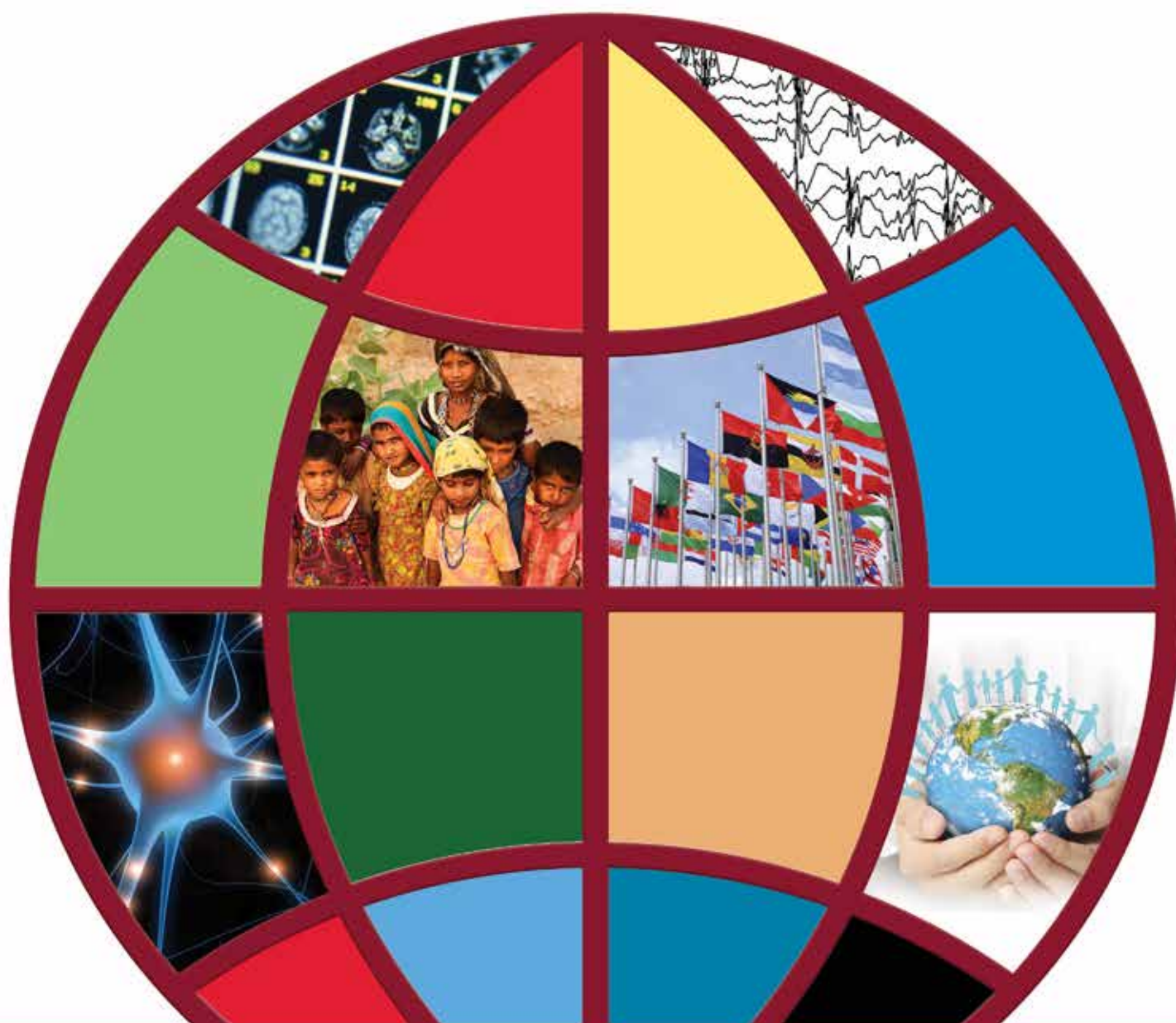


A Global Agenda

2015 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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Headquarters Office

342 North Main Street, Suite 301
West Hartford, Connecticut, USA
06117-2507
Tel +1 860.586.7547
Fax +1 860.586.7550
Website: www.ilae.org

Chapter Services Office

7 Priory Hall
Stillorgan
Co. Dublin
Ireland
Tel +353.1.278.4908
Fax +353.1.205.6156

EXECUTIVE COMMITTEE

2013-2017

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Finland

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Australia

INVITEES:

EPILEPTIC DISORDERS

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EPILEPSIA OPEN

CO-EDITORS-IN-CHIEF

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PRESIDENT'S REPORT



Emilio Perucca

The last 12 months saw many important developments within our community. No doubt, the most significant event was the approval, on May 26, 2015, of the *Resolution on the Global Burden of Epilepsy and the Need for Coordinated Action at the Country Level to Address its Health, Social and Public Knowledge Implications* by the 68th World Health Assembly (WHA).¹ The Resolution, which calls on Member States to step up actions to improve epilepsy awareness, care and research, came almost 20 years after the establishment of the Global Campaign and represents a true milestone in the social history of epilepsy.

As we explain in detail in an editorial published in *Epilepsia*², this event did not occur by chance, but is the result of real teamwork, involving close collaboration between ILAE, the International Bureau for Epilepsy (IBE) and the World Health Organization (WHO) (photo below). In particular, I wish to acknowledge the remarkable contribution made by Dr Shichuo Li and the Chinese Association against Epilepsy, who liaised with Chinese Health Authorities in producing the initial draft of the Resolution, and by the Co-chairs of the Joint ILAE-IBE Global Outreach Task Force, Alla Guekht and Mary Secco, in coordinating the mobilization campaign that eventually led to the approval of the Resolution. Above all, however, the Resolution was primarily the outcome of impressive efforts made by ILAE Chapters and IBE Associations in sensitizing their governments about the unmet needs of people with epilepsy. It is largely thanks to

their mobilization that so many nations around the world now recognize epilepsy as a top health priority – this is testified, among other things, by the fact that delegates from as many as 28 countries, including the most populous five on the planet, stood up and made strong motions in support of the WHA Resolution. With the Resolution, our members now have a powerful tool to engage governments and health authorities into stepping up concrete actions to improve epilepsy services, promote awareness and education, and support epilepsy research.

The League would not exist without the support and dedication of thousands of epilepsy professionals worldwide. The many volunteers who contribute to our commissions and task forces have been working tirelessly and produced 16 published reports over the last two years. The Seizure Type Classification Task Force has also finalized a comprehensive report on the operational classification of seizure types.³ Because of its pivotal importance for our profession, this report will undergo the comprehensive approval process required for “official” ILAE position documents – this implies that the report will soon be placed on the League’s website, input will be solicited from the entire community, and an ad hoc task force will be appointed to ensure that the comments received are evaluated and incorporated into the final version as appropriate. A sister ILAE position paper, the report by the Commission for Classification and Terminology, which refines the 2010 proposal on the classification of the epilepsies⁴, already



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

PRESIDENT'S REPORT (continued)

received extensive public feedback, and a roadmap involving further engagement of our community has been implemented, aiming at reaching consensus on the most critical issues and finalizing the document before the end of the current term.

Our leading research journal, *Epilepsia*, continues to thrive, and its latest impact factor (4.571) remains well above those of other epilepsy journals. Credit for this must be given to our constituency, who continue to submit their top quality research work to the journal, but also to the great efforts of our editors. Michael Sperling joined the team of the Editors-in-Chief early in 2015 and it is my privilege to welcome him to his new position and thank him for his superb contribution to the direction of the journal. Our contract with the *Epilepsia* publisher is due to expire in 2016 and the ILAE Executive Committee determined to initiate a request for proposals (RFP) process for the publishing of the journal beyond that date. Our Treasurer, Sam Wiebe, has been coordinating skillfully the RFP process and provides further information about this in his report.

In 2013, the League expanded its publication portfolio through the acquisition of *Epileptic Disorders* as its educational journal, and I wish to thank Alexis Arzimanoglou, the Editor-in Chief, for his great work in reshaping the content and structure of the journal according to its new mission. Recognizing that existing journals do not allow us to fully address the diverse needs of our constituency, we also decided to launch, before the end of 2016, a new research-based open-access journal. More information about this important development is provided in the Treasurer's report.

Publications are only one of many ways by which ILAE advances epilepsy knowledge and education. The 31st International Epilepsy Congress (IEC) that took place in Istanbul provided a rich educational and scientific program which was attended by over 2700 delegates. Preparations for the 3rd Eastern Mediterranean Epilepsy Congress (hosted jointly with the Emirati League against Epilepsy in Dubai, 4-5 March 2016, <http://cemaepilepsy2016.org/>), the 11th Asian and Oceanian Epilepsy Congress (Hong Kong, 13-16 May 2016, www.epilepsyhongkong2016.org), the 9th Latin American Congress on Epilepsy (Cancun, Mexico, 20-23 August 2016, www.epilepsycancun2016.org) and the 12th European Congress on Epileptology (Prague, 11-15 September 2016, www.epilepsyprague2016.org) are underway.

In addition, we continue to invest a major portion of our resources into epilepsy courses, training programs, and other initiatives especially aimed at supporting young colleagues committed to epilepsy care and research. These activities are being nicely coordinated

by our Education Commission, led by Jaime Carrizosa, and by a newly created Education Task Force led by Sam Wiebe, which has been specifically asked to identify ways to improve the reach of our educational efforts. In particular, I am very grateful to Sam for initiating a highly innovative endeavor, i.e. an agreement between the League and Wikipedia whereby our organization will gradually take responsibility for improving and supervising Wikipedia's epilepsy-related content. Given the staggering impact that Wikipedia has in providing information not only to the general community, but also to medical students and health professionals (including physicians and neurologists), we believe that this initiative will contribute to a major extent in serving our educational mission. In relation to educational activities, I would also like to mention a project implemented by our North American Commission, aimed at promoting and mentoring on a global scale the epilepsy leaders of tomorrow. Details on this initiative, which addresses a goal very dear to me, are provided in the report by Sheryl Haut, our North American Commission Chair.

In addition to spreading epilepsy knowledge, it is the League's duty to promote epilepsy research. The Joint ILAE/AES Translational Research Task Force is making important progress in producing recommendations to improve the quality and translational value of preclinical research. Two reports published in 2015, one by the ILAE Commission on Asian and Oceanian Affairs⁵ and one by the ILAE-IBE Epilepsy Advocacy Europe Task Force⁶, highlighted a number of research priorities from a regional perspective. A new task force, led by our Secretary-General Helen Cross and by Philippe Ryvlin, has recently embarked on a more ambitious task, i.e. preparing a consensus document on research priorities from a global perspective, including priorities that could benefit from the setting up of global networks of researchers. The ultimate aim is to sensitize governments and funding agencies about the need to promote large-scale international, high quality collaborative epilepsy research. The report by our Secretary-General provides more information on this project.

We recognize the value of partnering with other organizations and scientific societies in activities that bring added value to our mission. Thus, we continue to work in close association with IBE in promoting epilepsy awareness and in advocating for support of epilepsy research – this is done through our many joint commissions and task forces, our joint congresses, and our carefully coordinated activities in many projects, including the promotion and celebration of International Epilepsy Day.⁷ Our collaboration with WHO has been strengthened by the WHA Resolution, and we continue to work with them to facilitate implementation of the Resolution at regional

PRESIDENT'S REPORT (continued)

and country level, with a special focus on the need to improve access to treatment in low- and middle-low income countries. We have also developed a truly excellent relationship with the World Federation of Neurology (WFN), and I wish to thank personally the WFN President Raad Shakir and his team for their support in promoting the WHA Resolution, for dedicating the 2015 World Brain Day to epilepsy⁸, and for welcoming our collaboration in finalizing a very well attended epilepsy program at the World Congress of Neurology in Santiago, Chile. As in the past, ILAE and WFN also joined forces in providing funding for an epilepsy research grant, which was awarded to a multicenter project to be carried out in four South Asian countries (Bangladesh, India, Pakistan and Sri Lanka) under the sponsorship of the Indian Academy of Neurology. Collaborative initiatives are also ongoing with the European Academy of Neurology in relation to the organization of courses and congresses, and with the International Federation of Clinical Neurophysiology Societies (IFCN) in relation to the program of the 31st International Congress on Clinical Neurophysiology due to take place in Washington DC, USA, in May 2018.

I cannot close my report without remembering two great leaders of our community who left us in 2015. Jean Aicardi, a much loved physician and scientist who mentored so many leaders in child neurology and epileptology⁹, passed away on August 3. Hanneke de Boer, the advocacy champion who fought for decades for the rights of people with epilepsy in all parts of the world, left us on October 12.¹⁰ Although these giants are no longer with us in person, they are still vividly alive in our memory and will continue to inspire our community for generations to come.

Emilio Perucca
President

1 <http://www.ilae.org/visitors/News/documents/WHO-Epilepsy-2015.pdf>

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7 Perucca E. Why an International Epilepsy Day? *Epilepsia* 2015;56:170-1.

8 <http://www.wfnepidemiology.org/world-brain-day-2015-devoted-to-epilepsy>

9 <http://www.ilae.org/visitors/farewells/Aicardi.cfm>

10 <http://www.ilae.org/visitors/farewells/deBoer.cfm>

TREASURER'S REPORT



Samuel Wiebe

In opening remarks for the year, leaders of the largest world banks stated what we all know from experience – that the economic outlook was uncertain. Poor performance of financial markets, drop in prices of commodities and changes in fortune of emerging and leading economies all contributed to the uncertainty.

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

1. Financial Statement

The League is fiscally sound. We ended year 2014 with a strong balance sheet that preserved our endowment and allowed us to draw on our investments to maintain and strategically increase our activities. The table below shows the balance sheet for 2014 in terms of assets, liabilities and reserves of the League.

Balance Sheet – Dec 2014			
Assets		Liabilities & Reserves	
Operating Accounts	\$176,072	Accounts Payable	\$364,908
Congress Accounts	\$719,227	Deferred Revenue	\$94,044
Investments	\$15,198,196		
PrePaid Expenses	\$421,598	Total Liabilities	\$458,952
Accounts Receivable	\$363,048	Reserve Funds	\$16,419,189
Total Assets	\$16,878,141	Total Liabilities & Reserves:	\$16,878,141

However, over the past 5 years, reduced congress surpluses (See "Congresses" below) and a volatile stock market have impacted our end-of-year financial statements. The table below shows our proposed budget for 2015. Our two main sources of revenue are *Epilepsia* and our Congresses. Our two main expense categories are: a) Operating expenses (the costs of running the organization and supporting central activities), and b) Commission expenses (support for activities of our Commissions and Task Forces). We estimated that our operational revenues would be higher than our operational expenses by about \$400,000. We allocated about \$1.1 million to our Commissions and Task Forces, and we estimated a surplus from Congresses of about \$190,000. Because this resulted in a significant deficit budget, we estimated having to draw about \$350,000 from our investments. This resulted in a final budget with a deficit of about \$230,000.

2015 Budget

Budget Categories	Revenue	%	Expenses	%	Net
Operating	\$1,661,940 ¹	41%	\$1,261,175 ²	30%	\$400,765
Commissions	\$77,000	2%	\$1,195,218	28%	\$-1,118,218
Congresses	\$1,924,761	48%	\$1,737,321	41%	\$187,440
Investments	\$350,000 ³	9%			\$350,000
Other			\$50,000	1%	\$-50,000
TOTAL	\$4,013,701		\$4,243,714		\$(230,013)⁴

Our Aim:

To accomplish our mission with balanced budgets going forward.

¹ Revenue largely from our Journals.

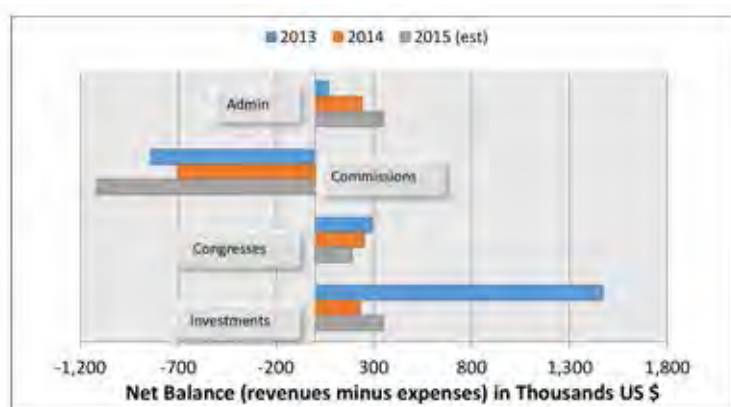
² Costs of running the organization and supporting central activities.

³ Amount to be drawn from our investments to help with the deficit budget.

⁴ Net Budget balance, after injecting \$350,000 from our investments.

TREASURER'S REPORT *(continued)*

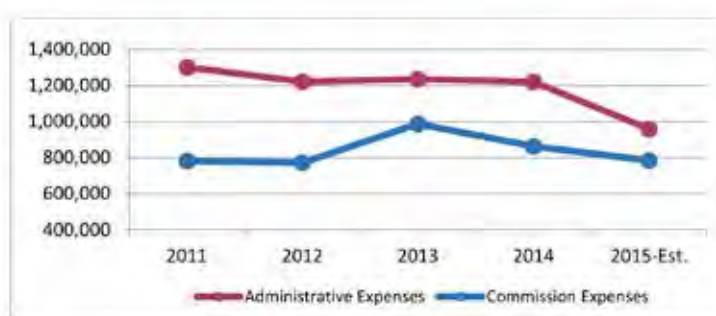
For comparison, the graph below shows the trends in Net Balance (revenues minus expenses) over the last three years, in the four main categories shown in the budget table (above).



Net Balance – the last 3 years:

- Increasing savings in Administration
- Stable or increasing funding for Commissions
- Decreasing congress revenues
- Decreasing return on investment

Given the steady decrease in revenues from various sources, the Finance Committee charged the Treasurer with reducing expenditures according to an approved spending policy. The figure below illustrates how we have accomplished this goal, by comparing trends in expenditures in Administration and in our support for Commissions and Task Forces, in US dollars.

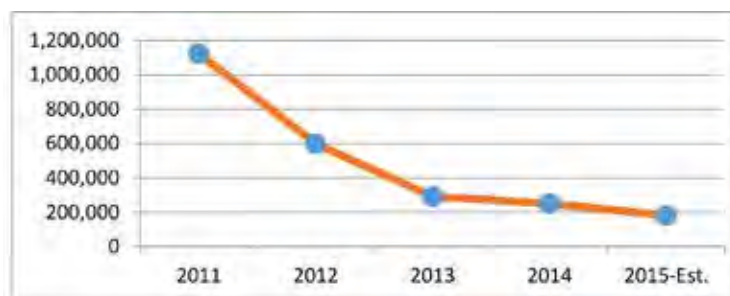


We Reduced Expenses:

To meet financial challenges, we adopted a responsible spending policy that takes into account revenues and inflation. Since 2011 we have reduced the ILAE administrative expenses by about 25% while maintaining the same level of financial support for our commissions.

2. Congresses

The League lowered the registration fee for junior delegates by about half, resulting in a total reduction for Istanbul of about \$18,000. We also provided discounts to members of chapters in good standing and offered a lower rate for junior delegates, totaling over \$71,000 for Istanbul.



Declining industry support:

In spite of a steady decrease in support that led to a significant reduction in congress surpluses (83% lower in 2015 than 2011), we have increased our support for attendees and maintained high quality scientific programs.

TREASURER'S REPORT (continued)

3. Investments

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



Protection from volatile markets

A conservative, diversified portfolio has provided some protection against extremely volatile stock markets. Still, we experienced a net loss of approximately 4% in 2015.

We continue to rely on our expert Financial Advisors to guide us through market fluctuations.

4. Our Journals

For the past few years the League anticipated the trend toward open access publishing. This created opportunities for wider dissemination of our publications, but also a potential threat to our journal *Epilepsia*, a major source of revenue for the League. Thanks to the relevance and high quality of articles in *Epilepsia*, this threat has not materialized. In fact, the impact factor for *Epilepsia* has increased substantially. This has favorably positioned the League in negotiations led by the Treasurer for a new 5-year contract with the publisher. This new contract will also include provisions for the League to develop its own open access journal, *Epilepsia Open*, an initiative that is well under way. In addition, the League continues to publish *Epileptic Disorders* as its main educational journal. Finally I led the development of a major publication initiative in collaboration with Wikipedia, the most highly used tool for medical questions worldwide. This will allow us to publish and widely disseminate high quality entries related to all aspects of epilepsy in Wikipedia, including full-fledged articles that can be jointly published in our open access journals and in Wikipedia. This promises to have far-reaching benefits for our community.

