent in May 2014 to the ILAE mailing list. Approximately 650 answers were received. An executive summary of the answers is shown below. A first discussion of these results took place at the full day meeting of the TF held in Stockholm during the European Congress. It was felt that the results constitute a useful baseline against which we can gauge changes in the future. *Epilepsia* and the website appear to reach the highest number of participants, whereas the other three items reached levels that could be improved, particularly Gray Matters.

It was decided that Commission and Task Force Reports that are to be published or posted on the website should have a one page lay summary. Instructions on how this should be done will be included in the Commission Manual.

It was decided that the ILAE website should endeavor to create content or links to content in at least the following languages: Chinese, Spanish, French, Russian, Arabic, possibly Portuguese.

The TF recommended that each Congress Organizing Committee designate a person during the planning process to write an article on the highlights of the Congress, including photographs. These reports will be posted prominently on the website.

The TF also recommended that we improve communication between the various ILAE-related offices: the executive office, the journals and the congress office. This is particularly important in the context of sending emails and coordinating messages.

A set of professionally filmed and edited patient/primary care educational videos were created at very low cost as a trial venture a few years ago through an agreement with a company called Knowlera Media. Working with Ed Bertam, they produced and distributed the videos through their various media partners. The League is acknowledged in the videos. Knowlera Media has invited us to do a new series of videos. Suggested topics include safety tips for teachers, tips for dating, job hunting, ketogenic diet, etc. Ed proposed that if there is interest in doing



# COMMUNICATIONS TASK FORCE (continued)

another set that it be done in collaboration with IBE. There was consensus to move forward with this initiative in collaboration with IBE (Ed to evaluate with MC and IBE).

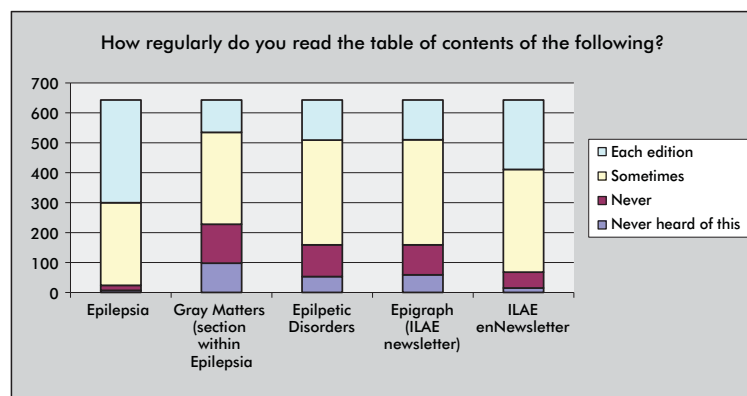
effectiveness in light of its increased complexity.

Finally the TF recommended that the ILAE website be reviewed to ensure its continued viability and

## Summary of Survey Results

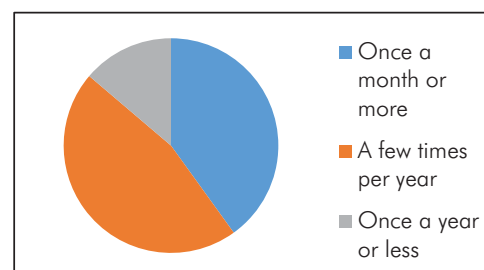
1. How regularly do you read the table of contents of the following?

Answer Options	Each edition	Sometimes	Never	Never heard of this	Response Count
Epilepsia	343	276	17	7	643
Gray Matters (section within Epilepsia)	108	307	130	98	643
Epileptic Disorders	134	350	106	53	643
Epigraph (ILAE newsletter)	133	351	100	59	643
ILAE eNewsletter	232	343	53	15	643
				answered question	643
				skipped question	0



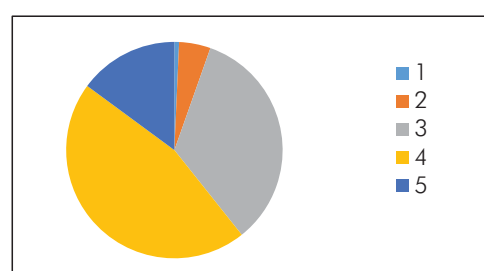
2. How often do you visit the ILAE website?

	Response Percent	Response Count
Once a month or more	40.1%	256
A few times per year	46.2%	295
Once a year or less	13.8%	88
answered question		639
skipped question		4



3. If you visit the ILAE website, rate it between 1 (poor) and 5 (excellent)

Answer Option	Response Percent	Response Count
1	0.7%	4
2	4.7%	27
3	33.9%	196
4	45.8%	265
5	14.9%	86
answered question		578



# EPILEPSY GUIDELINES TASK FORCE



Nathalie Jetté

## Chair

Nathalie Jetté (Canada)

## Members

Jo Wilmschurst (South Africa)  
Nobukazu Nakasato (Japan)  
Yuping Wang (China)  
Sanjeev Thomas (India)  
Colin Dunkley (UK)  
Eva Kumlien (Sweden)  
Jozsef Janczy (Hungary)  
Emilio Perucca (Italy)  
Horacio Senties (Mexico)  
Solomon Moshé (USA)  
Khara Sauro (Canada)

## MC Liaison

Samuel Wiebe (Canada)

## Subcommission Members

Colin Dunkley (UK)  
Emilio Perucca (Italy)  
Alejandro deMarinis (Columbia)  
Jacqueline French (USA)  
Nathalie Jette (Canada)  
Khara Sauro (Canada) - PhD student  
Samuel Wiebe (Canada)

## Aims

### Aims of Original Task Force:

1. Systematic review of published epilepsy related guidelines
2. Identification of gaps in guidelines
3. Recommendations regarding which guidelines need to be updated

### Aims of Clinical Practice Guidelines Process Working Group

1. Examine what guideline development processes currently exist (e.g. AAN, NICE, SIGN)
2. Examine what grading systems are available to grade the evidence
3. Develop a framework for epilepsy related clinical guideline development that will be recommended for guidelines that will be endorsed by the ILAE

Not applicable - see Aims

## Commission Activities from June 2013 through June 2014

This original Task Force completed the search for a systematic review (7 databases and 6 grey literature sources) to identify epilepsy/seizure related clinical guidelines in all languages; 9766 abstracts have been screened in duplicate with 359 full text articles (13 languages) also screened in duplicate for

eligibility. Forty-nine guidelines have been identified for inclusion in the systematic review. Data has been abstracted in duplicates and manuscript writing is in progress to synthesize the evidence. Next steps will be to identify the gaps in guidelines and highlight key areas for future directions. The group met at the American Epilepsy Society meeting in Seattle in December 2014 to plan the final steps for this original group.

The Process Working Group reviewed the clinical practice guidelines development frameworks from key organizations (e.g. AAN, IOM, SIGN, WHO, etc.). The group then reached consensus on which aspects from each guideline development framework should be incorporated in the future ILAE guideline development framework. Tools to evaluate the quality of the evidence were also reviewed and the group agreed to use the GRADE. A number of documents with educational resources have been developed to guide ILAE chapter members on the process involved in developing high quality guidelines. To date, the following documents have been developed: introduction to clinical practice guidelines (terminology, etc.), methods regarding how this framework was developed, and documents on how to grade the evidence and how to formulate recommendations. The group will complete the last series of articles with expected timeline of spring 2015 for the full series to be published. The group will continue to work with GRADE experts to also develop additional knowledge exchange materials for ILAE chapter members.

## Accomplishments (2013-2014)

As noted above (Commission activities from June 2013-June 2014)

## Recommendations for Future Work

The work of these groups is expected to be completed in fall 2015. Future work will be in the hands of the Process Working Group, which will finalize its series of documents on how to develop high quality clinical practice guidelines. The group will also hold a guidelines development process symposium at the International Epilepsy Congress in Istanbul (Sept. 2015). A demonstration project that will test the usability and feasibility of the new framework will also take place.

# ICD-11 TASK FORCE



Donna Bergen

## **Chair**

Donna Bergen, MD (USA)

## **Members**

Ettore Beghi (Italy)

Dale Hesdorffer (USA)

Nathalie Jetté (Canada)

Marco T. Medina (Honduras)

## **MC Liaison**

Solomon L. Moshé (USA)

## **Liaison to Classification Commission**

Sameer M. Zuberi (UK)

## **Aims**

To prepare an analysis of the relationship of various classification and terminology sets, specifically ICD-9, ICD-10, and the revised ILAE classification and terminology of seizures and epilepsy. The ICD-11, recently prepared, will also be reviewed.

**Mission:** To prepare a manuscript dealing with the results of this analysis, to clarify these issues for clinicians and others.

## **Commission Activities June 2013 through June 2014**

Several phone conferences were held, with lengthy discussions about the best way to make this analysis and to present the results. A meeting in person was held in Stockholm at the ILAE congress, with the chair participating via Skype. A consensus about the shape of the draft manuscript was reached, and the first draft was prepared with most members contributing segments reflecting their particular expertise and experience. A final draft was written and assembled by Dr. Jetté, and extensively critiqued and revised by the other members. It was estimated that the final manuscript would be ready for submission to the ILAE by the end of August.

## **Accomplishments (2013-2014)**

The manuscript was finalized on 31 Aug. 2014 and will be submitted as a white paper.

## **Recommendations for Future Work**

A similar project should be aimed at the ICD-11 when it is

# GLOBAL OUTREACH TASK FORCE



Alla Guekht



Mary Secco

## Co-Chair

Alla Guekht (Russia)  
Mary Secco (Canada)

## Members

Hanneke de Boer (Netherlands)  
Thanos Covanis (Greece)  
Emilio Perucca (Italy)  
Helen Cross (UK)  
Tarun Dua (Switzerland)  
Silvia Kochen (Argentina)  
Shichuo Li (China)  
Alexandra Martiniuk (Australia)  
Sammy Ohene (Ghana)

## Aims

### Goals of the Task Force:

1. To improve the visibility of epilepsy and the activities of the Global Campaign
2. To promote activities of all epilepsy projects on a country and regional level
3. To assess and strengthen healthcare systems for Epilepsy a. Increase partnerships and collaboration with other organizations
4. To eradicate stigma and discrimination through education

## Commission Activities

June 2013 through June 2014

### Meeting “Improving Access to AEDs in Low- and Middle-Income Countries”

The meeting took place in the WHO Collaborating Center “Oasi Maria SS.” based in Troina, Italy, and was organized in collaboration with the World Health Organization, the International League Against Epilepsy and the International Bureau for Epilepsy.

Given the importance of access to antiepileptic medicines, this workshop brought together key stakeholders to discuss opportunities for achieving long-term affordable access to essential medicines for epilepsy in low- and middle-income countries.

According to the meeting structure, the key issues from the DEMAND and SUPPLY perspectives were presented, discussed in detail and evolved into the working plan that will become a white paper. The working group will look at many facets of the treatment gap including diagnostic and therapeutic deficits; lack of personnel (manpower gap); limited AED supply; poor adherence to medication; economic conditions and cultural beliefs. A number of demands, especially important for the lower and middle-income countries were acknowledged, including the role of non-specialist healthcare providers and the impact of ignorance and stigma.

The need to update the Essential Medicine List was identified. The steps to create and disseminate the white paper were planned.

From the SUPPLY perspective, workshop participants agreed on the need for a template for conducting situation analyses on country-by-country basis. The importance of the support of the development of Standard Treatment Guidelines was stressed, as was the importance of working with the WHO Prequalification Program to include AEDs. The challenges of funding low cost, effective treatment and the need to support the collection of data surrounding procurement, availability and selling prices (therapeutic group survey) were presented.

## Young Adult Summit

Twenty young adults ranging in age from 21 to 29 came together in Washington, D.C. to identify a project the group could spearhead that would improve the lives of other young adults living with epilepsy.

The invitational summit was supported by the Epilepsy Foundation and the North American Region—of the International Bureau for Epilepsy (IBE). Participants from across the North America Region: United States, Canada, Jamaica and Puerto Rico—competed for the right to attend this inaugural summit. Each participant was asked to submit a one-page personal statement with details of how epilepsy had impacted their life. The multinational group brought a wide and important range of personal and lived experience.

The goal of the weekend was to provide an opportunity for the young adults to share inspirational stories of struggle, resolve and perseverance. It was also to

# GLOBAL OUTREACH TASK FORCE *(continued)*

identify a project that the group could champion to affect change at the international level. Epilepsy education was a consistent theme among many of the projects discussed. Ultimately, the group chose a project that aims to educate and inspire through the sharing of their personal stories. The stories will be taped and distributed using social media channels.

## **Accomplishments (2013-2014)**

Collaboration with the World Federation of Neurologists (WFN) with the focus on the World Brain.

## **Alliance**

The mission of the WFN is to foster quality neurology and brain health worldwide through the promotion of global neurological education and training. The Task Force enhanced ILAE involvement in various educational initiatives of the WFN, including the World Congresses that could be an important platform for the ILAE, and promoted collaboration between ILAE and WFN leadership. The WFN has created the World Brain Alliance (WBA) to further their mission and has invited the ILAE to be one of 10 member organizations in this collaborative.

## **Recommendations for Future Work**

- Initiatives towards improvement of the visibility of epilepsy (contacts with Russian, Azerbaijan and Uzbek Ministries of Health)
- Activities targeted on the amelioration of treatment gap in the European Central Asia regions (in collaboration with CEA), including Astana event in 2015



# PUBLICATIONS TASK FORCE



Torbjörn Tomson

## Chair

Torbjörn Tomson (Sweden)

## Members

Alexis Arzimanoglou (France)  
Ed Bertram, III (USA)  
Jean Gotman (Canada)  
Gary Mathern (USA)  
Astrid Nehlig (France)

## MC Liaison

Emilio Perucca (Italy)

## Aims

Priority has been given to developing and clarifying the distinct roles of the two ILAE journals, *Epilepsia* and *Epileptic Disorders*, in order to guide potential authors as well as the readership.

The Publications Task Force was formed in 2013 to assist the ILAE in matters related to the ILAE publications.

## Commission Activities June 2013 through June 2014

The Task Force has had two face-to-face (December 6, 2013, Washington, DC and February 26, 2014) Hoboken, NJ, Teleconference June 13, 2014.

## Epileptic Disorders

**Mission:** Create educational links between epileptologists and other health professionals in clinical practice and scientists or physicians in research-based institutions.

**Target readership:** Physicians and other health professionals involved in the diagnosis, management and care of persons with epilepsy.

**Target authorship:** Experts in any epilepsy-related domain that can provide the readership with manuscripts of outstanding educational value to enhance optimal epilepsy care and research

### Types of articles

- Articles on new case series, or case reports, with a meaningful value for everyday clinical practice (in terms of seizure semiology, treatment, neurophysiology, neuroimaging

and neuropsychology);

- Commentaries and viewpoints, updates on recent developments, and comprehensive seminar manuscripts of high educational value to the practicing clinician;
- Review articles summarizing the state-of-the-art on specific topics, of high educational value to neurologists and child neurologists with an expertise in epilepsy;
- Educational documents supportive to ILAE Commissions and Task Force reports.
- Video teaching material for clinicians and basic science researchers

### Special features:

- Ability to accompany all manuscripts with video material or other multimedia supplemental data (video-EEG; neuroimaging; neuropathology; neurosurgery techniques)
- Supplements on educational topics of particular interest to a region or country (including educational material in languages other than English).

The Task Force has also suggested awards for outstanding publications that will further reflect the distinct profiles of the two journals. The Epilepsia Prize will award original research articles in the journal whereas the Epileptic Disorders Education Prize will recognize the best educational contribution to the journal.

## Accomplishments (2013-2014)

The essence of this work to clarify and fine tune the profiles of the two journals has been expressed and summarized in the following brief descriptions of *Epilepsia* and *Epileptic Disorders* that have been posted on the ILAE website.

**EPILEPSIA Mission:** *Epilepsia* is one of the journals of the ILAE. The Journal publishes original articles on all aspects of epilepsy, clinical and experimental. The journal also publishes timely reviews, as well as commission and task force reports from various ILAE groups.

**Target readership:** Professionals and experts who treat and do research related to all aspects of epilepsy.

**Target authorship:** Any healthcare professional, clinical researcher or basic scientist involved in epilepsy related research

### Types of articles:

- Regular articles and brief communications

# PUBLICATIONS TASK FORCE *(continued)*

(excluding single case reports unless of particular clinical or research importance).

- Invited reviews, Commentaries, and Controversies require approval prior to submission or they will not be accepted for peer review.

**Special features:** Supplements are considered based on topic. Prospective authors should contact the editorial office at [epilepsia@epilepsia.com](mailto:epilepsia@epilepsia.com).

## **Recommendations for Future Work**

Continue to monitor the development of the two journals and their profiles, and to contribute to the development of the overall ILAE publications strategy.

# RESEARCH ADVOCACY TASK FORCE



Shichuo Li

## Chair

Shichuo Li (China)

## Members

Ding Ding (China)  
Jaime Fandiño (Colombia)  
Alla Guekht (Russia)  
Margaret Jacobs (USA)  
Pierre MK Luabeya (DR Congo)  
Gay Mitchell (Ireland)  
Terence O'Brien (Australia)  
Makiko Osawa (Japan)  
Mary Secco (Canada)  
Andy Shih (US)

## ILAE President, Ex Officio

Emilio Perucca (Italy)

## IBE President, Ex Officio

Athanasios Covanis (Greece)

## Aims

**Long term goal:** To facilitate international synergism in promoting research for epilepsy.

**Short-term goal:** To stimulate and promote the collaborative research for epilepsy in Asian-Oceanian region.

To initiate and advocate with governments and international institutions about the need to support epilepsy research. Encouraging and promoting regional and international collaboration is another important target. Strategies should include not only connecting with politicians, but also mobilizing the public.

## Commission Activities

### June 2013 through June 2014

1. March 26, 2014: Research Advocacy Task Force (RATF) teleconference: to discuss the composition of the RATF and the Mission, target and work plan of the RATF;
2. June 20, 2014: OASI, Troina, Sicily, Italy: Informal meeting, to discuss new members to be invited and complete the RATF composition;
3. Prepared "IBE Statement" in the WHO Western Pacific Regional Committee Meeting on Oct. 13 - 17, in Manila, Philippines. Participated in the RCM *Shichuo Li* as IBE's

representative to promote strategic action for epilepsy in WHO/WP region;

4. Submitted a proposed subject, "Global burden of epilepsy and need for a coordinated action at the country level to address its health, social and public knowledge implications" to be discussed in the WHO Executive Board Meeting in January 2015 through the China National Health & Family Planning Commission (underway);
5. Prepared a face-to-face RATF meeting during the AES Annual Meeting in Seattle, USA in December to further discuss the action plan of the RATF.

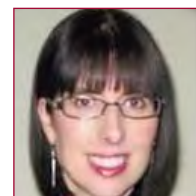
## Accomplishments (2013-2014)

See above-mentioned

## Recommendations for Future Work

1. Conducting a survey to collect information on the current situation of epilepsy research and on perceived priorities for epilepsy research, beginning with Asia-Oceanian ILAE chapters and IBE associations.
2. Making a coordinated advocacy plan for epilepsy research.
3. Attending meetings of policy makers at different levels (country, region, global, WHO), and calling on the support of epilepsy research.
4. Organizing a workshop for the exchanging of epilepsy research, and to provide an opportunity for collaboration. (This can be held at the IEC or regional epilepsy congresses).
5. Developing a close relation with associations or organizations of other conditions which can be important co-morbidities of epilepsy (e.g. autism, mental disorder, etc.), and trying to find opportunities for collaboration.
6. Promoting large sampled and multi-centered collaborative studies across regions with different ethnicities, especially encouraging developing countries to participate in existing collaborative projects in EU and US.

# STIGMA TASK FORCE



Nathalie Jetté

## Chair

Nathalie Jetté (Canada)

## Members

Gretchen Birbeck (Zambia/USA)  
Manjari Tripathi (India)  
Hanneke de Boer (The Netherlands)  
Ann Jacoby (United Kingdom)  
Helen Cross (United Kingdom)  
Janet Mifsud (Malta)  
Tarun Dua (Switzerland)  
Amza Ali (Jamaica)  
Patricia Braga (Uruguay)  
Paula Fernandes (Brazil)  
Samuel Wiebe (Canada)  
Kirsten Fiest (USA)  
Nico Moshé (USA)  
Karen Parko (USA)

## Aims

1. To carry out an up-to-date international systematic review focusing on epilepsy-related stigma: Tools to measure it, frequency and nature of stigma, and interventions to address it.
2. To make recommendations regarding gaps and future research needs in the area of epilepsy-related stigma.

## Commission Activities

The group has been working on a very comprehensive systematic review of the evidence regarding stigma in epilepsy. This has been the primary activity all year.

## Accomplishments (2013-2014)

- Completed full-length data abstraction for the intervention (n=11) and tool development (n=27) for full-text articles.
- Completed short-form data abstraction for the factors related to and frequency of stigma articles (n=271) to identify potential duplicate studies.
- Began long-form data abstraction (short-form work carried over) for all frequency/factor articles—this work is well under way.

- First drafts of the intervention and tool development manuscripts have begun and are expected to be completed by March 2015.

## Recommendations for Future Work

- The task force will make recommendations regarding future direction in the area of stigma in epilepsy.
- Results of our work to date suggest that the following are needed:
  - Investigate the mechanisms of stigma in epilepsy
  - Assess stigma in epilepsy longitudinally, as most studies are cross-sectional
  - Establish recommendations for tools to measure stigma in epilepsy through validation
  - Determine if there are long-lasting benefits to stigma education programs
  - Examine the impact of stigma on persons with epilepsy, their caregivers, family, and society in the short and long term
  - Address the different aspects of stigma: enacted and felt; internalized, interpersonal, and institutional

All of the above recommendations for future work should take a patient-centered approach.

Report by:

*Nathalie Jetté & Kirsten Fiest*



# Regional Commissions 2013-2017

# COMMISSION ON AFRICAN AFFAIRS



Amadou Gallo Diop

## Chair

Amadou Gallo Diop (Senegal)

## Members

### Secretary General

Yacouba Njankouo Mapoure (Cameroon)

### Treasurer

Angelina Kakooza (Uganda)

### Education Officer

Jo Wilmshurst (South Africa)

### Research Officer

Pierre Luabeya (DR Congo)

### Communication Officer

Birinus Ezeala Adikaibe (Nigeria)

## Subcommissions and Members of Task force on Access to care:

Chair: Sammy Ohene, (Ghana)

## Aims

1. To set up the organization of the commission on African Affairs,
2. To strengthen the communication and ILAE global outreach campaign of the CAA,
3. To establish and strengthen the education activities of the CAA,
4. To improve the access to care for patients with epilepsy,
5. To establish and co-ordinate epilepsy-related research activities in the African continent.

## Mission of the Commission

The ILAE Commission on African Affairs shall serve all health professions in Africa as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.

## Commission Activities July 2013 through June 2014

### 1. CAA Board Activities

1. Participation in Montreal International Epilepsy Congress, with CCA Board meeting on 22 June 2013
2. Participation in 9th International Congress of Societe Francaise de Pathologie Exotique, Dakar, 13 November 2013, and updating on Epilepsy in Africa
3. Participation to PAANS, Abidjan, 14 March

- 2014 and updating Epilepsy in Africa
4. Organization of the 2nd African Epilepsy Congress, Cape Town, 22-24 May 2014 (see below)
5. Board Meeting of CAA, Cape Town, 21 May 2014
6. Convention Chapters meeting, Cape Town, 21 May 2014
7. Participation in Executive Committee of ILAE, Stockholm, 27 June 2014

### 2. Election of New Members:

The following have accepted election to the Commission on African Affairs for the 2014-2017 term:

Chair: Amadou Gallo Diop (Senegal)

Secretary-General: Yacouba Njankouo Mapoure (Cameroon)

Treasurer: Angelina Kakooza (Uganda)

Education officer: Pr Jo Wilmshurst (South Africa)

Research Officer: Pr Pierre Luabeya, (DR Congo)

Communication Officer: Birinus Ezeala Adikaibe (Nigeria)

### 3. The 2nd African Congress on Epilepsy (ACE) held in Cape Town from 20 to 24 May 2014:

287 participants from worldwide attended the ACE. This participation rate was relatively inferior to the 1st Congress due to reduced number of paramedical participants. Concerning the venue of the 3rd ACE, Dakar (Sénégal) officially expressed its candidacy. Other African towns were also suggested: Accra (Ghana) and Addis-Ababa (Ethiopia). The final decision should be made by the ILAE Executive Committee.

**4. Communication:** The CAA newsletter is now published only electronically to reduce the cost. During the convention in Cape Town, the need to share information, between people involved in the domain of epilepsy was recognized. It was then recommended to communicate all information relative to training and bursaries to researchers and caregivers. Also, each chapter was encouraged to send or share their activity with the Communication officer for public diffusion.

**5. Education:** There is a need to organize training in the field of epilepsy in Africa but the main difficulty is not only the language barrier (English, French and Portuguese) but also the financial constraints. It was advised to introduce a new vision consisting of many associate partners (WFN, IBRO, SONA, PAANS, EAN,



# COMMISSION ON AFRICAN AFFAIRS *(continued)*

AAN, PAUNS, specialized neuro-societies) when organizing a training session. In this plan, a training on epilepsy for residents in neurology was organized in the Republic Democratic of Congo in September 2014 (convener: 2 Pierre Luabeya).

**6. Global Campaign against Epilepsy:** Progress has been made in some countries. But this remains insufficient and there is a need to involve more countries that are not yet ILAE-IBE Chapters. An awareness raising at World Health Organization (WHO) is currently done with the update document on epilepsy in Africa. The aim is to sensitize each African health ministry through WHO for doing something for epilepsy regarding: diagnosis, treatment, social implication (stigmatization, discrimination). The update document contains data from each country relative to population, care personnel and facilities, and socio-cultural and economic situation. The document is in the correction and publishing process within WHO-AFRO.

**7. New Chapters:** After the Montreal IEC General Assembly CAA officially has 3 new chapter members: DR of Congo, Cote d'Ivoire and Rwanda. Suggested to the ILAE Executive Committee to facilitate the integration of other African countries to the ILAE. Eight new African States have sent their candidacy to become members: Angola, Burkina Faso, Ethiopia, Malawi, Mozambique, Sierra Leone, Sudan and Zambia. Burkina Faso has succeeded in reorganizing its chapter. We hope to see it back in ILAE.

**8. Financial Matters:** Angelina Kakooza gave a brief report of the financial situation of the ILAE's CAA: \$97,000 US represent the global inflow. Presently, \$48,000 US are available. But this is quite different from \$113,000 US supposed to be available for CAA. Emilio suggested that for future Congress, CAA members should be chosen as speakers so that the Congress can pay their registration and accommodation fees.

## **9. News from Chapters:**

1. Benin: implementation of new education activities with new printed documents.
2. Cameroon League against Epilepsy organized a workshop for general practitioners and nurses in rural areas on the diagnosis and treatment of epilepsy.
3. Côte d'Ivoire: implementation of new training activities.

4. Mali: implementation of new education activities with new printed documents and care with generic forms of VLP and PHE, especially in rural areas.
5. Nigeria: Despite security instability in Nigeria, the Nigerian League Against Epilepsy achieved activities including sensitization of the population on epilepsy during World Epilepsy Day, research (many communications during the 2nd ACE and Congress at Montreal, Canada) and the establishment of the Nigerian Bureau of Epilepsy.
6. Senegal: 4th promotion of the University Diploma of Epileptology of Dakar University with 11 new epileptologists from 8 African countries. Forty three epileptologists have been trained since 2010. Two TV shows and 4 radio broadcasts for public awareness have been realized in public and private media. The weekly consultations of epileptology are still organized every Wednesday at Pikine, a sub-urban area of the capital city of Dakar. Pharmaceutical company Sanofi has given to the SLAE two brand-new EEG machines.
7. South Africa has held the 2nd AEC with success. In this country, the fight against epilepsy is conducted by Pediatric Neurology and Development Association of Southern Africa (PANDA) and Neurology Association of South Africa (NASA). The chapter has a strong relationship with its neighbor through training (workshops, internships, online distance neurophysiology teaching platform.)

## **Recommendations for Future Work**

1. Continue to increase the number of African ILAE chapters
2. Regular publication of the regional IBE and ILAE/CAA newsletter online
3. Publish the updated GCAE document in French, English and Portuguese
4. Organize epilepsy training courses in French, English (i.e. during SONA Congress in Durban) and in Portuguese with more trainees and more cooperation with international and regional institutions
5. Elaborate guidelines for management of seizures for African neurologists, GPs and allied medical professionals.

# COMMISSION ON ASIAN AND OCEANIAN AFFAIRS



Byung In Lee

## Chair

Byung In Lee (Korea)

## Members & Officers

As of October, 2014, CAO A has 20 chapters in the Asian and Oceanian region, which includes Australia, Bangladesh, China, Hong Kong, India, Indonesia, Japan, Korea, Malaysia, Mongolia, Myanmar, Nepal, New Zealand, Pakistan, Philippines, Singapore, Sri Lanka, Taiwan, Thailand, and Vietnam.

Nomination and election of the CAO A 2013-2017 Office Bearers occurred in the first and the second quarter of 2013. New members of CAO A took office officially in July 2013 and Co-chairs of CAO A-Research Task Force (A. Ikeda and CT Tan), Chair of Regional Committee of GCAE (E. Somerville), Chair of Pediatric Task Force (H.D. Kim), and Chair of Constitution Task Force (J. Dunne) joined the commission as Ex-officio members. In addition, Derrick Chan (Singapore) joined the Commission as co-chair of the Information committee (ex-officio) starting August 2014.

## Officers of CAO A (2009-2013)

### Chair

Byung In Lee (Korea)

### Secretary

Andrew Bleasel (Australia)

### Treasurer

Leonor Cabral-Lim (Philippines)

### Information Officer

Sunao Kaneko (Japan)

### Members

Man Mohan Mehndiratta (India)

Guoming Luan (China)

Kheng Seang Lim (Malaysia)

### Ex-Officio

Tatsuya Tanaka (Japan)

Shih Hui Lim (Singapore)

Derrick Chan (Singapore)

## Task Forces

### Constitution

John Dunne (Australia)

### Research Task Force

Akio Ikeda (Japan)

Chong Tin Tan (Malaysia)

## Global Campaign Task Force

### Pediatric

Ernest Somerville (Australia)

Heung Dong Kim (Korea)

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

## Officers of ASEPA (2007-2011)

### Chair

Chong Tin Tan (Malaysia)

### Secretary

Andrew Bleasel (Australia)

### Members

Gourie Devi (India)

Yushi Inoue (Japan)

Weiping Liao (China)

Shih Hui Lim

### Ex-Officio

Byung In Lee (Chair, CAO A)

## Office Bearers of ASEPA (September-2011-2015)

### Chair

Shih Hui Lim (Singapore)

### Members

Man Mohan Mehndiratta (India)

Yushi Inoue (Japan)

Weiping Liao (China)

Dede Gunawan (Indonesia)

Josephine C. Gutierrez (Philippines)

### Ex-Officio

Byung In Lee (Korea)

Chong Tin Tan (Malaysia)

## Aims and Missions of CAO A

### Aim

The aim of CAO A is to develop, stimulate, and coordinate the epileptology agenda in the Asian and Oceanian regions

### Mission

- To advance and disseminate knowledge concerning the epilepsies throughout the Asian and Oceanian region;
- To improve education and training in the field of the epilepsies in Asia via the formation of the Asian Epilepsy Academy;
- To organize the Asian Oceanian Epilepsy Congresses together with the International Director of Meetings (IDM) and IBE's Regional Executive Committees;

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

- d. To facilitate clinically relevant epilepsy research in Asia;
- e. To serve as a link between ILAE, IBE, WHO, and regional medical organizations to promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders in the Asian and Oceanian region;
- f. To promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda;
- g. To review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.

## Action Plans of CAO A: 2013 -2017

The following were formulated in the CAO A business meeting at Seoul, September 26, 2009, and newly added and revised at the business meeting at Seoul, September 27, 2013.

- 1. Construct CAO A and ASEPA website with its link with ILAE web and regional Chapter's web, and publish newsletter
- 2. Enhance education and training efforts and activities
  - (i) continue to provide teaching courses and workshops in regions in need
  - (ii) provide epilepsy fellowship (~6 months) for the nurturing of future epilepsy specialists of the region
  - (iii) continue to conduct EEG certification examination for the purpose of enhancing the standard of EEG recording and interpretation skills.
- 3. Organize the Asian and Oceanian Epilepsy Congresses every 2 years
- 4. Stimulate clinical and translational research
- 5. Promote new chapter formation
- 6. Facilitate Global Campaign Against Epilepsy (GCAE) activities
- 7. Facilitate interactions and communications among chapters and commissions
- 8. Initiate the "Asian and Oceanian Outstanding Achievement in Epilepsy Award"

Newly added action plans at the Initiation Meeting on September 27, 2014

- 9. Enact written BylawS of CAO A
- 10. Promote diagnosis and treatment of neonatal and childhood epilepsies in the region

- 11. Implement CAO A - demonstration projects for reduction of treatment gap in the region
- 12. Promote career development programs for talented young talented epileptologists in the region
  - (i) expand epilepsy fellowship programs
  - (ii) exchange programs for young research fellows
  - (iii) regional epilepsy school in collaboration with ILAE

## Commission Activities

### Communication and Business Meetings

A. Communication amongst members of CAO A and ASEPA were mainly through e-mails and during teaching courses/workshops/Congresses in the region.

(1) CAO A initiation business meeting was held on September 27, 2013, at Lotte City Hotel Mapo in Seoul, Korea. The discussion points included:

Progress reports of CAO A and adoption of new action plans for 2013-2017; progress reports of ASEPA (SH Lim); Budget for 2012 (J.J. Tsai); report of Research TF (C.T. Tan and A. Ikeda); report of Information Committee (S. Kaneko); report of GCAE TF (E. Somerville); report of Constitution TF (J. Dunne); report of Pediatric TF (H.D. Kim); budget plan of 2014 (L. Cabral-Lim); Myanmar Project (E. Somerville); and ASEPA Fellowships (C.T. Tan)

(2) Joint CAO A and ASEPA business meeting was held on August 6, 2014, at the Waterfront Hotel in Singapore. The discussion points included: Report of CAO A activities (B.I. Lee); report of ASEPA activities (S.H. Lim); budget for 2014 (L. Cabral-Lim); report of Information Committee (S Kaneko); report of Research TF (C.T. Tan and A. Ikeda); report of GCAE-TF (E. Somerville); report of Constitution TF (J. Dunne); report of Pediatric TF (H.D. Kim); report of 10th AOEC (K. Hodgson); message from ILAE (H. Cross); report from Indian Epilepsy Society (M.M. Mehndiratta); venue for the 11th AOEC; presentation by applying chapter: Hong Kong chapter (C. Lui) and Indonesian Chapter (K. Kusmasututi), IDM Perspectives (R. Holmes).

B. Communications with ILAE have been made mainly through e-mail, conference calls, and at the Executive meetings.

### C. New Chapter Formation

- i. Application of Myanmar Chapter was approved at IEC in Montreal, June 23-27, 2013

# COMMISSION ON ASIAN AND OCEANIAN AFFAIRS (continued)

- ii. Cambodia is in the process of applying for a chapter approval.

**Chapter Convention: 7 August 2014, 12:00-13:45, at the 10th AOEC in Singapore**  
Grand Copthorne Waterfront Hotel, Singapore

The convention included Welcoming Address and Opening Remarks introduction of chapter delegates including Laos, address by ILAE President, report from ILAE, report from CAOAO, budget of CAOAO, report of ASEPA, report of Information committee, Global Campaign Against Epilepsy, report of Asian and Oceanian Outstanding Achievement Award, report of Research Task Force, and report of Pediatric TF.

## **Information Committee (Chair: S Kaneko)**

Information Committee meetings have been held every year to seek advice, suggestions, or comments for improvement.

## **Project 1. Construct CAOAO Website**

CAOAO website (<http://www.caoa-epilepsy.org>) was opened in 2011. It is managed by JSE Company. Structures were remodeled by suggestions from the ILAE and it has been linked to the ILAE website. A previous attempt to link individual chapters was not successful due to lack of reply from each chapter. This will be attempted again. Contents include: a hands-on summary of epilepsy meetings in the region; slides of didactic lectures and workshops; information on meetings or epilepsy related events in the AO region; epilepsy treatment guidelines of each chapter, if there is any; reports and documents from CAOAO, ASEPA, TFs, or other organizations; news and advocacy from individual chapters.

## **Project 2. Publication of CAOAO Newsletter**

The first CAOAO newsletter was published in December 2012. The original plan was to publish two times/year, but the second newsletter is delayed due to a lack of content. Need to organize a network consisting of information officers from each chapter to gather appropriate, relevant information for the newsletter as well as website.

## **Action Plans**

- Organize a network consisting of information officers from each of the chapters (mail was sent to each chapter asking for the names and the address of information officers)
- Operation of CAOAO - Website, including: maintenance of website by JSE monthly; renewal of website this year; linkage between CAOAO website and that of each chapter; expand website contents to accommodate CAOAO action plans
- Publication of newsletter; two times/year starting in 2014
- Information Committee meeting will be held once a year.