5. Education

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

6. The Future

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

Samuel Wiebe
Treasurer

SECRETARY-GENERAL'S REPORT



Helen Cross

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

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

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

We also took the opportunity to update the sections of the Bylaws relevant to publishing, as *Epileptic Disorders* is now the education journal of the league. The revised agreed upon Bylaws can now be found in full in the relevant section of the ILAE website. (http://www.ilae.org/Visitors/About_ILAE/documents/Bylaws.pdf)

We have also written and agreed on Guidelines for the Management of International and Regional Epilepsy Congresses. These are guidelines for specific areas within the overall framework of the organization and management of the International Epilepsy Congresses and regional congresses: European Congress on Epileptology (ECE), Asian & Oceanian Epilepsy Congress (AOEC), Latin American Congress on Epilepsy (LACE), African Epilepsy Congress (AEC), East Mediterranean Epilepsy Congress (EMEC), and European Conference on Epilepsy & Society (ECES). These can be found at http://www.ilae.org/Visitors/About_ILAE/documents/GuidelinesMgtEpilepsyCongresses-03_2015.pdf

As highlighted in the President's report, many reports have been formulated and published by task forces and commissions on behalf of the league over the past twelve months. Having formulated new guidelines for paper approval as either ILAE position papers, or as papers written by constituents of the League as commission or task force members (<http://www.ilae.org/visitors/Documents/Guideline-PublPolicy-2013Aug.pdf>), a total of 16 papers have been approved over

this term, 11 over the past twelve months. Particularly important topics addressed in the latest reports include the definition and classification of status epilepticus¹; indications and expectations for neuropsychological assessment in routine epilepsy care²; recommendations on minimum requirements for ketogenic diet services in resource-limited regions³; recommendations for the management of infantile seizures⁴; guidance on the use of valproate within the context of the recent European Medicines Agency restrictions⁵; recommendations on the participation of people with epilepsy in sport activities⁶; an overview of the work being done for ICD coding for epilepsy⁷; a systematic review of existing epilepsy guidelines⁸ and recommendations for the preparation of ILAE guidelines in the future⁹.

Two of the papers published have been position papers from the European Joint Advocacy Task force¹⁰ and the Asian Oceanic Commission on research priorities in their respective regions¹¹. NIH have also published benchmarks for epilepsy research (<http://www.ninds.nih.gov/research/epilepsyweb/2014benchmarks.htm>). Recognizing that priorities may differ dependent on resources and region of the world, and different regions may share research priorities, we have sought your key priorities for research, specifically with relevance to the more global community. The priorities provided have been reviewed and assimilated by the Global Research Priorities and Advocacy Task Force. The next step is that they will be posted on the ILAE website in the new year for opinion with regard to ranking, with subsequent incorporation into a report.

The ILAE is often approached about funding opportunities, both from outside funders who wish to share on projects and from individuals with ideas that would require funding. However this is often on an ad hoc basis, neither of which may coincide. There has also been concern at times about possible conflicts of interest. Recognizing the need to capitalize on any opportunity, the management committee felt it would be a good way forward to draw up a list of projects that are in concordance with our overall strategy. We therefore sought ideas from the community with regard to possible projects that would be suitable for such an endeavor. Ideas have now been collected, and a small group, led by myself, assigned to review the next stage of the process. Funding of course is not guaranteed, but without such ideas we cannot be open when other organizations or individuals approach us.

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

Helen Cross
Secretary-General

SECRETARY-GENERAL'S REPORT *(continued)*

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11. Kwan P, Cabral-Lim L, D'Souza W, Jain S, Lee BI, Liao W, Lim SH, Otsuki T, Tan CT, Watanabe M, CAO Research Task Force. Research priorities in epilepsy for the Asia-Oceanian region. *Epilepsia* 2015;56:667-73.

VICE-PRESIDENT'S REPORT



Tatsuya Tanaka

The International League Against Epilepsy has achieved worldwide success over the first century of its existence. This success is reflected by the steady growth of League activities in all of our regions (Europe, North America, Latin America, Eastern Mediterranean Africa and Asia/Oceania) and the expanded collaboration among the regions with joint multinational educational and research activities. It has been almost two years since the beginning of the current Management Committee at the Montreal International Epilepsy Congress in 2013.

One of the important constitutional changes which was ratified at Rome IEC in 2011 is the direct election of the chairs of the regional commission by the member chapters of each region. This change ended the practice of the Executive Committee appointing the chairs and has assured that the voice of each region is more reflective of the wishes of the chapters. The elected Regional Chair will also now be a member of the Executive Committee, which will improve communications not only between the leadership of the League and the regions but also across regions, for the benefit of the ILAE as an international organization. It's a very positive change that I have experienced first-hand because I served under both the old and new Constitution and Bylaws.

The elected Chairs of six regional commissions are Drs Amadou Gallo Diop (Africa), Byung-In Lee (Asia-Oceania), Hassan Hosny (Eastern Mediterranean), Meir Bialer (Europe), Marco Medina (Latin America), and Sheryl Haut (North America). According to the new constitution, regional chairs are now members of the ILAE Executive Committee. With members of new Executive Committee, it has been an extraordinary pleasure to work with Management Committee colleagues, Emilio Perucca (President), Nico Moshé (Past President), Helen Cross (Secretary-General) and Samuel Wiebe (Treasurer).

Of special note, the ILAE and our friend the IBE performed many collaborative activities during past 12 months.

1. I have been encouraged by the recent WHO Executive Board resolution on epilepsy. This event, which came through the sustained

efforts of Emilio Perucca and Thanos Covanis of the IBE, has energized all of us because we may soon be successful in bringing real benefit to people with epilepsy around the world.

2. International Epilepsy Day will be held on the second Monday in February from 2016 onward.

The ILAE and IBE will have many collaborative ceremonies. The day will be also celebrated by many people around the world.

3. World Brain Day, 22 July 2015.
Epilepsy...is more than seizures.

World Federation for Neurology (WFN) and its partners, ILAE, IBE together with WHO announced that the focus for 2015's World Brain Day was epilepsy.

4. Epilepsy Awareness Day in Disneyland, November 5, 2015.

This amazing day at Disneyland in Los Angeles was founded to unite the epilepsy community, bring epilepsy out of the shadows, and stamp out epilepsy stigma. This special day was successfully done with many participants with our community for a day of fun with new friends and colleagues by collaboration with the ILAE and IBE.

Collaboration with the work of Commissions:

As a member of the EC Liaison Office of the Neuropsychiatry Commission (Kousuke Kanemoto, Chair) and Epilepsy Neurosurgery Commission (Bertil Rydenhag, Chair), I am happy to work with these very active commissions. Many collaborative works were performed during the past 12 months. As an EC Liaison Officer of the Commission of Asian Oceanian Affairs (CAOA), we have already started programming of the 11th Asian Oceanian Epilepsy Congress in Hong Kong 2016.

Tatsuya Tanaka
Vice-President



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

EPILEPSIA REPORT



Gary Mathern



Astrid Nehlig



Michael Sperling

Epilepsia had another successful year. Volume 55 (calendar year 2014) comprised 2,080 pages, which included twelve regular monthly issues and also the following supplements:

- S1: Perampanel – Bernhard Steinhoff, Guest Editor
- S2: 11th European Congress on Epileptology, Stockholm, Sweden, 29 June – 3 July 2014
- S3: Transition of Epilepsy Care from Children to Adults, Rima Nabhout and Peter Camfield, Guest Editors
- S4: Current Strategies for the Management of Lennox-Gastaut Syndrome, John M. Pellock and James W. Wheless, Guest Editors

During 2014, *Epilepsia* received over 1,100 submissions and accepted ~ 23% of peer-reviewed manuscripts. The accepted/published manuscripts can be categorized as follows: Full-Length Original Research reports = 189; Brief communications = 25; Reviews = 4; Special reports (ILAE Commission reports) = 7; Other (Supplement articles/Controversies in Epilepsy) = 19; Gray Matter material (not peer-reviewed, including Letters, Commentary, Workshop reports, My Epilepsy Story and various communications) = 82. The Editors balance the inclusion of papers likely to be cited with an equally important goal of serving the epilepsy research community by publishing a range of other reports. Financially, the Journal remains highly successful, bringing in net income to ILAE of over US\$1 million.

In bibliometric terms, in 2014 *Epilepsia* was ranked 25rd of 192 journals in the Clinical Neurology category, had an Impact Factor of 4.571 and an Eigenfactor of 0.04. The *Epilepsia* Impact Factor was higher than that of any of the other epilepsy sub-specialty journals.

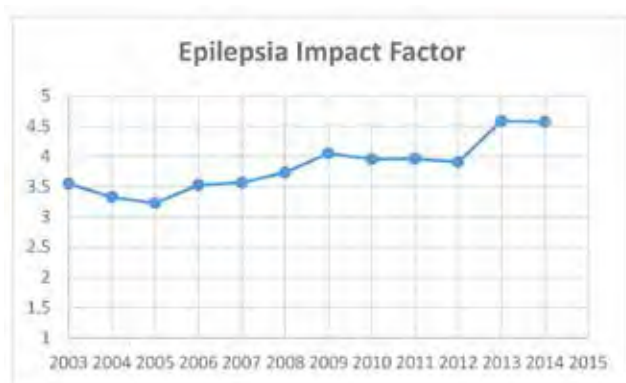
In terms of circulation and readership, below is the number of institutions having licensed access to the Journal.

Subscription Type	2014	%
Online	41	7%
Online Licensed	449	78%
Print	67	12%
Print & Online	15	3%
Total	572	

Epilepsia also participated in the HINARI program to provide the Journal free of charge or at a low cost. Our philanthropic initiatives extended low-cost or free access to 3,801 developing world institutions.

In 2014, there were over 1,300,000 full-text downloads from *Epilepsia*, reflecting a ~3.0 % increase over the previous year.

Michael Sperling, Astrid Nehlig and Gary W. Mathern
Editors-in-Chief, Epilepsia



EPILEPTIC DISORDERS



Alexis
Arzimanoglou

New developments in line with the educational mission of the ILAE

A) **Seminars in Epileptology** became a regular and well established section of the ILAE Educational Journal.

These are **OPEN ACCESS** 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**.

Already Published:

Epileptic auras: phenomenology and neurophysiology

Ghazala Perven, Norman K So

Treatable newborn and infant seizures due to inborn errors of metabolism

Jaume Campistol, Barbara Plecko

The natural history and prognosis of epilepsy

Ettore Beghi, Giorgia Giussani, Josemir W. Sander

Febrile seizures and genetic epilepsy with febrile seizures plus (GEFS+)

Peter Camfield, Carol Camfield

Incidence, prevalence and aetiology of seizures and epilepsy in children

Peter Camfield, Carol Camfield

Concept of epilepsy surgery and presurgical evaluation

Chaturbhuj Rathore, Kurupath Radhakrishnan

Management of epilepsy in resource-limited settings

Roberto Caraballo, Natalio Fejerman

The clinical pharmacology of traditional antiepileptic drugs

Frank J.E. Vajda, Mervyn J. Eadie

Interactions between antiepileptic drugs, and between antiepileptic drugs and other drugs

Gaetano Zaccara, Emilio Perucca

Intraoperative ElectroCorticoGraphy (ECog): indications, techniques, and utility in epilepsy surgery

Tong Yang, Shahin Hakimian, Theodore H. Schwartz

History of epilepsy: nosological concepts and classification

Peter Wolf

B) **Electroclinical Reasoning Reports** – a new challenging initiative coordinated by Associate Editors Mike Duchowny and Philippe Kahane

Electroclinical Reasoning Reports are aimed at providing the reader with a comprehensive approach for diagnostic or presurgical evaluation and epilepsy surgery strategies. The format of the reports includes an introduction and hypotheses regarding an epilepsy syndrome or epileptogenic zone(s), justification of the investigations chosen to support the hypotheses, conclusions based on the investigations, and final therapeutic action or diagnosis made.

EPILEPTIC DISORDERS (continued)

Ideally the title and abstract should NOT contain information pertaining to diagnosis or therapeutic strategy.

The template is available online:

SECTION 1
TITLE
ABSTRACT

SECTION 2. PATIENT DETAILS
Patient history <i>(other than epilepsy; state as negative if non-contributory)</i>
Family history
Clinical description of paroxysmal events
Surface Video-EEG findings <i>(interictal, ictal)</i>
AED treatment history
Other relevant information

SECTION 3. HYPOTHESIS 1
Localization(s) of the epileptogenic zone <i>(provide justifications and discuss in order of priority; discuss possible limits or pitfalls; support with references when necessary)</i>

SECTION 4. NON-INVASIVE INVESTIGATIONS
<i>Provide details for all investigations and the rationale for your choices. Provide also explanation(s) for all investigations considered "unnecessary"; if considered "of interest but not available in your centre" describe any alternatives used to obtain the requested information</i>
Ictal EEG
MRI <i>(if repeated provide details and explain why)</i>
PET
SPECT <i>(interictal, ictal)</i>
MEG
Neuropsychology
Other <i>(including genetic or metabolic screening)</i>

SECTION 5. INVASIVE INVESTIGATIONS
<i>If considered unnecessary, explain why</i>
Invasive technique <i>(describe technique chosen [grids, Stereo-EEG, other] and provide details on implantation performed and hypotheses investigated; figures with implantation details may be provided as supplementary data)</i>
Findings of depth/subdural electrode recordings <i>(EEG plates and video material may be provided as supplementary data)</i>

SECTION 6. HYPOTHESIS 2
<i>On the basis of all available data, provide, in order of probability, your hypothesis regarding the localization of the epileptogenic zone and whether the acquired information confirmed your initial hypotheses. Support with references.</i>

EPILEPTIC DISORDERS *(continued)*

SECTION 7. ACTION TAKEN

Surgical strategy

Drug treatment

Other

SECTION 8. FOLLOW-UP (both for surgical and non-surgical cases)

Results at 3 months from decision

Results at 12 months from decision (*minimum requirement*)

AED policy

Neuropsychology

SECTION 9: CONCLUSION

SECTION 10. REFERENCES

Provide no more than 15 references

SECTION 11. QUESTIONS AND ANSWERS

Provide at least three questions and answers

Published in 2015

Lesion-negative anterior cingulate epilepsy

Nuria Lacuey, Javier Chapa Davila, Bilal Zonjy, Shahram Amina, Marta Couce, John Turnbull, Jonathan Miller, Hans Lüders, Samden D. Lhatoo

Successful epilepsy surgery in frontal lobe epilepsy with startle seizures: a SEEG study

Ana Ciurea, Irina Popa, Mihai Dragos Maliia, Nagy Csilla-Johanna, Andrei Barborica, Cristian Donos, Jean Ciurea, Ioan Opris, Ioana Mindruta

C) The Multimedia Teaching Material section of the website is now open for submissions

To better serve its mission of educational journal of the International League Against Epilepsy, Epileptic Disorders created on its website (www.epilepticdisorders.com) a multimedia teaching section.

In this section epileptologists are invited to progressively build-up multimedia libraries of:

- short educational videos on specific aspects of semiology of epileptic seizures and electro-clinical features of epilepsy syndromes (Section Editors Pierre Thomas and Philippe Kahane);
- structural and/or functional neuroimaging (Section Editor Alexander Hammers) and neuropathology (Section Editor Ingmar Blümcke) images related to epilepsy;
- EEG and MEG figures (Section Editor Doug Nordli);
- videos or images of neurosurgical techniques.

The structure of the multimedia submissions should be conceived for educational purposes. Alongside the multimedia material, authors are requested to submit a title and a short abstract (not more than 100 words) summarizing the main message, as well as the subtitles of the video sequences or images included and the corresponding key words.

EPILEPTIC DISORDERS *(continued)*

Submissions are made via the submission platform: mc.manuscriptcentral.com/epilepticdisorders, under the manuscript type **Multimedia Teaching Material**, and are peer reviewed.

All Multimedia Teaching Materials will be constantly and freely accessible on our website.
The titles of newly submitted Multimedia Materials will appear on a specific page of the printed edition of the journal.

Published in 2015:

Cortical tuber: neuropathological findings in a 2-year-old patient with epilepsy and TSC2 mutation

Ingmar Blümcke

Department of Neuropathology, University Hospital Erlangen, Germany

Atlas of Electroencephalography

Ali A. Asadi-Pooya, Dennis J. Dlugos, Christopher T. Skidmore, Michael R. Sperling

Thomas Jefferson University, Philadelphia, PA, USA

Tapping-evoked spikes in a patient with Angelman syndrome

Gaetano Cantalupo, Elena Pavlidis, Benedetta Piccolo, Rosalia Geraci, Silvia Mazzotta, Francesco Pisani

Universities of Verona and Parma, Italy

Alexis Arzimanoglou

Editor-in-Chief, Epilepsia

ILAE members have OPEN ACCESS to all of the above:

www.epilepticdisorders.com

DIRECTOR OF INTERACTIVE MEDIA



Jean Gotman

The ILAE website 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 website. We primarily target two types of visitors: those who know about ILAE and who come to the 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 and ill-defined group. We feel however that the ILAE should in particular make available to this broad readership the *information that it generates*, such as guidelines or the definition of epilepsy. Educating the community is also part of the ILAE mission.

Highlights

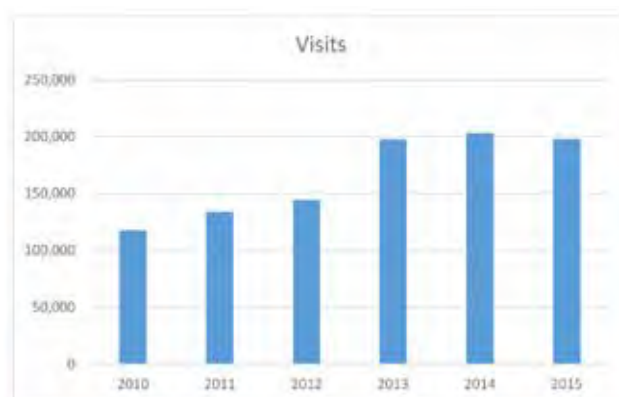
In May we reorganized the site, placing content for ILAE in the left hand navigation and that for outside/general audiences across the top, while reducing header size to allow more space for content. We also took this opportunity to review and reorganize the guidelines and classification information.

In 2014, we began implementing an important new aspect of the website: 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. This has expanded this year, and we now have information available in 10 languages.

We have continued with the “Chapter Spotlight,” in which we highlight on the home page a new chapter each month, using information obtained from national chapters. We have highlighted 19 chapters so far, from all regions of the world. In 2015 we highlighted Georgia, Portugal, Bangladesh, Canada, Cyprus, Turkey, Denmark, Pakistan, Sweden, the USA, and the Philippines. The featured chapter is announced in the monthly e-Newsletter.

Statistics

Website



While growth in number of visits has plateaued over the past three years, total visits to the website remain strong. Classification and Terminology Reports, Guidelines, and the Definition of Epilepsy remain our most-utilized content, and EpilepsyDiagnosis.org has seen excellent usage.

Social Media

In addition, we continued to ramp up our social media efforts, posting newsworthy items to our Facebook (www.facebook.com/ILAE.Epilepsy) and Twitter (@IlaeWeb) pages.