## **Business Meeting in Singapore**

- Derrick Chan was appointed co-chair of the Information Committee
- Discussion of the proposal for absorbing CAOAO website into the ILAE website indicated that we need further observation before a final decision. Pro issues include cost savings. Con issues include less freedom and diversity. Need to look at number of visits to the CAOAO website. If low then should go with the ILAE website umbrella.

## **CAOAO - Research Task Force (co-chairs A. Ikeda and C.T. Tan)**

### **Scope of Actions**

- improve research infrastructure
- understand etiologies and epileptogenesis
- decreasing psychosocial comorbidities
- achieve better treatment outcome

### **Recent activity:**

- P Kwan (former chair of RTF) submitted the AO Research Priorities document to *Epilepsia*
- Pre-congress basic research programs in collaboration with ASEPA at each AOEC

### **Plan for 2013-2017:**

- Promote research in the region by initiating multiple joint research projects dealing with clinically important questions related to epilepsy that do not require funding. Sound methodology that is publishable and experienced investigators to lead the projects.
- Some possible projects:
  - relationship between public attitude and stigma in different communities;
  - Multi-center studies related to various women's issues in the region;
  - Multi-center study to assess the traditional methods of treatment and their physiological basis;

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

- Other projects related to HLA-typing and skin rashes, rare diseases, surgery, and economic cost of epilepsy

## **GCAE - Task Force (Chair; E. Somerville)**

Encourage Groups outside of official Global Campaign to speak at the 10th AOEC

- Action against Untreated Epilepsy (AAUE) run by an Irish neurologist, Victor Patterson, running a clinic in Nepal
- An Indian woman doctor who works in a train going around India allied with AAUE
- ES has joined AAUE but they are not keen to join Global campaign.

## **Myanmar Project:**

- CAO A met with local neurologists for setting up a project, then WHO announced they were doing a project. CAO A's offer to collaborate was turned down; this caused some disquiet: CTT and ES attended WHO planning meeting as observers and had input.
- Other neurologists in Mandalay were keen to go ahead with CAO A and a proposal was made, met with local physician, and Minister of Health, other health administrator. Project was based upon GP who provides care. Budget was \$1,200.

## **Laos Project:**

The project is based on that undertaken by the Francophone Tropical Medicine Institute, where the CAO A's role is to provide education, mainly to train neurologists, and thus help to make the project long-term sustainable. To - date, have helped to train two neurologists.

## **Cambodian Project:**

This project is also mainly by the French group. It has resulted in some scientific publications. Cambodia has eight neurologists. Plan to have information network to share projects with those in the region. Strategy is to present overview of different activities; there are a great number of disconnected activities. A WHO sponsored meeting is scheduled in Europe to look at drug prices in low income areas.

## **Constitution Task Force (by J. Dunne)**

- Review of election rule of CAO A memberships
- Harmonization Meeting with H. Cross to comprise election rules of regional commission on August 9, 2014, at the 10th AOEC
- Election rules finalized by H. Cross and circulated in September 2014 by ILAE-Exc.

## **Pediatric Task Force (by HD Kim)**

### **Plans for 2013-2017**

- Network formation among pediatric representatives in chapters of CAO A
- Pediatric expert meeting in Singapore after pediatric parallel session on 8 August to discuss future plan of pediatric TF in our region
- Communication with chapters to support treatment gap in resource poor countries
- Conduct ILAE pediatric commission activities to our region
- Increase the number/proportion/quality of international exchange fellowship training
- Handling treatment and educational gaps
  - (1) Enhancing co-work with ASEPA
  - (2) Need increased proportion in educational subject/bursaries
  - (3) Develop new educational courses
    - Pediatric EEG teaching course and certificate
    - Joined local chapters and local child neurology society, e.g. KPEP joined with ASEPA in 2010, China-Korea PEP in Beijing in 2011
  - (4) Facilitate interaction and communication with well developed educational courses
- More teaching in line with ASEPA

## **ASEPA Report (by S.H. Lim)**

ASEPA, the educational arm of CAO A, has been conducting enormous educational and training activities consisting of 4 major activities:

- workshops/teaching courses,
- fellowships,
- EEG certifications, and
- publications of proceedings.

## **Asian and Oceanian Outstanding Achievement Award in 2014 (Third Award)**

Awarded at the opening ceremony of the 10th AOEC in Manila, Philippines, on August 7, 2014. Award Recipients: Maria Felicidad Soto (Philippines); Ming-shung Su (Taiwan); John Dunne (Australia); and Qifu Tan (China).

## **10th AOEC (by K. Hodgson)**

### **Scientific Organizing Committee:**

Co-chairs: B.I. Lee, S.H. Lim, V. Saxena

**Members:** T. Tanaka, R. Cole, D. Chan, C.T. Tan

The 10th Asian Oceanian Epilepsy Congress was held in Singapore 7 to 10 August 2014. There were 1307 registrations from 49 countries. The program covered a broad range of topics selected from recommendations

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

from Asian and Oceanian ILAE chapters and IBE members. The Chairman's Symposium was on drug resistant epilepsy and the three main sessions were on the burden of epilepsy, neurostimulation in epilepsy and neurophysiological markers of the epileptogenic zone. The main sessions were complemented by a comprehensive mix of post main and parallel sessions, didactic lectures, video quizzes, debates, forums, workshops and teaching courses. The Tournament of the Brainwaves quiz was a new feature to the program and was well received, pitting teams from across the region against each other in friendly rivalry.

- The Epilepsy & Society Symposium saw 150 attendees from Singapore and across the region. Topics ranged from anticonvulsants to stigma at work and school, and the truth about reflexology and stem cell therapy for epilepsy as well as heartfelt sharing from people with epilepsy and caregivers. The Epilepsy & Society Symposium was rounded off with an innovative mini fair.
- There were 105 speakers and chairs involved in the program.
- In total 400 abstracts were submitted of which 40 were selected for platform sessions and the rest were put up as posters. The Tadokoro Prize was awarded to the two best poster and platform presentations.
- Out of 114 travel bursary submissions, 45 received a travel bursary. For most, the travel bursary was only a contribution to the awardee's travel and accommodation but this did not seem to pose a problem.
- The Asian and Oceanian Outstanding Achievement Epilepsy Awards and the Outstanding Persons with Epilepsy Awards were handed out to recipients from across the region.
- Five satellite symposia were taken and the exhibition area was busy.
- Despite pre-congress operational issues with the Grand Copthorne Waterfront Hotel, it proved to be an excellent venue for the 10th AOEC.
- Singapore has always been an engaging city but it was enhanced by the ongoing celebrations for its National Day including a tremendous firework display.
- Members of the Scientific Organizing Committee (SOC) and the Scientific Advisory Committee (SAC) worked arduously on the full program. Particular credit goes to Shih Hui Lim for his unfaltering dedication to the congress.

## 11th AOEC

Two chapters (Hong Kong and Indonesia) applied for the venue of 11th AOEC in 2016 and they presented their facilities and strength of their hosting cities at the CAO-ASEPA business meeting on August 6, 2014. Following some debate, it was decided that the choice will be made by the IDM office and ILAE-IBE management committee after site - visits and negotiation with the tourist board of each country. The decision will be made by the end of October 2014.

It was also decided that two chapters will be chosen as the venue of either 11th or 12th AOEC with the order depending upon the final determination of the venue of the 11th AOEC in 2016.



# COMMISSION ON EUROPEAN AFFAIRS



Meir Bialer

## Chair

Meir Bialer (Israel)

## Commission Members (2013-2017)

Treasurer	Eugen Trinko (Austria)
Secretary	Matthew Walker (UK)
Liaison for Communication	Sandor Beniczky (Denmark) Dana Craiu (Romania) Emilio Perucca Torbjorn Tomson
MC Liaison	Annamaria Vezzani

## CEA Activities for 2014

- 11th European Congress on Epileptology (ECE) (Stockholm; 29/6-3/7/2014)  
The CEA awarded travel bursaries to young investigators (< 45 years) who submit good abstracts
- European Chapter Convention during the Stockholm ECE (29/6/2013). Thus continuing an annual dialogue between the CEA and the various ILAE-European chapters (44/46 chapters)
- CEA Awards given at the Stockholm ECE  
European Epileptology Award:  
C.A. Tassinari (Italy) & W. Loscher (Germany)

## Non-monetary Awards

- European Education Award: I. Rektor (Czech Republic)
- European Young Investigator Award (<45 years): T. Ravizza (Italy) & S. Vulliemoz (Switzerland)
- European Service Award: V. Hezser-v. Wehrs (Germany)
- A call for CEA-sponsored courses/symposia during 2014 was issued on 10/4/2013.

## CEA-Sponsored Courses/Symposia in 2014

### CEA-Core Courses (CCC)

- Pediatric Epilepsy Surgery Course (Brno, 13-17/1)
- 8th Migrating Course on Epilepsy (Dubrovnik, 5-10/10)

## CEA-Sponsored Activities (CSA)

- 4th Stereo-EEG Course (Lyon, 12-16/2)
- 6th Caucasian Summer School (Bakuriani, Georgia, 1-6/6)
- 9th Slovenian Epilepsy Int. Course (Ljubljana, 5-7/6)
- East-European Course on Epilepsy (Romania, 11-13/6)
- 2nd Dianalund Summer School on EEG & Epilepsy (13-19/7)
- 8th Baltic Sea Summer School (Trakai, Lithuania, 3-8/8)
- Epilepsy Workshop on Pediatrics (Bucharest, 12-13/9)
- 2nd Neuropathology Summer School (Erlangen, 29/9-3/10)
- Two visiting professorships (Portugal & Romania)

## CEA Sponsored Course/Symposia in 2015

- A call for CEA sponsored courses/symposia during 2015 was issued on 12/3/2014 (submission deadline: 23/6/2014)
- The submitted applications were discussed at the next CEA meeting (23/8/2014). Funding available will be limited due to the low expected surplus from the Stockholm ECE.

## The following courses will be supported by the CEA:

### CEA-Core Courses (CCC)

- 5th -European Basic Epilepsy Surgery Course -EPODES (Brno, Czech Republic, 12-16/1)
- 6th Eilat Educational Course on Pharmacology (Jerusalem, Israel, 11-16/10)

### CEA-Sponsored Activities (CSA)

- Course in European Central Asia (Astana, Kazakhstan, 8-11/4)
- 4th Colloquium on Status Epilepticus (London, UK, 9-11/4)
- 2nd International Resident Course on Drug Resistant Epilepsies in (Tagliacozzo, Italy, 3-9/5)
- 13th San-Servolo Course on Pediatrics (Venice, Italy 19-31/7)
- 9th Baltic Sea Summer School (Sigulda, Latvia, 9-14/8)

# COMMISSION ON EUROPEAN AFFAIRS

(continued)

## **CEA Awards to be given at the Prague ECE (submission deadline 31/12/2015)**

- European Epileptology Award
- Non - monetary Awards
- European Education Award
- European Young Investigator Award (<45 years)
- European Service Award

Establishing at the ILAE office in Dublin a repository of all participants who received bursaries for CEA-sponsored courses from 2011 to present.

## **Additional CEA Targets for 2014 and 2015**

- Making the 12th European Congress on Epileptology (ECE, 11-16/9/2016) in Prague at least as successful as ECEs in Vienna (2004), Helsinki (2006), Berlin (2008), Rhodes (2010), London (2012) and Stockholm (2014).
- Continual update of European chapters' chairs and secretaries
- Establish ILAE chapters in the remaining European countries
- Search for additional funds in light of the continued reduced surplus from the ECEs.

# COMMISSION ON LATIN AMERICAN AFFAIRS



Marco Medina

## Aims

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

## Members

Marco T. Medina (Honduras)  
Franz Chaves-Sell (Argentina)  
Roberto Caraballo (Argentina)  
Patricio Abad (USA)  
Eduardo Barragan (Mexico)  
Manuel Campos (Chile)  
Laura Guilhoto (Brazil)  
Lilia Maria Morales-Chacón (Cuba)  
EC Liaison  
Samuel Wiebe (Canada)

## Task forces and Activities

At the 30th International Epilepsy Congress in Montreal, June 2013, the Commission on Latin American Affairs prioritized several new task forces and previous CLAA activities:

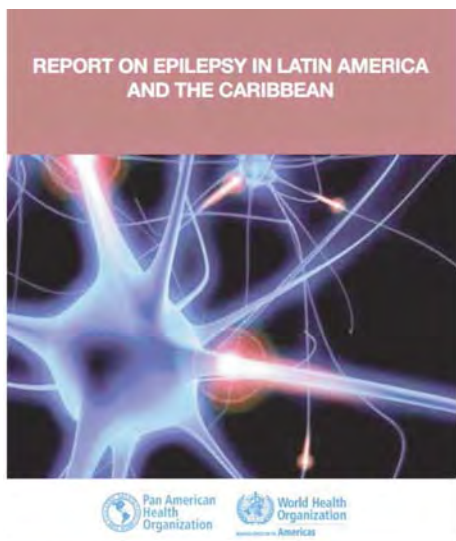
- 1) PAHO Strategy and Plan of Action on Epilepsy: Carlos Acevedo (IBE), Marco T. Medina (ILAE), Jorge Rodríguez (PAHO).
- 2) ILAE Website: Franz Chaves--Sell.
- 3) Health Primary Care: Lilia Morales.
- 4) Epidemiology and Publications: Patricio Abad, Patricia Braga, Laura Guilhoto
- 5) Epilepsy Surgery: Mario Alonso and Manuel Campos
- 6) Buenos Aires Latin American Congress: Roberto Caraballo, Silvia Kochen, Lilia Niñez, Sam Wiebe, Marco T. Medina and Patricio Abad.
- 7) LASSE: Esper Cavalheiro.
- 8) ALADE: Elza Marcia Yacubian, Jaime Carrizosa and Roberto Caraballo.
- 9) Latin America Epilepsy fellowships program coordinated by ALADE.
- 10) ILAE North American Commission collaboration.

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

Coordinated by Carlos Acevedo (IBE), Marco T. Medina (ILAE), Jorge Rodríguez (PAHO). At the 51st PAHO Directing Council meeting, representatives of PAHO/WHO Member States approved a Strategy and plan of action on epilepsy on September 29th, 2011, Washington D.C. with important support from ILAE and IBE. In this frame, a Memorandum of Understanding was signed between PAHO, IBE and ILAE during the 7th Latin American Epilepsy Congress in Quito, Ecuador (November 2012). From June, 2013 to June, 2014 we have been working in the following activities:

- a) Regional Workshop on Epilepsy: "Epilepsy in Latin America: "Success stories and lessons learned", was held in Santiago, Chile on August 9th-10th, 2013. It was a joint initiative between PAHO/WHO, IBE and ILAE and was organized by Chile's Ministry of Health and the Chilean League against Epilepsy. The Epileptology Society of Chile and the Society of Psychiatry and Neurology for Children and Adolescents co-sponsored the event. The workshop's main objectives were to discuss successful experiences and lessons learned in selected Latin American countries, with emphasis on primary care, thus contributing to the implementation of the Strategy and plan of action on epilepsy in Latin America, and establishing priorities for action. Among the attendants were members and experts of the sponsoring organizations and representatives from Argentina, Brazil, Chile, Colombia, Honduras, Mexico and Uruguay.
- b) A Report on Epilepsy in Latin America and the Caribbean was published in 2013. This report was prepared with the collaboration of ILAE and IBE. Information from 25 out of 33 countries (70%) that responded a survey on plans, services and resources.
- c) Several Latin American and Caribbean countries are implementing the mhGAP-IG (mental health treatment gap program) as an important component in the process of integrating mental health and neurological disorders into primary health care. Epilepsy is one of the modules being implemented.

# COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*



- d) A Pilot program on Primary Health Care is going on in Bolivia.
- e) The Treatment Gap Pilot Project is developing in Olancho, Honduras.
- f) Many Memorandum of Understanding at country level are implementing the Plan of Action and focusing resources on Epilepsy.
- g) The “Liga Chilena contra la Epilepsia” was designated PAHO/WHO Collaborating Center (first in the region on the epilepsy field); and the National Autonomous University of Honduras is in process to obtain this condition.  
We have reports from Cuba, Mexico, Guatemala, Honduras, Colombia, Ecuador, Argentina, Chile, Uruguay, Brazil etc. about the progress on the PAHO Plan, based on these reports we are having a significant progress locally.

## **2) ILAE en Español and Portuguese websites**

Coordinated by Franz Chaves--Sell (Chair)  
ILAE en Español ([http://www.ilae.org/Visitors/Centre/Trans\\_Spanish.cfm](http://www.ilae.org/Visitors/Centre/Trans_Spanish.cfm)) and Portuguese ([http://www.ilae.org/Visitors/Centre/Trans\\_Portuguese.cfm](http://www.ilae.org/Visitors/Centre/Trans_Portuguese.cfm)) websites have been developed. The ILAE en Español has 12 ILAE chapters' websites, 11 from Latin America. We have included important information on Epilepsy Classification, ketogenic diet, genetics, PAHO reports, books, etc.

## **3) Health Primary Care**

Coordinated by Lilia Morales--Chacon (Chair).  
A Survey was done on the status of the epilepsies in

the context of primary health care in the countries of Latin America, 15 countries had completed the survey. The results of the survey were discussed during the Latin American Congress of epilepsy in Buenos Aires.

## **4) Epidemiology and Publications:**

Coordinated by Patricio Abad (Chair)  
A Workshop and paper on Epidemiology Update and Guidelines for future studies was organized for the Latin American Epilepsy Congress in Buenos Aires (participants: Patricio Abad, Etorre Bhegi, Jorge Burneo, Arturo Carpio, Eduardo Barragan). A survey project on Epilepsy Services in Latin America is in process.

## **5) Epilepsy Surgery**

Coordinated by Mario Alonso (Chair) and Manuel Campos  
Support for the development of the Epilepsy Surgery program in Lima, Peru and Guayaquil, Ecuador. Participation of Epilepsy Surgery Centers in Mexico, Chile, Brazil, Argentina, Costa Rica, etc. Educational conferences on Epilepsy Surgery in Brazil, Cuba, Ecuador, Peru, Mexico, Guatemala and Chile.

## **6) Buenos Aires Latin American Congress:**

Coordinated by: Roberto Caraballo, Silvia Kochen, Lilia Niñez, Sam Wiebe, Marco T. Medina and Patricio Abad  
The 8th Latin-American Congress was held in Buenos Aires, September 17-20, 2014. The program is covering a broad range of topics selected from recommendations across the region. The abstracts were published in English, Spanish and Portuguese in a supplement of Epileptic Disorders.

## **7) Latin American Summer School in Epilepsy (LASSE)**

Coordinated by Esper Cavalheiro and colleagues  
The 8th Latin American Summer School on Epilepsy (LASSE VIII) took place between 16 and 25 February 2014. The central theme of this eighth edition was “Epilepsy in neurodegenerative diseases and aging”. Of the 286 candidates, the organizing committee selected 63 participants attended the event and actively participated in all activities. Thus, the program could be completed in its entirety. On the last day, the students, divided into 8 groups presented the research projects developed during the school under mentoring of teachers. The lessons always related to the central

# COMMISSION ON LATIN AMERICAN AFFAIRS

(continued)

topic, were chosen by the students themselves. The discussions were stimulating and warm and involved the participation of all students and several teachers who remained until the end of LASSE. The projects submitted by groups of students were:

**Group 1:** Experimental model of status epilepticus for the evaluation of neuroprotection in immature and adult brains.

**Group 2:** Inflammatory biomarkers Involved in the development of epileptic seizures in familial Alzheimer's disease: The role of astrocytes.

**Group 3:** Biomarkers in Encephalopathy related to status epilepticus During Sleep.

**Group 4:** The story of Cain & Abel: Neurogenesis & epileptogenesis.

**Group 5:** Degenerative alterations in neurons and astrocytes from epileptogenic tubers of the Tuberous Sclerosis Complex and possible clinical correlation.

**Group 6:** Pharmacoresistant Temporal Lobe Epilepsy as a risk factor for Alzheimer's disease in animal models.

**Group 7:** A multicentric, longitudinal and interventional study on the evolution of early Mesial Temporal Lobe Epilepsy Diagnosed (MTLE) with Hippocampal Sclerosis (HS): Impact of physical activity and the possible role of oxidative stress. Group 8: Alzheimer's disease and epilepsy.

Analysis of the evaluations made by the students showed that, once again, the LASSE is an educational activity admired by all. The best evaluated items were, once again, the program and the quality and dedication of teachers and tutors. Thus, we are convinced that it is worth continuing with new editions of the Latin American Summer School on Epilepsy that its role is crucial in the formation of new thinkers in the area.

## 8) ALADE (Latin American Academy of Epilepsy)

Elza Marcia Yacubian (Chair), Jaime Carrizosa, Roberto Caraballo, Guilca Contreras and Loreto Rios have performed educational activities in different countries:

- a) ALADE Conference during the LASSE VIII on Neurodegenerative diseases: The view of a Pediatric Neurologist.
- b) Course of Epilepsy Surgery on March 3rd and 4th, 2014, Havana, Cuba;
- c). Launch and distribution of 300 copies of the book Tratamento Medicamentoso das Epilepsias in Portuguese during the 35th Congress of the Brazilian League of Epilepsy on April 3rd to 5th 2014, Foz do Iguaçu, Brazil;
- d). Launch and distribution of 300 copies of the book Tratamiento Farmacológico de las Epilepsias in Spanish during the 32nd. SOPNIA Congress of Child Neurology Chilean Society, in April 15th to 17th, 2014, at Punta Arenas, Chile.

## 9) Latin American Epilepsy fellowships program:

CLAA and ALADE have identified the "Epilepsy Centers" in Latin America for epilepsy training (clinical, EEG, surgery, etc.). We have had the ILAE support for three fellowships. We are evaluating the educational impact of this program.

## 10) ILAE North American Commission

**collaboration** and the Partnering Epilepsy Centers in the Americas (PECA) program. PECA aims specifically to support and expand exchange programs between the members of the Latin American Commission, the North American Commission and the Caribbean chapters of the ILAE, in order to significantly impact epilepsy care in these regions. The North American commission has supported visits to the Costa Rica, Panama, Mexico, Dominican Republic, Argentina, Ecuador, Peru, etc.

The American Epilepsy Society has a "Spanish Symposium" each year at the AES Congress.

Submitted by  
*Marco T. Medina and*  
*Franz Chaves-Sell*

# COMMISSION ON NORTH AMERICAN AFFAIRS



Sheryl Haut

## Members

Chair	Sheryl Haut (USA)
Secretary	Nathalie Jetté (Canada)
Treasurer	Jose Cavazos (USA)
	Jaideep Kapur (USA)
	Peter Carlen (Canada)
	Dave Clarke (USA/Caribbean)
	Vicente Iragui (USA)
AES President	Elson So (USA)
CLAE President	Nizam Ahmed (Canada)
MC Liaison	Samuel Wiebe (Canada)

## Education Task Force

Epilepsy 101 Program - Sheryl Haut (Chair) and members: Howard Goodkin (co-Chair), Ed Bertram and Elson So

## Intercommission Educational Outreach

Jose Cavazos (Chair) with members Nizam Ahmed, Lionel Carmant and Peter Carlen

## Harmonization of Regulatory Activities

Jacqueline French (Chair) with international members Alexi Arzimanaglou (France), Emilia Bagiella (Columbia), Michel Baulac (France), Meir Bialer (Israel), Rusty Katz (USA), Patrick Kwan (Australia), Scott Mintzer (USA), Jack Pellock (USA), Emilio Perucca (Italy), Steven Schachter (USA) and Eugen Trinka (Austria)

## Leadership Development Task Force

Jaideep Kapur (Chair) with members Jacqueline French, Sheryl Haut, Samuel Wiebe, Patricia Braga (Latin American Commission), Amadou Gallo (African Commission), C.T. Tan (Education Commission), Marco DeCurtis (LASSE)

## Caribbean Task Force

Dave Clarke (Chair) and members (all from Caribbean) Amza Ali, Remy Bellance, Mesha Gay-Brown, Tamika Haynes-Robinson and Morris Scantlebury

## Hispaniola Task Force

Lionel Carmant (Chair)

## ICD-11 Working Group (NARC in collaboration with Classification Commission)

Donna Bergen (Chair) with international members Ettore Beghi (Italy), Dale Hesdorffer (USA), Nathalie Jetté (Canada), Marco Medina (Honduras), Solomon Moshé (USA) and Sameer Zuberi (UK)

## Stigma Task Force

Nathalie Jetté (Chair) and the following international members: Amza Ali (Jamaica), Joan Austin (USA), Helen Cross (UK), Tarun Dua (Switzerland), Patricia Braga (Uruguay), Gretchen Birbeck (Zambia), Hanneke de Boer (Netherlands), Paula Fernandes (Brazil), Kirsten Fiest (Canada), Ann Jacoby (UK), Diane Lorenzetti (Canada), Janet Mifsud (Malta, IBE), Solomon Moshé (USA), Karen Parko (USA), Manjari Tripathi (India), Samuel Wiebe (Canada)

## PAHO Working Group

Sheryl Haut and Vicente Iragui (co-Chairs) and member Samuel Wiebe

## Aims

The commission established a number of task forces and working group to accomplish its stated goal, in line with the following ILAE goals:

- 1) ILAE shall serve all health professions as the premier international resource for current and emerging knowledge on epilepsy prevention, diagnosis, treatment, and research.
- 2) ILAE shall serve as an international information resource and leader for optimal, comprehensive epilepsy care

## Mission of the Commission

n/a

## Commission Activities June 2013 through June 2014

## Education Task Force

Epilepsy 101 Program – This program, supported by the NARC and the AES, aims to reach non epilepsy trained providers (physicians, nurses, allied health professionals) and introduce them to introductory concepts in the diagnosis and management of epilepsy. The focus this past year was to finalize the



# COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

teaching materials (slides) for the program and begin to examine options for financial sustainability. This has been completed.

## **Recommendations for future work**

Copyright issues and revenue generation strategies (to ensure sustainability) will be finalized and dissemination will begin.

## **Intercommission Educational Outreach**

The PECA program has continued to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. In the current year, 5 programs have been established or continued in Costa Rica, Panama, Peru, Ecuador and Mexico. Some of these programs had more than one visit this past year (e.g. Peru) with matching funds obtained from another source.

## **Recommendations for future work**

More visits are planned for 2014-2015. The 6P model will be considered (patient, program, practice, publications, policy, partnerships) to evaluate outcomes of the PECA program.

## **Harmonization of Regulatory Activities**

The task force on regulatory activities has been very productive this past year. This is a task force in collaboration with the European Commission. The goal of this effort is to identify and refine optimal clinical trial methodologies for new anti-epileptic drugs. The task force worked on three reports this past year (submitted or to be submitted) including: (1) A paper on a unified indication (incorporating both monotherapy and polytherapy) for epilepsy was written; (2) The PEACE (pediatric extrapolation academic consortium in epilepsy) initiative has been working with the FDA and has been preparing a paper related to this issue; (3) A paper on time to baseline seizure frequency as an add-on study design was also started.

## **Recommendations for future work**

A face to face meeting was planned with key stakeholders (regulatory representatives, task force members and observers) in July 2014 where the three topics written as papers were to be discussed. The three papers will be finalized in 2014-2015.

## **Leadership Development Task Force**

It is important for non-profit organizations to demonstrate strengths and one way to do this is to incorporate leadership development in their strategy. The NARC thus created this task force to contribute to the leadership training of junior/early mid-career academics. This past year, a leadership development consultant was hired to assist in developing the program and a needs assessment was done (sent to ILAE leaders and chapter members). The results of the needs assessment are pending.

## **Recommendations for future work**

Engagement of other commission will be a priority. Nominations for candidates for this program will be sought. Program will be finalized (along with faculty). The first program will be held at the IEC meeting in Istanbul in September 2015. Pre and post evaluation forms will be developed to ensure outcomes are evaluated.

## **Caribbean Task Force**

The Caribbean Epilepsy Society held its 4th biennial meeting in St. Lucia. The meeting was a success. The task force succeeded in obtaining an EEG machine (donated from Global Diagnostics) for St. Lucia. They have also implemented some clinical care audits in a variety of centers. News and media initiatives took place in 2013-2014 to address epilepsy misconceptions with the general public. The task force also lobbied for new AEDs to be available at no cost to patients and they were successful in getting several AEDs on the formulary. A social driving initiative was also created in collaboration with the International Foundation of Applied Disability; the aim of this initiative will be to go to government to, lobby for new laws for drivers with epilepsy.

## **Recommendations for future work**

They will continue to work on the initiatives discussed above. Recruitment of additional epilepsy trained providers will continue to fill gaps in clinical care.

## **Hispaniola Task Force**

In 2014, a second regional epilepsy center was added in Haiti. The most compelling story of this task force is that in the very short time since the epilepsy care centers were created, more than 5,000 people living with epilepsy in Haiti have been seen. The clinics have been so successful that they are now facing treatment gaps issues because they do not have sufficient AEDs for everyone.

# COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

## **Recommendations for future work**

More clinics are planned for 2015 including one in Jacmel where Dr. Carmant and others will be installing an EEG machine, and doing further training (refresher course) in all the centers. Neurosurgery will also be introduced. Part 2 of the the neurocysticercosis project (prevalence in controls) will be initiated.

## **ICD-11 Working Group (NARC in collaboration with Classification Commission)**

This new working group was established in 2013-2014 with the aim of preparing a document addressing conversion from ICD-9-CM in the US to ICD-10. The group met on a few occasions (IEC Montreal 2013, etc.) to discuss the paper and completed its task. The paper is called: ICD coding for epilepsy: Past, present and future—a report by the International League Against Epilepsy Task Force on ICD codes in epilepsy. It is in press in *Epilepsia*.

## **Recommendations for future work**

A smaller working group created before this larger working group (E. Beghi, D. Bergen and N. Jetté) continue to collaborate with the WHO in ensuring that the upcoming ICD-11 is in line with the ILAE revised terminology and concepts for the classification of seizures and epilepsy. They also continue to be involved in the planning of the field testing comparing ICD-10 to the new ICD-11 codes.

## **Stigma Task Force**

The Stigma Task Force is continuing its work on synthesizing the worldwide evidence on stigma in epilepsy. This past year the members worked on data abstraction (in duplicate) of around 300 manuscripts. Two papers have been in progress this past year— one summarizing validated scales to measure stigma in epilepsy and one summarizing the evidence around interventions to address stigma in epilepsy.

## **Recommendations for future work**

This upcoming year, the third manuscript, summarizing the evidence around the frequency of stigma and factors associated with stigma will be completed, along with the two other manuscripts which were started in 2013-2014. Abstracts summarizing this work will be submitted for the IEC meeting in Istanbul.

## **PAHO Working Group**

Drs. Wiebe and Haut attended the PAHO meeting in Santiago, Chile in August 2013.

## **Recommendations for future work**

Future initiatives which are being examined include primary care programs in Santa Cruz, Bolivia; Center of Epilepsy for LA in Chile; and a center in Honduras. They are also interested in developing educational programs for nurses and will consider using the Epilepsy 101 program to avoid duplication of efforts.

## **The North American Commission**

**Symposium** in collaboration with the European Commission was held at the American Epilepsy Society meeting in Washington in December 2013. The symposium was chaired by S.Haut/N. Jetté and M. Bialer. Topics included: (1) Setting standards: International collaboration for pediatric epilepsy surgery through the ILAE (G. Mathern, USA); (2) International pregnancy registries: A global approach to a global challenge (T. Thomson, Sweden); (3) International clinical trials—threats and opportunities (E. Trinka, Austria); and (4) Epilepsy, big data and international research (B. Litt, USA).

## **Recommendations for future activities**

The NAC will run a symposium on pediatric epilepsy neurosurgery at the AES Annual Meeting in Seattle in 2014.

## **AES, CLAE and CES activities**

Please see separate annual reports for each of these chapters for their respective activities.

## **Accomplishments (2013-2014)**

See above under “Commission Activities.”

Report by  
*Sheryl Haut*



# Topic-Oriented Commissions 2013-2017

# COMMISSION ON CLASSIFICATION AND TERMINOLOGY



Sameer Zuberi

## Chair

Sameer Zuberi (Scotland)

## Members

Nerses Bebek (Turkey)  
Robert Fisher (USA)  
Jackie French (USA)  
Edouard Hirsch (France)  
Jukka Peltola (Finland)  
Kate Riney (Australia)  
Eliane Roulet Perez (Switzerland)  
Muhammad Salisu (Nigeria)  
Nobukasu Nakasato (Japan)  
Ingrid Scheffer (Australia)

## MC Liaison

Nico Moshé (USA)

## Subcommission Members:

### Task Force on Classification

Ingrid Scheffer (Australia), Task Force Chair Sameer Zuberi (United Kingdom), Nico Moshé (United States), Edouard Hirsch (France), Helen Zhang (China), Jacqueline French (United States), Gary Mathern (United States), Sam Wiebe (Canada), Torbjörn Thomson (Sweden), Satish Jain (India)

### EpilepsyDiagnosis.org & Syndromes Task Force

Kate Riney (Australia) Task Force Chair, Roberto Caraballo (Argentina), Norimichi Higurashi (Japan), Vivek Jain (India), Floor Jansen (Netherlands), Lieven Lagae (Belgium), John Paul Leach (United Kingdom), Rima Nabbout (France)

Ingrid Scheffer (Australia), Elizabeth Thiele (United States), Federico Vigevano (Italy), Khaled Zamel (United Arab Emirates), Sameer Zuberi (United Kingdom), Mike Kerr (United Kingdom), Liaison to Commission on Neuropsychobiology

### Neonatal Seizures Task Force

Ronit Pressler (UK) Task Force Chair, Roberta Cilio (USA), Magda Nunes (Brazil), Perrine Plouin (France), Sampsa Vanhatalo (Finland), Elissa Yosawitz (USA), Sameer Zuberi (UK) Commission Liaison

## Aims

- To develop the classification of seizures and epilepsies to reflect scientific advances in understanding of the etiology of epilepsies, epilepsy syndromes and their associated co-morbidities.
- Global education relating to epilepsy classification and the revision of terms used to describe seizures and epilepsies.
- Development, launch and global marketing of EpilepsyDiagnosis.org online diagnostic manual for the epilepsies.
- To develop a classification of neonatal seizures and epilepsies applicable to all healthcare settings worldwide that reflects the framework for the developing classification of seizures and epilepsies.
- To develop a scientifically-based approach to the classification of seizures and the epilepsies and to improve diagnosis of epileptic seizures and syndromes globally.

## Commission Activities June 2013 through June 2014

The Commission has continued to work on developing the classification of the epilepsies. A paper authored by the 2009-2013 Commission led by Ingrid Scheffer was posted on the ILAE website and submitted to *Epilepsia*. Comments were received from 6 expert peer reviewers and from the wider epilepsy community via the website. This area remains one of considerable debate and controversy. The commission reviewed the comments and a Task Force on the Classification of Epilepsies and Seizures was established to develop a roadmap for the ILAE Classification of Seizures and Epilepsies with the ultimate aim to publish an ILAE position paper during the term of the Commission. A classification taking into account seizure type, syndrome and etiology is developing. Importantly epilepsies will also be classified by seizure type if a syndromic diagnosis cannot be made. A seizure types subgroup of the Commission in partnership with the Syndromes Task Force will revise the ILAE glossary of terms to inform the new classification.

A substantial amount of work, led by Kate Riney in partnership with eResearch at the University of Melbourne, has taken place to allow EpilepsyDiagnosis.org to go live in 2014. The goal of this major educational initiative of the ILAE is to

# COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

make available, in an easy to understand form, the latest concepts relating to seizures and the epilepsies. The principal goal is to assist clinicians who look after people with epilepsy anywhere in the world 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 caring for people with epilepsy and we hope will also serve as a useful teaching aid.

The Neonatal Seizures Task Force chaired by Ronit Pressler has reviewed the evidence underlying current classifications of neonatal seizures and has undertaken a critical appraisal of the widely used classifications. The Task Force is developing a shared terminology for neonatal seizures based on group review of video EEG examples of neonatal seizures.

## Accomplishments (2013-2014)

- Online posting of “The Organization of the Epilepsies: Report of the ILAE Commission on Classification & Terminology.” Review of online comments and development of a roadmap for further engagement with the epilepsy community. Classification has now been retained as a term for the overall framework rather than organization.
- Launch of EpilepsyDiagnosis.org. Initial marketing to all ILAE Chapters and members. A detailed business plan for marketing and site development has been submitted to the ILAE Management Committee. Google analytics confirms several thousand visitors to the site per month.
- Classification symposium at European Congress on Epileptology and acceptance of proposals from the Commission and Task Force for symposia at the International Epilepsy Congress in Istanbul, 2015.

## Recommendations for Future Work

- To develop the classification through continuing engagement with the epilepsy community to include a series of controversy pieces in *Epilepsia*.
- To further develop EpilepsyDiagnosis.org and actively market the site to primary, secondary and tertiary care services, national and international physician and lay organizations and educational establishments around the world. Develop a CD version of the site and continuing medical education programs linked to the site.
- To revise the ILAE Glossary of Terms acknowledging developments in the scientific understanding of epilepsy.
- Global education and engagement program on epilepsy classification at national, regional and international epilepsy congresses.
- Neonatal Task Force to prepare a paper critically reviewing current neonatal seizures and develop a glossary of terms to describe and classify clinical and electrographic seizures.