	2015	2014	2013	2012
Facebook Likes	2,959	1,179	503	126
Twitter Followers	981	374	378	134

REGULAR ACTIVITIES

Home Page Center section

In addition to making almost daily changes to the news on the home page (featured articles from *Epilepsia* and *Epileptic Disorders*, links to noteworthy articles and ILAE accomplishments), we seek to engage our readers and inform them of ILAE activities by regularly changing the main news section of the home page:

DIRECTOR OF INTERACTIVE MEDIA *(continued)*

Date	Description
6 January	Change to Congresses (IEC Istanbul, EMEC Amman, and ECE Prague) from 8th LACE report
19 January	Changed the layout of the congresses, and added abstract submission and early registration information to the IEC
21 January	International Epilepsy Day; refreshed further on 2/9
12 February	WHO and Epilepsy
9 March	Istanbul and Prague congresses
7 May	Highlights of coming Istanbul congress
27 May	Refresh with 2 new highlights
28 May	WHO Resolution on Epilepsy
22 June	Revert to second Istanbul highlights
14 July	3rd set of Istanbul highlights
18 August	Winners of awards to be presented in Istanbul
17 September	Epileptic Disorders educational initiatives
4 October	Farewell tribute to Hanneke de Boer
9 November	Highlights of 31st IEC Istanbul
3 December	Commission on European Affairs Educational Activities

We continue to manage the websites of the regional and topical commissions, pro-actively encouraging them to provide up-to-date information on their activities.

General support of ILAE activities

In addition to changing content on the website, the team supported the ILAE mission through activities such as creating post congress surveys for different commission and task force supported congresses, supporting the sharing of our information through Creative Commons licensing of our content, maintaining rosters of all commissions and task forces, and assisting the Congress Secretariat with publicizing deadlines and other critical congress information via eblasts.

We sent monthly e-Newsletters to the ILAE mailing list. We also have monthly conference calls with the Dublin Congress office to coordinate mailings of important items across the different mailing lists (ILAE, Congress, *Epilepsia*, and *Epileptic Disorders*).

OPERATIONS

Our Web Manager Deb Flower has continued to take care of the many updates and changes we make to the website. 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 website. In addition, Karan Murray and Sean Coyne provided support for the structural changes to the website. The daily supervision of activity is provided by Priscilla Shisler. The web team meets for a weekly conference call.

Plan for 2016

We plan to continue our various activities to provide useful information about ILAE and reach a broad community through the website, social media and e-Newsletters. Particular effort will be placed on increasing the multilingual content of the site.

We have become aware of the increasing use of smart phones and tablets to access the web in general and our website in particular. The statistics below speak for themselves. Our website is not designed to change its appearance depending on the device, as are more advanced websites. It is quite awkward to access the different pages or reports on our website with a phone. Sites that are so-called "responsive" adapt their display to the type of device, using in particular less information per page and larger characters if a phone is used. In addition, Google downgrades, in terms of search priority, sites that are not responsive. We have therefore decided to transform the ILAE site to a responsive design to better serve the growing number of users accessing via mobile devices. This represents a major project since the whole site needs to be reorganized and we need to decide how to present information on a computer, a tablet, and a phone.

Device Category	2015	% change	2014	2013	2012
Desktop	74.29%	-8.90%	79.35%	86.01%	91.735
Mobile	17.10%	36.70%	12.17%	7.55%	4.61%
Tablet	8.61%	-1.17%	8.48%	6.44%	3.66%

Submitted by
Jean Gotman, Priscilla Shisler, Deb Flower

ILAE-IBE INTERNATIONAL DIRECTOR OF MEETINGS REPORT ON CONGRESSES



Richard Holmes

From July 2014 to June 2015, the Congress Team managed the 10th Asian & Oceanian Epilepsy Congress and the 8th Latin American Congress on Epilepsy.

These congresses had a total of 2,059 attendees, 192 speakers and chairs, 586 abstracts/ posters received and 81 bursaries 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.

Conference program:

- The program comprised 47 sessions, with 105 speakers and chairs.
- The program covered a 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 of the program.
- 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 programme 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, two platform sessions, two sponsored sessions (including one 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, 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 on 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.

INTERNATIONAL DIRECTOR OF MEETINGS *(continued)*

- 186 abstracts were received and 36 bursaries were awarded.

Future Congresses

The 31st International Epilepsy Congress took place in September 2015 and will be included in the Annual Report for July 2015-June 2016.

The Congress Team is currently working on arrangements for the upcoming congresses in 2016:

- 3rd East Mediterranean & 5th UAE Joint Epilepsy Congress, Dubai
- 11th Asian & Oceanian Epilepsy Congress, Hong Kong
- 9th Latin American Congress on Epilepsy, Cancun
- 12th European Congress on Epileptology, Prague
- 14th European Conference on Epilepsy & Society, Prague

and in 2017 (3rd African Epilepsy Congress, Dakar; 32nd International Epilepsy Congresses, Barcelona), as well as the regional congresses in 2018 and IEC in 2019.

Richard Holmes

International Director of Meetings

HEADQUARTERS AND CHAPTER SERVICES STAFF



As Administrative Director, Priscilla Shisler works with the Management and Executive Committees, Commissions and Task Forces in the implementation of the League's strategic goals and initiatives, and provides support in the planning, organizing, and execution of programs and activities. She also provides oversight for the VIREPA distance learning program and collaborates regularly with the website team.



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 coordinates the monthly e-Newsletter, Epigraph and the Annual Report.



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 the ILAE's financial transactions and the production of the monthly financial statements and liaises with the League's accountant on the preparation of the annual tax return and Audit report.



As Lead Coordinator for the VIREPA program, Verena Hézser-v.Wehrs works closely with the Education Commission, course directors and tutors to administer, moderate and evaluate the successful VIREPA program.



Gus Egan, based in the Chapter Services Office in Dublin, Ireland, 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, promotes the League through the use of the booth and collaborates with the Elections Committee on the elections process for the Executive and Regional Commissions.



Task Force Reports 2013 – 2017

EPILEPSY GUIDELINES TASK FORCE



Nathalie Jetté

Chair

Nathalie Jetté (Canada)

Members

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

MC Liaison

Samuel Wiebe (Canada)

ILAE Guidelines Process Working Group

Nathalie Jetté (Canada), Chair
Alejandro de Marinis (Colombia)
Colin Dunkley (UK)
Jacqueline French (USA)
Emilio Perucca (Italy)
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

Commission Activities from June 2014 through June 2015 Original Task Force

This original task force completed the systematic review (seven databases and six grey literature sources) to identify epilepsy/seizure related clinical guidelines in all languages. Screened 10,926 abstracts in duplicate with 410 full text articles (13 languages) also screened in duplicate for eligibility. Sixty-three guidelines were identified for inclusion in the systematic review. The systematic review is in press in *Epilepsia* with an anticipated publication date (open-access) in 2016. The group met at the International Epilepsy Congress in Istanbul in September 2015 to plan the next steps for the task force.

Process Working 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 guidelines development toolkit. Tools to evaluate the quality of the evidence were also reviewed and the group agreed to adopt the GRADE. A number of educational resources were developed to guide ILAE chapter members on the process involved in developing high quality guidelines. The resulting document and associated toolkit are published in *Epilepsia* (ePub ahead of print).

Accomplishments (2013-2014)

As noted above, the task force and the sub-commission published two documents in *Epilepsia*.

Recommendations for Future Work

The original tasks of these groups were completed. Future tasks for the Epilepsy Guidelines Task Force are to: identify the gaps in guidelines and highlight key areas for future guideline development; systematically review on an annual basis published epilepsy guidelines and evaluate the quality of these guidelines; review protocols for future guideline development; and develop a certification and training module for using the toolkit that will facilitate the future development of high quality epilepsy guidelines.

Report by:

Nathalie Jetté and Khara Sauro

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)

Michael Sperling (USA)

MC Liaison

Emilio Perucca (Italy)

Aims

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

Commission Activities

June 2014 through June 2015

The task force has had one face-to-face meeting on June 12, 2015 in New York with follow-up through e-mail correspondence.

Accomplishments (2014-2015)

The Task Force has continued the work to fine tune the definition of material suitable for *Epileptic Disorders* or *Epilepsia*. There was consensus that commission reports containing materials such as position papers, guidelines, and topics specific to research will go to *Epilepsia* while case studies, videos, and other types of material with didactic tools will go to *Epileptic Disorders*. For material published in *Epilepsia* with relevant educational implications, authors should be encouraged to provide a summarized version focusing on the educational messages. Editors of the two journals should coordinate closely to this end. With respect to material developed by ILAE commissions and task forces, the Publications Task Force has proposed the following principles and procedures for publication and allocation to *Epilepsia* or *Epileptic Disorders* that have been adopted by the ILAE:

Depending on the content and the target, reports aimed for publication should be written for either of the ILAE's two journals, *Epilepsia* or *Epileptic Disorders*. There is also a possibility to consider

publishing different versions and aspects of the reports in *Epilepsia* and *Epileptic Disorders*, respectively.

- Deliverables in terms of reports should be considered already at the planning stage of the work process of a commission or task force and discussed and agreed with the ILAE EC. This consultation can include a discussion on the target journal for the report. For some reports it is appropriate with two separate versions, one main report for *Epilepsia* and a second for *Epileptic Disorders* with didactic tools and practical applications.
- The approval of a report and the decision concerning which of the ILAE journals the report should be submitted is ultimately with the EC after review of the submitted report. However, it is recommended that commissions/task forces consult their ILAE EC liaison before writing up their report so that the text can be adjusted to the most suitable target.
- Commissions/task forces planning to develop publications in direct collaboration with a specific journal should always consult with the EC beforehand.
- Commissions/task forces should always include executive summaries of their report. Lay summaries should be written for a general readership aiming at publication on the ILAE website and, as appropriate, the IBE website.
- Commissions/task forces should consult the Instructions for Authors of the respective journals and adjust the format of the report to the requirements of the target journal. It is recommended that a proposed outline of the report is submitted to the Editors for comments and approval before writing up the report. For *Epilepsia*, most commission/task force manuscripts are published as "Special reports" whereas for *Epileptic Disorders* the label depends on the type of report. Irrespective of the journal, the length of the manuscript should not exceed 4000 words.

It is for the Executive Committee of the ILAE to decide

- Reports or work that is of primary educational character, and in particular those that target professionals who are epilepsy specialists or are in training, will be considered for *Epileptic Disorders*.

PUBLICATIONS TASK FORCE *(continued)*

- Position papers and guidelines will in general be directed to *Epilepsia*.
- Reports that contain original scientific data or that are relevant to research or research methodology will also be directed to *Epilepsia*.
- Guidelines as well as other reports that are aimed for *Epilepsia* can also be complemented with educational material aimed for *Epileptic Disorders*. It is for the Editors in Chief of the respective journals to decide whether a submitted report should be published following the regular peer review process.

Special features: Supplements are considered based on topic. Prospective authors should contact the editorial office at epilepsia@epilepsia.com.

Recommendations for Future Work

The Publications Task Force should be a forum for strategic development of the expanding publication portfolio of the ILAE and for communication between the editors of the different journals and between the editors and the ILAE leadership.

STIGMA TASK FORCE



Nathalie Jetté

Chair

Nathalie Jetté (Canada)

Members

Gretchen Birbeck (USA)
Manjari Tripathi (India)
Helen Cross (UK)
Ann Jacoby (UK)
Hanneke de Boer (Netherlands), deceased
Janet Mifsud (Switzerland)
Tarun Dua (Switzerland)
Patricia Braga (Uruguay)
Paula Fernandes (Brazil)
Kirsten Fiest (Canada)
Diane Lorenzetti (Canada)
Samuel Wiebe (Canada)
Amza Ali (Jamaica)
Joan Austin (USA)
Solomon 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 from July 2014 through June 2015

Stigma Task Force met at the American Epilepsy Society Meeting in Seattle, Washington - December 2014.

Accomplishments (2014-2015)

- Manuscript drafts of tools to measure stigma paper and interventions to reduce stigma paper complete
- Long-form data abstraction completed for frequency/factors related to stigma (n=278)
- Began long-form data abstraction (short-form work carried over) for all frequency/factor articles

Recommendations for Future Work

- 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 difference 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 ASIAN AND OCEANIAN AFFAIRS



Byung-In Lee

Chair

Byung-In Lee (Korea)

Members & Officers

Sunao Kaneko (Japan), Information Officer
Andrew Bleasel (Australia), Secretary
Leonor Cabral-Lim (Philippines), Treasurer
Kheng Seang Lim (Malaysia)
Guoming Luan (China)
Man Mohan Mehndiratta (India)
John Dunn (Japan) chair of ASEPA
Derrick Chan (Singapore), co-chair of
Information Committee
Tatsuya Tanaka (Japan), EC Liaison

Task Forces

Constitution Task Force

John Dunne (Australia)

Global Campaign Task Force

Ernest Somerville (Australia)

Information Committee

Chen Chein (Taiwan)
Ding Ding (China)
Seok Ho Hong (Korea)
Man Mohan Mehndiratta (India)
Hirokazu Oguni (Japan)

Pediatric Task Force

Heung Dong Kim (South Korea) Chair

Research Task Force

Akio Ikeda (Japan)
Chong Tin (CT) Tan (Malaysia)

Constitution Task Force

John Dunne (Australia)

ASEPA

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

2011-2015:

Shih Hui Lim (Singapore), Chair
Dede Gunawan (Indonesia)
Yushi Inoue (Japan)
Weiping Liao (China)
Man Mohan Mehndiratta (India)
Byung In Lee (Korea), ex-officio

2015-2019:

John W Dunne (Australia), Chair
Kurnia Kusumastuti (Indonesia)
Weiping Liao (China)
Zarine Mogal (Pakistan)
Parthasarthy Satishchandra (India)
Derrick Chan Wei Shih (Singapore)
Chong Tin Tan (Malaysia)
Byung In Lee (Korea), ex-officio
Shih Hui Lim (Singapore), ex-officio

Aims

The main aim of the Commission on Asian and Oceanian Affairs is to develop, stimulate, and coordinate the epileptology agenda in the Asian and Oceanian regions

Mission

- To advance and disseminate knowledge concerning epilepsy throughout the Asian & Oceanian region;
- To improve education and training in the field of epilepsy 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;
- To facilitate clinically relevant epilepsy research in Asia;
- 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;
- To promote the activities of local chapters, encourage similar policies and administrative structures and facilitate their involvement within the global ILAE agenda;

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

- 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 the CAO A: 2013 -2017

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 a CAO A and ASEPA website and link to the ILAE and regional chapters' sites, and publish a 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 in the region.
 - (iii) continue to conduct EEG certification examinations 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 Epilepsy Award"

Action plans added at the Initiation Meeting on September 27th, 2014:

- (9) Enact written Bylaws of CAO A
- (10) Promote the diagnosis and treatment of neonatal and childhood epilepsies in the region
- (11) Implement CAO A demonstration projects for reduction of the treatment gap in the region
- (12) Promote career development programs for young talented epileptologists in the region
 - (i) Epilepsy fellowship programs
 - (ii) Exchange programs for young research fellows
 - (iii) Regional epilepsy school in collaborations with ILAE

Commission Activities

1) Communication and Business Meetings

- Communication among members of CAO A and ASEPA were mainly through e-mails as well as during teaching courses/workshops/congresses in the region.

- The CAO A-ASEPA joint meeting was held on September 6th, 2015, at the Convention Center in Istanbul, Turkey

The discussion points included (1) Progress reports of 11th AOEC in Hong Kong, (2) Reports of Treasurer (L Cabral-Lim), (3) Report of Research TF (CT Tan and A Ikeda), (4) Report of Information Committee (D Chan), (5) Report of Pediatric TF (HD Kim), (6) Special report on Cambodia and Laos (CT Tan)

The meeting was well summarized in the Minutes (by D Chan)

- Communications with ILAE have been made mainly through e-mail, teleconference, and at the executive meetings
 - ILAE and IBE joint Executive Meeting on March 27th-28th, 2015, in Dublin, Ireland
 - ILAE Executive Meeting on Sept. 5th, 2015, in Istanbul, Turkey
 - ILAE-IBE Joint Executive Meeting on Sept. 7th, 2015, in Istanbul, Turkey
 - Communications with ILAE through teleconferences of ILAE Executives
 - Jan. 16th, 2016
 - Feb. 14th, 2016
- New Chapter Formation
 - The Laos Chapter application was halted due to internal difficulties
 - Cambodia is in the process of preparing for a chapter application.

2) Information Committee (Co-Chairs: S. Kaneko and D. Chan)

At the Information Committee meeting in Singapore (at the 10th AOEC), it was decided to appoint Derrick Chan as co-chair of the Information Committee to help and share the work with Dr. S Kaneko, and also to expand the scope of action.

Project 1. Construct CAO A-Website

The CAO A Website (<http://www.caoa-epilepsy.org>) was launched in 2011 and has improved significantly since then. Currently,

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

- It is under management by JSE company
- Structures were remodeled following suggestions from the ILAE
- It is linked to the ILAE website
- Currently, the CAOAO website links to individual chapters of the region through the ILAE website. Direct links to chapter websites is possible to only seven chapters.
- Contents to be included are:
 - Hands-on summaries of epilepsy meetings in the region
 - Slides of didactic lectures and workshops
 - Information on meetings or epilepsy related events in the Asian Oceanian region
 - Epilepsy treatment guidelines of each chapter, if any
 - Reports and documents from CAOAO, ASEPA, task forces, or other organizations
 - News and advocacy from individual chapters

Project 2. Publications of CAOAO-Newsletter

The first CAOAO Newsletter was published in December 2012

- The original plan was to publish twice each year, but only one issue was published in 2013 and 2014, due to shortages of content
- Two issues were published in 2015, November and December
- Need further help from CAOAO membership and individual chapters
- Need to organize a network consisting of information officers from each chapter to gather appropriate, relevant information for the newsletter as well as the website

Action Plans of CAOAO-Information Committee: 2013-2017

- Organize a network consisting of information officers from each of the chapters of Asian Oceanian region (a mail was sent to each chapter asking for the names and the addresses of information officers), which will be discussed at the Information Meeting in Hong Kong during the 11th AOEC.
- Operation of CAOAO Website
 - Maintenance of website by JSE at least monthly
 - Increase the direct links between CAOAO website and that of each chapters
 - Expand website contents to align with the purpose of CAOAO action plans

- Publish the Newsletter two times, in November and December, 2015

3) Research Task Force (co-chairs; A Ikeda and CT Tan)

Scope of Action:

- improve research infrastructure
 - understand etiologies and epileptogenesis
 - reduce psychosocial comorbidities
 - achieve better treatment outcome
- Asian Oceanian Research Priorities (by Kwan et al.) was published in *Epilepsia* (2015, 56: 667-673), and will be a guideline for future research in our region
 - A special session for Epilepsy Research was held at the 11th AOEC.
 - Research Priority of Asian and Oceanian region by Patrick Kwan
 - Presentation of two Abstracts selected by the task force

Plan for 2013-2017:

- Promote research in the region by initiating multiple joint research projects dealing with clinically important questions related to epilepsy in the region that do not require funding, sound methodology that is publishable, and with experienced investigators to lead the projects.
- ESA Fellowship recipients in 2016
 1. Jianhong Wang, Resident, Department of Neurology, Huashan Hospital, Fudan University, Interested in the First Seizure clinic at the Austin Melbourne
 2. Mandadige Sanjaya Shanthiputhra, Acting Consultant in Paediatric Neurology, Teaching Hospital Anuradhapura, Sri Lanka
- Projects under progress include
 - AEDs adverse reaction and HLA by multichapter trials in Southeastern Asia
 - Yangon General Hospital (Myanmar) and University of Malaysia Medical Center (KL)
 - Chinese multicenter trial
 - Relationship between public attitude and by epilepsy patients in Laos
 - Employment of epilepsy patients in Vientiane, Laos, in collaboration with University of Malaysia Medical Center

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

- Plan to organize a “Epilepsy Summer School” in collaboration with GCAE-TF

4) Global Campaign Against Epilepsy Task Force (Chair: E Somerville)

- Encourage groups outside of official Global Campaign to speak at the 11th AOEC
 - “Action Against Untreated Epilepsy (AAUE)” led by Irish neurologist, Victor Patterson, who runs a clinic in Nepal.
 - ES has joined AAUE but they are not keen to join Global campaign.
- Myanmar project:
 - Formulation for the Project, which is based upon GP who provide care are still under progress.
 - Collaboration with University of Malaysia Medical Center (CT Tan) for research of AED adverse reactions and HLA-type
- Laos project:
 - This project is based upon that undertaken by the Francophone Tropical Medicine Institute, where the CAOAs’ role is to provide education, mainly to train neurologists and thus help to make the project sustainable over the long term.
 - ASEPA held a clinical Epilepsy Workshop in January at Vientiane, which was very fruitful for both education and network formation.
 - Submitted a chapter application to ILAE
- Cambodian project:
 - The project is also mainly by the French group. It has resulted in some scientific publications.
 - Cambodia is in preparation for chapter application.
- Plan to create an information network to share projects with those in the region
 - There are a great number of disconnected activities.
 - The strategy is to present an overview of the different activities
- Plan to organize an “Epilepsy Summer School” in collaboration with RTF and ASEPA
 - One to two week course for a small class of 10-20 young neurologists from Low income or Low Middle income countries
 - The school will be held in one of developing countries for low cost accommodation
 - Tutors are mainly from the region

5) Constitution Task Force (J Dunne)

At present, the election of ILAE President is in progress, and will be followed by the election of the Management Committee members and Commission Chairs. The elections are guided by the Election Rules finalized by the Harmonization Taskforce (Chair: H Cross) and approved by ILAE Executive Committee in the previous year.