# COMMISSION ON DIAGNOSTIC METHODS



Ingmar Blümcke

## Chair

Ingmar Blümcke (Germany)

## Members

Fernando Cendes (Brazil)  
Andrea Bernasconi (Canada)  
Sarah Wilson (Australia)  
Donald Schomer (USA)  
Philippe Kahane (France)  
Callixte Kuete (Cameroon)  
Riki Matsumoto (Japan)

## MC Liaison

Sam Wiebe (Canada)

## Task Forces

### Task Force for Neuroimaging

Chair      Andrea Bernasconi (Canada)  
Secretary      Fernando Cendes (Brazil)  
Ingmar Blümcke (Germany)  
Graeme Jackson (Australia)  
Paolo Federico (Canada)  
Richard Hogan (USA)  
Matthias Koepp (UK)  
Angelo Labate (Italy)  
Philippe Ryvlin (France)  
William Theodore (USA)  
Eduard Hirsch (Liaison with  
Commission on Surgical Therapies)  
Anna Elisabetta Vaudano (Italy)

### Task Force for Neuropathology

Chair      Ingmar Blümcke (Germany)  
Eleonora Aronica (Netherlands)  
WHO liaison      Felice Giangaspero (Italy)  
Maria Thom (UK)  
Hajime Miyata (Japan)  
Karl Rössler (Germany)  
Lara Jehi (USA)  
Harvey Sarnat (Canada)  
Roberto Spreafico (Italy)

### Task Force for Neurophysiology

Chair      Philippe Kahane (France)  
Francois Dubeau (Canada)  
Cigdem Özkara (Turkey)  
Samden Lhatoo (USA)  
Jean Gotman (Canada)  
Demetrios Velis (Netherlands)  
Pavel Krsek (Czech Republic)  
Simon Harvey, (Australia)

Laura Tassi (Italy)  
Fabrice Bartolomei (France)  
Prasanna Jayakar (USA)  
Andre Palmini (Brazil)  
Andreas Alexopoulos (USA)  
Alice Wu (Taiwan)  
Sinclair Liu (China)  
Riki Matsumoto (Japan)

### Task Force for Neuropsychology

Chair      Sarah Wilson (USA)  
Christoph Helmstaedter (Germany)  
Bruce Hermann (USA)  
Masako Watanabe (Japan)  
Sallie Baxendale (UK)  
Mary-Lou Smith (Canada)  
Severine Samson (France)  
William Barr (USA)  
Sherifa Hamed (Egypt)

## Aims

Our commission covers all 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 a cost-effective diagnosis of epilepsy and their related comorbidities as well as use of consensus classification systems for underlying etiologies. We have set up 4 Task Forces to achieve this goal, with particular emphasis to bridge any validation gap when using advanced as well as standardized technologies for the diagnosis of epilepsy. Our work very much depends on interaction with other ILAE commissions, dissemination and training. All Commission and Task Force members are actively engaged in setting up training facilities, such as the annual International Summer School for Neuropathology and Epilepsy Surgery or the annual European and North-American SEEG training courses. We are also looking forward to establishing a new Neuropsychology Summer School as well as a new long-distance e-learning facility for reading MRIs of the epileptic brain.

### Task Force for Neuroimaging

This Task Force will focus on building new evidence-based consensus criteria for the non-invasive diagnosis of hippocampal sclerosis and focal cortical dysplasia on MRI. This objective will be achieved through a multicenter approach, giving access to a large



# COMMISSION ON DIAGNOSTIC METHODS *(continued)*

spectrum of patients and provide quantitative measures of cross-site diagnostic reliability and variance. The systematic description of these frequent epileptogenic lesions will allow formulating a much-needed standardized definition of “MRI-negative” epilepsy, currently a moving target. This initiative will also set the basis for subsequent MRI-histology validation using the ILAE classification systems and serve educative purposes through virtual distant-learning platforms. A strategic plan has been prepared and will be finalized in the months to come.

## **Task Force for Neuropathology**

This term’s challenge for the Neuropathology Task Force addresses tumor-related epilepsies. Neuropathology agreement has shown dramatic inter-rater variability 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%). Despite their histopathologic WHO definition, 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 large series of LEAT variants by a panel of international neuropathologists and to encourage discussion between WHO, Intl. Society of Neuropathology, and ILAE chapters and commissions to achieve consensus on terminology use and acceptance of a revised tumor classification system. The work is disseminated by our collaborative Summer School initiative, which was held for the second time in Erlangen in 2014. The next course will be organized 26 – 30 of July 2015 in Campinas, Brazil.

## **Task Force for Neurophysiology**

Consensus terminology use, protocols and guidelines for minimum requirements to apply neurophysiology measures are the major concern of this Task Force. Increased interest for invasive EEG (iEEG) methodologies around the world will require, however, also standardized practice parameters or criteria that determine clinical indications for intracranial EEG monitoring. Comprehensive reviews summarizing indications, types and placement of intracranial electrodes (ECoG, SEEG, Strips, Grids) are in progress

and will be shared with the ILAE community. Additional guidelines and recommendations for intracerebral EEG recording and stimulation methodologies, as well as data interpretation are also envisaged. A survey aiming at establishing to what degree the experience varies among centers, regions and countries was launched in 2013 and received feedback from many epilepsy surgery centers worldwide.

## **Task Force for Neuropsychology**

Another important aspect of our commission’s work has addressed neuropsychological assessment in the routine care of people with epilepsy in a way that is understandable to epileptologists and other epilepsy clinicians when interpreting results across different domains. Particular topics include the assessment of focal cognitive impairments, neurodevelopmental delay, behavioral or learning difficulties, and cognitive decline, as well as the assessment of antiepileptic drug treatment or EEG pathology (electrophysiological epileptic activity). Consensus protocols for the assessment of hemispheric dominance (IAT, fMRI) and more specialized presurgical assessment, as well as measures of everyday functioning are also being developed. An official report defining minimum standards for neuropsychology assessment in routine epilepsy care has been finalized during this year’s Task Force meeting at the ECE in Stockholm, and already submitted to the ILAE management and executive committees for review and approval. Plans are also currently underway to establish a Neuropsychology Summer School, to commence in 2016.

# COMMISSION ON EDUCATION



Jaime Carrizosa

## Chair

Jaime Carrizosa (Colombia)

## Members

Chong Tin Tan (Malaysia)  
Alexis Arzimanoglou (France)  
Patricia Braga (Uruguay)  
Shih Hui Lim (Singapore)  
Walter van Emde Boas (Netherlands)  
Lionel Carmant (Canada)  
Amina Gargouri (Tunisia)  
Guenter Kramer (Switzerland)  
Dali Magazi (South Africa)  
Hiba Mahmud (Pakistan)

## MC Liaison

Sam Wiebe (Canada)

## Aims

Previous to the 11th European Epilepsy Congress held in Stockholm, the Education Commission had its first face to face meeting. Having in mind education as the main mission of the ILAE, delegates of each continent, VIREPA coordinators and *Epileptic Disorder's* editor discussed the main needs in education and the strategies to reduce the educational gap in epilepsy.

## Commission Activities

### June 2013 through June 2014

The Latin American Commission with its academic branches ALADE (Academia Latinoamericana de Epilepsia) and LASSE (Latin American Summer School on Epilepsy) organized a number of activities where professors volunteer their time. Each year LASSE lasts 10 days with diverse types of attendees from physicians to social workers and is held in Sao Paulo, Brazil. There are 50 students per year and each year a different topic is reviewed covering basic, clinical and social aspects. Financial support for this activity is a concern. Bursaries are obtained from the government of Brazil, ILAE and pharmaceutical companies. Additional three-day courses are supported by ALADE. For instance in the past year, three were held in Cuba, Guatemala and Venezuela covering the main topics of semiology, EEG, treatment and primary health care in epilepsy. One-year fellowships in epileptology are also available for deserving trainees in Latin America. The commission now offers three bursaries of \$12,000, two for neurologists and one for a neurosurgeon in 2014. There are more than 20 applications per year. This is the fourth year of the program and every fellow has to return to his country for at least 1-2 years to work in a public or university hospital.

The Asian Epilepsy Academy (ASEPA) organizes the Asian Regional Congress as its main activity. However, concern exists that it was only reaching out to physicians in the richer countries who can afford to travel. Therefore in 2013, the Asian Commission launched a series of local workshops, eight in 2013 and four in 2014. The major barriers to education are that physicians only speak native languages and the small number of neurologists per population. It is necessary to train the trainers and there is a need for sustained support. Asia also holds a summer school in China, which is in its third year. Its course duration is 10 days and it has around 50-60 students. The Asian Commission has given a total of 53 fellowships during the past 10 years each for \$6,000 US. They also have an EEG certification examination which has tremendously helped raise the quality of EEG reading in Asia. The certification costs \$100 and around 70% of participants pass the examination.

In North Africa and the Middle East each country has a chapter. But there are limited CEMA activities other than the bi-annual Congress. There is a need to develop an annual course for neurologists, primary caregivers and nurses. This course could be attached to the sub-regional congresses. There is also a need to encourage web-based educational activities. In Sub-Saharan Africa, there are even concerted efforts and the need for improved communications in Africa is evident. There is also a need to educate the population, traditional healers and local leaders, not only physicians. South Africa offers training for a number of African physicians in adult and pediatric neurology. There are also workshops, but these are organized by pharmaceutical companies. The only activity organized by the CAA is the bi-annual congress. This year was more successful with more international attendees than in Kenya two years ago and a large number of participants.

Regarding the journal of *Epileptic Disorders*, over the past year a team of editors met to develop the new educational mission of the Journal. The number of papers has doubled despite the fact that the number of published issues remains at four per year. In addition, the Journal can now be accessed from the ScholarOne platform. Quarterly alerts are sent out to 3,000 epileptologists. The open rate is 20%, but there were 10 times more downloads in 2013 compared to 2011. Additional ideas to reinforce the educational mission of the Journal are:

# COMMISSION ON EDUCATION

(continued)

- Commissioned submissions could be increased including publications from members of the Education Commission.
- Develop didactic sections that will be self-sustained.
- Publish ILAE reports and commentaries from the Commissions
- Supplements could be published following the ALADE and ASE programs.
- Re-enforce the link between paper version and online version
- Promote the nearly 300 video sequences that are free at the website.
- Ask authors to develop two slides with their main educational message for each approved paper. There will also be 2-3 questions per paper.
- Add a new section on neuroimaging and neuropathology
- Include a video atlas of animal models and EEG
- Publish an editorial by the Educational Commission of the League reviewing efforts around the world.

## Recommendations for Future Work

The Education Commission focused on developing a strategy to increase education on epilepsy more specifically and it was believed the target across the world should be to educate first line physicians, health officers and nurses in epilepsy and to do this in a financially sustainable fashion. It is necessary to think of offering new products for education using web-based or other innovative technologies. Finally the group discussed the strategy to assess needs at the different levels: university, training programs, physicians/first line responders and general neurologists. It would be important to know the expected minimal knowledge medical students should have. Then it can be done the same for each level of practice: GP, internal medicine, pediatrics, and neurology including diploma in epileptology.

VIREPA is the optimal format but regionally oriented, less costly and time consuming online courses could be alternatives. The Spanish course for primary care would be a good new course to test another format. VIREPA plans to offer in 2015 the courses of:

- Basic EEG course (again with a concurrent course starting early 2015)
- Advanced EEG course (new)
- Pediatric EEG course
- Epilepsy & Sleep – Clinical (new)
- Medical Treatment of Epilepsy – Introductory

The number of students in all offered courses steadily increased from 81 in 2010/2011 to 211 in 2013/2014. A percentage of almost 50% was reached for bursary grants vs. self-payers.

A discussion about CME accreditation has been held. The possibility of ILAE as the accreditation body needs to be reassessed. The possibility for a more widely recognized certification of the VIREPA courses was again discussed as a way of improving the program's marketability in those areas where CME is required. The VIREPA coordinators were asked to inquire about the accreditation process and related cost for the European Accreditation Council for Continuing Medical Education (EACCME) and the American Accreditation Council for Continuing Medical Education (AACCME).

# COMMISSION ON EPIDEMIOLOGY



David Thurman

## Chair

David Thurman (USA)

## Members

Ettore Beghi (Italy)  
Dale Hesdorffer (USA)  
Charles Newton (Kenya)  
Arturo Carpio (Ecuador)  
Jakob Christensen (Denmark)  
Wendyl D'Souza (Australia)  
Sandra Helmers (USA)  
Mu Jie (China)  
Touré Kamadore (Senegal)

## MC Liaison

Emilio Perucca (Italy)

## List of SubCommission Members

### Epilepsy Prevention Task Force

Charles Newton (Kenya), Co-chair David Thurman (USA), Co-chair Arturo Carpio (Ecuador), Wendyl D'Souza (Australia), Sandra Helmers (USA), Dale Hesdorffer (USA), Mu Jie (China), Touré Kamadore (Senegal), Charles Begley (USA), Karen Parko (USA)

### Burden of Mortality in Epilepsy Task Force

David Thurman (USA), Co-chair Charles Newton (Kenya), Co-chair Ettore Beghi (Italy), Giancarlo Logroscino (Italy), Allen Hauser (USA), Dale Hesdorffer (USA), Fulvio Scorza (Brasil), Ley Sander (UK), Torbjörn Tomson (Sweden)

### Comorbidity in Epilepsy Task Force

Dale Hesdorffer (USA), Chair Ettore Beghi (Italy), Arturo Carpio (Ecuador), Jakob Christensen (Denmark), Andres Kanner (USA), Mu Jie (China), Charles Newton (Kenya), Michael Trimble (UK), Roberto Tuchman (USA), Ruth Ottman (USA)

### Epilepsy Registries Task Force

Jakob Christensen (Denmark), Co-chair Wendyl D'Souza (Australia), Co-chair Sandra Helmers (USA), Dale Hesdorffer (USA), David Thurman (USA), Donna Bergen (USA)

## Aims

To accomplish its mission, the Commission on Epidemiology 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 seeks:

- to review available epidemiological evidence, assess the strength of such evidence, and summarize this evidence for the planning and management of relevant ILAE programs, where requested;
- to identify needed epidemiological research, to promote improvements in research methods, and to strengthen such research capacity, including research to inform epilepsy prevention and control programs of the ILAE;
- to thereby enhance research and prevention programs in world regions where the burden of epilepsy and its adverse consequences are highest, especially lower income countries;
- to educate the epilepsy community and health ministries and departments about the burden of epilepsy, and to promote discussions of program development toward the prevention of epilepsy and its adverse consequences.

## Commission Activities from June 2013 through June 2014

In the first year of its new term, the Commission on Epidemiology reexamined its mission and appointed 4 new or continuing Task Forces to support this mission. In a meeting convened in December 2013, the Commission defined the goals of these Task Forces as described in the following section.

## Accomplishments (2013-2014)

The Prevention Task Force represents a new initiative whose purpose is to assess opportunities for epilepsy prevention and to develop strategies toward implementing prevention measures. The Task Force 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—studies of incident epilepsy, addressing causes and modifiable risk factors in both higher and lower income countries; studies of epilepsy treatment gaps and treatment non-adherence; studies of effectiveness of epilepsy prevention strategies, including primary prevention, as well as early secondary and secondary prevention.

# COMMISSION ON EPIDEMIOLOGY *(continued)*

- Recommendations based on these reviews to identify priorities for epilepsy prevention programs, identify major gaps in understanding causes and risk factors in different world regions.

The Epilepsy Registry Task Force, also a new initiative, was proposed to explore opportunities to develop epilepsy registries, promote the development of new and existing registries, and promote methods to facilitate the international sharing and comparison of data across registries. Such registries have value in providing data to better understand:

- the public health burden and clinical spectrum of epilepsy,
- the distribution of epilepsy types in populations, and
- clinical and demographic determinants of outcomes. As conceived, the objectives for this Task Force were ambitious; however, funding to proceed with the range of activities to achieve them was not approved, due to financial constraints and other considerations. Accordingly, this Task Force is re-considering its objectives to reduce their number and extent.

The Mortality Task Force continues from the previous Commission term. Its purpose is to describe the mortality risk and causes of death among people with epilepsy, and to assess and recommend strategies to prevent premature death in epilepsy. To this end, the Task Force has undertaken systematic reviews to identify incidence and causes of death in epilepsy, separately assessing these in higher-income countries and lower- and middle-income countries. These data have been compiled and analyzed, and manuscript reports are now in preparation. Based upon these reviews of causes of death in epilepsy and risk factors for preventable causes of death, the Task Force will seek to develop potential prevention strategies in collaboration with the Prevention Task Force.

The Comorbidity Task Force also continues from the previous Commission term. Its purpose is to identify and assess the burden of comorbidities among people with epilepsy. This assessment is now focused primarily on psychiatric comorbidities; as time and resources permit, cognitive comorbidities may be addressed subsequently. To this end, the Task Force is in the process of a systematic review to identify psychiatric comorbidities of epilepsy. The publication of this report will enable further work, described as follows.

## **Recommendations for Future Work**

The work of recent and current Task Forces of the Commission on Epidemiology is ultimately intended, to a large extent, to help promote the primary and secondary prevention of epilepsy and its adverse consequences.

The Prevention Task Force will be addressing this aim directly. Its systematic reviews will yield published recommendations that the Commission will promulgate in coordination with other ILAE Commissions, WHO, PAHO, and other relevant agencies to promote research and public health interventions for epilepsy. The work of the Mortality Task Force will also lead to the development of prevention strategies that may be similarly promulgated. And 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.

# COMMISSION ON MEDICAL THERAPIES



Patrick Kwan

## Chair

Patrick Kwan (Australia)

## Members

Martin Brodie (UK)  
Steve Schachter (USA)  
Alejandro De Marinis (Chile)  
Jacques Doumbé (Cameroon)  
Eric Kossoff (USA)  
Hazel Paragua (Philippines)  
Dong Zhou (China)

## MC Liaison

Emilio Perucca (Italy)

## Subcommissions and Members

**AED Trials and Regulatory Affairs:** Jackie French (Chair), Emilia Bagiella, Michel Baulac, Russell Katz, Patrick Kwan, Takaya Maeda, Eugen Trinka

**Botanicals:** Steve Schachter (Chair), Dana Ekstein, Elisabeth Ngo Bum, Siegwald Elsas, Nikolaus Sucher

**Dietary Therapy:** Eric Kossoff (Chair), Nabil Al Macki, Mackenzie Cervenka, Heung Dong Kim, Jianxiang Liao, Kath Megaw, Janak Nathan, Ximena Raimann Tampier, Rocio Rivera, Adelheid Wiemer-Kruel, Beth Zupec-Kania, Emma Williams

**Efficacy Outcomes:** Mark Cook (Chair), Weiping Liao, Christian Elger, Paul Boon, Fernando Cendes, Gayane Melikyan, Brian Litt, Mark Richardson

**Emergency Treatments:** Eugen Trinka (Chair), Reetta Kalviainen, Jaideep Kapur, Célestin Kaputu Kalala Malu, Andrea Rossetti, Francesco Brigo, Gagandeep Singh

**Pharmacogenomics:** Patrick Kwan (Chair), Larry Baum, Martin Brodie, Tracy Glauser, Michael Johnson, Sunao Kaneko, Terence O'Brien, Sanjay Sisodiya, Nigel Tan

**Psychobehavioral Therapy:** Rosa Michaelis (Co-chair), Markus Reuber (Co-chair), David Rosenstein, Venus Tang, Laura Goldstein, William C. LaFrance Jr., Avani Modi, Janelle Wagner

## Aims

To advance the use and development of medical (drugs and other nonsurgical) therapies for epilepsy.

## Mission of the Commission

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

aspects of the ILAE Strategic Plan. The Commission on Medical Therapies has a broad mandate to review current treatments and to advocate for improvements. The scope of the Commission covers issues related to drug therapies and other nonsurgical interventions, including diets, natural products and psychological approaches, as reflected in the creation of separate task forces.

## Commission Activities

### June 2013 through June 2014

The Commission has held teleconferences and met at the ECE in Stockholm in July 2014. Activities of individual task forces are listed below:

### AED Trials and Regulatory Affairs Task Force

The Task Force held a meeting on regulatory issues, on July 2014 as part of the European Congress on Epileptology in Stockholm, Sweden. It was attended by regulatory representatives: Norman Herskowitz (FDA), Manuel Haas (EMA), N. Yabana, and H. Nakamura (PMDA); Task Force Members: Jacqueline French (chair), Rusty Katz, Patrick Kwan, Emilia Bagiella, Eugen Trinka, Jack Pelloch, Alexi Arzimanoglou, Emilio Perucca, Michel Baulac; Observers: Tatsuya Tanaka, Makiko Osawa, Masako Watanabe (Japan Epilepsy Society). The three topics discussed were: Pathway to Monotherapy approval, Extrapolation from Adult Studies to Pediatric Approvals, and Utilizing Time-to-Event Designs for Adjunctive Trials. The meeting was very successful. The European and US regulators agreed they would be willing to entertain a submission by industry using these approaches.

### Botanicals Task Force

Continued the development of the Epilepsy Naturapedia, a wiki to be hosted on the ILAE website, that 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.

### Dietary Therapy Task Force

The Task Force has had a highly productive first year:

- A website (in English and Spanish) with information and resources on ketogenic diet is now up and fully operational (<http://www.ilae.org/Commission/medther/keto-index.cfm>).
- On October 7, 2014, the Task Force held a meeting in Liverpool, UK, to discuss its past, present



# COMMISSION ON MEDICAL THERAPIES (continued)

and future activities. The primary purpose of the meeting was to create a publishable document regarding the minimum requirements for a new ketogenic diet center. Recognizing that the 2009 ketogenic diet consensus statement is very detailed and often perceived as expensive, this document will outline what is truly necessary (vs. optimal perhaps).

## Psychobehavioral Therapy Task Force

This is the newest task force of the Commission created in 2014. It has initiated a project to update the previous Cochrane meta-analysis of psychobehavioral interventions published in 2008.

## AED Trials and Regulatory Affairs Task Force

This has been a very productive year for the task force:

- A white paper on a unified indication (incorporating both monotherapy and polytherapy) for epilepsy was written and submitted for publication.
- The PEACE (pediatric extrapolation academic consortium in epilepsy) initiative has been working with the FDA and is in the process of submitting a white paper.
- A white paper on time to baseline seizure frequency as an add-on study design is in progress.

## Botanicals Task Force

The website is close to completion and launch. Among its many features, Epilepsy Naturapedia enables users to search for information using:

1. Common names
2. Scientific names
3. Names of compounds
4. Names of historical neurologists
5. Historical use
6. Pharmaceutical information
7. Published evidence for use in the treatment of epilepsy

Users may apply for privileges to create new pages or edit existing pages by adding links, images, and their own text.

## Dietary Therapy Task Force

- Maintain and update the ketogenic diet website. The website has received many visits and positive comments
- Working on the draft for the ketogenic diet center guideline, which will be submitted to *Epilepsia*.

## Psychobehavioral Therapy Task Force

The review proposal has been submitted to the Cochrane Epilepsy Group outlining the review objective and responsibilities of task force members. It will cover a range of psychological or behavior modification techniques, and studies related to adults and children will be analyzed separately. Types of outcomes will include health-related quality of life, psychiatric comorbidities, self-management/self-efficacy, adherence parameters, as well as seizure-related outcomes including seizure frequency and severity/duration. To integrate literature on trials with children we will collaborate with the Self-Management in Pediatric Epilepsy task force that belongs to the managing epilepsy well (MEW) network.

## Accomplishments

- Continue work with the regulatory agencies in AED trial design
- Complete and launch the Epilepsy Naturapedia website
- Publication of ketogenic diet center guidelines
- Complete review on psychobehavioral therapy
- Create recommendations on treatment and research based on the meta-analysis of clinical studies and the clinical experience represented by the experts, covering presentation of diagnosis, intervention elements, early phase treatment and treatment maintenance, including a reference to possible health-care system level influences.
- Create minimum requirements for a psychobehavioral treatment center to include individuals and centers providing expert service in a web-based registry in order to facilitate training, treatment and research collaborations.

# COMMISSION ON GENETICS



Daniel Lowenstein

## Chair

Dan Lowenstein (USA)

## Members

Sam Berkovic (Australia)

Alica Goldman (USA)

Ingo Helbig (Germany)

Yuwu Jiang (China)

Mitsuhiro Kato (Japan)

Heather Mefford (USA)

Steve Petrou (Australia)

Parthasarathy Satishchandra (India)

Nigel Tan (Singapore)

## MC Liaison

Helen Cross (UK)

## Subcommission Members

## Aims

- To organize the search for human epilepsy genes on a worldwide scale through broad participation by members of ILAE chapters.
- To prioritize complex epilepsies suitable for multicenter collaborative gene mapping studies.
- To make the results of genetic research on the epilepsies readily accessible to clinicians.
- To improve the public understanding of genetic factors in epilepsy.
- To work with related ILAE commissions to increase understanding of newly identified genes and their role in basic mechanisms of epileptogenesis and anti-epileptogenesis.
- Improving knowledge and application of genetics in epilepsy across the world.

## Commission Activities

### June 2013 through June 2014

**Initiative 1:** Facilitate access to information regarding the identification and interpretation of gene mutations associated with epilepsy.

- a. EpiGAD: The EpiGAD has been regularly maintained, updated and audited.
- b. ILAE Genetics Commission Blog: To provide better outreach and communication to the professional community, the ILAE Genetics Commission has decided to run a blog on topics related to genes and seizures. We have adopted the "Beyond the Ion Channel" blog that was previously initiated by the European EuroEPINOMICS consortium. As of June

2014, this blog is now officially run by the ILAE Genetics Commission and we have usually posted 1-2 posts per week that are well received by the professional community. In June, we officially moved the blog to a self-hosted website and we are currently rebuilding the audience and online presence of the new website. Currently, the ILAE Genetics blog receives 2,000-5,000 views per month, largely from the US and Europe. Over the course of the last two years, this blog has had more than 60,000 visitors including epilepsy professionals, patient organizations and families. In addition to the blog, we issue "The Channelopathist," a weekly email newsletter for the epilepsy community.

- c. Epilepsiome: As an extension of our current online strategy, we are in the process of developing a concept for a comprehensive database on epilepsy and genes that may allow professionals, patient organizations and families to quickly gather relevant information on epilepsy-related genes. For this effort, we have already enlisted the help of ~30 scientific volunteers who have indicated their willingness to coordinate this project. The Epilepsiome project is currently in an advanced planning stage, coordinating efforts with other initiatives such as ClinGen, ClinVar and EGI prior to presenting a full project proposal for the ILAE to approve. We are also exploring different options of supporting this project through patient organizations such as CURE (Citizens United for Research in Epilepsy) and intramural grants of the participating institutions.

**Initiative 2:** Assist in the creation of a centralized database of complete sequence data with variant calls paired with clinical information for as many patients as possible throughout the world that are sequenced for epilepsy of unknown cause. This concept, formally known as the "Epilepsy Genetics Initiative (EGI)" has now been launched as a result of planning between the NIH-sponsored "Epi4K Center Without Walls" and the Chicago-based "Citizens United for Research in Epilepsy," and with substantial assistance from members of the Genetics Commission. See: <http://www.cureepilepsy.org/egi/index.asp>. ILAE members are encouraged to track the growth of this project and become actively involved in helping patients learn about the benefits of participation.

# COMMISSION ON GENETICS *(continued)*

**Initiative 3.** Continue the important work of the ILAE Consortium on Complex Epilepsies, led by Sam Berkovic. The highlight of the Consortium's work this year was the publication in *Lancet Neurology* (Sept 2014; [http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(14\)70171-1/fulltext](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(14)70171-1/fulltext)) of our first meta-analysis of GWAS data involving nearly 9,000 subjects. This 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 being planned to investigate epilepsy comorbidities, by combined analyses with consortia investigating migraine and neuropsychiatric disorders. Finally, the possibility of enlarging the data set of epilepsy patients is being explored.

**Initiative 4:** Improve genetic literacy among both patients and providers.

- a. Educational Brochures: An English version of the educational brochure entitled "Epilepsy and Genetics: Things You Want to Know," designed by Alica Goldman and other Commission members for patients and family members, is now available through the ILAE Genetics Commission website. Positive public reception of the material has 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, the Commission plans to pursue the same strategy for creating similar brochures in Chinese, Japanese and other languages considered to be high priority by the ILAE.
- b. Genetic Literacy Series: Recognizing that clinicians are often uncertain about or uncomfortable with genetic testing in epilepsy and epilepsy genetics, the Genetics Commission, under the leadership of Nigel Tan, is starting a new series on Genetic Literacy in *Epilepsia*. This series of 12 papers aims to update and educate practicing clinicians about clinically relevant epilepsy genetics, using modern evidence-based educational methods to promote learning and knowledge retention. The series will start in 2015.

## Recommendations for Future Work

Increased effort needs to be placed on helping clinicians stay up-to-date on the latest findings in epilepsy genetics, with an eye toward the emergence of individualized therapies based on the patient's genomic profile. We also need to encourage patients and family members living with epilepsy to understand the role that genetic testing may play in the evaluation of a seizure disorder, and the value of involvement in the Epilepsy Genetics Initiative.

# COMMISSION ON NEUROBIOLOGY



Marco de Curtis

## Chair

Marco de Curtis (Italy)

## Members

Norberto Garcia-Cairasco (Brazil)

Aristea Galanopoulou (USA)

Damir Janigro (USA)

Hoon-Chul Kang (Korea)

Katja Kobow (Germany)

Merab Kokaia (Sweden)

Richard Idro (Uganda)

Wei Ping Liao (China)

Astrid Nehlig (France)

Jeff Noebels (USA)

Terry O'Brien (Australia)

Vicky Whittemore (USA)

## MC Liaison

Solomon Moshé

## Mission and Aims

ILAE Neurobiology Commission (NBC) advocates an integrated view of neurobiology and clinical experimental research in the field of epilepsy and promotes this perspective by organizing workshops, events and educational initiatives that involve both neuroscience and epilepsy communities at different levels. NBC has developed a plan according to the following objectives:

- improve translation of basic research into clinical care
- define best methodologies for neurobiology research
- promote and enhance international and regional training/education on neurobiology of epilepsy
- stimulate discussion on new findings related to the understanding of the neurobiological mechanisms of epilepsy
- endorse the involvement of young emergent scientists around the world in epilepsy research

## Objectives and Task Forces

The main objectives will be defined during the 4-year NBC term through activities of specific topic-oriented Task Forces. A broad and close interaction with other ILAE Commissions is planned to realize the following initiatives.

**Initiative 1:** Promote and optimize preclinical antiepilepsy strategies. By the Joint ILAE-AES

Translational Research Task Force chaired by Terence O'Brien and Michele Simonato and by Aristea Galanopoulou and Jacqueline French from the American Epilepsy Society. Members: M. de Curtis, A. Ikeda, A. Pitkanen, A. Brooks-Kayal, F. Jensen, H. Scharfman.

**Initiative 2:** Establish a catalog/list of laboratories and tools of valuable resources. Organized by the Resource Mapping Task Force chaired by Astrid Nehlig, Vicky Whittemore. Members: D. Janigro, R. Idro, G. Kostopoulos, M. Kokaia, N. Garcia-Cairasco.

**Initiative 3:** Endorse educational activities supported by NBC. By the Education and Beyond Task Force chaired by Marco de Curtis. Members: G. Avanzini, M. Bentivoglio, E. Bertram, R. Idro, K. Kobow, WP. Liao, M. Scorza, HC. Kang.

**Initiative 4:** Advance professional training in neurobiology aimed at solving regional epilepsy issues and seed new research developments in less advantaged geographical areas. By the Education and Beyond Task Force (see above).

**Initiative 5:** Organize 2015 and 2017 editions of the Workshops on Neurobiology of Epilepsy (WONOE). By the WONOE Task Force chaired by Katja Kobow and Raman Sankar. Members: K. Kobow, A. Galanopoulou, Y. Murashima, J. Noebels, HC. Kang.

**Initiative 6:** Disseminate neurobiology of epilepsy contents at neuroscience and epilepsy venues and communities. By the Neurobiology Dissemination Task Force chaired by Merab Kokaia and Asla Pitkanen. Members: G. Avanzini, A. Galanopoulou, A. Ikeda, U. Heinemann, D. Janigro, A. Nehlig, J. Noebels, H. Scharfman, N. Garcia-Cairasco, V. Whittemore

## Activities July 2013 through June 2014

The NBC organized two meetings, the first in Washington (December 5, 2013) and the second in Stockholm (June 28, 2014). The Translational TF gathered in Washington (December 6, 2013) and in Stockholm (June 30). The WONOE TF meeting was held in Stockholm on June 29 2014.

During and between these encounters, all initiatives were discussed and progressed as detailed below.

# COMMISSION ON NEUROBIOLOGY *(continued)*

## Initiative 1

A plan of activities was discussed during TF meetings. The following tasks were defined and preliminary working teams were identified:

**Task 1**, co-led by Aristeia Galanopoulou, Marco de Curtis, Akio Ikeda aims at harmonizing methods for video-EEG interpretation and analysis across experimental studies using in vivo and in vitro models of seizures. This task will be accomplished by 6 different work groups.

**Working Group 1** will identify standards for adult rodent EEG interpretation including: methods of EEG recording; types of electrodes, montages, systems of recordings; terminology and classification system of normal EEG patterns; definition and classification of abnormal EEG patterns, including epileptic activities or background abnormalities and status epilepticus.

**Working Group 2** will develop standards for EEG interpretation in immature rodents, in particular for methods of EEG recording, terminology and classification system of normal EEG patterns from surface or epidural recordings, definition and classification of abnormal EEG patterns, including epileptic or background abnormalities and status epilepticus.

**Working Group 3** aims at the development of standards for depth electrophysiological recordings, for in vivo brain recordings (electrodes, recording systems and methods, terminology and interpretation of recorded patterns and associated behaviors).

**Working Group 4** will develop standards for utilization and interpretation of in vitro seizure models to predict validity and relevance to in vivo models and human seizures, to develop methodological standards for in vitro electrophysiological studies and to develop terminology of normal and abnormal (ictal/interictal epileptic or other) patterns.

**Working Group 5** will develop infrastructures to harmonize the analysis of video-EEG data from animal models through existing database-depositories of raw data that will be accessible by all interested investigators. The team will define standards for software-based analysis of rodent EEG and seizure behaviors.

**Working Group 6** will consult on matters that relate to the publications, in particular the atlas of rodent EEGs, and will oversee the creation of a secure video-EEG library of epileptic and nonepileptic events from animal models (*Epileptic Disorders*). Furthermore, this group will oversee issues on translatability of rodent video-EEG patterns and seizures to those seen in humans.

**Task 2**, led by Michele Simonato, Amy Brooks-Kayal and Frances Jensen has the overall goal of undertaking a systematic review of animal model data for particular clinical syndromes, including treatments, biomarkers, and comorbidities through a Cochrane-like collaboration. The working group will organize and coordinate a systematic review of selected topics regarding animal research in epilepsy and establish means to publish/collect them (journals, websites). Creation of focused working groups to address specific issues is planned in the immediate future.

**Task 3**, led by Jacqueline French, Asla Pitkanen, and Helen Scharfman will develop Preclinical Common Data Elements (CDEs) and standardized procedures and protocols based on minimal requirements defined in experimental practice and will create standardized data acquisition forms for preclinical research to allow consistent data collection across different laboratories. Working groups have been formed to generate preclinical CDEs for Behavior, Pharmacology, Physiology, and EEG studies.

**Task 4** (formerly 5), led by Terence O'Brien, Akio Ikeda and Solomon Moshé, will develop the infrastructure to organize multi-center preclinical studies for epilepsy research, through a partnership among government-related funding organizations, industry, philanthropic foundations and academia. A collaboration with the MULTI-PART (Multicenter Preclinical Animal Research Team) group has been initiated, and this is thought to accelerate the progress of this initiative.

## Initiative 2

A questionnaire developed by the TF was posted on the website and will be available either for download or for online compilation. The future of this initiative will be reconsidered after evaluating the response to the online survey.

# COMMISSION ON NEUROBIOLOGY *(continued)*

## Initiative 3

Starting in 2015, a formal application will be used to request a NBC contribution to educational events. Two types are identified in the proposed application form (soon available on line): scientific contribution and economic support. Application deadline is 15 July of the year before the planned event. The new procedure and the application request/form will be finalized and disseminated to all ILAE Commissions and to the organizers of previously sponsored events.

## Initiative 4

One of ILAE's aims is to promote epilepsy training to improve standard treatments and diagnostic capabilities of countries in less advantaged geographical areas. Initiative 4 seeks to advance forward epilepsy training generated at ILAE-sponsored courses, by promoting and launching new seeding research developments aimed at solving regional epilepsy issues in less advantaged countries. The NBC is evaluating the possibility of developing a competitive call for a Beyond-Training Epilepsy Grant Program, in collaboration with co-funding agencies. Project funding should support seeding research/diagnostic activities in the hosting country with limited resources in collaboration with other nations, to realize develop more extensive international collaborative studies that will support research activities on region-specific epilepsy topics.

## Initiative 5

The XIII WONOEP is scheduled for August 31–September 4 2015 on Heybeliada Island, Istanbul, Turkey, as a satellite event of the Istanbul ILAE Congress. The Scientific Organizing Committee is formed by Katja Kobow, Raman Sankar, Filiz Onat, Candan Gurses and Marco de Curtis. The main topic is Biomarkers in Epilepsy. Details on the XIII WONOEP location, application form, etc. are available at <http://www.ilae.org/Commission/neurobio/index.cfm>. The call for abstracts will be published through WONOEP mailing list, on the ILAE website and on *Epilepsia*, *Epilepsy Currents*, and *Epigraphs*. Abstract submission will open November 15, 2014 and will close January 15, 2015. Invitations and fellowships will be announced by April 1, 2015.

## Initiative 6

The program of neurobiology activities organized by the NBC for the 2015 ILAE meeting in Istanbul was defined and a flier for dissemination was prepared and will be distributed at neuroscience and epilepsy venues. The following events are included in the 2015 ILAE meeting program: WONOEP Highlights. A special session will provide delegates with highlights of the most significant issues discussed at 2015 WONOEP XIII.

Neurobiology Symposium: Optogenetics to cure epilepsy: facts and feasibility. Speakers: M. Kokaia, R. Wykes, E. Krook-Magnuson, G. Carmignoto.

Neurobiology of Epilepsy/Translational Epileptology

- 1) Personalizing mTOR inhibition for epilepsy treatment: From bench to bedside. Speakers E. Aronica, P. Crino, N. Burnashev, S. Jozwiak
- 2) Exploring new therapies for human monogenic epilepsies using personalized models. Speakers J. Noebels, H. Caglayan, S. Petrou, K. Yamakawa.
- 3) Epilepsy across species and ages: translating video and EEG terminology from animals to humans and back. Speakers A. Galanopoulou, T. O'Brien, N. Garcia-Cairasco, A. Arzimanoglou

Other sessions/titles with neurobiology content:

- The complexities of epilepsy genetics
- Epilepsies related to the immune system
- SUDEP: From understanding mechanisms to clinical prevention
- Pitfalls of preclinical AED studies
- Status epilepticus: Translation from animal models to humans
- Brain development: Common mechanisms between autism and epilepsy spectrum
- Different flavors of interictal discharges
- Genetic causes of epileptic encephalopathies
- Where is the next big breakthrough coming from?
- Mechanisms of developmental toxicity of AEDs
- Modeling epilepsy comorbidities in animals



# COMMISSION ON NEUROBIOLOGY *(continued)*

Educational events: The best of two worlds:  
Translational epileptology

1. Of mice and men: Clinical and neurobiological perspectives in temporal lobe epilepsy
2. When a seizure is a seizure
3. What do and can clinicians expect from neuroscientists?
4. Beyond the neuron(s): Where is epilepsy Young Scientist Awards to the best platform presentation.

## **The NBC sponsored the following events:**

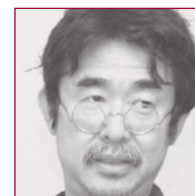
2014 Epilepsy Gordon Research Conference (GRC), entitled Mechanisms of Epilepsy and Neuronal Synchronization held August 17-22, 2014 in the Mount Snow Resort in Vermont, U.S.A., organized by Jack Parent, Scott Baraban and Heiz Beck.

2014 Advanced San Servolo Course Bridging Basic with Clinical Epileptology—focus on focal epilepsy progression: July 20-August 1, 2014. The 12-day course gathered a faculty of 17 tutors and 12 lecturers from 11 countries and involved 40 students from 32 different nations worldwide.

2014 Session at the 17th World Congress of Basic and Clinical Pharmacology (WVP2014), Cape Town, South Africa. The session was on “Optimizing anti-epileptic drug discovery” on July 15, 2014 and was organized by Michele Simonato with the following invited speakers: Terence O’Brien, Asla Pitkanen, Jerome Engel Jr., Aristeia Galanopoulou. This session provided an update on ongoing work to define guidelines that improve and standardize the design, reporting, and validation of data across preclinical and clinical antiepilepsy drug development studies targeting drug-resistant seizures, epileptogenesis and comorbidities. Session on network synchronization in epilepsy at 9th IBRO meeting (July 7-11, 2015), Rio de Janeiro, Brasil. K. Deisseroth, D. Kullmann, J. Huguenard, M. Kokaia.

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

# COMMISSION ON NEUROPSYCHIATRY



Kousuke Kanemoto

## Chair

Kousuke Kanemoto (Japan)

## Members

Mike Kerr (UK)  
Marco Mula (Italy)  
Andres Kanner (USA)  
José Francisco Téllez-Zenteno (Canada)  
Sungpa Park (South Korea)  
Markus Reuber (UK)  
Robert Kuba (Czech Republic)  
David Dunn (USA)  
Gerardo Filho (Brazil)

## MC Liaison

Tatsuya Tanaka (Japan)

## Subcommission Members

### TF on Intellectual Disabilities

Mike Kerr (UK), Co-chair  
Kousuke Kanemoto (Japan), Co-chair  
Christian Brandt (Germany)  
Vicente Villanueva (Spain)  
Christine Linehan (UK)  
Yukari Tadokoro (Japan)  
Sarah Wilson (Australia)

### TF on Psychiatric Aspects of Epilepsy Surgery

Gerardo Filho (Brazil), Chair  
Steffi Kochstoecker (German)  
Mike Kerr (UK)  
Kousuke Kanemoto (Japan)  
Mayu Fujiwara (Japan)  
José F. Téllez-Zenteno (Canada)  
Sara Wilson (Australia), Diagnostic Commission liaison

### TF on Psychogenic Non-Epileptic Seizures

Markus Reuber (UK), Chair  
Kette de Valente (Brazil)  
Chrisma Pretorius (South Africa)  
Masharip Atadzhanov (Zambia)  
Zhou Dong (China)  
Yogesh Patidar (India)  
David Gigineishvili (Georgia)  
Ibrahim Hakki Bora (Turkey)  
Aliakbar Asadi-Pooya (Iran)  
Alejandro De Marinis (Chile)  
Rod Duncan (New Zealand)  
Curt LaFrance (USA)  
Kousuke Kanemoto (Japan)

## TF on Psychoses

Robert Kuba (Czech Republic), Chair  
Tomohiro Oshima (Japan)  
Yukari Tadokoro (Japan)  
Bertrand de Toffol (France)

## TF on Depression

Sungpa Park (South Korea), Chair  
Andy Kanner (USA)  
Kousuke Kanemoto (Japan)  
Aileen McGonigal (France)  
Dongmei An (China)

## TF on Discussion between Neurologists and Psychiatrists

Andres Kanner (USA), Chair

## TF on Education

Marco Mula (Italy), Chair  
Alfredo Thomson (South America)  
Sara Wilson (Australia)  
Çigdem Özkara (Turkey)  
Alla Guekht (Europe)  
Andres Kanner (USA)  
Esper Abrao Cavalheiro (South America)  
Hyang Woon Lee (South Korea)

## TF on Child Neuropsychiatry

David Dunn (USA), Chair  
Paula T. Fernandez (Brazil)  
Jo M. Wilmshurst (South Africa)  
Frank Besag (UK)

## Aims

The main aim of the commission is to develop, stimulate and coordinate research and medical education in the field of the neuropsychiatry of epilepsy.

## Missions

The mission of the commission is to

1. Ensure that health professionals, as well as patients and their care providers have: educational and research resources essential for understanding, diagnosing, and treating various psychiatric manifestations in patients with epilepsy.
2. 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.

# COMMISSION ON NEUROPSYCHIATRY *(continued)*

## Commission Activities July 2013 through October 2014

- A) Face to face meetings and symposia  
7 December, 2013 (Washington, D.C.).  
The first meeting of the Neuropsychiatric Committee. Attendees: Kousuke Kanemoto (Japan), Mike Kerr (UK), Andres Kanner (USA), Josè Francisco Tèllez-Zenteno (USA), Sungpa Park (South Korea), Markus Reuber (UK), David Dunn (USA), Curt LaFrance (USA). One additional member (Gerardo Filho) sent a presentation, which was shared with the attendees.

8 December 2013 (Washington, D.C.). Psychosis Task Force small meeting. Attendees: Robert Cuba (Czech Republic), Kousuke Kanemoto (Japan).

29 June, 2014 (Stockholm). PNES Task Force meeting, PNES around the world. Attendees: Markus Reuber (UK), Kette de Valente (Brazil), Chrisma Pretorius (South Africa), David Gigineishvili (Georgia), Aliakbar Asadi-Pooya (Iran), Alejandro De Marinis (Chile), Curt LaFrance (USA), Kousuke Kanemoto (Japan), Mike Kerr (UK) as treasurer. One additional member (Ravi Paul, Zambia) sent a presentation, which was shared with the attendees.

At Stockholm, Mike Kerr attended the meeting of the Task Force on Syndromes & the Diagnostic Manual as liaison.

30 September, 2014 (Tokyo). Surgery task force small meeting. Attendees: Mayu Fujikawa (Japan), Kousuke Kanemoto (Japan), Sarah Wilson (Australia).

1 October, 2014 (Tokyo). Epilepsy, behavior and intellectual disability: A time for change. Joint symposium of the ILAE and the Japan Epilepsy Society. Christine Linehan (Ireland), Mike Kerr (UK), Kenji Sugai (Japan), Christian Brandt (Germany), Sara Wilson (Australia), Kousuke Kanemoto (Japan), Jun Kawasaki (Japan), Hirano Keiji & Yukai Tadokoro (Japan), Jo Wilmshurst (South Africa).

- B) NDDIE translations.  
The translation of NDDIE is currently in progress. Aileen McGonigal is translating the French version and Dongmei An the Chinese version.
- C) Presurgical psychiatric evaluation.  
A draft of systemic review on presurgical assessment tools for depression is being made by Mayu Fujikawa. This draft was reviewed and examined at the Tokyo meeting and commented on through e-mail from TF members.
- D) Awareness gap about psychosis in patients and medical personnel. Preliminary inquiry was made about the awareness gap between medical personnel and patients about psychosis, applying the Emotions with Persecutory Delusions Scale (EPDS) to 80 Japanese patients.
- E) VIREPA e-learning (completed in 2013).

## Accomplishments July 2013 through October 2014

- A) Task Force on Intellectual Disability.  
The symposium, "Epilepsy, behavior and intellectual disability: A time for change. An international ILAE conference," was successfully held in Tokyo 1 October, 2014, in association with the annual meeting of the Japan Epilepsy Society (1 to 3 October, 2014). The purpose of the meeting was to discuss key areas of need, and solutions to these, to reduce the burden of psychological and behavioral problems especially in adult people with an intellectual disability and epilepsy.

The program was as follows.

10:00-10:05 Opening remarks.

Kousuke Kanemoto (Japan)

Session I (10:05-12:25)

Christian Linehan & Jo Wilmshurst (chairs)

10:05-10:40 The burden of disease, a public health perspective: epidemiology measurement of impact.

Christine Linehan (Ireland)

10:40-11:15 Challenging behavior & psychological distress in people with EP and ID including the role of seizures. Mike Kerr (UK)

# COMMISSION ON NEUROPSYCHIATRY *(continued)*

11:15-11:50 Understanding behavior and mental health: the impact of causation. Kenji Sugai (Japan)  
 11:50-12:25 Autism, behavior and epilepsy: challenges in adolescence. Jo Wilmshurst (South Africa)  
 Session II (13:15-15:00) Kousuke Kanemoto and Sara Wilson (chairs)  
 13:15-13:50 Understanding behavior and mental health: the impact of AED. Christian Brandt (Germany)  
 13:50-14:25 Treatment: psychological approaches. Sara Wilson (Australia)  
 14:25-15:00 Treatment: role of medication. Kousuke Kanemoto (Japan)  
 Session II (15:20-17:30) Mike Kerr and Christian Brandt (chairs)  
 15:20-15:50 Characteristic behavioral problems in patients with intellectual disability with and without epilepsy. Jun Kawasaki (Japan)  
 15:50-16:20 Social change: policy and family burden UK and Ireland. Christine Linehan (Ireland)  
 16:20-16:50 Social change: policy and family burden Japan. Hirano Keiji and Yukai Tadokoro (Japan)  
 16:50-17:30 Overall discussion and future direction of the task force  
 17:30-17:35 Closing remarks Mike Kerr (UK)

The last speech delivered by Kenji Hirano, vice-president of IBE Japanese branch and father of a 26-year-old daughter with Dravet syndrome, symbolized this fruitful symposium, which strongly supported the need to pay attention to this group of patients. Speakers noted in particular the difficulty in transition from pediatric care to the adult care in people with an intellectual disability and epilepsy.

B) Task Force on Psychogenic Non-Epileptic Seizure  
 A meeting titled "PNES around the world" was held in Stockholm in association with the annual meeting of ECE. The purpose of the meeting was to promote awareness of PNES around the world. A cross-cultural PNES study that compares diagnosis and treatment approaches is planned, because PNES may vary according to different social and cultural backgrounds. The program was as follows.

11.00-11.15: Welcome and Introductions - Kousuke Kanemoto, Markus Reuber and Mike Kerr  
 11.15-11.45: PNES, PNES services & research in Brazil – Kette Valente  
 11.45-12.15: PNES, PNES services and research in the USA - Curt LaFrance  
 12.15-12.45: PNES, PNES services and research in Chile – Alejandro De Marinis  
 13.00-13.30: PNES, PNES services and research in Iran – Aliakbar Asadi Pooya  
 13.30-14.00: PNES, PNES services and research in Georgia - David Gigineishvili  
 14.00-14.30: PNES, PNES services and research in Zambia – Ravi Paul  
 15.30-16.00: PNES, PNES services and research in Japan – Kousuke Kanemoto  
 16.00-16.30: PNES, PNES services and research in South Africa – Chrisma Pretorius  
 16.30-17.00: PNES surveys conducted in the UK: a possible model for surveys elsewhere? – Markus Reuber  
 17.15-19.00: Design of research plans for global PNES Task Force.

Although there is no universally agreed upon definition of PNES, the phenomenon of PNES is recognized around the world, and there is currently no evidence of major differences in terms of prevalence or semiology of PNES in different cultures. Current evidence suggests that PNES presenting to medical settings is as disabling as epilepsy. Worldwide, the experience of the Task Force members and the available evidence suggests that only a small minority of patients with PNES have access to experts capable of making the diagnosis, appropriate diagnostic facilities and treatment modalities.

## Recommendations for Future Work

- A) TF on Intellectual disability:
- 1) A task force paper on epilepsy intellectual disability and epilepsy, focusing on management recommendations and research gaps will be produced as an outcome of the Tokyo symposium. This is already being planned and in progress, which will be preferably submitted to *Epilepsia*.
  - 2) The strong statements made by the father of the patient at the end of Tokyo symposium will be published in *Epilepsy & Seizure* (official English Journal of JES).

# COMMISSION ON NEUROPSYCHIATRY *(continued)*

- 3) The difficulty in transition from pediatric care to the adult care should be specially addressed and collaboration between child and neuropsychiatric committee should be further promoted. This link will be pulled up during the AES in Seattle 2014.
- B) TF on PNES
- 1) Two questionnaires about the treatment of PNES have been produced and approved by committee members as well as the executive committee. One questionnaire will be distributed by PNES TF members to people involved in the care of patients with PNES in their respective countries. The other questionnaire will be sent to all chapters of the ILAE and is intended to be completed by each chapter.
  - 2) A symposium on PNES is planned to be held at Nagasaki, Japan on 29 October, 2015. We will soon begin with financial planning and approval procedure for ILAE.
  - 3) Papers will be produced as a fruit of these activities.
- C) TF on depression
- 1) French version and Chinese version of NDDIE, should be completed
  - 2) Thai version is proposed
  - 3) Considering the potential difference of cut-off points based on different cultural backgrounds, trials in Hong Kong and Taiwan are also proposed
  - 4) Translation of GAD is suggested by the TF chair.
- D) TF on Psychiatric Aspects of Epilepsy Surgery
- 1) A systemic review in the making should be completed and published
  - 2) Other psychiatric issues other than depression should be addressed after scales for depression have been accomplished.
- 3) A face to face meeting should be held to promote discussions preferably in South America. Funding to support this key endeavor of the group will be sought through the ILAE.
- E) TF on Psychosis
- 1) Candidates for possible screening tools for psychosis in patients with epilepsy will be reviewed.
  - 2) Awareness gap on this matter between patients with medical personnel will be identified on the basis of preliminary work.
- F) TF on Child Neuropsychiatry
- Collaboration with child committee will be intensified especially concerning transition between child and adult care.
- G) TF on Education
- 1) A comprehensive textbook on neuropsychiatric issues will be published.
  - 2) VIREPA course on psychiatric aspects in adult patients with epilepsy.
  - 3) VIREPA course on psychiatric aspects in children with epilepsy.
  - 4) Survey on educational needs of neurologists and psychiatrists.
- H) TF on Discussion between Neurologists and Psychiatrists. The collaboration with AES is proposed.

# COMMISSION ON PEDIATRICS



Jo Wilmshurst

## Chair

Jo Wilmshurst (South Africa)

## Members

Perrine Plouin (France)  
Hans Hartmann (Germany)  
Patrick Van Bogaert (Belgium)  
Stephane Auvin (France)  
Amy Brooks-Kayal (USA)  
Petia Dimova (Bulgaria)  
Marilisa Montovani Guerreiro (Brazil)  
Makiko Osawa (Japan)  
Vinayan [K. P.] Puthenivill (India)  
Pauline Samia (Kenya)

## Epilepsy Surgery Liaison

William Gaillard (USA)

## MC Liaison

Helen Cross (UK)

## Subcommission Members

### Task Force for Adaption of the Neonatal and the Infantile Recommendations:

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

### Task Force for comorbidities in Pediatric Epilepsy

Chair: Stephane Auvin (France)

### Advocacy Task Force – the rights of the child to access consistent and reliable AEDs

Chair: Jo Wilmshurst (South Africa)

### Pediatric Epilepsy Surgery Task Force

Chair: William Gaillard

## Aims

The Commission on Pediatrics will aim to develop tools to enable clinicians to provide appropriate standard levels of care, and to identify the optimal levels of 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

1. the accessible collation and development of relevant guidelines / recommendations,
2. the “translation” of these guidelines / recommendations to ensure they are viable and understandable in different geographical settings, (“translation” refers to more than language - to the actual integration and use of the recommendation/guideline, making sure that they

are in-line with regional capacity and health-care systems)

3. facilitating chapters in lobbying for access to these resources
4. supporting education in the dispersion of these guidelines/recommendations for the management of epilepsy in children
5. identifying the “epilepsy teams” in the different regions who should be supported and targeted to promote and develop the above points. As such the definition of the “tool” extends beyond the guideline/recommendation itself and involves the role of healthcare workers (at all levels – PHC/community to tertiary), support of lobbying to government for essential aspects of the guidelines/recommendations and so on.

## Commission Activities

### June 2013 through June 2014

The Commission has held four informal meetings 2013-2014 at major international meetings where a concentration of the commission members were present. This has allowed focused planning and discussion on the various task forces the commission is working on over the current cycle. The following outcomes have occurred.

The Task Force for Adaption of the Neonatal and the Infantile Recommendations: The adaptation of existing neonatal and infantile seizures guidelines is needed to ensure that they are viable for use at local levels. Specific teaching courses designed for this purpose have been explored, concentrating on the British Paediatric Neurology Association’s (BPNA) Pediatric Epilepsy Training program (PET), which is directed to all medical professionals working at first and secondary levels of care. Options for cooperation between the BPNA and ILAE to support pediatric epilepsy training for clinicians involved in the care of children with epilepsy from the different regions are under review. This subcommission is assessing the PET1 course for its compliance with the guideline. It is proposed that a Delphi type approach involving Commission Members can be used to ensure consensus of adapting ILAE recommendations on neonatal (published) and infantile (pending) seizure management into the PET1 format. It is envisioned that ongoing adaptation will be needed to ensure recommendations are viable at regional levels. This task force is collaborating with the Education Commission and has recruited members to join the project.



# COMMISSION ON PEDIATRICS *(continued)*

The Task Force for Comorbidities in Pediatric Epilepsy. 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. The task force plans to document the accepted definitions and the known epidemiology of comorbidities overall, and for pediatric epilepsy, noting where this is not known and why (lack of resources, stigma, disclosure). This will include analysis of regional variations and of differing etiologies. A comorbidity could be regarded as part of the “overall brain make up” or parallel process e.g. tuberous sclerosis or acquired by an e.g. post meningitis. The findings are expected to vary across regions, for example in resource poor countries with prevalent acquired insults (neuroinfections, trauma, poor nutrition, lack of interventions) these will dominate the etiologies. The document will aim to address useful clues as to assessing the etiology, to identify which antiepileptic drugs (AEDs) are associated with comorbidities and which should be avoided as a result.

Further, evidence for interventions and attempting to “normalize the EEG” will be assessed. Red flags to help identify a patient in need of early intervention will be developed. Taking the reverse view, the task force will assess the specific epilepsy syndromes in which comorbid complications are commonly seen e.g. CSWS, LKS. Existing data will be graded using the GRADE system and recommendations must cover approaches at primary / secondary and tertiary / quaternary levels of health care.

Recommendations must state if regarded as standard (relevant for any child in any setting i.e. safe practice) or optimal (state of the art). Members of the neuropsychiatry commission have been recruited to be part of this task force. The final text will provide an approachable, clear, simple recommendation and include tables, flow diagrams and “red flag” messages. i.e. to be of use the clinician “working at the rock face”!

**Advocacy Task Force** – the rights of the child to access consistent and reliable AEDs. The rights of the child are threatened worldwide by the autonomy of pharmaceutical companies to withdraw or limit access to AEDs based on revenue, as well as the budget limitations on health care at a government level. There is no legislation to require a pharmaceutical company to take into account the consequences of removing access to a product. In many settings worldwide,

children either have no access, unreliable access, or are managed with a combination of AED generics of different bioavailability. Legislation exists in some European countries which states that changing a child who is stable on one AED brand to another is unethical. This task force will compile initially a documentation of common practice with regard to regional variation in AED supply, and will identify where legislation exists. Data will then be collected to establish the evidence to support the hypothesized risks to children with epilepsy, of changing prescribed agents to different brands and well as the evidence to support the safety of use of AEDs in children. It is hoped that the information will permit an evidence based working document to be completed with a position statement on the matter from the ILAE. It is planned that this task force will involve recruitment of members from the therapeutics and the advocacy commission in 2015.

## **Pediatric Epilepsy Surgery Task Force.**

This task force meets at the European and American Epilepsy Society Meetings. This year the consensus statement generated by the task force “Diagnostic test utilization in evaluation for resective epilepsy surgery in children.” was published in *Epilepsia*. A satellite meeting at Stockholm, held at Gothenberg, and supported by the task force (and the Surgical Commission) convened to review and discuss current neurosurgical techniques and practices. This conference gathered neurosurgical and neurological representatives from the leading pediatric epilepsy centers from across the globe. At this meeting Arthur Cukiert reported on the task force neurosurgical survey on pediatric neurosurgical techniques and practice (50 responses), now being prepared for publication. The pediatric neuropsychology subcommission, led by Madison M. Berl, has completed their survey of pediatric neuropsychology presurgical evaluation practice. This survey was conducted in conjunction with a subcommittee of the neuropsychology subcommission 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. The long-term plan is to arrive at a consensus to standardize assessments and facilitate global efforts to assess neuropsychological presurgical cognitive and behavioral deficits and assess post surgical outcomes. Barriers were identified and plans are being made to overcome them. Susan Koh and Guido Rubboli are leading an effort to establish

# COMMISSION ON PEDIATRICS *(continued)*

the range of training and experience that currently exist across the globe for pediatric epilepsy surgery programs for neurology, neurosurgery, neuropsychology psychiatry and radiology. Smaller centers in resource challenged countries have expressed the view that such data would be very helpful for petitioning for resources and training. The final draft of the survey is under review and is due to be sent out in October with the aim to review results at the American Epilepsy Society meeting. Prasanna Jayakar has completed the draft of the surgical approach survey and will be moving to a second project on cortical mapping for pediatric epilepsy surgery. William D. Gaillard is leading a subtaskforce to devise a pediatric epilepsy severity scale that can be used to assess efficacy of surgical interventions on outcomes. To understand changes in epilepsy surgery practice, 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 2004) for 2014. The survey has been designed by A. Simon

Harvey and will be piloted at 5 sites before implementation in January 2015. The task force is planning a larger meeting in Istanbul to report on the five active projects and to plan on a follow up pediatric epilepsy surgery meeting to be held in Prague. In all the task force is establishing the range of training and practice to help establish consensus to improve assessments, treatments, and outcomes of pediatric epilepsy surgery and to evaluate advances in practice in epilepsy surgery care and outcomes.

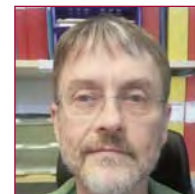
## **Accomplishments (2013-2014)**

Included in the narrative above.

## **Recommendations for Future Work**

Included in the narrative above.

# COMMISSION ON SURGICAL THERAPEUTICS



Bertil Rydenhag

## Chair

Bertil Rydenhag (Sweden)

## Members

Bernhard Steinhoff (Germany)

Kristina Malmgren (Sweden)

Mike Sperling (USA)

Christine Bulteau (France)

Pavel Krsek (Czech Republic)

Andrew McEvoy (UK)

Sanford Hsu (Taiwan)

Mario Alonso (Mexico)

Serge Vuilliemoz (Switzerland)

Taisuke Otsuki (Japan)

## Aims

See also mission below. The most important aim is to promote quality, safety and international collaboration in epilepsy surgery.

- To continue the work of ILAE of international collaboration and to spread knowledge of techniques for evaluation and surgery of patients with epilepsy
- To promote good long time results
- To promote maximal safety for the patients in both evaluation and treatment
- To promote and assist in evaluation of new techniques
- To promote education in epilepsy surgery
- To support epilepsy surgery programs and building in developing countries and countries with minimal resources

## Commission Activities June 2013 through June 2014

The commission has had two full-day meetings, one in Washington at AES December 2013 and one in Stockholm at the ECE June 2014.

## Accomplishments (2013-2014)

There is an active process to take advantage of the work within the EU project E-epilepsy. The first part of this has been started by Kristina Malmgren regarding a new web-based complication classification to be attached to the E-epilepsy database and future registry. The intention is to take advantage of this work also at an international level. Especially the complications related to invasive investigations and epilepsy surgery are important to register prospectively in great detail to increase the safety and the possibility for a benefit/risk discussion with the patient.

## Impact of diagnostic techniques on surgical outcome

Serge Vuilliemoz has started the work to review the impact of diagnostic techniques on surgical outcome. This is also work possible to coordinate with the Epilepsy project, since this project aims at in-depth literature review of MRI postprocessing and electric source imaging.

## Hemispherotomy

Christine Bulteau has started a work on hemispherotomy focusing on very small children. It includes the planning of a web page. The work regards the diagnostic work-up, etiology and also consequences as increased hemiplegia, hemianopia and the cognitive development. Christine Bulteau has also taken contacts to plan a pediatric neuropsychological survey.

## Outcome reporting of Epilepsy surgery

Pavel Krsek is working on how outcome of epilepsy surgery is reported, with the main goal to overcome the apparent inconsistency in reporting surgical outcomes. There are several important domains that are seldom reported.

## Gothenburg pediatric Epilepsy surgery meeting

(PedEpiSurg Gothenburg 2014, 4-5 of July 2014) This meeting was held after the specified period, but the planning was done within the period June 2013-June 2014. The meeting will be reported separately in detail, but was in short a very successful meeting gathering 80 pediatric epilepsy surgeons from all over the world in Gothenburg to discuss specific neurosurgical issues. All the main important techniques were discussed. The meeting was supported by a collaborative effort from the Commission on Surgical Therapeutics and the Pediatric Task Force of the Commission on Pediatrics from where the original initiative came some years ago. Economically it was fully financed by sponsors.

The epilepsy surgery course in Brno 12-16 January 2015. After discussions and approval from the Executive of ILAE and treasurer Sam Wiebe the commission redirected funding to support this important educational activity to finance grants for participants from all over the world.

## Recommendations for Future Work

Within the commission the work will continue also with a focus on epilepsy in developing countries led Andrew McEvoy. Mike Sperling will do further work on risks of epilepsy surgery vs. benefits. This process has already been started in the work with Epilepsy.



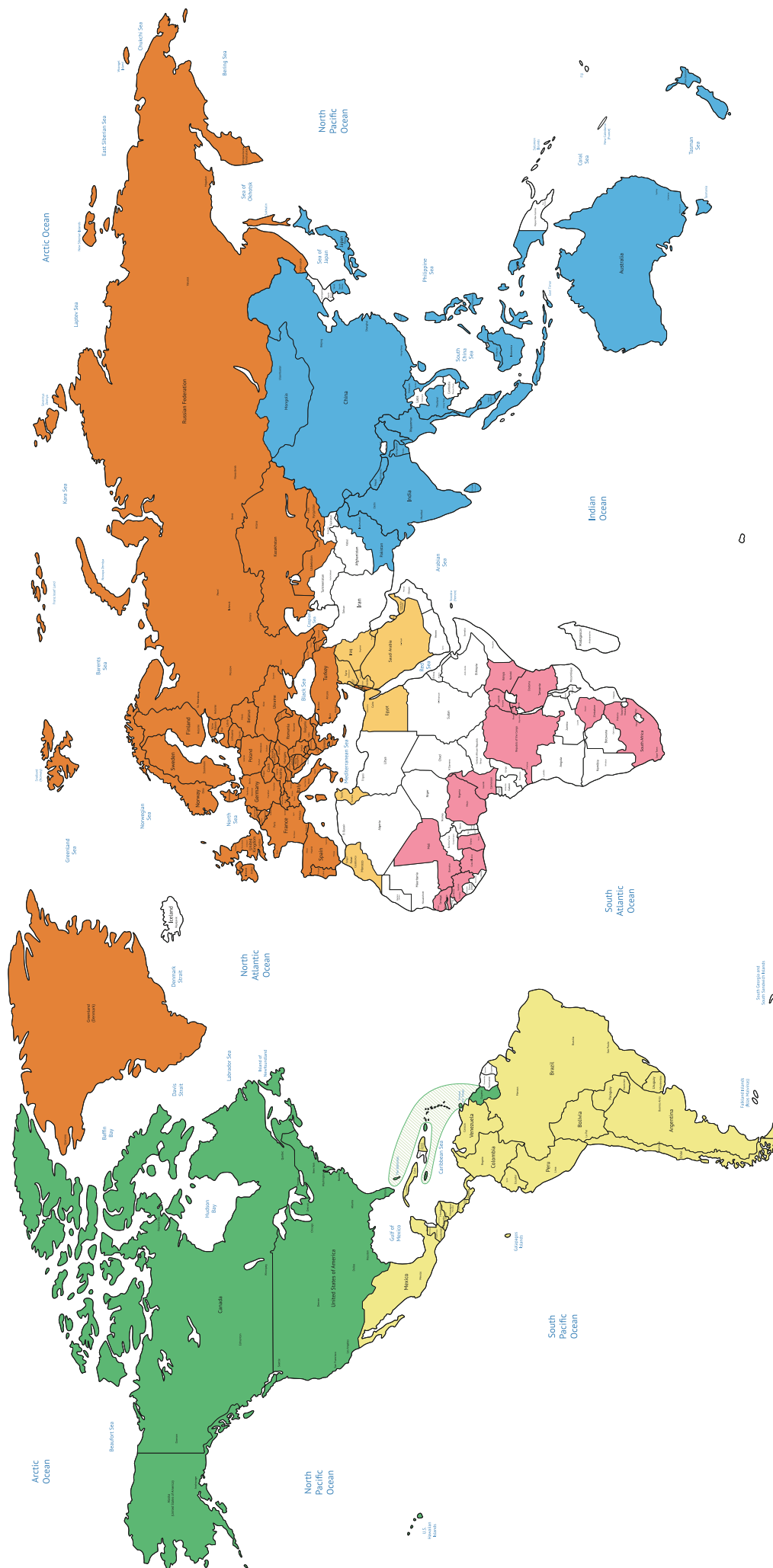
# Chapter Reports 2013-2017

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Zimbabwe

\*Antigua, Bahamas, Barbados, Guyana, Jamaica, Martinique, 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



# CHAPTER REPORTS

## THE EPILEPSY SOCIETY OF AUSTRALIA

### Summary of Activities in 2013 and 2014

The Annual Scientific Meeting is the Epilepsy Society of Australia's (ESA) major annual activity of the year. Held in Sydney in 2013, keynote speakers included Michael Wong of St. Louis, Missouri (USA) and Chris Semsarian of Sydney. Major topics that were addressed included tuberous sclerosis, epilepsy in the elderly and SUDEP. The 2014 meeting was held in Melbourne and featured the topics of status epilepticus, EEG in ICU and the epilepsies phenomena arising from zones or networks. David Treiman of Phoenix, Arizona (USA) and Theodore Schwartz of New York were the keynote speakers and their participation was highly valued by attendees. The meetings attracted audiences of about 250 attendees. The quality of scientific presentations either as poster or platform continues to improve year-over-year, leading to more time being allocated to this portion of the meeting.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

The International Affairs committee of the ESA continues to work actively with the Commission on Asian and Oceanian Affairs. Currently, Andrew Bleasel serves as Secretary-General and John Dunne as Chair of the Constitution Task Force. Several other members, including Ernie Somerville and Wendy D'Souza, have participated in the Asian Epilepsy Academy workshops held throughout the region.

An Overseas Clinical Observership for young neurologists/epileptologists from the Asian and Oceanian region has also been established. This is for a period of three months at an epilepsy unit within a teaching hospital. The Observership provides funds of A\$10,000 to assist with travel and living expenses. The first recipient was Dr. Achrya of Fiji and the second will be Dr. San Oo of Myanmar.

### Educational Activities

The ESA organizes annual EEG and Clinical Epilepsy meetings. These serve as training activities for young neurologists with the Australian and New Zealand Association of Neurologists and are held over three days in February. Both the 2013 and 2014 meetings took place in Melbourne.

Scholarships to support travel to ILAE international meetings and present research work performed in Australia in the amounts of A\$2,500 are awarded yearly to young health professionals. There were six awarded in 2013 and five in 2014.

### Activities in Conjunction with Local IBE Affiliate

The ESA and the Joint Epilepsy Council of Australia (JECA) are attempting a joint bid to host the 33<sup>rd</sup> International Epilepsy Congress in 2019. The Co-chairs are Robert Cole and Ingrid Scheffer.

State-based members of JECA continue to receive support from ESA members through participation on committees, and in workshops and symposia.

### Future Plans

The EEG/Clinical Epilepsy course is to be held February 13-15, 2015 in Sydney.

The Annual Scientific Meeting will be October 21-23, 2015 in Adelaide.

The feasibility of travel scholarships to be offered to young neurologists within the Asian and Oceanian region to attend the EEG course is under examination.

### Officer Election Date

October 22, 2015.

### Respectfully Submitted

Dan McLaughlin, President

## AZERBAIJAN LEAGUE AGAINST EPILEPSY

### Publications

Five articles were published in 2014 on topics related to epilepsy.

### Meeting

The Azerbaijan League Against Epilepsy (ALAE) sponsored its Scientific-Practical Conference.

### Summary of Activities in 2013 and 2014

ALAE participated at the 6th Caucasian Regional Summer School on Clinical Epileptology, which took place at the 11th European Congress on Epileptology.

### Educational Activities

ALAE hosted the Organization of the School on Epilepsy for patients with epilepsy and their relatives.

### Future Plans

Future plans include the organization of our offices and a center for epilepsy.

### Officer Election Date

June 2014.

### Respectfully Submitted

Magalov Sh.I., Melikova Sh.Y.

## BRAZILIAN LEAGUE AGAINST EPILEPSY

### Publications

The Brazilian League Against Epilepsy (BLAE) was featured in the *Journal of Epilepsy and Clinical Neurophysiology*.

### Meeting

BLAE's meeting was held April 3-5, 2014.

### Summary of Activities in 2013 and 2014

#### 2013

BLAE took action steps along with the Brazilian Ministry of Health to establish protocols for epilepsy diagnosis at the primary care level.

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Additionally, it participated at the Latin American Summer School of Epilepsy (LASSE) February 17-26, 2013.

BLAE was represented at the International Epilepsy Congress in Montreal, Canada June 23-26, 2013.

It organized and developed different activities on September 9, 2013, National Epilepsy Day, including hosting booths in five cities, and participating in radio and television interviews.

From October 25 through 27, 2013, members participated in and supported the International Epilepsy Symposium in Sao Paolo.

Members also participated in and supported the Brazil/Italy Epilepsy Symposium held October 31-November 2, 2013 in Recife, Pernambuco.

BLAE organized and supported a task force regarding the use and indication of VNS therapy, which led to the publication of a position paper outlining the Chapter's position on the indication and use of that technology.

### 2014

BLAE participated at LASSE February 16-25, 2014.

It organized and conducted the 35th Brazilian Epilepsy Congress April 3-5, 2014 at Iguassu Falls, Parana, Brazil.

### Officer Election Date

April 3, 2014.