6) Pediatric Task Force (by HD Kim)

Plans for 2013-2017:

- Network formation among pediatric representatives in chapters of CAOAs
- Pediatric experts’ meeting was held in Singapore after pediatric parallel session on 8th Aug, 2014.
- Communication with chapters to support treatment gap in resource poor countries
- Conduct ILAE pediatric commission activities in our region
- Increase the number/proportion/quality of international exchange fellowship training
- Handling treatment and educational gaps
 - Enhancing co-work with ASEPA
 - Need to increase the proportion in educational subject/bursaries
 - Develop new educational courses
 - Pediatric EEG teaching course and certificate
 - Joined together local chapters and local child neurology society, e.g. KPEP joined with ASEPA in 2010, China-Korea PEP in Beijing in 2011
- Facilitate interaction and communication with well-developed educational courses

(7) ASEPA Report (by John Dunne)

ASEPA, the educational arm of CAOAs, has been conducting an enormous number of educational and training activities consisting of the following four major activities; (1) workshops/teaching courses, (2) fellowships, (3) EEG certifications, and (4) publications of proceedings.

- Educational Programs
 - (a) Teaching Courses and Workshops in July 2015 – March 2016

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

	Workshops / Teaching Courses	City / Country	Organizers	Date	Persons-In-Charge	CAOA-ASEPA Speakers
1	EEG Teaching Course (ANZAN Format - 2 days)	Kuching, Sarawak	Malaysian Society of Epilepsy & ASEPA	7 th and 8 th August 2015	KS Lim and WC Law	E Somerville, J Dunne, S-J See, D Chan, C-T Tan, RA Ali, H-J Tan, K-S Lim, R Sim, W-C Law
2	Epilepsy Syndrome Workshop	Hohhot, Inner Mongolia, China	CAAE & ASEPA	14 th & 15 th August 2015	J Dunne & WP Liao	E Somerville, J Dunne, C-S Chi, CT Tan, WP Liao,
	International Epilepsy Congress	Istanbul, Turkey		5 th - 9 th Sept, 2015		
3	EEG Teaching Course (ANZAN Format – 2 days)	Guangzhou, China	CAAE & ASEPA	9 th -10 th Oct 2015	J Dunne & WP Liao	E Somerville, J Dunne, D Chan, C-T Tan, C Wong, Chen Li, JJ Tsai (to confirm)
4	Epilepsy Syndrome Workshop	Chittagong, Bangladesh	Bangladesh Epilepsy Foundation & ASEPA	20 th - 21 st Nov 2015 <i>(deferred)</i>	MA Mannan & SH Lim / J Dunne	<i>Deferred To first quarter of 2016</i>
5	Indian Epilepsy School EEG Certification examinations	Udaipur, India	IES & ASEPA	23 rd -25 th October 2015	SH Lim & MM Mehndiratta & M Tripathi	KS Lim, CT Tan, S-J See, MM Mehndiratta
6	Pre- Indian Epilepsy School EEG Workshop	Udaipur, India	IES & ASEPA	23 rd -25 th October 2015	M Tripathi & SH Lim	KS Lim, CT Tan, S-J See, MM Mehndiratta
7	Clinical Epilepsy Workshop	Vientiane, Laos	ASEPA	7 th -8 th Jan	CT Tan and Dr Somchit	SH Lim, CT Tan, J Dunne, D Chan
8	Seizure Localisation Workshop	Vietnam	Local Chapter & ASEPA	5 th -6 th Mar	Le Van Tuan & J Dunne	S Harvey, W Maxmir, J Dunne, BI Lee

(b) ASEPA Precongress Courses at the 11th AOEC

1. Diagnosis: Is it a seizure?
2. Diagnosis: Localization of seizures

(c) ASEPA Didactic Lectures at the 11th AOEC

1. Epilepsy and memory (Dr M. Mula, Italy)
2. Obesity, osteoporosis and epilepsy, Why and what to do? (Dr. T. O'Brien, Australia)
3. Can genetic tests guide us? (Dr W. Liao, China)
4. Contemporary management of women with epilepsy across the lifespan (Dr T. Tomson, Sweden)

5. Can I stop my drugs? (Management of well controlled patients) (Dr M. Cook, Australia)

d) ASEPA- EEG Certification Exam (since 2005)

1. ASEPA-ASNA EEG Certification Examination
 - In collaboration with the ASEAN Neurological Association (ASNA) since 2005; for candidates from Asian Oceanian region except China & India
2. ASEPA-ASNA-CAAE EEG Certification Examination
 - In collaboration with China Association Against Epilepsy (CAAE) since 2009; for candidates in China

COMMISSION ON ASIAN AND OCEANIAN AFFAIRS *(continued)*

3. ASEPA-ASNA-IES EEG Certification Examination
 - In collaboration with Indian Epilepsy Society (IES); from 2012, for candidates in India
4. EEG certification Exam consists of Part 1 and Part 2 Exam
 - Part I (2005 to 2014); Total applicants: 608; Pass: 376 pass rate: 61.8%
 - Part II (2006 to 2014); Total applicants: 338; Pass: 247 pass rate: 73.1%
 - Total Pass Rate: ~ 40.7 %
- e) ASEPA Fellowships (by CT Tan)
 - ASEPA fellowships: two persons/year (stipend for 6mo/ person, \$7,000/ person)
 - Awardees: Ma Le Quan from HCMC and Hnin Wint Wint Aung from Myanmar
 - Six travel grants were awarded to attend the clinical Epilepsy and EEG course in Sydney in February 2015, funded by the Epilepsy Society of Australia and ANZAN. The grants were coordinated and decided upon through ASEPA
 - From Japan, two or three fellowships from JES, two fellowships from JERS
 - ESA offers two observerships per year for three months each: applications assessed by the International Affairs Committee of ESA, with direction provided by ASEPA
- Role of multimodal imaging including MEG to maximize non-invasive presurgical evaluation: Dr M Tripathi (India)
- SEEG for localization of the epileptogenic zone : Dr S Liu (China)

(9) 11th AOEC (by K Hodgson)

- Scientific Organizing Committee (SOC):
 - Co-chairs: BI Lee, Ada Yung, D. Chapman
 - Members: D Ding, P Satishchandra, J. Dunne, SH Lim, T. Tanaka, V. Saxena, G. Luan
 - Abstract Review Team; D. Chan, H. Leung and CAO-A-ASEPA members
- SOC meeting at Istanbul on September 6th, 2015.
 - AGENDA: Scientific Programme:
 - Quizzes, etc.
 - Abstracts
 - Bursaries
 - Promotion including the Announcement, Website and Related Congresses
 - Logistics: Venue, Accommodations, Welcome Ceremony,
 - Sponsorship including City Support
 - Review of Timelines including Abstract Milestones
- Scientific Program was finalized
- 351 Abstracts were submitted and 348 were selected by ART with 42 for oral presentation (2 abstracts will be presented at the Research Task Force Session) and 306 for poster.

(8) CAO-A Collaboration with Other Related Organizations

- A. 15th AOCN in Kuala Lumpur on August 18-21, 2016.
 - CAO-A-AOCN Joint conference will be held
- B. 9th AESC (Asian Epilepsy Surgery Congress) in Udaipur, India, October 24-25
 - Combined CAO-A-AESC Symposium: Presurgical Evaluation: Chair: BI Lee and S. Jain
 - How to decide the candidates of epilepsy surgery: Dr EK Shon (Korea)
 - Modern concept for evaluation of epilepsy: Dr J. Stern (USA)

(10) 12th AOEC

- Bali (Indonesia) was determined as the venue for the 12th AOEC in 2018

COMMISSION ON EUROPEAN AFFAIRS



Meir Bialer

Chair

Meir Bialer (Israel)

CEA liaison for education and the CEA representative at the ILAE-RC & IBE-EREC Joint Task Force (JTF) for Epilepsy Advocacy (or Epilepsy Advocacy Europe-EAE)

Members & Officers

Eugen Trinko (Austria), Treasurer,

Regulatory Activities Liaison

Matthew Walker (UK), Secretary

Sándor Beniczky (Denmark), Communication Liaison

Dana Craiu (Romania), Global Outreach Liaison

Torbjörn Tomson (Sweden)

Anna Maria Vezzani (Italy), Neurobiology Liaison

Emilio Perucca (Italy), EC Liaison

CEA Activities for 2015

1. Update of the CEA educational agenda
2. Epilepsy Advocacy Europe (EAE) through a joint ILAE-IBE Task Force in partnership with European ILAE chapters and IBE associations. A new Joint ILAE/IBE European legal entity in Ireland was established to enable the EAE to apply for EU grants.
3. Formed a CEA-European Academy of Neurology (EAN) task force on EMA restrictions of the use of valproic acid in women and girls that published a position paper in *Epilepsia*.
4. Established a collaboration with the European Academy of Neurology (EAN). A joint CEA-EAN working group was formed to substantiate this collaboration in joint annual symposia/courses during and beyond the EAN and the ECE Congresses as well as on issuing joint guidelines.
5. A call for CEA-sponsored courses/symposia during 2016 was issued on 22/3/2015 (submission deadline: 22/6/2015). The submitted applications were rigorously discussed at the CEA meeting on 29/8/2015. Funding availability will be limited due to the low surplus from the Stockholm-ECE.

CEA Awards to be given at the Prague-ECE

- European Epileptology Award (EUR 5,000) (submission deadline 31/12/2015)

Non-monetary Awards

- European Education Award
- European Young Investigator Award (<45 years)
- European Service Award

CEA-Sponsored Courses/Symposia in 2015

CEA-Core Courses (CCC)

- Pediatric Epilepsy Surgery Course (Brno, 13-17/1)
- 6th Eilat Educational Course on Pharmacology (11-15/10)

CEA-Sponsored Activities (CSA)

- Course in European Central Asia, Astana, Kazakhstan (8-11/4)
- 5th London-Innsbruck SE, London (9-11/4/2015)
- 2nd International Course on Drug Resistant Epilepsies, Tagliacozzo, Italy (3-9/5)
- San-Servolo Course on Pediatrics (Venice, 19-31/7)
- 9th Baltic Sea Summer School, Sigulda, Latvia (9-14/8)

CEA Sponsored Courses/Symposia in 2016

- A. A call for CEA-sponsored courses/symposia during 2016 was issued on 22/3/2015 (submission deadline: 23/6/2015)
- B. The submitted applications were discussed at the next CEA meeting (23/8/2015). Funding availability will be limited due the low expected surplus from the Stockholm-ECE.
- C. The following courses will be supported by the CEA:

CEA Core Courses (CCC)

- 6th European Basic Epilepsy Surgery Course -EPODES (Brno, Czech Republic, 11-15/1)

CEA-Sponsored Activities (CSA)

- 7th Stereo-EEG Course (Venice, 12-16/2)
- 3rd International Course on Drug Resistant Epilepsies (Tagliacozzo, Italy, 8-14/5)
- 7th Caucasian Summer School (Baku, Azerbaijan, 22-28/5)
- 10th Baltic Sea Summer School

COMMISSION ON EUROPEAN AFFAIRS *(continued)*

- (Trakai, Lithuania, 5-10/6)
- 2nd East European Course on Epilepsy (Romania, 8-10/6)
- 2nd Dianalund Summer School on EEG (Denmark, 17-23/6)
- 4th Neuropathology Summer School (Erlangen, 31/7-4/8)
- 2nd Inflammation & Immunity Conference (Milan, 13-15/10)

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 & secretaries
- Establish ILAE chapters in the remaining European countries
- Searching for additional funds in light of the continued reduced surplus from the ECEs

COMMISSION ON LATIN AMERICAN AFFAIRS



Marco Medina

Chair

Marco Medina (Honduras)

Members & Officers

Roberto Caraballo (Argentina), Treasurer
Franz Chaves-Sell (Costa Rica), Secretary
Patricio Abad (Ecuador)
Eduardo Barragán (Mexico)
Manuel Campos (Chile), Past Chair
Laura Guilhoto (Brazil)
Lilia Maria Morales-Chacón (Cuba)
Samuel Wiebe (Canada), EC Liaison

Aims

1. To provide and promote epilepsy education and research with excellence, quality, efficiency 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

Task Forces and Activities

1. PAHO Strategy and Plan of Action on Epilepsy: Carlos Acevedo (IBE), Marco T. Medina (ILAE), and Devora Kestel (PAHO).
 2. 8th Latin-American Congress was held in Buenos Aires, September 17 - 20, 2014: Roberto Caraballo, Silvia Kochen, Lilia Nuñez, Sam Wiebe, Marco T. Medina and Patricio Abad.
Preparation of the 9th Latin American Congress to be held in Cancun Mexico, August 20th to 23rd, 2016: Gerardo Quiñonez, Tomas Mesa and Marco T. Medina.
 3. ALADE: Alejandro Scaramelli, Elza Marcia Yacubian and Patricio Abad
 4. LASSE: Esper Cavalheiro
 5. ILAE website: Franz Chaves-Sell
 6. Health Primary Care: Lilia Morales
 7. Epilepsy Surgery: Mario Alonso and Manuel Campos
 8. Ketogenic Diet Project: Roberto Caraballo, Laura Guilhoto, Eduardo Barragan, Alejandro Scaramelli and Patricio Abad
 9. ILAE North American Commission collaboration
- 1) **Pan-American Health Organization (PAHO) Strategy and Plan of Action on Epilepsy**
On September 20, 2014 at the 8th Latin-

American Congress in Buenos Aires a PAHO, IBE and ILAE meeting on the PAHO Strategy and Plan of Action on Epilepsy was held with the new chief of the PAHO Mental Health and Substance Use Unit, Devora Kestel. During this meeting a report of activities was made as well as long term planning. Dr. Jorge Rodriguez is retired from PAHO but he will keep working on this project as an advisor.

From June 2014 to June 2015 we have been working on the following activities:

- a) Strategy and plan of action on epilepsy in Bolivia 2015: A pilot project
Chairs: Mario Camargo, Franz Chaves Sell, Roberto Caraballo, Alejandro Scaramelli, Carlos Acevedo, Tomas Mesa and Marco T. Medina.

The epilepsy week in Bolivia was held from 13 to 17 June 2015 in Santa Cruz, Bolivia. The main goals of this pilot project were:

1. Educate epilepsy patients, their families and the general population in order to raise public awareness. 2. Reduce the stigma, discrimination and social exclusion surrounding patients with epilepsy. 3. Train employees of the primary healthcare institutions in order to improve their skills to diagnose and treat epilepsy patients. 4. Establish a neurologic and mental health network in the secondary and tertiary level of health care to appropriately manage patients with epilepsy. **Activities:** 1. Educational course directed to the relatives of epilepsy patients, primary school teachers and general population (Attendance: 400 participants).
2. An advertising campaign was held during the "epilepsy week in Bolivia" with press conferences, media tours and participation of local authorities. Information on "Epilepsy week in Bolivia" appeared in the most important newspapers, TV news and radio frequencies throughout the country. Authorities from SEDES (State Government Health Service) were actively part of this campaign. 3. Educational course provided to primary care physicians aiming to improve their skills diagnosing and treating patients with epilepsy. (Attendance:

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

100 primary care physicians). 4. Neurologists, child neurologists and EEG technicians were trained in order to achieve standardization of care and to encourage the establishment of Epilepsy Centers throughout the country. (Attendance: 50 neurologists and child neurologists; 25 EEG technicians). 5 Massive distribution of educational material throughout the city.

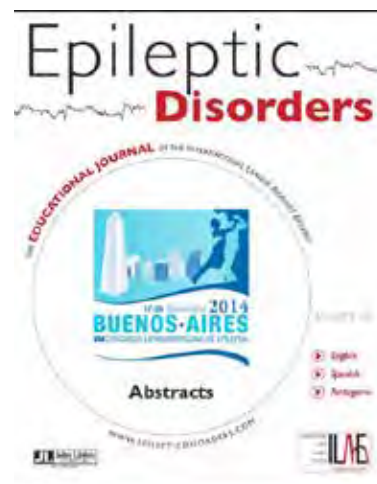
- b) A Report on Epilepsy in Latin America and the Caribbean was published in 2013. This report was prepared with the collaboration of ILAE and IBE. Information from 25 of 33 countries (70%) that responded to the survey on plans, services and resources.
- c) Several Latin American and Caribbean countries 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.
- d) A pilot program on Primary Health Care is going on in Bolivia.

2) 8th Latin American Congress on Epilepsy (LACE) Buenos Aires, September 17th to 20th, 2014

Chairs: Roberto Caraballo, Silvia Kochen, Lilia Nuñez, Samuel Wiebe, Marco T. Medina and Patricio Abad

The Congress was attended by 756 delegates from 40 countries. The program covered a broad range of topics selected from recommendations across the region and featured eminent speakers from the region and around the world. A total of 182 abstracts were submitted from centers across America. The subjects ranged from cutting-edge basic science to critical community and epidemiological work. These abstracts were published in English and Spanish in the supplement of *Epileptic Disorders*.

The opening ceremony was framed by talks of Buenos Aires culture and diversity. Welcome words were from Dr. Roberto Caraballo, director of the Congress, and Dr. Silvia Kochen, local president of IBE, followed by the chair of the Latin-American chapter of the ILAE Dr. Marco Tulio Medina, and the chair of the Latin-American IBE, Dr. Lilia Nuñez Orozco, and finally, the president of the ILAE, Emilio



Perucca, and IBE president Athanasios Covanis. A children's symphonic orchestra played at the closing ceremony.

Didactic lectures were held each day, underlining the educational mission component, and three excellent symposia on vagus nerve stimulation, advances in juvenile myoclonic epilepsy, and rational polytherapy took place.

A very interesting ALADE course on epilepsy pharmacotherapy, epileptic syndromes, type of seizures, and electroencephalography was also organized with full attendance the day before starting the congress. Other topics, such as discrimination, disability and epilepsy as well as national and Latin-American employment perspectives were also included.

Main sessions ranged from epilepsy in children, epileptic encephalopathy, non-convulsive status epilepticus, and genetics to epidemiological, psychiatric, and neuropsychological aspects as well as epilepsy translational research. The parallel sessions covered anticonvulsant cost, side effects, and generics, epilepsy surgery in children and adults in America, the ketogenic diet, PAHO strategy and plan of action in epilepsy, Castells and Mendilaharsu symposium and epilepsy in the tropics, among others.

Platform sessions were of good quality and many countries were represented. The posters filled the exhibition rooms to capacity and a wide range of topics were on display, showing quality research in each of the fields.

Topics ranged from anticonvulsants to stigma at work and school, and epilepsy and daily activities as well as epilepsy and women were

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

also considered. Fun was also to be had, with Tango dancing. There were many opportunities for discussion and networking.

The Chapter Convention was well attended by member chapters as well as candidate chapters. Many business meetings were held, notably that of the Commission of Latin American Affairs.

Preparation of the 9th Latin American Congress to be held in Cancun Mexico, August 20 to 23, 2016 is in process. Gerardo Quiñonez, Tomas Mesa and Marco T. Medina are the co-chairs.

3) ALADE (Latin America Academy of Epilepsy) Report

Alejandro Scaramelli (Chair), Elza Marcia Yacubian (Past Chair) and Patricio Abad (Secretary)

In April 2015 the ILAE Commission on Latin American Affairs (CLAA) elected the members of the Latin American Academy of Epilepsy (ALADE) for the 2015-2019 term. This election process was supported by the ILAE.