### Respectfully Submitted

Luciano De Paola, MD (President, 2012-2014)

## CANADIAN LEAGUE AGAINST EPILEPSY

### Publications

Six issues of CLAE Connections, our league newsletter, were published in 2013 and 2014. This newsletter highlights our Canadian League Against Epilepsy (CLAE) rising stars, innovative programs and services (clinical, research or advocacy), major publications from our members, information on epilepsy-related meetings, success stories in major grant competitions, etc.

### Meeting

Our biennial meeting was held in London, Ontario October 17-19, 2014.

### Summary of Activities in 2013 and 2014

Our biennial meeting was a great success (see below under educational activities). As mentioned above, we also distributed six issues of our newsletter, CLAE Connections.

In addition, 2014 marked the renewal of our bylaws and the completion of a major financial audit (with no concerns). The past two years were significant for our Board, as we had a new management company, which

resulted in some slowdown of activities earlier on due to this major transition.

We funded two epilepsy fellowships and awarded our usual trainee/allied health awards for best publications (fellow award, grad student or medical student award, resident award and allied health student award).

Our membership was 223 in 2013 (2014 numbers are pending). Two of our founding members were awarded prestigious honors: Juhn Wada received the Lifetime Achievement Award for Epilepsy Research from the ILAE and Warren Blume received the Order of Canada.

In 2014, we had a number of new individuals elected to our executive board. These include:

<i>President-Elect:</i>	Jorge Burneo
<i>Secretary:</i>	Mary Lou Smith
<i>Treasurer:</i>	Jose Tellez-Zenteno
<i>Junior Representative:</i>	Colin Josephson
<i>CPEN Representative:</i>	Kathy Speechley
<i>ILAE Representative:</i>	Samuel Wiebe

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

Nathalie Jetté (incoming CLAE President) continues to lead the ILAE Stigma Task Force, which should be completing some of its initial tasks shortly. The task force includes members from a number of ILAE regions and chapters, WHO, IBE, and the global campaign against epilepsy. The group is finalizing a systematic review and report of the worldwide literature on stigma in epilepsy (more than 300 articles will be included in this report).

### Educational Activities

Our biennial meeting was held in London, Ontario in October 2014 and was a major success. Topics covered were an update on epilepsy in Canada, epileptic encephalopathies, video-EEG monitoring in critically ill patients, surgical failures, stigma, barriers and driving, neuroengineering and epilepsy, genetic counseling in epilepsy, and controversies and advances in neuroimaging of epilepsy and ictal semiology.

The CLAE was very pleased to have our IBE affiliate, the Canadian Epilepsy Alliance, facilitate a plenary session entitled, "Working Together to Improve Epilepsy Care in Canada," that highlighted the tremendous work going on across our diverse country to improve the lives of people living with epilepsy, and their families.

There were 155 attendees at the biennial meeting (a 50% increase from the previous meeting). We also had a significant increase in poster submissions-from 15 in 2012 to 40 in 2014.

### Activities in Conjunction with Local IBE Affiliates

The CLAE is committed to working with community based epilepsy organizations. To that end, we have developed strong ties with the Canadian Epilepsy Alliance (CEA), which is a full-member organization of

# CHAPTER REPORTS

the International Bureau for Epilepsy. As such, the CLAE welcomed the CEA into the planning of our 2014 biennial meeting.

## Future Plans

The incoming President, Nathalie Jetté, has proposed the following activities over the next two years:

1. Needs assessment of our members;
2. Reevaluation of our Mission Statement;
3. Development of a five-year strategic plan;
4. Creation of committees/task forces to include a fund generation committee, awards committee, education committee, publication committee, guidelines committee, web content committee, and a driving guidelines harmonization task force;
5. Increased collaboration with the Canadian Epilepsy Alliance (our local IBE group) and increased collaboration with other NARC chapters (AES, Epilepsy Society of the Caribbean).

## Officer Election Date

October 17, 2014.

## Respectfully Submitted

Dr. Nathalie Jetté (President-elect)

## EPILEPSY SOCIETY OF THE CARIBBEAN

### Meeting

The Epilepsy Society of the Caribbean (ESC) held its biennial North American Regional Caribbean Congress on Epilepsy.

### Summary of Activities in 2013 and 2014

The Epilepsy Society of the Caribbean was officially recognized as a member of the International League Against Epilepsy during its Annual Meeting held in Montreal, Canada in June 2013. To date, we have approximately 64 active members in the society. The ESC has held quarterly epilepsy clinics supported by several members of the Executive Board, as well as a visiting EEG technologist and a physiatrist supported in collaboration with Dell Children's Medical Center of Central Texas. This team travels to Antigua, St. Lucia and Tobago to support local clinics. A total of seven clinics have taken place since April 2013.

A ketogenic conference was held in March 2014 in Kingston, Jamaica. Presenters at the conference were Beth Zupec, a consulting dietician for the Charlie Foundation, and Mary Beth Joy and Karrie Stuhlsatz, registered dietitians from Dell Children's. This conference was initially requested, and then hosted, by two physicians at the University of the West Indies—Roxanne Chambers and Judy Tapper, who are stationed at Bustamante Hospital in Jamaica. The conference was well-received, with over 30 dietitians attending and several patients were started on the diet that was presented.

Since that time, further patients have been initiated and follow-up data was presented by the dietitians in question, as well as Drs. Tapper, Chambers and Clarke at the 4th Global Symposium Ketogenic Dietary Therapies for Epilepsy and Other Neurological Disorders held in Liverpool, England on October 8, 2014 and hosted by Matthew's Friends. The 4th North American Regional Caribbean Congress on Epilepsy (NARCCE) was held in St. Lucia, May 22-24, 2014. It was a very well-attended conference that featured speakers from both North America and the Caribbean. The theme of the conference was "Caring for Patients with Epilepsy: Moving Beyond Medication."

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

Other projects have been developed as a result of networking efforts from the 4th NARCCE that include the better organization and population of the ESC website featuring educational material from the Caribbean Task Force of the North American Commission. EEG training has been ongoing with the visiting EEG technologists; however, a US-based company, Global Diagnostics, has recently donated an EEG to St. Lucia and has agreed to provide online training as well. Accommodations will be made for trainees to travel to the US for one month for training.

### Educational Activities

As mentioned above, the 4th North American Regional Caribbean Congress on Epilepsy was held in St. Lucia, May 22-24, 2014. Speakers included Mary Zupanc, Selim Benbadis, Lionel Carmant, Peter Calen, and Raman Sankar. The President of the American Epilepsy Society, Sheryl Haut, and the President of the International League Against Epilepsy, Diogenes Santosviloria, were also in attendance. The lecture given by Elaine Wyllie, Professor at Lerner College of Medicine Epilepsy Center (Cleveland Clinic) highlighted the need for telemedicine and improving IT. The lecture was given via Skype teleconference with a live question and answer session.

Feedback from the conference was overwhelmingly positive, with participant comments including, "this was my first epilepsy conference and it was wonderful" and "excellent meeting-very well organized. Content was appropriate and a good mix for all level of attendees," and "an excellent conference; it made me more interested in reading more about epilepsy and it will improve my competence." The 5th North American Regional Caribbean Congress on Epilepsy will be held in Barbados in March 2016 and there are requests currently being made for information on this conference.

### Future Plans

Future initiatives include educating teachers and children in the Caribbean about epilepsy and continuing to promote the driving initiative. Other plans include the 5th NARCCE (Barbados) as described above, training of EEG technologists, and continuing to explore and initiate a surgical site in Jamaica. Amza Ali in Jamaica is spearheading this initiative. A final initiative includes the expansion of quarterly clinics to St. Vincent and the continued expansion of the ESC.

# CHAPTER REPORTS

**Officer Election Date**  
December 2014.

**Respectfully Submitted**  
Dave F. Clarke, President

## SOCIETY OF EPILEPTOLOGY OF CHILE

(Chilean Chapter of the International League Against Epilepsy)

### Directory:

President:	Cayetano Napolitano
Vice President:	Daniela Triviño
General Secretary:	Carla Manterola
Treasurer:	Juan Luis Moya
Director:	Marcelo Devilat
ANLICHE Director:	Carlos Acevedo Tomás Mesa

## 1. SUMMARY OF ACTIVITIES

### 1.1 Regular Meetings

Meetings took place the second Saturday of every month during 2013 and 2014.

#### Saturday, January 12, 2013

- The topic was entitled, "The Analysis of the Strategic Plan for Epilepsy in Latin America by the Pan American Health Organization," presented by Marcelo Devilat.
- A ministerial GES plan for non-refractory epilepsy in adults was presented by Dario Ramirez.

#### Saturday, March 9, 2013: Annual General Meeting

- The topic was entitled, "Neurocysticercosis as a Model for the Study of Focal Epilepsies," presented by Daniel Andreu, Neurology Resident at Salvador Hospital.

#### Saturday, April 13, 2013

- The topic was entitled, "The Contribution of Neuropsychological Assessment to the Evaluation of the Epilepsies," presented by Paz Carolina Hernandez, Neuropsychologist at the Neurology Unit of Hospital DIPRECA.

#### Saturday, May 11, 2013

- The topic was entitled, "Vagal Stimulator: Experience in Pediatrics," presented by Viviana Venegas, Pediatric Neurologist at San Juan de Dios Hospital - German Clinic.

#### Friday, June 7 and Saturday, June 8, 2013

- The XIII Winter Symposia in Epilepsy was held at the Hotel Neruda in Santiago.

#### Saturday, July 13, 2013

- The topic was entitled, "The Ketogenic Diet and Genetics in Epilepsy," presented by Juan Luis Moya, Pediatric Neurologist at the Luis Calvo Mackenna Hospital.

#### Saturday, August 10, 2013

- The topic was entitled, "Vagal Nerve Stimulator: Experience at Asenjo Institute of Neurosurgery" and was presented by Osvaldo Olivares, Neurologist at Asenjo Institute of Neurosurgery.

#### Saturday, September 28, 2013

- The topic was entitled, "The Proposal of New Criteria for Clinical Diagnosis of Generalized Tonic-clonic Seizures," presented by Dario Ramirez, Neurologist at Salvador Hospital.

#### Saturday, November 9, 2013

- The topic was entitled, "Bi-temporal Epilepsy: Dangerous Relationships?" and was presented by Cayetano Napolitano, Neurologist at Military Hospital.

#### Saturday, December 14th, 2013

- The topic was entitled, "Allergic Reaction to Carbamazepine: Pharmacogenetics" and was presented by David Martínez, Neurologist at Salvador Hospital/Chilean League Against Epilepsy.

#### Saturday, January 11, 2014

- The topic was entitled, "Vagal Nerve Stimulator: Neuropsychiatric Aspects" and was presented by Fernando Ivanovic-Zuvic, Psychiatrist at the Psychiatry Clinic, University of Chile. He is also President of the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN).

#### Saturday, March 8, 2014

- General Ordinary Assembly and Celebration of the 15th Anniversary of the Chilean Society of Epileptology.

#### Saturday, April 12, 2014

- The topic was a clinical case of DRESS Syndrome, presented by Carolina Gallegos, Neurologist at DIPRECA Hospital – Carabineers Hospital.



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## Saturday, May 10, 2014

- The topic was Dravet syndrome and was presented by Joanna Bórax, Pediatric Neurologist at Carabineers Hospital.

## Saturday, July 12, 2014

- The topic was a clinical case of status epilepticus and porphyry presented by Luis Espinoza, Neurologist at Bicentennial Clinic.

## Saturday, August 9, 2014

- The topic was entitled, "Non-lesional Temporal Lobe Epilepsy Surgery: Clinical Case and Invasive Monitoring," and was presented by Karina Rosso, Pediatric Neurologist at Catholic University of Chile.

## Saturday, September 13, 2014

- The topic was entitled, "Clinical Guides in Epilepsy," and was presented by Lilian Cuadra, Pediatric Neurologist at Asenjo Institute of Neurosurgery – Chilean Ministry of Health.

## Saturday, October 25, 2014

- The topic was epilepsy surgery in children and was presented by Christian Cantillano, Neurosurgeon at Sótero del Río Hospital.

## Saturday, November 8, 2014

- The topic was epilepsy and music. It was presented by Claudia Rizzo, Pediatric Neurologist at Catholic University of Chile.

## Saturday, December 13, 2014

- The topic was epilepsy and mitochondrial disease. It was presented by Juan Luis Moya, Pediatric Neurologist at Calvo Mackenna Hospital – University of Chile.

## 1.2 Congresses and Symposia

### XIII Winter Symposium in Epilepsy 2013

On June 7-8, 2013, the XIII Winter Symposium in Epilepsy was held at the Neruda Hotel. Its theme was "The Clinics and Electroencephalogram as a Guide for Epilepsy Treatment."

The Organizing Committee consisted of Ledda Aguilera and Perla David (co-presidents), Marcelo Devilat, Andrea Aguirre and Mario Gonzalez. The symposium included conferences headed by leading local neurologists and neurophysiologists, industry symposia, and presentations of 16 original works in the form of posters.

### SOPNIA Congress 2013

On October 23-26, 2013, the XXXI Congress of the Society of Psychiatry and Neurology of Childhood and Adolescence (SOPNIA) was held in the city of Viña del Mar. This event was sponsored by our Society.

### XI Symposium in Neurophysiology 2013

The XI Symposium in Neurophysiology, which was organized by the Chilean Society of Clinical Neurophysiology, was held November 12, 2013, in the main auditorium of the University of Chile.

### SONEPSYN Congress 2013

On October 17 through October 19, 2013, the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) held its LXVIII Congress in the city of Viña del Mar. This event was sponsored by our Society.

### XIV Winter Symposium in Epilepsy 2014

On June 6 and 7, 2014, the XIV Winter Symposium in Epilepsy was held at the Neruda Hotel. Its theme was "Frontiers: Demarking Epilepsy and its Treatment." The Organizing Committee was made up of Juan Luis Moya and Cayetano Napolitano (Co-presidents), Carla Manterola, Marcelo Devilat and Perla David.

It included conferences facilitated by renowned neurologists, pediatric neurologists and neurophysiologists, industry symposia, and included a presentation of 18 original works in the form of posters.

### SOPNIA Congress 2014

On October 16 through 18, 2014, the XXXII Congress of the Society of Psychiatry and Neurology of Childhood and Adolescence (SOPNIA) was held in the city of Punta Arenas. This event was sponsored by our Society.

### SONEPSYN Congress 2014

From October 9-11, 2014, the Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN) held its LXIX Congress in the city of Puerto Varas. This event was also sponsored by our Society.

### XII Symposium in Neurophysiology 2014

The XII Symposium in Neurophysiology, organized by the Chilean Society of Clinical Neurophysiology, was held on November 12, 2014, in the main auditorium of the Davila Clinic.

## 1.3 New Members

In 2013, the Society added the following new members

- 1) Daniel Andreu (March); and
- 2) Paz Carolina Hernández, Neuropsychologist (April).

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In 2014, the Society added the following new members:

- 1) Karina Rosso (August);
- 2) Christian Cantillano (October); and
- 3) Claudia Riffo (November).

## 1.4 Working Hours/Opening Hours

Luisa Esparza is our current secretary. Her working schedule is: Monday, Wednesday and Friday from 6:30 pm to 8:30 pm. Phone: +56222310172. Fax: +56222340671. E-mail: socepchi@tie.cl

## 2. ACTIVITIES IN RELATION TO THE GLOBAL CAMPAIGN

### 2.1 Celebration of Latin American Day of Epilepsy

Our society celebrated the Latin American Day of Epilepsy on September 9, 2014. The Chilean League Against Epilepsy organized diverse activities to commemorate this day, including the participation of patients and their families in several events.

At our meeting held on September 13, Perla David gave a commemorating speech.

## 3. EDUCATIONAL ACTIVITIES

### 3.1 Chilean Journal of Epilepsy

The *Chilean Journal of Epilepsy* is the official publication of our Society. Dr. Perla David serves as its main editor, and this year, Dr. Ledia Troncoso joined the editorial board, which has provided a great contribution to this publication. During 2013 and 2014, we released the 12th and 13th volumes of this Journal. This year (2014) we will release three new chapters. The materials include original papers, case reports, reviews and updates. We also achieved indexation in SciELO in October 2014. Our current official ISSN number is 0719-5397. This is the product of the hard work and dedication of the Journal staff, due in large part to the efforts of Perla David. The magazine is also available online with its own website at [www.revistachilenadeepilepsia.cl](http://www.revistachilenadeepilepsia.cl).

### 3.2 Webpage

Our website, [www.epilepsiadechile.com](http://www.epilepsiadechile.com), is available to members and the general public. The site was updated during 2014. On the site, we have published information about the Society and issues related to epilepsy, broken down into the following sections:

1. Introduction
2. Activities (regular meetings, Winter Symposium in Epilepsy)
3. Notes (updates on epilepsy, history of epilepsy)
4. News about epilepsy

### 5. Staff and Associates

### 6. Links to ILAE, IBE, WHO and MINSAL; as well as to the *Chilean Journal of Epilepsy*

### 7. Contact information

The site has played an important role for university students, who are the most frequent users (asking for references), as well as for patients and their relatives. We have collaborated with many organizations to provide epilepsy-related topics actively throughout this website.

## 3.3 Library

Our library, located at the Society's headquarters, hosts a great number of journals and other publications. Issues of *Epilepsia*, the official publication of the ILAE, are archived in our library (from 1999 to present), and they are available for members at the headquarters of the Society of Epileptology of Chile, in addition to being offered online.

## 4. ACTIVITIES IN CONJUNCTION WITH LOCAL IBE AFFILIATES

### 4.1 National Affiliations

Our Society maintains continuous interaction with:

- The Society of Neurology, Psychiatry and Neurosurgery (SONEPSYN);
- The Society of Psychiatry and Neurology of Infancy and Adolescence (SOPNIA);
- The Chilean Society of Pediatrics (SOCHYPE);
- The Chilean Society of Clinical Neurophysiology (SOCHINEUROFISIOLOGIA); and
- The Association of Leagues Against Epilepsy, Chile (ANLICHE).

Various Society members also participate in the Epilepsy Regulatory Group of the Ministry of Health of Chile (MINSAL).

### 4.2 International Affiliations

The Society is a member of the Latin American Affairs Committee of the International League Against Epilepsy. It participated in the Organization of the VIII Latin American Congress on Epilepsy, which was held in Buenos Aires, Argentina in September 2014.

### 4.3 Celebration of Latin American Day of Epilepsy

As mentioned previously, we celebrated the Latin American Day of Epilepsy on September 9, 2014. The Chilean League Against Epilepsy organized diverse activities to commemorate this day, including the participation of patients and their families in several events.



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In our meeting held on September 13, Perla David gave a commemorating speech.

## Respectfully Submitted

Dr. Cayetano Napolitano

Dr. Daniela Triviño

President

Vice President

Dr. Marcelo Devilat B.

Director

## CAAE PRIMARY ACTIVITIES OF CAAE IN 2013 & 2014

CAAE participated in many activities during the period of 2013-2014, including:

- Participation at National Conferences such as the 5th CAAE International Epilepsy Forum (2013), the 4th CAAE National EEG & Neurophysiology Congress (October 22-25, 2014) in Suzhou.
- Training courses in collaboration with ASEPA (2-3 times a year).
- Web-based training and the national examination of EEG technicians/doctors (certificate).
- Participation in International Epilepsy Caring Day (June 28), which was celebrated in most of the provinces/cities and featured public education and volunteer patient consultation.
- The preparation and publication of pilot issues of the *Chinese Journal of Epilepsy* in collaboration with *Epilepsia*.
- The establishment of subcommittees under the CAAE Board, including a CAAE Youth Committee, CAAE TSC Special Committee, CAAE Epilepsy Center Promotion Committee, and PWE's Subcommittee (as a branch of IBE). They all have had related activities to support part-time epileptologists working in poorer areas, which received good results.
- The new establishment of Shanxi & Shaanxi provincial associations against epilepsy. There are now a total of 18 provinces that have established provincial level epilepsy organizations.
- Education programs in collaboration with other international NGOs/pharmaceutical companies such as "Rainbow Bridge" (Project Hope, UCB), Dandelion Project (UCB), Livelihood Project (Basic Needs), etc.
- Providing technical support to the "National Epilepsy Prevention and Control Project in Rural Areas" (GCAE).

## Summary of Activities in Relation to Global Campaigns in 2013 and 2014

By the end of 2013, the project covered 18 provinces and 135 project counties representing a total population of 74.95 million people and with 2,414 township hospitals.

The national project has been funded by the State government, which has provided four million CHY/year (\$0.64 million US). It began in 2005 in 10 provinces and is now presently in 18 provinces. Funding was also increased to 15.15 million CHY/year (\$2.43 million US).

### Key statistics:

1. Total number of screened patients: 181,706
2. Total number of confirmed: 143,696
3. PHB treated: 82,943
4. VPA treated: 11,143
5. PHB+VPA: 2,297

Additionally, many public health workers have been trained, including 1,196 on a provincial level and 22,870 on a county level.

### Educational Activities

1. Training courses in collaboration with ASEPA (2-3 times per year);
2. Online training and national examination of EEG technicians/doctors (certificate);
3. Public education with the IECD (June 28);
4. Educational programs in collaboration with other international NGOs/pharmaceutical companies including "Rainbow Bridge" (Project Hope, UCB), Dandelion Project (UCB); Livelihood Project (Basic Needs), etc.

### Activities in Conjunction with Local IBE Affiliates

- PWE conference in collaboration with IBE during the 5th CAAE International Epilepsy Forum
- PWE Summer Camp as part of the "Rainbow Bridge" Project;
- PWE education in different "Epilepsy Centers".

### Future Plans:

1. Election of CAAE Board by the end of 2014;
2. Formal publication of (Chinese) Epilepsy Journal;

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3. Another 2-4 provincial associations to be set up soon;
4. Continuation of other educational programs.

### Respectfully Submitted

Shichuo Li  
President of CAAE

## COLOMBIAN LEAGUE AGAINST EPILEPSY

### Meeting

#### The National Congress of Epilepsy (Colombia)

##### Summary of Activities in 2013 and 2014:

The activities undertaken during these two years were primarily to complete all of the paperwork that must be submitted to finally get the Colombian League Against Epilepsy recognized as an association of health professionals that are dedicated to the care of those with epilepsy.

Steps were also taken to incorporate the official Law #1414 from the year 2010, and continuing to educate about epilepsy.

##### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

We participated in reforms made to Colombia's mandatory health plan, where coverage was achieved for second-line anticonvulsant drugs such as topiramate, lamotrigine, levetiracetam, oxcarbazepine, vigabatrin and lacosamide.

Working in conjunction with OPS, we implemented a model of care for patients with epilepsy based on resources available in Colombia, which are supported by the mhGAP strategy.

We also worked in conjunction with the Ministry of Health to adopt a guide for epilepsy care and supported arrangements for the initial development of the Colombian national guidelines for the management of epilepsy.

### Educational Activities

We sponsored a course on the difficulty of epilepsy in Medellín in November 2013 with strong participation from both national and international speakers, who addressed neurologists, pediatric neurologists and other staff involved in the management of epilepsy. The course was used to gather and disseminate information to the institutions that are developing epilepsy groups throughout the country. At the same event, three scholarships were given to residents of neurology and neuro-pediatrics who submitted the best research. UCB sponsored the scholarships.

In 2013, we organized three regional courses and supported the organization for a fourth year. All courses are geared toward educating general practitioners and other health professionals involved in the care of patients with epilepsy. These courses were

held in the cities of Pereira, Barranquilla, Neiva and Cali, Colombia.

### Activities in Conjunction with Local IBE Affiliates

During the regional courses community, we held meetings to inform attendees about the rights and duties of patients in accordance with Law #1414 of the year 2010, as well as amendments to mandatory health plans in regard to patients and their families.

We also held meetings with the Ministry of Health for the development of the Bureau of Permanent Work on Epilepsy, as outlined in Law# 1414, enacted in 2010. We continue to encourage patients to organize a united front to work with the Bureau.

### Future Plans

1. Legalize documents with the Colombian League Against Epilepsy in order to attain independence from its predecessor, and ensure a greater chance of success.
2. Reactivate community education and scholarships for residents who perform research in epilepsy.
3. Organize the XVI National Epilepsy Congress as a high-level course for physicians, neurologists and neurologists, particularly for those with an interest in the comprehensive management of epilepsy.
4. Elect of a new Board.

### Officer Election Date

August 2, 2012.

### Respectfully Submitted

Angelica M. Uscátegui Daccarett  
Secretary

## THE CONGOLESE LEAGUE AGAINST EPILEPSY

The Congolese League Against Epilepsy (Ligue congolaise contre l'Epilepsie) was established in December 2012.

### Summary of Activities in 2013 and 2014

The main activity during the term 2013-2014 was a workshop on epilepsy organized in Kinshasa and held September 6-12, 2014. This workshop was co-financed by ILAE and the International Brain Research Organization (IBRO). During this meeting, subjects discussed included the epidemiology of epilepsy, etiology, physiopathology, EEG and treatments for epilepsy. Presenters came from Africa, the USA and Europe. Participants were from DR Congo (DRC), Congo-Brazzaville, Burundi, Cameroon, Bénin, Sénégal and Morocco.

### Publications

There were two publications from members of the League.

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## Future Plans

Next year, we plan to implement both a National Bureau Against Epilepsy and an educational campaign across the country.

## Respectfully Submitted

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## COSTA RICA CHAPTER OF THE ILAE

### Meeting

A meeting was held on October 28.

### Summary of Activities in 2013 and 2014

On August 28, 2014 the election of the Chapter's Director, Board and new President was held.

On October 20, the chapter held a meeting with the candidates for the IBE board, selecting the next meeting date for November 17, 2014.

On October 28, 2014, the 2014 Electroencephalography Meeting took place at Hospital Calderón Guardia in San José.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

March 26, 2014 was the National Day of Epilepsy. On this day a meeting with epilepsy associations and patients was held at Hospital Raúl Blanco Cervantes, San José. At the event, a speaker from ILAE Costa Rica talked about pharmaco-resistant epilepsy.

### Educational Activities

On October 28, 2014, the 2014 I Electroencephalography meeting was held at the Hospital Calderón Guardia in San José.

The chapter created a short-term fellowship for neurology residents in epilepsy at the Social Security.

The chapter also created a short-term fellowship for general physicians in epilepsy at the Social Security.

### Activities in Conjunction with Local IBE Affiliates

On October 20, a meeting with the candidates for IBE board was held during which time the group chose November 17, 2014 as the next meeting date.

### Future Plans

We met on November 17 with IBE Costa Rica to officially establish the Association.

### Officer Election Date

August 28, 2014.

### Respectfully Submitted

Roberto Vargas Howell

## CROATIAN LEAGUE AGAINST EPILEPSY

### Summary of Activities in 2013 and 2014

#### In 2013, our Chapter:

- Celebrated Epilepsy Day in Croatia on February 14. The event was organized by the Croatian League Against Epilepsy, Croatian Child Neurology Society, Association for Epilepsy, and City Hall.
- Held public lectures in the city of Zagreb as part of Epilepsy Day on February 14 at the City Hall.
- Participated at the 42nd Symposium of Croatian Child Neurology Society.
- Held a summer camp for children with epilepsy.

#### In 2014, our Chapter:

- Again celebrated Epilepsy Day in Croatia in February.
- Again held public lectures at City Hall (Zagreb) as part of Epilepsy Day.
- Held a course on epilepsy in Dubrovnik in October.
- Participated in the 11th Croatian Symposium on Epilepsy in the city of Osijek November 6-9, with international participation.
- Held a seminar entitled, "Controversies in Neurology," which was organized by the Department of Neurology, UHC Zagreb, Rebrow.
- Participated in the 43rd Symposium of the Croatian Child Neurology Society with international participation. The event was held in Zagreb in December.

### Educational Activities

The Chapter offered a course on epilepsy in Dubrovnik in October 2014.

### Future Plans

We have plans to promote epilepsy awareness, and to connect and cooperate with national and international societies and organizations dedicated to health promotion and education in the field of epileptology. We would like to also increase the number of new specialists and subspecialists who are educated in the field of epileptology, and to improve pre-surgical diagnostics for epilepsy, as well as surgery for epilepsy in adults and children with refractory epilepsy in Croatia.

### Officer Election Date

June, 2012.

### Respectfully Submitted

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## CUBAN EPILEPSY CHAPTER OF ILAE

### Publications

Please visit our website at [www.epilepsysocu.sld.cu](http://www.epilepsysocu.sld.cu) for a complete list of publications.

### Summary of Activities in 2013 and 2014

Since 2012, our website [www.epilepsysocu.sld.cu](http://www.epilepsysocu.sld.cu) has been available. It contains information about the Chapter as well as other sections. The website has played an important educational role in Cuba. Other activities in 2013-2014 included:

- Participation in national epilepsy meetings at the Neurological National Institute in Havana.
- Four epilepsy symposiums during the IV International Conference for Neurological Restoration in Havana, Cuba which was held in March 2014.
- Participation in a Halifax course focused on epilepsy surgery at the Amejeiras Hospital in Havana.
- An "Epilepsy and Intensive Care Unit" course that took place November 7-8, 2014 in Havana.
- Active participation in LASSE, due to the LASSE awards.
- Participation in the Latin Epilepsy Congress due to the ILAE-LACE awards.
- The publication of many papers and textbooks by our members.
- Awarding four young medical doctors ALADE fellowships.
- Participation in national and international epilepsy research projects.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

We have started to work with the Latin American epilepsy program, Strategic Plan on Epilepsy, together with PAHO and the Cuban Health Minister.

A document discussing Cuban pharmacoresistant epilepsy treatment was published in October 2014.

### Educational Activities:

We are organizing a continuing educational program on epilepsy.

We are also holding ALADE Courses (I, II and III). These courses are conducted by the Cuban epilepsy chapter, and ALADE was held in 2012, 2013 and 2014. All meetings were well attended with more than 100 participants.

A regional epilepsy primary care course and online courses are now being offered as well.

EEG and epilepsy courses are now available, with the target audience being neurologists, clinicians,

neurophysiologists, neurosurgeons and psychiatrists in training.

### Activities in Conjunction with Local IBE Affiliates

- A systematic meeting with patients and family support.
- Activities for the STAND UP Campaign.

### Future Plans

- To improve our knowledge and research in epilepsy.
- To organize our National Congress.
- To continue working in the Latin American epilepsy program (Strategic Plan on Epilepsy) together with the local PAHO chapter and the Health Minister of Cuba.

### Officer Election Date 2016.

### Respectfully Submitted

Lilia Morales Chacon, President

## DANISH EPILEPSY SOCIETY (DANSK EPILEPSISELSKAB)

### Meeting

The next Annual Meeting will take place March 6-7, 2015.

### Summary of Activities in 2013 and 2014

- We held a 1½ day Annual Meeting and another separate one-day meeting both years.
- We held an "Introduction to Epileptology" course at the Danish Epilepsy Center at Dianalund each year.
- We sponsored two bursaries for participation at the Baltic Sea Summer School in Epilepsy each year.
- We sponsored two bursaries for participation at the Dianalund Summer School on EEG and Epilepsy in 2014.
- We provided research grants amounting to 50,000 DKK awarded annually from the Lennart Gram Memorial Fund.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

Board members have assisted in planning and evaluating the results of a UCB-sponsored survey among epilepsy patients, general practitioners and hospital-based epileptologists regarding accessibility to,

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the quality of, and unmet needs in relation to epilepsy services in Denmark. The results will be further analyzed by the Danish IBE affiliate in order to define future initiatives in optimizing epilepsy care.

## Educational Activities

One of the main goals of our Annual Meeting is to promote education in the field of epilepsy. Below are dates and information about our meetings in 2013 and 2014:

- Annual Meeting, March 1-2, in Aarhus. Subject: Differential Diagnoses in Epilepsy
- Autumn Meeting, October 24, 2013, in Copenhagen. Subject: Epilepsy & Autoimmune Encephalitis
- Annual Meeting, March 7-8, 2014, in Copenhagen. Subject: Epileptic Syndromes
- Autumn Meeting, October 24, 2014, in Copenhagen. Subject: Mortality in Epilepsy

A lecture competition for young doctors is held during the Annual Meeting, with prizes awarded for the best lectures.

The three-day "Introduction to Epileptology" courses are held under the auspices of the Society, but organized by the Danish Epilepsy Center at Dianalund.

## Activities in Conjunction with Local IBE Affiliates

A meeting between the Society Board and representatives from the local IBE affiliate (Dansk Epilepsiforening) has been held each year.

## Future Plans

A common database of VNS treatment in Denmark is being planned.

## Officer Election Date

Officers are elected at the General Assembly.

## Respectfully Submitted

Ioannis Tsiropoulos, Secretary, DES

## DUTCH LEAGUE AGAINST EPILEPSY

### Meeting

The League meets 3-4 times a year.

### Summary of Activities in 2013 and 2014

- We reviewed Dutch regulations for epilepsy patients and obtaining driver's licenses.
- We evaluated studies on SUDEP and ESES.
- We pursued seizure detection methods available for patients/parents.

## Summary of Activities in Relation to Global Campaigns in 2013 and 201

The summary was coordinated by the Chairman of the League.

## Educational Activities

Once a year, a symposium on epilepsy, specifically for neurologists, pediatricians and others is held. Additionally, we publish a journal entitled "Epilepsie."

## Future Plans

We hope to implement the new Dutch policy on epilepsy in daily practice.

Respectfully Submitted

Dr. G. Hageman, Neurologist, Secretary

## DEUTSCHE GESELLSCHAFT FÜR EPILEPTOLOGIE (DGfE NETHERLANDS)

### Publications

Journal of Epileptology

(<http://link.springer.com/journal/volumesAndIssues/10309>)

### Meeting

Information about our upcoming meeting in 2015 can be found at [www.epilepsie2015.de](http://www.epilepsie2015.de).

### Summary of Activities in 2013 and 2014

From a clinical perspective, the DGfE has been working to continuously define and describe standards of treatment and to improve them based on new insights. Numerous sub commissions of the DGfE perform invaluable expert work in providing guidelines and benchmarks in a number of fields (e.g. guidelines for driving license regulations, rehabilitation, quality criteria for epilepsy centers, epilepsy health care centers, deep brain stimulation and/or imaging technologies). The DGfE has also been centrally involved in measures that support continuous improvement of services and assistance for people with epilepsy; especially with respect to prevention, diagnosis and treatment.

Regarding research, the DGfE has furthered its efforts to support research towards improved diagnosis and treatment of epilepsy patients. For instance, the DGfE has implemented a program for supporting research and offers support for young scientists seeking extramural research funding. Members of the DGfE have been extremely successful in attracting funding of large consortia, both nationally and internationally, for epilepsy research.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

As a society in an economically privileged part of the world, the DGfE recognizes its responsibility for helping to provide epilepsy care in developing countries. The DGfE is strongly committed to contributing to their improvement and has already implemented and financed several international support projects, embedded into a common initiative. For instance, the



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DGfE is currently supporting an epilepsy project in Namibia aimed at improving care and treatment for epilepsy patients in this country. All individuals and centers meet annually within a global outreach forum at the yearly meetings of the society.

## Educational Activities

We are committed to furthering education about epilepsy, both amongst the general public and healthcare professionals. The German chapter offers a defined curriculum in clinical epileptology for medical doctors, culminating in a formal Certificate of Epileptology. During the annual conferences and at additional venues, education for clinicians is supported by the Academy of Education in Epileptology, which was founded in 2004 and provides a wide-ranging course program. The DGfE also supports a number of further measures for training and education in the fields of clinical and basic epileptology, including the Otfried-Förster Stipends for young doctors, which enable them to pursue epilepsy-related research projects.

Communication between researchers, clinicians and the general public is one major goal of the DGfE, which is provided by conferences, in print, e-publications and using other media. Our annual conferences aim to promote scientific exchanges and strongly support further education of our members. They now also incorporate a "patient day," which took place for the first time in 2014 in the former plenary hall of the German Government.

Publications of the DGfE include the quarterly print medium, "Zeitschrift für Epileptologie" (Journal of Epileptology). In addition, the DGfE hosts the Information Center Epilepsy, an online-only information resource for patients, doctors and the general public. The DGfE also participates in the production of educational films on the topic of epilepsy, as well as other outreach activities.

## Activities in Conjunction with Local IBE Affiliates

The DGfE has been cooperating intensively with the German chapter of the IBE, the "Deutsche Epilepsievereinigung," on a number of issues. The DGfE has set apart a full day of its national annual meeting for patients, to be organized in close collaboration with the IBE chapter. Furthermore, the DGfE has been closely interacting with the IBE chapter on critical patient issues, such as those related to the licensing of new anticonvulsant drugs by the German government.

## Future Plans

The DGfE is committed to intensifying integration within both the European and international community, to improving its educational and outreach programs, and to continue supporting epilepsy research.

## Respectfully Submitted

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## EMIRATI LEAGUE AGAINST EPILEPSY (ELAE)

### Publications

The League issued several publications pertaining to the topics of driving and epilepsy, the discontinuation of AEDs, psychogenic seizures, and neuropsychiatric issues in patients with epilepsy.

### Summary of Activities in 2013 and 2014

We held our 2nd Annual ELAE Congress in Abu Dhabi, that was attended by 201 delegates from 17 countries. Additionally, we held our 3rd ELAE and first joining Emirati Saudi Congress in Dubai, that was attended by 271 delegates from 18 countries.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

- In March 2013, we sponsored Epilepsy Awareness Week by providing seminars at several large governmental hospitals in the country.
- In April 2014, we sponsored Epilepsy National Awareness Week again, by providing seminars at several public facilities. Several radio talk shows and TV interviews were also conducted that week to further enhance the mission of increasing the awareness and understanding of this disorder.

### Educational Activities

Four scientific meetings were held in 2013. They were attended by more than 40 delegates. These meetings were very well received and generated fruitful discussions. Faculty members grew year-over-year and became more international when compared to the UAE-based faculty. In addition, over the past two years we have initiated a series of topics to tackle various social issues that impact the lives of patients with epilepsy.

Four scientific meetings were also held in 2014, attended by 40-50 delegates. This year, we have incorporated a series of topics to tackle various social issues that impact the lives of patients with epilepsy.

### Activities in Conjunction with Local IBE Affiliates

ELAE has continued its outreach programs to educate healthcare providers about this disorder, and its diagnostic challenges, and update them on various treatment options. We held two programs each year. The last program was held in Fujairah and was very well attended by more than 60 healthcare providers. The feedback from this activity continues to be extremely positive.

### Future Plans

1. The preparation for our 4th Annual Epilepsy Congress is underway, with an ambitious plan to host more delegates, both locally and regionally. We also are aiming to join our efforts with regional societies, as we did



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successfully this past year, with the 1st Joint Emirati-Saudi Congress. We hope to continue to attract renowned international, as well as regional, speakers to present at the congress.

2. A task force for the Epilepsy Purple Day 2015 is planning week-long activities aiming to increase public awareness about the disease through media forums, and other interactive open public sessions.
3. Outreach programs will continue, with a plan to reach out to other Emirates and regions throughout the year.
4. We hope to enrich the Scientific chapter meetings by incorporating other formats in addition to didactic lectures, and preparing challenging case studies, Journal club materials, and EEGs cases.
5. We aim to boost and further advocate the associate membership activities. This new category was established in late October 2013, under which EEG technicians, social workers, and nursing staff can participate, with an objective of promoting educational activities for all of them.
6. We will continue to work on enhancing the epilepsy support group activities in collaboration with our colleagues in contributing hospitals.

### Officer Election Date

October 2015.

### Respectfully Submitted

Taoufik Alsaadi, MD, FAAN - President

## INDIAN EPILEPSY SOCIETY (IES)

### Publications

The Society publishes *Epilepsy India* and the *International Journal of Epilepsy*.

### Meeting

IES participated at the Annual Conference of the Indian Epilepsy Association & Indian Epilepsy Society.

### Summary of Activities in 2013 and 2014

Indian Epilepsy Society's 8th EEG Workshop. This was held at Janakpuri Super Speciality Hospital (an autonomous post-graduate institution) in New Delhi, India November 12-13, 2013 under the aegis of the Indian Epilepsy Society. Man Mohan Mehndiratta was the course organizer and Manjari Tripathi was the course director for the 8th EEG Workshop. We planned to restrict the registration to a maximum of 60 attendees, but because of the enthusiastic response, we had to accept more registrations so the total number of registered delegates was 113. This time, we further

enhanced the participation of faculty from across India, and we invited 37 national and international faculties for this EEG workshop.

There were a total of eight sessions: Interesting Case Presentation with Impact of EEG on the Diagnosis, Basics and Normal EEG, Evolution of EEG and Identifying Normal EEG, Value of EEG in Epilepsies and Emergency Situations, Pediatric Age Group Symposium, EEG Quiz, and Spot the Diagnosis: Videos and Case Presentation. All presentations received from international and national faculty were converted into PDF format and placed on DVD to save on the cost of printing and copying.

As in the past, we provided Wi-Fi to the delegates so they could access the speakers' PowerPoint presentations & EEGs on their laptops, tablets and other mobile devices. We also made available access to presentations anywhere in the world. Another milestone (like last year) during the EEG workshop was offering 150 multiple choice questions covering various aspects of EEG that had to be completed in three hours. The purpose of the EEG Certification examination is to establish and improve standards of training and professional practices of EEG in Asia's joint EEG Certification examination (Part 1) for neurologists, neurology residents and EEG technologists. A total of 16 delegates registered for the examination and 15 appeared.



Figure 1. Inauguration ceremony: Lighting of lamp from left to right are M.S. Gopinath, Meena Gupta, Manjari Tripathi, Satish Jain, John Stern, Man Mohan Mehndiratta, Lim Shih-Hui and Derrick Chan.



Figure 2. Group photograph of EEG workshop participants.

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**Indian Epilepsy School.** The residential Indian Epilepsy School was organized jointly by the Indian Epilepsy Society (IES) and Indian Academy of Neurology (IAN), under the aegis of the Commission on Asian and Oceanian Affairs (CAOA), Asian Epilepsy Academy (ASEPA), and the International League Against Epilepsy. It was held at Hotel Atrium, Surajkund, Faridabad (NCR) November 13-16, 2013. The theme of the school was "Enhancing Clinical Acumen in Epilepsy Management."

We had five foreign faculty, Lim Shih-Hui (Singapore), Derrick Chan (Singapore), M.S. Gopinath (Australia), John Stern (UCLA) and S.B. Hong (South Korea) and 54 national faculty in attendance, as well as local faculty during the Epilepsy School. A total of 116 delegates from different parts of India participated in (Figure 3).

A total of fourteen sessions were held, which were spread over four days. Session titles included: Differential Diagnosis of Epilepsy, Faints & Funny Spells; Approach to a Person with New Onset Epilepsy; Epilepsy Video Presentation Quiz by Faculty; Benign Epilepsy Syndromes; Treatment Decisions; When to Stop AEDs?; Non-epileptic Paroxysmal; Morbidity & Mortality in Epilepsy; Epilepsy Surgery; and Video and Case Presentations by the faculty and delegates.



Figure 3. Group photograph of participants of Epilepsy School.

**Annual Epilepsy Conference 2014.** The 15th Annual Conference of the Indian Epilepsy Association and Indian Epilepsy Society was held in Kolkata January 31-February 2, 2014 at the Taj Bengal. A pre-conference workshop was held on January 31 and was attended by 250 participants. The theme was pediatric epilepsy. In the pre-lunch session, topics related to paroxysmal non-epileptic disorders in children were discussed. A post-lunch topic included a discussion of epileptic encephalopathy by F. Dimario (USA), Philippe Ryvlin (France), Ulrich Steffani (Germany), Deb Pal (UK), Rohit Das (USA), Vrajesh Udani (India), Manjari Tripathi (India) and P. Satishchandra (India), that incorporated case studies as part of the presentation.



Ulrich Steffani giving his presentation.

### Summary of Activities in Relation to Global Campaign in 2013 and 2014

We submitted nominations for the Asian and Oceanian Outstanding Achievement Epilepsy Awards (AOEA), which was to be presented at the 10th Asian and Oceanian Epilepsy Congress in Singapore in August 2014, and we proposed three names of medical professionals to the Indian Epilepsy Society (Drs. Sanjeev Thomas, V.V. Nadkarni and H.V. Srinivas).

### Educational Activities

An "Epilepsy Conclave" was held in Goa July 12-13, 2014 under the aegis of the Indian Epilepsy Society and the Indian Epilepsy Association.

### IES – Phenobarbitone Drug Status Guidelines.

We had a very successful first meeting of the Advisory board on July 19, 2014.





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## Advisory Board (Attendees)

Man Mohan Mehndiratta  
Satish Jain  
Manjari Tripathi  
Sheffali Gulati  
Sita Jayalakshmi  
Parampreet Singh  
Atma Ram Bansal  
Suvasini Sharma  
Atam Preet Singh



The Board determined that the advantages of phenobarbitone include:

- Being easily available
- Serving as a broad spectrum drug
- Having a longer half-life
- More than 30 years of experience with the drug
- Cost can be brought down to less than \$1 US
- NICE recommends it as first line for neonatal or as adjunct in pediatric cases.

The second Advisory Board meeting to finalize the document was held the first week of September 2014.

*International Journal of Epilepsy (IJE):* The first Issue of IJE has been launched. We received a total of 30 articles. Fifteen articles were accepted, two articles withdrawn, five articles rejected, and eight articles are under the review process.

## Activities in Conjunction with Local IBE Affiliates

National Epilepsy Day on November 17, 2013 was jointly celebrated by the Indian Epilepsy Society and the Indian Epilepsy Association across India. We have organized various programs to educate the people of India about epilepsy.

Ms. Shenaz Haveliwala from India received an award from IBE honoring an outstanding person with epilepsy during the 10th Asian Oceanian Epilepsy Congress opening ceremony.

## Future Plans

9th Indian Epilepsy Society EEG Workshop (2014). The 9th IES EEG Workshop (Case-based Basics to Advanced EEG Workshop) was held at the Novotel & HICC Complex in Hyderabad November 29-30. It was organized by the Indian Epilepsy Society in association

with Krishna Institute of Medical Sciences & Pediatric Epilepsy Society Hyderabad.

Annual Epilepsy Conference 2015. The 16th Annual Joint Conference of the Indian Epilepsy Association (IEA) & Indian Epilepsy Society (IES) will be held February 6-8, 2015 at Taj Coromandel, Chennai, India.

## Officer Election Date

August 31, 2014.

## Respectfully Submitted

Dr. M. M. Mehndiratta  
Secretary-General  
Indian Epilepsy Society

## INDONESIA LEAGUE AGAINST EPILEPSY

### Summary of Activities in 2013 and 2014

1. The League has completed its epilepsy epidemiological research. The results were reported at the 10th AOEC in Singapore.
2. We revised our national epilepsy guideline book in 2014.
3. We organized some academical activities in conjunction with ASEPA and local branches.
4. We celebrate Purple Day every March, in conjunction with the local IBE.

### Summary of Activities in Relation to Global Campaign in 2013 and 2014

In these last two years, we have promoted a greater understanding about epilepsy to everybody through public seminars, radio, newspapers, etc. We also provided master classes on epilepsy throughout Indonesia.

### Educational Activities

1. We held an ASEPA Teaching Course in Padang July 5-7, 2013.
2. We were present at the National Scientific Meeting in Surabaya May 6-8, 2014.
3. We hosted an epilepsy symposium in conjunction with a regional neurological group.
4. We hosted an EEG course for EEG technicians in Surabaya, Bandung, Semarang and Jakarta.

### Activities in Conjunction with Local IBE Affiliates

The League celebrated Purple Day in March 2013 and 2014 in every branch.

### Future Plans

We hope to recruit more members to ILAE, to introduce new generation AEDs to the national health insurance, and reduce stigma by creating more public discussion about epilepsy.

## Respectfully Submitted

Kurnia Kusumastuti and Diah Kurnia Mirawati

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## IRAQI SOCIETY AGAINST EPILEPSY

### Summary of Activities in 2013 and 2014

- The Chapter held monthly meetings on the last Monday of each month throughout the year, with two lectures per meeting presented by chapter members about epilepsy issues or by guest lecturers about issues in common with other specialties like psychiatry and gynecology.
- Regular administrative meetings were held, usually in conjunction with the scientific ones.
- In 2013, a one-day symposium entitled "Issues of Women With Epilepsy," was held in conjunction with the medical college and Yarmook Teaching Hospital.
- The Chapter participated in the 3rd and 4th Iraqi Neuroscience Symposiums at Al-Kufa Medical College in 2013 and 2014.
- We had active participation at the Annual Joint Conference of Baghdad Medical College and City in 2013.
- There was ongoing work and discussion by Chapter members in an attempt to establish "Iraqi Guidelines in the Management of Epilepsy."
- Ongoing work and discussion by Chapter members to build a written protocol for the management of Status Epilepticus.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

The Society actively participated in:

1. The 8th Epilepsy Symposium held in Dubai in 2014 and sponsored by CEMA.
2. The 2nd Conference of the Jordanian Chapter Against Epilepsy in 2014.

We also planned participation in the Saudi Society Against Epilepsy Conference in 2014.

### Educational Activities

A series of lectures were presented at different hospitals in Iraq by Chapter members about "Epilepsy New Definition" and classification. Additionally, we held a number of media meetings in Iraq for better public education.

### Future Plans

- Hold a one-day symposium entitled "Epilepsy's New Definition and Classification," in March 2015.
- Have active participation in the 2nd Conference for the Iraqi Neurology Society in February 2015.

- Participate in the next Annual Joint Conference of Baghdad Medical College and City.

### Officer Election Date

Spring 2015.

### Respectfully Submitted

Dr. Ghaieb Aljandeel, Vice President

## IRISH EPILEPSY LEAGUE

### Summary of Activities in 2013 and 2014

In 2013 and 2014, the Irish Epilepsy League (IEL) continued to strengthen its membership base and regularly communicated with its members about events and news that would be of relevance to them. Membership in the IEL has more than doubled during this period.

The Irish Epilepsy League, as the Irish chapter of the ILAE, was heavily involved in setting up the European Forum on Epilepsy Research, which took place in the Convention Center in Dublin May 25-27, 2013 as part of the Irish Presidency of the European Union.

Following two successful Epilepsy Expert Days that showcased the work of, and developments in, epilepsy achieved by professionals at the national and international levels, the IEL organized a third event in Dublin in November 2013. The fourth Epilepsy Expert Day was held in November 2014.

### Educational Activities

European Forum on Epilepsy Research. IEL members actively participated in the first European Forum on Epilepsy Research, which took place in Dublin May 25-27, 2013 as part of the Irish Presidency of the European Union. The forum had three primary goals: 1) More focused research funding to improve diagnosis and treatment; 2) Raise public awareness and reduce stigma associated with epilepsy; and 3) Access to optimal standards of care across Europe for people with epilepsy. The forum brought together leading epilepsy researchers and policy makers to discuss a coordinated strategy for epilepsy research in Europe. A total of 270 participants from 57 countries, including each of the 27 EU Member States, were present at the Forum. More details can be found at [www.epilepsyresearcheurope.org](http://www.epilepsyresearcheurope.org).

**2013 – Third Epilepsy Expert Day.** The third annual Epilepsy Expert Day was held in November 2013 and was organized in conjunction with UCB (Pharma) Ireland Limited. This annual Expert Day for epilepsy is now a focal point for increasing ILAE activity within Ireland. The event was chaired by IEL President, Norman Delanty, and speakers included Desmond O'Neill, Consultant Physician at Adelaide & Meath Hospital; Mathew Walker, Consultant Neurologist, Queens Square, London; Donncha O'Brien, Consultant Neurosurgeon at Beaumont Hospital; Maire White, Advanced Nurse Practitioner at Beaumont Hospital; Amre Shahwan, Consultant Neurophysiologist at Temple Street; and Kieran Murphy,

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Chairman, Department of Psychiatry, RCSI. A lively and engaging debate took place on whether the generic switching of AEDs is hazardous to patient well-being. Arguing in favor was Colin Doherty, Consultant Neurologist, St. James's Hospital and arguing against was John Lynch, Consultant Neurologist, University College Hospital Galway. The day concluded with a guest lecturer: Philippe Ryvlin, Consultant Neurologist, Hospices Civils de Lyon in Lyon. The topic was "Morbidity and Mortality Aspects of Epilepsy."

## Activities in Conjunction with Local IBE Affiliates

The European Forum on Epilepsy Research (ERF 2013) was an initiative of Epilepsy Advocacy Europe (EAE), a collaborative task force of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE). The Forum was co-funded by the European Commission's 7th Framework Program and hosted in conjunction with the Irish Presidency of the Council of the European Union during the European Month of the Brain. Epilepsy Ireland, as the Irish member association of the IBE, and the Irish Epilepsy League, as the Irish chapter of the ILAE, were heavily involved in setting up this forum.

The IEL and Epilepsy Ireland (Irish IBE member) are both actively involved in the National Epilepsy Clinical Care Program under the Irish health system, launched in May 2010, which has as a central tenet the creation of a new cohort of Epilepsy Nurse Specialists, trained to Advanced Nurse Practitioner level, which includes a newly designed epilepsy master's course at the Royal College of Surgeons in Ireland. The main goal of this program is to change epilepsy care in Ireland with a model-of-care delivery, which will be underpinned by access to specialist nurses and improvements in quality, access and cost.

## Future Plans (as of October 2014)

**2014 – Fourth Epilepsy Expert Day.** The Fourth Epilepsy Expert Day was held in Dublin on November 28, 2014. As with previous events the day was educational and thought-provoking. The day was chaired by Norman Delanty, IEL President. The talks included: "Dual Epilepsy – What is it, and How Common is it," by Michael Hennessy, University College Hospital Galway; "Guest Lecture: Psychogenic Non-Epileptic Seizures," by Markus Reuber, Sheffield; "Advanced Imaging Techniques in Epilepsy Surgery Evaluation," by Ronan Kilbride, Beaumont Hospital; "Tuberous Sclerosis Complex," by Colin Doherty, St James's Hospital; "Real-life Challenges in Managing Epilepsy in a Learning Disability Patient," by Jean Lane, Daughters of Charity, Clonsilla; "The New Genomics of Epileptic Encephalopathies," by Mary King, Temple Street Children's Hospital.

These talks were followed by a debate entitled, "All Patients with New Onset Convulsive Seizures Should be Admitted to the Hospital." Arguing in favor was Kevin Murphy, Consultant Neurologist, Sligo General Hospital, Sligo and arguing against was Elijah Chaila, Consultant Neurologist, Limerick Regional Hospital. A talk on a current hot topic, "Cannabis and Epilepsy," by Peter Kinirons, Bons Secours, Cork, ended the day.

## Respectfully Submitted XXXXX

## JAPAN EPILEPSY SOCIETY

### Publications

Official journals of the Society include *Tenkan Kenkyu* (published three times a year) and *Epilepsy & Seizure* (published once a year).

### Meeting

There were two annual meetings: the 47th in Kitakyusyu in 2013, and the 48th in Tokyo in 2014.

### Summary of Activities in 2013 and 2014

In many aspects, 2013 was a momentous year in the 47-year history of the Japan Epilepsy Society (JES). Highlights:

- Makiko Osawa was elected as President of the JES, the first pediatrician and the first woman elected as President. The new president soon decided on a policy of promoting active participation of women and young persons, and initiated the Committee on Gender Equality.
- The 47th Congress of the JES was held in Kitakyushu. It was chaired by Sadatoshi Tsuji, the first neurologist to chair the Congress, and had nearly 900 participants. Being a society comprised of many medical disciplines and specialties, our first Congress chaired by a neurology specialist started a new era of a truly interdisciplinary society.
- The new Executive Committee decided to create the Committee on Constitution Amendment, the Ethical Committee, and the Committee on the Promotion of Basic Research. It was decided to further strengthen basic research as well.
- The 30th International Epilepsy Congress was held in Montreal June 23-27. More than 3,000 participants from around the world attended. At the Congress, Tatsuya Tanaka took office as Vice President of the International League Against Epilepsy for a second term. Juhn Wada, honorary member of JES, received the Lifetime Achievement Award, the most prestigious award of ILAE and the first Japanese to earn this award. In addition, Sunao Kaneko, Past President and Honorary Member of JES, received the Ambassador Award.
- The issue regarding driver's licenses for people with epilepsy remains a big social concern. The JES communicates frequently with the Japan Epilepsy Association, the National Police Agency, and other related academic societies, and continues activities in order to provide consultations about the welfare and safety of the entire nation.

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## Summary of Activities in Relation to Global Campaign in 2013 and 2014

On September 30, 2013, a Japanese Declaration on Epilepsy was issued. It reads as follows:

Epilepsy is a well-known disease from ancient times. However, people with epilepsy have many problems in their lives even today. The Japan Epilepsy Association and Japan Epilepsy Society have been working together on these problems over the years. To encourage close liaison, there have been joint meetings from 2010. At the 8th joint meeting on September 1, 2013, the following Declaration on Epilepsy was adopted.

We declare every October to be a special month to focus on epilepsy in Japan.

We proclaim the following, to all people related to health care, organizations and policymakers, in order to solve global issues surrounding epilepsy:

- To place epilepsy on a top priority in medical policy.
- To establish a medical system for epilepsy and assure that people with epilepsy have access to modern and proper medical and health care.
- To promote social integration and eliminate discrimination against epilepsy in all spheres of life, especially work, school and mobility.
- To encourage educational activities for all people to understand epilepsy and thereby reduce stigma and prejudice.
- To provide experts and volunteers in the field of health care, education, and employment with appropriate training about epilepsy.
- To introduce appropriate legislation to protect the rights of all people with epilepsy.
- To support and promote basic, clinical, psychological and social research on epilepsy in all areas including medicine, education, health and welfare, and employment.

Additional statements for a proper understanding of epilepsy:

- Epilepsy is one of the most common brain disorders, estimated to affect one million people, and 50,000 people are diagnosed with epilepsy annually in Japan.
- Epilepsy occurs in all ages irrespective of gender. Infants and the elderly especially have the highest incidence.
- Since epilepsy is a chronic disease, it requires long-term treatment and care.
- The prognosis of epilepsy varies: from seizure freedom to therapy resistance, with or without comorbidities.

- Although 70 to 80% of people with epilepsy could be seizure-free with appropriate treatment, many people do not receive such treatment due to inadequate medical care.
- Epilepsy can have serious physical, psychological, social and economic consequences for the afflicted and their families, but adequate countermeasures against such consequences are largely lacking:

Physical consequences include risk of injury, fracture and death.

Psychological consequences result from fear of seizure, lack of understanding and the stigma of epilepsy.

Social consequences include discrimination and restrictions in mobility, education, employment, and within the legal system.

Economic consequences include a financial burden on the patients, medical costs, and economic loss due to low employment.

- Optimal medical facilities, healthcare education and enlightenment activities may reduce the cost of epilepsy treatment.
- Research funding for prevention, diagnosis, treatment and psychosocial care of epilepsy is insufficient.

Keiji Tsurui, President, Japan Epilepsy Association

Makiko Osawa, President, Japan Epilepsy Society

## Educational Activities

Japan Epilepsy Society (JES-ILAE) has 2,641 active members including 473 certified epilepsy clinical specialists in 2013, and are, together with its seven branches, conducting scientific and educational activities, including public awareness. In 2012, in cooperation with the Japan Medical Association, JES conducted a series of educational seminars for primary physicians in 45 prefectures. JES proposed new driving guidelines in 2012. Epilepsy treatment guidelines published in 2010 are now under revision, and a guidebook for epilepsy specialists was published in 2014.

The Internet has been increasingly and effectively used for diagnosing, treatment, care and research for epilepsy, especially after the disaster in 2011. There are remote epilepsy clinics, remote case conferences, e-lectures for physicians, and e-registries of rare epilepsy syndromes. Information provision through social media has become more popular. Epilepsy hotlines (phone/email) are available 365 days a year.

## Activities in Conjunction with Local IBE Affiliates

The Japan Epilepsy Association (JEA-IBE), with 5,000 members and 47 branches, conducts activities for patient/parent support and public awareness through media, posters, monthly journals, publications, camps, seminars, etc. It also provides consultations. It covers research activities, most recently on stigma.



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JES and JEA adopted the Declaration on Epilepsy in 2013, which includes "Epilepsy Month" (October) as a joint activity for raising awareness nationwide. The advertising poster highlights that epilepsy, a disorder of the brain, occurs in one out of every 100 people.

In addition to the activities of JES and JEA, there are other national, regional, and individual actions available for people with epilepsy.

## Future Plans

An epilepsy care framework was proposed, consisting of primary, secondary and tertiary care systems. Until now, 664 institutions applied for secondary care and 136 institutions for tertiary care. As a result, regional epilepsy care networks have been developing nationwide, and the Association for Epilepsy Centers was established with 23 centers in 2013, where the education of medical staff is one of the main activities. The Association for Epilepsy Rehabilitation was also founded, which aims to improve the quality of the daily lives of people with epilepsy.

These activities will bloom in the near future.

## Officer Election Date

October 2015.

## Respectfully Submitted

Masako Watanabe, Secretary-General

## JORDANIAN EPILEPSY CHAPTER

### Publications

The Chapter published a book entitled "EEG Technology."

### Summary of Activities in 2013 and 2014

The Chapter Participated at the 1st International Epilepsy Symposium in 2013, as well as the 2nd International Epilepsy Conference in 2014 in collaboration with the ILAE.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

Many TV interviews were arranged.

### Educational Activities

Lectures on a variety of topics were given in public and private hospitals.

### Future Plans

We will be hosting the next CEMA Conference in 2015.

## Respectfully Submitted

Dr. Mohammed Shehab

## KOREAN EPILEPSY SOCIETY

### Publications

The Chapter publishes the *Journal of Epilepsy Research*.

### Meeting

The Annual Meeting took place June 12-14, 2014.

### Summary of Activities in 2013 and 2014

- Professor Eun-Ik Son began his term in office as the 9th President of the Korean Epilepsy Society in September 2013.
- The Korean Epilepsy Society convened one Congress and one educational course in both 2013 and 2014.
- At the 2014 Congress, over 50 international attendees participated, resulting in a successful event.
- In November 2013, the Society held an educational course for young epileptologists, with over 150 attendees.
- We provided doctors from underdeveloped countries with an international fellowship program in Korea.
- Working with the Korean Epilepsy Bureau, we implemented several social propaganda campaigns designed to improve the quality of life of epilepsy patients.
- The Society helped to provide anticonvulsant medications to epilepsy patients in North Korea.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

The Korean Epilepsy Society recently changed the Korean name of epilepsy, "gan-jil" (which implies a crazy, convulsive disease), to a neutral and scientifically explainable name of "noi-jeon-jeung" (a cerebroelectric disorder). After changing the name, we have worked hard in various areas including social awareness, disability claims, life insurance, etc. We even succeeded in changing the official name in laws.

### Educational Activities

The Society provided an educational course in November 2013 and again in October 2014. Additionally, we participated in the Korean Epilepsy Preceptorship at the Korean Epilepsy Congress in June 2014 and awarded two international fellowships in 2014.

### Activities in Conjunction with Local IBE Affiliates

Various efforts for patient welfare are being conducted through social programs. Cooperation with the Korea Epilepsy Bureau will continue to improve the social awareness and welfare of epilepsy patients. Various activities, including epilepsy awareness enhancement education for the public and a PR forum, are being conducted to improve the epilepsy culture in Korea.

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## Officer Election Date

June 12, 2015.

## Respectfully Submitted

Chun Kee Chung, Secretary General

## ASSOCIATION AGAINST EPILEPSY OF KOSOVO

### Meetings

Three meetings were held.

### Summary of Activities in 2013 and 2014

- We organized activities for European Epilepsy Day (February 11, 2013 and February 11, 2014).
- We participated in activities for Purple Day (2013 and 2014).
- We held three professional meetings: Epileptogenesis of Benign Tumors Compared with Malignant Tumors; Quality of Life and Depression in Epilepsy; and Symptomatic Epilepsy Due to Cerebrovascular Disease.
- We continued our educational activities through written and audio-visual media.

### Summary of Activities in Relation to Global Campaign in 2013 and 2014

As referenced above, we conducted three professional meetings:

1. Epileptogenesis of Benign Tumors Compared with Malignant Tumors
2. Quality of Life and Depression in Epilepsy
3. Symptomatic Epilepsy Due to Cerebrovascular Disease

### Educational Activities

We conducted three professional meetings:

1. Epileptogenesis of Benign Tumors Compared with Malignant Tumors
2. Quality of Life and Depression in Epilepsy
3. Symptomatic Epilepsy Due to Cerebrovascular Disease

### Activities in Conjunction with Local IBE Affiliates

No activities of local IBE affiliates have been recognized for years.

## Respectfully Submitted

Valbona Govori, President

## MACEDONIAN LEAGUE AGAINST EPILEPSY

### Publications

The League publishes *Epilepsy & Neurology*.

### Meeting

The League's Annual Meeting was held in December 2014.

### Summary of Activities in 2013 and 2014

Three meetings were held in 2013 and 2014. The first, in April 2013, focused on depression and epilepsy. The second, held in December 2013, focused on refractory epilepsy and the third, held in December 2014, was the Annual Meeting.

### Educational Activities

In May 2013, a regional teaching course in conjunction with the European Federation of Neurological Societies was held. Epilepsy was one of the main topics covered.

### Officer Election Date

2016.

## Respectfully Submitted

Cvetkovska Emilija, President

## EPILEPSY SOCIETY OF MALTA

### Summary of Activities in 2013 and 2014

The Society established a specialized epilepsy outpatient clinic in the main general hospital, set up an epilepsy registry and launched a study on the pharmacoepidemiology of epilepsy in Maltese children.

### Educational Activities

The Society provides talks in schools and to other healthcare professionals on epilepsy. It also cooperates with the Malta Medical Students Association for outreach and information on epilepsy.

### Activities in Conjunction with Local IBE Affiliates

- The Society collaborated with the Caritas Malta Epilepsy Association at the National Epilepsy Conference held in February 2014.
- It distributed epilepsy information (leaflets and posters) in outpatient facilities and in schools, in both English and Maltese.
- It participated in media interviews on TV and radio to discuss epilepsy.

### Future Plans

Plans include creating a study on first onset seizures in adults in Malta.

### Officer Election Date

2016.

## Respectfully Submitted

Janet Mifsud, Secretary

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## CAMELICE (MEXICO CHAPTER)

### Summary of Activities in 2013 and 2014

Gerardo Quiñones Canales, President, participated in the 4th International Congress held at ABC Hospital and Cleveland Clinic Foundation, with a theme of "Epilepsy in Latin America." At the event, the National Register of Epilepsy (RENAEP) was presented.

### Educational Activities

The CAMELICE XXXVII National Congress was held in conjunction with the Priority Program of Epilepsy and the Mexican Academy of Neurology, with a significant amount of academia present. There were 83 members, including 15 teachers (12 of whom were foreigners). Additionally, there were 289 nonmembers and a total of 651 attendees, including from Colombia, Ecuador, Guatemala, El Salvador and Nicaragua.

### Future Plans

We plan to hold regional meetings, and the 2015 CAMELICE XXXVIII Congress is planned in conjunction with the Cleveland Clinic, the Priority Program of Epilepsy and the Mexican Academy of Neurology.

### Respectfully Submitted

Gerardo Quiñones Canales, Neurologist  
President, CAMELICE

## MONGOLIAN EPILEPSY SOCIETY

The Mongolian Epilepsy Society (MES) has made certain advancements in improving the diagnosis, treatment and social health assistance for patients with epilepsy.

### Background

The statistical data from recent years indicates that the prevalence rates of epilepsy are increasing year-over-year, and this is a major concern for us. For instance, it was observed that the epilepsy prevalence rate was 2.5 per 1,000 residents in Ulaanbaatar city, and in accordance with health statistical data, 11,759 patients with epilepsy were registered in 2010 and 12,144 in 2012, meaning an increase on average of 300-400 cases per year.

In this regard, the Government of Mongolia is undertaking step-by-step activities to improve the medical aid for patients with epilepsy by means of providing central hospitals in cities and rural areas, as well as regional diagnostic centers with tools and equipment, approving new regulations on the free allocation of certain antiepileptic drugs at discounted rates that are subsidized from the health insurance fund, and will further continue these support activities in cooperation with professional organizations.

### Main Activities

Based on the above situations and to improve the diagnosis, treatment and health care of epilepsy, the MES has organized a series of trainings on epilepsy to advance the professional skills of Mongolian healthcare personnel by inviting both national professionals and

renowned international experts to participate; conducted a number of research surveys, and also prepared and submitted to the Government several policy actions and documents.

### 1. International Epilepsy Symposium

We have successfully organized epilepsy symposiums in September 2012 and again in June 2014 in Ulaanbaatar, in cooperation with ILAE, the Commission on Asian and Ocean Affairs, the Asian Epilepsy Academy, WHO's Western Pacific Region's Representative Office and the Ministry of Health of Mongolia. The objective was to improve the knowledge and skills of neurologists for the quality and access of epilepsy care.

Over 120 neurologists, psychiatrists, child epileptologists and other neurology-related professionals from the cities and rural areas have participated in the symposium, along with professor teams of 5-7 members from abroad:

- B.I. Lee, Chairman of the Commission on Asian and Oceanian Affairs of the ILAE
- S.H. Lim, Chair of the Asian Epilepsy Academy
- Y. Inoue, Director of the National Epilepsy Center in Shizuoka
- J.W. Dunne, Head of the Epilepsy Center and Clinical Neurophysiology Laboratories at Royal Perth Hospital in Western Australia
- Tatsuya Ishikawa, Professor of the Department of Clinical Psychology of the Faculty of Child Development at Nihon Fukushi University
- Yasumichi Koide of the National Epilepsy Center in Shizuoka, Japan

During these two-day events, the invited guests and Mongolian participants made numerous presentations with the following titles:

- Seizure Semiology and Classification
- Causes and Diagnosis of Epilepsy
- Differential Diagnosis of Seizures and Epilepsy
- EEG in the Diagnosis and Management of Seizure Disorders
- Common Epilepsy Syndrome in Childhood
- Treatment of Epilepsy
- Psychosocial Aspect of Epilepsy
- Drug-resistant Epilepsy
- MRI Diagnosis of Epilepsy in Mongolia
- Epilepsy Surgery Management etc.

The welcome message for participants was delivered by the Minister of Health of Mongolia, Natsag Udval, M.D., MPH, PhD, D.Sc. and by Wiwat Rojanapithayakorn, WR/Mongolia.

Following up on the symposiums, we then had roundtable discussions with the invited speakers.

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Managerial members of CAO and ASEPA gave also several important and valuable recommendations and advice to MES on how to improve epilepsy care in Mongolia.

## 2. Epilepsy Colloquium

In June 2012, we organized the National Epilepsy Colloquium, at which over 50 neurologists, psychiatrists, child epileptologists and other neurology-related professionals from the cities and rural areas of Mongolia participated.

## 3. Inclusion of anti-epileptic drugs in the essential drugs list

The MES, as the result of its activities, managed to include two new antiepileptic drugs, Levetiracetam and Topiramate, in the essential drugs list.

## 4. Research on epilepsy

Our young member scholars have successfully conducted research and survey activities related to the following topics:

### A. "Survey of Public Knowledge and Attitudes Toward Epilepsy in Ulaanbaatar"

**Purpose:** To study the awareness, knowledge and attitude toward epilepsy, and to reveal some contributing factors in order to develop recommendation guidelines to improve health education and reduce the stigma of epilepsy.

**Methods:** 700 randomly selected people between the ages of 18-64 from six districts in Ulaanbaatar city were interviewed using a questionnaire. The research finished in June, and we are now translating it into English and seeking to publish it in a journal abroad.

### Conclusion:

1. A level of knowledge toward epilepsy among the population is 42.1% while the positive attitude towards epilepsy is 29.7%. There are obvious reasons to increase both knowledge and attitude.
2. Significant association was observed between the knowledge and attitudes towards epilepsy, and the age of participants ( $p=0.022$ ) and their level of education ( $p=0.015$ ). We noted positive attitudes commonly among educated young adults.
3. There are negative public attitudes towards studying with (66.9%) and employing (71.7%) people with epilepsy. According to these results, we need to improve the health education programs offered to the population.

### B. "Clinical Manifestation of Post-traumatic Epilepsy"

**Purpose:** To study the clinical features of post-traumatic epilepsy (PTE) and factors influencing its development.

**Methods:** We performed a descriptive, observational study of 109 patients with PTE coming to district health associations in Ulaanbaatar and the Central First clinic during the period of 2011-2013. We obtained the history of patients and questionnaires, and a clinical examination was conducted to evaluate the seizures in accordance with the appropriate classification of epileptic seizures by the International League Against Epilepsy. Clinical data was then matched with the results of the EEG, CT and MRI investigations.

**Conclusion:** Clinical features of PTE are presented by partial (15%), secondary generalized seizure (85%) and by motor phenomena (60.5%). PTE is characterized by long durations, with high frequency of seizure (90%), various clinical manifestation ( $r = -0.32$ ,  $p < 0.001$ ). PTE is caused by severity, type of head injury and neurosurgical treatment ( $p < 0.05$ ).

## 5. Policy action and documents

As everyone working to improving epilepsy care is well aware, WHO Executive Board members are going to discuss a topic entitled "Global Burden of Epilepsy and the Need for a Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications" in Geneva from January 26 through February 3, 2015.

This is certainly a great opportunity for our Chapter to improve the epilepsy care in our country, and, in order to drive our own government to take initiatives in the action to support the global epilepsy agenda, we have approached both a representative with the Ministry of Health and Sports of Mongolia, and a WHO representative with official requests to make a statement of support.

We are hoping that the official statement of the Mongolian government will be delivered to the EB meeting either by the Minister of Health and Sports in person (or through an authorized delegate) or by a WHO representative, or simply by means of sending the official letter.

### Respectfully Submitted

A.Tovuudorj, MD  
Secretary-General, MES

## NEW ZEALAND CHAPTER OF THE INTERNATIONAL LEAGUE AGAINST EPILEPSY

In 2014, the New Zealand chapter of the International League Against Epilepsy (NZILAE) developed a strategic plan to lead the organization forward for the next three years. Our goals are focused on three areas: medical care, education and communication.

This past year, we have been actively working with the New Zealand Ministry of Health to improve epilepsy care in our country by allowing our members to be part of an Epilepsy Improvement Project. It has been determined that the provision of epilepsy care within

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New Zealand varies and that the provision of clinical guidelines will help improve the standard and equity of care throughout the country.