The CLAA elected Alejandro Scaramelli as the ALADE Chair and Patricio Abad as the ALADE Secretary. The full list of elected members are:

1. Patricio Abad (Ecuador)
2. Roberto Caraballo (Argentina)
3. Jaime Carrizosa (Colombia)
4. Guilca Contreras (Venezuela)
5. Li Li Min (Brazil)
6. Loreto Rios (Chile)
7. Alejandro Scaramelli (Uruguay)
8. Elza Marcia Yacubian (Brazil)
9. Alicia Bogacz (Uruguay/ ex-officio member from IBE)

During this period, the following activities were carried out:

1. ALADE Courses during the LA Epilepsy Congress, Buenos Aires, 17 to 19 September, 2014, Hotel Hilton, Buenos Aires, Argentina: EEG of the epilepsies; semiology of epileptic seizures and epilepsy pharmacotherapy.
2. In May 2015, the process for assigning the ALADE fellowships began. These fellowships

consist of a support of US 12,000 each for 3 neurologists or child neurologists, or neurosurgeons from Latin America selected from a list of applicants who wish to study in recognized epilepsy centers of the region for one year. This process began with the identification of such centers willing to receive fellows. Once confirmed, and in order to publicize the program widely, ALADE made the call for 2015 Fellowships through the ILAE web and via all LA chapters. In 2015 we had 13 candidates. The applications were evaluated according to a set of pre-established selection criteria. There was funding for a total of 3 fellows, but a fourth one wished to make use of the opportunity and was able to find funding elsewhere. This year's fellows were:

- a) Dr. Eva López (Venezuela) accepted at the F.I.R.E. Center, Cartagena, Colombia. She completed her general neurology training at Ciudad Hospitalaria "Dr. Enrique Tejeras," Valencia, Venezuela.
- b) Dr. Liza Núñez (Perú) accepted at the Clínica Las Condes, Santiago, Chile. She is an adult neurologist at the department of epilepsy, Instituto de Ciencias Neurológicas, Lima, Perú.
- c) Dr. Martha Ríos (Cuba) accepted at the Clínicas, Riberão Preto Hospital, Brazil. She is a child neurosurgeon who studied at "Juan Manuel Márquez" Hospital, La Havana, Cuba
- d) Dr. Vanessa Benjumea (Colombia), accepted at Ramos Mejía Hospital, Buenos Aires, Argentina. She completed her neurology residence at CES University, Medellín, Colombia.

4) Latin American Summer School on Epilepsy (LASSE)

Esper Cavalheiro (Chair)

The 9th. Latin American Summer School on Epilepsy (LASSE IX) was held in São Paulo, Brazil, between 22 February and 3 March 2015. From the 183 applications, we selected 60 professionals and/or graduate students from Latin America. The central theme, "Epilepsy: Comorbidities and Complications," was approached by the most important experts

COMMISSION ON LATIN AMERICAN AFFAIRS *(continued)*

in the field allowing an updating on the general aspects of the main comorbidities and complications, whether psychiatric, physical or social, that could impact the life of PWE in different periods of their lives. During the school, students were asked to prepare-in groups and under tutoring-research projects related to the central theme which were presented on the last day of LASSE. The dedication and enthusiasm in the preparation of these projects were amazing.

Research projects presented by the students:

1. Does cannabidiol restore memory loss and decrease the number of seizures in PWE?
2. Evaluation of the number of seizures and cognitive performance in patients with epilepsy undergoing a second hippocampectomy or deep brain stimulation.
3. Effect of adaptive neuroplasticity on memory in patients with absence seizures.
4. Epilepsy and sexual dysfunction.
5. Prevalence of the most frequent comorbidities in PWE living in South America.
6. Studies of pro-inflammatory cytokines in patients with juvenile myoclonic epilepsy with major depression.
7. Is omega-3 effective in the prevention of depression associated with epilepsy? Insights from an experimental model.
8. CPAP anti-inflammatory effect in epilepsy resistant to drug treatment.

The discussions that took place after the presentation of each project were very rich. All students would discuss, give suggestions, and point out alternative solutions. Discussions with teachers were very exciting and high level.

5) ILAE en Español and Portuguese websites Franz Chaves-Sell (Chair)

ILAE en Español: (http://www.ilae.org/Visitors/Centre/Trans_Spanish.cfm) and Portuguese: (http://www.ilae.org/Visitors/Centre/Trans_Portuguese.cfm) websites are very active. 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 videos, reports, books, etc.

6) Health Primary Care

Lilia Morales-Chacon (Chair).

A health primary care project in Bolivia was established. A regional program with the PAHO support is in process

7) Epilepsy Surgery

Mario Alonso (Chair) and Manuel Campos Support for the development of the Epilepsy Surgery programs in Lima, Peru and Guayaquil, Ecuador. Participation of Epilepsy Surgery Centers in Mexico, Chile, Brazil, Argentina, and Costa Rica.

The first epilepsy surgery program was established in Santa Cruz with the support of Manuel Campos and Mario Camargo.

8) Ketogenic Diet Project

Roberto Caraballo, Laura Guilhoto, Eduardo Barragan, Alejandro Scaramelli and Patricio Abad are working on regional guidelines.

9) 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 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

Sheryl Haut (USA), Chair
Nathalie Jetté (Canada), Secretary
Jose Cavazos (USA), Treasurer
Jaideep Kapur (USA)
Peter Carlen (Canada)
Dave Clarke (USA/Caribbean)
Vicente Iragui (USA)
Solomon Moshé (USA), EC Liason
AES President, Amy Brooks-Kayal (USA)
CLAE President, Nathalie Jetté (Canada)

Subcommissions and Members

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 Jaideep Kapur, Peter Carlen, Lionel Carmant, Amza Ali, Jorge Burneo and Sheryl Haut

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 Trinko (Austria)

Leadership Development Task Force

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

Caribbean Task Force

Initial Board: Dave Clarke (President) and members (all from Caribbean) Amza Ali, Remy Bellance, Meshia Gay-Brown, Tamika Haynes-Robinson and Morris Scantlebury.

Newly Elected Board (during this period): David Corbin (President), Remi Bellance (Vice-President), Tamika Haynes-Robinson (Secretary), Peter Kowlessar (Treasurer), Natalie Dick, Paula Lashley and Dave Clarke (immediate past president)

Hispaniola Task Force

Lionel Carmant (Chair)

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), Sheryl Haut (USA), 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)

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.

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 translate the slide set into Spanish. This was accomplished by our colleagues in Latin America.

Recommendations for Future Work

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

COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

Intercommission Educational Outreach

The PECA program continues to support partnerships between epilepsy centers in the Americas to promote education and improvements in epilepsy care. In the current year, 5 programs were established or continued in Costa Rica, Panama, Peru, Ecuador and Mexico. Several of these programs were successful in obtaining funding from external sources to support or supplement these partnerships.

Recommendations for Future Work

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

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.

An AES town hall was held with many members of the FDA addressing the work of this task force, mostly focusing on time to baseline seizure frequency as an add-on study design. There were differing opinions expressed from participants. The FDA is still willing to consider time to seizure as an outcome. The task force and relevant stakeholders met in Prague at the European Commission meeting and also met at the annual AED development meeting in May 2015.

Recommendations for Future Work

A joint US-European meeting is planned in Prague for 2016 to continue the momentum of this important initiative.

Leadership Development Task Force

The North American Commission designed the ILAE Leadership Scholarship Program under the direction of Course Directors Sheryl Haut and Jaideep Kapur. To achieve its mission, the ILAE needs strong leaders who can start and grow new chapters that engage

members; lead global, national and local advocacy efforts; advance research agendas and clinical care for epilepsy patients and recruit young talent to the field. The skills required of these leaders are rarely addressed in graduate and medical training programs. This training gap was addressed by the leadership course.

A class of 21 impressive participants representing every ILAE region enrolled in the 2-day training program that included a networking lunch with the ILAE Executive Team. There were sessions on strategic planning, financial planning, scientific communication, electronic communication, conflict resolution, how to run an effective meeting, and personal leadership style among others. Evaluations and feedback from participants and faculty were incredibly positive. The Leadership Program has successfully completed its inaugural year within the allocated budget.

Recommendations for Future Work

Plan for next program in Barcelona in 2017 and expand the program to provide more advanced applied learning and skill building sessions and networking and mentoring opportunities for ILAE's most prominent rising leaders.

Caribbean Task Force

The Caribbean Epilepsy Society held Epilepsy Week in Antigua from November 9-13, 2015 with teams from the University of Texas (Austin) and New York University. During this week, 106 patients were seen in clinics and this included neuropsychology assessments and plans for optimization of future clinics. Data collection from epilepsy and quality of life questionnaires for research purposes are under way. There were also educational sessions with community, nurses and physician talks. All were very well attended and interactive.

Two publications were generated from this task force:

- Melbourne-Chambers R, Clarke D, Gordon-Strachan G, Tapper J, Tulloch-Reid M. The UWIMONA Paediatric Epileptic Seizure Screening Questionnaire for use in a Resource Limited Setting was found to be valid and reliable in a pilot study. *J Clin Epidemiol.* 2015 Sep;68(9):988-93
- Kruass G, Sandy S, Corbin D, Bird-Compton J, Jack F, Nelson B, Jalonen T, Ali A, Fortune T, Clarke DF, Okolie J. Epilepsy Care in the Southern Caribbean. *Epilepsy Behav.* 2015 Aug 21;51:267-272.

COMMISSION ON NORTH AMERICAN AFFAIRS *(continued)*

Recommendations for Future Work

Plans are under way for the 5th NARCCE meeting March 3-5, 2016 in Barbados with stellar speakers from North America and the Caribbean. The group will continue their work to improve education and clinical care in the Caribbean.

Hispaniola Task Force

In 2014-2015, the Haiti portion of this task force was highlighted by the opening of a third site in the city of Jacmel in the southern portion of the island. A family physician and an EEG technologist/nurse were trained and now run the program under the mentorship of a neurologist. They also launched their website www.clidep-haiti.com or www.clidep.org and have recruited medical students to their program.

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 and are now followed. The clinics continue to face serious treatment gap issues because they do not have sufficient AEDs for everyone (many cannot even afford phenobarbital and therefore have breakthrough seizures when they run out of their medications). Only the Mirebalais site has free access to medication via the NGO Partners in Health. The PAHO program for access to medication is not in place in Haiti.

In the Dominican Republic, the study of controls with no history of epilepsy has started. As of end of November 30, out of 100 patients were recruited and tested. Preliminary results are pending. We remember the first part of this study where in patients with epilepsy, more than 25% were affected by neurocysticercosis and those affected had a high family history of epilepsy. This has led to the development of a parallel project funded by the Dominicans, where they are looking at the role of genetic markers of inflammation in the patients with neurocysticercosis and epilepsy. It is expected that recruitment and analysis of this cohort will be completed by the end of 2016.

Recommendations for Future Work

Part 2 of the neurocysticercosis project (prevalence in controls) will continue and is expected to be completed at the end of 2016. Dr. Lionel Carmant will be leading fundraising activities in Haiti and in Montreal. A group of colleagues of Dr. Carmant's also plan a 3-day training session in the region (Drs. Anne Lortie, Dang Nguyen, Alexander Weil and Sylvain Chouinard).

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 are ready for submission – one summarizing validated scales to measure stigma in epilepsy and one summarizing the evidence around interventions to address stigma in epilepsy. These will be submitted as companion papers with the final two papers addressing frequency of stigma and factors associated with stigma.

Recommendations for Future Work

It is expected that all four papers synthesizing the evidence surrounding stigma in epilepsy will be completed by June 2016. These will highlight gaps in the area of stigma in epilepsy research and provide recommendations for future research.

PAHO Working Group

This group highlighted the importance of epilepsy educational programs in Latin America, and collaborated with Latin American members to translate the ILAE educational slides for implementation in Latin America. An "Epilepsy Week" with educational symposia, public education and broad exposure to the local media was organized in Bolivia (Dr. Camargo). A number of other educational programs were also developed in Honduras (Dr. M. Medina) and in Chile (Dr. T. Mesa).

Recommendations for Future Work

Perform an inventory of existing educational programs/resources to avoid duplication of efforts, define educational goals for different levels of health care providers and the public, and explore teaching methods and venues. The group is proposing piloting the final educational program in 2-3 countries before widespread dissemination.

AES, CLAE and CES Activities

Please see separate annual reports for each of these chapters for their respective 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)
Nobukasu Nakasato (Japan)
Jukka Peltola (Finland)
Kate Riney (Australia), Treasurer
Eliane Roulet Perez (Switzerland)
Muhammad Salisu (Nigeria)
Ingrid Scheffer (Australia), Secretary
Solomon Moshé (USA), EC Liaison

Aims

1. To develop the classification of seizures and epilepsies to reflect scientific advances in understanding of the etiology of epilepsies, epilepsy syndromes and their associated comorbidities.
2. Global education relating to epilepsy classification and the revision of terms used to describe seizures and epilepsies.
3. Development, launch and global marketing of EpilepsyDiagnosis.org, an online diagnostic manual for the epilepsies.
4. To develop a classification of neonatal seizures and epilepsies applicable to all health care settings worldwide and which reflects the framework for the developing classification of seizures and epilepsies.

Mission

To develop a scientifically-based approach to the classification of seizures and the epilepsies and to improve diagnosis of epileptic seizures and syndromes globally. The commission oversees the work of four task forces.

Task Force on Classification

Ingrid Scheffer (Australia), Task Force Chair
Jacqueline French (USA)
Edouard Hirsch (France)
Satish Jain (India)
Gary Mathern (USA)
Solomon Moshé (USA)

Emilio Periecea (Italy)
Torbjörn Tomson (Sweden)
Sam Wiebe (Canada)
Helen Zhang (China)
Sameer Zuberi (UK)

This group met for the first time in Stockholm in 2014 and was tasked with developing a classification framework for the epilepsies taking into account the epilepsy community's feedback on proposals relating to classification from the commission over the previous four years. A paper "*Classification of the epilepsies: New concepts for discussion and debate. Special Report of the ILAE Classification Task Force of the Commission for Classification and Terminology*" was prepared and circulated within the task force, the commission, and the ILAE Management Committee. The paper was discussed in Istanbul and at the AES meeting in 2015. The developing classification emphasizes the importance of considering etiology at all stages of classification and proposes a framework encompassing seizure type, epilepsies classified by seizure types, epilepsy syndromes and a new category of epilepsy with etiology. The term "Classification" has been re-instituted, replacing "Organization." The task force has brought etiology to the forefront of epilepsy classification to reflect increasing scientific knowledge and the wider aim within medicine to encourage the practice of personalized or precision medicine. There are many areas within the document which will produce debate within the epilepsy community. The paper will be published in the new open access journal of the ILAE in 2016 with the aim of soliciting immediate comment from the readership.

Task Force on Seizure Types

Robert Fisher (USA), Task Force Chair
Helen Cross (UK)
Jacqueline French (USA)
Norimichi Higurashi (Japan)
Edouard Hirsch (France)
Floor Jansen (Netherlands)
Lieven Lagae (Belgium)
Jukka Peltola (Finland)
Eliane Roulet Perez (Switzerland)
Ingrid Scheffer (Australia)
Sameer Zuberi (UK)
Solomon Moshé (USA), EC Liaison

To accompany the framework for the Classification of the Epilepsies a task force is working on updating the classification of seizure types and the ILAE glossary of terms. The group met in London in February 2015,

COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

communicated by email and teleconference and met again in Istanbul. A paper “Operational Classification of Seizure Types by the International League Against Epilepsy” was written by the task force led by Bob Fisher. There are several reasons for devising a new classification of seizure types. Some seizure types, for example tonic or epileptic spasms, can have either a focal or generalized onset. A lack of knowledge about the onset makes a seizure unclassifiable with the 1981 system. There is a need to move away from preservation or alteration of awareness, responsiveness or consciousness as the only descriptor of a focal seizure, although it remains an important descriptor. Some important seizure types are not included in previous classifications.

The paper is regarded as a position paper of the ILAE in development and as such will be put on the ILAE website for comment and submitted to *Epilepsia* for peer review. A further task force will then review comments received prior to producing the final document for publication.

EpilepsyDiagnosis.org & Syndromes Task Force

Kate Riney (Australia), Task Force Chair
Nerses Bebek (Turkey)
Roberto Caraballo (Argentina)
Norimichi Higurashi (Japan)
Vivek Jain (India)
Floor Jansen (Netherlands)
Lieven Lagae (Belgium)
John Paul Leach (UK)
Rima Nabbout (France)
Muhammad Salisu (Nigeria)
Ingrid Sheffer (Australia)
Elizabeth Thiele (USA)
Federico Vigevano (Italy)
Khaled Zamel (United Arab Emirates)
Sameer Zuberi (UK)
Mike Kerr (UK), Liaison to Commission on Neuropsychobiology

EpilepsyDiagnosis.org is a major educational initiative of the ILAE the aim of which is to make available latest concepts relating to seizures and the epilepsies in an easy to understand form. 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 is also a useful teaching aid. The site works well on a smartphone as well as on a computer or tablet, and contains very useful videos of seizures. Usage continues to increase steadily, growing from a few thousand at launch to more than 27,000 page views per month, and climbing. Feedback from users has been uniformly positive. The task force led by Kate Riney manages and develops the site.

This year, task force members have written a major new section on epilepsies with a structural etiology, including examples of imaging. This will go live in the first quarter of 2016. The task force has agreed to a Creative Commons License for text from the site so that it can be shared with Wikipedia’s epilepsy pages. This should bring further traffic to EpilepsyDiagnosis.org, help ensure Wikipedia’s content is current and further promote epilepsy education.

The task force is currently working with Translators Without Borders on translations of the content of EpilepsyDiagnosis.org into other languages. The website is promoted by task force members at every opportunity, was presented at Istanbul in September 2015 and will be showcased again at the 12th ECE in Prague in September 2016.

Neonatal Seizures Task Force

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

The neonatal seizures task force has developed a Framework for Classification of Neonatal Seizures which reflects that developed by the Task Force on Classification but which acknowledges factors specifically relevant to this age group. The group has undertaken collaborative video – EEG review exercises to facilitate the development of relevant terminology. These have informed a seizure type classification that reflects the Seizure Type Task Force work but does not separate seizures into generalized and focal. Symposia were held to present the group’s work in Istanbul 2015 and will be in Prague 2016.

COMMISSION ON CLASSIFICATION AND TERMINOLOGY *(continued)*

Accomplishments

1. Preparation & writing of “Classification of the epilepsies: New concepts for discussion and debate. Special Report of the ILAE Classification Task Force of the Commission for Classification and Terminology” – to be published in ILAE open access journal 2016.
2. Preparation and writing of “Operational Classification of Seizure Types by the International League Against Epilepsy” special report of the Task Force on Seizure Types.
3. Inaugural year of EpilepsyDiagnosis.org. Marketing to all ILAE Chapters and members and to congress participants. A detailed business plan for marketing and site development was submitted to the ILAE Management Committee. Further development of site with major new “Structural” section. Approximately 11,000 visitors per month. Agreement to share content with Wikipedia.
4. Classification symposium at International Congress on Epileptology, Istanbul and acceptance of proposals from the commission and task forces for symposia at the European Epilepsy Congress in Prague, 2016.