The NZILAE held an educational meeting in Auckland on September 12, 2014. The meeting, entitled "Epilepsy in the Early Years: Dealing with the Severe End of the Spectrum," was well attended by pediatricians and other healthcare professionals from across New Zealand. Our guest speaker, Annie Bye, Associate Professor at the University of New South Wales, was excellent and all of the speakers were well received. We were fortunate to have received educational sponsorship for this meeting from bioCSL. The event was videotaped and will be sent to all regional hospital pediatric departments.

The NZILAE remains committed to advocating for coordinated and cohesive community services for individuals with epilepsy in New Zealand. To this aim, we have liaised with Epilepsy New Zealand and the New Zealand Epilepsy Foundation to promote complementary approaches to their service provision.

In the next two years, we plan to:

1. Promote the establishment, implementation and monitoring of guidelines and clinical pathways for the diagnosis and management of epilepsy in New Zealand;
2. Provide an annual Epilepsy Education Day for specialist physicians involved in epilepsy care;
3. Advocate for local neurologists to provide regional seminars on epilepsy diagnosis, management and research aimed at local GP and allied health professionals;
4. Establish minimal standards of epilepsy education for undergraduate and post-graduate medical courses in New Zealand;
5. Establish a register of epilepsy research projects and researchers in New Zealand in order to enhance collaboration and increase awareness of these research projects; and
6. Continue to advocate for coordinated and cohesive community care and support for New Zealanders with epilepsy.

### Respectfully Submitted

Associate Professor Lynette Sadleir  
President of the New Zealand Chapter of the ILAE

## NIGERIAN LEAGUE AGAINST EPILEPSY

### 2013

2013 was a great year for the Association. Amongst other things, we held our Congress in Benin City, the beautiful capital city of Edo State. Despite being held during a period of labor crisis, the conference

experienced solid attendance. The Nigeria Bureau of Epilepsy was formed to accommodate non-doctors and those from other walks of life. The new bureau was headed by Mrs. Angela Asemota of the Angie Epilepsy Foundation. The bureau is tasked with amalgamating all other epilepsy associations and societies in the country, so that we can work as a group. Presently, three associations have been registered with the bureau.

The Edo conference also witnessed the delivery of lectures by prestigious Nigerian scholars including Professor Ogunrin of the University of Benin.

In 2013, members of the League saw a moderate turnout in Montreal, Canada where we also had the highest number of poster presentations from the African continent.

### 2014

Despite some challenges posed by prolonged industrial action by doctors, which led to the postponement of our Congress, we still achieved a lot. The Nigerian Society for Neurological Sciences, for the first time, gave NLAE a symposium at the 2014 Annual Congress. The symposium, delivered by Dr. Ezeala-Adikaibe, focused on the challenges and strengths of the Association and how to best move forward. Following the session, the registered membership grew. Furthermore, the future congresses of the NLAE will be synchronized with those of NSNS to improve participation and interest. Through our efforts, many Nigerians attended the Cape Town CAA Congress and presented many posters.

### Epilepsy Day

The Epilepsy Day celebrations over the past two years have been wonderful. In addition to routine school, hospital, and church/mosque awareness programs, in 2014 we had the wonderful privilege of hosting a one-month (done every week) radio program. The public response to our program was far-reaching as evidenced by improved hospital attendance and phone calls. The program had Dr. Ezeala-Adikaibe, Dr. Ekochin and Dr. Onyebeze as guests. Dr. Onyebeke is a psychiatrist.

Without doubt, while there are many activities in the country, the present Islamic hostilities have made travelling a little difficult and public awareness programs are scarier to put on. NLAE's report includes only the activities by the NLAE and not other epilepsy associations.

Our next meeting will be in March 2015.

### Respectfully Submitted

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### PANAMANIAN LEAGUE AGAINST EPILEPSY

#### Summary of Activities

The activities of the Panamanian League Against Epilepsy are mainly concentrated on the medical treatment of patients with epilepsy, and more recently in surgical aspects of their treatment. The education promotion in epilepsy for patients and their relatives, as well as for primary care physicians, contains crucial components about understanding this disease and offering of a better quality of life for our patients.

#### Summary of Activities in Relation to Global Campaign

The Panamanian League Against Epilepsy has grown in number to 17 adult neurologists and eight pediatric neurologists. Multiple activities related to the education of primary care physicians, patients and their relatives have been taken every year throughout the country, trying to offer appropriate information to sensitize a large population to improve acceptability and treatment. In some regions of Panama, welfare donations of antiepileptic medications are still received for the more needy patients.

#### Educational Activities

To commemorate the Latin American Day of Epilepsy, some second and third level hospitals, and some private health institutions, organized a program of conferences, including:

- Publication of the first Epilepsy Manual in Panama (November 2012): "Epilepsy in Adults. Manual Management in Primary Care." The chief editor was Fernando Gracia.
- A Symposium on Epilepsy on February 23, 2013 or organized with the National Association of Physicians of Panama.
- A continued medical education program in Panama in February, August and September 2013.
- A session entitled "Workshop on Epilepsy for Patients and Families" (March 2013).
- A proposal for the first residency program of neurology in Panama (2013).
- An "Actualization Course of Epilepsy" in August 2014 (held in Chitre, Herrera, Republic of Panama).
- The First National Congress of Neurology of Panama in conjunction with the 16th Centro American Congress of Neurology and the 17th Ibero-American Congress of Cerebral Vascular Disease (SIECV) in Panama City October 1-3.

The national expositors are neurologists who work in our institutions.

In Santo Tomas Hospital, administrative and educational activities have been held with clinical applications. The educational activities were mainly focused on patients and their families, more than ten weekly programs, and more than 500 people attending. These were held in waiting areas of the Neurology Service offices and educational information was distributed to the public. The participation of the patients and their relatives was very active.

In Panama, we have cases of refractory epilepsy that have been treated with Vagal Nerve Stimulation in the last three years, helping to improve the quality of life of these patients.

Educational activities directed to the doctors focusing on diagnosis and treatment have been programmed. Two neurosurgeons were trained in functional neurological surgery in Argentina two years ago. We now have the first adult neurologist trained in Epilepsy in Panama (Manuel Aguilar) through the Continuing Medical Education Program of the ILAE for Latin America, held from April 16, 2012 to April 15, 2013, in the Universidad de Campinas in Sao Paulo, Brazil.

#### Future Plans

We hope to continue to provide an educational agenda for patients and their families, and local conferences for physicians. These activities will be accomplished over three periods of the year, particularly in September. We wish to create a national reference center of epilepsy to offer a comprehensive evaluation, diagnosis and treatment facility for our patients.

#### Officer Election Date

October, 2013.

#### Respectfully Submitted

Dr. David Roman Dondis Camaño

### POLISH SOCIETY OF EPILEPTOLOGY

#### Publications

The Society published an article (in Polish) entitled, "Recommendation of Polish Society of Epileptology for seizures treatment in adults," in the *International Journal for Clinical and Experiment*

#### Meeting

In 2014, the Society organized the VII Congress on Epilepsy that was held in Warsaw, with 400 participants in attendance. Election of new members took place at the meeting.

#### Summary of Activities in 2013 and 2014

Many public lectures and discussions in group meetings have been organized with neurologists around the topic of public health awareness. We also organized a forum for key opinion leaders across medicine, government, and healthcare organizations.



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## Summary of Activities in Relation to Global Campaigns in 2013 and 2014

On February 14 of both years, we patronized and supported the Valentine Epilepsy Days. "Notice Me" is the national campaign of different patient associations from across Poland. It was launched in 2009 in Warsaw. In 2011, the campaign added a new event, the Nordic Walking March. The motto of the march was "Notice me-walk healthy."

In September 2013 and 2014, the Polish Society of Epileptology (PSE) prepared a report that examined knowledge of epilepsy among Polish society as well as problems with treatment gaps among epileptic patients. The report was sent to all members of Parliament and to the Ministry of Health in Poland.

An important part of our activities in 2013 and 2014 was meetings with the Ministry of Health and the National Health Fund. The main issue we faced was reimbursement to patients for new AEDs in epilepsy. Finally, levetiracetam is now free for patients with newly diagnosed (I line) epilepsy, and retigabine and lacosimide is free for patients with III line epilepsy treatment.

## Educational Activities

The Society sponsors regular educational courses and workshops on epilepsy in Poland. There are working groups for epilepsy and pregnancy, for quality of life, and for the elaboration and validation of an original questionnaire for patients and caregivers. We also have a working group on videos, who manage a collection of informative videos on different seizure types and provide tools for the didactic presentation of the material.

## Activities in Conjunction with Local IBE Affiliates

We continue helping the activities of the organization, maintaining an umbrella-like function and coordinating the local societies. We continue patronizing the Valentine Epilepsy Days held each year. At the moment in Poland, there are 14 organizations of patients (nine of them are district chapters of Polish People Suffering from Epilepsy, which was established in 1985).

## Future Plans

We will continue offering regular educational courses as well, to promote the new standards of quality control as it relates to epilepsy care in Poland.

We are working with the Polish Neurological Society to publish national guidelines for the diagnosis of epilepsy in adults and children and are working on a new publication entitled "Differential Diagnosis in Epilepsy."

## Officer Election Date 2018.

## Respectfully Submitted

Joanna J. Drzejczak

## PORTUGUESE LEAGUE AGAINST EPILEPSY

### Publications

The Portuguese League Against Epilepsy (LPCE) publishes Epilepsy News and articles are available on the Chapter's website, [www.epilepsia.pt](http://www.epilepsia.pt).

### Summary or Activitied in 2013 and 2014

#### Meetings 2013

- The 25th National Epilepsy Meeting was held in Porto in March 2013 (please see the program at [http://www.epilepsia.pt/lmgs/1Anuncio\\_25ENE.pdf](http://www.epilepsia.pt/lmgs/1Anuncio_25ENE.pdf)). We had more than 350 registered participants.
- The Epilepsy Surgery Forum occurs twice a year (March and November) and gathers the five Portuguese centers involved in epilepsy surgery programs. More information about this forum can be found here: <http://www.epilepsia.pt/lpce/forum-de-cirurgia-da-epilepsia>.
- We participated at the Portuguese League Awards: <http://www.epilepsia.pt/pt/lpce/premio-bolsa-lpce>
- The Portuguese League also took part in the organization of the scientific program presented at the BIAL Neurology Forum, which was held in Lisbon in October 2013.
- A basic epilepsy course for general practitioners was held in Faro, in November 2013. Photos from the event can be seen here:

<https://www.facebook.com/IIJornadasInternadoMedicoAlgarve/photos/pb.688682541159242.2207520000.1416415322.699905843370245>

#### 2014

- In January of 2014, we organized a full-day hands-on epilepsy course in Coimbra for neurology residents: <https://www.facebook.com/media/set/?set=a.781374461890153.1073741825.160804227280516>
- The Portuguese League was involved in a "train the trainer" course in epilepsy, which was held in Maputo, Mozambique in March 2014, under the auspices of WHO and ILAE.
- The League was also involved in the organization of an epilepsy course in Cape Verde which took place in April 2014.
- The 26th National Epilepsy Meeting was held in Lisbon in March 2014 (please see the program details here: <http://www.epilepsia.pt/lmgs/programafinal26ENE.pdf>). We had 326 registrations.

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- The Portuguese League awards were held. More information can be seen here: <http://www.epilepsia.pt/pt/lpce/premio-bolsa-lpce>
- In a collaborative effort with the Portuguese Neurology Society, we organized a comprehensive epilepsy course for interns and residents in May 2014. More information can be found here: <http://www.justnews.pt/noticias/forum-de-neurologia-2014-continua-a-apostar-na-formacao-dos-internos#.VGyEsTSsW3g>
- The Epilepsy Surgery Forum occurs twice a year (in March and November) and brings together the five Portuguese centers involved in epilepsy surgery programs: <http://www.epilepsia.pt/lpce/forum-de-cirurgia-da-epilepsia>
- The Portuguese League also took part in the organization of the scientific program at the BIAL Neurology Forum, which was held in Lisbon in October 2014. More information can be found here: <http://www.epilepsia.pt/pt/lpce/outras-iniciativas>
- The Iberian Epilepsy Meeting took place in Lisbon in September 2014, addressing the refractory epilepsies: <http://www.epilepsia.pt/pt/lpce/reuniao-luso-espanhola-de-epilepsia>

### Educational Activities

In 2013, we launched three educational projects in close collaboration with a patient association (EPI); two of them targeted the general public and another focused on specific groups of people with epilepsy. Simultaneously, we have been running an epilepsy multimedia exhibition that was visited by several hundred people throughout the country. The link below has more information:

<https://www.facebook.com/196492423714390/photos/a.623314797698815.1073741845.196492423714390/623315064365455/?type=1&theater>

### During 2014

- We introduced the European campaign "Epilepsy is More than Seizures" (watch the video clip: <http://www.epilepsia.pt/lpce/campanha-epilepsia-e-mais-do-que-ter-crisis> <http://www.epilepsia.pt/pt/lpce/videos-lpce>)
- Running for Epilepsy was introduced (as part of the commemoration of the 35th anniversary of the National Health Care System): <http://www.epilepsia.pt/pt/lpce/comemoracao-dos-35-anos-do-sns-3>
- The Portuguese League was able to participate in several TV programs that aim to increase public awareness about epilepsy.

- We are proud of maintaining a very close partnership with EPI ([www.epilepsia.pt/epi](http://www.epilepsia.pt/epi)). Recent collaborations have resulted in three ambitious projects:

- ProjectaNOS +: Aims to increase epilepsy awareness in the general population.
- Integrar(TE): Defines personalized physical exercise programs for people with epilepsy.
- GPEIS: Evaluates job skills and promotes labor integration in conjunction with national enterprises.
- EPI's library, where health professionals can easily find guidelines and articles about epilepsy, can be found here: <http://www.epilepsia.pt/pt/lpce/epi-biblio-2> and <http://www.epilepsia.pt/pt/lpce/artigos-comentados>

### Summary of activities in relation to Global Campaigns in 2013 and 2014

#### 2013

- The Audition of the Portuguese League against Epilepsy in the Health Commission of the Portuguese Parliament took place in January 2013. More information can be found here: <http://www.parlamento.pt/ActividadeParlamentar/Paginas/DetalheAudiencia.aspx?BID=94539>
- During the commemoration of the 25th anniversary of the National Epilepsy Meeting, the Portuguese League organized a dinner debate with several politicians from the Parliament's Health Commission, entitled: "How to Contaminate our Politicians with the Flame of Epilepsy." More information can be found here: [http://www.epilepsia.pt/lmgs/25ENE\\_Jornal\\_Epileptologia\(1\).pdf](http://www.epilepsia.pt/lmgs/25ENE_Jornal_Epileptologia(1).pdf)

#### 2014

After the elections for the EU Parliament, we have started to contact our national MEPs, a process still running. Additionally, the Portuguese League has been partnering with specific working groups and has been consulted by the General Health Office of Health Ministry.

#### Officer Election Date 2015.

#### Respectfully Submitted Francisco Sales

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## QATAR LEAGUE AGAINST EPILEPSY

### Publications

An article written by Hassan Al Haile Al Hail entitled "Epidemiology and Etiology of Intractable Epilepsy in Qatar" was published in the *Qatar Medical Journal* Volume13/Number1 in June of 2004, pages 11-13.

### Summary of Activities in 2013 and 2014

#### Activities included

- The Qatar Annual Neurology and Epilepsy Meeting in February 2013 and 2014.
- Celebration of Epilepsy Awareness Day on March 26, 2014.
- Sending five neurologists from Hamad Hospital to attend the 28th International Epilepsy Congress in October 2013 in London.
- Sending six neurologists to attend the recently held Saudi Emirate Epilepsy Conference.
- Sending six neurologists from Hamad Hospital to attend the AAN Congress in the USA in April 2014.

#### Educational Activities

- Several training workshops on electroencephalography for young neurologists were held in the Department of Neurology at Hamad General Hospital.
- We provide regular training for medical students from Weil Cornell Medical Faculty in Doha.
- We participate in epilepsy cases in the hospital's weekly "neurology grand rounds."

Additionally, the League offers exchange programs for internationally known neurologists and epileptologists serving as visiting consultants for patient care and lecture presentations. Last year, we invited Dr. Wisser from Switzerland and Dr. E. Perucca from Italy, as well as many other neurologists from the region, to the 6th Qatar Regional Neurology Conference. In February 2014, different international and national speakers focused on epilepsy and other neurology topics at the 7th Qatar Neurology Conference.

We had several topics related to epilepsy written by Boulenouar Mesraoua, Dirk Delev, Hassan Al Hail, Gayane Melikyan and Heinz Grego Wieser, that were specifically related to different aspects of JME, diagnosis and treatment.

Several educational media programs about epilepsy were made for local Qatar TV and published in local newspapers.

An intranet site was established in our hospital website. The site, <http://qatarneuroscience.webs.com>, focuses on epilepsy education.

Our neurology department staff members have attended and participated in many regional, local and international epilepsy conferences over the last two years.

### Activities in Conjunction with Local IBE Affiliates

The Qatar League against Epilepsy (QLAE) was established in 1995 and, since that time, is part of the Qatar Chapter of the International League against Epilepsy (ILAE) and the International Bureau of Epilepsy. During recent years, QLAE has initiated several educational and Congress-related activities. Several local and regional (Gulf Region) neurology and epilepsy conferences also took place. An invitation will be sent to the IBE office for our annual neurology conference, so that they can share and exchange knowledge with us.

### Future Plans

- There will be an upcoming 8th Annual Neurology Conference, including the Qatar Chapter of Epilepsy, and Epilepsy Awareness Day will take place in February 2015.
- There is an upcoming annual pediatric epilepsy training (PET3) that will take place from February to March 2015.
- We have already started to work on developing a comprehensive epilepsy center.

### Officer Election Date

March 2016.

### Respectfully Submitted

Dr. Hassan Al Hail and Dr. Tage Eldin Sokrab

## RWANDAN LEAGUE AGAINST EPILEPSY

### Summary of Activities from 2013 to 2014

An International Conference on Epilepsy was organized, with medical doctors/physicians and other health professionals participating. There were a total of 71 participants, of which 11 were professors from Europe and the United States of America.

The 3rd General Assembly of the Rwandan League against Epilepsy was organized and held on March 22, 2014. At the meeting, a report of activities from the previous three years was presented, and a vote for members of the new Executive Committee took place.

### Summary of Activities in Relation to Global Campaigns from 2013 to 2014

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## Educational Activities

We held a "training of trainers" to raise epilepsy awareness in four districts of the Western Province of Rwanda. The project is headed by Handicap International and the training was held October 27-31, 2014.

## Future Plans

In partnership with Handicap International and with financial support from the General Director of Belgium Development Cooperation, a project against epilepsy was put into place to help epilepsy patients and their families, along with providing education about epilepsy to the general public and teachers, in 2014 and into 2015. Another goal of this project was to improve the quality of care of children with epilepsy.

Training of health professionals from two district hospitals and the training of community health workers regarding the caring for, and follow-up, of patients with epilepsy will be organized in 2014 and 2015.

The 2nd International Conference/Symposium on Epilepsy is organized for 2015-2016, assuming there is financial support available.

## Officer Election Date

March, 2017.

## Respectfully Submitted

Dr. Fidèle Sebera

## SAUDI CHAPTER OF EPILEPSY

### Publications

Multiple publications were issued over the two-year period.

### Meeting

The Chapter held several meetings.

### Summary of Activities in 2013 and 2014

1. We developed a new budget for SES. The primary source of income will come through meetings, courses and conferences. Attendees will pay to attend, in addition to donations.
2. We incorporated a strategic plan that was agreed upon by all members after input was collected.
3. We developed guidelines for epilepsy and driving, working very hard to make progress.
4. We performed a study related to "Epidemiology of Epilepsy in Saudi Arabia" and many members are interested in conducting further research.
5. Our previous website will now be linked to the new one.
6. The SES account has been approved by the Saudi Hollandi bank for the SES membership.

7. We made a third revision to the SES Bylaws and Constitution.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

We held a VNS Awareness Day and an Epilepsy Awareness Day. For the first time in the Kingdom of Saudi Arabia, we also conducted World Epilepsy Day in six cities, in conjunction with Novartis, on March 26, 2014.

### Educational Activities in 2013 and 2014

1. We conducted the 21st Saudi Neuroscience Meeting in Riyadh November 23-25, 2013 in conjunction with SES.
2. The 3rd Annual UAE Epilepsy Congress 2014 and the first Joint Emirati Saudi Epilepsy Congress were held in Dubai April 4-5, 2014.
3. We held a one-day course for health specialists entitled "Neuroimaging in Epilepsy," in collaboration with SES and the Department of Neurosciences and Medical Imaging at KFSHD, on September 25, 2014 in Dammam.
4. We offered a neurophysiology diploma (two-year course) that was recognized by the Saudi Council for Health Specialists, at King Fahad Specialists Hospital, Dammam in 2014.
5. Some SES members are starting to be recognized internationally and were invited to the International Epilepsy Congress. In 2015, members will speak at the 31st IEC (International Epilepsy Congress) in Istanbul September 6-10, while others will participate in a scientific committee at the 3rd East Medilence Epilepsy Congress in Jordan, on March 19-21, 2015.

### Activities in Conjunction with Local IBE Affiliates

A 4th Annual Confererence was held November 26-27, 2014 at the Ritz Carlton hotel in Riyadh and the Saudi International Pediatric Neurology Conference was held November 9-10 at KFMC in Riyadh.

### Future Plans

We plan on implementing the rules of epilepsy and driving in Saudi Arabia. Additionally, we will add two new committees: the Neuroradiology Committee and the Epilepsy Guidelines and Regulations Committee.

### Officer Election Date

September 18, 2014

### Respectfully Submitted

Raidah AlBaradie

# CHAPTER REPORTS

## UNION OF SERBIAN AND MONTENEGRIN LEAGUES AGAINST EPILEPSY

### Publications

The League published "Series of Proceedings: Quality of Life in Patients with Epilepsy" (15th Epilepsy School, 2013) and "Approaches to the Patient with Severe, Disabling Epilepsy."

### Summary of Activities in 2013 and 2014

There was international participation at the 9th Congress of Serbian Neurologists held in Belgrade on November 14-16, 2013, including courses given on epilepsies in childhood.

Below is the educational cycle of Epilepsy School courses and Educational EEG Workshops:

- 3rd EEG workshop, 2013
- 15th Epilepsy School, 2013
- 4th EEG workshop, June 2014
- 16th Epilepsy School and the 6th Regional Meeting of Epileptologists, November 2014.

The Leagues also participated with the EURAP project and collaborated with a number of other national ILAE Chapters, especially with regional Leagues.

The 15th Epilepsy School was organized in the Republic of Srpska (B&H) as a means of promoting the regional initiative, while the 6th Regional Meeting of Epileptologists rallied experts from the region.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

Educational and public-awareness activities were presented to the press and visual media. Lectures on epilepsy and sporting activities, stigmatization of school children and adolescents, and difficulties in professional occupation and driving license procedures were offered at the 16th Epilepsy School held in Castel, Ečka November 7-9, 2014. Other issues discussed included quality of life in patients with severe, disabling epilepsy and the impact of epilepsy surgery on daily life.

### Educational Activities

- The 3rd EEG workshop was held on September 26, 2013 in the Stanisic Ethno Village, Bijeljina, Republic of Srpska, Bosnia-Herzegovina.
- The 15th Epilepsy School took place September 27-29, 2013 in the Stanisic Ethno Village, Bijeljina, Republic of Srpska, Bosnia-Herzegovina.
- The 4th EEG workshop was held June 7-8, 2014 in the Monastery of St. Bishop Nikolaj in Soko Grad (Ljubovija).

- The 16th Epilepsy School and 6th Regional Meeting of Epileptologists took place November 7-9, 2014 at Castel Manor, Ečka.

### Activities in Conjunction with Local IBE Affiliates

No activities of the local IBE have been recognized for years, nor any activities held in conjunction with the local IBE. The Chapter does not know if the local IBE still exists.

### Future Plans

#### Upcoming plans include:

- 17th Epilepsy School in Kotor, Montenegro in September 2015.
- 5th EEG Workshop in Kotor, Montenegro in September 2015.
- 18th Epilepsy School in Predejane, Serbia in November 2016.
- 6th EEG Workshop at the Monastery Decani, Serbia in May and June 2016.
- A summer camp for leisure, sporting activities and friendship, for children and adolescents, lasting ten days (Kopaonik, Serbia) in July 2015 and 2016.
- The issuance of publications related to epilepsy that will be edited by the League.
- 9th Serbian Neurology Congress in Belgrade in November 2015.
- 4th Epilepsy Congress of Serbia and Montenegro in 2015.

### Respectfully Submitted

Dr. Nebojsa J. Jovic, Chapter President

## SPANISH LEAGUE AGAINST EPILEPSY

The period of 2013-2014 has been crucial for the Spanish Chapter in several respects, as described below.

**Update of member census:** This has been the first census for over 20 years. The census has been updated with two changes. The first requires payment of annual dues for the last two years, which had not been enforced in prior years. The second is that all 220 members for whom no email address was available were contacted by mail. Around half replied. Most had retired, passed away or had moved out of the field of epilepsy, and they were removed from the census.

**Change of regulations:** Once the census has updated, the Chapter was in a position to change its Rules and Regulations. The Chapter regulations dated back to the 1950 and were not in accordance with present Spanish law. In particular, they required an



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unrealistic quorum for general assemblies. This had been exploited by some members effectively prevent the remaining members to meeting in assemblies, which has prevented the Spanish Chapter from accepting new members for years. This year, the Board managed to gather a sufficient quorum to change the regulations, which now allows members to assemble with any quorum. In the General Assembly celebration on November 28, this allowed us to add 17 new members who had long been waiting to be approved.

**Intensive courses:** Over the last two years, the Spanish Chapter has delivered one-day intensive courses at a moderate price, given a day before the Annual Meetings in 2013 (Madrid) and 2014 (Seville). In 2013, the intensive course's topic was "Electroencephalography in Epilepsy." In 2014, the intensive course focused on epilepsy surgery. These courses have proven to be very popular, with 70 attendees in 2013 and 55 in 2014. The courses have been of the highest standard, featuring national and international speakers (Professor M. Koutroumanidis, Dr. Valentin and Dr. Alarcon). The feedback has been excellent. They not only provide a modest income to the Chapter, but also attract young consultants and trainees who usually also attend the Annual Meeting the next day. Courses have been evaluated by the corresponding governmental agency and granted credits for continuous professional development.

**Annual Meetings:** Just as the intensive courses described above did, the Annual Meetings over the last two years have focused on specific topics. In 2013, the Annual Meeting concentrated on advances in the management of epilepsy, while in 2014 it focused on the social and legal aspects of epilepsy. We invited national experts and leading international speakers (Professors Matthew Walker and Quian Quiroga). Again, the feedback has been very positive. The Annual Meetings have been evaluated by the corresponding governmental agency and granted credits for continuous professional development.

### Future projects

- *New members:* The number of members dropped very substantially over the last ten years due to the obstacles we faced in not being able to accept new members (see above), together with the natural loss of members due to retirement, disease, death and/or members changing to other fields outside epilepsy. The main objective of the Chapter was to accept those members already waiting and to attract more. The recent change in regulations has been the first step.
- *Funding:* We are contacting individuals and commercial firms to obtain external funding, which is needed.
- *Publications:* We are planning to write a brief booklet to educate the general public, patients and relatives.

- *Next Intensive Course and Annual Meeting:* The Intensive Course and Annual Meeting for 2015 will be in Majorca and will focus on pediatric epilepsy.

### Our leadership team is as follows:

- President: Gonzalo Alarcón Palomo
- Vice President: José María Castilla Garrido
- Secretary: Ángel Ponce de León Paredes
- Treasurer: Fernando Carceller Benito
- Voice of the ILAE: Germán Sierra Paredes
- Voice of the Bulletin: Antonio Rossiñol Far

### Respectfully Submitted

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## SRI LANKA LEAGUE AGAINST EPILEPSY (SLLAE)

The activities during this time period from the SLLAE were based on improving patient awareness, enhancing epilepsy education and establishing new epilepsy care services.

A special program to have a monthly epilepsy educational activity in the form of a case-based discussion has been started this year. Up until now, several topics have been covered. Epilepsy cases presented by the senior registrar (fellow) are subsequently discussed by the neurologist. These discussions are open to medical officers, EEG technicians and nursing officers.

A media seminar was held in the middle of 2014 to enhance the public's education about epilepsy control, and focused on anticonvulsant medications and services currently available in the country for epilepsy care.

A special meeting with the health ministry was held to promote regular adherence to guidelines for epilepsy treatment by all medical officers in the country. These guidelines have already been formulated.

The primary project that is currently underway is the construction of the special epilepsy unit at the National Hospital of Sri Lanka. This is an eight-story building with state-of-the-art equipment dedicated solely for epilepsy patients in this country. It serves both adults and children, and has facilities for investigating patients for epilepsy surgery. It will be equipped with a newly designed video monitoring unit, a 3 T MRI, a bi-planer SPECT scanner and a PET scanner. The SPECT scanner will be the very first such scanner in the country and the PET scanner is the first scanner in the public health service. The new facility will also house a theater for performing epilepsy surgery. The construction of this building began in the later part of 2013 and it is hoped it will be completed by the end of 2014. It will be equipped and operational in the first half of 2015.

### Respectfully Submitted

Dr. Jithangi Wanigasinghe  
Joint Secretary/SLLAE



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## SWEDISH EPILEPSY SOCIETY

### Publications

Please visit our website for educational programs and guidelines.

### Meeting

The Society's Annual Meeting took place November 6-7, 2014.

### Summary of Activities in 2013 and 2014

- We held our Annual Meeting in 2013 that focused on the Swedish National Epilepsy Register and included the topic, "Clinical Neurophysiology in Epilepsy-Updates and News."
- The Annual Meeting of 2014 focus was, "Epilepsy, Seizures and Inflammation."
- We were the proud host of ECE Stockholm 2014.

### Summary of Activities in Relation to Global Campaign in 2013 and 2014

We produced a video about five people with epilepsy to raise public awareness and reduce the stigma associated with epilepsy.

### Educational Activities

- The Society established guidelines and practice parameters critical for epilepsy professionals to provide quality care to adults and children with epilepsy.
- We implemented a national epilepsy register as part of a nationwide neurology register.
- We offered an educational course for neurology residency training in cooperation with the Swedish Neurological Society.
- We offered educational courses for physicians and nurses in epileptology.

### Activities in Conjunction with Local IBE Affiliates

Media contacts and press releases.

### Future Plans

We will continue to promote research and development of epileptology in Sweden. We will also offer annual courses, workshops and the development of a national register. In addition, we will participate in the education of neurologists and epilepsy nurses.

### Officer Election Date

November 7, 2014

### Respectfully Submitted

Eva Kumlien

## SWISS LEAGUE AGAINST EPILEPSY

### Publications

The journal *Epileptologie* (Epileptology), is published four times a year, containing 50-70 pages each, with information about new developments in epilepsy research.

### Meeting

The 2013 8th Joint Meeting of the German, Austrian and Swiss Chapters of the International League against Epilepsy (ILAE) was held in Interlaken, Switzerland May 8-11.

### Summary of Activities in 2013 and 2014

#### 2013

- The 8th Joint Meeting of the German, Austrian and Swiss Chapters of the International League against Epilepsy (ILAE) took place in Interlaken, Switzerland May 8-11.
- Three annual events for laypersons were held in different cities (Chur, Berne and Geneva), with several lectures held by epilepsy experts. The main topic was "Living with Epilepsy."
- Three annual events for professionals were held in different cities (Chur, Berne and Geneva), with several lectures by epilepsy experts.
- The main event on the Day of Epilepsy (October 3) took place in Lausanne, Switzerland. It was an exhibition of Sylvie Loeb, an artist who has epilepsy.
- We held a special day for patients and their relatives. The topic discussed was, "Epilepsy: Balancing Act with Safety Net."
- The League presented an award for the best dissertation on the subject of epilepsy.
- We presented the Tissot Medal of the Swiss League against Epilepsy to Giuseppe Scollo-Lavizzari, who is located in Basel, Switzerland.
- We gave a research support grant for a promising study in Switzerland in the field of epileptology.
- The League presented the Hauptmann Award to the German-speaking Epilepsy Societies/Leagues in Interlaken, Switzerland.

#### 2014

- The League held the Joint Annual Meeting of the Swiss Society of Intensive Care, the Swiss Society of Neurology, the Swiss Society of Neuroradiology, the Swiss Society of Emergency Medicine (SGNOR) and the Swiss

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Stroke Society, with the Swiss League Against Epilepsy as a guest, in Interlaken, Switzerland October 29-31.

- We held three annual events for laypeople in different cities (Aarau, Lucerne and Lugano), with several lectures by epilepsy experts. The main topic was "Living with Epilepsy."
- We held three annual events for professionals in different cities (Aarau, Lucerne and Lugano), with several lectures by epilepsy experts.
- For the campaign on the Day of Epilepsy (September 22-October 11), we produced a video clip with information about epilepsy that appeared in every post office in Switzerland.
- The League held a special day for patients and their relatives with a theme of "Epilepsy in the Kaleidoscope: Facets of an Illness."
- We presented a research support grant for a promising study in Switzerland in the field of epileptology.
- We launched a campaign entitled "Epilepsy in the Elderly," as well as provided continuing education for caregivers.

## Summary of Activities in Relation to Global Campaigns in 2013 and 2014

### 2013

- The main event on the Day of Epilepsy (October 3) took place in Lausanne, Switzerland. It was an exhibition of Sylvie Loeb, an artist who has epilepsy.

### 2014

- Our campaign on the Day of Epilepsy, which lasted September 22-October 11, was the production of a video clip with information about epilepsy that appeared in every post office in Switzerland.

## Educational Activities

### 2013

- The League held three annual events for professionals in different cities (Chur, Berne and Geneva), with several lectures by epilepsy experts.
- We provided lectures for members of the pharmaceutical industry.

### 2014

- Once again, we held three annual events for professionals in different cities (Aarau, Lucerne and Lugano), with several lectures by epilepsy experts.

- As in 2013, we provided lectures for members of the pharmaceutical industry.

## Activities in Conjunction with Local IBE Affiliates

### 2013

We held a special day for patients and their relatives, with a theme of "Epilepsy: Balancing Act with Safety Net."

### 2014

As in 2013, we held a special day for patients and their relatives. This time, the topic was "Epilepsy in the Kaleidoscope: Facets of an Illness."

## Future Plans

We are planning a campaign entitled "Youth and Epilepsy." This will entail the evaluation of a social media project to enhance knowledge about epilepsy in young people.

## Officer Election Date

Spring 2016.

## Respectfully Submitted

Swiss League against Epilepsy

## TAIWAN EPILEPSY SOCIETY

### Publications

The Society issued a revision of Taiwan's epilepsy guidelines, which were published in the Archives of Taiwan Epilepsy Society, and we produced a Taiwan electroencephalography guideline document.

### Meeting

The 2014 Annual Meeting of the Taiwan Epilepsy Society was held March 22-23.

## Summary of Activities in 2013 and 2014

- A Young-Star Epilepsy Training Program was held once a year. This program was prepared for young investigators in the fields of neurology/neurosurgery/pediatric neurology, especially for those who recently passed the Neurology Board Examination. The latest one was held in November 2014.
- EEG educational courses of different levels were conducted nine times in 2013 in the northern, central and southern parts of Taiwan: three for the basic level, three for the intermediate level and three for the advanced level.
- "Introduction and Managing Patients with Epilepsy" sessions were conducted three times in 2014, to provide comprehensive epilepsy education to nursing professionals.
- An "Introduction to Epilepsy" course was conducted three times in 2014. The course

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aimed to raise awareness, communication and education about epilepsy for school staff and nurses working in the schools. More than 1,000 teachers or school nurses participated in these courses.

- Three research awards are given annually, including the Young Investigators Travel Award, the Epilepsy Best Paper Award, and the Epilepsy Research Award.
- Our Annual Meeting was held in March 2014.

## Summary of Activities in Relation to Global Campaigns in 2013 and 2014

We will support the Association of Patients with Epilepsy to help organize a “Taiwan Epilepsy Day” activity in February 2015. It will be a outdoor activity held at Taipei’s city hall.

## Educational Activities

- A Young-Star Epilepsy Training Program was held once a year. This program was prepared for young investigators in the fields of neurology/neurosurgery/pediatric neurology, especially for those who recently passed the Neurology Board Examination. The latest one was held in November 2014.
- EEG educational courses of different levels were conducted nine times in 2013 in the northern, central and southern parts of Taiwan: three for the basic level, three for the intermediate level and three for the advanced level.
- “Introduction and Managing Patients with Epilepsy” sessions were conducted three times in 2014, to provide a comprehensive epilepsy education to nursing professionals.
- An “Introduction to Epilepsy” course was conducted three times in 2014. The course aimed to raise awareness, communication and education about epilepsy for school staff and nurses working in the schools. More than 1,000 teachers or school nurses participated in these courses.