Recommendations for Future Work

1. To develop the Classification of the Epilepsies Framework and Seizure Type Classification through continuing engagement with the epilepsy community to include open access papers, online posting and feedback.
2. 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.
3. To revise the ILAE Glossary of Terms acknowledging developments in the scientific understanding of epilepsy.
4. Global education and engagement program on epilepsy classification at national, regional and international epilepsy congresses.
5. 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

Andrea Bernasconi (Canada), Secretary
Fernando Cendes (Brazil), Treasurer/Past Chair
Philippe Kahane (France)
Callixte Kuate Tegoue (Cameroon)
Riki Matsumoto (Japan)
Donald Schomer (USA)
Sarah Wilson (Australia)
Samuel Wiebe (Canada), EC Liaison

Task Forces

Task Force for Neuroimaging

Andrea Bernasconi (Canada), Chair
Fernando Cendes (Brazil), Secretary
Ingmar Blümcke (Germany)
Paolo Federico (Canada)
Edouard Hirsch (France)
Richard Hogan (USA)
Graeme Jackson (Australia)
Matthias Koepp (UK), Past Chair
Angelo Labate (Italy)
Philippe Ryvlin (France)
William Theodore (USA)
Anna Elisabetta Vaudano (Italy)

Task Force for Neuropathology

Ingmar Blümcke (Germany), Chair
Eleonora Aronica (Holland)
Felice Giangaspero (Italy) WHO Liaison
Edouard Hirsch (France)
Lara Jehi (USA)
Hajime Miyata (Japan)
Karl Rössler (Germany)
Harvey Sarnat (Canada)
Roberto Spreafico (Italy)
Maria Thom (UK)

Task Force for Neurophysiology

Philippe Kahane (France), Chair
Andreas Alexopoulos (USA)
Fabrice Bartolomei (France)
Francois Dubeau (Canada)
Jean Gotman (Canada)
Simon Harvey (Australia)
Prasanna Jayakar (USA)
Pavel Kršek (Czech Republic)
Samden Lhatoo (USA)

Sinclair Liu (China)
Çiğdem Özkara (Turkey)
Andre Palmieri (Brazil)
Laura Tassi (Italy)
Demetrios Velis (Netherlands)
Alice Yu (Taiwan)

Task Force for Neuropsychology

Sarah Wilson (Australia), Chair
Bruce Hermann (USA), Secretary/Past Chair
Gus Baker (UK)
William Barr (USA)
Sallie Baxendale (UK)
Sherifa Hamed (Egypt)
Christoph Helmstaedter (Germany)
John Langfitt (USA)
Severine Samson (France)
Mary-Lou Smith (Canada)
Masako Watanabe (Japan)

Education Task Force for Summer Schools in Diagnostic Methods

Ingmar Blümcke (Germany), Chair
Eleonora Aronica (Netherlands)
Sallie Baxendale (UK)
Sandor Beniczky (Denmark)
Fernando Cendes (Brazil)
Simon Keller (UK)
Riki Matsumoto (Japan)
Sarah Wilson (Australia)

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 five 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. Another important topic of our commission is to develop state-of-the-art teaching courses addressing WHAT ? WHY? and HOW? to apply diagnostic methods, accessible for all ILAE members throughout the world. Our work thus very much depends on interaction with other ILAE commissions, dissemination and training.

COMMISSION ON DIAGNOSTIC METHODS *(continued)*

Task Force for Neuropathology

This term's major effort of the Neuropathology Task Force addresses tumor-related epilepsies. Neuropathology agreement has shown poor inter-rater agreement in the classification of brain tumors associated with long-term epilepsies (LEAT). LEATs mostly encompass glio-neuronal tumors, i.e. gangliogliomas and DNT (approx. 60-80%), and their frequencies vary largely between regional case series. We have built a collaborative virtual microscopy platform, which allowed us to review large series of LEAT variants by a panel of international neuropathologists and to encourage discussion between WHO and International Society of Neuropathology to achieve consensus terminology use and acceptance of a revised tumor classification system. Our task force has also organized a main session on brain tumors and epilepsy at the International Epilepsy Congress in Istanbul, September 7, 2015. The work was further disseminated by our International Neuropathology Summer School in Campinas, Brazil, July 26-30, 2015. In 2016, next courses will be organized in China (West China Hospital, Chengdu, August 29-September 1) and Erlangen, Germany (October 6-9).

Task Force for Neuropsychology

An important aspect of our commission's work addressed neuropsychology measures during presurgical evaluation to be understandable for epileptologists when using or interpreting different test domains. Particular topics include measures for assessment of developmental hindrance, measures sensitive to antiepileptic drug treatment or sensitive to EEG pathology (electrophysiological epileptic activity, single spikes & spikewaves, grouped activity, nonconvulsive [cognitive] seizures). Consensus protocols for assessment of hemispheric dominance (IAT, fMRI, functional Doppler, dichotic listening), measures sensitive to surgical treatment, and measures and markers for assessing everyday functioning are other important issues. An official report defining minimum standards for neuropsychology assessment in epilepsy was published in 2015 (Wilson et al. *Epilepsia*. 2015 May;56(5):674-81. doi: 10.1111/

epi.12962) and a second report on neuropsychological measures in epilepsy surgery is envisaged for 2016. The task force will organize a first training course on neuropsychology and epilepsy in France, April 10-15, 2016. Thirty-six participants will take part in lectures, case presentations, and discussions designed to illustrate principles of differential diagnosis and case formulation in neuropsychological practice in epilepsy. Five days of course material will be presented by leading clinical experts in the field, including clinical neuropsychologists working in epilepsy programs from around the world.

Task Force for Neurophysiology

A major goal of the Neurophysiology Task Force is to provide international consensus recommendations on WHAT? WHY? and HOW? to apply intracranial EEG (IEEG) investigations. The first manuscript is entitled: Diagnostic Utility of Invasive EEG for Epilepsy Surgery: indications, modalities and techniques, and has been finalized by all task force members. It will be submitted to ILAE's official journal *Epilepsia* in due time. Two additional projects will further address 1) recording and stimulation methodologies, including the results of a survey conducted among several epilepsy surgery centers and 2) data interpretation and results. Consensus recommendations will also be published in *Epilepsia*. These two papers will accompany similar work in progress from the Translational Task Force of ILAE's Neurobiology Commission aiming to provide methodological standards and functional correlates of electrophysiological in vivo depth recordings in rodents.

The Neurophysiology Task Force also aims to promote training for surface and intracranial EEG. The European and North-American SEEG courses have been successfully established since 2010, and trained almost 400 neurologists, neuropediatricians and neurosurgeons. The course includes didactic lectures, but primarily practical sessions to allow the acquisition of medical skills through case-based discussions. The Neurophysiology Task Force will also help to develop a third Asian SEEG training course, as well as two additional summer schools dedicated to EEG in neonates and advanced scalp EEG analysis.

COMMISSION ON EDUCATION



Jaime Carrizosa

Chair

Jaime Carrizosa (Colombia)

Members

Chong Tin (CT) Tan (Malaysia), Past Chair
Alexis Arzimanoglou (France), Epileptic Disorders
Sándor Beniczky (Denmark)
Patricia Braga (Uruguay), ALADE
Shih Hui Lim (Singapore), ASEPA
Walter van Emde Boas (Netherlands), VIREPA
Lionel Carmant (Canada)
Amina Gargouri (Tunisia)
Guenter Kraemer (Switzerland)
Daliwonga Magazi (South Africa)
Hiba Mahmud (Pakistan)
Sam Wiebe (Canada), EC Liaison

Task Force

Distance Education

During the 31st IEC in Istanbul, educational courses had a privileged place in the program. The courses were organized in five series that covered highly actualized and also controversial topics guided by recognized experts in the field. During five days, 66 teaching sessions with 39 speakers were offered to the attending public for a total of 33 educational hours. Special interest of the audience could be seen during the sessions of "Case oriented series," "The best of two worlds," or lectures open to discussion regarding classification, diagnosis or therapeutic approaches. Intense work in the planning of this exceptional educational course was done under the leadership of Walter van Emde Boas and Sándor Beniczky.

A pilot educational project in epilepsy started in October in Latin America trying to reach general practitioners working in primary health care in rural and urban places. The National University and the Neurologic Institute of Uruguay gave their logistic experience and support to reach nearly 50 physicians from several countries of Latin America. During eight weeks, themes regarding epidemiology, semiology, diagnosis, pharmacology, referral systems, social and legal aspects like international drafts or local laws were studied and discussed with the tutoring of recognized professors of several universities of Latin and North America. The evaluation of the course is in process at the moment of this writing and we hope that regarding the outreach, quality, satisfaction and economic aspect, the course can be replicated during 2016 and serve as an example for implementation in other parts of the world with a wide possibility to reach distant areas.

A survey regarding epilepsy-training opportunities was finally constructed and sent out to ILAE Chapters during October and November 2015. The survey covers questions regarding opportunities for physician training programs in epilepsy and neurophysiology, number of university hospitals with an identified epilepsy department or units, training hours and contents for graduate and postgraduate students, continuous medical education opportunities in epilepsy, resource training materials, availability/accessibility, research opportunities in basic, clinical, social sciences, and ILAE Chapters contact with universities and hospitals. Analysis and final report is programmed for September 2016.

COMMISSION ON EPIDEMIOLOGY



David Thurman

Chair

David Thurman (USA)

Members

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

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)
Kamadore Touré (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 (Brazil)
Ley Sander (UK)
Torbjörn Tomson (Sweden)

Comorbidity in Epilepsy Task Force

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

Mission of the Commission

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 2014 through June 2015

In the second year of its new term, the Commission on Epidemiology pursued its mission through the work of its four task forces. The Commission met in Stockholm in July 2014 to review progress and plan continued work as described in the following section.

COMMISSION ON EPIDEMIOLOGY *(continued)*

Accomplishments (2014-2015)

In its second year, the Prevention Task Force refined its goals to assess the need and opportunities for primary and early secondary epilepsy prevention and to recommend steps toward prevention. The task force commenced a systematic review, searching Medline and EMBASE databases for studies of epilepsy incidence that address causes and modifiable risk factors in both higher and lower income countries. The citations and abstracts retrieved for this search have been screened, of which 255 have been judged potentially relevant. The full articles of these have been retrieved, and a review of the quality of evidence and extraction of data are underway. Publication of findings and recommendations based on these reviews is anticipated in 2017.

The Epilepsy Registry Task Force, which was proposed in 2013, intended to identify and promote opportunities for developing epilepsy registries. This task force did not receive funding in 2014. After further consideration of modified, less ambitious goals, the task force determined to suspend its activities for the duration of this term of the commission.

The Mortality Task Force, continued from the previous commission term with the purpose of systematically reviewing the mortality risks and causes of death among people with epilepsy and recommending strategies to prevent premature death in epilepsy. Separate teams are addressing mortality in high-income countries (HIC) and in lower- and middle-income countries (LMIC). During 2014-15 the task force completed its systematic review of articles and drafted a manuscript report for HIC, while nearing completion of the systematic review and manuscript preparation for LMIC. The task force anticipates submitting both manuscripts together to the ILAE Executive Committee in Spring 2016.

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

Recommendations for Future Work

The aims of the three continuing task forces of the Commission on Epidemiology serve to promote the primary and secondary prevention of epilepsy and its adverse consequences.

The work of both the Mortality and Prevention Task Forces will yield published assessments and recommendations that the commission will promote in collaboration other ILAE commissions, WHO, and other governmental and nongovernmental agencies to promote research and public health interventions for epilepsy. Similarly, the findings of the Comorbidity Task Force will be translated into prevention work in several ways: first, to increase awareness through publication, educational symposia, and dissemination of materials to health ministries, and also by the development of assessment and training materials for clinicians to help them identify comorbidities, understand their impact, and improve their treatment.

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

COMMISSION ON GENETICS



Daniel Lowenstein

Chair

Dan Lowenstein (USA)

Members

Sam Berkovic (Australia), Past Chair

Peter de Jonghe (Belgium)

Alica Goldman (USA)

Ingo Helbig (Germany)

Yuwu Jiang (China)

Mitsuhiro Kato (Japan)

Heather Mefford (USA)

Steve Petrou (Australia)

Parthasarathy Satishchandra (India)

Nigel Tan (Singapore)

Helen Cross, (UK), EC Liaison

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 2014 through June 2015

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, and is up-to-date for 2015. There continues to be ongoing access to the database, which is encouraging as it shows the epilepsy community at large finds the information there helpful. To unify the Commission on Genetics approach to online epilepsy genetics initiatives, we plan to merge epiGAD into the Epilepsiome project in the next 12-18 months.
- b. ILAE Genetics Commission Blog: To provide better outreach and communication to the professional community, the ILAE Commission

on Genetics has decided to maintain 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 Commission on Genetics and we have usually posted 1-2 posts per week that are well received by the professional community. We have completed our move to a self-hosted website and have rebuilt our audience and online presence of the new website, even increasing our readership by more than 50% over the last few months. Currently, the ILAE Genetics blog receives 5,000-7,500 views per months, largely from the US and Europe, but with readers from more than 40 countries worldwide. Looking back at the last 18 months of our blog as the information portal of the ILAE, Commission on Genetics, our 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. For the commission, the blog has proven extremely valuable as an outreach tool the community.

- c. Epilepsiome: As an extension of our current online strategy, we have developed a concept for a comprehensive database on epilepsy and genes that would allow professionals, patient organizations and families to quickly gather relevant information on epilepsy-related genes. Over the last 12 months, we have had various strategic discussions regarding the particular niche and relative role of the Epilepsiome project compared to other available online resources (ClinGen, GeneReviews). The Epilepsiome will integrate with these other resources but will have "trusted expert opinion" and regular updates as distinguishing features. We have enlisted the help of 40 scientific volunteers who are organized in expert groups on specific genes and who are fully engaged in the gene curation efforts of this project. The Epilepsiome project is currently in a beta phase where we have reviewed and published first gene summaries on 15 genes and are currently fine-tuning the Epilepsiome format and the process of updating information. With respect to the overall format, we are coordinating efforts with other initiatives such as ClinGen, ClinVar and EGI and are planning to provide first proposal for a new visually oriented web interface prior to presenting a full project

COMMISSION ON GENETICS (continued)

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 Commission on Genetics. 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.

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.ncbi.nlm.nih.gov/pubmed/?term=lancet+neurology+++consortium+on+complex+epilepsies>) 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 subanalyses 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 Commission on Genetics website. Positive public reception of the material has prompted culturally sensitive Spanish and Arabic translations aimed at the Spanish speaking Latin American and Arabic populations (<http://www.ilae.org/Commission/genetics/>). These documents are now posted on the ILAE website. Broad public interest in learning the essential principles of epilepsy genetics has led to Japanese translation that is under the review of the Japanese Epilepsy Society and the approval is planned for early 2016. At the same time, the commission plans to pursue the same strategy for creating similar brochures in Chinese 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 Commission on Genetics, 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 first paper in this series has just been published in November 2015, with the second paper currently under review after revisions, and the 3rd to 5th papers being in the writing phase. We are encouraged by the reviewers’ feedback and comments, and we anticipate this series will run through 2016 to mid-2017.

Recommendations for Future Work

We feel that there needs to be further effort placed on helping clinicians stay up-to-date on the latest findings in epilepsy genetics, given that we are now beginning to see the emergence of individualized therapies based on the patient’s genomic profile. We 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. Finally, we intend to explore the potential value of a global registry of patients with defined epilepsy gene mutations, with the goal of expediting observational studies and treatment trials.

COMMISSION ON MEDICAL THERAPIES



Patrick Kwan

Chair

Patrick Kwan (Australia)

Members

Martin Brodie (UK), Treasurer
Steve Schachter (USA), Past Chair
Alejandro De Marinis (Chile)
Jacques Doumbé (Cameroon)
Eric Kossoff (USA)
Hazel Paragua (Philippines)
Dong Zhou (China)
Emilio Perucca, EC Liaison (Italy)

Task Forces

AED Trials and Regulatory Affairs:

Jacqueline French (USA), Chair
Emilia Bagiella (USA)
Michel Baulac (France)
Russell Katz (USA)
Patrick Kwan (Australia)
Takaya Maeda (Japan)
Makiko Osawa (Japan)
Emilio Perucca (Italy)
Eugen Trinka (Austria)

Botanicals:

Steve Schachter (USA), Chair
Dana Ekstein (Israel)
Siegward Elsas (Switzerland)
Elisabeth Ngo Bum (Cameroon)
Nikolaus Sucher (USA)

Dietary Therapy:

Eric Kossoff (USA), Chair
Nabil Al Macki (Oman)
Mackenzie Cervenka (USA)
Heung Dong Kim (Korea)
Jianxiang Liao (China)
Kath Megaw (South Africa)
Janak Nathan (India)
Ximena Raimann Tampier (Chile)
Rocio Rivera (El Salvador)
Adelheid Wiemer-Kruel (Germany)
Beth Zupec-Kania (USA)
Emma Williams (USA)

Efficacy Outcomes:

Mark Cook (Australia), Chair
Paul Boon (Belgium)
Fernando Cendes (Brazil)
Christian Elger (Germany)
Weiping Liao (China)
Brian Litt (USA)
Gayane Melikyan (Qatar)
Mark Richardson (UK)

Emergency Treatments:

Eugen Trinka (Austria), Chair
Reetta Kalviainen (Finland)
Jaideep Kapur (USA)
Célestin Kaputu Kalala Malu (DR Congo)
Andrea Rossetti (Switzerland)
Francesco Brigo (Italy)
Gagandeep Singh (India)

Pharmacogenomics:

Patrick Kwan (Australia), Chair
Larry Baum (Hong Kong)
Martin Brodie (UK)
Tracy Glauser (USA)
Michael Johnson (UK)
Sunao Kaneko (Japan)
Terence O'Brien (Australia)
Sanjay Sisodiya (UK)
Nigel Tan (Singapore)

Psychobehavioral Therapy:

Rosa Michaelis (Germany), Co-chair
Markus Reuber (UK), Co-chair
Laura Goldstein (UK)
William C. LaFrance Jr. (USA)
Avani Modi (USA)
David Rosenstein (Africa)
Venus Tang (Hong Kong)
Janelle Wagner (USA)

Aims

To complete efforts begun by the previous commission and to define and pursue opportunities for progress consistent with the ILAE Strategic Plan in several key therapy-related areas. Significant progress has been made in several projects, which are reported below.

AED Trials and Regulatory Affairs Task Force

This year we continued to work on three targeted areas:

1. Harmonization on extrapolation of efficacy determined in adult add-on trials in focal seizures to the pediatric age group. The EMA had already accepted that drugs approved in adults for add-on therapy of focal epilepsy should also be approved in children down to the age of 2. The PEACE initiative (Pediatric Extrapolation Academic Consortium in Epilepsy), a group led by Jack Pellock, submitted a white paper that suggested a similar extrapolation for FDA approvals. This effort was also a part of the FDA critical path. As a result of these efforts, the

COMMISSION ON MEDICAL THERAPIES *(continued)*

FDA has accepted extrapolation down to the age of 4. This is a momentous decision, based on a substantial PK/PD modeling effort. As a result, new drugs will reach pediatric patients faster, and fewer children will need to be exposed to placebo in clinical trials.

2. Monotherapy approvals: The task force submitted a white paper to the FDA suggesting that drugs should be approved for indications (e.g., focal epilepsy, Lennox-Gastaut syndrome) for both monotherapy and polytherapy use, irrespective of the way the trials were performed (i.e., as monotherapy or polytherapy). A paper was subsequently published in *Lancet Neurology* supporting the arguments in the white paper (Mintzer S*, French J*, Perucca E, Cramer J; Messenheimer J, Blum D, Rogawski M, Baulac M. [*shared first authors] Is a separate monotherapy indication warranted for antiepileptic drugs? 2015 *Lancet Neurology*, 14: 1229–40). The FDA is considering the arguments.
3. Time to event: Drs. French and Bagiella have accumulated evidence to write a white paper suggesting that regulatory studies can be performed as time to event rather than parallel studies. This would shorten placebo exposure times. The FDA and EMA are considering the approach.

Plans for the Future

A meeting is in preparation in conjunction with the Prague European Congress of Epilepsy, during which FDA, EMA and PMDA will continue to discuss the issues above.

Botanicals Task Force

The task force has finalized the content 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. The actual launch of the website is being planned. 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.

Dietary Therapy Task Force

After the meeting in Liverpool in October 2014, we were able to write our proceedings into a manuscript and it was published in *Epilepsia*. The full reference is: Kossoff EH, Al Macki N, Cervenka MC, Kim HD, Liao J, Megaw K, Nathan JK, Raimann X, Rivera R, Wiemer-Kruel A, Williams E, Zupec-Kania B. What are the minimum requirements for ketogenic diet services in resource-limited regions? Recommendations from the International League Against Epilepsy Task Force for Dietary Therapy. *Epilepsia*. 2015 Sep;56(9):1337–42.

We also have continually updated our task force Ketogenic Diet webpage:

<http://www.ilae.org/Commission/medther/keto-index.cfm>

Psychobehavioral Therapy Task Force

In 2015 the task force met two times during the ILAE meeting in Istanbul and the AES meeting in Philadelphia to work on two goals:

- 1) Update Cochrane review of psychological treatments for people with epilepsy with a focus on HRQOL: By the end of 2015 the literature search and risk of bias evaluation of identified studies have been concluded. The review protocol will soon be published on Cochrane.org after which the data analysis will be conducted. We plan to publish the final results in *Epilepsia* after online publication on Cochrane.org.
- 2) Create treatment recommendations on psychological management for adults in children with epilepsy based on Cochrane review, systematic review (Tang et al. 2014) and the clinical experience represented by the experts in this task force: A first draft of these recommendations is structured as follows: Key intervention strategies and components are presented as they seem suitable to address various treatment targets that arise across the illness trajectory in epilepsy. A detailed description of the intervention elements will be published in a glossary as supplementary material online. A brief overview of treatment modalities including options for resource-poor settings, service evaluation measures, and

COMMISSION ON MEDICAL THERAPIES *(continued)*

implications for training and facilities offering psychological services for people with epilepsy is provided. To increase comparability and reproducibility of future studies, the inclusion of outlined key intervention elements should be clearly referenced and the standard use of the QOLIE-31 as primary or secondary outcome parameter is recommended.

COMMISSION ON NEUROBIOLOGY



Marco de Curtis

Chair

Marco de Curtis (Italy)

Members

Aristea Galanopoulou (USA)
Norberto Garcia-Cairasco (Brazil)
Richard Idro (Uganda)
Damir Janigro (USA)
Hoon-Chul Kang (Korea)
Katja Kobow (Germany)
Merab Kokaia (Sweden)
WeiPing Liao (China)
Astrid Nehlig (France)
Jeff Noebels (USA)
Terence O'Brien (Australia), Treasurer
Rodney Scott (USA)
Vicky Whittemore (USA)
Solomon Moshé (USA), EC Liaison

Task Force Chairs

Jacqueline French, Asla Pitkänen, Raman Sankar,
Michele Simonato
Liaisons: Solomon Moshé, Annamaria Vezzani

Activities

The activities of the Neurobiology Commission (NBC) focus on the development of experimental research strategies that address clinically relevant issues in the field of epilepsy. The main goal of the commission is to organize and promote international and regional educational and dissemination initiatives to enhance the reciprocal interaction between the neuroscience and epilepsy communities. This goal is achieved by implementing a strategic plan and through the endorsement and the discussion by consolidate and young emergent scientists of new translational basic research findings relevant for clinical care.

The commission strategic plan is organized in five main initiatives implemented by ad hoc task forces. The progress of task force activities were verified and updated during two meetings of the commission in June 2014 and September 2015, just before the 2014 European Congress in Stockholm and the 2015 ILAE Congress in Istanbul. The commission reports and new documents generated by commission activities are updated on the ILAE website every 3 months by the commission member responsible for the interaction with the Communications Task Force (K. Kobow). The forms for the registration to the WONOEP and for NBC support requests to organize meetings/workshops were recently posted on the NBC website (<http://www.ilae.org/Commission/neurobio/index.cfm>). A website

section dedicated to advertise jobs/postdoctoral/PhD positions will be soon implemented and highlighted on the NBC website.

Update of Dissemination and Educational Task Force Activities

NBC Activity at 31st ILAE Congress 2015:

The NBC contributed to the organization of scientific and educational events at the 2015 ILAE Congress in Istanbul, described on a flyer that was circulated at neuroscience and clinical epilepsy congresses during 2014/2015. The following events were supported by the NBC:

- Educational sessions entitled "The Best of two Worlds: Translational Epileptology" developed in collaboration with Walter van Emde Boas:
 - *Of mice and men: clinical and neurobiological perspectives in temporal lobe epilepsy*; speakers C. Özkara and A. Depaulis
 - *When a seizure is a seizure*; speakers M. de Curtis and P. Kahane
 - *What do and can clinicians expect from neuroscientists?*; speakers J. Engel Jr. and G. Avanzini
 - *Beyond the neuron(s): where is epilepsy*; speakers D. Janigro and E. Perucca
- Neurobiology Symposium on "Optogenetics to cure epilepsy: facts and feasibility". Speakers: Merab Kokaia, Robert Wykes, Esther Krook-Magnuson, Giorgio Carmignoto
- WONOEP Highlight Session

Young Neuroscientist Award

NBC promoted for the first time an award for the best neuroscience contribution submitted to the international ILAE meeting. During the selection process it was proposed to entitle this Young Neuroscientist Award to the Harinarayan family that generously contributed to NBC funding. The winners of 2015 Award, Cristina Ruedell and Ping Zheng, were selected from more than 100 candidates.

COMMISSION ON NEUROBIOLOGY *(continued)*



Cristina Ruedell (Dublin, Ireland) and Ping Zheng (Melbourne, Australia), winners of the 2015 Young Neuroscientist Award, awarded during the 2015 ILAE Congress in Istanbul.

For future ILAE meetings the applications for this award will be advertised on the congress registration form. Candidates should prove 1) to support an independent research activity by signing the congress abstract as last author and 2) no more than 5 years after graduation.

NBC Activity Planned for 12th European Congress on Epilepsy, Prague 2016

The NBC proposal of a Neurobiology Symposium on “Learning about focal ictogenesis from patients (and animal models)” was accepted. The speakers are Wilson Truccolo, Kaspar Schindler, Marco de Curtis and Julia Jacobs.

Other Dissemination Actions:

The NBC supported the organization of the following courses and workshops:

- 5th San Servolo Course Bridging Basic with Clinical Epileptology, Venice, Italy, July 18-31, 2014
- Gordon Conference on Epilepsy, August 17-22, 2014, Mount Snow Resort in Vermont, USA
- Joint IBRO/ILAE symposium on network synchronization in epilepsy, at IBRO Congress in Rio de Janeiro, Brazil, July 8, 2015
- Joint IUPHAR/ILAE session on optimizing anti-epilepsy drug discovery in epilepsy at the World Congress of Basic and Clinical Pharmacology in Capetown, South Africa, July 15, 2014

Opposing “Stop Vivisection” Initiative

A letter proposed by Aristeia Galanopoulou on behalf of the ILAE-AES Translational Task Force and the NBC Commission was sent to the President, Martin Schulz, and to all members of the European Parliament,

to oppose the European Citizen’s Initiative “Stop Vivisection.” This initiative was submitted in March 2015 to request the abrogation of the directive 2010/63/EU of the European Parliament and of the Council of 22 September 2010 on regulation of animal experimentation and to ban animal research. Following the submission of this initiative against research on animals in Europe, multiple academic institutions were mobilized against this initiative. The ILAE letter, co-signed by the ILAE and IBE presidents, supported the existing directive 2010/63/EU to provide for ethical and justified use of animals for biomedical research, thus allowing the progress in scientific advances that have significantly benefited both human and veterinarian care.

In June 2015 there was a positive resolution by the EU Parliament decision, which did not favor the “Stop Vivisection” initiative. However, one of the EU actions that followed the European Parliament decision was to organize a debate/conference by the end of 2016, to emphasize the importance of addressing and discussing animal experiments in scientific meetings and on publications and to analyze the value of experimental studies to science and medicine so far. These dissemination activities are part of the Translational Task Force efforts on the refinement of animal epilepsy model techniques to improve animal welfare, and is one of the goals of ILAE NBC.

Regional Commission Joint Task Force

In February 2015 the NBC chair met with the CEA, following the initiative of CEA member Annamaria Vezzani, to evaluate potential interactions between the two commissions on the following issues:

- Support translational neurobiology topics at regional courses/meetings
- Contribute to the participation of young independent European scientists at WONOE
- Reinforce the interactions for neurobiology events at ECE
- Monitor the participation of neurobiologists and clinical neuroscientists at ECE

It was agreed that it would be helpful to form a joined NBC/CEA task force to address the proposed program. During the 2015 NBC meeting it was proposed to explore the interest of other regional commissions to work on a similar program in the geographical area of pertinence.

COMMISSION ON NEUROBIOLOGY *(continued)*

Monitor Neurobiologists' Participation in ILAE Meetings

The participation of neurobiologists working in epilepsy in ILAE-sponsored international and regional meetings was analyzed by the NBC with the help of the ILAE/IBE Congress Secretariat. The participation of neurobiologists at international and regional congresses in the last 4 years is summarized in the following table:

Congress	year	total attendance	# neuro scientists	%
29th International Epilepsy Congress, Rome	2011	3,963	159	4
1st African Epilepsy Congress, Nairobi	2012	291	6	2
9th Asian & Oceanian Epilepsy Congress, Manila	2012	1,213	12	1
10th European Congress on Epilepsy, London	2012	3,637	146	4
7th Latin American Congress on Epilepsy, Quito	2012	627	10	1.5
30th International Epilepsy Congress, Montreal	2013	2,334	173	7.4
2nd African Epilepsy Congress, Cape Town	2014	287	13	4.5
11th European Congress on Epilepsy, Stockholm	2014	2,300	105	4.5
10th Asian & Oceanian Epilepsy Congress, Singapore	2014	1,305	22	1.6
8th Latin American Congress Epilepsy, Buenos Aires	2014	754	13	1.7

It is a NBC priority to continue monitoring the participation of neuroscientists and clinical neuroscientists at epilepsy meetings to evaluate if the dissemination initiatives of the NBC have an impact on the attendance of neurobiologists at ILAE-sponsored international and regional congresses.

Translational TF Activities Update International Activities and Collaborations

The AES/ILAE Translational Task Force in coordination with the NBC and with the support of the leadership of the ILAE and IBE prepared and submitted to all members of the European Parliament a letter outlining the official position of the ILAE/IBE opposing the "STOP Vivisection" European Citizens' Initiative (ECI) (please see previous section Opposing "stop vivisection" in this report).

An official agreement of collaboration was signed early this year between the Translational Task Force and the Multi-PART (Multicenter Preclinical Animal Research Team) group to facilitate opportunities for preclinical multicenter studies in epilepsy (goal of TASK4).

A collaboration has been established with the CAMARADES (Collaborative Approach to Meta Analysis and Review of Animal Data from Experimental Studies) group to facilitate systematic reviews on animal models of seizures (TASK2) and on evaluating methodologies and interpretation of rodent video EEG studies (TASK1 group). Liaisons in this effort are David Howell, Malcolm Macleod and Emily Sena (University of Tasmania and University of Edinburgh). In collaboration with TASK2, Dr. Howell is developing a teaching platform that will be used

to instruct the group on the theory and practice of systematic reviews and meta-analyses.

Following discussions with Brandy Fureman and Jackie French, Walter Koroshetz (NINDS Director) has expressed the strong support of NINDS for the effort to generate preclinical common data elements (CDEs), which is a goal of the TASK3 group. TASK3 co-leaders are currently working closely with the NINDS liaisons to advance this collaborative initiative.

The TASK1 group has also been in contact with the European veterinarian consortium so as to facilitate the creation of consistent classification systems for seizures in both rodents (planned by TASK1) and companion animals (completed by the veterinarian consortium). Liaison is Holger Volk, who was invited to update the veterinarian classification at the Istanbul meeting. The TASK1 group has also liaised with Nathalie Jetté (chair of the ILAE Epilepsy Guidelines Commission) who will be collaborating with our group for the Delphi consensus process during the development of the classification system for rodent EEGs.

The Translational Task Force has been in contact with the NC3R group (liaisons Michele Simonato, Asla Pitkänen) and has provided feedback on the recent NC3R report on "Outlining opportunities for improving animal welfare in rodent models of epilepsy and seizures" (Lidster K et al., *J Neurosci Methods*, 2015).

Publications

The first set of reports from the Translational Task Force are currently in preparation and planned for submission for an *Epilepsia* Supplement (2016).

COMMISSION ON NEUROBIOLOGY *(continued)*

This will include manuscripts outlining the scope and progress of the four TASKs and special working group reports that will provide the first products of the TASK1 working group. These will discuss methodological, technical, and interpretation standards of video-EEG recordings in adult and immature rodents used as experimental controls, using surface or depth electrodes; methodological standards for in vitro electrophysiological studies; standards involved in the signal analysis of electrophysiological recordings using computerized methods and specific software. This will be a first step before addressing the classification of seizures in rodents and interpretation of controversial or abnormal patterns.

Meetings

The AES/ILAE Translational Task Force has organized two meetings to discuss progress and agree on strategies for the next steps that the four TASKs will undertake. These meetings were co-sponsored by the ILAE and AES (American Epilepsy Society).

The first meeting was organized as a satellite of the IEC in Istanbul (September 9, 2015). Malcolm Macleod (University of Edinburgh) represented the Multi-PART and CAMARADES consortia. He updated members about the goals and progress of these groups and the planned collaborative studies with the TASK2 and TASK4 groups, which will focus on systematic reviews on animal studies using models of seizures and preclinical multicenter studies for epilepsy therapy development. Holger Volk (Royal Veterinary College, Hatfield, Herts; UK), representative of the European veterinarian consortium, updated on the recent consensus statements for the classification of seizures in companion animals, which will be useful for the work of TASK1 in classifying seizures in rodents. The second meeting was organized as a satellite of the AES meeting in Philadelphia (December 8, 2015).

Other

With the financial support of the AES, we opened an open call for a part-time project manager of the Translational Task Force. Following interviews and evaluation of the credentials of the applicants, we offered the position to Lauren Harte-Hargrove who accepted this one-year position, effective November 15, 2015.

WONOE Task Force Activities Update

A new WONOE logo was created by Bryony Reed (patient of WONOE Task Force Chair, Raman Sankar) and was utilized for the first time at XIII WONOE.



Raman Sankar and Bryony Reed



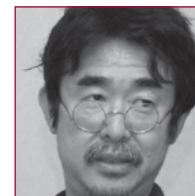
Group photograph at the 2015 WONOE XIII

The XIII WONOE was successfully organized at Halki Palace on Heibelyada Island (Turkey) by the Scientific and Organizing Committee formed by Filiz Onat, Candan Gurses, Katja Kobow, Raman Sankar and Marco de Curtis, with the local assistance of Medine Gulcebi and the generous support of Harinarayan Family Foundation, Cyberonics Inc., Insys Therapeutics Inc., Astellas Pharma, Meiji Seika Pharma and MSD. The main topic of XIII WONOE was Biomarkers.

The issues discussed at XIII WONOE were reported during a highlight session at the Istanbul ILAE Congress and will be the focus of topical reviews (WONOE Appraisals) to be submitted to *Epilepsia* on peripheral biomarkers, brain damage biomarkers, comorbidity biomarkers and imaging biomarkers. The next WONOE is planned for 2017 in Spain.

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), Treasurer
Marco Mula (UK), Past Chair
Andres Kanner (USA)
Jose Francisco Tellez-Zenteno (Canada), Secretary
Sungpa Park (South Korea)
Markus Reuber (UK)
Bertrand de Toffol (France)
David Dunn (USA)
Gerardo Filho (Brazil)
Tatsuya Tanaka (Japan), EC Liaison

Subcommission Members

TF on Intellectual Disabilities

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

Task Force on Psychiatric Aspects of Epilepsy Surgery

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

Task Force on Psychogenic Non-Epileptic Seizures

Markus Reuber (UK), Chair
Aliakbar Asadi-Pooya (Iran)
Masharip Atadzhanov (Zambia)
Ibrahim Bora (Turkey)
Alejandro De Marinis (Chile)
Kette de Valente (Brazil)
Rod Duncan (New Zealand)
Wissam El-Hage (France)
David Gigineishvili (Georgia)
Coraline Hingray (France)
Kousuke Kanemoto (Japan)
W. Curt LaFrance (USA)
Yogesh Patidar (India)
Ravi Paul (Zambia)

Chrisma Pretorius (South Africa)
Zhou Dong (China)

Task Force on Psychoses

Bertrand de Toffol (France), Chair
Naoto Adachi (Japan)
José Augusto Bragatti (Brazil)
Maurice Clancy (UK)
Tomohiro Oshima (Japan)
Perminder Sachdev (Australia)
Hisateru Tachimori (Japan)
Yukari Tadokoro (Japan)

Task Force on Depression

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

Task Force on Discussion between Neurologists and Psychiatrists

Andres Kanner (USA), Chair

Task Force on Education

Marco Mula (Italy), Chair
Esper Abrao Cavalheiro (Brazil)
Alla Guekht (Russia)
Andres Kanner (USA)
Hyang Woon Lee (South Korea)
Daliwonga Magazi (South Africa)
Çiğdem Özkara (Turkey)
Alfredo Thomson (Argentina)
Sara Wilson (Australia)

Task Force on Child Neuropsychiatry

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

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.

Mission

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

COMMISSION ON NEUROPSYCHIATRY *(continued)*

for understanding, diagnosing, and treating various psychiatric manifestations in patients with epilepsy.

2. Reduce prejudice, as epilepsy patients with psychiatric comorbidities are easily exposed to a double prejudice that can affect medical personnel involved in their treatment.

Commission Activities November 2014 through December 2015

A) Achievements

- A-1) 6 December 2014 (Seattle Sheraton Hotel, Seattle, WA USA). The second meeting of Neuropsychiatric committee Attendees: Kousuke Kanemoto (Japan), Mike Kerr (UK), Markus Reuber (UK), Sung Pa Park (South Korea), Gerardo Filho (Brazil), David Dunn, (USA), José F. Téllez Zenteno (Canada), Mayu Fujikawa (Japan).
- A-2) 6 September 2015 (Hilton Istanbul Bosphorus, Istanbul, Turkey). Attendees: [Kousuke Kanemoto (Japan), (South Korea), Mike Kerr (UK), Markus Reuber (UK)]
- A-3) 29 October 2015 (Nagasaki Sinbun-Bunka Hall, Nagasaki, Japan). "PNES around the world: let's learn more about this neglected disorder and see how we might help. A joint meeting of the ILAE and the Japan Epilepsy Society (JES)". Speakers: [Kousuke Kanemoto (Japan), Yozo Miyake (Japan), Curt LaFrance (USA), Markus Reuber (UK), Kazutaka Jin (Japan), Rod Duncan (NZ), Tomohiro Oshima (Japan), Yukari Tadokoro (Japan), Etsushi Kat (Japan), Hiroko Goji (Japan), Hiroko Ikeda (Japan), Sung Pa Park (South Korea), Go Taniguchi (Japan), Dong Zhou (China), Ravi Paul (Zambia), David Gigineishvili (Georgia), Mike Kerr (UK)]
- A-4) 7 December 2015 (Marriott Philadelphia Downtown, Philadelphia, PA USA). Annual meeting of neuropsychiatric committee: Attendees: Kousuke Kanemoto (Japan), Mike Kerr (UK), Sung Pa Park (South Korea), Markus Reuber (UK), Marco Mula (UK), David Dunn (USA), José F. Téllez Zenteno (Canada)

Initiatives in Progress

- A-5) 9-10 October 2016 (Nagakute, Japan). A symposium titled "Depression in patients with epilepsy: how could neurologists, psychiatrists

and neurosurgeons co-work and how much do Asian colleagues acknowledge it?" is planned. The date and the venue may be changed because of financial reasons.

- A-6) 22 October 2016 (São Paulo, Brazil). A symposium on psychiatric issues before and after surgery waits for ILAE approval. Planned attendees and speakers are as follows: Gerardo Filho (Brazil), Jose Téllez Zenteno (Canada), Elza Marcia Yacubian (Brazil), Andres Kanner (USA), Mayu Fujiwara (Japan); Kousuke Kanemoto (Japan), Marco Mula (UK), Markus Reuber (UK), Steffi Koechstecker (Germany), Mike Kerr (UK)

B) Depression Task Force (chaired by Sung Pa Park) - Achievements

- B-1) NDDIE and GAD translations.
- 1) Validations of the NDDIE in Chinese (by Dongmei An) and French (by McGonigal) were completed and published.
 - Micoulaud-Franchi JA, Barkate G, Trébouchon-Da Fonseca A, Vaugier L, Gavaret M, Bartolomei F, McGonigal A. One step closer to a global tool for rapid screening of major depression in epilepsy: validation of the French NDDI-E. *Epilepsy Behav.* 2015;44:11-6.
 - Tong X, An D, Lan L, Zhou X, Zhang Q, Xiao F, Park SP, Kanemoto K, Kanner AM, Zhou D. Validation of the Chinese version of the Neurological Disorders Depression Inventory for Epilepsy (C-NDDI-E) in West China. *Epilepsy Behav.* 2015;47:6-10.
 - 2) McGonigal encouraged Hansen to validate a Danish version of NDDI-E. The results was published in *Seizure* (2015;33:41-45). A cut-off point was 13.
 - Hansen CP, Amiri M. Combined detection of depression and anxiety in epilepsy patients using the Neurological Disorders Depression Inventory for Epilepsy and the World Health Organization well-being index. *Seizure.* 2015;25;33:41-45.