## Future Plans

1. Taiwan’s electroencephalography guidelines were released at the end of 2014, which try to establish a comprehensive guide about the techniques and interpretation of EEG.
2. We are planning a revision of Taiwan’s epilepsy guidelines before 2015.
3. More than 20 outstanding pediatric neurologists will begin to work on the first version of the Pediatric Epilepsy guidelines, which will include three volumes (neonatal, infant, and children). It will be released in 2015.

4. The 4th Symposium of the World Association of Chinese Epileptologists (WACE) was held October 18-19, 2014 in Kaohsiung, more than ten years since last time, when it was held in Guangzhou. There was a special session case presentation for young investigators in the afternoon at October 18, followed by a full day of plenary sessions on October 19.
5. The 2015 Annual Meeting will be held March 28-29, 2015 in Taipei.

## Officer Election Date

March 28, 2015

## Respectfully Submitted

Chien Chen, MD, Secretary-General

## TURKISH LEAGUE AGAINST EPILEPSY

### Publications

The Turkish League Against Epilepsy publishes *Epilepsi* Journal three times a year, with two supplements (one for the Congress abstract and one on epilepsy).

### Meeting

The 9th National Epilepsy Congress took place May 15-19, 2014 in Fethiye, and the Epilepsy Symposium was held June 7-9, 2013 in Bolu Abant.

## Summary of Activities in 2013 and 2014

Alternating events—a bi-annual symposium and a Congress—were held in Bolu Abant (Epilepsy Symposium, June 7-9, 2013) and Fethiye (9th National Epilepsy Congress, May 15-19, 2014).

National educational monthly meetings were also arranged. Topics and speakers were chosen to fulfill educational needs. There were also foreign speakers. Lectures targeted a wide variety of professionals who treat patients with epilepsy. There have been between 300 and 375 attendees at each national meeting.

## Monthly meetings

- January 11, 2013: “Antineuronal Antibodies in Epilepsy and Encephalitis” was presented by Erdem Tüzün.
- January 25, 2013: “Genetics of Epilepsy - Istanbul University Experience” was presented by Ugur Ozbek.
- February 22, 2013: “Teratogenesis and Epilepsy” was presented by Kimford Meador.
- March 29, 2013: “Recent Imaging Findings in Juvenile Myoclonic Epilepsy and Multimodal Imaging in Cryptogenic Focal Epilepsy” was presented by Christian Vollmar.
- April 26, 2013: “Coherent Neural Activity and Brain Synchronization During Seizure-induced Loss of Consciousness” was presented by Fabrice Bartolomei. On the same date,

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"Functional Connectivity in Epilepsy" was presented by Maxime Guye.

- October 25, 2013: "Case Discussions" was presented by Ay in Dervent.
- November 29, 2013: "Epilepsy Treatment and Pregnancy" was presented by Tobjörn Tomson.
- December 27, 2013: "Case Discussions" was presented by Aysen Gokyigit.
- January 31, 2014: "Semiological Approach in Epilepsy" was presented by Philippe Kahane.
- February 28, 2014: "A New Surgical Technique in Medial Basal Temporal Lobe Epilepsy Surgery" was presented by Ugur Türe.
- April 25, 2014: "Generic Antiepileptic Drugs, Fact and Fiction" was presented by Michael Privitera.

## EEG courses

On November 30, 2013, we held a Pattern EEG Course consisting of 17 lectures and case discussions.

## Annual Semiology Meetings

On November 2-3 2013, a meeting entitled "Semiology-Case Discussions" was delivered by Professor Philippe Kahane, Suheyl Noachtar, Candan Gürses, and Berrin Aktekin.

## Educational Activities

The National Epilepsy Congress and Symposium provide educational opportunities for clinicians, researchers and other epilepsy professionals. Some of the archived programs, lectures and texts for clinicians and patients are available at our website, free of charge.

Additionally, Turkish ILAE-funded rewards for publications related to epilepsy were given during the National Epilepsy Congress.

## Activities in Conjunction with Local IBE Affiliates

Our association with IBE was recently established and has not had any activities yet.

## Future Plans

An international congress, a national symposium, and educational and monthly meetings will be arranged during the next year, including:

- September 27, 2014: "EEG and Semiology in Different Epilepsy Syndromes," which consisted of 17 lectures in five main sessions.
- October 18-19 2014: "Semiology and Case Discussions," delivered by F. Chassoux, Minotti, Çigdem Özkara, and Berrin Aktekin, MD.
- November 7-9, 2014, EEG courses were offered.

Monthly meetings:

- October 24, 2014: Epilepsy and Pregnancy
- December 26, 2014: Case Discussions
- January 30, 2015: Genetics and Epilepsy
- February 27, 2015: Case Discussions
- March 27, 2015: High Frequency Oscillations (presented by Professor Schulze-Bonhage)
- April 17, 2015: Case Discussions
- June 2015: Epilepsy Symposium, "Treatment in Epilepsy"

Additionally, WONOE will be held August 31-September 4, 2015 in Istanbul and the International Epilepsy Congress will take place September 5-9, 2015, also in Istanbul.

**Officer Election Date**  
2016.

**Respectfully Submitted**  
F. Irsel Tezer

## ILAE UK CHAPTER

### Publications

Publications from the UK Chapter can be found online at <http://www.ncbi.nlm.nih.gov/pubmed/23551079>.

### Summary of Activities and Educational Activities in 2013 and 2014

In 2014, we held four meetings:

1. ILAE UK Chapter Annual Scientific Meeting, in Nottingham
2. ILAE UK Chapter Junior Doctors Epilepsy Teaching Day, in London
3. ILAE UK Chapter (in conjunction with the Royal College of Psychiatry Neuropsychiatry Section) one-day meeting on Epilepsy and Neuropsychiatry
4. ILAE UK Chapter Primary Care Meeting, in Birmingham

### Future Plans

We have five meetings planned for 2015

1. ILAE UK Chapter Annual Scientific Meeting, in London
2. ILAE UK Chapter Specialist Registrars Teaching Weekend, in Oxford

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3. ILAE UK Chapter Junior Doctors Epilepsy Teaching Day, in London
4. ILAE UK Chapter (in conjunction with the Neuro-anesthesia Society of Great Britain and Ireland) one-day meeting entitled "Epilepsy and Critical Care: The Interface," in London
5. ILAE UK Chapter Primary Care Meeting, in London

## Officer Election Date

Council Place Available in 2015.

## Respectfully Submitted

Juliet Solomon

## VENEZUELA LEAGUE AGAINST EPILEPSY (LIVECE)

Activities taking place during this time period

- Educational Talks about Epilepsy and Prevention were held in the different chapters of the country. We closed the cycle with a Symposium entitled "Cranial Injuries and Consequences," which was delivered on November 15 at the Faculty of Medicine of the Central University of Venezuela, with the assistance of undergraduate, post-graduates and students of Public Health and Nursing.
- Campaigns about the grave situation of the absence of AEDs throughout the country were transmitted through radio and television, and in newspapers and magazines.
- A donation request for AEDs was organized by LIVECE to support patients in need.
- Assistance was provided to epilepsy patients who fell into a convulsive state due to lack of drugs through different electronic media, Twitter, the internet, and by telephone and consultations. Many of them had been free of seizures for more than 15 years.
- LIVECE participated in the National Congress of Neurology held in Valencia September 23-27, 2014 as well as in the organization of the Module Epilepsy conferences, with high scientific and topical relevance.
- LIVECE provided educational talks to nurses in different chapters throughout the country.
- We provided the course "Research Methodology, From the Project to the Publication" to seven universities within the country. Three more are scheduled for 2015.
- We continue to provide psychological advice to parents and relatives of people with epilepsy.

## Respectfully Submitted

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## ZIMBABWE LEAGUE AGAINST EPILEPSY

### Publications

No publications were issued during this time period.

### Meeting

Two meetings were held.

### Summary of Activities in 2013 and 2014

During this period, we focused on mobilizing members. The membership has now grown from four active members to 15 active members. We had two important meetings as well. The first one was in Cape Town during the Africa Epilepsy Congress in May. The second one was held in July in Harare, where new members were recruited.

### Summary of Activities in Relation to Global Campaigns in 2013 and 2014

We planned to resuscitate monthly meetings on the Global Campaign Against Epilepsy with the World Health Organization (Zimbabwe) and Ministry of Health (Zimbabwe), but by the time of this report, we had not started the meetings.

### Educational Activities

We created a Facebook page to share information on epilepsy, which currently has 29 "likes."

### Activities in Conjunction with Local IBE Affiliates

We continue giving our support to the Epilepsy Support Foundation (ESF), which is an affiliate of IBE. Our members provide free services, primarily as it relates to treatment and EEG.

### Future Plans

We are planning the following activities:

1. Awareness and education in collaboration with ESF.
2. Research on epilepsy.
3. Holding an annual conference.

### Officer Election Date

February 2015.

### Respectfully Submitted

Jacob Mugumbate and Clotilda Chinyanya



# CONSTITUTION

## Article I — Name

The name of this international organization, founded on 29 August 1909, in Budapest, is the International League Against Epilepsy (hereinafter called “the ILAE”).

## Article II — Effective Date

This Constitution is amended and valid as of 31 August 2011.

## Article III — Objectives

The objectives of the ILAE are to:

1. Advance and disseminate throughout the world knowledge concerning the epilepsies.
2. Encourage research concerning the epilepsies.
3. Promote prevention, diagnosis, treatment, advocacy and care for all persons suffering from these disorders.
4. Improve education and training in the field of the epilepsies.

## Article IV — Methods

To that end, but without restricting the main objectives of the ILAE, and insofar as the same shall be wholly charitable, the ILAE shall:

1. Encourage the establishment and maintenance worldwide of societies with the same objectives as the ILAE which will be members of the ILAE (hereinafter designated “Chapters”).
2. Seek to establish and maintain effective cooperation with other organizations worldwide, active in the field of the medical sciences, public health, and social care, who are, or may become concerned with problems related to the epilepsies.
3. Promote publications concerning the epilepsies and arrange for the publication of the journal of the ILAE, *Epilepsia*, and other ILAE educational and informational materials.
4. Organize or sponsor international Congresses, symposia, or other meetings, in particular the International Congress of the ILAE, to be held at the time and place as prescribed in the Bylaws.
5. Appoint special commissions or individuals for the purpose of studying specified problems related to the aims of the ILAE and making recommendations for implementation of specific activities.
6. Develop and apply other methods consistent with the objectives of the ILAE.

## Article V — Legal Status

The ILAE is a non-profit, tax exempt, international organization incorporated in the District of Columbia, USA.

## Article VI — Membership

1. Member Chapters are composed of professionals who are involved in patient care or research in epilepsy and whose primary concern is with the problems of epilepsy. The minimum membership of a Chapter is nine professionals which is deemed to be the minimum number that would allow the rotation of President, Secretary-General and Treasurer. Exceptionally, a Chapter may consist of a mixed professional and lay membership for a period of time. In this situation, only professional members constitute the basis for dues, voting, and holding

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

2. There shall be only one Chapter in each country defined as any State recognized as a member of the United Nations and/or World Health Assembly. When there is more than one eligible organization in a country, the Executive Committee shall recommend for membership that organization which, in its opinion, can best accomplish the objectives of the ILAE. Organizations in territories/regions that do not fall within the above definition of a State, or in groups of two or more states, may exceptionally be considered for membership by the Executive Committee and ratified by the General Assembly.
3. The Chapters shall be voted into the ILAE upon the approval of the Executive Committee and two-thirds vote of those attending the meeting of the General Assembly. Pending approval by the General Assembly, a prospective chapter may be provisionally admitted to the ILAE by decision of the Executive Committee which will entitle the prospective chapter to all rights of membership except the right to vote.
4. By applying for membership a prospective chapter agrees to fulfill all obligations of Chapters as stated in this Constitution and Bylaws. The Chapter must submit to the Secretary-General a list of names and addresses of its own members. After a Chapter is approved, it must pay its annual dues.
5. A Chapter may withdraw from membership by giving notice in writing to the Secretary-General.
6. On recommendation of the Executive Committee, membership may be terminated by a two-thirds vote of those attending the meeting of the General Assembly, if the Chapter fails to pay its annual dues or if, for any other reason, it no longer fulfills the stated requirements for membership.
7. The Chapters are organized into Regions as determined by the Executive Committee.

## Article VII — Governance

The ILAE shall be governed by the Executive Committee and the General Assembly.

## Article VIII — The Executive Committee

1. The Executive Committee shall conduct the affairs of the ILAE subject to ratification by the General Assembly.
2. The Executive Committee shall consist of:
  - a. The President, Vice President, Secretary-General, Treasurer, and the Immediate Past President, and the Chair of each of the recognized ILAE Regions as voting members. Within the Executive Committee, Regional Chairs will work on behalf of, and in the best interests of the ILAE globally.
  - b. The President, Secretary-General and Treasurer of the International Bureau for Epilepsy, (hereinafter called the “IBE”), as Ex-Officio, non-voting members.

- c. The Editor-in-Chief of *Epilepsia* as a non-voting member, appointed by the voting members of the Executive Committee.
- 3. The Management Committee:
  - a. Shall consist of the President, Vice President, Secretary-General, Treasurer, and Immediate Past President.
  - b. The Management Committee will implement the policies approved by the Executive Committee and govern the League between meetings of the Executive Committee.
  - c. The geographic distribution of the elected officers, including the President, shall be restricted as follows: Each of the newly elected Management Committee members must be primary members of different Chapters. Primary membership is defined by the location in which professional activities are performed. No more than two of the newly elected members of the Management Committee shall come from the same Region, as defined by the geographic Regions recognized by ILAE.
  - d. The President shall serve one term. Candidates for the Presidency must have served, or be in the process of serving, at least one term on the Executive Committee either as an elected or Ex-officio member. After serving as President, the person shall automatically serve one term as Immediate Past President.
  - e. The term of office for any Executive Committee member is four years. The members of the Executive Committee may be re-elected or re-appointed for one additional term to any of these offices. No member of the Executive Committee can serve more than two terms as an elected officer, unless elected as President. No person may occupy a seat on the Executive Committee for a period exceeding a maximum of sixteen years.
  - f. If the current President cannot fulfill the full term of office, a new President will be selected in accordance with the Bylaws. Should any vacancy in the Executive Committee occur it shall be addressed by the Executive Committee subject to ratification by the General Assembly.
  - g. The President shall appoint an independent Elections Commission. The Elections Commission shall be chaired by the Immediate Past President. It will include one person from each of the recognized ILAE Regions and the Immediate Past Chair of the Elections Commission. The Executive Committee shall not interfere with the business of the Elections Commission. The Commission is to conduct the elections and establish appropriate procedures as described in the Bylaws and that are not in conflict with the Constitution.
  - h. The Executive Committee may hold meetings at any time or in any place which may be convenient to its members; it may conduct its business also by other appropriate means of communication. The business decisions of the Executive Committee, once taken, become effective, will be recorded in minutes, and the minutes will be approved at the next meeting.
  - i. Two-thirds of the voting members of the Executive Committee constitute a quorum. Decisions are made by a majority of the voting members attending. In the event of a tie, the President has a deciding vote.

- j. The Executive Committee shall have the power to formulate at any time Bylaws not in conflict with the Constitution. These Bylaws are legally binding, but a posteriori corrective action may be taken by the General Assembly to revoke or amend these rules.
- k. The Executive Committee shall approve the annual budget of the ILAE and shall set the dues to be paid by the Chapters.

## Article IX — The General Assembly

1. The General Assembly consists of all approved Chapters of the ILAE.
2. Regular meetings of the General Assembly shall be convened during each International Congress of the ILAE. Participants shall consist of one delegate from each Chapter who carries the total number of votes of that Chapter.
3. Representatives from more than fifty percent of the Chapters attending a meeting of the General Assembly shall constitute a quorum. Decisions will be taken by a majority of the votes of those attending.
4. The General Assembly shall receive and consider for vote of approval the reports of the President, the Secretary-General, and the Treasurer.
5. The General Assembly shall vote on proposals submitted by the Executive Committee.
6. The General Assembly shall approve the admission of new Chapters and the termination of membership of Chapters.
7. Meetings of the General Assembly are open unless a number exceeding ten percent of the delegates present requests to the Chair to close the meeting to observers. Only delegates may speak and vote. Exceptionally the presiding officer with the approval of the General Assembly may invite a non-delegate to speak, but not to vote.
8. Between regular meetings of the General Assembly, should urgent business arise requiring General Assembly action, this shall be carried out in writing, using available technology as determined by the Executive Committee. Such business must involve responses from at least fifty percent of the Chapters, and decisions would require a majority of the votes of those responding.
9. Chapters whose total votes correspond to a minimum of twenty-five percent of all available votes may request a written consultation by the General Assembly. Reasons for doing so must be sent to the Executive Committee ninety days before the consultation.

## Article X — Finances

1. The ILAE shall have the authority to accept and administer gifts, legacies, movable or immovable properties, donations, and assets of any kind without any restrictions as to the amount or value and to collect annual dues of its Chapters.
2. The assets of the ILAE shall be used to further the objectives of the ILAE as authorized by the Executive Committee.
3. No portion of the assets of the ILAE shall be paid directly or indirectly to any Officer, members of its Commissions and Task Forces, or officers of its Chapters, except for payment of expenses made in the interest of the ILAE.

4. Proper books of account shall be overseen by the Treasurer and they shall be certified by a qualified auditor at the end of each fiscal year.

#### **Article XI — *Epilepsia***

1. The Editor-in-Chief of *Epilepsia* shall be responsible for editing *Epilepsia* in accordance with the general policies established by the Executive Committee.
2. The Editorial Board shall consist of editors appointed by the Editor-in-Chief. The term of office of the editors is four years and editors may be reappointed for one additional term.
3. The editorial Advisory Board of *Epilepsia* shall consist of the Executive Committee and shall approve all contracts related to the publication of *Epilepsia*.
4. All financial responsibilities of *Epilepsia* reside with the Treasurer and the Executive Committee of the ILAE.

#### **Article XII — Commissions and Task Forces**

1. Commissions and Task Forces in unlimited number may be appointed by the President of the ILAE as recommended by the Executive Committee. The President, Secretary-General and Treasurer of the ILAE shall be Ex-Officio members of all Commissions and Task Forces, except the Elections Commission.
2. No expenses shall be incurred by a Commission or Task Force on behalf of the ILAE without the consent of the Executive Committee.
3. Annual budgets and financial reports of the Commissions and Task Forces must be approved by the Executive Committee.
4. Regional Commissions must have written rules of procedure that are in agreement with the League's Constitution and Bylaws. A copy must be kept in the League's Headquarters Office. Any changes in these rules must be submitted to the Executive Committee for ratification.

#### **Article XIII — International Bureau for Epilepsy**

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

#### **Article XIV — Amendments**

1. The present Constitution may be amended by a two-thirds vote of those attending the meeting of the General Assembly.
2. Amendments may be initiated by the Executive Committee, or by Chapters whose total votes correspond to a minimum of twenty-five percent of the votes of the General Assembly. Such amendments must be submitted to the Secretary-General at least ninety days before the next meeting of the General Assembly, and due notice of such amendments shall be given to all Chapters by the Secretary-General at least sixty days before the meeting of the General Assembly.

#### **Article XV — Dissolution or Merger**

1. The ILAE may be dissolved or merged with another body having similar objectives on proposal of the Executive Committee, ratified by two-thirds of the available votes of the General Assembly as well as two-thirds of the total number of Chapters.
2. In the event of dissolution, the assets of the ILAE may not be divided among its members but shall be transferred to one or more other international organizations of similar interests, as agreed by the General Assembly.

Approved August 2011  
Rome, Italy

# BYLAWS

Ratified on October 02, 2011, Amended April 2012, June 2012, June 2013

The Executive Committee is empowered by the Constitution (Article VIII-8) to establish Bylaws as necessary to achieve the objectives of the League, subject to their not being in conflict with the Constitution and to their ratification by the General Assembly.

The Secretary-General shall keep a book containing the current Bylaws, in which all modifications are entered as they are made.

## Article I – Elections

1. For each phase of the election, the Elections Commission shall ascertain if candidates are available and willing to serve. Candidates will provide the Elections Commission with appropriate background information on their candidacy. This information will be sent to each Chapter and publicized in the ILAE Website.
2. Each Chapter has from 1-6 votes. The number of votes accorded to each Chapter shall depend on the number of professional dues paying members in that Chapter according to the most recent statement provided by the Chapter. The number of votes shall be determined by a sliding scale as follows:  
  
up to 50 members: 1 vote  
51 – 150 members: 2 votes  
151 – 350 members: 3 votes  
351 – 750 members: 4 votes  
751 – 1500 members: 5 votes  
above 1500 members: 6 votes  
  
Chapters that do not collect dues shall have one vote.
3. All votes are secret. To ensure secrecy in all voting processes, the Election Committee shall appoint an independent third party, who shall be responsible for receiving the chapters' votes. The third party will inform chapters by Email or fax within 72 hours that their vote was received, and will transmit the counts of votes to the Election Committee. The number of votes received by each candidate at each election stage will be disclosed publicly at the completion of all election stages, unless there is a run-off election.
4. For the election of the President, the Elections Commission shall submit to the Chapters a list of persons fulfilling the requirements of the Constitution (Article VIII), who are available and willing to serve. The Elections Committee will ask each Chapter to vote for one of them by Email or fax. If one of the candidates receives more than fifty percent of all possible weighted votes, this candidate shall be elected.
5. If this is not the case, a run-off shall be held between the two candidates who received the highest number of weighted votes. The candidate in the run-off that receives the highest number of weighted votes cast shall be elected. If both candidates receive the same number of votes, the candidate with the highest number of un-weighted votes will prevail. If the tie still holds after counting un-weighted votes, the candidate who had been in the Executive Committee for 8 years already will prevail. In the event that the tie still holds, the older candidate will prevail.
5. Following completion of the Presidential Election, the Elections Commission shall request each Chapter to submit a slate of five names from at least 3 different regions, without any ranking, as candidates for the remaining officer positions.
6. The geographic representation of the candidates must allow for the eventual election of officers who meet the geographic distribution requirement stated in the Constitution (Article VIII).
7. The Elections Commission shall choose a slate of fifteen candidates on the basis of non-weighted multiple nominations from the lists submitted by the Chapters. The slate must include candidates from at least 3 regions. The slate may be smaller if less than 15 people are nominated. The Commission shall ascertain that these candidates are available and willing to serve.
8. The Elections Commission shall then submit the slate to each Chapter for voting by Email, or fax. In this process, each chapter shall vote for five candidates from at least 3 different regions, without any ranking. The final votes for each candidate will be determined by the sum of the weighted votes received from all Chapters. If two or more candidates obtain the same number of weighted votes, the candidate(s) from the ILAE region(s) with the least representation among the other elected officers will prevail. If a tie persists after consideration of regional representation, the candidate with the highest number of unweighted votes will prevail. If a tie still persists, the oldest candidate(s) will prevail.
9. The President-Elect with the advice of the Election Committee will appoint the Secretary-General, Treasurer, and the Vice-President from the newly elected slate.

## Article II – Duties of Officers

1. The President serves as the chief elected officer of ILAE, and shall
  - a) preside at meetings of the Executive and Management Committee and the meeting of the General Assembly

- b) call regular and special meetings of the General Assembly, and conduct necessary mail ballots in accordance with guidelines outlined in the Constitution;
  - c) In conjunction with ILAE staff and Executive Committee members, prepare the agenda for the Executive Committee meetings;
  - d) Serve as a spokesperson for ILAE to the public, press, legislative bodies, and other related organizations;
  - e) After consultation with the other Executive Committee Officers, appoint the chairs and members of ILAE Commission and Task Forces, and outline their purposes and duties consistent with the ILAE strategic plan;
  - f) Serve as an ex officio member of all Commissions and Task Forces, except for the Election Commission;
  - g) Promote active participation in ILAE activities, and reports the activities of the executive Committee and ILAE to the chapters through E-mail broadcasts, the ILAE Website, Epigraph and other publications;
  - h) Serve as an ILAE representative on the IBE Executive committee and maintain liaisons with other related organizations;
  - i) Monitor the activities, programs, and developments of ILAE, supporting and promoting policies and programs adopted by the chapters; Executive Committee, and Commissions.
  - j) Provide the leadership for monitoring the ILAE strategic plan;
  - k) Recommend initiatives, research, and special assistance whenever necessary for Executive committee approval;
  - l) Assume a key role in the orientation and transition of the President-elect;
  - m) Identify, recruit and cultivate future leaders of the ILAE;
  - n) Assume other duties and responsibilities as may be assigned by the Executive Committee.
2. The Secretary-General ensures that records are maintained of all General Assembly and Executive Committee Meetings, and encourages chapter development. Specifically, the Secretary-General shall:
- a) Serve as a member of the Executive and Management Committee;
  - b) Oversee the maintenance of the official records of ILAE including (i) minutes of regularly called meetings of the General Assembly and Executive Committee; (ii) affiliated chapters in good standing; (iii) official correspondence to and from ILAE and other entities;
  - c) Maintain the Constitution and Bylaws, including responsibility for the process of amending the official documents;
  - d) Give timely notice of all meetings of the General Assembly and Executive Committee;
- e) Conduct a roll call of the members at the meetings of the General Assembly and Executive Committee meetings, assuring that a quorum is present;
  - f) Promote chapter development and support activities; review applications and supporting documents for the establishment of new chapters and provide guidance to the Executive Committee regarding the approval process;
  - g) Serve as an ex officio ILAE representative on the IBE Executive Committee;
  - h) Represent ILAE with other associations or entities as assigned by the President or Executive Committee;
  - i) Receive, process and maintain the reports of Commission and Task Forces, submitting such reports for Executive Committee approval and to *Epilepsia*;
  - j) Oversee the publication of the Annual Report;
  - k) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
3. The Treasurer ensures the integrity of the fiscal affairs of ILAE. Specifically, the Treasurer shall:
- a) Serve as a member of the Executive and Management Committee;
  - b) Ensure that the ILAE accounts are maintained according to international accounting standards, assuring the financial integrity of ILAE;
  - c) Exercise prudence in maintaining the assets of ILAE;
  - d) Report on the financial condition of ILAE at the meeting of the General Assembly and the Executive Committee;
  - e) Submit the financial account of ILAE to an annual audit;
  - f) Working with the staff, develop the annual budget for review and approval by the Finance and Executive Committees;
  - g) Monitor the financial performance of ILAE in relation to the annual budget
  - h) Ensure the timely payment of all ILAE financial obligations;
  - i) Oversee financial long-range planning;
  - j) Serve as an ex-officio ILAE representative in the IBE Executive Committee;
  - k) Retain authority and responsibility for the financial activity of ILAE when such activities are delegated to staff or contracted with an external entity;
  - l) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee.
4. The Vice-President will:
- a) Serve as member of the Executive and Management Committee;
  - b) Assume the responsibilities of the President in his or her absence.



5. The Immediate Past President assists the President with guidance and advice based upon knowledge of previous Executive Committee policies and past practices. Specifically, the Immediate Past President shall:
  - a) Serve as a member of the Executive and Management Committee;
  - b) Serve as a Chair of the Elections Commission;
  - c) Provide advice and counsel to the President and act as an information source;
  - d) Assist in providing continuity between terms of office;
  - e) Perform such other duties and assume such responsibilities as may be assigned by the President or Executive Committee;
6. The Management Committee will meet as needed between meetings of the entire Executive Committee.
7. In case that a member of the Management Committee or the Executive Committee resigns or is unable to serve for the rest of the term the following procedures will be undertaken:
 

**Management Committee:** Should the President resign or is unable to serve for the rest of the term, the Vice-President will step into this role. There will be then an election for a new Vice-President following the procedures for worldwide elections and maintaining the regional requirements that pertain to the elected members of the Management Committee (article 1, item 7).

Should a vacancy involve another member of the Management Committee (with exception of the position of Past President), there will be an election for a new member following the procedures for world wide elections and maintaining the regional requirements that pertain to the elected members of the Management Committee (article 1, item 7).

**Executive Committee:** Should a vacancy involve the positions of regional chair, an election will take, place according to the rules for regional elections and approved by the EC. If such rules are not available at the time of the special election, the election procedures used for the 2013 elections will be followed.
8. The Editor-in-Chief of *Epilepsia* shall be appointed by the Executive Committee and serves at its discretion, and conducts the day-to-day editorial business of *Epilepsia*, the official journal of ILAE. It may be appropriate for the Executive Committee to appoint more than one Editor-in-Chief of *Epilepsia*. The editorial content of *Epilepsia* is the responsibility of the Editor(s)-in-Chief. Specifically, the Editor(s)-in-Chief of *Epilepsia* shall:
  - a) Make the final decision on the acceptance or rejection of submitted manuscripts, including reports and documents produced by ILAE Commission and Task Forces and approved by the Executive Committee;
  - b) Make recommendations to the Executive Committee regarding number and role of Associate Editors and Managing Editor;
  - c) Appoint the associate editors and the members of the editorial Board, and supervise communication with the Board;
  - d) Call meetings of the Editorial Board as needed;
  - e) Recommend an annual budget for *Epilepsia* to the Executive Committee;
  - f) Liaise with the Publisher and oversee compliance with the contract;
  - g) Assist the Treasurer in supervising expenditures for the *Epilepsia* office
  - h) Perform other tasks as necessary for the operation of, and maintenance of quality, of the journal.
9. The President, Secretary-General and Treasurer of IBE serve as ex-officio, non-voting members of the ILAE Executive Committee. Their function is to facilitate a close and collaborative understanding between IBE and ILAE.

### Article III – General Assembly

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

### Article IV – Epilepsia

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

### Article V – Resource- and Topic-specific Commissions and Task Force

1. Each Resource- and Topic-oriented Commission and Task Force shall have a Chair appointed by the President in discussion with the Executive Committee. Each Commission and Task Force shall designate a Secretary, Treasurer, information officer, and representative to the Global Outreach activities. If appropriate the commission should appoint a liaison to the neurobiology commission. Liaisons to other commissions are encouraged. The President will appoint one member of the Executive Committee as the primary contact who serves as an ex-officio member.
2. Funds raised by an individual Commission, when not spent within the next fiscal year, may be allocated to the same commission for the subsequent fiscal year, subject to the Commission

providing a plan for the utilization of the funds and approval of the plan by the Executive Committee. At the end of the term of each Commission, any unused funds will be incorporated into the general ILAE assets.

3. The term of office of each Commission shall expire within six months of the end of the term of the Executive Committee to complete unfinished business. It is recommended that the out-going Chair(s) be involved in the generation of the revised Strategic Plan for the new Presidential term. No member of the Commission can serve for more than two terms, unless he/she is elected as Chair after having completed two terms.
4. Task Forces are appointed for specific purposes and their term of office expires when their duties are completed.
5. The Chair of each Commission and Task Force shall make interim reports and recommendations to the Executive Committee as deemed necessary and shall submit a final report at the conclusion of their term. Said final report shall be communicated to the Chapters.

#### **Article VI – Chapters’ Obligations**

1. Chapters shall be open for membership to all professionals working for epilepsy in that country, territory or region as defined in the Constitution.
2. Each Chapter must send to the ILAE Secretary-General the names and contact information of its officers within thirty days after the Chapter’s General Assembly Meeting during which a new Executive Committee takes office. If changes in contact addresses occur these must be immediately reported to the Secretary-General of the ILAE.
3. Within thirty days after each Chapter’s General Assembly meeting, the Chapter must submit any changes to its Constitution and Bylaws (in English) to the Secretary-General.
4. By March of each year, every chapter is requested to upload/enter their database, including e-mail addresses, to the ILAE website.
5. Before October 1 of each year, each Chapter shall pay to ILAE annual dues which shall be proportional to the number of dues paying members as of December 31 of the previous year, and shall be fixed for each fiscal period of the General Assembly. Dues for a Chapter are 3% of the annual dues that the Chapter charges each member, multiplied by the number of Chapter members, or a minimum payment of \$10 (U.S.) whichever is highest. In countries where exchange regulations do not allow for remittance of funds outside the country, then Escrow accounts may be established with the approval of the ILAE Treasurer.
6. If a Chapter without consent of the Executive Committee omits paying its dues it will be once invited to do so. If the next year dues are again not paid, the Executive Committee may propose

disaffiliation to the General Assembly in writing and/or have its right to vote at the meeting of General Assembly revoked. Two thirds of votes cast (with at least two thirds of all available votes having been cast) have to confirm disaffiliation.

#### **Article VII – Fiscal Year**

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

#### **Article VIII – Staff**

1. The location of the ILAE’s Headquarters Office will be determined by the Executive Committee.
2. The Executive Committee is empowered to retain such staff and contract for other professional services as may be necessary to carry out the functions of the League.

#### **Article IX – Meetings**

1. The International Congress of ILAE shall be held ordinarily every two years, in conjunction with the International Bureau for Epilepsy.
2. In the year between two International Congresses of the ILAE, the Regional Divisions of the ILAE will organize Regional Congresses with the support of the ILAE.
3. The International Congress of ILAE and the Regional ILAE Congresses will be organized with the assistance of the ILAE-designated International Director of Meetings.
4. The ILAE may sponsor or support, wholly or in part, other meetings relevant to its objectives. Such a meeting shall not be designated as an International Congress of the League.

#### **Article X – Regions**

1. Regional Commissions shall consist of: a) representatives elected by the local chapters comprising the region (with each chapter casting one vote) and b) up to two additional members appointed by the President, in consultation with the Executive Committee, among professionals from the region. The Chair will be elected first, followed by the election of the remaining members. The total number of elected members is five. If more than one candidate receives the same number of votes, the oldest candidate in age will prevail. Each member of the commission must be a primary member of a different chapter. Appointments to various positions within the commission are decided by the commission members based on their rules of procedure. It is recommended that Regional Commissions have education and information officers, and liaisons to global outreach and to neurobiology. Chapters can belong to only one region. Special arrangements will be made for regions with fewer than 6 chapters.
2. Regional Commissions should meet from one to three times a year and must submit an annual budget for approval to the Executive Committee.

3. Regional Commissions should aim to develop, stimulate and coordinate the epileptology agenda in their part of the world.
4. Regional Commissions should promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda.
5. Regional commissions can have designated funds which they access via the budget process.
6. Regional Commissions should coordinate local educational activities.
7. Regional Commissions should run their congresses under the direction of the International Director of Meetings.
8. Regional Commissions should review epilepsy services and the size of the treatment gap in each country and aim to improve the former and reduce the latter.
9. Regional Commissions should develop documents with the aim of stimulating local medicopolitical initiatives and improving patient care.
7. Chairing of each JEC shall be shared equally between the ILAE and IBE Presidents, or their nominees, in a manner acceptable to both. The Chairperson of a JEC shall not have a casting (i.e., tie-breaking) vote.
8. A quorum for a JEC shall be the presence of a majority of the members of each of the ILAE and IBE Executive Committees.
9. A JEC may be convened at any time mutually acceptable to the Presidents of both the ILAE and IBE.
10. To be considered by a JEC, a motion must be moved by a member of one Executive Committee, and seconded by a member of the other.
11. Responsibility for administration, minuting etc. of JECs shall be shared equally between the Secretaries-General of the ILAE and IBE, in a manner acceptable to both.
12. Responsibility for overseeing all financial matters considered by JECs shall be shared equally between the Treasurers of the ILAE and IBE, in a manner acceptable to both.
13. A Joint Committee, consisting of the voting members of the ILAE Executive Committees and the Management Committee of IBE, is authorized to take actions in the name of a JEC between JEC meetings. Such actions must:
  - a) Be approved by a majority of each of the Committees of the ILAE and IBE;
  - b) Be in accord with policies of both the ILAE and IBE;
  - c) Involve neither Executive Committee in expenditure exceeding a sum to be set by each Executive Committee;
  - d) Be notified to each Executive Committee as soon as possible;
  - e) Be ratified by each Executive Committee at its next meeting.

#### **Article XI – Cooperation with the International Bureau for Epilepsy (IBE)**

1. ILAE shall cooperate with IBE on all levels: international, national, regional, and chapter to ensure maximum efficiency in promoting quality of life for people with epilepsy.
2. Each ILAE chapter shall promote the establishment and/or assist in establishing a chapter of the Bureau, if such a chapter does not exist.
3. At least annually, and more frequently if necessary, the Executive Committee shall meet jointly with the Executive Committee of the IBE, to consider matters of mutual interest and/or responsibility to both Executive Committees. Such a meeting shall be known in full as a Joint Meeting of the Executive Committees of the ILAE and IBE, and in brief as a JEC.
4. A JEC shall have no financial or constitutional power or existence independent of the Executive Committees of the ILAE and IBE. It is a meeting of two separate and independent constitutionally defined bodies, not an entity in itself.
5. Matters to be considered by a JEC shall include co-organized Epilepsy Congresses and the Global Campaign, and such other matters as the ILAE and IBE Executive Committees shall consider appropriate to be delegated to consideration and decision by a JEC.
6. A proposed action by a JEC should not be in conflict with the Constitution of the ILAE and must be ratified by the two ILAE and IBE Executive Committees prior to implementation.

#### **Article XII – Indemnification**

Executive Committee members, officers, and other authorized staff, volunteers, or agents of the ILAE shall be indemnified against claims arising in connection with their positions or activities on behalf of the ILAE to the full extent permitted by law.

#### **Article XIII – Amendments**

The Executive Committee shall have the power to amend these Bylaws by the affirmative vote of a majority of the voting Executive Committee members then in office.