COMMISSION ON NEUROPSYCHIATRY (continued)

- 3) McGonigal exhibited the French version of NDDIE in the homepage of the French Epilepsy Society.
- 4) Sung Pa Park completed the study investigating the relationship between perceived stress and depression in PWE. It was presented in IEC, Istanbul. (Depression exerted direct effect on perceived stress regardless of seizure control).

Initiatives in Progress

B-2) NDDIE and GAD translations.

- 1) Thai version of the NDDIE is proposed. Chinvarun, Neurology division, Dept. of Medicine, Pramongkutklao Royal Army Hospital and Medical College, Bangkok, completed the translation of Thai version NDDI-E. Now he enrolls patients.
- 2) Considering the potential difference of cut-off points based on different cultural backgrounds, trials in Hong Kong and Taiwan are also proposed. Hong Kong: no reply. Taiwan: Hsiang-Yao Hsieh, Department of Neurology, from Chang-Gung Memorial Hospital, LinKou, replied how the validation is conducted.
- 3) Polish version of NDDIE is suggested to Jerzy Majkowska (a chief editor of *Journal of Epileptology*). Bartłomiej Gmaj, MD, PhD, Department of Psychiatry, Medical University of Warsaw may proceed with the process.
- 4) Dongmei An from China completed the validation study of GAD, and submitted it to *Epilepsy Research*. Dr. McGonigal enrolls patients for validation of GAD.

C) Psychosis TF (chaired by Bertrand de Toffol) - Achievements

- C-1) Awareness gap about psychosis in patients and medical personnel. A preliminary investigation is done on this matter and published.
- Kanemoto K, Tsuda H, Goji H, Tadokoro Y, Oshima T, Tachimori H, DeToffol B. Delusional experience awareness gap between patients and treating doctors - Self-reported EPDS questionnaire. *Epilepsy Behav.* 51: 60-4, 2015.

Initiatives in Progress

- C-2) Validation for EPDS as a simple screening tool for psychosis in patients with epilepsy. This initiative is now in progress.
- C-3) Special issue or positional paper for pharmacological treatment of psychosis in patients with epilepsy. This is planned by Bertrand and Kanemoto, then approved by Task Force members. Potential contributors are Michael Trimble (UK), Dale Hesdoreffer (USA), Perminder Sachdev (Australia), Kousuke Kanemoto (Japan), Andres Kanner (USA), Maurice Clancy (UK), Naoto Adachi (Japan), Steffi Kochstoecker (Germany), José Augusto Bragatti (Brazil), Marco Mula (UK), Bertrand de Toffol (France).

Recommendation

- C-4) ILAE supported definition of psychoses in patients with epilepsy. A survey in order to evaluate the knowledge of psychiatrists in western countries about PIP is suggested.

D) Education Task Force (chaired by Marco Mula) - Achievements

- D-1) Highlighting psychiatric comorbidities in regional and local courses. Task force members have been very active in promoting information on psychiatric comorbidities in regional and local meetings and educational events.
- (1) The 9 Latin America Summer School on Epilepsy organized by Esper Cavalheiro (Brazil) and held in Sao Paulo was dedicated to comorbidities in epilepsy with several sessions dedicated to psychiatric comorbidities in children and adults with epilepsy.
 - (2) Alla Guekht (Russia) organized two workshops, one in Russia and one in Kazakhstan, and special attention was given to somatic and psychiatric comorbidities of epilepsy.

Initiatives in Progress

- D-2) VIREPA courses. The task force worked on two formats for VIREPA: (1) Psychiatric aspects in adults with epilepsy (co-chaired with Andy Kanner) and (2) Psychiatric Aspects in children (Co-Chaired with David Dunn). Course (1) was ready to run with all educational material already prepared but it is not adopted due to

COMMISSION ON NEUROPSYCHIATRY *(continued)*

financial reasons. Accumulated material is worth disseminating, so efforts to publish it will be continued.

- D-3) Survey on educational needs. The task force has prepared a survey for neurologists and psychiatrists about psychiatric comorbidities of epilepsy. The survey is currently running. Apart from the usual ILAE pathways (regional commission chairs) the following societies have been contacted in order to disseminate the survey: World Federation of Neurology, European Academy of Neurology, European Society of Child Neurology, World Psychiatry Association, World Federation of Societies of Biological Psychiatry, European Psychiatry Association, Child and Adolescent Psychiatry Association. Results will be analyzed and disseminated during the first semester of 2016.

E) Task Force on Intellectual disability. Initiative in Progress

- E-1) The results of Tokyo presentations are amalgamated and being now processed by Mike Kerr and Christine Linehan, becoming soon ready for submission

Recommendation

- E-2) Transition from child care to adult care. This topic was suggested to be picked up intensively in the remaining tenure of this committee. Because this includes a variety of challenges ranging from simple misunderstanding to lack of appropriate institutes, the simple task such as a minimum requirement of referred letter is suggested as the first step. Collaboration with the child committee is strongly recommended.

F) Task Force on Psychogenic Non-Epileptic Seizure. Initiatives in Progress

- F-1) Survey about the treatment of PNES around the world. Two years ago the PNES Task Force decided to focus on the topic of "PNES around the world." The ultimate goal of this project was to allow more patients to gain access to appropriately trained and equipped diagnostic and treatment services. The core group involved in this project, task force members, was subsequently joined by Wissam El-Hage (France) and Coraline Hingray (France). An international ILAE PNES Task Force steering group met at the European Epilepsy Congress

in Stockholm on 30 June 2014. We heard presentations describing the challenges faced by patients with PNES in different countries and formulated our plans for two surveys:

- 1) a more detailed survey of health practitioners in a number of countries around the world and
- 2) a brief survey of all ILAE chapters.

The surveys were drafted, circulated and approved by the ILAE between August 2014 and February 2015. From February 2015 until November 2015 more detailed surveys were undertaken in Japan, UK, US, Canada, Chile, Georgia, France, Zambia, and South Africa. The ILAE chapter survey has been completed by 53 chapters. Some preliminary findings of the surveys were presented at a joint meeting of the PNES Task Force and the Japanese Epilepsy Society in Nagasaki, Japan, on 29 October 2015. Data analysis and preparation of a report are underway. Several of the coordinators of the more detailed national surveys are planning to publish reports focusing on the findings in their countries.

- F-2) A symposium on PNES at Nagasaki, Japan on 29 October 2015. The symposium ended with great satisfaction both to speakers and audience. A position paper is planned and now being processed as a result of this symposium.

Recommendations

- F-3) We have discussed that after completion of the report about the international surveys the ILAE Task Force may define different levels of PNES treatment, which would allow centers to identify themselves as providing an internationally comparable range of diagnostic and therapeutic options for people with PNES.
- F-4) An ILAE supported definition of PNES is recommended to be discussed. An international consensus is expected to come out of it.

G) Presurgical Psychiatric Evaluation. Initiative in Progress

- G-1) A symposium in Brazil. This is a prioritized initiative for our committee next year. By focusing our applications of budget to ILAE on this matter, we will try again to get approval for this initiative.
- G-2) Position papers from Brazil meeting. If this initiative is approved, several papers are expected to appear.

COMMISSION ON NEUROPSYCHIATRY *(continued)*

G-3) Systemic review on presurgical assessment tools for depression. Mayu Fujikawa is in charge of this and processing.

H) Task Force on Child Neuropsychiatry. Initiatives in Progress

- H-1) Special issues. The series of reviews have been submitted to *Epileptic Disorders* and Frank Besag has received editorial comments. Revisions are being completed and should be in to *Epileptic Disorders*. My assumption is that they will be accepted and publication will occur over the next year or two.
- H-2) Collaboration with the pediatric commission. The pediatric commission of ILAE has established a Task Force on Comorbidities. For this coming year, I will work with them on a review of aspects of ADHD in children with epilepsy. Lead for this project is Stéphane Auvin.
- H-3) Screener for epilepsy clinics. The psychosocial workgroup at AES is developing a screener for use in comprehensive epilepsy clinics. The screeners will be piloted and then presented to the AES membership.

I) Task Force on Discussion between Neurologist and Psychiatrist -

Recommendations

Collaboration with AES is proposed.
A symposium at the world neurology congress is proposed.

COMMISSION ON PEDIATRICS



Jo Wilmshurst

Chair

Jo Wilmshurst (South Africa)

Members

Perrine Plouin (France), Past Chair
Hans Hartmann (Germany), Treasurer
Patrick Van Bogaert (Belgium), Secretary
Stéphane Auvin (France)
Amy Brooks-Kayal (USA)
Petia Dimova (Bulgaria)
William D. Gaillard (USA)
Marilisa Montovani Guerreiro (Brazil)
Makiko Osawa (Japan)
Vinayan [K. P.] Puthenivill (India)
Pauline Samia (Kenya)
Helen Cross (UK), EC Liaison

Subcommission Members

Task Force for Adaptation of the Neonatal and the Infantile Recommendations:

Hans Hartmann (Germany), Chair

Regional chairs: Pauline Samia (Africa), Vinayan Puthenivill (Asia), Marilisa Guerreiro (South America)

Task Force for Comorbidities in Pediatric Epilepsy

Stéphane Auvin (France), Chair

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

Jo Wilmshurst (South Africa), Chair

Pediatric Epilepsy Surgery Task Force

William D. Gaillard (USA) Chair

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, (NB “translation” refers to more than language but to the actual integration and use of the recommendation/guideline, making sure that they are in line with the regional capacity and health care systems)

3. facilitating chapters in lobbying for access to these resources
4. supporting education in the dispersion of these recommendations/guidelines for the management of epilepsy in children
5. identifying who are 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 but involves the role of health care 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 2014 through June 2015

The guidelines for infants with seizures were completed in 2015 and published in *Epilepsia*. The Commission on Pediatrics has held one formal and three informal advantageous meetings over the period July 2014–June 2015 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 which the commission is working on over the current cycle.

In addition to these meetings, the commission supported an epilepsy workshop in Durban in collaboration with the Commission on African Affairs and SONA. Bursaries were allocated for junior doctors to attend and two invited speakers contributed to the program, Prof. Lieven Legae representing the pediatric elements of the workshop. The commission supported bursaries as well for the most recent 13th International Course on Epilepsy in July, the theme of which was “Seizures and Epilepsies in Childhood: Comorbidities, Advocacy and Adaptation of Guidelines.” Most members of the Commission on Pediatrics were able to contribute to this course. In addition the guidelines for infants with seizures were completed in 2015 and published in *Epilepsia*, various members of the past and present commission contributed to this report.

COMMISSION ON PEDIATRICS *(continued)*

Commission Activities

June 2014 through June 2015

The following outcomes have occurred through the commission task forces.

Task Force for Adaptation of the Neonatal and the Infantile Recommendations.

Chair Hans Hartmann (Germany).

The adaptation of existing neonatal and infantile seizures guidelines is needed to ensure that they are viable for use at local levels. The Pediatric Epilepsy Training programs (PET) (established by the British Paediatric Neurology Association (BPNA)) are excellent platforms to introduce this level of knowledge. The courses are directed to all medical professionals working at first and secondary levels of care and have reached an international level. Issues of cooperation between BPNA and ILAE on pediatric epilepsy training (PET) were further explored and PET courses organized by BPNA in Africa and India attended by commission members. It is envisioned that in 2016 commission members will take part in train-the-trainer courses in order to build up an international faculty, and ILAE will endorse PET courses in Cape Town and South India.

In order to make the 2011 WHO/ILAE/IBE guideline on neonatal seizures more widely known, the task force has started updating the guideline in collaboration with the neonatal task force of the Commission on Classification and Terminology, aiming for publication in *Epilepsia*. During this year's San Servolo summer school, adaptation of guidelines to a national and local level and implementation were discussed intensely. Participants were encouraged to promote this process following their return to their home countries.

To assess incidence of epilepsy in children and awareness and knowledge, a demonstration project focusing on the Galle district in Sri Lanka was drafted and will be further pursued by Gemunu Hewawitharana. This task force is collaborating with the Education Commission and has recruited members to join the projects.

Task Force for Comorbidities in Pediatric Epilepsy.

Chair Stéphane Auvin (France)

The aim for this task force is to develop a "user friendly text" that documents the known data, identifies what is not known, and highlights red flags where interventions are needed. After extensive debate surrounding this large and challenging area, the working group agreed

that the task force should focus on key common and high impact conditions and to use this protocol as a template to potentially address parallel scenarios. The task force will focus on pediatric epilepsy and ADHD. A working group has been invited and key study questions devised. These will be addressed by small subcommittees who will be tasked with producing evidence based assessments of the key questions. The final format of the report will be a consensus document which will aim to assist the clinician in practice and also raise awareness of this comorbidity risk in children with absence and the optimal approach. All 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). The final text is planned to provide an approachable, clear, simple recommendation and to consist of tables, flow diagrams and "red flag" messages, to be of use to the clinician "working at the rock face." Members of the Neuropsychiatry Commission and Education Commission have been recruited to be part of this task force. The neuropsychiatry group has also been active compiling a report focusing on the behavior problems in people with epilepsy and intellectual disability, members of the Pediatrics Commission are part of this project.

Advocacy Task Force – The Rights of the Child to Access Consistent and Reliable AEDs.

Jo Wilmshurst (South Africa), Chair

The Global Burden of Epilepsy was approved by the World Health Assembly in May 2015. The resolution addressed the global burden of epilepsy and the need for coordinated action at the country level to address its health, social and public knowledge implications through the following points:

- Strengthen effective leadership and governance
- Introduce and implement national health care plans
- Integrate epilepsy management into primary health care
- Improve accessibility to and promote affordability of safe, effective and quality-assured antiepileptic medicines
- Ensure public awareness
- Promote actions to prevent causes of epilepsy,
- Improve investment in epilepsy research and increase research capacity

COMMISSION ON PEDIATRICS *(continued)*

- Engage with civil society and other partners in these actions.

The Advocacy Task Force has formed a working group with additional members from the IBE to address how the above resolution relates to children with epilepsy and what must be in place to ensure it is effective.

Pediatric Epilepsy Surgery Task Force.

Chair William D. Gaillard (USA)

The Epilepsy Surgery 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's neurosurgical survey on pediatric neurosurgical techniques and practice (50 responses), now under review for publication in *Epilepsia*.

Pediatric Neuropsychology Subcommittee,

led by Madison M. Berl, completed their survey of pediatric neuropsychology presurgical evaluation practice. This survey was conducted in conjunction with a subcommittee of the Neuropsychology Subcommittee of the Commission on Diagnostic Methods. 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 subcommittee is working on a draft manuscript. Susan Koh and Guido Rubboli are leading an effort to establish 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

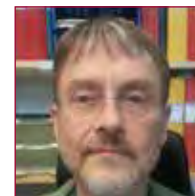
helpful for petitioning for resources and training. Initial responses from the survey show bias toward North America; efforts are being made to expand geographic participation in the survey. Prasanna Jayakar completed the surgical approach survey and will be preparing the manuscript.

William D. Gaillard is leading a sub task force 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, in patient selection, diagnostic testing, and surgical techniques that have occurred over the past ten years the task force plans a survey of sites from the 2004 and 2008 surveys (all based on surgical cases 2004) for 2014. The survey, designed by A. Simon Harvey, has been at five sites and will be distributed to the remaining 15 sites in summer 2015. The task force is planning a larger meeting in Istanbul to report on the four 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.

Recommendations for Future Work

Ongoing projects will include a workshop in Turkey at the IEC relating to the Pediatric Epilepsy Surgery Task Force and the Comorbidities Task Force. The commission members will actively train as many as possible to be PET instructors to develop an international faculty. The neonatal guidelines will be updated. The advocacy group will complete a position statement. The comorbidities group will be able to start data collection early in 2016. The epilepsy surgery group will expand on their current projects as listed above.

COMMISSION ON SURGICAL THERAPEUTICS



Bertil Rydenhag

Chair

Bertil Rydenhag (Sweden)

Members

Bernhard Steinhoff (Germany)
Kristina Malmgren (Sweden), Secretary
Mike Sperling (USA), Treasurer
Christine Bulteau (France)
Pavel Kršek (Czech Republic)
Andrew McEvoy (UK)
Guoming Luan (China)
Mario Alonso (Mexico)
Serge Vuillimoz (Switzerland)
Tatsuya Tanaka (Japan), EC Liaison

Aims

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

Mission

- To continue the ILAE work of international collaboration and to spread knowledge of techniques for evaluation and surgery of patients with epilepsy
- To promote good long-term time results
- To promote maximum 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 and build epilepsy surgery programs in developing countries and countries with minimal resources

Commission Meetings

During this period the commission work has been handled through emails. No official meeting has taken place.

Accomplishments

Complication classification

A new multi-axial classification of complications related to invasive procedures as well as to therapeutic surgical procedures has been developed and has been endorsed both by the Surgical and the Pediatric Commissions. It has also been endorsed by the EU supported project E-epilepsy, and the complication classification is now running within the E-database of E-epilepsy. The classification has been presented as a poster in Istanbul September 2015 at the 31st IEC.

Impact of diagnostic techniques on surgical outcome

Serge Vuillimoz collaborates with the epilepsy consortium on the source localization task force including a systematic review of the literature on the clinical validity of electric source imaging and magnetic source imaging.

In this context, original research papers and reviews on the topics have been attributed to a pair of expert reviewers who had to rate the paper's contribution to the clinical validity of electric source imaging or magnetic source imaging. Review papers had to be screened for relevant references to be subsequently added to the review process. This work was started in the period of the report and the current phase is almost completed as of November 2015.

Outcome reporting of Epilepsy surgery

Pavel Kršek has started the work on a planned educational paper on outcome measures of epilepsy surgery. The purpose of the manuscript is to summarize the most important outcome domains, discuss available standardized measures and surveys, and give practical advice, taking into account varying resources for follow-ups. A planned title of the report is "A guide to reporting outcomes of epilepsy surgery." The plan is to publish it on behalf of the Commission on Surgical Therapies in *Epilepsia*. The author team consists of 14 recognized experts covering all important outcome domains. Both adult and pediatric aspects of individual issues will be covered. The deadline for receiving individual sections from co-authors is April 2016.

Epilepsy surgery in countries with limited resources

Andrew McEvoy had taken the lead on this. The plan is to publish an educational paper; work is ongoing.

Gothenburg Pediatric Epilepsy surgery meeting (PedEpiSurg Gothenburg 2014, 4-5 July 2014)

This meeting was very successful, gathering 80 pediatric epilepsy surgeons from all over the world in Gothenburg to discuss specific neurosurgical issues. To our knowledge it is the first meeting that specifically addressed surgical issues for pediatric epilepsy surgeons. All the main important techniques were discussed. The meeting was supported by a collaborative effort from the Commission on Surgical Therapies and the Pediatric Task Force of the Pediatric Commission from which the original initiative came some years ago. Economically however it was fully financed by sponsors. The meeting resulted in a plan

COMMISSION ON SURGICAL THERAPEUTICS *(continued)*

to publish the proceedings in *Epilepsy*. A follow up meeting is also planned in Prague in September 2016.

The Epilepsy surgery course in Brno 12-16 January 2015

After discussions and approval from the ILAE Executive Committee and Treasurer Sam Wiebe, the commission redirected funding from the PedEpiSurg to support this important educational activity in order to finance bursaries for extra-European participants. The course was successful, with high ratings from the participants.

Recommendations for Future Work

Mike Sperling will further work on risks of epilepsy surgery vs. benefits.

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.
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.

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.
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.
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 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.